

William O'Donohue · Larry James
Cassandra Snipes *Editors*

Practical Strategies and Tools to Promote Treatment Engagement

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Editors

William O'Donohue
Department of Psychology
University of Nevada
Reno, NV, USA

Larry James
School of Professional Psychology
Wright State University
Dayton, OH, USA

Cassandra Snipes
Department of Psychology
University of Nevada
Reno, NV, USA

ISBN 978-3-319-49204-9

ISBN 978-3-319-49206-3 (eBook)

DOI 10.1007/978-3-319-49206-3

Library of Congress Control Number: 2017931655

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Printed on acid-free paper

This Springer imprint is published by Springer Nature

The registered company is Springer International Publishing AG

The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

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Contributors

Leonardo F. Andrade, PhD, BCBA Department of Psychology, Westfield State University, Westfield, MA, USA

Andrea R. Ashbaugh, PhD School of Psychology, University of Ottawa, Vanier Hall, Ottawa, ON, Canada

Marie C. Barrett, MA Department of Psychology, Western Michigan University, Kalamazoo, MI, USA

Lindsay Bartram, DO Department of Pediatrics, Section of Developmental and Behavioral Pediatrics, Nationwide Children's Hospital, Columbus, OH, USA

Claudia C. Bartz, PhD, RN Telehealth Nursing Working Group, International Society for Telemedicine & eHealth, Suring, WI, USA

Irene Blackberry, PhD College of Science, Health and Engineering, La Trobe University, Wodonga, Australia

Department of General Practice, The University of Melbourne, Carlton, Australia

Michelle R. Byrd, PhD Department of Psychology, Eastern Michigan University, Ypsilanti, MI, USA

Nicholas Hardiker, RN, PhD Chair, School of Nursing, Midwifery, Social Work & Social Sciences, University of Salford, Salford, UK

Vanessa E. Haro, BA Department of Psychology, La Sierra University, Riverside, CA, USA

Larry James, PhD, ABPP School of Professional Psychology, Wright State University, Dayton, OH, USA

Sara S. Johnson, PhD Pro-Change Behavior Systems, Inc., South Kingstown, RI, USA

Melissa Keller, PsyM Department of Psychology, Wright State University, Dayton, OH, USA

Shian-Ling Keng, PhD Department of Psychology, National University of Singapore, Singapore

Rachel Kentor, MS Department of Psychology, Eastern Michigan University, Ypsilanti, MI, USA

Noam Lindenboim, PhD REACH—Domiciliary Care for Homeless Veterans, VA Boston Healthcare System, Brockton, MA, USA
Department of Psychology, University of Washington, Seattle, WA, USA

Marsha M. Linehan, PhD Department of Psychology, University of Washington, Seattle, WA, USA

Anita Lungu, PhD Lyra Health, Cupertino, CA, USA

Leslie R. Martin, PhD Department of Psychology, La Sierra University, Riverside, CA, USA

Leanne M. Mauriello, PhD Behavioral Science and Lifestyle Management, Spectrum Health System, Grand Rapids, MI, USA

Caroline Murphy, PhD Department of Pediatrics, Section of Psychology, Nationwide Children's Hospital, Columbus, OH, USA

Amy E. Naugle, PhD Department of Psychology, Western Michigan University, Kalamazoo, MI, USA

William O'Donohue, PhD Department of Psychology, University of Nevada, Reno, NV, USA

Akiko Okifuji, PhD Pain Research & Management Center, Department of Anesthesiology, University of Utah, Salt Lake City, UT, USA

Allison J. Ouimet, PhD School of Psychology, University of Ottawa, Ottawa, ON, Canada

Megan Perez, MS Department of Psychology, Eastern Michigan University, Ypsilanti, MI, USA

Nancy M. Petry, PhD Department of Psychiatry, University of Connecticut Health Center, Farmington, CT, USA

Janice M. Prochaska, PhD Pro-Change Behavior Systems, Inc., South Kingstown, RI, USA

Eric Reinhart, PsyD Department of Psychology, Wright State University, Dayton, OH, USA

Leon Sawh, MPH Department of Psychiatry, University of Massachusetts Medical School, Worcester, MA, USA

David Smelson, PsyD U.S. Department of Veterans Affairs, National Center on Homelessness Among Veterans, Bedford, MA, USA

Department of Psychiatry, University of Massachusetts Medical School, Worcester, MA, USA

Cassandra Snipes, PhD Department of Psychology, University of Nevada, Reno, NV, USA

Laura E. Stayton, MA Department of Psychology, Western Michigan University, Kalamazoo, MI, USA

Dennis C. Turk, PhD Department of Anesthesiology and Pain Medicine, University of Washington School of Medicine, Seattle, WA, USA

Jennifer R. Walton, MD, MPH Department of Pediatrics, Section of Developmental and Behavioral Pediatrics, Nationwide Children's Hospital, Columbus, OH, USA

Part I
Introduction

Chapter 1

Treatment Engagement: An Introduction

William O'Donohue, Cassandra Snipes, and Larry James

Increasingly, the field of behavioral health has recognized that there is a problem that might be called: the problem of behavioral health service delivery (O'Donohue & Dyer, 1993). That is, just because there are individuals who have problems (or will have problems); just because there is knowledge about how to remedy (or prevent) these problems; and just because there are professionals who are willing to deliver interventions—perhaps even evidence-based interventions, and just because there are entities (third parties or the consumers themselves) who are able and willing to pay for these interventions does not mean that treatment will be delivered. Aligning all of these dimensions is the core problem of behavioral health service delivery. Sometimes in research or scholarly work only one dimension of this problem is addressed. For example, typically, clinical researchers try to increase the knowledge base regarding clinical efficacy with little or no attention to the other dimensions necessary for this treatment to be actually delivered. Or, in other cases, behavioral health professionals deliver therapy with little or no attention to the other factors—for example, to the knowledge base about treatment efficacy or effectiveness. Each of these dimensions is important in the problem of behavioral health service delivery and must receive its due attention.

This volume addresses each of these dimensions but concentrates on the first dimension: potential consumers. Increasingly, the behavioral field is recognizing that the old saw of “build it and they will come” is simply not true. Some come but many do not. Also some of those that come drop out early. Others that come do not adhere and are not helped. Sometimes, those that do come are not the most important

W. O'Donohue, Ph.D. (✉) • C. Snipes, Ph.D.
Department of Psychology, University of Nevada, Reno,
1664 N. Virginia Street/Mail Stop 298, Reno, NV 89557, USA
e-mail: wto@unr.edu; snipes.cassandra@gmail.com

L. James, Ph.D., A.B.P.P.
School of Professional Psychology, Wright State University, Dayton, OH, USA
e-mail: jamesbdaddy@aol.com

intended targets—they are individuals with lower magnitude problems, for example. Again, the problem of behavioral health service delivery is nuanced and complex.

Part of this realization of the importance of the problem of behavioral health service delivery has come about because the health care field has become more proactive instead of just reactive. Those that design healthcare delivery systems, largely due to the problems associated with the well-known “healthcare crisis,” have sought to target certain patients by a variety of mechanisms to reduce or contain costs. The basic idea is that certain costly patients can be identified (by algorithms revealing sentinel events, or by past high utilization, or by certain comorbidities, etc.) and the hypothesis is if these individuals can be treated in some manner future, more expensive, health care utilization can be prevented or minimized. For example, an individual with diabetes who does not renew his or her insulin prescription (i.e., the sentinel event) can receive a phone call from a nurse trained in Motivational Interviewing (Miller, 2000) and be encouraged to obtain their prescription thus preventing an emergency room visit due to a glycemic crisis. However, all too often these programs find that the targeted patient simply will not engage—he or she opts out by not consenting or signing up for the program, or does not answer the phone, or cuts the intervention short when it is being delivered, etc. This kind of “treatment interfering” behavior is what is meant by the phrase “patient engagement.”

Another example will round out the understanding of patient engagement. Many depression programs were designed and sold to insurance companies or primary care practices. The basic idea is that the patients in medical settings would be screened for depression due to the high comorbidity and/or due to the notion that depression was the actual driver of future medical costs—thus also avoiding a medical error associated with a missed diagnosis (and a potentially costly omission) by correctly identifying all depressed patients. Further, if the patient produces a positive depression screen then he or she would be asked to enroll in, say, a brief 6 week cognitive behavioral depression course, perhaps in person or perhaps online. Epidemiology would suggest a high rate of depression in primary care and these programs are sold partly on these kinds of potential penetration. However, typically, these programs are stymied by severe problems with patient engagement including the following: (1) some patients will refuse to take the depression screen; (2) of those individuals who screen positive for depression, a low percentage will actually agree to participate in the online intervention; (3) of those individuals who agree to participate, a low percentage will actually start the intervention; (4) of those individuals who start the intervention, a low percentage will complete the intervention; (5) of those who complete the course a low percentage of the individuals will do all that they are asked to do, e.g., homework, complete follow-up assessments, and finally (6) of those who complete the intervention a moderate percentage experience clinically significant change—and perhaps (7) of those who experience clinically significant change, a number relapse. Given this cascade of problems—the overall treatment program is not seen as a success—it, due to this sequencing of problems associated with poor patient engagement, actually helps a very low percentage of those that it could possibly help. Thus, a key meta-problem in designing an effective

health is system is that too few patients engage—specifically at stages 1–3. If more patients were to engage, perhaps the overall program could be judged worthwhile because the dollars spent would be actually responsible for more clinical change for more people in the population—a much better return on investment. And of course, more people will be helped to overcome their depression.

Thus, patient engagement is a key problem in the behavioral health field. However, it generally receives a disproportionately low amount of attention. Researchers are generally oriented toward successful clinical trials—but often show little concern about patient enrollment or engagement in these innovative treatments—sometimes patients in clinical trials are even offered incentives such as payments or chances to be in lotteries that they will not experience in real-life settings to enroll in the clinical trial. Clinical researchers are much more focused on the question of “Once enrolled, how do I keep patients in the trial and how do I show a good clinical effect size for my experimental treatment?” Rather than the question, “How do I generate sufficient enthusiasm or incentives or commitment for the treatment so that patients will naturally want to enter and complete therapy?” This later question again is much more the focus of this book.

It may be worthwhile exploring some general hypotheses regarding why patient engagement is so difficult:

1. Some potential consumers want to deny or minimize that they have the problem—entering some sort of intervention may require a difficult psychological admission. People may be in denial about their weight, their drinking, or their mood. Our field needs to understand much better the problems in individuals accepting or admitting that they have a healthcare problem—and in a way that produces effective instrumental behavior as opposed to despair, being overwhelmed, or inactivity.
2. Some potential consumers may experience problems such that as part of their problem (e.g., depression) may feel hopeless and pessimistic, for example they may be pessimistic that therapy is worthwhile. Or, for example, with substance abuse, they may be too intoxicated to make good decisions or follow through with effective responses. The problem by its nature may interact with the decision to commit to treatment.
3. Some potential consumers may feel—correctly—that therapy will be hard or painful. This is the sort of reason why dentists have problems with engagement and sometimes we as professionals may need to see that the patient is substantially correct—for example, that cognitive behavior therapy exposure treatment for PTSD can be quite painful and difficult (Foa). Urine alerts (Friman) require being awakened for many nights, possibly multiple times.
4. Sometimes, potential consumers may feel that therapy will be simply too long and too involved. Potential consumers simply are not prepared for that an effort of that duration. Again, this is at least partly rational. It is true that even our “brief” psychotherapies can last 12–18 weekly sessions and long-term therapies for years. As a field we need to realize this is quite a commitment for someone to make. Primary care visits sometimes can rectify the problem in 15 min (with,

- for example, an effective prescription). We need to design interventions that are much more efficient so that engaging in these requires much less effort.
5. At times potential consumers may fear the stigma associated with behavioral health treatment.
 6. At times potential consumers may think the probability of a positive outcome for them is simply too low to justify engagement and at times they could be right. The effect sizes of many of our psychotherapies are modest and outcome data indicate that many individuals are not even helped. And our relapse rates are often unacceptably high.
 7. At times potential consumers may be confused or put off by the high rate of variance of the quality of the therapist. Or even confused by the vast array of therapists—marriage and family counselors, social workers, psychologists, psychiatrists, psychiatric nurses, etc. We need to examine how confusing our field may be to potential consumers.
 8. At times potential consumers may be put off by the deep debates and controversies in the field about what are effective and safe therapies—psychotropic medication, behavior therapy, any therapy (the so-called Dodo effect), art therapy? We as a field often do not have coherent or compelling messages about best practices or the most effective treatment pathways.
 9. At times potential consumers may be put off by pragmatic problems associated with treatment engagement—the physical distance, or the need for computer literacy for online therapy, a disparity of language for many minority consumers, etc.
 10. At times the field may do a poor job of increasing the consumer's health literacy so they understand what problems they are experiencing and can make a reasonably informed decisions about rational courses of action.
 11. At times, we have paid little attention to the aesthetics of our field—we are much more like Dell than like Apple. The excitement produced by the aesthetics of an Apple product or store is rarely embodied in our services. We can have unsightly offices and uninspired websites or paper and pencil testing that takes a week or so to score—much like the 1950s. We need to be more concerned about the entire “patient journey” and more attentive to the total experience of our products and services.
 12. At times, healthcare professionals may not be trained to value the perspective of the patient and may not be trained to behave in a patient-centric manner due to the fact that these models are relatively recent.
 13. At times, payment is unclear or problematic.
 14. There is too little attention paid to patient preferences. Although in recent years “patient-centered” care has been a focus; there is still too little understanding of patient preferences, customization for individual patients, quality improvement protocols designed to identifying patient satisfaction, and suggestions for improvement. Instead, healthcare delivery remains largely hierarchal with little direct involvement of patient feedback. Healthcare professionals need to be trained or retrained in models of “shared decision making.”
 15. Key times for patient engagement need to be identified and processes in place to assure sufficient attention is given to patient engagement during these junc-

tures. This can also enhance continuity of care. Key junctures would include possible discharge, possible transition from one care center to another, referrals to other professionals, possible use of adjunctive treatments, possible change in medications, etc.

16. At times, it may be useful to try to engage the consumer's support network to help with patient engagement. This approach, which can include family, neighbors, religious leaders, teachers, friends, etc., needs to be administered carefully due to HIPPA concerns.
17. Micro-analyses of healthcare professionals communication styles need to be examined. There could be a number of problematic practices including too frequent use of technical terms, words that are beyond the consumer's educational level, too much information, authoritative statements, not asking for patient's input, etc.
18. Incentives need to be aligned to promote patient engagement. For example, with Medicare there are meaningful use criteria associated with Electronic Health Records that if successfully implemented qualifies the organization for additional payments.
19. How can technology improve patient engagement? Are there dashboards or apps, or email reminders that can engage patients—particularly younger patients who are more accustomed to these?
20. Do group medical appointments or group psychotherapy promote treatment engagement for some consumers?
21. More theory and research is needed regarding patient engagement in minority populations. Are their increased feelings of distrust, alienation, and powerlessness in ethnic or sexual minorities or the poor? Are there unintentional but still problematic indices of ageism, sexism, or racism involved in the delivery of healthcare that decreases patient engagement?
22. It ought to be recognized that certain patients will present severe challenges to patient engagement; for example, homeless individuals, acute substance abuse, individuals suffering from psychoses, individuals with certain personality disorders, individuals suffering from bipolar disorder, individuals with developmental delays, and individuals with Alzheimer's disease and other cognitive impairments. Separate models need to be developed for these individuals.

Many of the subsequent chapters in this book will explore these questions. To be sure a priority in contemporary healthcare delivery is what might be called the psychology of treatment engagement.

Self-Management of Health and Patient Engagement

There is another, and what might be regarded as a deeper sense, of "patient engagement" however. In this sense, it is the field's task to engage the patient so that they are motivated and informed to self manage their health. In this sense, patient engagement

is not engagement in some “one shot” intervention but rather a reorientation to continually lead a healthier lifestyle, engage in appropriate prevention, become health literate, as well as to seek the optimal level of healthcare services, to be a critical, informed consumer of these, and to adhere to treatment regimens. This is a tall order. However, the basic idea is that individuals vary on a continuum with respect to this. At one end of the continuum—the optimal end—there are individuals who do not smoke, who exercise, who eat well, who wear seat belts, who engage in relaxation and other stress reduction, who are socially connected, who are very health literate, who go for routine physicals, etc. On the other end of the continuum are individuals who are often the “high fliers”—expensive patients—who do much the opposite. And in doing so, they have multiple interconnected health problems, which they are not managing well, and their problematic life styles exacerbate, and who show up to emergency rooms and then often do not adhere to regimes prescribed. Engagement then is attempting to move the latter to become more like the former.

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Part II
Specific Strategies for Promoting
Treatment Engagement

Chapter 2

Behavior Economics and Treatment Engagement

Leonardo F. Andrade and Nancy M. Petry

Behavior economics is a field that integrates concepts of psychology and economics to explain individuals' decision making. In the past few years, this field has been increasingly incorporated into health care settings to promote healthier lifestyles. Typically, participants are given monetary incentives when a target behavior or goal is objectively verified. In this chapter, we describe this evidence-based treatment usually referred to as contingency management. This chapter is structured in four parts. Section "Background" reviews the historical background of incentive-based interventions as applied to substance abuse treatment. Section "Application of Incentive-Based Intervention to Medicine Targets" describes the application of these interventions to other medicine targets, such as vaccination, medical screenings, diabetes monitoring, physical activity, and weight loss programs. Section "Fundamental Elements and Concepts Embedded in Incentive-Based Interventions" explains fundamental concepts and elements embedded in effective incentive-based interventions, and the final section discusses issues related to the application and dissemination of incentive programs.

Background

Individuals often make irrational decisions. Drinking, smoking, overeating, and physical inactivity are a few examples of unhealthy patterns of behavior that many individuals engage in despite knowledge of the devastating consequences that may

L.F. Andrade, Ph.D., B.C.B.A. (✉)
Department of Psychology, Westfield State University, Westfield, MA 01085, USA
e-mail: landrade@westfield.ma.edu

N.M. Petry, Ph.D.
Department of Psychiatry, University of Connecticut Health Center,
263 Farmington Avenue, Farmington, CT 06030-3944, USA
e-mail: npetry@uchc.edu

result. Poor diet and physical inactivity, for example, is a modifiable unhealthy lifestyle responsible for 17% of deaths in the United States (Mokdad, Marks, Stroup, & Gerberding, 2004).

A growing number of studies have been published in the past three decades demonstrating the efficacy of incentives to address clinical conditions. These incentive-based interventions, also known as contingency management, are based on principles of behavior economics and behavior analysis. In these interventions, tangible reinforcers or incentives are delivered contingent upon the observation of the target behavior, and withheld when the behavior is not observed.

No other area contains more compelling evidence of the efficacy of incentives to promote clinically relevant behaviors than substance abuse research. It is in this research arena that incentives strategies have been studied most systematically. In incentive-based interventions for substance abuse treatment, patients earn prizes or vouchers exchangeable for goods and services every time the target behavior—e.g., abstinence from drugs—is objectively verified via analysis of biological markers, such as urine and breath samples (Higgins, Silverman, & Heil, 2008; Petry, 2012).

The systematic evaluation of monetary-based incentives in improving substance use treatment outcomes began in the early 1990s with the studies reported by Steve Higgins and colleagues from the University of Vermont (Higgins, Budney, Bickel, & Foerg, 1994; Higgins, Budney, Bickel, & Hughes, 1993; Higgins, Delaney, Budney, & Bickel, 1991). Higgins et al. (1994), for example, conducted a clinical trial aimed at evaluating the effects of incentives in the treatment of 42 cocaine dependent patients. In this trial, half of the sample was randomized to a standard outpatient treatment condition, and half was randomized to the same standard treatment condition combined with vouchers incentives. Vouchers were worth a certain amount of money, and they were exchangeable for monetary-based products, such as clothing, electronics, or gift cards, contingent upon submission of drug negative specimens. Voucher incentives were given in the first 3 months, but the study lasted for 6 months. Results showed that treatment retention and abstinence were substantially higher for the patients receiving incentives relative to those who were not. The rates of treatment completion at 3 and 6 months for patients receiving vouchers were 90% and 75%, compared to 65% and 40% for those not receiving vouchers during the same periods. Further, 55% of patients in the incentive group achieved at least 10 weeks of continuous abstinence, whereas only 15% of the patients in the no-incentive group achieved at least 10 continuous weeks of abstinence. This study was conducted in a research clinic that applied extensive outreach to engage and retain patients in care, regardless of their treatment assignment, and hence relatively high rates of treatment participation occurred, even in patients not receiving incentives.

In community-based substance abuse treatment programs, rates of treatment engagement are much lower. Retention is a long-standing problem in community clinics, and attrition typically exceeds 30% in the first month (Lefforge, Donohue, & Strada, 2007; Substance Abuse and Mental Health Services Administration, 2008). Studies implementing incentive-based interventions in community-based clinics find that less than 15% of patients assigned to standard care conditions

remain engaged in care for 12 weeks. In contrast, 30–60% of patients assigned to incentive conditions, in which they receive the chance to win monetary-based prizes worth \$1–100, remain in treatment for 12 weeks (Petry et al., 2004, 2006; Petry, Alessi, & Ledgerwood, 2012; Petry, Alessi, Marx, Austin, & Tardif, 2005; Petry, Martin, & Simcic, 2005; Petry, Weinstock, & Alessi, 2011).

Further, randomized clinical trials show that incentives are highly efficacious in retaining patients in treatment and promoting abstinence from a wide range of substances, such as opioid, marijuana, alcohol, methamphetamines, cocaine, and tobacco (see Higgins et al., 2008, for review). A meta-analysis concluded that incentive-based interventions had the largest effect size of all psychosocial therapies in treating substance use disorders (Dutra et al., 2008), and the Veterans Administration in the USA has recently begun implementing this approach nationwide in its substance abuse treatment programs (Petry, DePhilippis, Rash, Drapkin, & McKay, 2014).

Therefore, robust evidence shows that incentive-based interventions are highly efficacious in engaging individuals in the treatment for one of the disorders with the highest attrition rates—substance abuse. More recently, incentive-based interventions have been applied to other behavioral targets relative to medical care, including vaccination and medical screenings, self-monitoring in patients with diabetes, and engagement in diet and exercise. In the following section, we describe some of these studies.

Application of Incentive-Based Intervention to Medicine Targets

Vaccinations, Medical Appointments, and Attendance at Group Meetings

Performance of health prevention programs is often suboptimal and incentives can be incorporated successfully into these programs. An example of how incentives can be used effectively to improve immunization rates was reported by Hoekstra et al. (1998). In that study, food vouchers were used to reinforce immunization rates in inner-city Chicago. Families enrolled in the Women, Infants, and Children programs of Chicago were given 3-month supply of food vouchers if the child was age-appropriately vaccinated; otherwise, families received a 1-month supply of food vouchers until the child was vaccinated appropriately. Data from a total of 16,581 children 24 months old or younger were analyzed, and the results showed that the vouchers had a remarkable effect on immunization rates. During the 15-month period of evaluation, immunization rates increased from 56% to 89% at the sites where voucher incentives were made available.

Incentive-based intervention can also be efficacious for promoting compliance with medical appointments. Mayer and Kellogg (1989) used incentives to promote

mammography screening in 96 women 35 years and older. Approximately half of the participants received an information packet explaining mammography procedures and an incentive coupon combined with a prompt, whereas the other half received only the information packet. The coupon was redeemable for a nutritional information kit (worth \$2) when presented at the appointment in the clinic. Women randomized to the incentive group were significantly more likely to make appointments (81 %) compared to those randomized to the control group (59 %) ($p < .05$). Remarkably, nearly all appointments made in the incentive condition were kept—97 %. Similarly, Duer (1982) and Friman, Finney, Rapoff, and Christophersen (1985) found that prompts combined with \$5 incentives alone or in combination with free transportation to clinics, babysitting, and parking permits increased compliance with papanicolau smears and pediatric visits, respectively.

These studies show that prompts combined with relatively inexpensive incentive strategies can effectively promote greater appointment making and appointment keeping. In Mayer and Kellogg's (1989) study, for instance, the incentives awarded totally only \$106 and yielded a 22 % increase in appointments.

In addition to being used in screening prevention programs, incentive-based interventions hold potential to increase attendance rates to groups. Stevens-Simon, Dolgan, Kelly, and Singer (1997) used monetary incentives to promote participation of young mothers (<18 years) at pregnancy prevention peer-support groups. The incentive was comprised of \$7 delivered at the weekly meetings. Fifty-eight percent of the girls who were offered incentives participated in the peer-support groups, whereas only 9 % of those who were not offered incentives participated in the group activity.

Diabetes Care Activities

According to the Center for Disease Control and Prevention (2010), one in every ten adults today living in the United States has diabetes, and if the current trends continue, as many as one in three will have this condition by 2050. Controlling diabetes is extremely challenging because it involves lifestyle changes (such as exercise, weight loss, adherence to strict diets), self-monitoring, and frequent clinical visits and laboratory tests.

Recently, a few studies have shown that the use of incentives helps individuals engage in diabetes monitoring (Austin & Wolfe, 2011; Raiff & Dallery, 2010). Austin and Wolfe (2011), for example, used a quasi-experimental design to assess the effectiveness of an intervention designed to encourage clinical visits for glycosylated hemoglobin (A1c) testing among non-compliant patients with Type 2 diabetes. The intervention was comprised of a reminder letter and a gasoline gift card worth \$6 for attending the appointment and undergoing blood testing. A total of 464 patients received reminders and incentives, and their performance was compared with 693 controls who did not receive the reminders or incentive. Participants who received the reminders and the gas card came to significantly more visits for

screening test relative to those who did not receive reminder or gift card (3.3 vs. 2.7, respectively). Approximately half of the participants receiving the reminders and incentives had A1c levels in the clinically desired range, whereas only 36% of participants in the comparison group had A1c levels in this range.

Raiff and Dallery (2010) used a within-subject reversal design (A-B-A) to evaluate the effects of incentives to promote engagement with frequent blood glucose testing among adolescents with Type 1 diabetes. In this study, participants received voucher incentives for submitting self-monitoring blood glucose testing videos at least four times per day over the study's Web site. More specifically, participants earned \$1 dollar per video plus a \$3 bonus after the fourth video submitted. The intervention increased substantially the number of times participants tested their glucose levels. During the incentive phase, participants sent an average of 5.7 blood glucose tests per day, compared to 1.7 and 3.1 tests per day during the initial and posttreatment nonincentive conditions, respectively.

Physical Activity and Weight Loss

A risk factor for type 2 diabetes is physical inactivity. One form of exercise that has been targeted in incentive-based interventions because it is largely accessible and easily monitored is walking. Petry, Andrade, Barry, and Byrne (2013) randomized 45 sedentary older adults with moderate to mild high blood pressure to a 12-week intervention consisting of guidelines of walking 10,000 steps per day and pedometers or that same intervention with the opportunity to earn prizes for meeting walking goals. Participants receiving prizes walked, on average, 9395 ± 2220 steps per day and met walking goals on $82.5\% \pm 25.8\%$ of days, whereas participants on the non-incentive treatment walked, on average, 7407 ± 3330 steps per day, and met walking goals on only $55.3\% \pm 37.1\%$ days ($ps < .02$). Significant effects of the incentive intervention were noted in several clinical parameters, such as greater improvement in fitness indices, and reductions of body weight and blood pressure.

Incentive interventions may also be efficacious in making individuals engage in weight loss programs. Volpp, Troxel, Norton, Fassbender, and Loewenstein (2008) used financial incentives to encourage weight loss in overweight adults. Fifty-seven overweight participants were randomized to an intervention comprised of monthly weigh-ins or monthly weigh-ins with chances to win money for meeting monthly weight loss goals. After the 16-week intervention phase, patients receiving incentive lost significantly more weight than the control group. More specifically, patients receiving incentives lost a mean of 6.1 kg (13.6 lb), whereas those in the control condition lost a mean of 1.8 kg (3.9 lb).

These results were replicated by Petry, Barry, Pescatello, and White (2011) in a study in which 56 overweight individuals were randomized to one of two treatment conditions: a structured weight loss intervention with weekly weigh-ins and counseling, or the same weight loss intervention combined with chances of winning prizes of monetary value for each pound lost. At the end of the 12-week treatment

phase, participants receiving prizes lost significantly more weight (6.1 kg) than patients receiving the weight loss intervention alone (2.7 kg). In addition, 64 % of participants in the incentive group achieved clinically significant weight loss of 5 % baseline weight, compared to 25 % of the participants in the no incentive weight loss.

Fundamental Elements and Concepts Embedded in Incentive-Based Interventions

In order to design and implement an incentive-based program, it is important to consider some key variables that are central to behavior analysis and economics. In this section, we describe some of the most important elements and fundamental concepts embedded in efficacious incentive programs.

Delay to Incentives and Delay Discounting

The field of behavioral economics has identified a number of decision-making biases that help explain why individuals often make irrational decisions, such as engaging in self-defeating behaviors or behaviors that are not optimal in the long run (Loewenstein, Brennan, & Volpp, 2007). One decision bias that has been extensively studied and underlies impulsive decisions is delay discounting. The term delay discounting refers to the process by which the decision maker devalues future events. Compelling evidence exists that the value of an incentive decays hyperbolically in relation to the delay to its occurrence—that is, the value decreases quicker in the short run compared to the long run (see Green & Myerson, 2004 for a review of delay discounting). This behavioral process is reflected in individuals' tendency to overvalue events that are closer in time.

This disproportional emphasis on the present leads some individuals to seek immediate gratification even when it produces non-maximizing or self-defeating consequences in the long run. For example, choosing to engage in substance abuse treatment programs and remain sober leads to meaningful consequences—such as better health and improved family relationship—that should outweigh the more immediate and less meaningful consequences of consuming drugs—such as the high from the drug. On the same token, avoiding high-calorie food and engaging in exercise routines lead to important delayed consequences—such as weight loss and improved health—that should outweigh the more immediate and less meaningful consequences of eating high-calorie food and not exercising. Nevertheless, because individuals overvalue proximal events, they often choose to consume drugs and overeat when the opportunities arise to use drugs or eat a highly palatable food.

Many of the ultimately positive consequences of treatment are long delayed in time, making engagement in treatment challenging because its positive effect exerts little immediate impact on the behavior. Incentive-based programs take advantage of the biases individuals have toward immediacy. By applying incentives in close proximity toward treatment seeking, service providers are essentially exploiting a bias toward immediacy to guide persons toward choosing healthier behaviors (Loewenstein et al., 2007).

Although all individuals have the tendency to overvalue proximate events, some individuals do so substantially more than others. For example, most individuals with impulse control problems, such as those presenting with substance abuse, gambling, and/or obesity problems, have a tendency to overvalue proximate events to a greater extent than those individuals without these problems (MacKillop et al., 2011; Reynolds, 2006; Weller, Cook, Avsar, & Cox, 2008). One way to increase the efficacy of incentive programs is to provide incentives more immediately. The shorter the delay between the target behavior and the incentive, the most efficacious the incentive intervention is. Rowan-Szal, Joe, Chatham, and Simpson (1994), for example, reinforced methadone maintained patients for providing negative urine samples with stars exchangeable for retail goods immediately or after the passage of a certain amount of time. The patients who were exposed to the condition in which the stars could be exchanged at a later point in time provided less negative urine samples than the group who could exchange the stars sooner. A meta-analytical review of studies providing incentives revealed that the provision of incentives more immediately was associated with significantly larger effect sizes (Lussier, Heil, Mongeon, Badger, & Higgins, 2006). Thus, in designing incentive programs, one should make the incentives available as soon as possible after the individual exhibits the behavior.

Prospect Theory/Loss Aversion

Daniel Kahneman was awarded the Nobel Prize in 2002 for his work on prospect theory. Prospect theory is a highly influential theory in behavior economics which assumes that value depends on the “frame” or reference point (Kahneman & Tversky, 1979). Research in this area has produced robust evidence that when events are framed as losses, they have a more profound impact on behavior/preference than when the same events are framed as gains (Kahneman, Knetsch, & Thaler, 1990; Tversky & Kahneman, 1991, 1992). In other words, the subjective value attributed to loss is substantially greater than the subjective value attributed to gains. For instance, the prospect of losing \$50 dollars has a greater impact on choice than the prospect of gaining the same \$50. This tendency to respond more to events framed as losses than gains has been termed loss aversion.

Insights from studies on loss aversion can be incorporated in incentive-based interventions. For example, Volpp, Troxel, et al. (2008) used deposit contracts to promote weight loss. Participants in this condition made monetary deposits that

were refundable contingent on meeting weight-loss goals (16-lbs over 16 weeks). Approximately 47% of participants making monetary deposits attained the 16 pounds weight-loss goal, compared to only 10.5% in the non-incentive control group.

Deposit contracting has been used as an effective strategy in other incentive studies targeting reductions in cigarette smoking and drinking (Bigelow, Strickler, Liebson, & Griffiths, 1976; Dallery, Meredith, & Glenn, 2008; Elliott & Tighe, 1968; Paxton, 1980, 1981; Romanowich & Lamb, 2013). To date, however, few studies in clinical settings have compared the gain-loss asymmetry in clinical settings (Romanowich & Lamb, 2013; Volpp, Troxel, et al., 2008). Romanowich and Lamb (2013) compared the effects of framing incentives as either gains or losses in a smoking treatment program. During the 5-days intervention phase, participants could either earn or lose money (\$75) each day nicotine abstinence was verified. Results indicated that the participants in the loss-frame group were more likely to initiate abstinence compared to the gain-frame group. Nevertheless, those in the gain-frame group maintained abstinence more than the alternative group. Therefore, framing events as losses holds potential to improve initial engagement in treatment, but further studies are warranted to understand how to most effectively apply these constructs to improve both short and long-term outcomes.

Incentive Magnitude

In addition to how incentives are framed and the delay between the target behavior and the receipt of the incentive, another variable that greatly impacts behavior and therefore may impact the efficacy of the intervention is the magnitude of the incentives. In general, treatment efficacy increases in direct function of the incentive amount (e.g., Petry et al., 2004; Silverman, Chutuape, Bigelow, & Stitzer, 1999; Stitzer & Bigelow, 1983, 1984). Petry et al. (2004), for example, compared the effect of two different magnitudes of prizes on drug abstinence and found that prizes of higher magnitude engendered greater duration of abstinence. A meta-analytical review found that incentive magnitude impacted effect sizes of incentive-based interventions (Lussier et al., 2006).

Another important feature common to effective incentive-based interventions is the escalating magnitude of the incentives to promote sustained performance. For instance, in Higgins et al.'s (1994) study using vouchers to reinforce abstinence from cocaine, the first negative specimen resulted in \$2.50 voucher, and the amounts for each subsequent sample incremented by \$1.25. In addition to this increment, a bonus of \$10 was given each time participants submitted three negative samples consecutively. If the patient failed to submit a sample or submitted a positive sample, voucher amount was reset to its initial value (\$2.50). For example, a patient who provided negative samples for four consecutive tests then provided a positive sample on the fifth test, and a negative sample on the sixth test would earn the following monetary vouchers: \$2.50, \$3.75, \$15 (\$5 + a bonus of \$10), \$6.25, \$0, and \$2.50.

Petry, Andrade, et al. (2013) also incorporated an escalating prize system to promote engagement in exercise. In this study, participants had a chance to draw from a prize bowl and earn prizes for each day they walked the target number of steps (10,000 steps or more). In addition, participants received bonus draws every week they met the target number of steps on at least 6 of 7 days. The bonus started at three draws and incremented by 3 each consecutive week participants met target goals on at least 6 days. If participants did not meet the target goals on more than 1 day, they received no bonus and bonus draws were reset to the initial value.

One study (Roll, Higgins, & Badger, 1996) directly compared a fixed versus an escalating rate of incentives in cigarette smokers. Participants assigned to a fixed monetary condition earned \$9.80 in vouchers for each daily negative breath test. Participants assigned to an escalating monetary condition earned \$3 in vouchers for the first negative test, and each consecutive negative test increased by \$0.50. In addition, participants in this group earned a \$10 bonus for every three consecutive negative tests in a row. Patients receiving escalating vouchers were less likely to smoke than those in the fixed voucher condition, which provided an overall similar amount of incentives. Therefore, the escalating feature of incentives can impact the effectiveness of the intervention.

In sum, individuals have biases when making decisions, and these biases can be considered in designing incentive-based interventions. In addition to how events are framed, decisions are highly impacted by the magnitude and the delay to incentives. Typically, the most effective interventions are the ones with the shortest delay between the target behavior and the receipt of the incentive, as well as the interventions that provide the highest magnitude and escalating incentives. The provision of immediate and high-value incentives, however, increases the overall costs of the treatment intervention. Most treatment facilities have limited resources, and thus the costs associated with utilizing incentive approaches may be prohibitive. The next section discusses costs and other important implementation issues.

Special Considerations

Cost

Cost-related concerns are one of the greatest challenges in the application of incentive interventions. New approaches are needed to minimize costs while retaining efficacy. One solution is to take advantage of the loss aversion decision bias individuals have and implement a deposit contract paid in full or in part by the participant. As described earlier, deposit contract interventions have been applied for decades (Bigelow et al., 1976; Elliott & Tighe, 1968; Paxton, 1980, 1981), and more recently, Volpp, Troxel, et al. (2008) used this approach in a weight-loss program. While effective, these approaches require that patients are committed, willing, and able to provide deposits, which in essence excludes all but the most motivated

patients. These approaches would likely be ineffective in addressing engagement in treatment among many patients in need of services.

Another solution to decrease cost relates to applying a probability-based system to receiving tangible incentives. In the prize-based incentive system (also known as the fishbowl technique), participants earn chances to pick from an urn and win prizes of different magnitude every time the target behavior is verified (see Petry, 2012). More specifically, participants can earn “small,” “medium,” and “large” prizes. Small prizes are items that cost about \$1, such as food items, bus tokens, and \$1 gift cards. Large prizes are prizes worth about \$20, such as clothing, sports goods, and store and restaurants gift cards. The jumbo prizes cost up to \$100, and consist of items such as e-readers, ipods, gift cards, or a combination of smaller value goods. The probability of receiving each type of prize is inversely related to its magnitude. Usually, the probability of receiving a small, a large, and a jumbo prize is 41.8 %, 8.0 %, and 0.2 %, respectively. The probability of not receiving any prize is 50 %.

Because the target behavior results in a tangible reinforcement only about half the time and higher value prizes are delivered with very probabilities, the overall costs of this system can be substantially lower than other forms of incentive-based interventions in which the behavior is reinforced with set monetary or voucher amounts (Petry, Alessi, Hanson, & Sierra, 2007). In addition to promoting engagement to treatments targeting abstinence from a wide range of drug modalities (e.g., Alessi, Petry, & Urso, 2008; Petry et al., 2007; Petry, Weinstock, et al., 2011), prize-based incentive interventions have also been used successfully in programs targeting attendance to group meetings (Ledgerwood, Alessi, Hanson, Godley, & Petry, 2008; Petry, Martin, et al., 2005; Sigmon & Stitzer, 2005), job-seeking activities (Petry, Andrade, Rash, & Cherniack, 2013), physical activities (Petry, Andrade, et al., 2013), and weight loss (Petry, Barry, et al., 2011). Volpp et al. used a similar approach making different monetary amounts, rather than prizes, available to incentivize weight loss, and medication adherence (Volpp et al., 2008; Volpp, Troxel, et al., 2008).

One of the reasons this prize system works so effectively is because individuals have a decision-making bias toward low probability, high magnitude outcomes. More specifically, individuals have a tendency to overweight small probabilities of large magnitude outcomes (Kahneman & Tversky, 1979; Loewenstein, Weber, Hsee, & Welch, 2001), which might help explain the attractiveness of gambling and lotteries in general. This incentive system, however, is not gambling because the participant risks nothing of value (Petry et al., 2006; Petry & Alessi, 2010).

Incentive Programs Stir Controversy

The incorporation of incentives into health programs often elicits strong reactions (Priebe et al., 2009; Promberger, Brown, Ashcroft, & Marteau, 2011; Promberger, Dolan, & Marteau, 2012). Individuals who oppose these types of interventions often

note that they are paternalistic and that they may have unintended results, such as motivate healthy individuals to start adopting unhealthy lifestyle to receive incentives. The use of incentives may also be interpreted as coercive when applied to disadvantaged and low-income populations.

Promberger et al. (2011) evaluated public attitudes toward financial incentives in the United Kingdom and in the United States, and they found that individuals perceive incentives-based programs as less acceptable than equally effective alternative programs using pills or injections. Furthermore, the authors also reported that the public views the utilization of incentives more favorably when it is used as an intervention to treat individuals who are not responsible for their health condition. For example, the use of incentives in mental health patients is viewed more favorably than its utilization in substance abusers. The public's acceptability of incentives also appears to relate to the type of incentive awarded. The utilization of grocery vouchers, for example, is judged much more acceptable by the public than cash or vouchers exchangeable for luxury items (Promberger et al., 2012).

Importantly, public opinion about incentives is influenced by the effectiveness of the intervention. Promberger et al. (2012) found that even small increases in effectiveness of incentive interventions impact the degree to which individuals accept these interventions. These data suggest that as more research demonstrates effectiveness of these approaches more programs may be willing to implement them, and ultimately, the public may be more willing to endorse them.

In conclusion, the field of behavior economics has been increasingly incorporated into health care settings to promote health-related behavior change. This chapter provides an overview of studies that have provided incentive to promote engagement in treatment and outcomes in a number of different patient populations. This chapter has also described fundamental elements and concepts embedded in incentive-based programs that should be carefully considered when designing and implementing these interventions. Finally, we provided discussion on issues that are critical to the application and dissemination of these interventions.

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Chapter 3

Meeting Patients Where They Are At: Using a Stage Approach to Facilitate Engagement

Leanne M. Mauriello, Sara S. Johnson, and Janice M. Prochaska

Introduction

In response to the increasing percentages of Americans who have multiple poor health behaviors (Ford, Zhao, Tsai, & Li, 2011), are overweight or obese (“Obesity and Overweight,” 2015), and are diagnosed as prediabetic or diabetic (“Employers Are Working to Defeat Diabetes,”), our nation is finally dedicating attention, resources, and even legislation toward health and wellness programs. There are more accountability and requirements placed on health care providers to assist with disease prevention and management (Koh & Sebelius, 2010). Employers are responding to the sky rocketing cost of insuring an unhealthy workforce by offering wellness programs and onsite health clinics (Mattke et al., 2013). Health coaching is a burgeoning field and there are countless mobile apps for every health condition imagined. With a myriad of support options literally at their fingertips, at first glance it may appear bewildering as to why people, even those who need the help most, are not engaging in the many low or no cost options that abound.

To gain a clearer picture, let us take a closer look at typical engagement strategies:

L.M. Mauriello, Ph.D. (✉)
Behavioral Science and Lifestyle Management, Spectrum Health System,
648 Monroe Ave. NW, Suite 400, Grand Rapids, MI 49503, USA
e-mail: Leanne.mauriello@spectrumhealth.org

S.S. Johnson, Ph.D. • J.M. Prochaska, Ph.D.
Pro-Change Behavior Systems, Inc., 1174 Kingstown Rd.,
Suite 101, South Kingstown, RI 02879, USA
e-mail: sjohnson@prochange.com; jmprochaska@prochange.com

1. When an employer sends an email promoting a Biggest Loser or Couch to 5 K program, which employees are likely to participate?
2. When a physician recommends quitting smoking to a patient and offers a prescription for a nicotine replacement product or drug, which patients are likely to fill the prescription?
3. When an insurer sends a postcard offering free telephonic or digital health coaching for diabetes, which members are likely to respond?

The answer to those three questions is the same— those who are **READY** to change.

Each of the typical engagement scenarios above make certain assumptions: that the majority of individuals are ready to change, that the same recruitment message and programming will be applicable and effective for everyone, and that good information is enough to help people change.

Over the last 35 years, research using the Transtheoretical Model of Behavior Change (TTM) has identified that for any particular behavior the majority of any at-risk population is not ready to change (Laforge, Velicer, Richmond, & Owen, 1999; Velicer et al., 1995). Yet, the majority of programs are geared to those who are ready to change. The ground-breaking insights of Dr. James O. Prochaska and colleagues who developed the TTM teach that people who are not ready are often uninformed, under-informed, and unwillingly or too discouraged to take action (DiClemente & Prochaska, 1982; Prochaska & Diclemente, 1983). Working with people across many different areas of health, we have also learned that *wanting to change* is not necessarily the same things as *intending to change*. You might ask, why would someone want to change but not intend to change? Take a moment to think about your own life. Certainly, you can think of an area in which you'd like to make a change, one which you'd know it would be good to change, but despite this interest and awareness, you just keep doing your old behavior. Why does this happen? Your attention and efforts might be focused elsewhere, you might not know how to get started, or maybe you've tried in the past, failed, and feel demoralized. In this chapter, we'll describe how the Transtheoretical Model (TTM) can be applied to facilitate engagement in health behavior treatment. By recognizing that not everyone is ready to change, we can adapt our perspective, communications, strategies, and programs to engage individuals across different stages of readiness to change.

The overarching goals of this chapter are to:

- Provide an overview of the Transtheoretical Model of Behavior Change and the efficacy of using the model to facilitate behavior change
- Describe characteristics of individuals across the stages of change and how they relate to engagement
- Identify key principles of using a stage approach to facilitate treatment engagement

The TTM can help multidisciplinary health care providers and clinicians (physicians, nurses, pharmacists, health coaches, etc.) to effectively communicate with patients around their health behaviors and match engagement strategies to their patient's level of readiness to change. The TTM also can help researchers across various health disciplines, psychology, and behavioral sciences to successfully

recruit and engage individuals who are not ready, getting ready, and ready to engage in their research.

Using a stage approach often requires a significant shift in perspective. With this Model, change is conceptualized as a process and journey. Success is measured incrementally by engagement in the journey rather than just upon reaching the destination. It requires recognizing progress not only when you help a patient make a change, but also when you help someone begin to consider making a change. It requires patience and follow-up, as you guide patients through the journey, knowing that with each step you help them take, they are that much closer to the destination. It may require changing your default messages and suggestions to patients around health behavior changes. You may need to practice identifying someone's readiness to change and matching your engagement strategy accordingly. For some, this might entail small shifts in your work flow and for others it might mean significant overhaul. Any successful change requires readiness to change, a commitment to change, an understanding of how to change, perceived benefits of changing for you and others, support, and reinforcement. As you embark on your own journey, consider your level of readiness to integrate a stage approach in your work. Are you not ready, getting ready, ready, recently implementing it, or maintaining it? It's ok if you're not yet ready to embrace the stage approach. Try to keep an open mind as you read this chapter, and we'll ask your intentions again at the end.

Overview of the Transtheoretical Model of Behavior Change

The Transtheoretical Model of Behavior Change (TTM), also known as the Stages of Change model, is a comprehensive model that integrates ideas of several different theories and approaches to change (hence the name "transtheoretical") to explain and predict how and when individuals stop high-risk behaviors or adopt healthy ones (Prochaska, 1979). The TTM construes the change process into distinct stages of readiness (Precontemplation, Contemplation, Preparation, Action, and Maintenance) and provides approaches to help people move forward through the stages (Prochaska & Diclemente, 1983). Decades of research on a wide variety of health behaviors has found that certain principles and processes of change work best at each stage to reduce resistance, facilitate engagement and progress, and prevent relapse (Prochaska, 1994). These include decisional balance, self-efficacy, and processes of change.

Readiness to Change

Stages of Change is the TTM's central organizing construct. Longitudinal studies of change have found that people move through a series of five stages when modifying behavior on their own or with the help of formal interventions (Diclemente & Prochaska, 1982; Prochaska & Diclemente, 1983). Understanding the stages of change allows us to

Fig. 3.1 Stages of Change

appreciate change as a dynamic process and helps us learn the variability in patients' responses to and uptake of health behavior interventions. As you read the following characterizations of the stages of change, consider examples from your own work (Fig. 3.1).

Precontemplation

Precontemplation is the stage of change in which individuals are not intending to change a target health behavior in the foreseeable future (typically defined as the next 6 months). It's important to understand that there isn't just one prototype of the typical patient in Precontemplation. Patients may be not ready to change for a myriad of reasons. Individuals may deny they have a problem (it's normal to have a few beers every night), may be unaware of the negative consequences of their behavior (my weight is fine so it doesn't matter what I eat), believe the consequences are insignificant (nothing is going to happen if I don't take my cholesterol medicine every day as long as I take it sometimes), or feel helpless toward avoiding a negative consequence (everyone's going to die from something, why not enjoy life while I can). Other precontemplators may want to change, but are not ready to do so because of perceived barriers (how can I quit when everyone around me smokes), have low self-efficacy (I've tried to exercise in the past but never kept it up for more than 2 weeks), or lack of information on how to get started (I'd like to add strength training but I have no idea how to get started). Depending on their perspective, precontemplators may express denial, defensiveness, discouragement, demoralization, resistance, rationalization, or minimization of the problem. Precontemplators often perceive more cons to changing than benefits, and may experience change as coerced. These are the most difficult patients to engage in the change process, therefore are often ignored and dismissed as unchangeable. The good news is that by using a change approach, you can effectively communicate with and engage precontemplators.

Contemplation

Individuals in Contemplation are intending to make a behavior change in the next 6 months. They are more likely to recognize the benefits of changing their behavior than those in Precontemplation, but they also are acutely aware of the cons or

drawbacks of changing. This ambivalence can get them stuck in Contemplation (sometimes referred to as chronic contemplation). These individuals often lack the confidence and commitment they need to make the behavior change. Patients in Contemplation likely will agree with you that change is important and would be helpful, but they'll also list many barriers to changing. Health professionals sometimes misclassify contemplators in Preparation because of their interest in changing. Remember desire to change does not equal intention or readiness to change. Patients in Contemplation might say, "Yes, I need to get more physical activity. I'll start taking walks once the weather breaks," or "I want to quit smoking. I know how bad it is for my health and the health of my family." Those patients might initially appear engaged and ready, but later in the chapter, we'll describe how to appropriately stage and engage them.

Preparation

Individuals in Preparation are seriously intending to make a behavior change within the next 30 days and have already begun to take small steps toward the goal. They identify more pros to changing than cons, and they are confident about their plan to make a change. Patients in Preparation are ideal program participants for action-oriented programs like Weight Watchers or nicotine replacement therapies. These are the easiest patients to engage as they are ready to make a change. We'll review later the important strategies to utilize toward engaging them in treatment so as to increase movement to Action.

Action

Individuals in Action have adopted a health behavior change within the last 6 months and are actively using strategies to maintain the change. At this point, the new behavior takes a good amount of effort and they may experience a strong urge to revert back to the old behavior. Unfortunately, relapse tends to be the rule rather than the exception. The good news is that after a slip, it's typically easier to get back on track to Action than when making the initial change. Patients in Action need continued engagement to support and reinforce their change efforts and prevent relapse.

Maintenance

Individuals in Maintenance have been able to sustain Action for at least 6 months and are actively striving to prevent relapse. Those individuals are characterized by higher self-efficacy and improved coping skills. Traditional programs tend to exclude those in Maintenance; however, patients in Maintenance can benefit from reinforcement, boosts in self-efficacy, and continued support to prevent relapse.

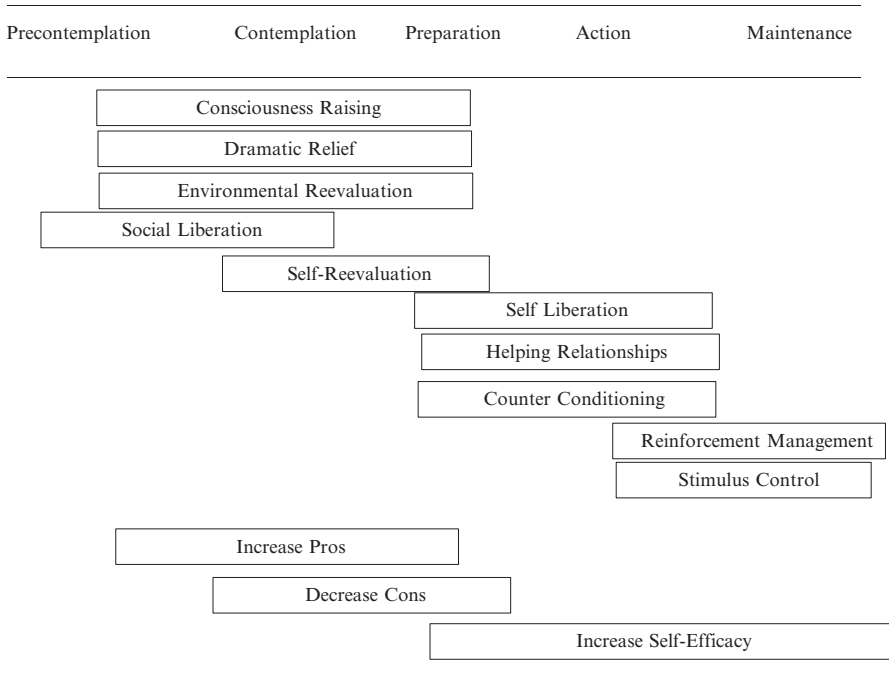


Fig. 3.2 Processes of Change

Beyond Stage of Change: Other Important Change Variables

An individual’s stage of change has important implications for selecting engagement and treatment strategies and messaging. Other constructs of the TTM, including decisional balance, self-efficacy, and processes of change, can be leveraged to facilitate engagement and progress. Figure 3.2 depicts for each stage of change which of these constructs are most important to be addressed.

Decisional Balance

Decisional balance represents an individual’s relative weighing of the pros (benefits) and cons (drawbacks or barriers) of changing (Velicer, Diclemente, Prochaska, & Brandenburg, 1985). A meta-analysis across 48 behaviors demonstrated a replicable and robust pattern of how the weighing of the pros and cons shift as individuals progress through the stages of change (Hall & Rossi, 2008). Research also found that raising the pros is twice as important as reducing the cons, as successful changers tend to increase their pros by double the amount that the cons decrease. In Precontemplation the cons outweighed the pros, by the middle stages the pros

surpassed the cons, and by the Action stage the pros outweighed the cons (Prochaska, 1994). Examples of the pros of changing a health risk behavior might be: feeling better, having more energy, or being a good role model. Examples of the cons of changing a health risk behavior might be: it'll take too much effort, I don't have the time, or I'll feel out of place.

Self-Efficacy

Self-efficacy is the degree to which an individual believes he or she has the capacity to attain a desired goal (Bandura, 1982). Within the TTM it is operationalized as confidence to make and sustain changes or temptation to relapse in difficult situations. Self-efficacy differs systematically across the stages of change and can predict who is likely to take action and sustain positive outcomes. TTM research demonstrates that across behaviors and populations, individuals further along in the stages generally experience greater confidence, individuals further along in the stages generally experience less temptation (Diclemente et al., 1991). Identifying tempting situations is critical for relapse prevention. Given the importance of self-efficacy, it needs to be addressed early by assisting individuals in setting and achieving small goals that will build their confidence for taking on increasingly difficult challenges.

Processes of Change

The processes of change represent both the covert and overt behavior change strategies that individuals use to progress through the stages of change (Prochaska, Diclemente, & Norcross, 1992). Individuals in the early stages of change tend to rely on experiential processes of change (cognitive, affective, and evaluative techniques) and individuals in the later stages of change tend to rely upon behavioral strategies of change (social support, commitments, and behavior management techniques) (Prochaska, Velicer, Diclemente, & Fava, 1988). Research demonstrates that processes differ significantly across the stages of change. Table 3.1 lists and defines each of the processes of change.

The Data Don't Lie: Using a Stage Approach Increases Impact

Before we explore how the TTM can facilitate engagement, let's briefly summarize the supporting data. Toward comparing TTM-based approaches to non-TTM-based approaches, it's important to appreciate that the impact of treatment is a combination of both the participation or engagement and the efficacy (Velicer & DiClemente, 1993). This is represented by the following equation: $\text{Participation} \times \text{Efficacy} = \text{Impact}$.

Table 3.1 Processes of change

Consciousness Raising	Learning new facts, ideas, and tips that support the healthy behavior change
Dramatic Relief	Experiencing negative emotions (fear, anxiety) that go along with the old behavior or the positive emotions (e.g., inspiration) that go along with behavior change
Environmental Reevaluation	Realizing the negative impact of one's behavior—and the positive impact of change—on others
Self-Reevaluation	Realizing that the behavioral change is an important part of one's identity
Social Liberation	Realizing that social norms are changing to support the healthy behavior
Helping Relationships	Seeking and using social support to make and sustain changes
Counter Conditioning	Substituting healthy alternative behaviors and thoughts for unhealthy ones
Reinforcement Management	Increasing the intrinsic and extrinsic rewards for healthy behavior change and decreasing the rewards for old behaviors
Stimulus Control	Removing reminders or cues to engage in the old behaviors, and using cues to engage in the new healthy behavior
Self-Liberation	Believing in one's ability to change and making a commitment to change based on that belief

In this section, we'll review how the stage approach facilitates both participation and efficacy, thereby producing more meaningful impact on overall patient populations.

TTM-based approaches result in increased participation and engagement because they appeal to the whole population rather than just the minority ready to take action. TTM research across many behaviors and populations has demonstrated repeatedly that only a minority of any at-risk group are in Preparation (typically 20%) with the majority in Precontemplation and Contemplation (typically 80%) (Velicer et al., 1995; Wewers, Stillman, Hartman, & Shopland, 2003). Yet, most behavior change messaging and treatments are action-oriented and assume readiness to participate. Such methods engage just the 20% or so of people who are ready to change and mis-serve the majority of at-risk people who are not prepared to take action. With this information at hand, it isn't surprising that the average participation of health promotion programs is quite modest with one worksite health promotion review of 59 studies finding a median retention rate of 57% (Soler et al., 2010), while TTM-based programs often achieve greater than 80% participation (Prochaska, Velicer, Fava, Rossi, & Tsoh, 2001). TTM approaches engage whole populations because they are perceived as more respectful, relevant, engaging, and appealing, thereby reducing resistance and reactance among early stage individuals. By using a stage approach, more people are engaged, which is a critical factor toward population-based impact.

Consider this example: You have a patient who is middle aged, overweight, has elevated blood sugar levels, and a family history of diabetes. You've diagnosed the patient as prediabetic. You know the patient needs intensive lifestyle changes and

support to reverse the path toward Type II Diabetes. It may seem logical to recommend the Diabetes Prevention Program at the local hospital, as that is an evidence-based national program for improving lifestyle, losing weight, and reversing elevated blood sugar. Diabetes Prevention Programs entail 6 months of personalized coaching, group sessions, and structured exercise, and another 6 months of monthly meetings (Knowler et al., 2002; “The Diabetes Prevention Program,” 1999). For which stage do you think this program is best suited?

The Diabetes Prevention Program would be ideal for someone in Preparation. But, what if your patient is in Precontemplation? Do you think someone not intending to change would be willing to make such an intensive time commitment? This example elucidates why it’s important to know the stage of readiness of your patients, and to engage them in a treatment matched to their readiness. Perhaps a better initial engagement strategy for someone in Precontemplation is to ask if they’d be willing to meet with a diabetes educator to learn more about prediabetes and their risk factors. Such an engagement strategy can work to increase their awareness of their health risks and potentially move them to Contemplation. If they agree to see the diabetes educator, that step might even prepare them to be ready for engagement in the Diabetes Prevention Program. A stepped-care approach is critical toward matching treatments based on stage of change.

It’s important to communicate upfront that the goals you set with your patient will correspond with where they are in the change process. By doing so you not only will engage more early stage individuals, you also will keep them engaged on an ongoing basis. In a current randomized clinical trial of a mobile health program for risky drinking adults, we’ve been able to retain 70% of the proactively recruited at-risk sample 12 months later because we engaged them with messages matched to their readiness to change (Mauriello, 2014). During the initial engagement, we worked to reduce resistance and reactance among high-risk drinkers in Precontemplation with such messaging:

“This program is not about asking you to stop drinking alcohol. It’s about helping you make the best choices about alcohol use in your life. This program is designed to help whether you:

- *Drink alcohol every day, every week, or once a month*
- *Are thinking about cutting back on alcohol or not*

We’re not pushing you to make any changes. Our goal is to respect where you’re at and develop a personal plan that works for you.”

Consider your own typical engagement messaging and treatment prescriptions. How matched are they to level of readiness to change?

TTM-based approaches can accelerate rates of behavior change. While, action-oriented programs may do well to help those ready to change, their impact is limited to the small percentage of people who are ready to change. By using a stage approach we not only increase participation, we also increase the likelihood that individuals will eventually take action. Research demonstrates that helping participants move forward at least one stage of change (such as moving from Precontemplation to Contemplation) can as much as double the likelihood that they will move to the

Action stage in the next 6 months. Helping them move two stages can triple their chances of taking action (Prochaska et al., 2001). This information leads us to reconceptualize success as stage progress rather than taking action. This reconceptualization is often reported by health professionals working to integrate a stage approach as the biggest shift in their perspective. By conceptualizing success as progress, you and your patients have the opportunity to appreciate change and success incrementally, while at the same time increasing the likelihood that they will reach the long-term desired outcomes.

TTM-based approaches are more efficacious. A large body of literature supports the increased efficacy of stage-matched programs over action-oriented and one size fits all interventions. Meta-analyses conclude that tailoring on TTM constructs produces greater impacts than tailoring on most constructs of other behavior change theories (Krebs, Prochaska, & Rossi, 2010; Noar, Benac, & Harris, 2007). TTM-based treatments have been found effective across dozens of behaviors and populations (Evers et al., 2006; Johnson, Driskell, Johnson, Dymont, et al. 2006; Johnson, Driskell, Johnson, Prochaska, et al. 2006; Johnson et al., 2008; Levesque, Ciavatta, Castle, Prochaska, & Prochaska, 2012; Mauriello et al., 2010), and have been found to surpass the average outcomes of other behavior change programs identified as benchmarks by a national task force (Johnson et al., 2013). Recent research demonstrates the additional impact TTM-based treatment can have on overall and specific domains of well-being (Prochaska et al., 2012).

TTM-based approaches impact multiple risks. During the last decade, several randomized clinical trials of TTM-based interventions have demonstrated the ability to impact multiple risks, even risks that were not specifically treated (Johnson et al., 2014; Johnson & Evers, 2015). This research includes areas such as adherence to antihypertension and lipid-lowering medication, weight management, and obesity prevention (Johnson et al., 2008; Johnson, Driskell, Johnson, Dymont, et al. 2006; Johnson, Driskell, Johnson, Prochaska, et al. 2006; Mauriello et al., 2010; Velicer et al., 2013). Through this research, the phenomena of coaction have been described as the increased probability that individuals who adopt one health behavior will adopt another health behavior. For example, in a randomized clinical trial of a TTM tailored weight management intervention for overweight adults, the treatment group demonstrated a 2.5–5.2 increased likelihood of success on a second behavior. The control group demonstrated a 1.2–2.6 increased likelihood of success on a second behavior (Johnson et al., 2014). Given the vast differences in probability of additional behavior change between successful changers in the treatment group compared to control, it can be concluded that this is not a naturally occurring phenomenon. Similar findings from other multiple behavior trials cumulate evidence that coaction occurs more in groups receiving tailored behavior change treatments. It can be hypothesized that by teaching individuals strategies that support the change process, they then apply those strategies successfully to other areas.

Key Principles of Using a Stage Approach to Facilitate Treatment Engagement

Let's apply the TTM principles to the topic at hand: treatment engagement. Whether you're a diabetes educator, nurse practitioner at a worksite clinic, family practice physician, midwife at a community health center, a registered nurse on an in-patient unit for cardiac rehabilitation, or a research scientist recruiting participants in a clinical trial on medication adherence, you likely face daily challenges in engaging patients and participants in health behavior change treatment. Using the TTM and stages of change as a framework in your interactions with patients, can provide helpful assistance in that process.

Assess Stage of Change

In order to use the stage approach, a necessary first step is identifying which stage of readiness best classifies your patient. First, we'll review what's entailed in assessing stage of readiness and then we'll describe how you can accomplish the assessment.

Operationalize the Target Behavior (Action Criteria)

A critical component of assessing stage of readiness is clearly operationalizing the target behavior and action criteria. This can be thought of as what one would be doing if they were in Action. Sometimes that's an easy step. For example, the action criteria for smoking cessation are not smoking. Sometimes, the behavior might have multiple criteria. For example, the national guidelines for getting enough exercise includes a specific level of moderate-level and/or vigorous-level aerobic activity combined with strength training. Whenever possible, it's best to use national guidelines for the definition of the target behavior's action criteria.

Assess Stage of Readiness to Do a Behavior Not Meet an Outcome

Another important consideration when identifying stage of readiness is assessing readiness to engage in a behavior and not to meet an outcome. It's not appropriate to stage on readiness to lose weight or lower their A1C. Those are outcomes that you'll monitor. It's important to stage on specific and concrete action criteria.

Assess Stage of Readiness for All Relevant Health Behaviors

In areas such as weight management or diabetes management, there certainly may be multiple behaviors that are important to assess and treat. While multiple behavior change is a challenging area, as described earlier the TTM has been used to successfully change multiple behaviors and reduce multiple risks. It's important that you understand your patient's readiness to do each of the relevant healthy behaviors. You'll be able to use that information to set appropriate goals and treatment plans.

For example, consider you're working with a patient with hypertension (let's pretend this patient is of normal weight so weight management is not an issue). Upon diagnosis, you may want to know if they smoke, if they drink alcohol heavily, if they are sedentary, if they have a high consumption of sodium in their diet. The patient reports smoking, very little physical activity, but reasonable levels of sodium and alcohol consumption. There are two health risks that you'll want to understand their readiness to change (smoking cessation and physical activity). But, you also plan to prescribe an antihypertension oral medication. You'll also want to know their readiness to take the medication as prescribed.

To begin with, you'll want to assess their readiness to quit smoking, to get at least 150 min of moderate exercise each week, and to take their newly prescribed medication according to your instructions. Upon understanding their readiness, you can use that information and your clinical judgment to set goals and identify treatment plans. In working with multiple risks, it's often beneficial to prioritize the at-risk behavior that the patient is most ready to change. If someone is in the Preparation stage, you can set goals and offer treatment options that will likely help them fairly quickly reach action. Upon making that successful behavior change, they will have a success under their belt and likely will have increased confidence and skills to make additional behavior changes. However, at times your clinical judgment might require addressing a critical behavior for which they are in an earlier stage of change. For example, you may need to focus in a stage-appropriate way on insulin adherence with an uncontrolled diabetic or smoking cessation with a heart failure patient or a pregnant woman because of the timely and critical nature of the condition.

Assessment Options

There are several options by which stage of change can be assessed in clinical and research settings. For many health areas reliable and valid assessment tools have been developed and can be found in published articles or online and available in the public domain. Other times measures can be licensed through the companies that developed them. To gather a complete assessment of patient health risks, Health Risk Assessments and Interventions can be licensed and incorporated within your patient portal or electronic medical software. A list of companies with Health Risk

Assessments certified by the National Committee for Quality Assurance (NCQA) can be found at <http://www.ncqa.org/>. Using certified assessment tools offers the most reliable and consistent way to monitor and report patient health behaviors and risks longitudinally. For those without the resources to implement standardized protocols, providers can administer staging questions during their patient interview. In doing so, it’s important to identify a specific and well-defined behavior and to ask their intention to do the behavior according to this sample:

- Do you intend to {insert action criteria}?
- No I don’t intend to do so in the next 6 months (Precontemplation).
- Yes, I intend to do so in the next 6 months (Contemplation).
- Yes, I intend to do so in the next 30 days (Preparation).
- Yes, I have been doing so for less than 6 months (Action).
- Yes, I have been doing so for more than 6 months (Maintenance).

Use Stage-Matched Communications

Once you’ve identified the action criteria and understand your patient’s intention to do the action criteria, the next step is to use that knowledge to target your engagement strategy. You can be empowered to be proactive and reach entire populations—not just those ready to change. To be successful, approach engagement as a process that is inclusive, empathetic, respectful, and optimistic. Below are guidelines for considering the patient perspective and approaching engagement by stage of change.

Precontemplation	
<i>Patient perspective</i>	<i>Approach to Engagement</i>
<ul style="list-style-type: none"> • Not ready to change/not intending to change • May experience change as coerced • Might feel defensive, demoralized, or reluctant • May respond with denial, reactance, or resistance • Under or unaware of problem • Identifies many cons to changing • Under-recognizes benefits to changing 	<ul style="list-style-type: none"> • Engage them in the change process • Use motivational interviewing techniques (e.g., open-ended questions, reflection) • Avoid lectures or confrontation • Increase awareness of the problem • Discuss benefits of changing • Move them emotionally based on current and future consequences of the unhealthy behavior • Encourage movement to Contemplation • Suggest less intense treatment options
Contemplation	
<i>Patient perspective</i>	<i>Approach to engagement</i>

(continued)

Contemplation	
<ul style="list-style-type: none"> • Aware that problem exists • Expresses some interest in changing eventually • Recognizes benefits to changing • Marked by ambivalence • Acutely aware of the cons or barriers to changing • Lacks commitment to change • Lacks confidence to change • Might feel stuck—not sure how to make progress 	<ul style="list-style-type: none"> • Resolve ambivalence so pros outweigh the cons • Help problem solve around significant cons perceived by patient • Reinforce benefits to changing (the longer the list the better) • Encourage self-reflection of own current behavior and patterns • Encourage reflection of how self-image would improve if behavior changed • Don't encourage action • Encourage small steps • Interventions can involve some level of demands (but still low intensity)
Preparation	
<i>Patient perspective</i>	<i>Approach to engagement</i>
<ul style="list-style-type: none"> • Intending to make a change in the next month • Preparing to act • Has taken some small steps • Recognizes more benefits than cons to changing • Expresses commitment to change • Has confidence in ability to change • Developing a plan toward meeting action criteria 	<ul style="list-style-type: none"> • Goal is to encourage, excite, and empower patient • Provide support • Create an action plan that includes start date and steps to action • Ensure patient has necessary support systems • Encourage reflection on how self-image will change • Problem-solve any barriers to change • Provide examples and inspiration of successful changers • Refer to more intense action-oriented treatment options
Action	
<i>Patient perspective</i>	<i>Approach to engagement</i>
<ul style="list-style-type: none"> • Recently made a behavior change • Still actively working (giving time and energy) to sustain the change • May experience strong urge to revert back to old behavior • Identifying difficult times to stay adherent • Slips and recycling to earlier stage common 	<ul style="list-style-type: none"> • Support action • Provide praise and recognition • Communicate that sustaining action takes effort and commitment • Encourage coping skills to handle urges to slip • Ensure patient recognizes rewards associated with the new behavior • Ensure their environment and routine support lasting action • Assist with strategies to prevent relapse • Intense treatment options still appropriate
Maintenance	
<i>Patient perspective</i>	<i>Approach to engagement</i>

(continued)

Maintenance	
<ul style="list-style-type: none"> • Maintaining a behavior change for at least 6 months • High confidence • High commitment • Slips still can happen • Experience fewer temptations to slip back • Risk for relapse highest during times of distress 	<ul style="list-style-type: none"> • Understand that change is dynamic and slips are the rule not exception • Consult on challenge of ongoing doing the healthy behavior • Focus on relapse prevention • Ensure good coping skills for times of distress and ongoing stress management • Assist with keeping confidence high • Create plan for dealing with distress • Encourage patients to learn from slips and plan accordingly

Call-Out Box:

Using a Stage Approach for Recruitment Messages

When introducing or advertising a health behavior treatment, it’s important that recruitment messages are representative of all stages or specific to a stage of readiness. Be cautious of action-oriented wording. Typical recruitment messages assume readiness and interest in changing. Here are some examples of promotional materials grounded in a stage approach:

If using one message to appeal to people across the stages:

Whether you’re ready, getting ready, or not ready....This program can help you. Wherever you are at, we can work with that.™ This program provides guidance based on your readiness for making lifestyle changes.

If using stage-matched materials specific to a stage:

For Precontemplation:

Not ready to quit smoking? We hear you and we can help. This program is designed to help you at your pace, when YOU are ready.

For Preparation:

Ready to quit smoking? This program offers the help you need to succeed.

Assist in Stage Appropriate Way

Part of your engagement strategy should include assisting with a stage appropriate goal or treatment plan. Table 3.2 lists some examples of stage-matched patient goals applied to exercise behavior. Just as your engagement strategy and treatment goals should be sensitive to stage of readiness, so should the treatment options and next steps. Stage of readiness and TTM principles of change should drive the design of behavior change programs. Programs need to be appropriate for patients in all stages of change or prescribed to those for whom it is relevant. TTM-based computer-tailored interventions are one option of health behavior counseling that is appropriate

Table 3.2 Example stage-matched goals for exercise

Precontemplation
<ul style="list-style-type: none"> • Make a list of the benefits of getting regular exercise and post it in a spot you can see every day • Make a list of people who are affected by your inactivity and how you could be a role model if you started exercising regularly • Consider one way you would be open to getting some physical activity • How many minutes of exercise are you confident you can increase by in the next month?
Contemplation
<ul style="list-style-type: none"> • Learn more about types of exercises you might want to try by: {talking with friends who exercise or visiting trustworthy web sites or mobile apps} • Make a list of how you would feel about yourself if you started exercising regularly • Feel inspired by talking with people who successfully get exercise regularly • How many minutes of exercise are you confident you can increase by in the next month?
Preparation
<ul style="list-style-type: none"> • Share your commitment to exercise regularly with others • Choose at least two people to support your efforts and ask each to support you in a specific way: {for example, encouraging you to exercise, exercising with you, and/or checking in to see how you're doing} • Instead of {relying on old ways of thinking}, say "I will {substitute positive thoughts about exercise}" • Set a start date for target behavior: When will you begin to exercise at least 150 min a week (or whatever level you agreed was safe and reasonable for the patient)?
Action
<ul style="list-style-type: none"> • Identify difficult times to get enough exercise, and list ways to overcome those barriers • Create environments and routines that support getting regular exercise • Share your successes with others • Continue to exercise at least 150 min a week (or whatever level you agreed was safe and reasonable for the patient)
Maintenance
<ul style="list-style-type: none"> • Keep a list of the rewards you notice as a result of exercising regularly • Identify difficult times that may cause a slip and plan for how you can overcome them • Continue to set new exercise goals to keep yourself motivated such as {trying a new type of exercise each month} • Continue to exercise at least 150 min a week (or whatever level you agreed was safe and reasonable for the patient)

for all patients because the programs are individualized based on their stage of readiness for specific target behaviors (for more information refer to <http://www.prochange.com/myhealth-lifestyle-management>). To see a demonstration of such a program, go to www.prochange.com/exercisedemo. Before referring patients to a treatment resource, consider how relevant and helpful the program will be given their intention to change. Remember that action-oriented programs such as weight loss programs or nicotine replacement products should be limited to those who are ready to change. In deciding if a program is suitable for someone in early stages of change, consider the intensity and demands, the goals, and the communication style

of the program. Joining an online support group around a specific health behavior or condition is an example of a low intensity, low demand, and convenient means to engage someone in Precontemplation or Contemplation.

Follow-up is an important aspect to assisting and engaging patients in health behavior change. When resources allow, it's ideal to follow up regularly to assess progress with goals. Follow-up touch points can be matched to readiness to change, with those in Preparation and Action requiring the most frequent follow-up. As patients progress through the stages of change, be sure to alter your recommendations based on their stage movement.

Conceptualize Success as Progress

As mentioned in the introduction, an important component to implementing a stage approach is re-conceptualizing success as progress rather than action. Actually doing the target behavior to criteria is a measurement of success for those in Preparation, Action, and Maintenance. That is not a reasonable goal for patients in Precontemplation and Contemplation. Instead, a patient progressing to the next stage of change is a measure of success. Helping patients move forward at least one stage of change (such as moving from Precontemplation to Contemplation) can be as much as double the likelihood that they will move to the Action stage in the next 6 months. Helping them move two stages can triple their chances of taking action (Prochaska et al., 2001). By re-conceptualizing success as stage progress rather than taking action, we are given opportunity to praise, appreciate, and endorse progress as metrics of change. At times incentives are used as a way to promote participation in health promotion activities. It's also reasonable to offer incentives to those in early stages for meeting stage-matched goals and for making stage progress. By recognizing progress, you can help your patients engage and embrace the change process.

Conclusions

After reading this chapter, hopefully you feel more enlightened, empowered, and prepared to incorporate a stage approach in your work. Recognizing the unique needs of individuals in early stages and re-conceptualizing progress as movement to the next stage can assist in significantly increasing the impact of your engagement with patients. Those who seek additional guidance can participate in an e-Learning module developed on using the TTM for coaching (details at www.prochange.com/e-learning) or refer to Mastering Change: A Coach's Guide to Using the Transtheoretical Model with Clients ("Mastering Change," 2001). Decades of research on and implementation of the TTM in clinical, worksite, research, community, and digital settings provides replicated evidence of the utility of the Model

to engage, effect, and impact health behavior change. Health professionals who have implemented the Model report great success and satisfaction both in their interactions with patients and their ability to effect change. Embracing a stage approach can be quite powerful and lead to systemic changes in how organizations approach patient interaction, behavior change programming, and metrics of success. There are many benefits integrating a stage approach to patient engagement including:

- Prepares you to communicate and work with entire populations wherever they are in the stages of change.
- Helps you to increase engagement and reduce resistance among your patients.
- Allows you to see and appreciate how your patients are making progress in stages.
- Enables you to set stage-matched goals with patients.
- Empowers you to offer and prescribe behavior change programs that are stage appropriate or population-based.
- Teaches you the principles and processes of change that are applicable across all health behaviors.
- Shows you an approach that's successful at increasing engagement, increasing health behaviors, reducing multiple risks, and enhancing multiple domains of well-being and productivity.

With the knowledge and tools needed to move forward, we end with a final question for your consideration.

How ready are you to integrate a stage approach in your work?

1. I don't intend to integrate a stage approach in my work in the next 6 months.
2. I intent to integrate a stage approach in my work in the next 6 months.
3. I intend to integrate a stage approach in my work in the next month.
4. I have been integrating a stage approach in my work for less than 6 months.
5. I have been integrating a stage approach in my work for more than 6 months.

Use your readiness to guide your next steps.

1. If you're in Precontemplation, look for more information on using a stage approach and consider how your work, your patient interactions, and your colleagues might benefit by adopting a stage approach.
2. If you're in Contemplation, learn more about using a stage approach by talking with others who use it and seeking additional training in the approach, identify what barriers might be in the way and consider ways to overcome them, and feel inspired by how the stage approach has helped others to more successfully engage patients.
3. If you're in Preparation, make a commitment to begin using a stage approach and share that commitment with others, build your confidence by role playing or practicing the approach with patients, and ask colleagues to support and assist your efforts, and notice the benefits.

4. or 5. If you're in Action or Maintenance, keep this chapter and other training materials visible to make it easy to use a stage approach, appreciate the benefits it offers you and your patients, and boost confidence by using the approach even with resistant patients.

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Chapter 4

DBT and Treatment Engagement in the Context of Highly Suicidal Complex Clients

Noam Lindenboim, Anita Lungu, and Marsha M. Linehan

Dialectical Behavior Therapy (DBT) (Linehan, 2014a, 2014b; Linehan, 1993) was developed by Linehan in the 1980s to treat individuals who were chronically at high risk for suicide and who met criteria for multiple mental disorder diagnoses. Many such clients with high risk for suicide met criteria for Borderline Personality Disorder (BPD) (Leichsenring, Leibing, Kruse, New, & Leweke, 2011). Linehan saw emotion dysregulation as a core problem for these clients that led to many dysfunctional or destructive behaviors that significantly interfered with their lives.

Linehan's goal was to treat this clinical population to help suicidal individuals build a life worth living, not to develop a new treatment. The intense suffering in the lives of suicidal individuals made change a mandate of treatment. Linehan reverted to classic behavior therapy (Goldfried & Davison, 1976; Skinner, 1974), the technology of change, as the means to achieve that change. However, an unwavering focus on change was not a good fit for individuals with emotion dysregulation and high sensitivity to invalidation. Clients responded negatively to this approach. They experienced suggestions for change as invalidating leading to intense shame, anger, and urge to suicide. Basically, clients experienced suggestions that they need to

N. Lindenboim, Ph.D. (✉)

REACH—Domiciliary Care for Homeless Veterans, VA Boston Healthcare System,
Mail Stop (181D), Brockton, MA 02301, USA

Department of Psychology, University of Washington, 3935 University Way NE,
Seattle, WA 98195-5915, USA

e-mail: Noam.Lindenboim@va.gov

A. Lungu, Ph.D.

Lyra Health, 20380 Stevens Creek Blvd. Apt 332, Cupertino, CA 95014, USA

e-mail: anital2@uw.edu

M.M. Linehan, Ph.D.

Department of Psychology, University of Washington, 3935 University Way NE,
Seattle, WA 98195-5915, USA

e-mail: linehan@u.washington.edu

change their behavior as messages that they were “bad,” or that they were to be blamed for their problems. A focus on standard cognitive techniques that challenged clients’ maladaptive beliefs was also nonproductive. Clients perceived cognitive restructuring as equally invalidating of their experience and communicating that once again they were “bad” and their suffering was their fault. These reactions were consistent with insights from the social psychological literature on consistency theory. Research by Swann and colleagues explains how information that does not confirm individuals’ self perception leads to increased arousal, cognitive dysregulation, and discarding of new information (Swann, Stein-Seroussi, & Giesler, 1992). A demand for change was extraordinarily painful for highly suicidal, diagnostically complex clients, and led to disengagement from therapy manifested by a variety of responses such as dissociation, lack of collaboration, abrupt termination of sessions, or ultimately abandoning therapy altogether.

Close empirical observations during therapy lead to the conclusion that a change-focused treatment approach was not effective for complex clients with high risk for suicide. As a result, Linehan changed her approach completely, moving to an acceptance-based Rogerian stance, based on the assumption that clients have the inner wisdom and capacity to solve their own problems and alleviate their own suffering. Such an acceptance-based approach was also perceived as invalidating by clients, who communicated to Linehan “If you really understood how much I am suffering, how could you suggest I don’t change anything?”.

Both unwavering change and unwavering acceptance were perceived as invalidating of clients’ suffering and were not successful in effecting clinical change. The solution that evolved and became the foundation of DBT was seeking a balance between accepting the clients as they are in the moment (and helping them accept themselves), while helping them change to build a life worth living. Dialectics emerged as the glue that helped contain these apparently mutually exclusive perspectives into a coherent philosophical stance (Linehan & Schmidt, 1995). It is this attempt that led to embracing an overarching dialectical philosophy to treatment.

Given the complexity of this clinical population, treatment engagement was a fundamental aspect to be addressed. Indeed, DBT includes an array of strategies for increasing treatment engagement. The importance of identifying and solving behaviors that got in the way of therapy led to defining a new concept—“therapy-interfering behaviors” (TIBs). Essentially, TIB represents any behavior from the client, therapist, or the greater environment that gets in the way of the client receiving therapy. The complexity and abundance of problems that needed to be solved to build a life worth living for highly suicidal individuals led to the creation of a hierarchy of primary targets to guide efficient allocation of therapy resources to the most critical problems (Linehan, 1993). At the top of the target hierarchy in DBT are decreasing life-interfering behaviors, followed by decreasing TIBs, then decreasing quality of life-interfering behaviors, and finally, increasing behavioral skills.

Although specific strategies targeting an increase in client engagement with treatment were initially developed in the context of diagnostically complex suicidal clients, such techniques have broad applicability and evidence for efficacy across a wide array of clinical populations and problems. In this chapter, we begin with a brief overview of research on DBT's efficacy and treatment retention across a broad range of clinical populations and problems and review engagement strategies that are part of DBT, with a particular focus on TIBs.

Overview of Research on DBT's Efficacy and Treatment Retention

Currently, DBT is an internationally recognized evidence-based treatment (EBT) for individuals meeting criteria for BPD (Kliem, Kroger, & Kosfelder, 2010; Stoffers et al., 2012) and other diagnoses. Multiple randomized clinical trials (RCTs) have evaluated DBT and found it efficacious for individuals specifically selected for high risk for suicide (Linehan et al., 2006; Linehan, Armstrong, Suarez, Allmon, & Heard, 1991; McMMain et al., 2009; Pistorello, Fruzzetti, MacLane, Gallop, & Iverson, 2012). For example, participants in DBT made half the number of suicide attempts, were less likely to visit the emergency departments for suicidality, and were 73% less likely to be hospitalized for suicidality compared to treatment-as-usual (TAU) (Linehan et al., 2006). DBT was also found superior in decreasing suicide attempts when compared to a psychodynamic treatment supervised by experts (Pistorello et al., 2012), but not when compared to general psychiatric management plus emotion-focused psychotherapy (McMMain et al., 2009).

Findings are mixed when evaluating DBT's efficacy compared to control treatments for decreasing suicide ideation, with some studies finding DBT to have superior outcomes (Koons et al., 2001) while others not finding such an effect (Linehan et al., 1991, 2006). In evaluating DBT's efficacy on reducing non-suicidal self-injury (NSSI) most RCTs found DBT to be superior to the control condition (Bohus et al., 2004; Koons et al., 2001; Linehan et al., 1991); however, some studies found no differences in reduction of NSSI between DBT and the control condition (Carter, Willcox, Lewin, Conrad, & Bendit, 2010; Linehan et al., 2006).

Use of crisis services is another outcome of interest particularly with individuals at high risk for suicide and who have a complex diagnostic picture. Some studies found DBT to be more effective at reducing visits to the emergency department, admissions to hospitals for psychiatric reasons, and duration of stay in psychiatric hospitals (Koons et al., 2001; Linehan et al., 1991, 2006), while others did not (Carter et al., 2010; McMMain et al., 2009).

In studies evaluating its efficacy in the treatment of BPD or suicidal behavior, DBT has also been found to be effective in treating co-occurring disorders. Compared to control conditions, DBT was found more effective for individuals

meeting criteria for BPD and comorbid substance dependence (Linehan et al., 1999, 2002) as well as in reducing high-prevalence co-occurring conditions such as depression and anxiety (Bohus et al., 2004; Koons et al., 2001; Pistorello et al., 2012; Soler et al., 2005).

Skills-only DBT groups represent a cost-effective treatment delivery option. Skills training was identified as a mechanism of change in DBT mediating outcomes as decrease in suicide attempts, NSSI, and depression, as well as increase in anger control over time (Neacsiu, Rizvi, & Linehan, 2010). In light of these findings, significant research has evaluated DBT skills-only as a treatment option for a wide variety of conditions. At least 12 published RCTs evaluating DBT skills-only treatment found it efficacious with clients with BPD (Soler et al., 2009), binge eating (Hill, Craighead, & Safer, 2011; Safer, Robinson, & Jo, 2010; Safer, Telch, & Agras, 2001; Telch, Agras, & Linehan, 2001), treatment-resistant depression (Harley, Sprich, Safren, Jacobo, & Fava, 2008), depressed older adults (Lynch, Morse, Mendelson, & Robins, 2003), incarcerated women with childhood abuse (Bradley & Follingstad, 2003), ADHD (Fleming, McMahan, Moran, Peterson, & Dreessen, 2014; Hirvikoski et al., 2011), bipolar disorder (Van Dijk, Jeffrey, & Katz, 2013), and other mood and anxiety disorders (Neacsiu, Eberle, Kramer, Weismann, & Linehan, 2014).

In an RCT comparing standard DBT with TAU, participants randomized to standard DBT were more likely to start therapy by coming for the first session. Specifically, 100 % of individuals referred to DBT started the treatment compared to 73 % in TAU. For participants who started therapy, a greater percentage remained in DBT therapy with the same therapist for 1 year of treatment (83.3 % in DBT compared to 42 % in TAU) (Linehan et al., 1991). Compared to community treatment by experts, participants in the DBT condition were three times less likely to drop out of therapy with the first assigned therapist or to drop out of therapy altogether (Linehan et al., 2006). No differences were found in rates of drop-outs for participants in DBT compared to psychodynamic treatment supervised by experts (Pistorello et al., 2012) or to general psychiatric management plus emotion-focused psychotherapy (McMain et al., 2009).

Participants with high emotion dysregulation who met criteria for one or more mood or anxiety disorders in DBT skills-only group were less likely to drop out compared to participants in an activity-based support group (32 % dropped out in the DBT skills-only group versus 59 % in the activity support group (Neacsiu et al., 2014). No reliable differences were found in drop-out rates among BPD veteran participants in DBT skills-only group compared with TAU control condition (23 % versus 17 %) (Koons et al., 2001). In a study comparing DBT skills for participants meeting criteria for BPD a greater number dropped out from the standard group therapy (the control condition) compared to the DBT skills-only group (63.4 % compared to 34.5 %). A study teaching DBT skills-only to individuals with bulimia experienced no drop-out for the DBT condition (Safer et al., 2001). Another study focusing on binge eating experienced a 15.5 % drop-out rate in the DBT skills group (Hill et al., 2011).

DBT Strategies for Engagement in Beginning Stages of Treatment

As mentioned above, DBT initially targeted a clinical population that was notoriously difficult to engage and retain in treatment. DBT targets engagement from the very beginning of treatment. First, for individuals identified as high risk for suicide (e.g., recently discharged from emergency room or an inpatient unit), DBT therapists are proactive and attempt to schedule and hold a first session as soon as possible. Although minimizing the time between referral and a first session is particularly relevant for suicidal clients, such an approach is likely to increase first session attendance for the majority of clients.

Engagement and Commitment Strategies Used During the First DBT Sessions

Treatment engagement is at the forefront of the initial therapeutic interactions with any therapy client. In a very real sense, the goal of the first session is the second session. If clients do not engage very early on, all other therapeutic tasks may not matter. The first four sessions of individual therapy in DBT are specifically focused on obtaining commitment to therapy, increasing engagement with treatment, and generating hope. For example, DBT therapists schedule the first four sessions of therapy when the client starts therapy eliciting an implicit commitment from the client to attend to more than the first session. No less importantly, advanced scheduling provides a structure to enhance the likelihood of attending a future therapy session (in essence, clients “opt-out,” rather than “opt-in,” future sessions). These 1–4 initial sessions are considered “pretreatment.” Several specific techniques borrowed from social psychology are utilized in the first few DBT sessions to assist with those goals. These techniques are specifically used in the initial DBT sessions, but can be revisited at any point in therapy when progress is blocked due to lack of commitment from the client (the therapist, of course, has to first assess and determine that low commitment is the interfering factor to advancing treatment).

Eliciting Client’s Goals for Therapy

The first session starts, as in other cognitive behavior therapies, by exploring reasons for seeking treatment and eliciting treatment goals. It is common for clients to have difficulty in the beginning to generate any goals. That can happen due to high hopelessness or fear of disappointment if goals are not met, particularly in the context of past failures in therapy. Any treatment goals throughout the first session are

linked to the client's goals. For example, therapists may have to articulate how engaging in suicidal, or other destructive behaviors, is ultimately incompatible with the client's goals and a life experienced as worth living. The therapist works to achieve client commitment to stop specific ineffective behaviors (e.g., self-injurious behaviors, substance use, binge-eating) and to engage in treatment for a specified period of time that may be renegotiated at the end of the contracting period. The public commitment is one strategy to enhance engagement that is supported by consistency theory and research on social psychology of public commitment (e.g., Heider, 1958; Schlenker, Dlugolecki, & Doherty, 1994). Engagement is increased when therapy tasks are specifically and transparently linked to clients' goals. Therefore, linking therapy tasks to these goals is used throughout treatment to increase client engagement and adherence (e.g., discussing the need to understand recent self-injurious behavior through a chain analysis to build a life free of self-destructive behaviors).

Pros and Cons Technique

The next step is to elicit commitment to the work of therapy by asking clients for their own reasons for engagement in treatment. If clients cannot articulate such reasons, therapists engage in a *Pros and Cons* technique of discussing with clients why therapy makes sense given the clients' goals as well as drawbacks of engaging in therapy (such as the time commitment involved, the hard work required, the discomfort of changing your behavior).

Devil's Advocate Technique

Once the client generates some reasons supporting commitment to treatment the therapist engages in a different technique called the Devil's Advocate in which the therapist challenges the client's reasons with the goal of eliciting from the client more reasons to back up the commitment (Goldfried, Linehan, & Smith, 1978). The essence of this strategy is to strengthen client commitment through argument against it. Once a client expresses a commitment to engage in, or to stop, a particular behavior, the therapist questions and challenges that commitment. The idea is to get the client to argue for the commitment and verbalize personal reasons for this treatment goal. The therapist strategically strengthens or backs away from challenging the client according to the client's responses until a firmer commitment is achieved. By articulating specific reasons why the client chooses to commit to treatment goals, the client also rehearses those reasons making it more likely that these would be accessible to memory in the future when doubts about treatment might surface.

Devil's Advocate Example:

Therapist: So it seems purging has been a problem for you for quite some time now.

Client: Yes, but now I am determined to stop it completely.

Therapist: Why in the world would you do that? You've done it for so long now, wouldn't you prefer to be able to purge if you feel you ate too much? Wouldn't that make you feel better?

Client: Yes, it makes me feel better on the spot but then I feel so guilty and ashamed. And I saw my doctor recently and she told me I am really damaging my health.

Therapist: Fair enough, feeling guilty and ashamed is definitely not pleasant. And it is damaging your health. But wouldn't you want to purge and try to not feel guilty and ashamed afterward? And you've done this for a long time and your body has taken it so far.

Client: I really want to stop feeling so bad about myself all the time. And I want a normal life when I don't focus on food and purging all the time. I want a family and kids. I can't do that if I spend so much time and energy on my eating.

Therapist: OK that makes sense. We'll have to remember those reasons if things get tough in treatment."

Figure 4.1 describes a workflow of sequencing the strategies presented above in the first DBT sessions.

Additional Commitment Techniques

Several other strategies are used to "sell" a commitment, particularly when clients express little motivation to change their behavior, and when they emphatically view their maladaptive behaviors as a result of a life of misery, not the cause of it (the DBT stance is that both are likely to be true). The "foot-in-the-door" (Freedman & Fraser, 1966) and "door-in-the-face" (Cialdini et al., 1975) are established social-psychological techniques to increase compliance with requests and previously made commitments. The first technique consists of making an easy request that is likely to be met with little to no resistance, only to be followed by a more difficult request. The second technique consists of asking something very hard and more than one anticipates clients to agree to, and subsequently asking for something easier. Another strategy that is often used is the "*freedom to choose and the absence of alternatives*," based on the notion that commitment and adherence are increased when people believe they have freely made a commitment and when there is no viable alternative path to their goal. Therapists may use this strategy to highlight to clients that they are free to cope with difficult life circumstances through self-injurious behaviors, but that alternative therapy would need to be found, as DBT requires the reduction of these coping mechanisms to be a goal in therapy.

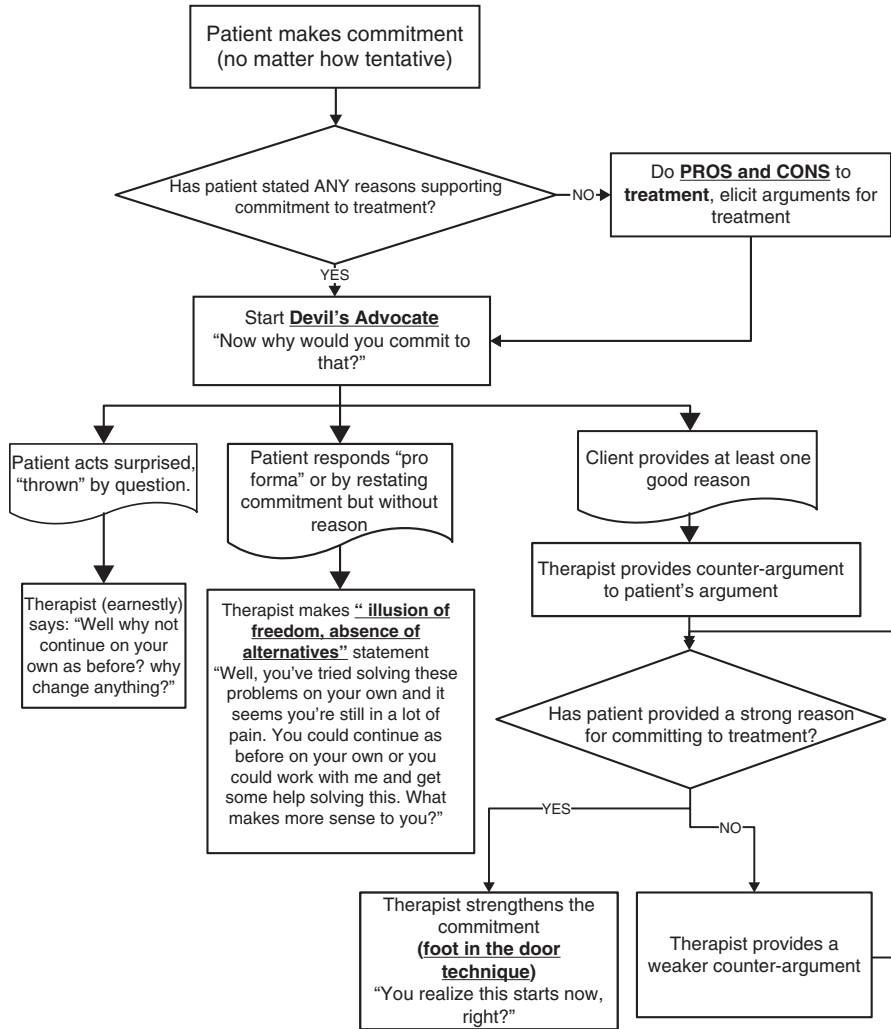


Fig. 4.1 Flow chart of getting commitment for treatment in initial sessions

Orienting the Client to Therapy Interfering Behaviors (TIBs)

From the first session, DBT pays attention to behaviors that could get in the way of therapy. While this approach has its roots in working with a clinical group that was hard to engage and keep in treatment, we hypothesize that observing and addressing such behaviors as they happen is likely to benefit psychotherapy with any clinical group. In DBT, the therapist orients the client to the idea of therapy-interfering behaviors from the pretreatment sessions. More precisely, the message is conveyed that the therapist and client will function as a team to be mindful of behaviors from

the client, the therapist, or the greater environment that can get in the way of the client getting therapy. Client are therefore invited to share the responsibility to notice and discuss TIBs from therapists, the environment, or themselves. TIBs are described at length below.

Engagement Strategies Used Throughout Treatment

Validation Techniques

Balancing acceptance and change represents the fundamental dialectic in DBT. Such balance does not entail allocating equal time and effort to acceptance and change but rather finding the right amount of acceptance and change that keeps the client and therapist advancing most effectively toward treatment goals. Validation strategies form the primary acceptance-based therapeutic strategies in DBT that function as a balance to the change-based cognitive-behavioral treatment strategies. They are typically used with greater frequency and intensity early in treatment with the expressed goal of increasing treatment engagement and strengthening the therapeutic relationship.

Validation can be conceptualized as any form of therapist communication that the client's behavior is somehow valid, true, meaningful, or relevant; that the behavior (including under this term thoughts, emotions, actions, physical reactions) makes sense. Validation strategies in DBT have been largely influenced by humanistic psychology, and Carl Rogers in particular (Rogers, 1959; Rogers, 1946) (see Linehan, 1997) for a thorough discussion of similarities and differences between Rogerian strategies and DBT validation strategies).

In addition to the influence of the humanistic traditions, validation strategies in DBT have their roots in the tradition of consistency theories, particularly the self-verification theory (Swann, 1983; Swann & Ely, 1984; Swann et al., 1992) which posits that individuals seek out information and relationship partners who help to confirm what they already believe, particularly about themselves.

Self-verification theory was applied in the context of DBT in a study evaluating whether it would have incremental utility in predicting two outcome variables intimately tied to treatment engagement: treatment dropout and therapy nonattendance (i.e., likelihood of missing future therapy sessions) (Lindenboim, 2009). The study focused on two populations notoriously difficult to engage in treatment: individuals who met criteria for BPD and either chronic suicidality or opioid dependence. Therapist verification was indexed using clients' subjective ratings, independent observers' ratings, and an objective measure of verification based on discrepancy between client and therapy ratings of client behaviors. Results indicated that objective measure of verification was associated with lower likelihood of dropout and longer duration in treatment prior to dropout. Interestingly, client-perceived verification was associated with reduced likelihood of missing future sessions, while the objective verification was not.

Results from the first randomized controlled trial assessing the efficacy of DBT for BPD and opioid dependence (Linehan et al., 2002) lend support to the importance of validation in facilitating treatment retention for this clinical group. DBT was compared to a 12-step facilitation in combination with Comprehensive Validation Therapy (CVT), which essentially comprised of the validation and acceptance strategies in DBT without the change-based strategies. While DBT condition had a relatively low dropout rate for this population, the CVT condition had an unprecedented 0% dropout rate. Although overall standard DBT was more efficacious than CVT, CVT was quite effective in keeping clients in treatment.

DBT validation strategies have been described in detail elsewhere (Koerner & Linehan, 2003; Linehan, 1997), we briefly outline them below. Validation in DBT is conceptualized as occurring at different levels, increasing in depth and meaning; the first four levels are considered essential for all competent and effective psychotherapies, while the last two levels are considered essential to DBT, and may not be regularly practiced across other forms of therapy.

Level 1—Unbiased Active Listening and Observing (“staying awake”)—This level of validation essentially consists of mindful attunement to the client. It is operationalized as verbal and nonverbal communication of interest and responsiveness to the client. Posture, curiosity, encouraging statements, and clarifying questions are the hallmark of this level of validation. Fundamentally, its function is to communicate to clients that they are important and worthy of being understood.

Level 2—Accurate Reflection (“highlighting”)—At this level of validation, the therapist highlights and summarizes the client’s narrative. It functions to communicate that the client’s experiences are understandable and that the therapist cares to understand them. It also facilitates increased awareness of covert experiences (thoughts and feelings) and greater coherence of experience—a particularly helpful function for individuals that perceive themselves as lacking a sense of self independence of their immediate social context.

Level 3—Articulating the Unverbalized (“mindreading”)—This level is defined as therapist articulation of the unarticulated. Therapist validation at this level essentially communicates understanding of thoughts and emotions clients likely experienced or behaviors they engaged in and did not verbalize (e.g., “you must have felt humiliated when he said that in front of your work group”). Its function is to communicate to clients that their responses are understandable and often “normal” (“if my therapist can guess what I’m feeling, maybe I’m not crazy”).

Level 4—Validating in Terms of Past Learning History and/or Biological Disorder (“Validating in terms of sufficient causes”)—This level of validation is based on the fundamental truth that all behaviors and experiences are caused and therefore understandable, even when they are somehow distorted or caused by faulty perceptions, logic, or disordered biological functioning.

Level 5—Validating as Reasonable in the Moment (“Validating in terms of normative causes”)—At this level, the therapist affirms behavior that has validity given current circumstances. The behaviors to validate could be normative human response to a particular circumstance (at times normal response to abnormal circumstances), are effective as a step toward achieving a particular long-term goal (i.e., “skillful

means”), or effective toward short-term goals, even when the behavior interferes with long-term goals. In the latter case, the validation is similar to “yes, but” communication, acknowledging both the validity and the limited effectiveness of the behavior. It is at this level that the wisdom in client’s behavior is acknowledged and amplified.

When the same behaviors can be validated at both Level 4 and Level 5, it is preferable for the DBT therapist to validate at Level 5. In these circumstances, validating at Level 4 may be experienced as invalidating because it tends to highlight the client’s disordered history, rather than its normative basis. For example, after a client describes being very upset during a first date that included going to a movie that prominently featured complex, dysfunctional and abusive relationships, a therapist’s Level 4 response could be “it must have been incredibly difficult for you given your relationship history.” This communication may be experienced as validating; however, from a DBT perspective, not as validating as a Level 5 validation, “no wonder...that sounds like a disastrous movie for a first date; what’s the plan for the second date – a wake?”

Level 6—Radical Genuineness (“treating the person as valid”)—At the highest level of validation, therapists communicate to clients both in statements in actions that they are valid as whole beings, and that the therapeutic relationship is a real relationship among equals. The equality here refers to importance rather than knowledge base or power. This level of validation also includes communication of faith in the client’s future capabilities, and cheerleading clients while challenging them in difficult therapeutic tasks. Interestingly, at this highest level of validation some Level 6 communication can feel invalidating in the moment when therapists communicate to clients that they view clients as more capable than clients view themselves. It is therefore imperative to explicitly acknowledge this difference, and to embody faith in the client similar to the faith that coaches have in their teams.

Verbal vs. Functional Validation

Therapists can validate in two basic ways, the first is by making verbal statements that serve to validate the clients’ emotions, thoughts, or actions. The second way therapist can validate their clients is by responding as if these clients’ experiences or actions are indeed valid. In effect, the second method of validation communicates to clients through actions that their behaviors are valid. Similar to the aphorism “actions speak louder than words,” when appropriate, functional validation is preferable to verbal validation. For instance, a therapist may communicate understanding of a client’s disappointment in her own behavior (e.g., recent heroin use after a few months of abstinence), which would constitute verbal validation. However, the therapist may also spend time with the client on understanding the factors leading to the behavior, and problem-solving those causal factors—in essence, functionally validating the communication function of the client’s distress. Another example involves therapist responses to clients’ complaints about their behavior. If the therapist assesses a complaint to be valid (e.g., being regularly and significantly late for

sessions), it would be imperative to verbally validate the client's perspective (e.g., "You must be upset about this. I know I would be if I were you"); it would be better, however, to do so functionally (i.e., actually work on solving this problem).

Engagement with Substance-Using "Butterfly Clients"

While validation strategies are effective in facilitating engagement and retention of many clients seeking DBT treatment, others are harder to draw into and to keep in treatment, and require additional attachment strategies. Often exhibited in substance using population, these are affectionately called "butterfly clients" (Dimeff & Linehan, 2008; Linehan, 1993; Linehan et al., 1999), as they appear to fly in and out the therapist hands. They exhibit episodic engagement, often not returning phone calls, have inconsistent attendance to individual therapy and skills training, and often leave treatment prematurely. DBT therapist may feel like they have to "compete with" substances as reinforcers in the clients' lives (Linehan et al., 2006).

DBT specifically geared toward substance using population includes strategies that aim to increase consistent engagement in the "butterfly client." First, this issue is raised early in treatment before the client engages in "butterfly behaviors," and the client is oriented to the therapist and team's efforts to find "lost clients." Therapists are encouraged to use flexibility and nontraditional format of therapy. For example, therapists consider longer, or more likely, shorter sessions, frequent phone calls and voice messages, and use of agreed upon list of family and friends to help reach the client. Clients are asked to complete "Where can we find you" worksheet that includes physical location and phone numbers where clients can be reached both when clean and when using.

Once clients are lost, therapists may try various strategies to find them and help them reengage in treatment. They may leave messages with a bartender at bars they frequent, with family members, or anyone else clients have agreed to in advance. They may leave multiple voicemails that vary from earnest to irreverent, trying to get the clients' attention. For example, in our clinic, therapists used to send letters with sticky notes with the message "stick with us" on them. Finally, therapists may decide to bring therapy to the client, by conducting therapy in the client's natural environment such as the client's home, in a park, in a car etc. Naturally, this decision has to be thoughtful and therapists need to consider and consult with their team regarding safety, privacy, and reinforcement concerns.

Additional Engagement and Commitment Strategies Used Throughout DBT Treatment

The strategies mentioned above are used at the beginning of therapy in the first 1–4 commitment sessions, but are also incorporated as needed throughout the entire DBT treatment.

Monitoring Urges to Quit

DBT therapists pay close attention to a range of behaviors that can get in the way of the client receiving treatment. A set of questions are posed to the client at the beginning of each session, and the client is oriented that these are similar to measuring temperature and blood pressure at a physician's office (i.e., "therapy vital signs"). The client is asked about urges to suicide, urges to escape (by using substances), and about urges to quit treatment. Asking about these urges each session maximizes the chance that they will be addressed and problem-solved in the session before the urges lead to maladaptive behaviors. In case urges to quit are high, the therapist performs an assessment to better understand what generated this change, and revisits commitment strategies if needed.

Therapy-Interfering Behaviors

Defining and Describing TIBs

A truism of therapy work is that a client can benefit from therapy only if he or she actually receives therapy and is engaged with it. The concept of Therapy-Interfering-Behavior (TIB) has been introduced in DBT to organize assessment and intervention around any behavior that can get in the way of the client receiving and engaging with therapy. The complex, multidagnostic clients who typically seek DBT treatment often present with a host of problems and seemingly unrelenting, ever-changing crises. To maximize the efficacious use of therapy time, DBT specifies a hierarchy of primary targets to be followed in each session and in conceptualizing treatment for each client (see Fig. 4.2). At the top of the hierarchy are life-interfering behaviors, followed by therapy-interfering behaviors, then by quality of life-interfering behaviors, and increasing behavioral skills. The target hierarchy illustrates the importance of TIBs in DBT by placing their priority second only to life-threatening behaviors.

It is important to describe how DBT conceptualizes and operationalizes TIBs. TIB is defined as any behavior that gets in the way of therapy. DBT classifies TIBs as being produced by the therapist, client, or the greater environment. Essentially, TIBs are seen as problems to be noticed, understood, and solved to prevent therapy coming to an end prematurely. Focus on TIBs is also intended to improve therapy outcomes by fostering more productive engagement in treatment. The therapy work on TIBs is performed as any other therapy task from a nonjudgmental stance. Thus focusing on TIBs is not done to blame or to shame the client, the therapist, or the environment, but to assess and solve a problem.

Paying attention to how the therapist's behaviors might interfere with therapy is in line with DBT's view that the therapeutic relationship is a relationship among (fallible) equals. Therapists presumably have greater knowledgebase in their area of expertise—the application of theory and science of human behavior to elicit behavior

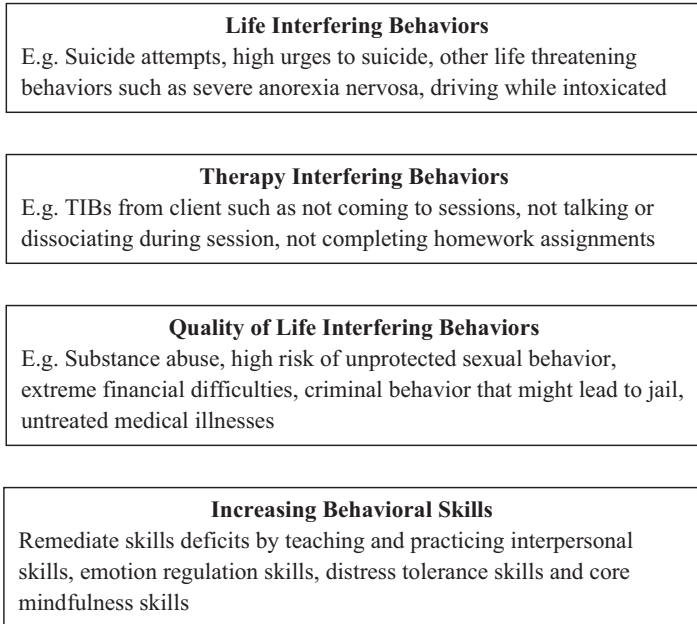


Fig. 4.2 Hierarchy of targets in DBT

change and alleviate human suffering. This knowledge notwithstanding, the laws of human behavior affect therapists and clients alike, and therapists, therefore, are also likely to behave in ways that interfere with therapy. Furthermore, this knowledgebase does not imply special status from the DBT perspective—therapists’ TIBs are just as important to address as clients’, or environmental, TIBs.

Client TIB

DBT recognizes three categories of Client TIBs. The first is any behavior that interferes with the client receiving the therapy offered. This category includes nonattentive behaviors, non-collaborative behaviors, and noncompliant behaviors. Nonattentive behaviors typically refer to missing sessions, coming late to sessions, cancelling sessions for nontherapeutic reasons, etc. They also refer to attending treatment physically but not psychologically such as using mind-altering substances before therapy sessions, dissociating, daydreaming, etc. In DBT, collaborative behaviors are both necessary for effective treatment, and are themselves a goal of treatment. Non-collaborative behaviors are therefore particularly targeted. These include inability or unwillingness to work in therapy, lying, refusing to talk or

answer questions, withdrawing emotionally during sessions, arguing incessantly, and dismissing therapeutic suggestions (“yes butting”). Noncompliant behaviors typically consist of non-completion of homework assignments, refusing to comply with previous agreements with the therapists and refusing to comply with treatment recommendations.

The second category of client TIBs consists of behaviors that interfere with other clients receiving therapy. This type of TIBs is most relevant in skills group setting, and in residential and inpatient treatment programs. These often include outwardly hostile, critical, and judgmental remarks toward other clients. They may also include a host of behaviors that are harmful to the milieu.

The third category of client TIBs consists of behaviors that burn out the therapist including those that push the therapists’ personal limits or decrease therapists’ motivation to continue therapy. Perhaps the most important of the common limit-pushing client behavior is refusal to engage in, or accept, therapeutic strategies that the therapist views as essential for therapeutic process (Linehan, 1993, p. 135). Other common TIBs that are likely to push the therapists’ limits include misuse or overuse of coaching phone calls, interacting with therapists in overly familiar way, interacting with therapist’s family and interpersonal relationships, among others. Not uncommon among clients seeking DBT treatments are behaviors that “push organizational limits”—those behaviors that interfere with unit or program functioning to warrant an intervention (e.g., client vandalizing the unit, creating financial burdens on top of adverse staff reactions). Finally, most client behaviors that function to reduce therapist, group, or family member’s motivation to treat the client are a form of client TIB.

Treating Client TIBs

Noticing TIBs

It is the task of all entities directly engaged in treating the client to keep track of, and notice TIBs. The client is oriented, during the pretreatment stage, to sharing in the responsibility to bring TIBs to the table by adding them to the session agenda. This might be very hard for some clients who have difficulties being assertive, hence reinforcement and shaping of bringing up TIBs to the agenda might be needed from the therapist. Modeling can be helpful in this regard. Therapists are encouraged to notice and highlight their own TIBs and offer solutions. This can have a twofold benefit of normalizing objective critique of the therapist’s behavior, and vicariously, the clients may learn nonjudgmental critique of their own behavior. While clients are encouraged to attend to TIBs, it is ultimately the therapist’s responsibility to monitor and work on TIBs. The DBT therapist consultation team is also responsible for pointing out TIBs as they happen.

Understanding TIBs

DBT offers prescriptive guidance to therapist behavior, style, and attitude in dealing with TIBs, and it also includes guidance for those behaviors, styles, and attitudes that are antithetical to DBT, and therefore proscriptive. The general approach to treat TIB is first to clearly and behaviorally define what the client is doing to interfere with therapy. The second step is to do a thorough assessment of the TIB using a behavioral chain analysis. The third step is to adopt a problem-solving plan including trouble-shooting. Whether conducting a chain analysis or assessing for a broad pattern of behavior, DBT therapists are rooted in behavior therapy, and are therefore committed to behavioral assessment rather than a priori theory about the adaptive and maladaptive nature of client behaviors or their causes. The DBT therapist therefore assesses rather than assumes. Clarifying questions, “what” rather than “why” questions, and presentation of hypotheses are common when starting to understand the nature of the problem.

The anti-DBT approach includes therapist assumptions about the client’s lack of motivation to change or to make progress, or any other a priori assumption about the TIB. Blaming the client or rigidly interpreting client’s behavior is also antithetical to DBT. The stereotypical example of this is the inflexible insistence that client’s behavior is an intentional self-sabotage. Another proscriptive behavior is refusal to acknowledge the therapist’s own contribution to the TIB when it exists. And finally, it is the placement of responsibility for change entirely on the client.

Chain Analysis of TIBs

An important stance in DBT is that a problematic behavior needs to first be understood and only then treated. This stance stems from a belief that many therapeutic mistakes are made when therapists jump into treating a behavior before understanding its generating and maintaining causes. DBT therapists utilize a behavioral chain analysis to understand and treat any behavior targeted to increase or decrease in treatment including TIBs. Chain analysis is an investigation of moment-to-moment events and (both overt and covert) behaviors that precede a problem-behavior, as well as its immediate and delayed consequences. It is therefore a strategy to help therapists formulate hypotheses about the controlling variables of the problem behavior (see Fig. 4.3).

Chain Analysis Step-by-Step

There are essentially eight major steps to a chain analysis (steps 1–5 are focused on assessment and steps 6–8 focused on treatment) (Linehan, 1993, 2014a). The first step is defining exactly what the problem behavior is. At times, this is very simple (e.g., calling last minute to cancel a session following an episode of self-harm), at times requires some refinement (e.g., appearing to show minimal effort in

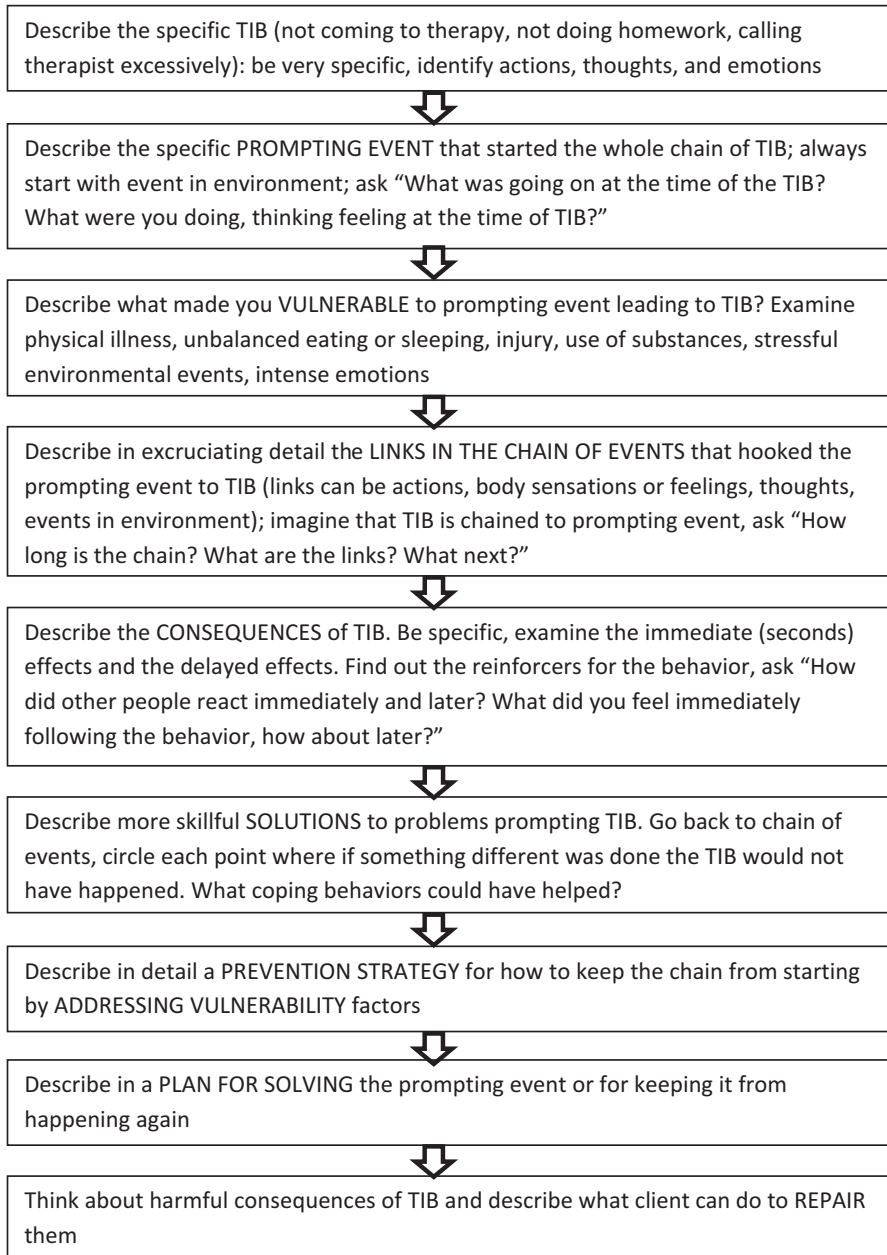


Fig. 4.3 Conducting a chain analysis for TIB

completion of homework assignments). The second step is assessing and defining what environmental event started the chain of events (i.e., the prompting event). The key here is to search for external, rather than internal stimuli as the beginning of the chain. The third step is identifying what factors made the client more vulnerable for

the problem behavior that day (e.g., lack of sleep, previously stressful interpersonal interaction, forgetting to take medications). The fourth step is identifying the links in the chain from the prompting event to the target behavior. This is probably the most difficult step, which requires attention to both external events, and to relevant thoughts, feelings, and behaviors that likely play a causal role leading to the problem behavior. Only after a thorough assessment, or often several, can the important causal links be identified. The fifth step is identifying the immediate and delayed personal and environmental consequences of the behavior. Clients often need help in identifying both the negative and positive consequences of the behavior for themselves and others. This crucial step, however, often helps to reveal the functional aspect of the behavior that helps to maintain it; it also helps in gaining insight into its destructive nature.

Once the assessment is done, the sixth step focuses on identifying skillful behaviors to replace problematic links in the chain to reduce the likelihood of reoccurrence. The seventh step consists of developing a prevention plan to reduce the vulnerability to the prompting event. Finally, the eighth step consists of repairing the negative consequences of the problem behavior. The key to proper repair is to understand the actual harm of the behavior, and to try to repair in a functionally meaningful way the harm that was done. For example, if the behavior analyzed is yelling and cursing the therapist on the phone before hanging up during a coaching call, bringing flowers as a repair is not functionally related to the harm. A better repair would be any behavior that would change the valence of future call from the client (i.e., make them more reinforcing/less punishing for the therapist).

Because focus on maladaptive behavior often elicits strong negative emotions such as shame, fear, and anger, chain analysis is often met with active and passive client resistance. Overcoming this resistance is of utmost importance. While resistance can take many forms, three types of resistance to chain analysis are often seen, namely, active avoidance and shame expression, minimizing the problem behavior, and general expression of distaste of chain analyses. If the therapist assesses that the client resistance is based on emotional avoidance, the therapist identifies more specifically the emotions at the root of the avoidance. The therapist then orients the client to the value of exposure, response prevention, and opposite action, and proceeds with the chain. The second type of common resistance is one where the client does not view the behavior as a major problem. The therapist assesses whether that is in fact the case, and then highlights to the client the incompatibility of the problematic behavior with any major treatment goal. This is sometimes more difficult to accomplish with TIB, particularly when there is a problem in the therapeutic relationship, and therapists may need to explicitly highlight the negative consequences of the behavior, or use additional strategies described below. The third common resistance is when the client hates conducting chain analyses in general. In this case, the therapist orients to the rationale for problem-solving maladaptive behavior and the importance of chain analysis in that process.

Specific Strategies for Addressing TIBs

The Four-Miss Rule

DBT includes structural elements that are designed in anticipation of problems with treatment engagement; perhaps the most important is the four-miss rule. The rule in standard DBT is that missing 4 consecutive weeks of scheduled therapy of any required element of treatment (e.g., individual psychotherapy, skills training group) counts as treatment dropout. It is the only formal termination rule (Linehan, 1993). The rule creates a structure that helps to clarify what constitutes treatment dropout, and helps to differentiate between more minor engagement problems and therapy-destroying behaviors. Perhaps more importantly, it creates a context that increases treatment providers' (individual therapists, skills trainers, etc.) motivation to address therapy nonattendance and client's direct or indirect communication of displeasure with the therapy. It also allows both therapists and clients to "save face" after a particularly difficult exchange. Therapists communicate to clients from the outset that if clients miss group or individual therapy, the team will "pine for their return." Outreach efforts are then made by relevant treatment providers in an effort to reengage the client. It is expected that once clients do return, the controlling variables of the therapy-interfering behaviors will be discussed as mentioned above. As a general rule, clients who want to return to therapy with the therapist may pursue that option at the end of the original contracting period (see Linehan, 1993 pp. 112–114 for a thorough discussion of treatment termination).

Contingency Management

Contingency management is sometimes an appropriate and effective strategy to address TIBs. It is, however, an extraordinarily difficult strategy to implement, particularly with highly complex, vulnerable, and disordered clients, especially suicidal clients. DBT places great emphasis on non-reinforcement of maladaptive behavior, especially suicidal behavior. Therefore, one has to be exceptionally thoughtful about making a contingency management plan that one could apply without fear that contingencies would need to be changed or postponed if the client becomes more distressed or suicidal. It is often critical to orient clients to applications and rationale of contingency management procedures and to try to tie them to the clients' ultimate goals. Whenever possible, this discussion is done when clients are relatively emotionally regulated so they can process this information as something other than one more punishing interpersonal experience in a lifelong stream of such experiences, often from healthcare providers.

The therapeutic relationship is often the most natural and powerful tool in the therapist's arsenal. Consistent with self-verification theory, DBT therapists work to establish themselves as relationship partners with which clients prefer to interact, and whose opinions they trust. As such, they can become powerful social reinforcers that can be used strategically to enhance client engagement. Therapists can choose to increase or decrease length or frequency of contact with clients (therapy sessions, coaching calls, etc.) contingent on client's own engagement. This could be particularly useful in trying to increase lower probability behaviors such as completing difficult homework assignments, or adherence to in-vivo exposure to emotion cues in sessions. Although not necessary, ideally clients could be part of the contingency management discussion and may negotiate the contingencies. For example, if a major goal of therapy is for the client to get back to work, and the client repeatedly does not engage in agreed upon activities such as job searches or job applications, the therapist may choose to come up with a contingency plan for reduced or increased therapy time contingent on the client's productive behavior. The client and the therapist may negotiate the exact terms of the plan as long as the essence of the plan remains intact. One of the key efforts in DBT is to make increased therapy contact contingent on client progress or adaptive behavior rather than maladaptive behavior (see Linehan, 1993 pp. 292–326, for a more thorough discussion of contingent procedures in DBT).

Self-Involving Self-Disclosure

Clinicians often complain that borderline clients “know how to push our buttons.” The DBT perspective is that these clients emit so many behaviors that can be interpersonally challenging that they are statistically likely to say or do something that providers may find particularly challenging, and may perceive as personally attacking. In other words, clients engage in many emotionally salient behaviors that they are likely to engage in some behaviors that any therapist would find challenging. Though detrimental, these behaviors are often unintentional. Furthermore, as discussed above, suicidal borderline clients often present with more wants and needs than any therapist can possibly meet, which has the effect of challenging therapists' own self-concept.

The self-involving self-disclosure strategy is a form of interpersonal contingency clarification. It essentially consists of communicating to the client the effect of his or her behavior on the therapist (“when you do x, I feel y”). This strategy puts the onus on therapists to discuss the effect of specific client behavior on the therapist. This can be helpful as clients are often unaware of the extent to which their behaviors are experienced as aversive and lead to burnout among many of their interpersonal relationships. In ideal circumstances, therefore, this strategy can also facilitate the acquisition of interpersonal effectiveness skills by helping clients gain relevant

insights. This strategy, though often difficult, can help to prevent the need to address an even more difficult conversation when client's behavior crossed the therapist's limits.

Observing Limits

DBT therapists observe their own limits rather than set arbitrary ones. Whether consistently asking for additional time in session while other people are waiting, cursing the therapist in session, or threatening to kill themselves over the phone before hanging up, client's behaviors can often step outside of the therapist's comfort. This is particularly true for chronically suicidal borderline clients for whom DBT was originally developed. The needs and difficulties of these clients at times require providers to stretch their limits when necessary, and at other times, hold firm to those limits. For example, a therapist may find it helpful to be available for more unscheduled calls and frequent sessions when a client is in suicidal crisis following a loss of a job or a relationship; at other times, however, the therapist may feel the need to adhere to established expectations. The therapist-guiding principle here is to evaluate risk, reinforcement principles, and their own comfort level. Consultation with supervisors and other team members is strongly encouraged.

There are a few philosophically important points about observing limits in DBT. First, it is the therapist's responsibility to observe her or his own limits—it is not the client's. Second, while ultimately therapists' observation of their limits may benefit their clients (ultimately by reduced risk of burnout), observing limits is done for the benefit of therapists and should be communicated as such. There are often valid needs and wants of clients that therapists may simply be unable, or unwilling, to fulfill. This does not delegitimize those needs. Therapists need to validate clients' needs while asserting their own limits. This is often one of the most difficult tasks for therapists, who can be uncomfortable when failing to meet client needs, and often falls outside of their self-concept as caring, helpful providers. This aversive incongruence may lead to a tendency to "blame-the-victim" rather than come to terms with the reality of treating these complex clients. It is imperative to avoid pathologizing this client behavior as it mirrors years of invalidation, and is often iatrogenic.

It is also important to understand that therapists' limits may change over time due to circumstances in the therapist's life (e.g., becoming a parent, changing workload, an illness). The DBT stance on changing limits is that it is the responsibility of therapists to communicate those, and to problem-solve with clients these changes as they occur (or preferably prior when these changes are foreseeable). When a client's lack of engagement crosses the therapist's limits, the therapist is tasked with addressing the issue directly as part of the principle of observing limits.

For example:

T: This is the third week in row that you haven't completed the homework that we agreed upon. I'm afraid this therapy is not going to work without doing work outside our sessions, and the thing is, I'm not willing to provide therapy I believe is ineffective, so I think we need to figure this out. I'm afraid it's not going to make sense for us to continue engaging in ineffectual therapy.

C: OK, so you are dumping me like my previous therapist! Great...

T: I didn't say that. But I did say that we have to figure it out because I want to keep seeing you, and I don't want to get to the point of ending our therapy for this reason.

C: So it's all on me now...

T: It's on us.

C How so?

T: Well, we have to figure out what really gets in the way of completing these assignments. Are they too difficult? Do they seem pointless? Are you avoiding being uncomfortable? Are you afraid of failing? Are you afraid of succeeding and what success might entail for you?

C: What's the point of this interrogation? I told you I didn't do them already...

T: The thing is I simply don't know of a way to help you without specific practice outside our sessions. And on a personal level, I feel like I'm putting my all into our work together: being on time for our sessions, being prepared with an agenda, doing my best to be completely present when we meet, making myself available for you to call in for skill coaching etc. When you regularly report that you are not doing your homework, it communicates to me that I am more invested in your treatment than you are. I could be completely mistaken about it obviously, but if I'm not, it may eventually cause me to hold back more.

C: Well, to be honest with you, I did try the homework all of these weeks, but I get overwhelmed and feel like a failure so I stop. I think what's the point? It's not going to help me anyway.

T: I'm glad you told me. It helps me understand what's going on for you. I'm curious to hear more about the specifics of what you've done in each assignment. We should discuss what it would take to complete them, and how to communicate when you have specific reservations about an assignment when we discuss them together.

Metaphors

Perhaps one of the most effective strategies to change the context of engagement problems and other TIBs is with the use of evocative, memorable, and apt metaphors. While in DBT the use of metaphors is considered a quintessential dialectical

strategy, it can be particularly helpful in addressing problems with engagement. Therapists may draw upon any metaphor that appears to fit the situation and helps clients view the pattern of their behavior, or its effects, more clearly. It is often helpful to have the client engage in this discussion, as this discussion can sometimes more easily lead to dialectical synthesis, and insights for both the therapist and the client about the controlling variables of the TIBs.

For example:

T: It is as if we are traveling together. You picked the destination, which you keep saying was really important you. You are driving, while I'm in charge of the navigation. While we're on the road, I am trying to show you what the map says and highlight relevant road signs, and sometimes it feels like you completely ignore me. I'm telling you, 'you can't get there from here,' and you keep driving into dead ends, or in opposite directions. I think we have to find a way to better manage our journey together.

C: Well, maybe you're right sometimes, but you keep sending me in these scary treacherous roads. I just don't feel safe most of the time.

T: But you never tell me. How am I supposed to know? Sometimes, I could look for alternative routes. Other times I could help to support you, as we go through this together, perhaps a little more slowly.

C: Well that's the point? Everyone around me is just zipping by, and I feel I can't even get up to anything close to the speed limit.

T: That makes sense. It's your first time driving on some of these roads. Of course some of these mountain roads would feel scary. So tell me, what's more important to you right now, getting to our destination or how fast we get there?

C: Definitely getting there.

T: Great. We could work on finding some slower roads, while helping you navigate those scarier roads. At the same time, we need to work on accepting that you are going to travel in a speed that is safe and manageable for you, and we'll get there when we get there.

C: Deal!

T: But I do need you to alert me when you get scared.

C: Alright, I'll try to be more direct.

Therapy-Enhancing Behaviors

Consistent with a dialectical philosophy, DBT targets the polar opposite side of TIBs, namely, therapy-enhancing behaviors, or TEBs. These are any behaviors that enhance therapy process and outcome. Enhancing the therapeutic relationship and

increasing therapist willingness to treat clients is particularly important in the treatment of personality-disordered clients. The DBT stance is that these behaviors are to be taught and reinforced, rather than expected. For example, clients' efforts to complete therapy assignment are TEBs that are worth noticing and reinforcing. Keeping up other therapy agreements is another. Often, improvements over previous TIBs constitute TEBs. The principle of reinforcing just-noticeable difference is important. For example, clients' behaviors during telephone calls may often need to be shaped. For clients who typically do not utilize telephone coaching when it would make perfect sense to do so (e.g., in order to avoid engaging in self-injurious behaviors) encouraging any such efforts would be important, even if the initial calls are not particularly productive. On the other hand, clients who call too frequently, or at highly inconvenient times, are aversive or help-rejecting while on the phone, or utilize phone calls as the only coping mechanism, will need specific guidance for skillful use of those calls. These clients will need to be reinforced for any efforts to shape this behavior. For example, asking the therapist if this is a convenient time is TEB to be targeted, taking "no" for an answer, is another.

Therapist TIB

As mentioned above, therapists may engage in a host of behaviors that function to interfere with treatment. Any therapist behavior that unnecessarily causes distress or interferes with progress, or is iatrogenic, fits in that category, consistent with the dictum "*do no harm.*" Similarly, defensiveness and rigidity when confronted with suggestions of TIB is in itself a form of therapist TIB. Reduced motivation, willfulness, and therapist hopelessness are particularly deleterious therapist TIBs that are unfortunately common in treating personality-disordered clients in particular. Finally, there are often logistical and institutional barriers that interfere with treatment (environmental TIBs). While these barriers are not considered therapist's TIB per se, it is nevertheless incumbent upon the therapist to problem-solve them to the extent possible. Table 4.1 summarizes typical therapist TIBs and contextual influences on the therapist that interfere with therapy.

Treatment of Therapist TIB Through the Therapist Consultation Team

While both therapists and clients are encouraged to bring up therapist TIBs, and therapeutic dyad is expected to work on solving these together, the primary source of support for solving therapist TIBs is the *Therapist Consultation Team*. The role of the DBT consultation team is to enhance therapists' capabilities to provide the treatment competently and their motivation to do so. Typically modeled after individual therapy target hierarchy, the team prioritizes life-threatening behaviors, therapy-interfering behaviors, quality of life-interfering behaviors, and therapist skills acquisition. Rather than focusing on specific clients during team meetings, the

Table 4.1 Summary of Therapist's TBIs

<i>Therapist's personal factors leading to TBIs</i>
Excessive travel
Not making needed arrangements for back-up when he or she is unavailable for therapy
Life stress at home or at work that is not managed well enough
Illness that is not managed well enough
Compartmentalizing clinical work to a small part of the week such that clinical demands are seen as intrusive during the rest of the week (especially relevant in academic environments)
Forgetting to have pager, cellphone, charged, and ready to be accessible to client as expected
<i>Therapist's functioning in the broader therapeutic context leading to TBIs</i>
Not bring up in DBT team items he or she needs help with in treating the client
For trainees: not getting the support needed from supervision (for example not challenging a supervisor who cancels supervision sessions or does not watch sessions, not calling the supervisor for guidance in the middle of a treatment crisis)
"Blaming the victim" attitude toward client
Fear of being sued by client controlling the therapy
Anxiety about client committing suicide controlling therapy
Reinforcing dysfunctional behaviors due to difficulty tolerating communication of distress from client
Not observing personal limits and not working on decreasing clinical burnout
DBT team interfering behaviors:
– Not coming to DBT team and thus (a) not receiving the help needed to treat therapist's own clients and (b) not offering help to other therapists
– Not asking for consultation from other DBT team members when needing it
– Not responding to requests for consultation from other DBT team members
Not keeping documentation up-to-date to convey clinical context to therapists providing back-up
<i>TBIs from therapist's behaviors creating therapeutic imbalance</i>
Imbalance of change versus acceptance:
– Excessive focus on change to the detriment of acceptance strategies
– Excessive focus on acceptance strategies to the detriment of change strategies
Imbalance of flexibility versus stability:
– Changing therapy strategies too quickly before allowing enough time for them to work; therapist modification of therapy according to non-theory-linked criteria due to impatience
– Insisting on specific strategy despite evidence that it is not working for a particular client and other strategies are available
Imbalance of nurturing versus demanding change:
– Disproportionate focus on doing things for the client and nurturing while not providing support to encourage and shape the client to do things for himself or herself; the client is often seen as too vulnerable, incompetent, or fragile to help himself or herself
– Disproportionate focus on pushing the clients to solve their own problems assuming that if they are motivated enough the needed behaviors will happen
Imbalance of reciprocal versus irreverent communication:
– Therapists becoming overly vulnerable in therapy sharing their personal problems outside of the context of what is helpful to the client
– Overemphasizing the distance between therapist and client
<i>Examples of a Therapist's Disrespectful Behaviors</i>
Misses or forgets appointments, cancels appointments without rescheduling

(continued)

Table 4.1 (continued)

Arbitrarily changes his or her policies with the client (e.g., changes phone policy, fees, appointment times)
Does not return messages or phone calls, or delays calling back
Loses papers/files/notes, does not read the notes/papers client gives to him or her
Is late to appointments
Appears or dresses unprofessionally, has a messy/unclean office space
Eats/chews gum/smokes/talks on the phone during appointments
Does not close door during therapy sessions
Forgets important information (name, relevant history/information)
Appears visibly tired/fatigued, dozes off with the client
Ends sessions prematurely, visibly watches the clock
Refers to client in sexist, paternalistic, or maternalistic manner
Treats the client as inferior to the therapist

main focus is the therapist, or the client-therapist dyad. One way in which the DBT team keeps track of TIBs in a way that conveys their importance is to have a separate moment in team meetings where all therapists are prompted to add TIBs to the agenda. Utilizing any and all DBT strategies, the team is tasked with helping therapists in their relationships with specific clients, or in areas that more broadly affect their ability or willingness to provide the therapy consistent with the DBT model—in other words, the team provides therapy for the therapist.

There are several essential agreements that DBT providers are expected to adhere to, which provide the foundation for effective functioning of the consultation team. Although all of the agreements are relevant to the problem of TIBs, perhaps the most pertinent are *observing-limits*, *phenomenological empathy*, and *fallibility* agreements. Discussed at length above, *observing-limits agreement* states that DBT therapists agree to notice and respond to their own comfort level in treating clients rather than set arbitrary limits. In the context of the team, this agreement also respects the fact that therapists may have different limits from one another, and there are no “correct” limits for therapists to adhere to. The *phenomenological empathy agreement*, which may be the most important in dealing with client engagement problems (and other ineffective client behavior), states that DBT providers work to find empathic nonpejorative explanations for client behavior. In the clinical experience of these authors, this guidance is probably the most helpful in problem-solving clients’ TIBs, as it helps in reducing difficult emotions in both therapists and clients. The same empathic stance is expected toward fellow team members and the therapist’s own behavior. The *fallibility agreement* enshrines the obvious and uncomfortable truth that despite their best intentions, providers are ultimately fallible and often have done what they were “accused of.” This agreement calls for therapists to drop their defensiveness and be open to complaints, advice, and corrective feedback. This agreement may be the most helpful in increasing therapists’ willingness to seek consultation for their own TIB’s and to accept other members’ interpretation of their behaviors as therapy-interfering.

The consultation team is expected to model DBT individual therapy by embracing dialectical framework, balancing acceptance and change strategies, modeling non-defensive and nonjudgmental stance toward problematic therapist behaviors, assessing the controlling variables for therapist TIBs using behavioral change analysis, and offering emotional and instrumental support. For example, the slow pace of recovery of “difficult-to-treat” clients often feels demoralizing to both clients and therapists. It is precisely the ability to maintain unwavering beliefs in the clients’ ability to improve and make progress toward clinical goals that is essential in keeping both therapists and clients engaged. Sometimes, it is incumbent upon the therapist to hold the “flag of hope and optimism” when the client has let it go. When the therapist finds it difficult to “hold the flag,” it is the job of the consultation team to help him or her do so. Similarly, when clients miss 3 weeks of treatment and are at high risk of dropout (especially when this is repeated occurrence), therapists may convince themselves that clients are not interested in treatment, or “not ready,” and may find it difficult to mobilize to prevent such an outcome. It is incumbent upon the team to help therapists reengage in treatment and problem-solve the clients’ attendance and engagement problems.

Conclusion

DBT was developed to treat a high-risk complex clinical population that was notoriously difficult to engage productively and retain in treatment, namely, suicidal individuals who met criteria for borderline personality disorder. It has since evolved and been utilized in a wide range of clinical populations and problems. DBT includes several strategies aimed at building and maintaining treatment engagement. Nevertheless, the high frequency of problems in therapy with high-risk complex clients led to conceptualizing these problems as therapy-interfering behaviors. The realization that clients, therapists, and environmental factors can all contribute to these problems led to explicit targeting of therapy-interfering behaviors on all fronts. Clients, therapists, and the consultation team are all tasked with identifying and problem-solving these behaviors throughout the course of treatment.

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Chapter 5

Use of Mindfulness in Promoting Treatment Engagement

Shian-Ling Keng

“The faculty of voluntarily bringing back a wandering attention, over and over again, is the very root of judgment, character, and will. No one is compassui [master of himself] if he have it not. An education which should improve this faculty would be the education par excellence. But it is easier to define this ideal than to give practical directions for bringing it about.”

—William James, 1890

Over the past three decades, there has been significant growth of interest within the scientific and medical community in the application of mindfulness as a psychological intervention to enhance physical and psychological health. One of the most commonly cited definitions of mindfulness is the awareness that arises through “paying attention in a particular way: on purpose, in the present moment, and non-judgmentally” (Kabat-Zinn, 1994, p. 4). Whereas other definitions of mindfulness have been proposed (e.g., see Baer, 2003; Bishop et al., 2004; Brown & Ryan, 2003), current conceptualizations point to two primary, essential elements of mindfulness: awareness of one’s moment-to-moment experience nonjudgmentally and with acceptance (Keng, Smoski, & Robins, 2011). The word *mindfulness* may be used to describe a psychological trait (i.e., the extent to which individuals are mindful in their daily life), a systematic practice for cultivating mindfulness (e.g., mindfulness meditation), a mode or state of awareness, or a psychological process (Germer, Siegel, & Fulton, 2005). The practice of mindfulness, in particular, involves the ability to voluntarily direct one’s attention to the present moment experience and adopting an attitude of nonjudgment and curiosity toward the experience. As William James (1890) acknowledged in the paragraph quoted above, the ability to voluntarily bring back a wandering attention is integral to one’s character development. Not only that, such ability is also a crucial aspect of good clinical practice, psychotherapy, and/or delivery of clinical services.

S.-L. Keng, Ph.D. (✉)
Department of Psychology, National University of Singapore, Singapore
e-mail: psykeng@nus.edu.sg

Numerous studies have demonstrated that trait mindfulness is associated with a variety of indicators of psychological health, such as higher levels of life satisfaction (Brown & Ryan, 2003), vitality (Brown & Ryan, 2003), self-esteem (Brown & Ryan, 2003; Rasmussen & Pidgeon, 2011), empathy (Shapiro, Schwartz, & Bonner, 1998), and pleasant affect (Brown & Ryan, 2003), as well as lower levels of depression (Brown & Ryan, 2003; Cash & Whittingham, 2010), neuroticism (Dekeyser, Raes, Leijssen, Leysen, & Dewulf, 2008; Giluk, 2009), rumination (Raes & Williams, 2010), social anxiety (Brown & Ryan, 2003; Dekeyser et al., 2008; Rasmussen & Pidgeon, 2011), difficulties with emotion regulation (Baer, Smith, Hopkins, Krietemeyer, & Toney, 2006), and general psychological symptoms (Baer et al., 2006). A number of psychological interventions have also been developed based on practices and principles of mindfulness, notably mindfulness-based stress reduction (MBSR; Kabat-Zinn, 1994), mindfulness-based cognitive therapy (MBCT; Segal, Williams, & Teasdale, 2002), dialectical behavior therapy (DBT; Linehan, 1993a), and acceptance and commitment therapy (ACT; Hayes, Strosahl, & Wilson, 1999). Collectively, these interventions have been shown to be effective in improving psychological health in a variety of populations, ranging from non-clinical populations (e.g., healthy adults; Robins, Keng, Ekblad, & Brantley, 2012; Keng, Smoski, Robins, Ekblad, & Brantley, 2012), psychiatric populations such as patients with a history of depression (Ma & Teasdale, 2004; Teasdale et al., 2000) and patients with borderline personality disorder (BPD; Linehan, Armstrong, Suarez, Allmon, & Heard, 1991; Linehan et al., 2006), to medical populations, such as patients suffering from chronic pain (Kabat-Zinn, 1982) and cancer (Specia, Carlson, Goodey, & Angen, 2000).

While research has demonstrated the effectiveness of mindfulness-based practices and interventions in improving psychological health, little work has systematically explored the potential of mindfulness as a tool to promote treatment engagement. Treatment engagement refers to the extent to which clients participate and engage in treatment, and is reflected by various factors such as whether clients attend treatment sessions regularly and consistently, the duration of their participation in treatment, and the degree of alliance or bond established between them and the treatment provider. Treatment engagement is a crucial yet challenging part of treatment. Whereas much work in the health service field has emphasized the importance of treatment adherence (which concerns the extent to which a treatment delivered adheres to an established set of principles or protocol), relatively less attention has been given to importance of treatment engagement. The fact that the clinical utility of mindfulness has been well established suggests that it may have strong potential as a tool to facilitate treatment engagement. In particular, the degree to which a service provider is able to embody attitudes of mindfulness (i.e., being kind and nonjudgmental) as well as utilize mindfulness-based practices as appropriate in treatment may have subtle yet significant impact on a client's ability to engage effectively in treatment.

The goal of this chapter is to highlight and discuss the potential of mindfulness as a tool to promote treatment engagement in clinical settings. The chapter will begin with a presentation of available research relevant to the value of mindfulness

as a treatment engagement tool, followed by a discussion of different ways through which mindfulness may be utilized as a strategy to enhance treatment engagement. The chapter also provides a few specific examples of mindfulness exercises that a clinician may use to engage clients more effectively in treatment. The chapter will end with a discussion of cultural issues relevant to the implementation of mindfulness in treatment as well as resources that clinicians may consider if they are interested in receiving further training in mindfulness-based intervention approaches.

Research Relevant to the Potential of Mindfulness as a Tool to Facilitate Treatment Engagement

Research to date that suggests that mindfulness may be an effective tool for promoting clients' engagement in treatment. First, there is evidence that the levels of trait mindfulness of treatment providers correlate positively with the quality and effectiveness of service delivered. One study involving four HIV speciality clinic sites in the United States (Beach et al., 2013) found that clinicians' self-reported levels of mindfulness were associated with higher levels of patient-clinician communication quality, as assessed through audio-recorded measures and a widely established communication coding system. In particular, clinicians higher on trait mindfulness engaged in more rapport building as well as displayed more positive emotional tone when interacting with their patients. Patients of these clinicians were also more likely to give higher ratings on perceived communication quality and overall satisfaction with treatment. Trait mindfulness has also been correlated with lower levels of compassion fatigue (a phenomenon in which treatment providers experienced reduced capacity for empathy toward clients due to repeated exposure to their trauma; Adams, Boscarino, & Figley, 2006), and higher levels of compassion satisfaction among volunteers and professionals working with victims of trauma (Thieleman & Cacciatore, 2014). Taken together, these findings suggest that being mindful may enable one to be more effective in not only communicating with clients, but also in managing emotional challenges commonly experienced in certain lines of clinical work.

A number of studies have also examined the effects of systematic training in mindfulness on treatment providers' well-being and ability to work with clients effectively. One study by Krasner et al. (2009) found that participation in an 8-week educational program in mindful communication was associated with improvements in empathy, mindfulness, burnout, emotional stability, and personal accomplishments among primary care physicians. Qualitative analysis of the findings showed that participants experienced improvements in their ability to be attentive and listen deeply to patients' concerns, as well as respond to patients more effectively. Participants also reported experiencing reduced professional isolation and greater levels of self-awareness. In another controlled trial, primary care health professionals randomly assigned to an 8-session mindfulness course reported significant improvements in burnout, empathy, mindfulness, and mood disturbance, whereas no

significant differences were observed in these variables in the control group (Asuero et al., 2014). Another study focusing on social work students further showed that incorporation of 10 min of mindfulness practice into each session of a class on clinical interviewing was associated with significant improvements in counselling self-efficacy among the students (Gockel, Burton, James, & Bryer, 2013). Further, a prospective, mixed-methods study that recruited clinical psychology trainees found that participation in an 8-week MBCT program predicted significant improvements in selected facets of mindfulness and empathy (Hopkins & Proeve, 2013). To sum up, these studies provide strong evidence that systematic mindfulness training results in beneficial changes on various dimensions of clinical skills relevant to treatment engagement, such as empathy and the ability to manage burnout.

In addition to examining clinician outcomes, research has also examined the effects of systematic training in mindfulness on clients' ability to engage in and benefit from treatment. It is plausible that enhanced communication and degree of empathy with clients may facilitate higher therapy alliance, which may translate into greater overall efficacy of treatment. A randomized, double-blind controlled study conducted in Germany found that patients of psychotherapists in training (PiTs) who were randomly assigned to practicing mindfulness meditation reported significantly better evaluations for individual therapy (in terms of clarification and problem-solving perspectives) as well as greater overall symptom reductions, compared to patients of PiTs who did not practice mindfulness meditation (Grepmaier, Mitterlehner, Loew, & Nickel, 2007). A form of mindfulness-oriented intervention, DBT, has also been shown across several trials to be more effective than treatment-as-usual or another active treatment in improving treatment adherence among patients with BPD (Linehan et al., 1991, 2006; Soler et al., 2009), a population known to have high rates of dropping out of treatment (e.g., see Bohus et al., 2004; Smith, Koenigsberg, Yeomans, Clarkin, & Selzer, 1995). While it is unknown the extent to which the higher rates of treatment retention observed among patients who received DBT were due to the mindfulness component of the intervention (given that the intervention consists of multiple components), this finding, along with that of other research, highlights the potential of mindfulness in enhancing not only clients' engagement in treatment, but also the effectiveness of the treatment itself.

Mindfulness as a Tool to Facilitate Treatment Engagement

Whereas empirical research has highlighted the value of mindfulness as a tool to facilitate treatment engagement, little work has examined how mindfulness may be utilized in clinical practice or service delivery for the purpose of enhancing treatment engagement. The following section elaborates on two primary ways through which mindfulness can facilitate clients' engagement in treatment: (1) through clinicians' own embodiment of qualities of mindfulness, and (2) through explicit use of mindfulness practices, either as a standalone intervention or as a tool complementary to other strategies.

Clinicians' Embodiment of Mindfulness as a Key Vehicle to Engage Clients

Within the literature on mindfulness-based interventions, there has been considerable emphasis on the importance of teachers (or instructors) of mindfulness-based interventions being able to embody the essence of mindfulness practices that they teach to clients (Crane, Kuyken, Hastings, Rothwell, & Williams, 2010). While the importance of clinicians keeping a regular, personal mindfulness meditation practice is not emphasized equally across different various mindfulness-oriented interventions (e.g., DBT; Linehan, 1993a), it is generally acknowledged that key elements of mindfulness, such as the ability to be fully attentive to the experience in the present moment, as well as to relate to the experience with an attitude of kindness and nonjudgment, are important processes that affect the quality of a client's experience with treatment. At a fundamental level, a client is likely not going to be very engaged in treatment if the clinician does not focus her attention fully on helping the client. Similarly, holding a judgmental attitude toward the client or his experience may result in treatment resistance on the part of the client. Therefore, to engage a client effectively in treatment, a clinician needs to bring her full presence into treatment and to relate to the client in a nonjudgmental manner, as best as she can.

There are additional ways through which embodying qualities of mindfulness may facilitate clients' engagement in treatment. Clinicians who are mindful would likely be attentive to a client's needs and perspectives, which would enable them to emphasize with the client and develop a strong therapeutic alliance. A client who feels supported and understood thus would likely be more willing to remain engaged in treatment. Further, as highlighted above, the ability to remain nonjudgmental is another important aspect of effective work with the client. This entails being aware of any conscious or subconscious biases one holds that may jeopardize the one's relationship with the client, and being able to work with these biases so that they do not get in the way of treatment. Maintaining a nonjudgmental attitude may also encourage a client to open up more in general (as a client learns that she will likely not be judged if she expresses a more vulnerable aspect of herself), which would help deepen engagement in treatment. In several mindfulness-oriented interventions (e.g., MBSR and DBT), being nonjudgmental is deemed as a key aspect of the delivery of treatment, and clinicians are explicitly trained to be nonjudgmental in their work with clients (e.g., through having a person who plays the role of a "watchdog," who would ring a bell whenever expression of a judgmental attitude is observed in a DBT consultation team; Linehan, 1993a). Stylistically, DBT clinicians are also trained to balance the use of change-based strategies (e.g., problem solving) with the use of validation, which involves seeing a situation from the client's point of view and expressing to the client that his or her experience, no matter how dysfunctional or painful it may seem to others, makes sense in a given context (Linehan, 1993a). The ability to validate a client's experience calls for the ability of a clinician to be mindful of the client's needs in the moment as well as recognize the "kernel of truth" in the client's experience

Clinicians' own dispositional mindfulness may also benefit clients' engagement in treatment via enabling a more accurate assessment of the clients' issues and emotional states. A clinician who is mindful may be more able to detect any subtle resistance (on the client's part) that arises during the course of treatment, as well as be aware of any overt or subtle behaviors that they themselves engage in that may interfere with clients' engagement with treatment (e.g., avoiding discussing issues that they are uncomfortable with with the client). Awareness of these therapy-interfering behaviors is crucial to address any potential conflicts or ruptures that may arise in the therapy relationship. Clinicians who are aware of their own emotions and transference are also generally more likely to be effective in their clinical work with patients.

In summary, a key way through which mindfulness promotes treatment engagement is through the clinicians' own embodiment of qualities of mindfulness—those of moment-to-moment awareness of both intra- and interpersonal experiences, as well as relating to the experiences with an attitude of openness, acceptance, and nonjudgment. These qualities facilitate the ability of a clinician to develop empathy toward the client, forge a strong therapeutic alliance, accurately assess the client's needs and emotions, as well as develop awareness of the clinician's own emotions and reactions to the client. Research has shown that dispositional qualities of mindfulness can be cultivated through systematic mindfulness training (e.g., Asuero et al., 2014, Krasner et al., 2009), which is good news for clinicians interested in further cultivating their own capacity for mindfulness. The section toward the end of this chapter suggests several potential avenues through which an interested clinician can pursue further training in mindfulness.

Use of Mindfulness Practices as a Treatment Engagement Tool

Another way through which mindfulness can facilitate clients' engagement in treatment is through explicit use of mindfulness exercises in the delivery of an intervention. In this context, mindfulness practices can be used either as a standalone tool or a complementary tool to enhance the effects of other treatment strategies.

Mindfulness Practices as a Standalone Treatment Engagement Tool

As a standalone tool, mindfulness practices can be used to increase a client's openness to experience, or— in other words—reduce the degree of avoidance that the client may have toward their diagnosis, the treatment, or difficult feelings that may come up during therapy. Avoidance, or avoidance-based coping, has been associated with poorer adherence to treatment (Amir, 1997), higher distress (Thompson, Gil, Abrams, & Phillips, 1992), and more severe psychological symptoms (Thompson & Waltz, 2010) in a variety of medical and psychiatric populations. Mindfulness, on the other hand, has been associated with reduced experiential

avoidance (Baer et al., 2006). Use of mindfulness practices may therefore facilitate greater receptivity and openness to treatment.

Mindfulness practices may also help a client develop greater awareness of his thoughts and emotions. This would be particularly useful for interventions that require psychological insight into one's thoughts, emotions, and behavior (e.g., cognitive-behavioral therapy). Mindfulness practices may also enable clients to develop greater clarity of their values and goals. Certain mindfulness-oriented interventions, such as ACT (Hayes et al., 1999), contain exercises aiming at helping clients increase clarity of their values. According to the ACT framework, over-identification or fusion with one's distressing thoughts and emotions often get in the way of clients developing insight into values that are important to them in their lives (Hayes et al., 2006). Mindfulness exercises therefore may help "defuse" a client from over-identification with his distressing thoughts and emotions, which will likely enable him to gain greater clarity of his values and goals. Acquiring such clarity is an important step in promoting treatment engagement, as it enables clients to see ways in which participating in treatment is consistent with their values or life goals.

Mindfulness practices also serve the function of reducing arousal and emotion dysregulation (Baer, 2003; Robins et al., 2012), problems that can get in the way of a client engaging in treatment effectively. Therefore, skillful use of mindfulness practices in moments of clients' distress may help them to calm down quickly and reengage in treatment. Further, mindfulness exercises help increase clients' attentional capacity and concentration (Chiesa, Calati, & Serretti, 2011), which are important for treatment engagement. Increased attentional capacity would help a client not only in connecting with the clinician (which would likely strengthen therapeutic bond), but also in absorbing and integrating information that they learn through treatment.

Mindfulness Practices as a Complementary Treatment Engagement Tool

As a complementary tool, mindfulness practices can be used to enhance the effectiveness of other intervention tools in facilitating treatment engagement. These practices may be particularly relevant when a client shows resistance to use of an intervention approach. Mindfulness has in fact already been formally incorporated into various treatment approaches, often as a tool to promote acceptance on the part of clients in the service of making positive changes. In other words, mindfulness may be used as a tool that paves the way for easier and potentially more effective implementation of other interventions. For example, one study (de Dios et al., 2012) developed an intervention that integrated motivational interviewing and mindfulness (MI-MM) and found that just two sessions of MI-MM were effective in reducing marijuana use among adult young females. In this intervention, brief mindfulness meditation exercises (with duration ranging from 5 to 15 min) were introduced, followed by problem-solving discussions based on principles of motivational interviewing.

Other intervention approaches such as DBT have also formally incorporated mindfulness as part of their treatment package. In the context of DBT, mindfulness falls under the “acceptance” side on the core dialectic of acceptance and change (Linehan, 1993a). It is taught as a skill to promote awareness and acceptance of difficult thoughts and emotions, so that clients learn not to over-engage with these thoughts and emotions (and as a result resort to impulsive or maladaptive acts). Within the context of ACT, practices and principles of mindfulness are expressed through two aspects of the ACT hexaflex model (Hayes et al., 2006), a model that outlines key psychological mechanisms through which ACT exerts its clinical impact. These aspects encompass contact with the present moment and observing of self as context—processes deemed as crucial for defusing a client from being overly attached to difficult thoughts, emotions, and memories, all of which can get in a way of engagement in actions that are consistent with their goals.

Examples of Specific Mindfulness Exercises that May Be Used to Promote Treatment Engagement

The below section outlines examples and scripts of specific mindfulness exercises that may be utilized to promote treatment engagement. It is recommended that a clinician gains a solid experiential understanding of mindfulness in order to implement these exercises in a skilful, effective, and context-appropriate manner.

Three-Minute Breathing Space

Three-minute breathing space is a brief mindfulness exercise that originated from MBCT (Segal, Williams, & Teasdale, 2002). This exercise involves first bringing one’s attention to the physical sensations, thoughts, and emotions in the present moment, shifting the attention to one’s breath, and then expanding the attention to the entire body. The purpose of this exercise is to enable a client to step out of the automatic pilot mode (in which individuals engage in actions habitually and without much conscious awareness) and cultivate a more mindful way of relating to the present moment experience. The exercise is intentionally designed to be brief (only 3 min long) so that it can be implemented even amid a busy daily schedule. Because of its brief nature, it tends to be a rather popular mindfulness exercise or tool among participants taking part in MBCT courses. It is also especially suitable for implementation in brief clinical sessions. In times when a client appears dysregulated or dis-engaged from the session, the exercise may be introduced to help calm down the client or to help the client re-engage in the session. Below is a script that a clinician may refer to when guiding a client through this exercise. The script also contains a brief introduction to the practice of mindfulness.

What this exercise involves is to simply pay attention to our experiences in the present moment in a nonjudgmental manner, to allow them to be as they are, without engaging in thinking about them, or pushing them away.

Typically, our natural tendency when we experience difficult thoughts and emotions is that we tend to think about them over and over again, judge our experiences as good or bad, or we try to push them away. Mindfulness involves letting go of these tendencies. Instead of ruminating on our thoughts and emotions or pushing them away, we practice bringing a kind of gentle, friendly awareness to these experiences, and recognizing them as simply mental events, or as physical sensations. The idea is to acknowledge and register our experiences in this moment as they are, whether it is our thoughts, feelings, or bodily sensations, in an accepting and nonjudgmental way.

Now, close your eyes, if that feels comfortable for you, and allow the body to relax. See if you can adopt a relatively upright yet relaxed posture... (PAUSE) The first step is becoming aware of what is going on with you right now... (PAUSE) Bringing the focus of awareness to your inner experience and notice what is happening in your thoughts, feelings, and bodily sensations.

Notice if there are any physical sensations in the body... for example, the weight of the body against the chair, or the hands touching the lap... (PAUSE). Next, becoming aware of any thoughts that are going through the mind... (PAUSE). Take a moment to register any of the experiences that you noticed (PAUSE). Becoming aware of how you are feeling in this moment (PAUSE)... Noticing any emotions that are present... If what you are experiencing is sadness, see if you can acknowledge the feeling as it is... perhaps saying at the back of your mind, "A feeling of sadness is arising". Acknowledging whatever that you are experiencing in this moment, even if it is unwanted or unpleasant. [Note: This portion of the exercise should last for about 1 min.]

Now, gently *Redirect* your full attention to the breath. Follow the breath all the way in and all the way out. If you like, you may note at the back of your mind: "Breathing in, breathing out."

Focus on the actual sensations of breath entering and leaving the body. There is no need to think about the breath—just experience the sensations of it. When you notice that your awareness is no longer on the breath, gently bring your awareness back to the sensations of breathing. [Note: This portion of the exercise should last for about 1 min.]

Lastly, allow your attention to expand to the whole body—especially to any sense of discomfort, tension, or resistance. If these sensations are there, then take your awareness there by "breathing into them" on the inbreath. Then, breathe out from those sensations, softening and opening with the outbreath. Say to yourself on the outbreath, "Whatever it is, it's OK. Let me feel it."

Becoming aware of your posture, facial expression and body as a whole. [Note: This portion of the exercise should last for about 1 min.]

When you are ready, you can open your eyes and bring your attention back to the room.

Mindful Breathing

Mindful breathing, or awareness of breath, is another mindfulness practice very commonly used in various mindfulness-based interventions (e.g., MBSR, MBCT, and DBT). This exercise involves bringing one's full attention to the physical sensations of breathing, maintaining the attention there, and repeatedly redirecting the attention back to the breath whenever one notices that the attention has wandered away from the breath to thoughts, fantasies, stimuli in the environment, emotions, and so on. This exercise, if practised over time, may help clients develop the ability to regulate attention more effectively. Also, even though this is not the goal of the practice, the practice may have a calming effect on the individual practising it (Baer, 2003). The practice may also help individuals develop the ability to de-center

from their thoughts and emotions; in other words, over time, individuals may learn to see their thoughts and emotions more as simply mental events rather than facts. The practice can be carried out for varying lengths of time, depending on an individual's preference and the purpose of practice. Shorter exercises (e.g., 10–20 min) can be helpful when an individual does not have time to do longer exercises and would like a brief practice to cultivate momentary awareness of the present moment experience. Longer exercises (e.g., 30 min to 1 h) may function to help an individual develop the ability to sustain attention for longer periods of time. In the context of treatment engagement, such an exercise can be very helpful for the client in becoming more focused on the treatment session, cultivating greater awareness of intra- as well as interpersonal processes in the session, and developing clarity of their goals and values. The following is a script that a clinician may refer to when engaging a client in a short mindful breathing exercise. The exercise is written for approximately 10 min of practice, but can be easily extended to a longer exercise (e.g., 20 min), by extending moments of silence during the guided session as well as interspersing the exercise with gentle reminders to maintain one's attention on the breath.

Now, close your eyes, if that feels comfortable for you, and allow the body to relax... see if you can adopt a relatively upright yet relaxed posture... Place both your hands on your lap... (PAUSE) The first step is becoming aware of what is going on with you right now... (PAUSE) Bringing the focus of awareness to your inner experience and notice what is happening in your thoughts, feelings, and bodily sensations.

Now, gently *Redirect* your full attention to the breath. Follow the breath all the way in and all the way out. Focus on the actual sensations of breath entering and leaving the body. There is no need to think about the breath—just experience the sensations of it.

You may become aware that the air that you breathe in is slightly cooler, and that the air you breathe out is slightly warmer and perhaps more full of moisture (PAUSE). Maintain your awareness on the constant flow of your breath (PAUSE). You may also notice that there is often times a slight pause between an out breath and the next in breath.

From time to time, you may notice that your attention wanders away from the breath to thoughts, emotions, other sensations in the body, or stimuli in the environment. This is completely normal, as this is what minds do. It wanders naturally. When you notice that your awareness is no longer on the breath, gently bring your awareness back to the sensations of breathing. There's also no need to judge yourself for having experienced distractions. The purpose of this practice is not to get anywhere necessarily; rather, the intention is to simply be aware of the experience in the present moment, whatever it may be. [Note: Throughout the practice, you may choose to repeat these instructions a few times to remind the client to redirect their attention continually back to the breath.]

When you are ready, you can open your eyes and bring your attention back to the room.

Leaves on a Stream Exercise

“Leaves on a Stream” exercise is a mindfulness exercise that originated from ACT (Harris, 2009). In brief, this exercise involves visualizing one's thoughts and feelings as leaves floating by on a stream, with one watching the leaves float on by without interfering with the process. This exercise may be particularly appealing to clients who are receptive to use of metaphors or visual imagery in the delivery of

interventions, and for clients who may struggle with other more traditional types of mindfulness exercises, such as mindful breathing. Like other mindfulness exercises that also utilize metaphors (e.g., the metaphor of clouds against the sky, or waves on the ocean), this exercise aims to help clients dis-engage from over-identifying with thoughts and feelings and refocus on the experiences in the present moment. Implementation of the exercise may facilitate treatment engagement especially when a client has a tendency to ruminate on negative thoughts and feelings that get in the way of her participating more fully in treatment. The practice can be done in varying lengths of time, e.g., ranging from 10 to 20 min. Below is a script that a clinician may refer to in guiding this exercise.

Begin by allowing your eyes to close, and bringing your awareness to your body. Becoming aware of sensations in the body in the present moment, as you are breathing in, and breathing out. Take the time to anchor yourself in the experience right in this moment (PAUSE).

Now, bring to mind the image of a clear flowing stream in a forest. Imagine that you are sitting by the stream, while watching the leaves on the stream float on by.

For the next few moments, take whatever thoughts that come to mind and put each thought on a leaf on the stream, and watch the leaf float on by.

For example, if you have a thought about what happened yesterday, go ahead and place the thought on the stream. Or you may have a thought about this session, for example, the thought that “this is boring,” or “this is pleasant.” Once you notice the thought, simply place the thought on the leaf that floats on by. Do the same regardless of whether the thought is pleasant or unpleasant.

Notice any tendency to want any particular leaf (or thought) to float on by, or go away quickly. Also, occasionally, you may observe certain leaves getting stuck in the stream. There is no need to hold on to any particular leaf, nor make the leaves go away quickly. Simply watch the flow of leaves as they float on by on the stream, at their own speed.

Occasionally, you may find your attention wander away from this exercise; when this happens, simply acknowledge that your attention has wandered and gently bring yourself back to this exercise. [Note: Throughout the practice, you may choose to repeat these instructions a few times to remind the client to redirect his or her attention back to the exercise.]

In a moment, this practice will come to an end. Take a moment to bring your attention to your experiences in this moment, noticing if there is any difference in how you feel before you engage in this exercise, and now.

When you are ready, you can open your eyes and bring your attention back to the room.

Cultural and Diversity Issues in the Implementation of Mindfulness-based Approaches

To date, mindfulness-based interventions have been implemented successfully and widely in many settings, due to their increasing popularity and accumulating evidence base. It is important to note, however, that mindfulness practices or meditation trace their roots most systematically to certain spiritual or religious traditions, in particular, Buddhism (Keng et al., 2011). Clinicians should be aware of the historical and spiritual origins of mindfulness and of potential responses that they may

receive when introducing mindfulness-based practices to a diverse group of clients. The fact that mindfulness practices have been most associated with Buddhism in terms of their origin may result in some clients feeling uncomfortable with the practices, especially if the client is not familiar with Buddhism or perceive a conflict between mindfulness practices and teachings of the religion they identify with. For a detailed discussion of ways in which mindfulness practices fit into the context of Buddhism, and of ideas to reconcile the spiritual origins of mindfulness and its secular adaptation, one may refer to Kabat-Zinn (2003).

There are several ways through which a clinician may introduce or orient a client to mindfulness-based practices and exercises in a culturally sensitive manner. The clinician may choose either not to highlight at all the spiritual origins of mindfulness, or to associate the origins of mindfulness with a variety of spiritual traditions, instead of with one predominant spiritual tradition (Linehan, 1993b). In fact, mindfulness practices or closely related practices can be found in spiritual traditions other than Buddhism, such as Sufism, Judaism, and the Christian Contemplative tradition. For a client who may be more sensitive to use of the word “meditation” (given its spiritual or religious connotations), a clinician may choose alternative terms to describe the practice introduced (if the practice involves traditional meditative practices, such as mindful breathing). For example, a clinician may describe the practice (in the case of mindful breathing) as a form of attentional training. It would also be helpful if clinicians can explore with clients ways in which mindfulness practice is consistent with their goals, worldview, and/or beliefs. For some other clients, mindfulness practices may in fact be already in line with their worldview and can be easily incorporated into their lifestyle. With these clients, a clinician may explore the possibility of integrating mindfulness into the client’s own cultural or spiritual framework (for example, supporting a Christian client’s engagement in contemplative practices to cultivate a closer relationship with God) to enhance his engagement in treatment.

Training Resources for Use of Mindfulness-based Approaches in Treatment Engagement

As highlighted in an earlier section of this chapter, an aspect crucial to the effective use of mindfulness in clinical practice relates to the clinician’s ability to embody qualities of mindfulness, not just in the way she relates to patients, but also in the way she relates to her own experiences. Unlike some other intervention approaches that involve teaching specific skills to the clients but do not necessarily require clinicians to also practice or engage with the skills regularly, a mindfulness-based intervention approach calls for a sincere intention on the clinician’s part to learn about mindfulness not only intellectually, but also experientially. This requires understanding not only the technical aspects of facilitating the practices, but also more fundamental aspects relating to the philosophical context of the practice and ways of working with difficulties that may come up during the practice. The importance of clinicians having an experiential understanding of mindfulness in order to deliver

a mindfulness-based intervention effectively and skilfully is highlighted aptly by Kabat-Zinn (2003, p. 150) in the below paragraph:

Unless the instructor's relationship to mindfulness is grounded in extensive personal practice, the teaching and guidance one might bring to the clinical context will have little in the way of appropriate energy, authenticity, or ultimate relevance, and that deficit will soon be felt by program participants. *For how can one ask someone else to look deeply into his or her own mind and body and the nature of who he or she is in a systematic and disciplined way if one is unwilling (or too busy or not interested enough) to engage in this great and challenging adventure oneself, at least to the degree that one is asking it of one's patients or clients?* How will one know how to respond appropriately and specifically to their questions if one cannot draw on one's own lived experience, not just on book knowledge and concepts, when the practice itself is all about seeing clearly and transcending (not getting caught up in and blinded by) the limitations of the conceptual mind while, of course, not rejecting the conceptual mind or the power and utility of thought within the larger context of awareness?

Therefore, whereas a clinician may utilize aspects of mindfulness practices to achieve limited goals in engaging clients (e.g., helping a client to be more focused in session), a more complete and skilful application of a mindfulness-based approach requires the clinician to also have an experiential understanding of mindfulness. Such experiential understanding may be obtained through several potential avenues. To start with, a clinician may gain a "taste" of mindfulness by attending one or several introductory mindfulness sessions. For a more immersive experience of mindfulness practices, a clinician may consider attending a standardized 8-week program, such as MBSR, which typically involves 8 weeks of 2–2.5 h of experiential mindfulness sessions (in which participants are taught a variety of mindfulness exercises, such as body scan meditation, mindful breathing, and walking meditation), in addition to a half day silent mindfulness retreat. Within the US context, the website of the American Mindfulness Research Association contains a directory of mindfulness training and research programs across the country: <https://goamra.org/resources/find-program/>. Attendance of a standardized 8-week mindfulness program is often times one of the prerequisites for enrolling in higher level training, such as teacher training for MBSR (for an example, see UCSD's Center for Mindfulness' Teacher Training Program: <http://mbpti.org/mbsr-teacher-qualification-and-certification/>). Additionally, there are programs that have been designed specifically to train therapists or mental health professionals in mindfulness-based approaches. These programs include an 8-week Mindful Therapy program (Aggs & Bambling, 2010) and MBSR adapted for healthcare professionals (Irving et al., 2014).

Conclusion

As a psychological intervention that has gained much empirical support in terms of its efficacy in treating a variety of conditions (Baer, 2003; Keng et al., 2011), mindfulness holds much promise as an effective treatment engagement tool.

Qualities fundamental to mindfulness, such as present-moment awareness, acceptance, curiosity, and nonjudgment, are all qualities fundamental to good clinical practice and treatment. Recent research has also provided promising evidence that incorporation of mindfulness in clinical practice enhances the quality of and effectiveness of the service. This chapter is among the first attempt to explore how mindfulness may be utilized systematically as a treatment engagement tool. It proposes that mindfulness can promote treatment engagement in one of two primary ways: (1) through clinicians' own embodiment of qualities of mindfulness, and (2) through the use of mindfulness practices as a standalone or complementary treatment engagement tool. A mindfulness-based approach to treatment engagement serves a variety of potential functions, ranging from increasing a client's receptiveness to treatment, enhancing clinicians' empathy, to increasing clinicians' awareness of treatment interfering behaviors on the part of the client and also the clinician himself. Given that mindfulness has its roots in spiritual traditions, clinicians should exercise certain caution when introducing mindfulness exercise to clients of diverse cultural backgrounds. Lastly, to utilize mindfulness effectively as a treatment engagement tool, it is recommended that a clinician obtains not only intellectual understanding, but also a deeper, experiential understanding of mindfulness through participating in introductory mindfulness classes or more intensive mindfulness training programs.

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Chapter 6

Promoting Engagement in Health Maintenance and Health Care in a Telehealth-Enabled Environment

Claudia C. Bartz and Nicholas Hardiker

Introduction

This chapter describes telehealth and broader eHealth as phenomena that are rapidly changing the nature of health and health care worldwide. Information and communication technology (ICT) holds great promise for increasing access and quality of health care, especially, but not exclusively, in the developing world. The continued growth of ICT-related processes and products in nearly all of the world's countries could hardly have been dreamed of just a few decades ago. As of 30 June 2014 (Internet World Stats, accessed 20 January 2015), there were more than three billion internet users, comprising 42% of the world's population. This represents an increase of 741% from 2000 to 2014. As to world internet penetration, the world average is about 42%, with North America having about 88% and Africa about 27% (Internet World Stats).

The promotion of engagement is here described as applying both to those who are maintaining their health (citizens) and those who have health care needs related to injuries, acute illnesses, or chronic diseases (patients). Both citizens and patients are sometimes labeled consumers. A health-related consumer is somewhere between being interested in health and being actively involved in, and well-informed about, his or her health care needs (Frist, 2014; Norman, 2011).

The concept of engagement is found throughout the health environment, from peer-reviewed literature to health organizations to the lay press. Webinars and

C.C. Bartz, Ph.D., R.N. (✉)

Telehealth Nursing Working Group, International Society for Telemedicine & eHealth,
14388 Cedar Lane, Suring, WI 54174, USA
e-mail: cbartz@uwm.edu

N. Hardiker, R.N., Ph.D.

Chair, School of Nursing, Midwifery, Social Work & Social Sciences, University of Salford,
MS1.12, Mary Seacole Building, Salford M6 6PU, UK
e-mail: n.r.hardiker@salford.ac.uk

conferences on engagement are being offered regularly. This chapter will focus on promoting engagement of citizens and patients in a telehealth-enabled environment. Three key concepts are described as essential elements of successful engagement for telehealth: health literacy, information and communication (ICT) literacy, and technology acceptance. Research findings are presented as sources of information for the reader who is looking for ways and means to increase citizen and patient engagement in health endeavors.

eHealth

eHealth is the use of information and communication technologies (ICT) for health. The World Health Organization (WHO) defines eHealth (WHO, accessed 14 January 2015) as the transfer of health resources and health care by electronic means, encompassing three main areas:

- The delivery of health information, for health professionals and health consumers, through the Internet and telecommunications.
- Using the power of IT and e-commerce to improve public health services, e.g., through the education and training of health workers.
- The use of e-commerce and e-business practices in health systems management.

The health care community has used ICT in many different ways for nearly a century, with telephones and radios being early examples of innovations that could improve the connection between care provider and person in need of care. In the past several decades, however, there has been a revolutionary proliferation of ICT technology and applications in health care. The ICT advancements aim to improve the quality of care delivery by more efficiently and effectively involving citizens seeking health information or improvement, and patients needing health care.

Tangible examples of eHealth are described in the National eHealth Strategy Toolkit, a collaborative product of WHO and the International Telecommunication Union (WHO & ITU, 2012). These include

- electronic medical records;
- electronic health records;
- personal health records;
- mobile health technologies and applications (mHealth);
- decision support systems;
- chronic disease management services;
- practice, patient, and clinical management systems;
- electronic medication services;
- health knowledge services;
- health knowledge resources;
- distance learning for health professionals (eLearning); and
- health information systems.

Chi and Demiris (2014) provide a useful addition to the list above, identifying telehealth tools and interventions. Tools include video, telephone (call, text), web-based, and telemetry/remote monitoring. Telehealth-based interventions include

- education;
- consultation (including decision support systems);
- psychological/cognitive behavioral therapy;
- social support;
- data collection and monitoring; and
- clinical care delivery.

Telehealth Definition

Telehealth, also called telemedicine or tele(specialty), has emerged and grown as the ICT-leveraging, human care delivery actualization of the broader and more abstract concept of eHealth. Tele(specialties) include, e.g., teleradiology, teledermatology, and telenursing. The American Telemedicine Association “has historically considered telemedicine and telehealth to be interchangeable terms, encompassing a wide definition of remote healthcare. Patient consultations via video conferencing, transmission of still images, e-health including patient portals, remote monitoring of vital signs, continuing medical education, consumer-focused wireless applications, and nursing call centers, among other applications, are all considered part of telemedicine and telehealth” (ATA, accessed 13 January 2015).

Telehealth with and for Citizens and Patients

Health care is complex; many people are involved, and transactions among people depend on communication and mutual goals for success. Individual, group, or community health is best described as a continuum, with health maintenance book-ending intermittent episodes of health care (Fig. 6.1). Health maintenance includes health promotion activities for individuals, groups, or communities, such as exercise and nutrition education. Health maintenance also includes disease prevention, such as smoking cessation and alcohol moderation programs. Episodes of health care for individuals would usually take place in clinics, hospitals, or homes and

1	Birth.....Youth.....Young Adult....Adult.....Early elder.....Mid-elder.....Old.....Death
2	Healthy...Illness/Injury....Healthy...Illness/Injury....Healthy...Illness/Injury...Healthy
3	Chronic disease...Chronic Disease...Chronic Disease....Final Illness/Injury/Disease

Fig. 6.1 Health, illness/injury, chronic disease continuum

would include care provider assessments, diagnoses, interventions, and evaluations. Individuals with health care needs could have acute events, with identified start and end dates (e.g., bone fracture, hernia surgery). Other people could have chronic needs over time, such as with diabetes, cardiovascular disease, or depression.

With a few exceptions, most people spend very little time per day seeking and receiving health care. For the U.S. civilian population, the American Time Use Survey shows that in 1 day, 0.09 h are spent in health-related self-care and 0.05 h is spent in medical and care services. That comes to 8.4 min per day, on average, being spent on health and health care (Bureau of Labor Statistics, accessed 20 January 2015). The U.S. Army estimates that the average soldier seeks and receives health care for about 100 min a year—five 20-min appointments on average. This leaves about 525,500 min in a year when they are not seeking care in hospitals and clinics (Horoho, 2014). For health care systems and providers, then, it is critically important to maximize the impact of health interactions using all methods available for assessment, diagnoses, interventions, education, and consultation.

Telehealth technology and applications can be integrated throughout the health continuum, extending the reach of health care providers across geographic distances and over socio-economic barriers. This integration is not without its challenges. Provider acceptance of telehealth is variable and may continue to be an issue influencing widespread integration (Brewster, Mountain, Wessels, Kelly, & Hawley, 2014; Taylor et al., 2014). Health care providers using telehealth are subject to the regulatory requirements of their practice specialty (ATA, 2014; Hutcherson, 2001). But, in addition to professional licensure, ethics, and scope of practice, the use of telehealth applications raises issues of multi-jurisdictional practice, standards for practice, and new competencies (Brooks, Turvey, & Augusterfer, 2013).

For people who receive health information (for health maintenance) and health care (for acute needs and chronic care) in a telehealth-enabled environment, there would need to be assessment and advancement of health literacy (Coulter, 2012). In addition, the recipients' ability to use communication devices and applications has to be considered. This ability is conceptualized in different ways, to include digital literacy (Belshaw, 2011; Wikipedia, 2015), internet skills (van Deursen, van Dijk, & Peters, 2011), and digital skills (van Deursen & van Dijk, 2009). However defined, the ability to use ICT would influence citizens and patients in their pursuit of health or health care. Technology acceptance is a third major factor influencing the receipt of health information and care by individuals, groups, and communities. Whether over distances or socioeconomic barriers, technology acceptance will determine the success of a person's engagement in using technology-mediated applications. The three concepts identified here (health literacy, ICT ability, technology acceptance) will be explored for their relationship with and impact on the movement toward greater engagement of citizens and patients in telehealth-enabled environments.

Promoting Engagement in Health and Health Care in Telehealth-Enabled Environments

Engagement in the telehealth context takes place at a number of different points and in a number of different ways throughout a person's lifetime continuum, across health maintenance and episodes of health care. A useful definition of engagement for the telehealth context comes from a White Paper published by the Center for Advancing Health (2010). Engagement represents the "actions individuals must take to obtain the greatest benefit from the health care services available to them" (Center for Advancing Health, 2010, p. 2). The definition focuses on behaviors of people needing health care services rather than on professional actors or institutional policies. With telehealth, telemedicine, or tele(specialty) for health maintenance or care delivery, the care recipient must be the engaged entity. This implies that the person is willing and able to allow the addition of, or the new use of, information and communication technologies to the complexity of health maintenance and health care. The person's readiness for ICT applications can be assisted and supported by the health care team using needs assessments and appropriate education and training (Huang, 2011).

Health Literacy. Literacy is the person's ability to read, write, speak, and compute and solve problems in order to function, achieve goals, and develop one's potential. Health literacy is the degree to which individuals have the ability to obtain, read, process, and act upon health information to make appropriate health decisions (Coulter, 2012; Institute of Medicine of the National Academies, 2004; www.health.gov accessed 14 January 2015). Health literacy depends on the communication skills of citizens, patients, and health care providers. It also depends on the cultural and socioeconomic context of the participants in health interactions.

Citizens seeking information and education for their own health management and improvement need a basic understanding of how the human body functions and how their specific concerns and goals can be developed and expressed. Telehealth technologies and applications can offer individuals or groups verbal or printed information via the internet at home or in the community. Of course, the verbal or printed information must be in the recipient's language and must use culturally appropriate content and graphics.

Engaging citizens with the wellness-focused telehealth modalities requires timely and well-positioned sources. For example, television or video offerings available and retrievable for people in their homes, community centers, or libraries may be useful sources of health information. Kiosks in city center squares, gathering clubs and shopping venues, and on public transportation could offer access to health information resources. To be useful, all of the information offered would have to be vetted by native speakers to be culturally and linguistically appropriate for the intended recipients. With these "push" modalities, periodic evaluation of numbers of users and frequency of access to offered web sites, phone consultation, or in-person visits could give direction for improvements in the offerings.

Patients who, by having assumed that label, have a health care need or problem would need at least a fundamental understanding of how their actual or potential problem is affecting them physically or psychologically or both. This would include knowledge about related signs and symptoms before, during, and after treatment. A person with hypertension, for example, would need to have some degree of health literacy to learn about measuring blood pressure, the effects and side effects of prescribed medication, dietary requirements, and symptoms of high and low blood pressure.

As a further example, a person who has been newly diagnosed with diabetes could be taught and encouraged to engage with the treatment regime through the exchange of information with the primary care provider, nurse manager, diabetes educator, possibly a pharmacist and others. With telehealth capability, the primary care provider or nurse manager could assess the patient's ability to receive management guidance about diabetes medication, diet or activity virtually, after transmitting data from the home. The physician or diabetes educator could use interactive video to assess learning needs, teach and counsel as necessary, with the aim of involving and engaging a well-prepared and confident patient.

Telehealth research is increasing the body of knowledge for advancing health literacy. In a randomized controlled trial by Glasgow et al. (2011) of engagement in a diabetes self-management website ($n=270$), the participants used the website fairly often but engagement decreased over 4 months. In findings of interest to telehealth website developers, the most common section visited was the "Track My Progress" section, where more than 75% of all participants used the tracking feature an average of once per week. This was followed by the "Action Plan" section, where participants completed an average of 1.7 of the three action plans; two thirds completed exercise and healthy eating plans and slightly less than half completed medication-taking plans. Third, fourth and fifth sections visited were "My ABCs," "Resources," and "Ask an Expert." When comparing patient characteristics, none stood out as predictive of engagement. Instead, the results indicated that participants varying in education, age, income levels, ethnic backgrounds, socio-demographic, psychosocial, and clinical characteristics were able to use the website.

A qualitative study explored with culturally and linguistically diverse communities the use of digital technology for education about disease (in this case, diabetes) (O'Mara, Gill, Babacan, & Donahoo, 2011). Participants were 38 elderly women from a Vietnamese community. Key findings were that digital technology (interactive video, YouTube video) improved capacity of the group to a limited degree. Also, supportive processes, such as face-to-face contact, language, and an interactive group session involving a respected member of the community from the same racial, cultural, and linguistic background, were used to increase awareness and engagement with technology for this group. Finally, a holistic use of ICT (communal, culturally and linguistically appropriate, in the preferred language and preferred digital technology) was shown to increase engagement of members of the group for improved engagement with digital technology for diabetes information.

Based on these research reports, developers and implementers of telehealth applications are encouraged to consider how their digital technology applications and expected outcomes fit with users' readiness to learn about their own health or

illness and their ability to engage in the use of ICT for health care. Understanding the cultural context would include knowing about users' language use and comprehension, communication preferences, and beliefs and values concerning health and illness.

ICT Ability. Digital literacy can be defined as the knowledge, skills, and behaviors used in a digital network device from smartphones to desktop personal computers. Wikipedia (2015), Belshaw (2011) and jPodcaster (2012) describe eight key elements of digital literacy. These can be applied to the process of engaging citizens and patients in health and health care. We will use "recipient" to represent the citizen seeking health maintenance, the patient needing health care, and the family or significant other(s) who may also be involved in the health episodes.

- Cultural—looking at the recipient's context for ICT, to include economic, social, and linguistic variables;
- Cognitive—assessing the recipient's thinking while using devices;
- Constructive—ability of the recipient to use health maintenance and care ICT purposefully;
- Communicative—ability of the recipient to use ICT to enhance communication with provider or educator;
- Confident—the recipient's degree of confidence in using digital technology;
- Creative—the recipient's acceptance of new ICT-based ways of interacting with health system;
- Critical—the recipient's ability to know what technology works well, what does not work; and
- Civic—the recipient's ability for an engaged citizen or patient to impart ICT knowledge and skills to others.

A framework for expanding the concept of digital (van Deursen & van Dijk, 2009) and internet (van Deursen et al., 2011) skills beyond being a subset of digital literacy aims to move researchers and policy-makers forward from the idea of "button-pushing" skills. The framework includes four aspects; these can also be applied to the goal of engaging citizens and patients, and, as appropriate, families and significant others, in health and health care:

- Medium-related skills
 - Operational skills with digital media;
 - Formal skills in handling digital structures such as menus and hyperlinks;
- Content-related skills
 - Information skills with the ability to search, select, and evaluate information in digital media; and
 - Strategic skills with the ability to employ digital information to reach a goal.

For each of the skills described by this framework, it would be important to know the recipient's skill level at the beginning of any health encounter. Then, the

necessary education or training could help to ensure successful interactions with providers or educators in a telehealth-enabled environment. In their study of digital skills, van Deursen and van Dijk (2009) asked 109 subjects to complete, on the internet, nine government-related assignments. On average, subjects successfully completed 80% of operational tasks, 72% of formal tasks, 62% of information tasks, and 22% of strategic tasks. While this is only one study, the findings are important in pursuing engagement-friendly and -supportive health encounters.

Mobile health (mHealth) is the use of mobile communication devices for health information. Smart phones, digital tablets, and wearable devices for the collection and transmission of health data can enhance motivation and promote engagement in health care activities (LoPresti et al., 2014). mHealth applications exploit the digital skills that have become second nature in many countries of the world. People using mobile phones for financial transactions, for example, would have little difficulty using mobile phones for data receipt and transmission. Content quality, data accuracy, and data confidentiality are some of the risks of using mobile technology, in particular smartphones (Bert, Giacometti, Gualano, & Siliquini, 2014).

Based on this research, developers and implementers of telehealth applications should anticipate and account for a range of digital knowledge and skills within and across user groups. Assumptions should be avoided regarding who would or would not be able to use the technology, e.g., older versus younger, urban versus rural, developed country resident versus developing country resident. With mHealth, attention must be paid to the reliability, validity, and usability of apps that are used for health care or reporting about health. Data confidentiality is always important in health-related endeavors.

Technology Acceptance. Health providers expect that citizens and patients faced with telehealth technologies are willing to engage: to learn new processes, participate as actively as necessary, and benefit from them. The Technology Acceptance Model (TAM) (Davis, 1989; Davis, Bagozzi, & Warshaw, 1989) was devised to represent the concepts and relationships necessary to explain and predict technology use (Fig. 6.2). Essentially, the model shows perceived usefulness and perceived ease of use affecting (a) attitude toward using, (b) behavioral intention to use, and (c) actual system use. Davis (1989), in an instrument development study, found that perceived usefulness had a significantly greater correlation with usage behavior than did ease of use. Davis et al. (1989), in a longitudinal study, found that perceived usefulness strongly influenced peoples' intentions, explaining more than half the variance at 14 weeks.

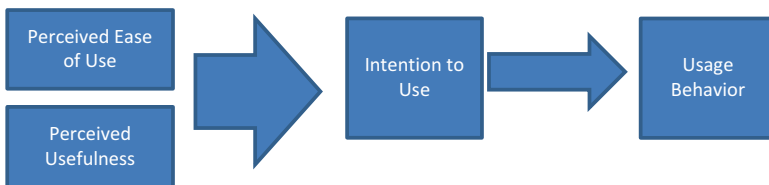


Fig. 6.2 Technology acceptance model

In its early development, the TAM applied to technology and not specifically to health care technology. Holden and Karsh (2010) identified this gap in knowledge and completed a review of 16 data sets in over 20 studies of clinicians using health IT for patient care. They found that certain TAM relationships were consistently found to be significant while others were inconsistent. Holden and Karsh (2010) concluded that the TAM predicted a substantial portion of the use or acceptance of health IT, but that the model could benefit from greater specification for the health care environment. In a study taking this work further, Or et al. (2011) proposed adding variables to the TAM, e.g., health information seeking preference. They used a cross-sectional secondary analysis of data from a study evaluating a technology-assisted home care nursing practice. In the final model (Or et al., 2011) added the concept of subjective norm, or social influence, as a precedent to perceived usefulness. This new model also included the concept of healthcare knowledge as a precedent to self-reported effective use.

Two more studies using the Technology Acceptance Model show that the model has good explanatory power (Huang, 2011, 2013). Interviews that provided complete questionnaires from 295 senior citizens (over age 60) were analyzed using the new, nonlinear method of back-propagation network (BPN), a type of artificial neural network analysis (Huang, 2011). The author reported that participants' perceived usefulness must be raised to effectively increase the adoption of telecare. In the second study (Huang, 2013), 269 people, most of them between ages 35 and 54, completed a questionnaire to evaluate the influence of behavioral factors on acceptance of telecare. Structural equation modeling was used to analyze the data. The strongest factor in the TAM was attitude toward use of technology, followed by perceived usefulness, perceived ease of use, subjective norms, and personal innovativeness.

Based on this research, developers and implementers of telehealth applications are encouraged to integrate the concepts and relationships of technology acceptance into their work. People pursuing health, patients in need of health care, and people who agree to be research participants all merit an assessment of their degree of technology acceptance. Is the proposed technology perceived as useful? Is it seen as easy to use? Will there be an intention to use technology? Are the person's social norms or influences, e.g., family members, supporting the person in using technology? Does the person have sufficient knowledge of his or her health needs to be motivated to use technology? Perhaps most important would be reassurance from the health provider or researcher that there will be support and encouragement for the actual use of the technology and that there will be some benefit to the user.

Readiness, Acceptance, and Engagement Research

Like everyone who is taking advantage of the rapid proliferation of information and communication technology, health care providers and researchers are examining respondents' readiness to use technology for information about digital applications

that can advance engagement in health. Exemplars of research using various technologies are described below, with particular attention to participants' responses to the technologies.

Telehealth is not always accepted by people with health care needs. Mair et al. (2006) approached 653 patients who were older and suffering from an acute exacerbation of a chronic illness, to participate in a study of home telecare. While 519 people met the eligibility criteria, only 104 (20%) people agreed to participate. The most common reason for refusal, accounting for 33% of the eligible people, was a stated preference for a face-to-face nurse visiting service rather than a telecare service. Findings for this same approach might be different now, 10 years later.

In the challenging environment of dealing with thousands of war veterans in the United States, telehealth research is proceeding vigorously. In a study by Poropatich, Pavliscsak, Tong, Little, and McVeigh (2014), 497 U.S. military veterans from Community-based Warrior Treatment Units (CBWTU) were asked to use a secure mobile messaging initiative called mCare. About 50% of soldiers in CBTWUs have chronic brain injury or posttraumatic stress injury. The mCare intervention included appointment reminders, health and wellness tips, and announcements. There was high acceptability of mCare, including improved appointment attendance. The authors noted that two primary factors were key in generating positive user impressions: ease of use and content relevance.

Two studies reported success using digital tablets with their participant groups (Cook et al., 2013; Crotty et al., 2014). In the Cook et al. study, participants were 149 cardiac surgical patients over age 50. The tablet program included a hospital plan of stay, education, recovery planning, and daily "to do" lists. They were asked to complete self-assessment modules preoperatively and then daily after transfer from the ICU. The modules included discharge planning information, a pain scale, and a mobility assessment tool. The subjects completed 98% of the 1418 self-assessments that were sent to them. The authors did not find the study participants to be "technophobic." Rather, they noted that an engaging technology-based intervention is feasible and effective in older inpatients after surgery. In the Crotty et al. study, 96 (of 121 eligible) participants completed the intervention. One group consisted of community patients who needed rehabilitation (e.g., poststroke) and people with complex disabilities living in the community (e.g., brain injuries). Nursing home residents made up the second group. The main elements of intervention included a coaching approach, the use of simple equipment and software, videoconferencing, activity monitoring using an app, an online questionnaire, and care-giver involvement. On average, participants felt they had achieved 75% of the goals set at the beginning of the program. They also reported high levels of satisfaction. There was a 50% reduction in home visits by the staff. Analysis of interviews of patients, families, and care-givers suggested that tele-rehabilitation was acceptable and perceived positively by older people.

Great effort is being made to use and study telehealth applications in people who have diabetes. In 2000, about 171 million people had diabetes and estimates are that by 2030 this number will more than double (Wild, Roglic, Green, Sicree, & King, 2004). A randomized controlled trial of online disease management for the

engagement and motivation of people with diabetes (Tang et al., 2013) used seven online processes with the intervention group. These were wireless reporting of glucometer readings with graphical feedback; patient summary reports; nutrition and exercise logs; insulin records; online messaging with the care team; nurse care manager and dietitian providing consultation and medication management; and personalized text and video education “nuggets.” At 12 months, there was no significant difference in the control and intervention groups’ A1C values but the intervention group had better LDL cholesterol. Significantly more intervention group members initiated online messages to providers. Subjectively, interview data showed that the intervention group members had better knowledge about blood glucose testing and understanding about diabetes. This group also had greater overall treatment satisfaction and willingness to recommend treatment to others.

Piette et al. (2013) assessed engagement with patient monitoring and support calls by aggregating data from one randomized controlled trial (RCT) and three programs that used interactive voice response (IVR) with their participants with heart failure (RCT), depression, diabetes, or cancer. IVR allows patients to communicate with clinicians asynchronously using a mobile or landline telephone. The 1173 patients had a mean age of 61 (SD=13.4) and most were white and male. Patients with diabetes or depression had been given an opportunity to participate with an informal care giver in their respective studies and 65% chose to do so. Call completion rates were higher for those in the heart failure (90%) and cancer programs (90%) than for those in the diabetes (81%) or depression (71%) programs.

The authors (Piette et al., 2013) suggest their findings dispel some concerns for IVR self-management support services. They found that IVR call completion rates were generally high; IVR call completion did not vary by race, education, marital status, or income; odds of call completion increased significantly with age; people with depression had reasonably high (71%) call completion rates; and, IVR participation rates did not necessarily wane over time. For example, patients with heart failure completed 90% of their calls over a year.

This selective review of published research suggests that, in terms of readiness, acceptance, and engagement, the findings give reason for optimism about the benefits of recipients’ participation in telehealth applications, especially for people with non-communicable chronic diseases and people with decreased access to health care due to distance or socio-economic barriers. Researchers are emphasizing the importance of patient or research participant engagement in care management and goal attainment.

Some have questioned the benefits of telehealth. After analyzing seven studies that involved 800 patients, a Cochrane Collaboration Review (Currell, Urquhart, Wainwright, & Lewis, 2010) concluded that various forms of telemedicine are feasible but that there was not yet enough evidence to show effects on health outcomes or cost-benefit of the expensive technology. Five years later however, Merrell and Doarn (2014) express great optimism about the advancements in telemedicine worldwide.

Summary

In this chapter we have briefly described telehealth and eHealth. The approach to engagement was framed around citizens, or people who are healthy but interested in maintaining their health, and patients, or people who have an injury or illness or chronic disease. Three concepts were identified as being relevant to engagement of citizens and patients for health and health care in telehealth-enabled environments: health literacy, ICT literacy, and technology acceptance. Selected research was described to highlight research-based findings as they apply to engagement. The studies included are a small sample of the telehealth research available today. However, telehealth developers, implementers, and researchers would be wise to consider the following:

- How do your digital technology, applications, and expected outcomes fit with users' readiness and ability to engage in the use of ICT for health care? How will you assess this and make the necessary interventions?
- What is the citizen, patient, or research participant's cultural context for technology-enabled health care or research and what interventions are needed to address cultural issues?
- How will you anticipate and account for a range of digital knowledge and skills within and across user groups? What are your assumptions about different individuals' or groups' capabilities and how will you test these and apply the results to care delivery, education, and research?
- When does the integration of the concepts and relationships of technology acceptance strengthen your work? How will you assess people or groups for their attitudes and intentions regarding the use of technology?

Health maintenance and health care continue to be more citizen- or patient-directed, as people have greater access to information about health, illness, and disease. People can make choices about health care and interventions that were not available to them in the past. The need for a productive, interactive engagement between citizen or patient and health care providers, developers, educators, and researchers cannot be over-emphasized. In technology-enabled telehealth environments, engagement must be actively pursued and established as distances and barriers are overcome.

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Chapter 7

Adherence Technologies and Treatment Engagement

Leslie R. Martin and Vanessa E. Haro

Why Adherence Matters

Non-adherence to treatment regimens of all sorts presents an ongoing threat to effective medical care. The challenge of non-adherence has long been recognized, yet despite hundreds of empirical studies on the topic, non-adherence rates remain high. Estimates of adherence failures vary substantially across disease type, severity, and complexity of regimen (DiMatteo, Haskard, & Williams, 2007) but one large-scale meta-analysis that included all English-language empirical studies from 1948 to 1998 ($N=569$) suggested that approximately one in four patients is non-adherent (DiMatteo, 2004a, 2004b, 2004c); and, the costs associated with non-adherence are striking—as much as \$290 billion annually in the United States (New England Healthcare Institute, 2009). Data clearly indicate that effective adherence is crucial for managing chronic illnesses, achieving viral suppression, reducing symptoms, minimizing relapses, and attaining a healthy immune system (Mahgerefteh, Pierre, & Wirshing, 2006; Westerfelt, 2004) and thus, effectively addressing the non-adherence problem is vital.

Poor adherence is linked to diminished health outcomes across a variety of domains; when medical regimens are not followed symptoms may not be improved and conditions typically worsen, leading to therapeutic failure, decreased satisfaction, and increased medical costs. For individuals with diabetes, non-adherence can result in higher blood glucose levels, all-cause hospitalizations, and mortality (Chisholm et al., 2007; Ho et al., 2006). For patients with viral conditions, failure to adhere may increase the risk of the virus becoming immune to the treatment (Westerfelt, 2004). Patients with other chronic diseases are also at greater risk, such

L.R. Martin, Ph.D. (✉) • V.E. Haro, B.A.
Department of Psychology, La Sierra University, 4500 Riverwalk Parkway,
Riverside, CA 92515, USA
e-mail: Lmartin@Lasierra.edu; vhar277@lasierra.edu

as in the case of asthma, where sufferers have an increase in frequency and severity of asthma exacerbations and a greater risk of hospitalization if they fail to adhere to treatment regimens (Gandhi et al., 2013). Improper adherence to chronic pain medication can exacerbate perceived pain and this may, in turn, contribute to medication abuse and addiction (Graziottin, Gardner-Nix, Stumpf, & Berliner, 2011) and failure to adhere to medications for managing cardiovascular disease (which remains the leading cause of death, globally) can also lead to a range of harmful, or even fatal, results (Albert, 2008). In all, it is clear that although the specific outcomes associated with non-adherence vary by disease type and severity, they are uniformly detrimental, costly, and discouraging.

Predictors of Adherence

Predicting adherence is nearly as difficult as achieving it, but among the factors found to influence it are: complexity of the recommendations, psychosocial issues, knowledge about the illness or treatment, and patient-provider relationships and communication.

Adherence is consistently linked to the complexity of the treatment regimen itself. Research has shown that when treatment regimens include more doses per day, multiple drug-related restrictions (such as strict dosing schedules or requirements that foods be avoided within certain time frames), and/or pervasive lifestyle changes individuals are less likely to successfully adhere to them (Ingersoll & Cohen, 2008). Patients with chronic diseases, who often undergo complex treatments that may interfere with their normal daily routines, struggle a great deal with treatment adherence (Hauber, Mohamed, Johnson, & Falvey, 2009; Mellins, Ezer, Cheng-Shiun, Havens, & Chesney, 2003; Westerfelt, 2004).

Another set of factors that plays a vital role with regard to adherence is the psychosocial. For example, the odds of non-adherence for patients with depression is significantly higher than for those who are not depressed (DiMatteo, Lepper, & Croghan, 2000; Grenard et al., 2011) and other mental health issues, including anxiety disorders, may also interfere with patients' motivation and ability to carry out treatment recommendations (Haskard-Zolnieriek & Williams, 2014). A large body of evidence not only demonstrates that psychosocial factors such as stress and depression are leading predictors of non-adherence, but also that these associations are similar across a multitude of different illnesses and diseases (Mackin & Areán, 2007; Mann, Ponieman, Leventhal, & Halm, 2009; Thames et al., 2012). Social support networks are also recognized as exerting important influence on adherence and chronic illness self-management, as demonstrated in several quantitative reviews (DiMatteo, 2004b; Gallant, 2003; Levy, 1983), with stronger social networks linking to better outcomes.

In addition to treatment-related and psychosocial factors, lack of knowledge (about one's disease, its treatment, and potential side effects) is a strong predictor of whether a patient is likely to adhere to treatment (Ingersoll & Cohen, 2008; Mei-Yu,

Su-Ching, Yorker, Chi-Chen, & Ya-Lin, 2008; Ulfvarson, Bardage, Wredling, von Bahr, & Adami, 2007). If patients have a better understanding of what they are being asked to do, why they are being asked to do it, and what outcomes are likely if they do (or do not) carry out the action, they are better able to comply with their treatment recommendations—they are better informed and more motivated (Martin, Haskard-Zolnierrek, & DiMatteo, 2010). This knowledge and its associated motivation are best achieved when clinicians engage with patients and create meaningful care-partnerships with them.

Data clearly indicate that engaged patients—those who share in decision-making and enjoy effective communication with their health care providers—are more adherent, have better health outcomes, and are more satisfied with their medical care (DiMatteo, 2004c; Golin, DiMatteo, & Gelberg, 1996; Guadagnoli & Ward, 1998; Hall, Roter, & Katz, 1988; Stewart, 1995). A key question, then, centers on how to engage patients in the process of their own care, so that optimal outcomes can be achieved.

Technology, Patient Engagement, and Adherence

Technology is regularly used in medicine to prolong life and improve its quality (Thompson & Walker, 2011) with tools ranging from genomic mapping and data storage/retrieval to sophisticated real-time scanning and robotic surgical techniques. Patients can access information more easily than ever before, and possibilities for healing and health seem endless as new medications, devices, and interventions are developed. But despite all the high-tech aids at the disposal of clinicians and their patients, non-adherence remains a serious problem. It is as C. Everett Koop, U.S. Surgeon General from 1982 to 1989 so aptly stated, “Drugs don’t work in patients who don’t take them.” Indeed, we may have the best medical care available, but if patients do not engage with that care and adhere to recommendations, that top-quality care cannot be effective. So, if patients are not following the recommendations of their clinicians, where are they getting their health advice?

It is estimated that about one quarter of those using social-network sites have followed medical advice given by other users based on their anecdotal experiences (Fox, 2012). There were approximately 1.35 billion active monthly users on Facebook as of July of 2014 and 284 million active Twitter accounts in October of 2014; these are just two of many hundreds of social-network sites. Add to these the many (sometimes cleverly disguised) health-related advertising sites, the governmental and nonprofit sites providing information, and scores of empirical research reports and articles and it is easy to see how one might be overwhelmed, confused, misled, or worse.

Patients have many reasons for seeking health-relevant information online, ranging from self-diagnosis to checking on the competency of their healthcare providers (Hay, Strathmann, Lieber, Wick, & Giesser, 2008). But although many patients say that the information they find online changes their overall approach to their health

(Tu & Cohen, 2008) most still desire professional, expert advice about their symptoms, conditions, and possible treatments (Czaja, Manfredi, & Price, 2003). Because there is little quality control associated with online health information, and inaccurate information is associated with negative health outcomes, it is vital that patients bring what they have found to their medical encounters for discussion with their providers. Correcting misconceptions and helping patients to be better consumers of health information is vitally important (Bird, Conrad, Fremont, & Timmermans, 2010). When clinicians are responsive to their patients' needs for information improved adherence, better symptom resolution, and greater satisfaction result (Bultman & Svarstad, 2000). But without a healthy, trusting relationship it is unlikely that patients will feel comfortable sharing alternate views or information garnered from online sources; this highlights the importance of establishing and maintaining strong partnering relationships with patients. Health beliefs, worries, and other potential barriers to adherence cannot be addressed if they are not identified.

From Marx to Turkle, technology has long been regarded with some suspicion and a sense that it may be alienating us from our communities and even ourselves (Turkle, 2012; Wendling, 2009). Thus, it is not surprising that people sometimes have a hard time thinking about technology as a means of strengthening and improving the partnerships between clinicians and their patients. Data suggest, however, that patients often have a difficult time reporting their adherence accurately, and also indicate that most patients want to please their physicians and to adhere to their recommended treatments—they do not want to be “bad patients” (Roter & Hall, 2006). Therefore, when technologies enable patients to better adhere, to better understand, or to take more responsibility for their own outcomes, technologies will surely contribute to stronger partnerships with their care providers and, ultimately, to better outcomes. Thus, we turn now to an examination of the ways in which technology can be used to improve adherence with a particular emphasis on the ways in which it might foster patient engagement.

Automated Messages and Text/SMS. One of the most widespread and useful technological tools used by both patients and health professionals is the short message service (SMS). The SMS technology can be used to remind patients of appointments and dosage schedules, to support their self-monitoring efforts, and to facilitate patients' sharing of information and treatment concerns with their providers. These prompts may help patients to feel more control over their care-management and can encourage them to engage in the day-to-day process of optimizing their own health.

A large proportion of the population possesses cell-phones making SMS and text messaging convenient mediums for communication and reminders. de Niet et al. (2012) describe SMS via mobile phone as easy to use, inexpensive, quick, and customizable to the patient and SMS has been shown to improve treatment adherence and reduce treatment dropout (de Niet et al., 2012; Hardy et al., 2011; Haug, Meyer, Dymalski, Lippke, & John, 2012).

Because SMS allows providers to interact with patients at times that are most practical and because they are not limited to a specific location, patients can often get their questions answered, their concerns alleviated, and their appointments

scheduled more promptly and efficiently. Additionally, it has been suggested that for some patients this form of communication is less anxiety-provoking and may feel more comfortable than face-to-face discussions or phone conversations.

Short message services may be particularly helpful in certain contexts, such as in rural areas with limited resources. For example, one study in rural Kenya found that patients who received text message treatment reminders were significantly more adherent and less likely to experience treatment interruptions than patients who had no text message reminders (Pop-Eleches et al. 2011); likewise, a study focusing on rural communities in the United States found that compliance rates of treatment in borderline personality disorder patients were much higher using text messages to monitor mood changes than compliance rates for the usual paper-pencil mood charts (Foreman, Hall, Bone, Cheng, & Kaplin, 2011). Similarly, a study in rural Bangladesh found that participants who received mobile phone calls and reminders for screenings were more likely to have their malaria detected and to receive appropriate treatment earlier than those who were not contacted via mobile phone (Prue et al., 2013). In neither of these studies were the living conditions of participants conducive to taking care of one's health. The reminders may have helped to keep health-related issues closer to the forefront of the participants' minds, thus improving their abilities to carry out health-related plans.

Although texting reminders are useful in rural and less economically secure areas, they have also gained popularity in more economically successful regions where the majority of the population possesses mobile phones. Adolescents with cell phones are much more inclined to be adherent when given SMS reminders (de Niet et al., 2012) and a wide range of screening, preventive, and disease management behaviors have been shown to improve with the use of electronic reminders, including oral contraceptive and other medication use; mammograms fecal occult blood screenings, and cholesterol screenings; smoking cessation; exercise; and weight loss (Castaño, Bynum, Andrés, Lara, & Westhoff, 2012; Cole-Lewis & Kershaw, 2010; Ornstein, Garr, Jenkins, Rust, & Arnon, 1991). Texting reminders would likely be useful for elderly adults, as well, since they may forget to take their medications or to come in for appointments; but there is little data on elderly patients and their experiences with text messages and other SMS technologies. This may be due, in part, to the relatively lower level of technological sophistication in this age-group but these age-related differences are rapidly diminishing.

Despite the promising nature of SMS and related technologies, the evidence for their effectiveness is by no means unequivocal. Recent reviews have found that medication adherence and appointment attendance are generally improved with electronic reminders (Gurol-Urganci, de Jongh, Vodopivec-Jamsek, Atun, & Car, 2013; Vervloet et al., 2012), but it is less clear that such interventions are as consistently effective at improving self-management of chronic diseases such as diabetes and asthma, although many studies to show promising results (Cole-Lewis & Kershaw, 2010; de Jongh, Gurol-Urganci, Vodopivec-Jamsek, Car, & Atun, 2012). Taken in total, the evidence suggests that automated reminders and SMS-style approaches may be most useful as supplements to more traditional, in-person communication (e.g., Granger & Bosworth, 2011).

Remote Videoconferencing and Telehealth. Another tool that aims to improve communication, strengthen clinician-patient relationships, and foster adherence is remote videoconferencing or telehealth. Remote videoconferencing can be convenient for both patients and clinicians since the parties can “meet,” share information, ask questions, and discuss concerns without the time-investment associated with traveling to meet physically in a single location. This technology has been shown to be particularly useful for patients who are chronically ill and find it difficult to leave home or patients who have diseases or infections about which they fear social stigma. For example, HIV-positive patients report that videoconferencing effectively meets their needs and concerns (Lillibridge & Hanna, 2009; Saberi, Yuan, John, Sheon, & Johnson, 2013). HIV-positive patients using telehealth technology reported that it was more convenient and more cost effective than regular doctor meetings and they also reported being more comfortable and less intimidated than in face-to-face meetings (Saberi et al., 2013). These patients felt that videoconferencing provided a quick and convenient way to get their questions answered while also helping them feel comfortable talking to their medical specialist as they felt less judged and stigmatized than when communicating in person.

Videoconferencing has also been shown to be useful for patients who have transportation constraints or are discouraged by distance from making regular doctor visits. Distance and geographical terrain can be a challenge for patients; living in a rural area where health services are difficult to access creates a real deterrent and, in many cases, videoconferencing can mitigate the problem. Research in pediatric care with children who live in rural areas shows that video conferencing eliminates the barriers of travel and unavailability of healthcare personnel for patients living with asthma (Chan, Callahan, Sheets, Moreno, & Malone, 2003). It can also enhance the success of early intervention techniques with patients who have disabilities such as spina bifida or Down syndrome, as daily-care providers can more easily interface with the clinicians providing physical and occupational therapy coaching and those clinicians can suggest ways to enhance treatment while they are watching the parent-client interact in real time, in their home environment (Olsen, Fiechtl, & Rule, 2012). Thus, videoconferencing can improve treatment adherence by increasing patients’ knowledge about what they are supposed to do, and by creating an environment in which patients feel comfortable and problems likely to be encountered in the home environment may be more readily apparent to the clinician. With personnel available in real time, videoconferencing allows patients to ask questions clarify any confusion or doubts they may have about their treatment.

Telehealth has not only been used by physicians but also by psychologists and their clients—in mental/behavioral health settings this technology may be referred to as “telemental health” (Baker & Bufka, 2011). There has been discussion about the degree to which it is appropriate to incorporate telehealth into psychological practice, mainly due to concerns over privacy and the lack of in-person, face-to-face interaction which has been the foundation of psychological therapeutic practice. Despite these concerns, early indicators seem promising and there are potential benefits associated with psychologists’ ability to conduct therapy and assessments by telephone and videoconference (Maheu, McMenamin, Pulier, & Posen, 2012). As in many traditional

medical encounters, psychologists can use videoconferencing therapy with clients who live in remote locations—eliminating the requirement that both parties be in the same location widens the opportunities for appropriate matches between therapist and client (Nelson & Velasquez, 2011), and clients are able to engage in therapy without leaving the comfort of their own homes. Videoconferencing in therapy has been shown to reduce hospitalization and thus seems to be an effective tool for managing mental health. A nationwide study by Godleski, Darkins, and Peters (2012) showed that, in a sample of 98,000 mental health patients being served by the Department of Veterans' Affairs, a 25 % reduction in hospitalizations occurred between the time of implementation of a videoconferencing telemental health system in 2006 and the follow-up in 2010. Thus, telemental health services represent a promising possibility for improving outcomes for those with a variety of mental health problems.

Videoconferencing in telemental health is also beneficial because computer technology allows therapists to gain additional information that may be difficult to obtain in face-to-face encounters but which can meaningfully inform the therapy. For example, with proper lighting therapists are able to zoom in to view nonverbal behaviors such as facial expressions, tics, and other physical manifestations in more detail (Nelson & Velasquez, 2011). This gives telemental health therapists an edge over those relying on traditional techniques since they may be able to detect cues, at the moment they occur, that would have been missed in face-to-face interactions.

Although the future of telemental health services looks bright, there is controversy over the use of these technologies. Perhaps the most serious critique of telemental health services and videoconferencing is the risk, real or perceived, to privacy. Clients may worry that since they are seen through video, that they may also be recorded; or that other people may be observing or listening to the encounter. If a patient believes that someone other than the therapist is listening, she or he might not feel comfortable sharing intimate information. This highlights the importance of building a strong bond with patients—perhaps especially with those being seen for mental health issues—prior to implementing telemental health approaches. And, therapists must be sure to follow the guidelines of informed consent and other ethical considerations when using video or audio therapy (Baker & Bufka, 2011; Maheu et al., 2012). Video recording in videoconferencing is also a confidentiality challenge that therapists and clients must be aware of. Guidelines for videoconferencing and other telemental health services are uncertain, as the use of these technologies is a fairly new approach in the clinical health field. Other potential concerns include technological disruptions due to inadequate internet service, poor video quality, and lack of referral services in patient's areas (Baker & Bufka, 2011). However, these technological services may prove to be very effective with more practice and as models for how therapists and providers should approach these technology-mediated interactions are refined.

Online Support Groups. Another useful strategy by which clinicians can support adherence and positive health outcomes is referral to online support groups. One good predictor of adherence is support from family, friends, or a caregiver. Particularly for those who have less in-person support from friends or family, these support networks can serve a vital function. And, even for those who have adequate

in-person support, these groups can provide the type of camaraderie, social comparison, and encouragement that can be so important to sustaining one through the ups and downs of treatment. Individuals who are struggling with the same issues may be able to make practical suggestions and troubleshoot in ways that even the most supportive non-sufferer cannot. For example, research on cancer support groups concludes that they are effective for enhancing the delivery of treatment information, of emotional support, and for encouraging active participation in decision-making (Beaudoin & Tao, 2007; Huber et al., 2011). The emotional support and peer-to-peer discussion of treatment options and coping strategies with others who are undergoing (or have conquered) similar obstacles can be of great benefit; clinicians who are able to facilitate connections to such groups may be doing their patients a great service.

Online support groups have not proved to be as effective for people with mental health issues such as depression, however (Griffiths et al., 2012; Melling & Houguet-Pincham, 2011). Much of the research on online support groups specifically for depression contains anecdotal evidence with little empirical evidence of efficacy. Although online support groups are helpful for some people, more research is needed to better understand the limitations for particular groups, and to identify cases in which online networks may be detrimental. Nevertheless, online support groups have generally been shown to associate with positive outcomes through their enhancement of emotional support and provision of environments conducive to the discussion of various aspects of treatment and coping.

Tracking Apps. As interfaces with technology become more seamless, mobile apps are likely to gain prominence as desirable tools for engaging patients in their own care and improving adherence. Although many of these apps are new and still being refined, there is a good deal of enthusiasm about the possibilities they suggest. One kind of app that is said to improve treatment adherence is MediSafe Project's *mobile pillbox*. The mobile pillbox health app has now gone through several trials and Horowitz (2013) reports that, using the app, patients with Type 2 diabetes are able to improve their adherence rates to about 80%. The pillbox app is set up to remind patients when to take their medication and sends an alert to someone close to the patient such as a family member or caregiver if a dose is missed. Once the patient indicates on the app that the dose of medication has been taken, the app stores the data to accurately report adherence rates. Caregivers can monitor patient adherence through the app's stored data, which can also be synced to the caregiver. Intel is also working with researchers on refinements to similar mobile apps to enable location sensors to remind patients about their medications at the most appropriate places and times (Janet, 2006).

Mobile apps that not only remind the user, but also engage the supportive community, tackle two large predictors of adherence at the same time: forgetfulness and lack of support. With this combination, patients are more likely to adhere to their recommended treatments as they are not only prompted to adhere but the supportive network that might foster the desired behavior is also cued to act. Despite the promise of apps like the mobile pillbox, only a small percentage of caregivers currently use adherence technologies to track patients' medication (Horowitz, 2013). Reasons

for this are not clear, but probably include varying levels of comfort with technology on the part of both clinicians and patients; concerns over integrating data from these systems with existing clinical software; and worry that more automation will decrease the hands-on, personal aspects of care. As these apps become more integrated into everyday care, however, it seems likely that they may not only be recognized as a useful tool in their own right but also as a means of facilitating conversation, partnership, and engagement in active decision-making for clinicians and their patients.

Moving from the high-tech to the ultra-high-tech, smart pills (or wireless motility capsules) can be swallowed like regular pills and used to track a variety of indicators including adherence. Along with an epidermal patch that must be worn and smartphone app specifically used for the pill, the smart pill can track medication taken, body temperature, and heart rate (Heart Beat, 2012). Since the FDA approved the wireless motility capsule in 2006, researchers and physicians have been using this device to track medication adherence, internal pressure, pH, and body temperature (Saad & Hasler, 2011). The pill has been primarily used with people who have delayed gastric emptying, but the pill has been receiving attention from providers and researchers who want to track other elements of patient health and treatment adherence. Although more invasive, this technology has the ability to do more than simply remind—it can accurately report on what a patient has (or has not) done, and record the body's responses. This can provide a solid foundation for beginning or continuing a discussion about the best ways for a patient to improve his or her health.

Leveraging Technology to Engage Patients

The integration of technology into one's practice to best serve the patient's needs is truly an art. It requires that the clinician be personally engaged and know the patient as an individual to achieve the best match. Some patients will move quickly to embrace new tools and others will be more hesitant; taking the time not only to think about one's recommendation but to explain its importance and utility (much as one might explain a new medication) is crucial. Making recommendations about technologies that help patients to self-monitor and self-manage sends an important message—that the clinician supports and sees the value in these actions. This strengthens the sense of shared commitment to and responsibility for patient health outcomes.

Many patients *will* use apps and various websites to garner information about their ailments and possible treatments; thus, it makes sense for clinicians to make recommendations about these. Without recommendations to reputable sites and products, patients may select suspect or even dangerous options and quality is likely to be low.

Clearly technology cannot, and should not, replace the relationship between the patient and his or her clinician. Technology should, however, help to maximize the

knowledge, autonomy, and confidence that each party brings to the encounter. It should help patients to be more accurate in their reports of their own behaviors, and to more effectively carry out the commitments they make regarding their health. And, it should facilitate the communication and partnership between the health care provider and the receiver of that care.

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Part III
Promoting Treatment Engagement with
Specific Populations

Chapter 8

The Integrated Well-Child Visit: Behavioral Health Treatment Engagement in Pediatric Primary Care

Cassandra Snipes and William O'Donohue

Behavioral health problems occur at a significant rate and have large impact across all age groups (SAMHSA-HRSA Center for Integrated Health Solutions, 2013). The Substance Abuse and Mental Health Services Administration reported (2013) that approximately one in four adults suffer from a diagnosable behavioral health problem in a given year (e.g., depression, panic disorder). Furthermore, those with a behavioral health problem, that receive treatment in the public mental health system, have a shortened life expectancy of 11–15 years on average when compared to the general population (SAMHSA-HRSA Center for Integrated Health Solutions, 2013). The burden of behavioral health problems is considerable and oftentimes this burden begins at a young age.

Kessler and colleagues found that behavioral health problems begin very early in life (Kessler et al., 2005). Half of all lifetime cases begin by age 14, and three-quarters have begun by age 24 (Collins, Hewson, Munger, & Wade, 2010; Kessler et al., 2005). In fact, one in five children have at least one behavioral health problem that interferes with daily functioning (Barnett, Griffin, Muse, Moreland, & Mian, 2008). For example, anxiety disorders often begin in late childhood and mood disorders in late adolescence (Substance Abuse and Mental Health Services Administration, 2013). Unlike chronic disease such as heart disease or most cancers, young people with behavioral health problems suffer disability when they are in the prime of life; which also serves as a platform for critical future development. Behavioral health problems such as treatment nonadherence, lack of proper diet and exercise, anxiety, depression, engaging in risk behavior, and bipolar disorder truly are the chronic diseases of early life (Centers for Disease Control and Prevention, 2012).

C. Snipes, Ph.D. (✉) • W. O'Donohue, Ph.D.
Department of Psychology, University of Nevada, Reno, 1664 N. Virginia Street/Mail
Stop 298, Reno, NV 89557, USA
e-mail: snipes.cassandra@gmail.com; wto@unr.edu

Treatment Access and Engagement

Germane to the early onset of most behavioral health problems is the fact that there are very long delays (sometimes decades) between first onset of symptoms and when people seek treatment or receive treatment (Substance Abuse and Mental Health Services Administration, 2013; World Health Organization, 2008). The National Comorbidity Survey (NCS), for example, estimated that approximately 80% of all people in the United States with a mental disorder eventually seek treatment, but that the median delay between first onset of the disorder and first treatment contact is nearly a decade (Wang, Berglund, et al., 2005; Wang, Lane, et al., 2005). Evidence shows that the current behavioral health system fails to engage a significant number of people with behavioral health problems for a myriad of reasons such as limited access to quality care, stigma, and geographical and financial constraints (Kazdin & Blase, 2011; McGuire & Miranda, 2008; World Health Organization, 2008). Furthermore, those it does reach often drop out or get insufficient, uncoordinated care (World Health Organization, 2008), and sometimes even unsafe care (Lilienfeld, 2007).

Alarming, when individuals do seek care they are often not treated with evidence-based assessment or treatment (Institute of Medicine, 2006). Instead psychometrically problematic assessment instruments are used and providers deliver lengthy, less than effective care (Wang, Berglund, & Kessler, 2000). Implementing less-effective therapies can create problems that require further expensive treatment, which results in unnecessary suffering (Institute of Medicine, 2006; Lilienfeld, 2007). An additional complicating factor is the considerable reliance on psychotropic medications, yet significant concerns with safety and efficacy persist (Brown et al., 2006). Despite the fact that there are very effective behavioral health interventions, those with behavioral health problems are still severely disadvantaged and unnecessarily suffer due to inadequate care (Collins et al., 2010).

This limited engagement in quality, coordinated care leads to more difficult-to-treat behavioral health problems and can contribute to the development of comorbid problems. Early-onset behavioral health problems that are left untreated are associated with a host of adverse events including school failure, teenage pregnancy, chronic medical problems, unstable employment, early marriage, and marital instability and violence (Substance Abuse and Mental Health Services Administration, 2013). Detecting and treating cases early could prevent enormous disability, before the illness becomes more severe. Early detection and treatment engagement could also intervene before co-occurring behavioral health problems develop, which only become more difficult to treat as they accumulate (Substance Abuse and Mental Health Services Administration, 2013). These concerns highlight the importance of prevention and early detection of behavioral health problems.

Disparities in Access to Care

Traditionally underserved groups, such as the young, the elderly, racial/ethnic minorities, and those with low income or without insurance, have the greatest unmet need for treatment (World Health Organization, 2008). Inverse relationships between socioeconomic status and health risk behaviors such as tobacco smoking, physical inactivity, and poor nutrition have been demonstrated (Pampel, Krueger, & Denney, 2010). Unfortunately, low socioeconomic status is also associated with significantly less anticipatory guidance provided in primary care (Irwin, Adams, Park, & Newacheck, 2009). Therefore, it can be argued that underprivileged populations, including underprivileged pediatric populations, not only have restricted access to care but also are in greater need of prevention and intervention. Additional barriers to access to care include financial constraints and a lack of ethnic diversity amongst providers (Cabassa, Zayas, & Hansen, 2006; McGuire & Miranda, 2008; Wang, Berglund, et al., 2005; Wang, Lane, et al., 2005). These disparities in access to care must be resolved in order to systematically address national unmet behavioral health need.

The Problem of Prevention

In addition to the significant barriers in access to quality care, behavioral health prevention efforts have been largely ineffective. Attempts at prevention have primarily been large-scale nomothetic public health interventions such as Project D.A.R.E. and anti-smoking campaigns (Ridenour, Pineo, Molina, & Lich, 2013). Some of these preventative efforts have been iatrogenic and most have modest efficacy, if any at all (Werch & Owen, 2002). We are currently unable to prevent behavioral health problems before they manifest, and this severely undermines our ability to lessen the overall burden of behavioral health problems. The fact that behavioral health prevention has been unsuccessful is an indication that a novel approach is warranted.

The Need for Integrated Care

Integrating behavioral health services into a primary care setting is the most viable and efficient way of delivering prevention and ensuring that people have access to needed behavioral health services (SAMHSA-HRSA Center for Integrated Health Solutions, 2013; World Health Organization, 2008). Most people first bring their behavioral health concerns to their regular doctor (Nielsen, 2013) and while patients typically present with a physical health complaint, data suggest that underlying behavioral health or substance abuse issues are often

triggering these visits. In fact, as many as 70% of primary care visits stem from psychosocial issues (O'Donohue & Cucciare, 2005; Robinson & Reiter, 2007). Unfortunately, most primary care doctors are ill equipped or lack the time to fully address the wide range of psychosocial issues that they encounter in practice (Collins, Hewson, Munger, & Wade, 2010). Most receive little training, are less interested in treating these problems, and have little time in a short medical appointment (15 min) to cover these potential problems.

Integrated care refers to a service delivery system that is coordinated so that both physical health and behavioral health problems can be addressed in one setting (O'Donohue, Cummings, Cucciare, Runyan, & Cummings 2006). Therefore, complex relationships between physical and behavioral health can be more effectively recognized and treated (Zeiss & Karlin, 2008). Patients receive one treatment plan with both physical health and behavioral health elements (Collins, Hewson, Munger, & Wade, 2010). Integrated care does not diminish the role of behavioral health providers in the community, as more chronic cases are referred to these providers, but assimilates important behavioral health resources into primary care. Behavioral health care delivered in an integrated setting can help to minimize stigma and discrimination, while increasing opportunities to improve overall health outcomes (Collins, Hewson, Munger, & Wade, 2010; Zeiss & Karlin, 2008).

Furthermore, evidence shows that quality of behavioral health care is superior when delivered by a collocated behavioral health practitioner, relative to other types of primary care providers. Patients with behavioral health problems or substance abuse disorders were more likely to get treatment from a primary care physician/nurse or other general medical doctor (22.8%), or from a nonpsychiatrist behavioral health specialist (16%), such as a psychologist, social worker, or counselor, than from a psychiatrist (12%), though adequacy of treatment is best when provided by behavioral health practitioners in a primary care setting (Layard, 2006; Substance Abuse and Mental Health Services Administration, 2013). Patients also prefer treatment by a behavioral health professional and go more often, relative to behavioral health care delivered by primary care providers (PCPs; Seligman, 1995). The superior provision of care and patient preference for behavioral health providers strengthens the argument for behavioral health integration in primary care.

Most importantly, integrated care has been shown to enhance overall health outcomes (World Health Organization, 2008; Zeiss & Karlin, 2008). Specifically, brief targeted behavioral interventions have been shown to reduce medical and surgical costs far beyond the cost of providing the behavioral interventions (Cummings, O'Donohue, & Cummings, 2009). Patients receiving care in an integrated system have also been shown to linearly improve across behavioral treatment sessions, with patterns that mirror the early stages of traditional outpatient psychotherapy. These patients also have been shown to maintain improvements in global mental health functioning at 2-year follow-up, regardless of additional behavioral health treatment (Ray-Sannerud et al., 2012). Moreover, patients prefer to receive behavioral health treatment in a primary care setting (Zeiss & Karlin, 2008). Integrated care improves physical health and behavioral health outcomes, increases access to care, and provides a forum for prevention efforts.

The Importance of Stepped Care

In order for integrated care to be most effective and efficient, care should be organized in a stepped fashion (Von Korff, Glasgow, & Sharpe, 2002). Specifically, more complex and expensive interventions should only be used when simpler interventions have been demonstrated to be inadequate (O'Donohue & Draper, 2011; Von Korff, Glasgow, & Sharpe, 2002). Stepped care posits that providers offer care that, (1) causes the least disruption in the patient's life, (2) is the least extensive required for positive results, (3) is the least intensive for positive results, (4) is the least expensive for positive results, and (5) is the least expensive in terms of staff training required to provide effective service (O'Donohue & Draper, 2011). Successful integrated care protocols utilize stepped care (Zeiss & Karlin, 2008), which is consistent with usual primary care practice.

An example of stepped care. Consider the case of an adolescent patient that did not display psychological impairment on screening measures but reported low mood, not accompanied by additional symptoms of clinical depression. Stepped care intervention would include: (1) increasing health literacy (educating the patient as to what symptoms are indicative of increased intervention, how low mood is maintained/alleviated, etc.), (2) idiographic prevention (i.e., support of healthy coping strategies and discouragement of use of avoidance coping), (3) referral to evidence-based bibliotherapy/eHealth options, (4) strengthening of the provider/patient relationship (specifically, informing the patient that should her symptoms worsen that the provider will be available to provide consultation and care), and (5) provision of a printed integrated care plan following the patient's visit with the PCP. Additionally, the BCP would enter information regarding identified low mood and intervention into the patient's EHR, in conjunction with discussing these findings with the patient's PCP in order to achieve the goal of coordinated care.

In the event that the patient's symptoms of low mood did not remit, a brief evidence-based cognitive behavioral intervention would be implemented in the primary care setting. If the patient's symptomology did not remit following brief intervention, a referral to an appropriate community provider through the behavioral health provider's (BCP's) accountable relationships with other entities would be appropriate.

Stepped care is an effective, cost-effective treatment modality that facilitates the provision of integrated care.

Integrated Pediatric Care

It has been over a decade since the U.S. Surgeon General called for pediatric primary care practice to expand their scope of practice to include behavioral health treatment and there has been increasing recognition of the importance of integrated pediatric care (Van Cleve, Hawkins-Walsh, & Shafer, 2013). In pediatric integrated care, there is greater focus on identifying early onset of behavioral health problems in children and youth (SAMHSA-HRSA Center for Integrated Health Solutions, 2013). However, a significant portion of pediatric primary care centers do not

implement integrated care and evidence shows that pediatric PCPs recognize only approximately one-third of patients with behavioral health dysfunction in their practice (Kuhlthau et al., 2011). Although the need for integrated pediatric care has been recognized, technologies to support implementation are still needed.

Is Screening Sufficient?

The argument can be made that proper screening would address the problem of at least detecting pediatric behavioral health concerns in primary care. In fact, there is evidence that behavioral screening during well-child visits results in a threefold increase in the detection of children at risk for a behavioral health condition (Kuhlthau et al., 2011). Unfortunately, even when this increase of detection was reported, results indicated that nearly half of the well-child visits still did not include behavioral screening (Kuhlthau et al., 2011). Furthermore, effective screening does not necessarily result in an appropriate level of intervention. Screening alone is simply not the answer and greater integration efforts are required to increase access to pediatric behavioral health care.

The Importance of the Well-Child Visit

The well-child visit is an important point of intervention in pediatric integrated care. Well-child visits are routine visits that should occur once per year until the patient is 21 years old (National Institutes of Health, 2015). These encounters account for more than 30% of physician visits for those patients 15 years and younger (Moyer & Butler, 2013). Broadly, the purpose of these encounters is the maintenance of health and prevention of disease—particularly physical disease. Well-child encounters are the context in which pediatric prevention and routine assessment is conducted, and the specific functions of these visits are discussed below. The well-child visit is a preexisting pediatric primary care practice that can aid in the implementation of integrated care by providing a forum for coordinated behavioral health wellness checkups. Well-child visits have typically been delivered and conceptualized in terms of fractionated care in which physical care is emphasized. The question becomes, what would an integrated well-child visit look like in which behavioral health concerns are also emphasized—and would it have superior outcomes to the traditional well-child visit?

Implementing a Solution

In order for integrated care to function successfully PCPs not only need education in regards to proper detection measures (i.e., behavioral health screens), but behavioral health specialists must also be available to support primary care. It is the

behavioral health specialist's role to provide effective and efficient interventions and referrals when problems are found on screening measures (World Health Organization, 2008). Although competencies for pediatric integrated care systems have been set forth (APA Task Force on Mental Health, 2010; SAMHSA-HRSA Center for Integrated Health Solutions, 2013), the most effective methods of implementing these core competencies in integrated care are still under investigation. More specifically, there is very little evidence regarding how best to achieve these competencies in the context of health maintenance well-child visits (SAMHSA-HRSA Center for Integrated Health Solutions, 2013). Creating space in these visits to deliver coordinated behavioral health wellness exams is critical to increasing preventative efforts and access to care.

An opportunity for a novel approach to prevention of behavioral health problems.

Integrated well-child visits can offer a remedy for current nomothetic behavioral health prevention efforts. We propose that an individualized approach to prevention and the use of a medical/behavioral health team has the potential to produce superior outcomes, relative to nomothetic approaches. Physical medicine began to advance such prevention in well-child visits more than a decade ago (American Pediatrics Task Force on Mental Health, 2010) and the behavioral health field can learn from this model.

An idiographic approach to prevention could provide more specific, and therefore, theoretically more effective prevention. For example, consider the case of a 13-year-old male patient that presented for a well-child visit and had recently begun to gain weight. A nomothetic approach would simply provide him with guidelines regarding a healthy diet and daily exercise. With this particular patient, idiographic assessment revealed that he had discontinued regular walks with his family because he felt that he did not get enough individual attention from his mother due to her focus on his younger sisters. An idiographic preventative intervention included eliciting a commitment from both the patient and his mother that they would walk together at least once per week without the rest of the family. The patient reported that this intervention would help him increase his exercise while helping to remediate the low mood he felt due to his perceived lack of family attention. It is likely that without uncovering the specific reason for this patient's individual weight gain that standardized prevention efforts would not have resulted in necessary behavior change.

Furthermore, this idiographic prevention has the potential to be more powerful when implemented by a medical/behavioral health team. For example, an integrated care team has the advantage of providing the patient with expert behavior modification techniques and is able to monitor progress towards treatment goals (i.e., weight, Body Mass Index). Whether an integrated care approach to idiographic prevention is more effective than standard nomothetic prevention is an open empirical question, and one that merits significant attention from the behavioral health field. An integrated well-child visit is an ideal forum in which to test the assumption that idiographic prevention is a superior approach.

Existing Clinical Guidelines

With the goal of utilizing well-child visits as a primary pediatric integrated care intervention point, existing clinical guidelines for nonintegrated well-child visits must be considered. Clinical preventive service guidelines for well-child visits have been issued by several professional medical and government organizations, including the American Academy of Pediatrics (AAP), the American Medical Association, the American Academy of Family Practitioners, and the Maternal and Child Health Bureau. In the late 1990s, the AAP consolidated these guidelines into an updated edition of Bright Futures (Irwin et al., 2009). It is now standard in the field to utilize the Bright Futures Guidelines (SAMHSA-HRSA Center for Integrated Health Solutions, 2013). These guidelines include recommended ways that PCPs should address physical health, as well as recommendations for PCP-administered behavioral health care, and are not tailored to provision of integrated care.

Bright Futures Guidelines

Bright Futures is a national health promotion and disease prevention initiative that seeks to address children's health needs in the context of family and community. These principles, guidelines, and tools are used in pediatric practice nationally (American Academy of Pediatrics 2013a, 2013b, 2013c). Bright Futures clinical guidelines are categorized by target of intervention (e.g., "Healthy Weight," "Oral Health") and by patient age (e.g., four stages: "Infancy," "Early Childhood," "Middle Childhood," "Adolescence") (American Academy of Pediatrics 2013a, 2013b, 2013c). These guidelines are "evidence-based," meaning that they were developed based on existing empirical evidence and constructed by a panel of experts. However, there are little to no data regarding whether these guidelines improve health outcomes in clinical practice (Moyer & Butler, 2004).

Lack of Empirical Data

Although a panel of experts created the Bright Futures guidelines, the guidelines have not been evaluated as to whether they adequately assess health functioning or contribute to enhanced outcome in any age group (e.g., increased treatment adherence or successful treatment of disease) (Barnett, Griffin, Muse, Moreland, & Mian, 2008; Irwin et al., 2009; Solberg, Nordin, Bryant, Kristensen, & Maloney, 2009). In fact, Irwin et al. (2009) found that only 10% of well-child visits addressed all recommended categories of behavioral and physical health anticipatory guidance. Moreover, limited direct evidence was found to support any of the recommended interventions in well-child visits according to a review done by Moyer & Butler

(2004). A literature search for manuscripts that cited this important (although arguably dated) review revealed no recent evidence that well-child visit guidelines have been demonstrated to enhance clinical outcomes.

Part of the reason for such lack of empirical data may be the nature of the guidelines themselves. Several goals outlined by the aforementioned guidelines are difficult to operationalize, which inherently limits testability of outcomes. For example, Bright Futures identifies, “engages in a positive way in the life of the community” as a marker of a healthy adolescent. This outcome would be difficult to evaluate given the fact that there is no further clarification regarding what exactly an adolescent might do to meet this goal. Moreover, as Schor (2004) suggested, unrealistic expectations about the content of well-child care may also contribute to the lack of empirical support for current well-child interventions.

This is startling and problematic due to the fact that inclusion of ineffective (or even potentially iatrogenic) aspects of well-child visits limit other, potentially more effective, elements that could be addressed during these routine encounters. There is a need for evaluation of both the components and the whole of well-child care (Moyer & Butler, 2004); in addition to assessment of how best to conduct these visits in the context of integrated care.

Opportunity for Change

Recent legislation such as the Affordable Care Act (ACA) mandates quality improvement initiatives in healthcare that include, but are not limited to, free preventative care and a focus on youth health care services (U.S. Department of Health & Human Services, 2015). The ACA also mandates that behavioral health prevention efforts are included in well-child visits. These and other measures within the Act are designed to reform health care services to achieve efficiencies by increasing access, and making the services more affordable and safe. To this end, the ACA covers well-child visits and depending on particular insurance plan, these visits may be provided at no cost to the patient (U.S. Department of Health & Human Services, 2015). Due to the implementation of these new mandates, well-child visits must routinely achieve a higher standard of care and integrated care can arguably achieve that goal.

Re-envisioning Well-Child Visits in the Context of Integrated Care

Development of pediatric integrated care behavioral health wellness exam that is systematically integrated into well-child visits could increase engagement in behavioral health treatment. The promise involves the following factors:

1. Yearly wellness visits allow more opportunities for case finding and thus decrease the likelihood that problems will go undetected.
2. Yearly wellness visits can allow lower levels/earlier stages of problems to be detected and thus patients may be more optimistic about the likelihood of change.
3. If patients do not engage in 1 year, each subsequent year is an opportunity to problem-solve their lack of engagement.
4. The physician-led team will likely contribute to the credibility of recommendations to initiate and continue to engage in treatment.
5. When the problem is uncovered in the context of routine care, it is reasonable to hypothesize that patients will be more likely to see that the problem is well defined and acceptable.
6. The healthcare team can jointly present treatment alternatives and problem-solve any lack of patient engagement.
7. The team can offer the patient a broader range of treatment options, which can increase the likelihood of patient engagement.
8. Because of yearly wellness visits the team can track and respond to any relapse.

Broad implications for patients and families include increased access to routine behavioral health care, an opportunity to catch emerging behavioral health problems early before they become problematic, and access to improved behavioral health prevention efforts without the burden of pursuing a separate appointment with a specialty provider. This access to a behavioral health expert and reduction of wait time during the well-child encounter delivers increased value to the pediatric patient and their family. This shift in the delivery of well-child visits could arguably solve the lack of early behavioral health treatment engagement and subsequently promote better population health.

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Chapter 9

Outreach and Engagement for Clients Experiencing Co-occurring Substance Use and Mental Health Disorders

Leon Sawh and David Smelson

Defining Co-occurring Disorders (CODs)

Engaging clients with substance use disorders (SUD) in treatment can be particularly challenging for treatment providers. Treatment engagement challenges are even more pronounced among those clients who also have co-occurring mental health (MH) disorders, including serious mental illnesses (SMIs), such as schizophrenia-spectrum disorders, bipolar disorder, and major depressive disorders (Carey, Carey, Maisto, & Purine, 2002). In this chapter, we use the Substance Abuse and Mental Health Services Administration's (SAMHSA) definition of co-occurring disorder (COD), which states “a diagnosis of COD occurs when at least one disorder of each type can be established independent of the other and is not simply a cluster of symptoms resulting from the one disorder” (Center for Substance Abuse Treatment, 2005, p. 3). Moreover, it is important to note that the presence of any mental illness, including mood, anxiety, personality, and schizophrenia-spectrum disorders, are associated with an increase in co-occurring substance use disorder

L. Sawh, M.P.H. (✉)

Department of Psychiatry, University of Massachusetts Medical School,
Worcester, MA, USA

e-mail: leonsawh@gmail.com

D. Smelson, Psy.D.

U.S. Department of Veterans Affairs, National Center on Homelessness Among Veterans,
Bedford, MA, USA

Department of Psychiatry, University of Massachusetts Medical School,
55 Lake Avenue North, Worcester, MA 01655-0002, USA

compared to the general population (Drake, Mueser, & Brunette, 2007). COD diagnoses can also be given when substance abuse and/or dependence is accompanied by other MH disorders not defined as SMIs, including simple phobias and anxiety disorders.

Prevalence of CODs and Treatment Concerns

A substance use disorder (SUD) is the most common psychiatric comorbidity among clients with SMIs (Adams, Drake, & Wolford, 2007; Brunette, Mueser, & Drake, 2004; Drake et al., 2007). Depending on setting, prior studies estimate that anywhere between 50–80% of individuals with SMIs have also been diagnosed with a lifetime substance use disorder (Essock et al., 2006; Nunes & Quitkin, 1997; Regier et al., 1990). The co-occurrence of MH and SUD often results in psychiatric symptom exacerbation, including an increased risk of suicide (Soyka, Albus, Immler, Kathmann, & Hippus, 2001). Among many clients, as substance abuse increases, psychiatric symptoms worsen, which in turn exacerbates both conditions. Further, those clients who fail to connect to outpatient services after discharge from inpatient treatment are at a higher risk of relapse (Dixon et al., 2009), and prior estimates suggest that less than half of all discharged psychiatric patients ever successfully transition to outpatient care (Boyer, 1997; Nuttbrock, Ng-Mak, Rahav, & Rivera, 1997).

In the literature, the most cited causes of treatment disengagement include missed initial appointments, referral failures from emergency services, and nonadherence with aftercare following hospitalization (Carey et al., 2002). Clients who suffer from COD are less likely to adhere to prescribed treatment regimens (Dobscha et al., 1999), and one study found that even relatively infrequent substance use (approximately 5–7 days of use per month) among clients with mental health problems resulted in significantly greater treatment discontinuation (Smelson et al., 2007). Chronic substance abuse has been found to also lead to legal problems, medical problems, including a greater risk for HIV and acquisition of hepatitis and other infectious diseases, violence, homelessness, greater family burden, and higher treatment utilization costs (Caton et al., 1994; Cuffel, Shumway, Chouljian, & Macdonald, 1994; Essock et al., 2006; Haywood, 1995; Rosenberg et al., 2001; Serper et al., 1995; Smelson et al., 2002).

Strategies to Improve Treatment Engagement Among Clients with COD

Engagement with services is fundamental to the efficacy of COD treatment. However, individuals with COD are often nonadherent with treatment and have difficulty engaging in outpatient care (Smelson et al., 2005, 2007). Low motivation is

often the primary explanation for poor outcomes in treatment, including the lack of engagement in treatment or reduction in substance use (Ziedonis & Trudeau, 1997). Positive outcomes in treatment depend upon engagement in psychosocial treatments and adherence to any prescribed pharmacotherapy interventions (McMurrin, Cox, Whitham, & Hedges, 2013). Thus, clinicians must be flexible, empathetic, respectful, nonjudgmental, committed, and persistent in promoting treatment engagement in the first one or two treatment sessions (Kraybill & Olivet, 2006; Tsemberis & Elfenbein, 1999).

While there are a number of established strategies to promote treatment engagement among clients with SUD and MH disorders, to date, there is no one premier treatment for CODs (Barrowclough et al., 2010; Bellack, Bennett, Gearon, Brown, & Yang, 2006; Bradizza, Stasiewicz, & Dermen, 2014). However, the most common treatments employ Motivational Interviewing (MI) techniques (Rollnick & Miller, 1995) to promote treatment engagement for clients with COD. Studies have demonstrated that incorporating MI techniques into the initial evaluation session is associated with positive effects on early retention in treatment. For example, in a multisite randomized trial evaluating the effectiveness of incorporating MI techniques into the intake/orientation session in community treatment programs, those patients who received the MI intervention were more likely to be enrolled in the program one month post randomization (Carroll et al., 2006).

In addition to MI, a number of other approaches are also commonly used among clients with COD to either treat or assist with engaging clients in care. Later in this chapter we explore approaches that combine different strategies to improve treatment engagement. However, we will first provide brief descriptions of some of the most common treatment approaches used to engage clients diagnosed with COD.

Motivational Enhancement Therapy (MET)

Motivational Enhancement Therapy (MET; Miller, 1995) is a brief therapy designed to enhance motivation by helping clients resolve ambivalence about addressing, and then changing problem behaviors (e.g., substance abuse) and is derived from the Motivational Interviewing (MI) counseling approach developed by Drs. William Miller and Stephen Rollnick (1995). As described by Miller (1995), MET is a systematic intervention, derived from principles of motivational psychology, designed to evoke rapid and internally-motivated change among problem drinkers by employing strategies that mobilize the client's own resources and natural abilities. MET also utilizes structured assessments and follow-up sessions to provide personalized feedback based on the findings of the assessments. MET program developers strongly recommend that clinicians administer an extensive assessment battery to identify the specific needs of the client (Miller, Zweben, DiClemente, & Rychtarik, 1992).

While MI posits that each client approaches treatment at a different—and fluid—level of readiness to change and/or address symptoms associated with mental illness, MET techniques have been designed to enhance counselor-client rapport.

This strategy is particularly useful during initial sessions with clients who have COD, given that the client's ambivalence may be about receiving any behavioral treatment for either mental health or substance abuse issues. Thus, the use of MET can assist the provider in promoting treatment engagement among clients who may be initially reluctant to participating in treatment.

As initially developed for and administered in Project MATCH (Sobell, Breslin, & Sobell, 1998), a large multi-site research study that explored which types of treatments worked best for different types of alcohol dependent patients, MET consisted of four individualized outpatient treatment sessions designed to be completed in 90 days (Miller et al., 1992). MET has since been adapted for use among clients with co-occurring schizophrenia and alcohol use disorders (Carey, Leontieva, Dimmock, Maisto, & Batki, 2007), as well as for problems with cocaine (Rohsenow et al., 2004), marijuana (Diamond et al., 2002), and opiate (Saunders, Wilkinson, & Phillips, 1995) dependence. Additionally, there have been cultural adaptations for Hispanic drinkers (Lee et al., 2011), and the MET approach has also been used in the management of chronic diseases such as diabetes (Patel et al., 2011).

Cognitive Behavioral Therapy (CBT)

Cognitive behavioral therapy (CBT) is a well-established and effective treatment for both substance use disorders (Barrowclough et al., 2010) and anxiety disorders (e.g., Hofmann & Smits, 2008). CBT is based on the assumption that negative feelings result from dysfunctional thoughts, beliefs, and assumptions about the self, the future, and the world (Beck, 2005), all of which can in turn negatively impact treatment engagement. According to Beck, "cognitive factors mediate all interactions between the individual, situational demands, and the person's attempts to cope effectively" (Center for Substance Abuse Treatment, 1999, p. 69).

CBT interventions are designed to help clients identify and alter problematic thoughts and assumptions when they arise, and also to guide any underlying "cognitive schemas." According to Beck, schemas can be thought of as cognitive templates through which information is processed and interpreted. Clients with COD may exhibit these negative feelings in the form of explicit, verbal self-statements, or with "silent assumptions." To address and further understand the root causes of negative feelings, clinicians can ask clients to explain the circumstances of how the event or belief in question could actually take place. The clinician can also encourage use of a thought diary as an additional strategy for engaging clients in treatment.

In the thought diary, clients record their beliefs about specific scenarios and the negative thoughts and emotions that follow. The thought diary exercise provides both the clinician and the client with an opportunity to review thought processes and patterns, discuss the likelihood of occurrence, and develop strategies for managing such thoughts when they arise. Adherence to homework assignments, such as completion of thought diaries, are considered to be one of the defining features of CBT compared to other forms of psychotherapy, and are essential to therapeutic change (Glenn et al.,

2013; Kazantzis, Deane, & Ronan, 2004). One recent study exploring CBT treatment dose and patient engagement as predictors of treatment outcome for patients with anxiety disorders found that higher treatment session attendance and completion of homework assignments predicted better treatment outcomes (Glenn et al., 2013). Moreover, other studies have integrated elements of MI (described above) along with CBT. In a Randomized Controlled Trial, comparing an integrated CBT+MI intervention vs. CBT alone among a sample of 327 clients with COD, the integrated CBT+MI intervention was found to have a significant effect on clients' readiness to change substance use at 12 months post treatment, and a significant reduction in the amount of substances used for at least 1 year after completion of therapy. However, there were no significant differences between the groups in improving hospitalizations, symptoms, or functioning outcomes (Barrowclough et al., 2010).

Relapse Prevention (RP) and Social Skills Training (SST)

Relapse is defined as the process of becoming dysfunctional in recovery (SAMHSA, 1996). Relapse Prevention (RP; Marlatt & Gordon, 1985) was developed from a combination of cognitive-behavioral and social learning models and most current psychosocial interventions include a 'relapse prevention' phase to increase the odds that clients will continue to use learned skills once treatment has ended (Harvey & Gumport, 2015). The goal of RP is to teach clients how to anticipate and cope with "triggers," or moods, thoughts, or situations that increase the risk of relapsing to substance use after a sustained period of sobriety. RP combines behavioral skills training with cognitive interventions designed to prevent or limit the occurrence of relapse. The cognitive component assumes that, if people attribute a relapse to factors that are internal, global, and/or uncontrollable, the risk for relapse is heightened. If the client views a lapse as external, unstable, and/or controllable, then the likelihood of relapse is decreased. Simultaneously, the social component of RP works to reconcile the guilt, shame, and hopelessness often triggered by the complex interplay between the client's previous ability to abstain from alcohol and/or drugs and the client's current use (Marlatt & Donovan, 2005).

Psychoeducation is an important component of RP, as both the provider and the client must identify expectations and treatment goals. Treatment using RP begins with the assessment of any potential risks for relapse including interpersonal, intrapersonal, environmental, and physiological factors (Marlatt, 1996). As clients practice specific adaptive coping responses as part of treatment, they may gain confidence in their abilities to successfully handle similar high-risk situations in the future. Clinicians can work with clients with CODs to learn how to perform steps through role-plays, and once the client has mastered each step, the steps can be combined so that the client can perform the desired, more complex behavior. Throughout this process, often referred to as Social Skills Training (SST), clinicians should give feedback, reinforce success, and repeat steps until the client feels more confident and more comfortable performing the complex behavior. SST can play an important role in the day-to-day functioning of

clients with COD and should be initiated early in the treatment process (Bellack, 2004; Bellack et al., 2006; Mueser & Bellack, 2007).

Relapse to substance use is highly prevalent among clients with COD as additional factors for relapse are often presented by the co-occurring mental health disorder (e.g., noncompliance with pharmacotherapy, psychotherapy treatment discontinuation, etc.). RP offers a framework for identifying those situations which may occur before relapse and teaches both cognitive and behavioral skills to reduce such risks (Bowen et al., 2014). Alongside the use of MET and CBT techniques, RP can be useful in identifying early warning signs and high-risk situations, and SST can help to improve functioning among clients with COD. Conducting a thorough assessment and using information obtained from the assessment, is essential for establishing treatment goals and identifying triggers for relapse upon treatment initiation, and should be leveraged by the therapist where possible, to further engage the client in care.

Blending Substance Use Disorder Treatment with Mental Health Treatment Approaches

As described earlier in this chapter, many individuals suffering from mental illness also abuse controlled (i.e., tobacco and alcohol) or illicit substances. Integrated treatment for CODs is one of several evidence-based practices (EBPs) demonstrating effectiveness in helping people with mental illness achieve recovery from SUD (Drake et al., 2001; McHugo et al., 2006) and a number of integrated psychosocial treatment models using an integrated treatment framework have been developed (Drake et al., 2007; Ziedonis et al., 2005).

Integrated treatment is defined as state-of-the-art treatment for COD that takes various approaches into consideration in order to provide optimal treatment for clients with COD (Ziedonis, 2004). Within an integrated treatment framework, both substance use interventions and mental health interventions are simultaneously implemented by the same team of health care providers in one location (Cleary, Hung, Matheson, Siegfried, & Walter, 2008; Drake, O'Neal, & Wallach, 2008; Essock et al., 2006; McHugo et al., 2006; Ziedonis, 2004). The creation of a single treatment plan, executed together by the client and a single provider (even if it refers to multiple services), echoes the integrated approach of addressing both MH and the SUD simultaneously. However, successful implementation requires a well-trained clinical staff and an organizational structure that is well prepared to serve clients with CODs. A significantly less desirable alternative is a parallel, nonintegrated treatment approach, in which MH and SUD are treated simultaneously, but by different providers (Mueser, Noordsy, Drake, & Fox, 2003, p. 17). This latter approach is often marked by disorganized communication, ineffective care coordination, and multiple competing treatment plans.

In a multisite randomized controlled trial, 216 individuals with COD were assigned to an integrated or concurrent treatment condition. Those who received integrated treatment demonstrated a greater reduction in the total number of psychiatric hospitalization days in the 12 months pre- and post-baseline assessment. Those receiving integrated treatment displayed a reduction from 5.7 to 2.4 ($p = .04$) psychiatric hospitalization days while those in the parallel treatment group increased from 2.5 to 6.1 days. Further, those in the integrated treatment group significantly reduced the incidence of arrest during the 12 months pre- and post-baseline from 11.4% to 7.3% ($p = .04$) compared to a 10.8% to 9.7% decrease in the parallel treatment group (Mangrum, Spence, & Lopez, 2006). However, as Bellack et al. (2006) suggests, it is difficult to engage clients with CODs in treatment not only because most of these clients present with ambivalence about needing to reduce their substance use, but also because their motivation to engage in treatment waxes and wanes over time. Thus, the use of extrinsic motivators, such as shelter, food, clothing, as well as assistance with money management and identification of employment opportunities, are often be required to keep clients engaged in care (Ziedonis, 2004).

Unfortunately, many traditional mental health care systems are not equipped to provide integrated care for clients suffering from CODs, as these clients often have a multitude of needs, requiring services from various providers. However, some of these system resource gaps are being addressed by researchers and clinicians who have developed comprehensive, integrated, and blended treatment approaches. Consistent with existing therapeutic models that manage both MH and SUD simultaneously, several integrated models have been developed and incorporate the use of MET, CBT, RP, and SST techniques to better facilitate treatment engagement and optimal service delivery among clients with COD (Bellack, 2004; Drake, McHugo, et al., 1998; Drake, Mercer-McFadden, et al., 1998; Minkoff, 1989; Shaner et al., 1997; Smelson, Sawh, Kane, Kuhn, & Ziedonis, 2011; Ziedonis & Trudeau, 1997).

In a randomized clinical trial (RCT), Bellack's integrated treatment model, *Behavioral Treatment for Substance Abuse in Severe and Persistent Mental Illness (BTSAS)*, was found to be significantly more effective than a nonstructured control treatment in keeping clients engaged in treatment and abstinent from illicit substances (Bellack et al., 2006). BTSAS is a highly structured social learning program that integrates various techniques found successful in treating substance abuse such as MI, RP, and SST (Bellack, 2004; Bellack et al., 2006). These techniques were then tailored to better address substance use among clients with co-occurring severe and persistent mental illnesses. BTSAS uses a harm reduction model in which small gains are reinforced and intermittent drug use is not punished. BTSAS also promotes treatment engagement by conducting individually tailored MI sessions with clients. Further, urinalysis contingency is applied in each session to serve as an additional motivating factor for abstaining from drug use and engaging in treatment (Bellack et al., 2006). In this RCT, individuals who failed to engage in treatment (defined as attending ≤ 2 treatment sessions) were differentiated from those who did engage in treatment (≥ 3 treatment sessions). Of the 175 participants who were randomized to BTSAS or the control group, 110 became engaged in treatment (61 vs. 49). BTSAS was found to be significantly more effective in retaining subjects who became

engaged in treatment ($p = .009$) and those in BTSAS achieved a mean of almost 59% clean urine test results, compared with 25% for subjects in the control group at follow-up. However, it is important to note that in this study, 26.9% of the randomized clients did not attend any sessions, further highlighting the need for more specified treatment approaches to address poor engagement among clients with COD.

Ziedonis and Stern (2001) also found that their Dual Recovery Therapy (DRT) approach for cocaine addiction, which combined RP and MET into an integrated model of treatment, was more effective in engaging clients in both individual and group treatment sessions, retaining patients in treatment, reducing psychiatric rehospitalizations, and decreasing cocaine use, compared to those assigned to the control condition. In a behavioral therapy development study, in which DRT was compared to a control condition, DRT significantly improved treatment retention (69% vs. 40%) and clinic attendance (64% vs. 25%), and decreased rehospitalization (20% vs. 50%). Further, twice as many DRT clients remained abstinent at follow-up compared to the control group. (Ziedonis & Stern, 2001).

Assertive Community Treatment (ACT) and Integrated ACT Models

Studies indicate that individualized services provided directly to clients in their own homes or communities, improved outcomes regarding the transition to community living from institutional care (Coldwell & Bender, 2007), especially among high utilizers of hospital services, clients with schizophrenia, and clients experiencing homelessness (Dixon et al., 2010). As the successes of outreach teams in the community became apparent, components of the Assertive Community Treatment (ACT; Stein & Test, 1980) model have been used to promote treatment engagement. According to Essock et al. (2006), the ACT model was developed for individuals with SMI who had poor levels of engagement with outpatient, community-based psychiatric services, who were at-high-risk for relapse, and who had high rates of rehospitalization. ACT distinguishes itself from traditional case management because of its low staff-to-client ratio (typically one clinician for every 15 clients, or less), the delivery of most services in the community (as opposed to at the clinic, thereby mitigating any potential transportation issues), 24-h responsibility for clients, and for providing the majority of services directly (rather than the brokering services out to other providers) (Essock et al., 2006; Fries & Rosen, 2011).

A meta-analysis of six RCTs for homeless patients with SMI found that use of ACT models led to a 37% greater reduction in homelessness and a 26% greater improvement in psychiatric symptoms compared to the use of standard case management practices (Coldwell & Bender, 2007). Further, a systematic review of RCTs for clients with SMI and a history of repeated hospitalization found that ACT led to a reduction in the number of days hospitalized relative to those receiving standard care, and those individuals assigned to receive an ACT intervention used fewer emergency services and more outpatient services, when compared to individuals receiving standard care only, demonstrating a higher level of engagement with the appropriate treatment services

(Dixon et al., 2010). One study in particular, randomly assigned clients to receive an ACT intervention or standard care. A survival analysis was conducted to compare clients' length of engagement and retention in treatment. By the end of the observation period of 870 days, ACT teams retained 69.8% of their clients compared to 49.6% in the usual care intervention ($p = .057$) (Herinckx, Kinney, Clark, & Paulson, 1997).

While ACT models have traditionally been used with success among clients with SMI, a few studies have examined the efficacy of ACT models on treating COD. However, findings to date have been mixed. Drake, McHugo, et al., 1998; Drake, Mercer-McFadden, et al., 1998 found evidence that individuals who received ACT reported decreased substance use on some outcome measures. However, Essock et al. (2006) compared use of an enhanced ACT intervention to a case management control condition and found no differences across groups on substance use outcomes. In another study conducted among homeless clients with COD, an integrated ACT intervention designed to specifically address substance abuse was compared to a traditional ACT condition and a standard case management intervention, and participants in all three groups yielded improved substance use measures over time, but no differences were observed among groups (Morse et al., 2006).

While these data regarding the efficacy of ACT in improving substance use outcomes is mixed, it is likely that integrated ACT interventions may be more effective than nonintegrated treatments, and SUD outcomes may be improved once the field is more informed by what specific SUD treatments to pair alongside ACT interventions (Fries & Rosen, 2011). Systematic combination of ACT's locally-based services with other treatment techniques have enabled clinicians to better meet the needs of clients whose recovery goals have not been adequately addressed by traditional treatment approaches as delivered in traditional treatment settings (Bellack, 2007; Drake et al., 2001, 2007; Smelson et al., 2007). Investigators have also found the integration of a time limited ACT model, known as Critical Time Intervention (CTI; Susser et al., 1997) alongside manualized COD treatments to be successful in reducing alcohol use to intoxication, increasing both inpatient and outpatient treatment attendance, engaging clients in substance abuse and mental health treatment services, and preventing psychiatric rehospitalizations (Smelson et al., 2007, 2012, 2013). In the next section, we will introduce an integrated treatment model that specifically integrates COD treatment alongside the time-limited CTI case management intervention.

The Maintaining Independence and Sobriety Through Systems Integration, Outreach, and Networking (MISSION) Approach

Development of the MISSION Intervention

As a result of the increased use of integrated treatment models and case management approaches targeting clients with COD (see section above on ACT models), Smelson and colleagues developed the Time-Limited Care (TLC) intervention in 1999. As a

wraparound services model, TLC was developed and later adapted to specifically meet the multifaceted treatment needs of particularly vulnerable subpopulations of clients (e.g., veterans, homeless, justice-involved) whose ability to return to independent community living after psychiatric hospitalization, homelessness, and/or incarceration was further complicated by a co-occurring SUD (Pinals, Smelson, Sawh, Harter, & Ziedonis, 2014; Smelson et al., 2007, 2011; Smelson, Sawh, Harter, Siegfriedt, & Ziedonis, 2014). As originally developed, TLC was designed as a brief, two-month intervention that systematically integrated COD treatment (Ziedonis & Brady, 1997), time-limited case management (Susser et al., 1997) and peer support services to promote treatment engagement and continuity of care across various treatment settings for clients with COD. As the model evolved, the duration of the TLC intervention was extended from a 2 month intervention to a 12 month intervention, and the name of the intervention was changed from TLC to *Maintaining Independence and Sobriety through Systems Integration, Outreach, and Networking (MISSION)* to better reflect the overarching goals of the program. MISSION systematically incorporates five key components, each of which has been cited in SAMHSA's *National Registry of Evidence-based Programs and Practices (NREPP)*.

The primary goal of MISSION is to facilitate rapid community engagement and achievement of personal goals by helping individuals participate in a comprehensive array of outpatient mental health and substance abuse treatment services as well as vocational and educational rehabilitation programs. MISSION was built on the theoretical framework of the Health Belief Model (Becker, 1974), and systematically integrates (1) Critical Time Intervention (CTI) case management (Susser et al., 1997), (2) Dual Recovery Therapy (DRT) (Ziedonis & Trudeau, 1997), (3) Peer Support (Chinman, Shoai, & Cohen, 2010; Yanos, Primavera, & Knight, 2001), (4) Vocational/Educational Supports (Bond, Drake, & Becker, 2008; Ellison et al., 2012), and (5) Trauma Informed Care (TIC) treatment considerations (Najavits & Cottler, 2014) to support individuals seeking to maintain recovery from CODs. Each MISSION client is assigned to a team consisting of one Case Manager and one Peer Support Specialist who both directly provide services to the client through case management, DRT COD treatment sessions, peer support sessions, and psychoeducational exercises. MISSION staff also facilitate needed service linkages in the community, such as referrals for additional outpatient mental health and substance abuse treatment services, primary and specialty medical care, housing support, vocational and educational rehabilitation services, and referral to higher levels of trauma-informed treatment if necessitated. The active ingredients of MISSION are provided in the table below.

Active Ingredients of the MISSION Approach

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| 1. | Critical Time Intervention (CTI) case management is used within MISSION as the core treatment intervention. MISSION focuses on the systematic, integrated delivery of time-limited case management to better serve difficult-to-engage clients. CTI is designed to give clients a "running start" and "safety net" by providing intensive services upon reentry into the community, thus establishing firm linkages between clients and needed services. |
|----|--|
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Active Ingredients of the MISSION Approach	
2.	Case managers provide Dual Recovery Therapy (DRT) to all MISSION clients. DRT sessions can be delivered in either a group or individual format. Discussion and exercises help raise awareness of the impact of mental illness, substance abuse, and other harmful behavior on clients' lives and offers tools to aid in recovery. Booster sessions are conducted throughout treatment to reinforce topics particularly relevant to each individual client.
3.	Peer Support is provided alongside case management to help clients maintain their mental health and sobriety, follow healthy lifestyles, and participate in needed supports, thereby bolstering the effectiveness of the other interventions (i.e., CTI, DRT) integrated into the MISSION model. Peer Support Specialists offer inspiration, the understanding of one who has "been there," and assistance in adjusting to new routines such as maintaining a home, working, and attending various treatment appointments outlined in the treatment plan.
4.	Vocational/Educational Supports are offered by the MISSION team to help clients find and maintain employment and achieve educational goals, contributing to daily living stability and improved self-esteem.
5.	MISSION incorporates Trauma-Informed Care Considerations. MISSION Case Managers and Peer Support Specialists are trained to screen clients for trauma-related symptoms and refer them as needed to treatment providers who are trained in delivering evidence-based treatments for the management of trauma symptoms.

Evidence Supporting the Use of the Integrated MISSION Intervention

MISSION uses several established Evidence-Based Practices (EBP) found to be useful among individuals with COD. While evidence to date supports the use of each MISSION component described above on its own, the outcomes are even more robust when delivered using the MISSION service delivery platform.

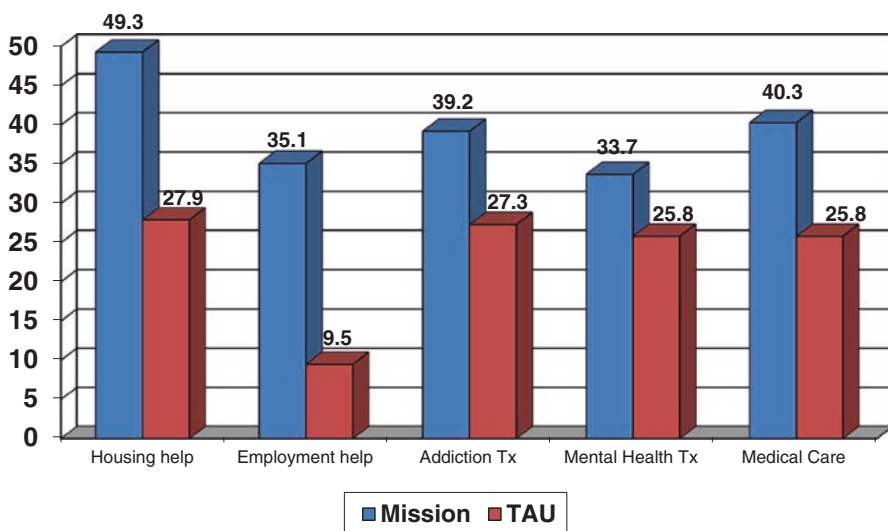
Four studies to date have been published on the use of the MISSION intervention (Smelson et al., 2005, 2007, 2012, 2013). Initially tested among clients transitioning from acute psychiatry to outpatient care (Smelson et al., 2005), data from a nonrandomized study of clients ($n=59$) who received MISSION compared to Treatment As Usual (TAU), found that MISSION significantly improved treatment attendance, ongoing engagement in outpatient treatment, positive substance abuse and mental health outcomes, and also led to reductions in psychiatric rehospitalization (Smelson et al., 2005, 2007). Individuals who received MISSION vs TAU, had significantly better treatment outcomes in terms of attendance at the initial intake appointment (92% vs. 52%, $p=.02$), sustained participation by the end of the second week of treatment (89% vs. 36%, $p<.01$), and completion of 8 weeks of treatment along with the final assessment (76.9% vs. 18%, $p<.01$). Pharmacy records were also examined as an indirect measure of treatment adherence, and all subjects in the MISSION group refilled psychiatric medication compared to 76% in the TAU group ($p<.01$) (Smelson et al., 2005). In a RCT, 69% of participants who received a 2-month MISSION intervention attended at least one outpatient appointment within 14 days

of discharge, compared to only 33% of participants in the control group ($p < .01$). Further, those who received MISSION were also more likely to be engaged in outpatient services at the end of the 2-month intervention period (44 vs. 22%, $p < .01$) (Smelson et al., 2012). In a quasi-experimental study, clients who received a 12-month MISSION intervention were more likely (77.8% vs. 21.9%) to have attended an outpatient mental health, substance use and/or case management session in the 30 days before the 12-month assessment compared to those who received TAU only, and had higher levels of engagement with a number of needed services as shown in Table 9.1 (Smelson et al., 2013).

Description of MISSION Implementation, Training, and Fidelity Resources

The MISSION treatment manuals (Smelson et al., available at www.missionmodel.org) serve as a guide for Case Managers, Peer Support Workers, Clinical Supervisors, and Program Administrators in implementing the MISSION COD integrated treatment intervention. A workbook is also available for participants to further engage them into the treatment intervention through a series of readings, exercises, and other resources to aid in their recovery. Per the MISSION model, peer support workers work closely with program participants to complete the items in the workbook that correspond with specific COD treatment sessions, and also use the workbook to help guide participants through the various stages of recovery. A study was recently completed exploring service delivery and fidelity to the peer support component as intended by the MISSION model (Ellison et al., 2016).

Table 9.1 Levels of engagement 12 months post baseline



The MISSION Treatment Manual contains several appendices to assist MISSION case managers and peer support workers in the delivery of services to promote fidelity to the model and further engage clients into care. Further, given the high rate of traumas among vulnerable subpopulations of clients diagnosed with COD including the homeless (Smelson et al., 2014), veterans (Smelson et al., 2011), and those clients with criminal justice issues (Pinals et al., 2014), the original MISSION materials were adapted to better meet the needs of these subpopulations of clients who have high rates of COD. It is important to provide a number of resources to clinicians when delivering integrated models of care that can assist with implementation of any intervention. MISSION is one such integrated COD treatment intervention with a number of available resources to assist clinicians and staff with engaging clients in care and promoting fidelity to service delivery as intended by the program developers. Manuals and training materials are also available from the developers of the other COD treatment interventions discussed earlier in this chapter.

Conclusions

In this chapter, we discussed the importance of treatment engagement among clients with co-occurring substance use and mental health disorders (COD). We also examined some of the challenges associated with engaging clients with COD into care. Several common strategies for engaging and treating clients with COD were also discussed. We reviewed the importance of integrating various approaches (MET, CBT, RP, and SST) to meet the complex needs of clients and introduced different integrated treatment models that have been successful in promoting treatment engagement (BTSAS—Bellack et al., 2006; DRT, Ziedonis & Trudeau, 1997; MISSION, Smelson et al., 2013).

It is important to keep in mind that the delivery of integrated treatment for COD is often challenging because integration must occur at the intervention-, program-, and system-levels (Ziedonis, 2004). It is also necessary to adapt interventions as necessary to better meet the needs of clients and promote higher levels of engagement among clients diagnosed with COD. As the literature on the treatment of CODs continues to develop, guidance for engaging clients with CODs in care may also become more specific (Drake et al., 2007).

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Chapter 10

Promoting Treatment Engagement with Specific Populations: Depression

Marie C. Barrett, Laura E. Stayton, and Amy E. Naugle

Introduction

Depressive disorders were identified as a leading cause of burden in the Global Burden of Disease studies conducted in 1990, 2000, and 2010. In the 2010 study, major depressive disorder (MDD) was identified as a contributor of burden allocated to both suicide and ischemic heart disease (Ferrari et al., 2013). The World Health Organization (WHO) ranks MDD as the fourth leading cause of disability worldwide and predicts that by 2020, MDD will be the second leading cause of disability. Data on the prevalence and costs of depressive disorders worldwide are limited, but existing studies suggest that lifetime prevalence rates are between 1.5 % and 19 %, with higher rates occurring in higher income countries. Epidemiological studies have identified costs related to depression that impact living in four domains: education, marital timing and stability, child-bearing, and occupation (Kessler, 2012).

The Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM–5; American Psychiatric Association, 2013) depressive disorders include major

M.C. Barrett, M.A. (✉) • L.E. Stayton, M.A. • A.E. Naugle, Ph.D.
Department of Psychology, Western Michigan University,
1903 W Michigan Ave, Kalamazoo, MI 49008, USA
e-mail: marie.c.barrett@wmich.edu; laura.e.stayton@wmich.edu;
amy.naugle@wmich.edu

depressive disorder, persistent depressive disorder (dysthymia), premenstrual dysphoric disorder, disruptive mood dysregulation disorder, substance/medication-induced depressive disorder, depressive disorder due to another medical condition, other specified depressive disorder, and unspecified depressive disorder. Although these disorders differ in duration, timing, and presumed etiology, these disorders all share the presence of sad, empty, or irritable mood and cognitive, somatic, and behavioral changes that impair daily functioning. Diagnoses of depressive disorders are dependent on patients meeting a minimum number of a range of symptoms (American Psychiatric Association, 2013).

A variety of studies have reported that the majority of depressed patients report a preference for psychotherapy over antidepressant medication, but that only 20 % of patients referred for psychotherapy go on to initiate psychological treatment and that of those who do, approximately half drop out of treatment (Mohr et al., 2010). Such discrepancies indicate the need to assess treatment barriers and strategies to enhance treatment engagement. Research suggests that depressive symptoms are both an indicator for treatment and a barrier to receiving it. It has been hypothesized that the low motivation associated with depression may exacerbate other psychosocial barriers, and it has been found that perceived barriers to treatment are more common among depressed than nondepressed patients (Mohr et al., 2010). In geriatric populations, low energy and resignation resulting from depressive symptoms have been identified as factors that impede treatment engagement (Raue & Sirey, 2011).

Additional barriers to treatment engagement include those that affect the use of mental health services globally and across diagnoses. The most significant barriers to addressing mental health problems globally are scarcity, inequitable distribution, and inefficiency of resources. Other significant barriers are factors such as financial cost, difficulties associated with transportation, and the limited availability of competent providers (Saxena, Thornicroft, Knapp, & Whiteford, 2007).

Given these findings, the importance of identifying and implementing strategies for treatment engagement cannot be overstated. Depressive disorders are costly to the individual and society as a whole. The ideographic nature of symptoms that may account for any one diagnosis of a depressive disorder indicates the importance of careful assessment of individual symptoms and treatment preferences and the importance of individualized care. The existing literature on barriers to treatment engagement suggests that depressed individuals are especially vulnerable to failing to initiate treatment, and this same literature suggests that the first step in increasing treatment engagement is assessing and addressing treatment barriers.

The present chapter presents strategies for treatment engagement in a stepped-care model, first presenting the strategies that are the least invasive and that require the least provider involvement. Higher steps progressively reflect strategies that are more invasive and that require increased provider involvement. For further reading on stepped-care approaches to care, see *Stepped Care and e-Health: Practical Applications to Behavioral Disorders* (O'Donohue & Draper, 2011).

Step One: Screening, Assessment, and Planning

Screening for depression is the first step in implementing any strategy to increase treatment engagement and is necessary to develop a treatment plan. Screening is a brief process that is designed to evaluate the likelihood that depression or depressive symptoms are present. Screening is additionally utilized to determine whether assessment—that is, a more detailed evaluation to define the specific symptoms present, determine any relevant diagnosis, and to inform selection of an appropriate intervention—is warranted. Screening, assessment, and treatment planning are minimally invasive, require minimal patient engagement, and generally require relatively minimal provider involvement. As such, they are presented here as the first step in this review of strategies for increasing treatment engagement in a depressed population.

The American Psychological Association's practice guidelines for depression (2010) state that the "optimal treatment setting and the patient's likelihood of benefit from a different level of care should be reevaluated on an ongoing basis throughout the course of treatment." In a stepped-care model, assessment is crucial for developing an ideographic treatment plan and informing decision making, such as determining whether a higher level of care is necessary at any point during treatment.

Research indicates that despite the prevalence of depression, it is recognized only about 50% of the time in settings such as primary care (Gilbody, Richards, Brealey, & Hewitt, 2007). These findings are concerning, given that primary care physicians, rather than mental health professionals, treat the majority of patients with symptoms of depression (Sharp & Lipsky, 2002). As such, screening and assessment should be implemented during initial contact in any setting in which providers may come into contact with depressed individuals. In addition to initiating assessment promptly, it is crucial that providers conduct ongoing assessment of depressive symptoms. Ongoing assessment is particularly crucial when working with depressed individuals, as it allows for regular assessment of suicidal and self-harm behaviors and determination of worsening symptoms all of which may require transition to more intensive forms of treatment.

Screening and assessment can be accomplished through a combination of self-report and clinical interview measures. A wide range of screening and assessment tools have been developed and rigorously evaluated. These assessment measures vary in length and detail, with some involving as few as nine questions and some providing indicators of symptomatology (i.e., minimal, mild, moderate, or severe levels of symptoms). Commonly used and highly valid and reliable assessments for depression include the Beck Depression Inventory-II, Hamilton Rating scale for Depression, Structured Clinical Interview for DSM-IV, Children's Depression Inventory, Reynolds Adolescent Depression Scale, the Geriatric Depression Scale, and the Patient Health Questionnaire. Strategies for assessing suicidal behaviors, such as the Modified Scale for Suicidal Ideation, also have been developed (Brotten, Naugle, Kalata, & Gaynor, 2011).

Models of outpatient care that incorporate ongoing assessment and monitoring of symptoms have been developed. One such approach, termed the Wilford Hall

model, involves patient orientation to assess symptoms, provide psychoeducation, and evaluate individual treatment preferences. This orientation stage is followed by collaborative decision-making between patients and providers in order to select the most appropriate form of treatment based on assessment findings, treatment goals, and patient preferences. The Wilford Hall model includes ongoing assessment of symptoms and treatment satisfaction (Kelleher, Talcott, Haddock, & Freeman, 1996). While the Wilford Hall model was developed for use with a military population, the model's attention to severity of symptomatology, individual treatment goals and preferences, and inclusion of ongoing assessment suggest that it could be a useful tool in more broadly implementing a stepped-care approach to the treatment of depression across populations and a useful tool in increasing treatment engagement among depressed patients.

Research has investigated the utility of brief interventions designed to address barriers to treatment engagement that exist on the individual level. A variety of individualized treatment engagement interventions have been developed. Three such interventions described by Raue and Sirey (2011) are an *open door intervention*, a *shared decision making intervention*, and a *treatment initiation program in primary care*. While these interventions were developed to address depression in an elderly population, the success, innovation, and strong theoretical underpinnings of these intervention recommends the development of parallel interventions for use with other populations.

Open Door Intervention. In an NIH-funded randomized controlled trial, Raue and Sirey (2011) evaluated a brief psychosocial intervention that focused on early treatment engagement following assessment and diagnosis of depression. Intervention involved two, 30-min face-to-face sessions with a community provider and a follow-up session conducted via telephone. The focus of these two sessions was the identification of any tangible or psychological barriers to seeking treatment, such as transportation difficulties or the perception that depression is an inevitable part of aging. Following the identification of these barriers, the provider utilized psychoeducation, problem-solving techniques, and motivational interviewing to aid the depressed individual in decision analysis about seeking treatment.

In a pilot study, this intervention was offered to all older adults to who scored 10 or higher on the PHQ-9 and were receiving home meal delivery. Sixty-two percent of the participants in the Open Door Intervention accepted a referral and scheduled an appointment with a health care professional following the open door intervention, compared to the historical control rate of only 22% (Raue & Sirey, 2011).

Shared Decision-Making Intervention. Raue et al. (2010) additionally developed a shared decision-making intervention for depressed, low-income patients in an inner-city hospital. As in the intervention described above, this treatment focuses on early-stage engagement. Specifically, the Shared Decision-Making Intervention focuses on the point in care at which primary care providers identify depression and the need for treatment. Raue et al. developed this intervention to directly address depressive symptoms such as helplessness and hopelessness, to enhance patient autonomy and empowerment, and with the goal of indirectly improving clinical outcomes by increasing patient engagement and adherence.

The intervention is designed to be delivered by a nurse in a primary care setting and consists of a single 30-min, face-to-face meeting followed by two weekly follow-up telephone calls that average 10–15 min in duration. In these interactions, the nurse and patient discuss the patient's treatment experiences, values, preferences, and concerns. Psychoeducation is provided about various treatment approaches, including information about the effectiveness, speed of onset, cost, and side effects of available treatments. Handouts with easy-to-understand language are provided to patients during the initial meeting, and the nurse strives for a mutually agreed-upon treatment decision. The focus of follow-up telephone calls is reviewing agreed-upon treatment decisions, reviewing relevant barriers and strategies to overcoming them, and when necessary, reengaging the patient in the shared decision-making process (Raue et al., 2010).

Treatment Initiation Program. The third intervention developed by Raue and Sirey (2011) focuses on a later stage in the authors' model of treatment engagement. This stage involves adherence to antidepressant medication. The intervention program is designed to target psychological and tangible barriers that impact adherence.

The Treatment Initiation Program involves three 30-min individual meetings during the first 6 weeks of pharmacotherapy and two follow-up telephone calls. The brief individual meetings are designed to allow the provider to establish an alliance with the patient while maintaining brevity that fosters independence and contrasts with psychotherapy. The intervention involves six distinct steps: (1) review of symptoms, current treatment regimen, and psychological and tangible barriers to treatment, (2) definition of a personal goal achievable with treatment engagement, (3) provision of psychoeducation about depression and depression treatment, (4) collaborative discussion of barriers, (5) collaborative creation of an adherence strategy, and (6) facilitation of direct communication between patient and primary care provider about any treatment concerns (Sirey, Bruce, & Kales, 2010).

In a randomized controlled pilot study that included 70 elderly primary care patients in New York City, patients who were given this intervention had higher rates of adherence compared to the usual-care group at 6, 12, and 24-week follow-up assessments. At 12-week follow up, 82% of patients who had been enrolled in the Treatment Initiation Program were adherent to prescribed medication at 80% or above, compared to only 43% of the patients who received usual care. At 24-week follow up, program-enrolled participants also reported a greater decrease in depressive symptoms compared to patients in the usual care group (Sirey et al., 2010).

While the authors developed this particular engagement-enhancing intervention for use with psychopharmacological interventions, we present it here due to its potential to be applied to a variety of other interventions. The six steps of the intervention, which are reviewed below, could be applied in part or in whole to the initiation of any form of treatment, including those which are less invasive than psychotropic medication.

Assessment of Treatment Preferences. Research has investigated the effects of patient preference on treatment efficacy and other outcomes, such as patient drop-out rates. Practice guidelines provided by the American Psychiatric Association advocate that, whenever feasible, providers consider patient preferences regarding

treatment type, and that this consideration may be an effective strategy in improving both outcomes and adherence (Gelenberg et al., 2010). While some evidence suggests that patient who are able to exercise control over their health care decisions experience improved treatment outcomes (Geers et al., 2013), the majority of studies conducted in this area have not found a direct relationship between patient preferences and treatment outcome. However, a review of research conducted on the effects of patient preferences indicates that patient preferences may have an indirect effect on outcome through other factors, such as treatment engagement, dropout, and satisfaction (Winter & Barber, 2013). While more research in this area is needed, this data supports the APA's current guidelines and recommendation that patient preferences regarding treatment type be evaluated and, whenever possible, honored by providers.

Step Two: Minimal Provider Involvement

Within a stepped-care approach, the second level of treatment for depression involves minimal provider intervention. These strategies include watchful waiting, bibliotherapy, and psychoeducation. All three of these approaches may be used best in cases of mild depression or prior to trying more intensive treatments.

Watchful Waiting. Watchful waiting involves withholding active treatment for a specified period of time and consistently measuring and monitoring symptoms during that time period (Hegel, Oxman, Hull, Swain, & Swick, 2006). These continued assessments should assess severity and progression of symptoms to determine whether active treatment should be initiated. It is assumed that by engaging in watchful waiting a proportion of cases of depression will remit on their own without requiring further intensive treatment.

One study found that of 121 patients entered into a 1 month watchful waiting period prior to participating in a randomized control trial, 9–13% showed remission of symptoms (Hegel et al., 2006). They also found that the rate of remission was lower for individuals with avoidant coping styles and those who engaged in fewer pleasant activities prior to initiating the trial. These findings suggest that for certain individuals, simply monitoring symptoms and checking to make sure they do not progress to more severe levels may be adequate for treatment. In addition, for individuals with the identified risk factors of avoidant coping and avoidance of pleasant events, it may be that rather than engaging in a more intensive treatment approach, pleasant events scheduling, or problem focused coping skills training may be enough to reduce symptoms of depression (Hegel et al., 2006).

When considering watchful waiting as an early-stage intervention, it is important to evaluate the preferences of the patient with regard to watchful waiting versus a more active form of treatment. Johnson, Meredith, Hickey, and Wells (2006) assessed primary care patients' preferences for depression treatments including watchful waiting. In this study, 16% of patients preferred watchful waiting over active treatments. In addition, those individuals who preferred watchful waiting

were less likely to use antidepressant medications or attend individual counseling sessions (Johnson et al., 2006).

These findings suggest that individuals who prefer watchful waiting are less likely to initiate another form of active treatment, and that their preferences reflect their real-life treatment choices. Therefore, it is important to assess patient preferences before beginning active treatment to determine whether they may prefer a less intensive approach such as watchful waiting, as they are more likely to engage in their preferred form of treatment. The research presented in the Assessment of Treatment Preferences section above suggests that it is equally important to evaluate and honor patient preferences if individuals report a preference for a more active form of treatment instead of watchful waiting.

In addition to assessing preferences, the provider should spend time considering the patient's particular constellation of symptoms and how they may interfere with continued assessment and monitoring. For example, if an individual with mild depression is experiencing difficulties getting out of bed due to hypersomnia, to increase engagement it may be necessary to work around their schedule to plan appointments at times they are most likely to attend. Patients who continue to experience symptoms following a period of watchful waiting may be more likely to engage in other treatment approaches as a result of knowing that they have already tried the least-invasive approach.

A variety of strategies may be useful to increase engagement with watchful waiting. Regular patient contact will facilitate troubleshooting any potential barriers to engagement as they become apparent. The provision of a rationale for watchful waiting (i.e., a description of the potential benefits and particular advantages of a watchful waiting intervention) may serve a similar function as the psychoeducation interventions described below, thereby enhancing engagement or outcomes in watchful waiting. Another strategy for engaging patients in watchful waiting treatment may involve the use of motivational interviewing (MI) strategies to promote faithful attendance of appointments for ongoing assessment.

Bibliotherapy. Another intervention that requires minimal provider involvement is bibliotherapy. Bibliotherapy involves a patient self-administering at home treatments using self-help books, structured materials, or technology resources recommended by a provider (Gregory, Canning, Lee, & Wise, 2004). Bibliotherapy may also involve standardized treatment in book format that the patient completes independently (Cuijpers, 1997).

One commonly used example of bibliotherapy for depression is *The Feeling Good Handbook* by Dr. David Burns (1990) (Gregory et al., 2004). The "Feeling Good Program" was first developed in 1980 and research has demonstrated its efficacy in reducing depressive symptoms immediately following participant engagement in assigned bibliotherapy (Smith, Floyd, Scogin, & Jamison, 1997). Research has also shown that participants maintain improvements in symptoms at 3 year follow up (Smith et al., 1997). The primary components of *The Feeling Good Handbook* involve the use of cognitive and cognitive behavioral strategies for managing anxiety and mood disturbances. In particular the book outlines "forms of twisted thinking," commonly known as cognitive distortions, and teaches readers to alter their thoughts

to improve mood and anxiety. The book includes education about a variety of topics and possible causes of depression, as well as worksheets and activities to engage the reader in applying the information to their own condition.

Another example of a commonly used self-help text for depression and other emotional difficulties includes *Get Out of Your Mind and into Your Life* by Hayes (2005). In contrast to *The Feeling Good Handbook*, this book emphasizes an acceptance approach to emotional difficulties and distressing thoughts rather than attempting to change thoughts or feelings. Hayes's approach promotes being aware of emotions and thoughts and changing one's relationship with them rather than changing the thoughts or feelings themselves. This approach promotes the idea that the individual can live a valued life even if their symptoms of depression do not disappear entirely. While there is no current outcome data regarding the use of *Get Out of Your Mind and into Your Life* as bibliotherapy for depression, it is derived from Acceptance and Commitment Therapy (ACT), an intervention that is considered by the APA (2006) to be an empirically supported treatment with moderate support for the treatment of depression (2006).

In addition to text versions of bibliotherapy, there are an increasing number of electronic or internet-based forms of self-help resources that patients may benefit from using. This option may be particularly attractive for patients who do not have access to mental health providers in their area or those who live in rural locations. A few examples of forms of electronic self-help resources include support group websites, CBT self-help guides, and organization websites that compile links to electronic resources, such as those provided by the United States Department of Veteran Affairs website (<http://www.mentalhealth.va.gov/depression.asp>). A few examples of English-language programs of electronic self-help for depression are MoodGym (<https://moodgym.anu.edu.au>), This Way Up (<https://thiswayup.org.au>), MoodHelper (<https://www.kpchr.org/moodhelper>), COPE (<http://www.cope2thrive.com>), and Beating the Blues (<http://www.beatingtheblues.co.uk>).

Bibliotherapy has a number of advantages that make it an appealing intervention. It can be cost-effective and easily accessible (Mains & Scogin, 2003). For many individuals with depression, treatment may be too expensive or not covered by their insurance plans. Therefore, bibliotherapy may be particularly useful in underserved groups. In addition, allowing patients to complete bibliotherapy at home may reduce concerns about stigma associated with seeking treatment for depression. In many settings, providers can introduce the bibliotherapy rationale and material in one brief individual or group contact, therefore limiting the strain on providers (Gregory et al., 2004).

While many bibliotherapy resources have been designed for patients to utilize independently at home, a provider may combine it with additional interventions. Research suggests that this is quite common in practice today, with one study reporting that in 60–97% of cases, bibliotherapy is used in combination with psychotherapy to enhance psychotherapy outcomes (Mains & Scogin, 2003). Similar to the approach of watchful waiting discussed above, a provider may recommend bibliotherapy for a patient to use at home, but continue to touch base with the patient to monitor symptoms as they progress through their selected self-help program. These contacts with the therapist are generally supportive or facilitative in nature (Cuijpers, 1997).

Gregory et al. (2004) conducted a meta-analysis of 29 studies evaluating the effectiveness of cognitive bibliotherapy for depression. They found an average effect size of .77 across a broad range of studies. This effect size is similar to those found in studies assessing the effectiveness of individual psychotherapy. Another meta-analysis found an effect size of .83 for self-administered bibliotherapy. The same meta-analysis found that when cognitive versus behavioral bibliotherapies were compared, both forms performed better than a control group who received no intervention (Mains & Scogin, 2003). These findings demonstrate that not only is bibliotherapy one way of addressing a number of barriers to engagement in more intensive forms of treatment, it is capable of achieving high levels of effectiveness.

Despite its demonstrated effectiveness, there are certain patients with depression for whom bibliotherapy may be less suitable. Research indicates that bibliotherapy may be less effective for individuals with severe depression, suicidal ideation, and those who have complicating comorbidities. In addition, individuals who have a pattern of externalized coping or defensiveness may be less likely to benefit (Mains & Scogin, 2003). Therefore, the provider should conduct assessment of each patient to determine the suitability of bibliotherapy.

As noted by Dysart-Gale (2008), research on bibliotherapy has focused on outcomes and neglected factors such as individual engagement with assigned texts. Should providers detect that engagement is lacking, they may use a variety of strategies developed for use with other interventions. For example, employing aspects of the open door intervention, shared decision making intervention, or a treatment initiation program described previously may be useful in addressing any barriers to engagement as they arise. If regular check-in appointments are scheduled with the patient, the provider may utilize assessment in an ongoing manner to ensure continued appropriateness of the bibliotherapy intervention. The use of motivational interviewing (MI) strategies may also be useful for engagement with the bibliotherapy materials. Developed by Miller (1983), MI is a patient-centered therapeutic style designed to enhance readiness for change by facilitating exploration and resolution of patient ambivalence toward treatment.

Psychoeducation. Psychoeducation aims to help patients develop knowledge about a condition and to inform them of possible tools to help them cope with symptoms (de Souza Tursi, von Werne Baes, de Barros Camacho, de Carvalho Tofoli, & Juruena, 2013). Additional goals of psychoeducation are to empower the individual, and to increase awareness about symptoms, treatments, and techniques to improve coping. One benefit of utilizing psychoeducation is that it can be conducted in many settings and with a variety of populations who may experience a diverse range of conditions (Colom, 2011). Therefore, psychoeducation can be used by a wide range of providers ranging from those in medical and primary care settings to specialty mental health providers.

The format in which psychoeducation is delivered can vary widely and may consist of a single one on one session with a provider or it can be more involved such as a 12 session group with weekly structured class meetings. Psychoeducation can be provided in individual or group formats, and can also be provided over the internet or telephone (de Souza Tursi et al., 2013).

One example of a commonly used psychoeducational approach is Lewinsohn's "Coping with Depression" program (Lewinsohn & Clarke, 1984). This program emphasizes a group-based, educational, and didactic approach to teaching participants about depression as well as teaching them techniques and strategies for coping with their symptoms. The program is based on social learning theory and the techniques most closely resemble cognitive behavioral therapies for depression. Throughout 12 lessons, the therapist educates participants about different skills and activities that may help them to cope with depression. The course is advertised as a class rather than a therapy and is therefore considered a psychoeducational intervention rather than group CBT. Although not stated as a goal by the authors, this classification as an educational course rather than a therapy may reduce stigma for interested participants.

To test the efficacy of this program, Swan, Sorrell, MacVicar, Durham, and Matthews (2004) administered the "Coping with Depression" program in a group format to 76 individuals who had previously responded poorly to other treatments. Of the 31 who completed the program, 35% achieved remission of depressive symptoms and reported an improvement in quality of life (Swan et al., 2004).

The "Coping with Depression" program is just one example of a psychoeducation intervention. This program, as well as psychoeducation in general, may be provided alone, or in conjunction with individual psychotherapy. Lewinsohn and Clarke (1984) estimated that approximately 30–40% of participants in their courses are usually involved in some other form of treatment. Although psychoeducation can serve as a standalone intervention, psychoeducation is often included as one component of empirically supported treatments such as cognitive behavior therapy (Ong & Caron, 2008).

A number of studies have reported on the effectiveness of psychoeducation in various populations. Ong and Caron (2008) reviewed seven empirical studies that tested the effectiveness of psychoeducation for families and children with mood disorders. Following their systematic review of the literature, they determined that although rigorous trials of psychoeducation have not been conducted, the use of these interventions is "probably efficacious," in the treatment of depression in children and family systems. They found that across multiple studies, families and children who participated in psychoeducation showed improvements in attitudes and behaviors related to depression as well as a reduction in depressive symptoms (Ong & Caron, 2008). Another review reported on 15 studies that provided psychoeducation to participants with depressive symptoms. They found that across studies, the use of psychoeducation improved participants' reported clinical course of depressive symptoms, treatment adherence, and psychosocial functioning (de Souza Tursi et al., 2013).

There is a dearth of research regarding engagement in psychoeducation and strategies to facilitate increased engagement. As discussed in previous sections of the present chapter, the use of various elements of the three interventions developed by Raue and Sirey (2011) may be useful for enhancing patient engagement, and scheduling regular patient contact may increase opportunities to utilize these strategies.

Another strategy for engaging patients in psychoeducational treatment may involve the use of motivational interviewing (MI) strategies. Sherman et al. (2009)

utilized a brief 20- to 30-min, individualized MI session with Veterans experiencing severe mental health difficulties and their families prior to their enrollment in a long-term, family-based psychoeducation program. In this brief session providers reviewed a number of previous self-reported goals of the Veteran and identified the advantages and disadvantages of participating in the upcoming psychoeducation program. Therapists utilized a number of other MI strategies including rapport building, reflective listening, affirmation of Veteran's openness, and reinforcement of self-motivating statements. They found that 30 % of Veterans who completed this initial engagement session completed at least one session of the psychoeducation program, which is higher than the 2–13 % rates found in previous research on lower-intensity activities, such as attending a single psychiatrist appointment (Sherman et al., 2009; Sherman, Faruque, & Foley, 2005). Therefore, providers may consider using regular check in's as well as motivational interviewing strategies to increase the likelihood that their patients will engage in psychoeducational approaches.

Step Three: Increased Provider Involvement

Within a stepped-care approach, the third level of treatment for depression involves an increase in provider involvement. These strategies include a variety of technology-based interventions, primary care interventions, and cognitive behavioral therapy. All these approaches may be effective in the treatment of mild, moderate, or even severe depression and may be utilized prior to the use of more intensive treatments.

Technology-Based Interventions. In recent years, technology-based interventions have garnered increasing attention for a variety of reasons. Technology has the potential to increase the capacity of mental health services, and to overcome some of the barriers to accessing mental health services, including stigma, traveling time for rural patients, treatment delays, and the low availability of skilled providers. A growing body of evidence supports the efficacy of technology-based interventions and in particular supports the efficacy of computerized cognitive behavioral therapy (Titov, 2007).

Technology-based interventions vary in the amount of provider involvement and the degree of invasiveness. Research to date has suggested that predominately self-help computerized cognitive behavioral therapy interventions are efficacious in the treatment of sub-threshold mood disorders and offer a less-intensive, cost-effective way to deliver treatments, but that provider-assisted interventions are more efficacious (Newman, Szkodny, Llera, & Przeworski, 2011).

Telephone-Based Interventions. Telephone-based interventions may involve assessment or psychological interventions delivered via phone calls between the provider and patient. These sessions may vary widely in duration and focus. A variety of studies have evaluated the use of telephone-delivered interventions to increase treatment engagement.

A study conducted by Mohr et al. (2012) compared telephone-delivered CBT to face-to-face CBT. In this study, the two treatment groups followed identical treatment protocols and varied only in the modality used to deliver treatment. The results of this study indicated that while the telephone-delivered intervention improved adherence, it also resulted in some increased risk of poorer maintenance of gains following the conclusion of treatment.

Motivational interviewing (MI) provided over the phone has been investigated as a possible method to increase treatment engagement. A study conducted by Seal et al. (2012) evaluated the efficacy of telephone-delivered in enhancing treatment engagement in veterans with mental health concerns. The intervention involved four 20–30 min telephone MI sessions conducted at baseline and 2, 4, and 8 weeks. The baseline session involved personalized feedback regarding psychological assessment, open-ended questioning about concerns, and empathic reflective listening. Subsequent sessions focused on building motivation and strengthening commitment to treatment. The use of a MI intervention resulted in 62 % of Veterans engaging in treatment compared to only 26 % in the control group.

Another study evaluated a telephone-based referral care management program implemented in a population of African Americans between the ages of 22–83, of whom 39 % had severe depression comorbid with substance use. The intervention involved addition of one or two MI sessions, averaging 15 min per week, which involved discussing patient symptoms, goals, and attitudes toward treatment. These brief MI sessions were provided in addition to the usual-care model, which involved session scheduling and a letter and telephone reminder of the scheduled appointment. The telephone-based referral care management program resulted in 70 % of patients engaging in treatment, compared to 32 % in the usual-care group (Zanjani, Miller, Turiano, Ross, & Oslin, 2008).

Internet-Based Interventions. In recent years, there has been much interest in the potential of use of the Internet to increase the availability and cost-effectiveness of treatment for a variety of mental health issues. Internet-based interventions have also been investigated for their potential to increase treatment engagement. To date, research has indicated that attrition from randomized controlled trials of Internet-based interventions are low relative to dropout from open access websites. The reasons for discrepancy in attrition remain unclear, however, and researchers in this area have emphasized that the development of theoretical models of adherence is just as important in the area of Internet research as it is in the behavioral health literature (Christensen, Griffiths, & Farrer, 2009).

Online cognitive behavioral therapy (CBT) programs for the treatment of depression have been developed. Sharry, Davidson, McLoughlin, and Doherty (2013) evaluated an online, provider-assisted CBT program that was specifically designed to address treatment engagement. Engagement was addressed via a variety of program features, including personalization options such as a custom homepage, user choice of module order, an interactive program interface that included the opportunity for users to provide feedback, support provided via an assigned provider who provided reviews of progress, and social features such as the option to anonymously contact with other users of the program.

Sharry et al. (2013) found that inclusion of these features resulted in a high level of engagement and a significant reduction in self-reported depressive symptoms. At the target week 8 or later, 79% of users were engaged with treatment. The reviews provided by providers appeared to be well-received by users: 50% were read within 24 h. The overall dropout rate in the program was 37.5%, which compares favorably to a 74% dropout rate for an unsupported program. These robust effects were accomplished with minimal involvement from the providers, who devoted only 10–15 min per week per patient to providing reviews.

Primary Care Interventions. Depression is frequently identified and treated in primary care settings and is the third most common reason for primary care appointments (Gilbody, Whitty, Grimshaw, & Thomas, 2003). While depression is commonly seen in primary care settings, it is not necessarily properly managed. Primary care providers are capable of treating depression and often utilize antidepressant medications to do so. However, patient adherence with medication is poor, and there is a lack of psychotherapy provided in primary care (Gilbody et al., 2003). A systemic change that may help to improve treatment engagement in primary care settings is colocation of mental health specialists. By collocating mental health specialists within primary care settings, a mental health provider resides in the same office as primary care providers allowing a patient to receive mental health care in an office they already visit on a semi-regular basis.

One study focused on evaluating care of older adults found that collocating mental health services resulted in improved access to care when compared to enhanced referrals to specialty care (Raue & Sirey, 2011). While primary care providers can refer patients to specialty mental health providers outside of their office, the rate of follow up on these referrals is often below 50% (Kessler, 2012). Gallo et al. (2004) found that physicians preferred integrated care with colocated mental health specialist over enhanced referral care for older depressed adults. Physicians additionally reported a number of benefits of integrated care including facilitation of communication with mental health specialists, reduction in stigma for patients, and more effective coordination of mental and physical health care (Gallo et al., 2004). These findings suggest that colocation has the potential to address many barriers to treatment engagement and to improve the quality of care received by patients.

Engagement in services may be further improved by implementing routine screening procedures in primary care settings. In a study assessing a two-tiered screening approach of university students, Klein, Ciotoli, and Chung (2011) utilized the PHQ-2 and PHQ-9 to screen all patients presenting for care. After the screening the physician would determine the severity of their symptoms and initiate a range of treatments including watchful waiting, antidepressant medication, or referral to mental health services.

They found that patients were more likely to engage in the recommended treatment if their depression symptoms were more severe (Klein et al., 2011). However, of those patients with moderate to severe depressive symptoms 42.8% did not engage in treatment within 30 days of screening (Klein et al., 2011). This suggests that primary care providers may want to screen all patients and speak openly with patients to determine the severity of their symptoms and their preferences for a

range of care options. If symptoms are more severe, the physician may want to consider more involved treatments. Screening patients more regularly may also increase likelihood of engagement.

In addition to assessing preferences, primary care providers may want to consider tailored communication prior to appointments to increase engagement in treatment. One study by Kravitz et al. (2013) screened a sample of 6191 primary care patients for depression. Of those screened, 925 individuals met criteria for the study and chose to participate. The sample was then randomly assigned to receive one of two different tailored communication interventions or a control intervention prior to a primary care appointment. The tailored communication groups consisted of a depression engagement video (DEV) and an individualized multimedia computer program (IMCP). The DEV informed patients about depression symptoms and was personalized to sex and age, the IMCP was an interactive computer program that utilized a number of patient inputs such as depression severity to individualize feedback and provided links to personalized information, and the control intervention was a sleep hygiene video (Kravitz et al., 2013).

The outcome measures included the percentage in each group who received antidepressant medications or referral to specialty mental health in the appointment as well as the percentage of patients who broached the topic of depression in the subsequent appointment with their primary care provider. The IMCP group was significantly more likely to receive antidepressant medication or referrals to specialty services than either the control or DEV groups. In addition, both the DEV and IMCP groups were more likely to request information about depression from their primary care provider than the control group (Kravitz et al., 2013).

The results of this study suggest that by providing patients with individualized information about depression, it may increase their likelihood of seeking out, and engaging in available treatments for depression. This suggests that primary care offices should be actively screening for depression symptoms, and providing some form of tailored communication to patients to increase the probability of patient engagement.

Cognitive Behavioral Therapy. CBT is a highly efficacious treatment for depression, but low engagement in treatment impedes its utility for many individuals. An observational study by Brown et al. (2011) assessed patient preference, attrition, and the cost effectiveness of CBT delivered in individual or group format. Prior to treatment, 70% of patients stated a preference for individual CBT, while 10% preferred a group format and 20% stated that they had no preference between the two modalities.

At post-treatment, both treatments resulted in significantly decreased depression scores. The results of the study indicated that attrition was similar in both modalities, independent of stated treatment preference or reported satisfaction. By post-treatment, 53% of the patients enrolled in the study who had initially expressed a preference for individual therapy but had received group therapy changed their preference. Group CBT was additionally found to be more cost effective than individual CBT (Brown et al., 2011).

Other studies have investigated predictors of treatment change and engagement in group CBT. One such study assessed 48 individuals enrolled in group CBT for

depression and found that individuals with higher pretreatment hopelessness scores were significantly more likely to drop out of treatment than those with lower scores. These findings suggest that negative expectations about treatment outcome may lead to both low treatment benefit and engagement as well as a greater risk of premature termination of treatment. In turn, these risks indicate a need for early assessment of patient expectations and additional interventions to decrease risks. The authors recommend strategies such as motivational interventions, involving family or significant others, or challenging pessimistic or hopeless thoughts early in treatment (Westra, Dozois, & Boardman, 2002).

A number of studies have investigated the utility of integrated motivational strategies to enhance treatment engagement with CBT for depression. Swartz et al. (2007) evaluated the impact of an engagement session designed for the first clinical interaction with a patient. This engagement session involved integration of motivational interviewing and ethnographic interviewing. Preliminary reports of the efficacy of this intervention are promising. The authors reported that among depressed, pregnant women who were assigned to either standard treatment or the engagement strategy, 96% of women who receive the engagement strategy subsequently attended an initial treatment session. Among women who received standard care, only 25% attended an initial treatment session (Swartz et al., 2007).

These findings strongly suggest the effectiveness of motivational interviewing techniques for enhancing engagement in CBT. Particular features of motivational interviewing that have been theorized to be particularly useful in increasing engagement in CBT are its focus on increasing intrinsic motivation for behavior change, strategies for addressing ambivalence and resistance, and its facilitation of a respectful, flexible, and supportive relationship between provider and patient (Arkowitz & Westra, 2004). These authors have suggested three ways to integrate MI and CBT to enhance engagement: MI as a prelude to CBT, MI as a response to CBT nonresponders, and MI integrated throughout CBT.

Step Four: Most Invasive Treatments and Provider Involvement

Following a stepped-care approach, the final level of strategies are the most invasive treatments. These strategies involve the use of psychotropic medication or the use of inpatient hospitalization to treat depression.

Psychotropic Medication. Psychotropic medication is often used as the first line of treatment and is often more readily available than evidence-based psychological treatments (Brotten et al., 2011). Research suggests the use of psychotropic medications is on the rise. A 2011 report issued by Medco Health Solutions analyzed the use of psychotropic medications in the United States between 2001 and 2010 and concluded that one in five adult Americans used such medications in 2010. The report indicates that antidepressants were the most commonly used psychotropic medication and that usage increased 29% in women and 28% in men during this time period.

The same report indicated that use of antidepressants for the treatment of children increased at the beginning of the decade, but peaked in 2004. This peak correlates with the Food and Drug Administration's (FDA) issue of a black box warning in 2004 for SSRIs, which was motivated by evidence that these medications are associated with increased suicidality in children. However, in 2010, the number of children receiving antidepressant medications increased for the first time since the black box warning was issued (Medco Health Solutions, 2011).

Despite the prevalence of antidepressant medications used as treatment, research evidence to recommend psychotropic medication is mixed. The American Psychological Association's practice guidelines for depression (2010) cites a large body of research that supports the efficacy of SSRIs. However, other research has concluded that, when compared with placebo, new generation antidepressants do not produce clinically significant improvement in patients with moderate or even severe levels of depression, and show limited effects among the most severely depressed patients (Kirsch et al., 2008). These authors have concluded that there is "little evidence to support the prescription of antidepressant medication to any but the most severely depressed patients, unless alternative treatments have failed to provide benefit" (Kirsch et al., 2008, 266).

Research has indicated that adherence to prescription medications is poor, which in turn results in poor outcomes and treatment failure. A retrospective chart review of 367 individuals with diagnoses of major depressive disorder who were receiving outpatient treatment revealed that only 44% continued taking medication for longer than 6 months. Other reports of long-term noncompliance in patients with MDD have reported rates as high as nearly 50% (Navarro, 2010). Studies have indicated that these high rates of nonadherence may account for dose escalation in one-third of patients who receive antidepressant therapies, as physicians may interpret lack of symptom reduction as evidence of an ineffective dosage rather than poor adherence (Mahoney, 2010). These findings suggest a need for strategies to assess and address adherence problems.

Some common reasons cited for nonadherence are lack of confidence in the efficacy of the prescribed medication, lack of experienced efficacy, adverse effects, and accidental omissions. Navarro (2010) have stressed that to improve adherence to medication, prescribing physicians must support patients in complying with their medication regimen by establishing and maintaining a supportive therapeutic relationship.

The other engagement enhancing strategies presented throughout this chapter—such as motivational interviewing techniques and assessment of and collaborative problem-solving barriers to treatment engagement—may also be useful in increasing adherence to medication regimens. In particular, the Treatment Initiation Program developed by Raue and Sirey (2011) and described early in the chapter may be useful to providers who prescribe medication, as this intervention is specifically designed to address the psychological and tangible barriers that impact adherence to pharmacotherapy.

Inpatient Hospitalization. Inpatient care for individuals with depression is highly restrictive to the individual and is one of the most intense levels of care. The American Psychological Association's practice guidelines for depression (2010)

state that the provider should seek to determine the least-restrictive setting for treatment that be most likely will ensure the patient's safety and improve the patient's condition. Therefore, inpatient hospitalization should be considered only if alternative methods of treatment are judged to be unable to meet this requirement. Inpatient hospitalization is also a costly intervention, with typical cost per individual between \$400–600 per day in the United States in 2004 (Cotterill & Thomas, 2004).

While inpatient hospitalization provides a highly controlled environment in which the provider has many opportunities to strive for treatment engagement, barriers still exist. Some of these barriers include concerns about stigma, risk of damage to the therapeutic alliance, and risk that individuals may lose their jobs due to time missed during hospitalizations (Brotten et al., 2011). Another identified barrier to engagement in inpatient settings is discrepancy between patient and provider perspectives of user engagement. One study found that patients reported limited ability to have meaningful input on their treatment, while providers reported difficulty engaging patients in discussion of treatment planning (Storm & Davidson, 2010).

Research on strategies for increasing treatment engagement in inpatient settings is limited. The existing research on treatment engagement suggests that assessment of patient preferences, increased opportunities for patients to give input on their care, and increased efforts to build and maintain a caring, supportive therapeutic alliance would all increase treatment engagement. The use of previously discussed strategies, such as psychoeducation or shared decision-making intermissions may also be useful. However, typical inpatient care settings may not allow much flexibility in patient and provider interactions due to limited resources and high demands placed upon providers. As such, changes to facilitate treatment engagement may require system-wide changes before some strategies can be implemented.

Conclusion

Depressive disorders are pervasive and costly to the individual and society. While research has identified a wide array of efficacious treatments for depression that can be used in a wide range of treatment settings, the existing literature also suggests that there are many barriers to engaging individuals with depression in treatment.

Fortunately, there is an increasing focus on identifying and developing a diverse array of strategies for increasing treatment engagement in depressed populations. These strategies may be employed in a wide variety of settings and via various modalities, including in primary care settings and over the telephone. These strategies include simple interventions that are minimally invasive and require minimal provider involvement, such as bibliotherapy, as well as more complex, system-wide changes to how and where mental health care services are offered to individuals.

This chapter has presented strategies for treatment engagement in a stepped-care model, first presenting the strategies that are the least invasive and that

require the least provider involvement, then presenting higher steps that reflect strategies that are more invasive and that require increased provider involvement. However, it is important to recognize that these steps are not mutually exclusive. For example, minimally invasive strategies, such as psychoeducation or motivational interviewing, may be useful in promoting treatment engagement within more intensive levels of care, such as inpatient treatment. Flexible use of these strategies throughout treatment and idiographic application of these strategies to individual patients and treatment settings is crucial for optimal enhancement of treatment engagement.

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Chapter 11

Childhood Behavioral Problems—Attention-Deficit/Hyperactivity Disorder (ADHD)

Jennifer R. Walton, Caroline Murphy, and Lindsay Bartram

Introduction

Attention deficit/hyperactivity disorder (ADHD) is one of the most common childhood mental health disorders. Studies have shown that ADHD occurs in about 5% of children and 2.5% of adults. ADHD, defined by DSM-5 Criteria, is “a persistent pattern of inattention and/or hyperactivity-impulsivity that interferes with functioning or development” (American Psychiatric Association, 2013). There are different subtypes of ADHD: inattentive presentation, hyperactive-impulsive presentation, and combined presentation. As described extensively in the literature, impairment associated with ADHD symptoms can reach far beyond the individual level, often disrupting sibling and parent–child relationships, classroom functioning, and community and extracurricular activities. Further, stress related to ADHD symptomatology can impact treatment engagement, especially if misperceptions about the neurodevelopmental etiology of the disorder are present, and if there is incomplete or inaccurate understanding and expectations for appropriate treatment outcomes and the actual interventions that comprise recommended treatments.

The American Academy of Pediatrics has guidelines on appropriate diagnosis, which includes parent and teacher information on a child’s inattentive and/or hyperactive-impulsive symptoms. Proper diagnosis is a necessary step toward accessing appropriate care, but the provision of a diagnosis alone is insufficient and does not

J.R. Walton, M.D., M.P.H. (✉) • L. Bartram, DO
Department of Pediatrics, Section of Developmental and Behavioral Pediatrics, Nationwide Children’s Hospital, 700 Children’s Drive, Columbus, OH 43205, USA
e-mail: Jennifer.Walton@nationwidechildrens.org;
Lindsay.Bartram@nationwidechildrens.org

C. Murphy, Ph.D.
Department of Pediatrics, Section of Psychology, Nationwide Children’s Hospital,
700 Children’s Drive, Columbus, OH 43205, USA
e-mail: Caroline.Murphy@nationwidechildrens.org

reliably predict meaningful outcomes for children and their families. Indeed, extant effectiveness data clearly documents the high likelihood that treatment obtained following diagnosis is variable, often incomplete, and lacking key components that reliably predict higher rates of treatment engagement, compliance with treatment, and therapeutic outcomes. For example, a critical component of treatment following initial diagnosis of ADHD is education, provided in a developmentally appropriate manner for the child and their parents/caregivers, about the underlying neurodevelopmental impairments associated with ADHD (e.g., “What do the various manifestations of ADHD symptoms look like on a daily basis?”), as well as anticipatory guidance about how youth may be affected physically, mentally, socially, and academically (Subcommittee on Attention-Deficit/Hyperactivity Disorder & Management, 2011). Education itself should be the bridge between initial diagnosis and the initial stages of treatment, as it should serve to increase each family’s clear understanding of the various diagnostic presentations, treatment options, and outcome expectations for different modalities of treatment. Following initial diagnosis and education, though, families have many options for intervention, and treatment engagement is critical, given the persistence of ADHD symptomatology. A brief review of the findings of the MTA Cooperative Group (1999), which is the gold standard investigation of the three main evidence-based interventions for ADHD, follows.

Behavior Therapy

In the MTA, behavior therapy for children with ADHD involved parent training, child-focused treatment, and school-based intervention. The parent training element focused specifically on working with parents in individual or group settings to teach new specific behavior management strategies and help them troubleshoot existing strategies, in order to promote more appropriate behavior and to decrease the impairment associated with ADHD symptoms. The child-specific intervention involved an 8-week, full-time summer camp program during which intensive behavioral interventions (e.g., token economies, differential reinforcement, social skills training) were implemented by highly trained aides supervised by specialty therapists. Finally, the school-based intervention involved biweekly teacher consultations that extended up to 16 sessions that focused on specific behavior management strategies, as well as provision of paraprofessional assistance to children in the classroom. Essential to this portion of the intervention was the *Daily Report Card*, which linked home privileges and consequences to school behavior. Often noted in critiques of the MTA is that fact that this level of intervention intensity is nearly impossible in real-world settings. Instead, evidence-based behavior therapy for children with ADHD typically involves only one component: parent training. The technology transfer from professional to parents involves building rationale for targeted and developmentally appropriate behavior programs, identification and assembly of particular behavior programs targeting specific negative behaviors, and anticipatory and acute troubleshooting at a general and specific level for times when a child’s behavior does not seem to be responding as planned (The MTA Cooperative Group, 1999).

Medication Management

Regarding medication, stimulant medication is the first line of medication management for children with ADHD. Evidence supports the use of stimulant medication, specifically methylphenidate and dexamphetamine, in children as young as pre-school age (Greenhill et al., 2006; The MTA Cooperative Group, 1999). If stimulant medication cannot be tolerated, the use of atomoxetine has been shown to be beneficial. The use of alpha agonist medication, clonidine and guanfacine, has also shown benefit in helping with symptoms of hyperactivity and impulsivity (Pliszka, 2007). In the case of treatment failure with stimulants, atomoxetine, and alpha agonists, evidence has supported bupropion and atypical antipsychotics as third line treatment options.

Primary care physicians (PCPs) provide much of the care for children with ADHD. PCPs are important in educating the family about an ADHD diagnosis, explaining of management, and monitoring of progress. Monitoring includes office visits initially 1 month (approximately) after starting a medication and then minimum of every 6 months (Kutcher et al., 2004; Pliszka, 2007) to review what is currently working and what still needs improvement (medication and/or behavior management). Teacher information should also be included in these visits.

Combined Modalities

The MTA study's findings echoed previous investigations in finding that ultimately, children with ADHD who received *both* medication management and behavior therapy were being maintained on lower psychostimulant doses at the end of the study than were youth who received only medication management. Both the AAP practice guidelines and the American Psychological Association's treatment recommendations clearly advocate for combined medication and behavioral treatment for school-aged youth with ADHD.

Though there are detailed guidelines on ADHD diagnosis and management, gaps continue to exist between effectiveness data in the extant literature and actual incidence of therapeutic outcomes in clinical practice. This may relate to the fact that treatment engagement for youth affected by mental health problems is problematic across the range of problems and interventions. Given that nearly half of youth who need mental health intervention never actually enroll in treatment (Merikangas et al., 2010) and half of youth who do engage end up prematurely terminating (Pellerin, Costa, Weems, & Dalton, 2010), interventions that promote treatment engagement are critically important to facilitate meaningful outcomes for children with ADHD. Available research on treatment engagement, however, is less than clear in guiding actual clinical practice, in part because of the myriad ways in which "engagement" in treatment has been defined within each study. A review of barriers to engagement in evidence-based treatment for ADHD in youth follows.

Barriers to Treatment Engagement for Children with ADHD

Common Barriers: Cost, Accessibility, Transportation, Scheduling

Previous chapters have clearly established common barriers to mental health treatment engagement, and these certainly hold true for children with ADHD and their families. In a review of the economic impact of ADHD in the USA, for children with ADHD the annual cost of illness likely now exceeds \$15,000, based on 2007 estimates (Pelham, Foster, & Robb, 2007), with per-person incremental of up to \$2720 beyond the annual health care costs of children without ADHD (Doshi et al., 2012). Additionally, there are approximately 4000 Mental Health Professional Shortage Areas (MHPSA) in the USA (“Shortage Designation,” 2015), and a significant number of children with ADHD do not have an easily accessible quality mental health professional to begin intervention. In such cases, barriers to treatment engagement include cost of transportation, ability of caregivers’ to acquire time off from work, and logistics of long-distance travel, including inclement weather and unforeseen changes in traffic patterns. Finally, with so many areas of the USA facing health professional shortage areas, the wait time for families to access quality intervention often leads them to never engage with that intervention, even if they are able to overcome the above barriers.

Medical System Barriers

Barriers exist within the medical system itself that affect quality access and deliverance of mental health services. There have been concerns with PCPs not adhering to the AAP guidelines on ADHD diagnosis and management. A quality improvement study was performed by Leslie and colleagues that assessed the adherence of San Diego’s PCPs to the ADHD guidelines. Though providers were accepting of the protocol, there were still barriers noted, such as limited knowledge of the use of specific ADHD rating scales, the importance of education to families on ADHD and treatment, and limited knowledge of community resources (Leslie, Weckerly, Plemmons, Landsverk, & Eastman, 2004). In 2014 Epstein and colleagues found that there is still improvement needed for community PCPs to provide evidence-based care. After reviewing 1594 patient charts from 188 providers across 50 primary care practices, 70.4 % of the charts had documented ADHD diagnostic criteria, 93.4 % of patients were taking medication, and 13 % of patients were receiving a behavioral treatment. However, parent- and teacher-rating forms were collected infrequently to monitor treatment response or side effects, and only 47.4 % of children prescribed medication connected with their pediatrician within the first month of treatment (Epstein et al., 2014).

There are also systems that involve collaboration between primary care providers and mental health professionals. Epstein and colleagues have strongly advocated for interdisciplinary collaborative care, that this type of service model could help primary care providers who lack the time and resources to both formally diagnose ADHD and to truly implement the AAP ADHD Treatment guidelines (Epstein et al., 2007). Follow-up investigation, however, documented that medication use improved in such collaborative care models, but behavioral outcomes did not (Power, Mautone, Manz, Frye, & Blum, 2008).

In addition to the above barriers, a study by Guevara and colleagues discussed emerging themes that lead to “fragmented care” when treating children with ADHD. Lack of clarity about which professional should serve as the primary manager of ADHD treatment, lack of specialty resources and training for providers to formally diagnose and treat ADHD, and lack of support from colleagues and families, as well as blaming of providers if treatment for ADHD “goes wrong,” all represent risk factors for fragmented care (Guevara et al., 2005).

Health Disparities in ADHD

There continues to be racial and ethnic disparities in ADHD care. Minority children are less likely to be identified and treated for ADHD than Caucasian children. Rowland and colleagues found that in children diagnosed with ADHD, 76% of Caucasian children were reported to take medication, compared to 56% of African-American children and 53% of Latino children (Rowland et al., 2002). Hillemeier and colleagues found that the perceptions of African-American parents on ADHD symptoms may be different from their white counterparts; therefore, clinicians must exercise caution in interpreting results (Hillemeier, Foster, Heinrichs, Heier, & Group, 2007). Bussing and colleagues discovered that among children at risk for ADHD, 82% of Caucasian students were diagnosed, compared to 28% of African-American students. They also documented decreased perceived support from social networks and increased caregiver strain among African American families of youth with ADHD, and these two factors significantly impacted families’ utilization of mental health services (Bussing, Gary, Mills, & Garvan, 2003; Bussing, Zima, Gary, & Garvan, 2003). African-American parents generally have decreased health literacy about ADHD, are less likely to apply this label to their child’s behavior, and are less likely to trust health professionals than Caucasian parents (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Bussing, Gary, et al., 2003; Bussing, Schoenberg, Rogers, Zima, & Angus, 1998).

Because of these concerns, minority families are more hesitant to seek mental health care (Fernández & Arcia, 2004; Risher & Fitts, 2002; Rowland et al., 2002), and this may relate to decreased attendance rates for initial appointments, as one study revealed about 48–62% of urban families referred failed to attend an initial appointment (Harrison, McKay, & Bannon, 2004; McKay & Bannon, 2004; McKay, McCadam, & Gonzales, 1996). These aspects also affect future care coordination

between the medical system, family, and the school, which can be difficult (Power et al., 2008). In addition, low-income parents of children with ADHD have an increased incidence of depression and adult ADHD, which have been associated with poorer child symptom trajectories (Ray et al., 2009; Silverstein et al., 2015). Clearly, though there is an overall increase in the amount of children diagnosed and treated with ADHD, there is still a significant level of unmet need, particularly in ethnic minority populations (Eiraldi, Mazzuca, Clarke, & Power, 2006).

Behavioral Health System Barriers

Implementation of evidence-based behavioral therapy (BT) for ADHD requires persistence and consistency from parents and, ideally, educators. Further, regular and objective information exchanges between families and school districts can be negatively affected by ever-increasing pressures related to economic and time constraints, just to name a few, and these are clear threats to both persistence and consistency. In one rural Appalachian area to which the authors of this chapter travel monthly to provide specialty assessment services, for example, at least one parent often travels 70 miles or more roundtrip each day just to access jobs. Parents often admit that traveling to areas of increased employment opportunities is an absolute necessity, yet they are conflicted because so much travel significantly decreases the time that they have to manage the implementation of BT strategies in the home. Further, the stress and fatigue associated with any number of the barriers cited above significantly decrease parents' ability to be consistent, persistent, and developmentally sensitive in the implementation of BT strategies in the home. Given that behavioral interventions outcomes are expected to decrease when implementation fidelity decreases (Durlak & DuPre, 2008), these barriers are of particular concern.

Behavior therapy is recommended as the first-line treatment of ADHD in preschool-aged children (Subcommittee on Attention-Deficit/Hyperactivity Disorder & Management, 2011), but a recent review indicated that only about half of preschool-aged children with ADHD actually receive BT (Visser et al., 2015). Furthermore, one in four of these children receive only medication management of their ADHD symptoms (Visser et al., 2015). This may be a key indicator of some of the barriers families of children with ADHD encounter when trying to access the behavioral health care system. As noted above, 4000 areas in the USA do not have a sufficient number of qualified mental health professionals to meet the population needs in those areas. This may be particularly true for professionals who have specialty training that facilitates their treatment of children who are younger than school-aged. Long wait times for accessing care, especially initial appointments, also prevent families from attempting to engage, especially when they are in crisis (Gallucci, Swartz, & Hackerman, 2014; McCullumsmith, Clark, Blair, Cropsey, & Shelton, 2015). Finally, behavioral health providers themselves often feel stuck between competing pressures between the demands created by educational systems, which have a responsibility to *all* of their students and families, and behavioral

health standards of care that guide providers to focus on patient-centered care, which can erode the quality and frequency of care offered even when families do engage.

Treatment Engagement: Confusion and Clarification

Before discussing existing and innovative interventions on treatment engagement, the definition of treatment engagement should be clarified; however, this is particularly difficult because it has been defined in so many ways. Historical definitions of treatment engagement have ranged from description of the process of identifying a child with a mental health problem (e.g., completion of initial diagnosis), to tabulation of that child actually receiving the initial mental health appointment, to proportions of completed versus scheduled appointments, to frequency counts of children who “completed” treatment with significant therapeutic progress. Though some have defined treatment engagement as a two-step process (i.e., initial attendance and ongoing treatment), McKay and Bannon expanded and clarified the definition of treatment engagement in such a way as to allow for description and measurement of a broader range of elements involved in the process: (1) the recognition by parents and/or other familiar adults involved that a child has a mental health problem; (2) the connection of a child and family to a mental health resource to address those needs; and (3) the actual transportation of the child to a mental health provider (McKay & Bannon, 2004). Note, however, that these focus on just the initial points of diagnostic identification, link to a mental health professional, and bringing the child to the first appointment. This does not cover cognitive preparation, attendance, or adherence, which have also been identified as key to treatment engagement (Becker, Lee, Daleiden, Lindsey, Brandt, & Chorpita, 2015; Chorpita, Daleiden, & Weisz, 2005). Thus, Becker et al. (2015) asserted that a variety of strategies should be used to increase and sustain treatment engagement because there are a variety of ways in which treatment engagement can be defined.

Cognitive Preparation

As described by Becker et al. (2015), *cognitive preparation* involves discussing with families their expectations about their role in treatment as well as treatment outcomes; assessing and fostering their motivation for change; and exploring parents’ perceptions of their own stress levels as well as their resiliency factors. Interestingly, data regarding these activities often are never obtained, much less studied. McKay and colleagues found that a pretreatment thirty minute telephone interview increased attendance to the first mental health session; however, this did not improve ongoing treatment engagement (McKay, Stoewe, McCadam, & Gonzales, 1998). Prompts and reminders to attend appointments often can be

helpful, but by themselves, are insufficient to promote treatment. It follows, then, that adding the content of cognitive preparation activities may have significant additional benefit beyond more traditional appointment reminders. For example, Szapocznik and colleagues investigated the utility of adding Strategic Structural Systems techniques to telephone reminder interventions for families of youth with substance abuse problems. This approach is based on the concepts of *joining* the family but not challenging the family structure, and *restructuring* only the family interactions that prevent family members from beginning treatment, concepts originally from structural family therapy (Minuchin, 1974). They found that those families who received the enhanced telephone intervention had an engagement rate of 93 %, versus that of families in the control group, who collectively had an engagement rate of 42 % (Szapocznik et al., 1988). Clearly, the use of simple communication (telephone) with enhanced techniques can make a significant difference in treatment engagement.

Attendance

Attendance rates are often the most commonly studied marker of treatment engagement, and the literature is rich with examinations of interventions focused on increasing attendance and attrition rates. These interventions include simple appointment reminders, clinician-facilitated discussion of families' perceived barriers to attendance, provision of incentives for actual attendance, and more recently, Motivational Interviewing. As detailed in the Becker et al. (2015) review, indicators of attendance across studies have examined data such as first-appointment attendance and attendance over time, cancellations and broken appointments, punctuality, and attrition versus treatment completion. Their review suggested that interventions that increased convenience and affordability of treatment (accessibility), deliberately gathered personalized characterizations of each child's strengths and needs (assessment), clearly and comprehensively reviewed the practical elements of treatments such as session frequency and content (psychoeducation), and thoughtful assessment and discussion of each family's perceptions of barriers to treatment were used by more than half of all studies that examined effective attendance interventions.

Adherence

Attendance certainly promotes treatment engagement, but adherence to treatment is critical to achieving expected outcomes. Ironically, less research on treatment adherence exists, likely due in part to the differences in actual intervention elements across treatments. Adherence in psychotherapy historically has been defined as "active, voluntary, collaborative involvement of the patient in a mutually acceptable

course of behavior to produce a desired preventative or therapeutic result” (Meichenbaum & Turk, 1987). Nock and Ferriter highlighted that even though adherence and attendance are arguably the most critical elements of treatment engagement, empirical investigations of treatment adherence remained limited. It was emphasized that examinations of treatment adherence in child and adolescent interventions were even more complicated because the child is not the sole client, as children usually cannot attend without parental consent. They also often do not participate in treatment unless mandated by parents (Nock & Ferriter, 2005). Their review focused on parent engagement in child and adolescent therapy interventions targeting behavioral functioning, and they build upon the Meichenbaum and Turk definition of adherence in asserting that adherence could be characterized as active demonstration of specific behaviors such as session participation and evidence of practice outside of sessions. At the time of the study, only 12 controlled studies of interventions focused on increasing parent-specific treatment attendance and adherence existed, and their review suggested that interventions focused on giving specific and developmentally appropriate information to children and their parents about what to expect in treatment sessions, clearly describing the roles and benefits of all persons involved in the treatment process, and clinicians’ joining of the family system through structural family systems techniques held most promise in increasing adherence. Finally, they advocated for interventions focused on increasing continuous engagement and adherence. These included provision of incentives, adding response cost measures for non-participation, and discussing parents’ needs and their coping strategies, which was particularly necessary when their caregiving stress was found to be high. Finally it is noted that the Becker et al. (2015) review found that nearly 89 % of successful study groups utilized homework assignments, designed to reinforce psychoeducation and to increase out-of-session practice, to increase treatment adherence, and that in more than 75 % of cases, accessibility promotions (e.g., information about referrals available in the local community and actual use of those referrals) had a positive impact on adherence. They emphasized that increasing and promoting accessibility, the intent of which is often captured in the phrase *meeting families where they are*, intervention specialists are directly reducing practical barriers, sometimes capturing families earlier in the help-seeking process and thereby increasing opportunities for praising and support their intent to access services, and perhaps even reducing misperceptions and mythologies about the treatment process.

ADHD Treatment Engagement Interventions

Turning now toward interventions specific to ADHD, we highlight that there is small but growing evidence that emphasizes partnering of families with their medical home and specialty care providers. Use of collaborative care models involving primary care and mental health specialists are showing benefit (Kelleher, Campo, & Gardner, 2006). In a recently published article Silverstein et al. (2015) completed a

comparative effectiveness trial evaluating basic ADHD collaborative care that is augmented with interventions addressing ADHD symptoms, and how this care improved outcomes. The augmentation involved use of mental health specialists who helped with diagnosis and management of ADHD, and also case managers who received training in motivational interviewing and the Positive Parenting Program, also known as Triple P (Sanders, 1999). These behavior interventions were aimed to address barriers to treatment, and to identify and manage challenging child behaviors. Results showed that those children with ADHD-consistent presentations had improved potential care collaboration (Silverstein et al., 2015).

Chacko and colleagues have studied the Strategies to Enhance Positive Parenting (STEPP) program, an amplified behavioral parent training program (BPT) aimed towards single mothers of children diagnosed with ADHD. The STEPP program involves traditional BPT but also concentrates on these additional aspects to enhance it: (a) an augmented intake addressing potential barriers to treatment, maternal perceptions and expectations for treatment, and acknowledgment of their children's behavior; (b) "a group-based coping modeling problem-solving format" (with goals such as providing hope and acceptance in the group to aid with problem solving); and (c) "a systematic, manualized problem-solving treatment" process addressing parent- and child-focused problems (Chacko et al., 2007). A study was completed with single mothers and their children diagnosed with ADHD attending the STEPP program, traditional BPT, or a waitlist group. Results showed that those who participated in traditional BPT and STEPP groups had acutely improved measures of a child's oppositional defiant behavior, parent-child interactions, observed parenting behaviors, and parenting stress compared to the waitlist group. Those participating in the STEPP program had increased engagement to treatment, as defined by percentage of (1) sessions attended by the single mother and child, (2) sessions attended on time, and (3) completed homework assignments. However, behavioral parent training overall did not "normalize" functioning for the majority of children with ADHD, and the acute benefits of measures above were not maintained when participants followed up 3 months later (Chacko et al., 2009).

Power and colleagues created Partnering to Achieve School Success program (PASS), a program providing evidence-based interventions and collaboration with PCPs in medication management (for the latter, if indicated). PASS was designed to address barriers to ADHD care that arise specifically in low-income urban communities. PASS involved telephone contact and motivational interviewing with the following elements: (a) understanding parents' chief concerns, (b) affirming parents for their efforts to seek help for their children, (c) refraining from judging parents for not being engaged in treatment, (d) identifying potential barriers to seeking care, and (e) engaging with parents in problem solving to reduce barriers to care (Power, Lavin, & Mautone, 2010). Services involved in PASS include brief family behavioral therapy, conjoint school consultation, collaboration with PCPs on medication management, and assistance on accessing additional resources. Utilizing all of these services was not required. There is evidence that PASS increased engagement at the initial visit, specifically the success rates of clinician-initiated telephone contact and number of parent-initiated telephone attempts independently predicted initial treatment.

The number of minutes of actual telephone contact also predicted initial treatment (Power et al., 2010). Upon further study, how successful the clinician was in contacting the families and the total time on the telephone before treatment also affected ongoing treatment engagement (Walton, Mautone, Nissley-Tsiopinis, Blum, & Power, 2014).

These are examples of interventions attempting to engage families in ADHD treatment initially and ongoing, and have demonstrated results, but further research is necessary.

Recommendations for Enhancing and Sustaining Engagement

Discussing treatment engagement, specifically for children with ADHD, can be complicated and controversial. The definition alone of treatment engagement is not always clear. This chapter discussed details on ADHD diagnosis and management, and illustrated previous research on strategies to improve treatment engagement of families of children with ADHD. Therefore, the recommendations to enhance and sustain engagement in this population are illustrated as follows.

First, accurate and developmentally appropriate education about ADHD across *all* involved parties is critical. The value of providing and reviewing *accurate* information about the neurodevelopmental nature of ADHD with *all* involved parties (e.g., parents, youth, teachers, medical providers, and behavioral intervention specialists) cannot be overstated. Numerous myths about ADHD still exist and are pervasive in the US. For example, many providers encounter caregivers who might say something like “he doesn’t have ADHD; he can get so focused on his videogames that I have to yell to get his attention,” which suggests the myth that if a child can focus attention on any one activity, ADHD is not present. Additionally and sadly, some still believe the myth that ADHD is caused by “bad parenting,” which only heightens the stigma related to this serious disorder and alienates parents and caregivers, likely decreasing their treatment engagement.

Beyond discussions and clarification of neurodevelopmental etiology, education regarding the diagnostic process, including how it is diagnosed and by whom, as well as the process of treatment, including recommended facets and the process of ongoing monitoring to evaluate response to intervention, is essential. We highlight again that practice guidelines and recent empirical investigation assert the value of collaborative care for youth with ADHD; thus if this foundational understanding is not properly emphasized across involved parties, it follows that continued treatment engagement will not be successful. Cognitive preparation interventions such as utilizing questionnaires to gauge involved parties’ understanding of ADHD, its treatment, expectations about *positive* outcomes (e.g., increased functioning versus lack of symptomatology), cultural beliefs about treatment, and explorations with parents and teachers about how mood and stressors likely impact fidelity of intervention implementation all seem particularly useful in clearly monitoring the impact of these educational interventions.

After education, the relationships between health care providers, children and their families, and school staff or other outside professionals involved in the child's care need to be established and maintained. If these relationships do not exist, research has shown this can contribute to mistrust between families and providers (Boulware et al., 2003; Bussing, Zima, et al., 2003), fragmented care for these children (Guevara et al., 2005), unmet need to utilize services (Eiraldi et al., 2006), and future collaborations on coordinating care (Power et al., 2008).

Once relationships are established and maintained, there must be consistent communication among everyone involved to improve management and monitor progress. Sustaining treatment engagement involves this important aspect, and earlier different ideas were discussed on monitoring of progress and sustaining engagement, including implementation of telephone contact (McKay et al., 1998), augmenting collaborative care with evidence-based interventions (Silverstein et al., 2015), enhanced behavioral parent training (Chacko et al., 2007, 2009), and utilizing multiple techniques of phone contact, motivational interviewing, behavior therapy, and medication management in coordinating care (Power, Hughes, et al., 2010; Power, Lavin, et al., 2010; Walton et al., 2014).

The ultimate incentive is a child's developmental and educational success, but just as incremental and relatively short-term incentives must be used on behavioral interventions for ADHD, similar incentive strategies are encouraged when targeting treatment engagement. These may include gift certificates of increasing value as the number of sessions attended and percentage of homework completed increases, provision of childcare during sessions, offering gas vouchers or other transportation aides, or food for families. School district-based incentives for educators who are asked to participate in home-school interventions such as the daily report card mentioned earlier also should be considered when possible.

Best-practice treatment for ADHD is a complex process that requires careful, consistent engagement from all stakeholders. It is a journey for everyone involved to reach this goal. It is well known that children with ADHD can become adults with ADHD who are successful personally and professionally, and these best outcomes are rooted in the consistent and collaborative efforts of fully engaged parents, clinicians, and educators. Continued efforts to define, monitor, and disseminate the elements that facilitate this engagement are strongly recommended.

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Chapter 12

Diabetes

Irene Blackberry

Diabetes: Prevalence and Trajectories

Diabetes affects 382 million people in 2013, which is just below 10 % of the global population, meanwhile an additional 175 million people remained undiagnosed (International Diabetes Federation, 2013). In the USA, there are currently over 24 million people being diagnosed with diabetes and nearly seven million undiagnosed cases. The International Diabetes Federation (IDF) projected the number of people with diabetes to increase to 600 million in the next two decades. About 90 % of people with diabetes have type 2 diabetes with the remaining having type 1 diabetes or gestational diabetes (International Diabetes Federation, 2013). Type 1 diabetes is an autoimmune disease that results in β cells of the pancreatic islets unable to produce insulin. The majority of type 1 diabetes is diagnosed during childhood. Type 2 diabetes is a metabolic disease caused by impaired insulin secretion and resistance to insulin. Type 2 diabetes generally occurs later in life; however, there is a growing prevalence among adolescents (Cameron & Wherrett, 2015). Gestational diabetes develops during pregnancy and is a risk factor for type 2 diabetes. Lastly, there is a small proportion of diabetes that is due to other causes (American Diabetes Association, 2014). Although there are differences in the etiology of diabetes types, their long term impact and psychological demands on daily life are quite similar.

Diabetes is responsible for 5.1 million premature deaths in 2013 (International Diabetes Federation, 2013). Furthermore IDF estimated that global health expenditure will increase significantly from \$548 billion in 2013 to \$627 billion in 2035 (International Diabetes Federation, 2013). At an individual level, the costs of care

I. Blackberry, Ph.D.

College of Science, Health and Engineering, La Trobe University, Wodonga 3689, Australia

Department of General Practice, The University of Melbourne, Carlton 3053, Australia

e-mail: i.blackberry@latrobe.edu.au

double once the person with diabetes develops diabetes-related complications (Baker IDI Heart and Research Institute et al., 2012). The burden of disease from diabetes and its complications, all of which are potentially preventable, has been steadily increasing. The second Diabetes Attitudes, Wishes and Needs (DAWN-2) study surveyed 8596 adults with diabetes from 17 countries and found that depression (WHO-5 Well-Being Index score ≤ 28) and poor quality of life (negative impact of diabetes on physical health, psychological health, social relationships, and environment as measured by WHOQOL-BREF) are common among this population (Holt & Kalra, 2013). The study also reported lack of knowledge among caregivers and healthcare professionals to support people to self-manage their diabetes.

Quality evidence-based care is critical to address these challenges. Understanding diabetes trajectories and the impact of diabetes on life demands is fundamental. The three critical timepoints in engaging patients are at diagnosis, during the initiation of treatment and in the ongoing monitoring of treatment. Step by step care and various practical ways clinicians can engage people with diabetes in their treatment over the course of the disease are presented next. Some strategies can be undertaken by individual clinicians with their patients (micro-level), or in partnerships within the care organization level (meso-level) and finally in the wider healthcare system and funding support (macro-level). The American Diabetes Association (ADA) issued standards of care based on the Chronic Care Model of holistic and comprehensive diabetes care (Standards of Medical Care in Diabetes-2016: Summary of Revisions, 2016). The standards are continually being updated as new research evidence emerges.

At Diagnosis Phase

The ADA states one of the following measures to diagnose diabetes (American Diabetes Association, 2014):

- **Glycated hemoglobin** (hemoglobin A1c) at or above 6.5% (≥ 48 mmol/mol)
- Fasting plasma glucose level at or above 126 mg/dL (7.0 mmol/L)
- Two-hour **plasma** glucose at or above 200 mg/dL (11.1 mmol/L) during oral **glucose tolerance test**
- A random plasma glucose at or above 200 mg/dL (11.1 mmol/L) with symptoms of hyperglycemia or hyperglycemic crisis

Despite diagnosing diabetes as being a relatively straightforward task, how the diagnosis being conveyed to the patient and their family matters. There is evidence that illness beliefs are developed soon after diagnosis is made and then these persist over the course of the disease (Skinner et al., 2014). These early illness beliefs have been found to negatively impact longer term stress and depression (Skinner et al., 2014). The following section illustrates patients' negative psychosocial accounts when they were diagnosed with diabetes. This will provide a context on the underlying strategies needed to engage patients prior to the initiation of their diabetes treatment.

Type 1 Diabetes

It is all happening within a short timeframe: from the moment a child is unwell, being referred to a hospital to visit a specialist, being diagnosed with type 1 diabetes, receiving an abundance of information and sympathy from healthcare professionals, and having to adjust to a new routine at home; this situation can be overwhelming for both parents and their children (Barnard & Lloyd, 2012). Parents often feel shock, scared, and angry about the diagnosis and there is also a sense of guilt and self-blame because their genes cause their children to suffer this condition for the rest of their lives (Barnard & Lloyd, 2012). At diagnosis, children commonly do not understand the seriousness of the disease but have to take greater responsibility of administering their insulin therapy. There is a fear of “being different” from peers at school, fear of death if insulin is not administered correctly, feeling of being a burden to the family, embarrassment in the social situation and isolation (Barnard & Lloyd, 2012). Indeed, public stigma surrounds type 1 diabetes exists, often labeling children as “lazy, unhealthy, fat, obese, lacking exercise, and having eating disorders” (Vishwanath, 2014).

Type 2 Diabetes

Similar accounts of shock, anger, denial, guilt, emotional distress, and fear of death were reported by people when they were being diagnosed with type 2 diabetes (Furler et al., 2008; Stuckey et al., 2014). The psychological reactions can persist years after diagnosis is made. Participants of the DAWN-2 Study reported that diabetes diagnosis means they are denied enjoyment in life such as favored foods and worry about the uncertainty of their future (Stuckey et al., 2014). While for some, the diagnosis is inevitable because they have one or more diabetes risk factors such as obesity, physical inactivity, poor nutrition, or family history, for others they believe that the underlying emotional distress due to major life events, such as the loss of loved ones or life trauma, cause their diabetes. Patients’ views on their diabetes symptoms, concerns, impact, and management are relatively stable over time. On the other hand, high emotional reactions upon diagnosis diminish as the disease progresses and instead being replaced with a sense of appreciation and understanding of their disease (Lawson, Bundy, & Harvey, 2008).

Stepped Care to Engage Patients Early in Their Disease Progression

Diagnosis stage presents a critical opportunity for clinicians to engage patients early in the course of their diabetes treatment. The ADA recommends tailoring approach to the individual circumstances, orienting towards patient-centered care and goals beyond glycemic control (American Diabetes Association, 2014). This is critical as

patient engagement is a continuum process of blackout, arousal, adhesion, and eudaimonic phases (Graffigna, Barello, Libreri, & Bosio, 2014). The blackout phase occurs at diagnosis when patients often feel isolated and in denial and therefore would benefit from psychological support. In the arousal phase, patients accept the diagnosis but find difficulty in understanding all the information from healthcare professionals about the new treatment and prescribed lifestyle modifications, and they often have limited access to learn new skills from their peers. In the adhesion phase, the doctor-patient relationship is key to ongoing patient motivation to engage in diabetes treatment. In the eudaimonic phase, patients are able to embed diabetes management into their daily life routine; however, they express specific needs for practical support from the wider healthcare system.

Although diabetes diagnosis is generally made by physicians (primary care physician, endocrinologists, or diabetologists), diabetes care requires interdisciplinary and collaborative approach involving the person with diabetes and their family, diabetes educators, nurse practitioners, nurses, dietitians, pharmacists, and mental healthcare professionals with expertise in diabetes (American Diabetes Association, 2014). The following practical strategies should be tailored to meet patients' circumstances and preferences as there will not be "one size fits all" approach in diabetes treatment engagement.

Clinicians' Factors

The first step in engaging patients at diagnosis and early in their treatment is to evaluate the clinicians' own personal beliefs, knowledge, and skills related to diabetes that may influence the interaction with patients and their families. Furthermore, understanding the healthcare system, funding mechanisms, and support structures available to patients are critical to facilitate successful patient engagement in their diabetes treatment.

Patient-Centered Care

Patient-centered care is about reorienting the healthcare system to support patients to become an active as well as to effectively manage their conditions (Von Korff, Glasgow, & Sharpe, 2002). Provision of structured and tailored educational information to empower people with diabetes can enhance the level of patient activation and strengthen patient treatment engagement (Gillani, Nevill, & Singh, 2015).

Communication Skills

The DAWN-2 study found that half of the 5000 healthcare professionals surveyed reported having a lack of communication skills with people with diabetes and with other diabetes team members (Holt et al., 2013). Effective communication skills

include the ability to actively listen, to address patients' concerns, to offer sufficient consultation time, to understand patients' circumstances, and to encourage patient active participation in their management plan (Corbin & Rosen, 2005). Effective communication also means positive language use (Speight, Conn, Dunning, & Skinner, 2012). Some words such as "diabetic sufferer," "noncompliant," or "failure" are known to have negative impact on people with diabetes (Speight et al., 2012). Effective communication skills may change patient's disease perception and influence outcomes (Nam, Chesla, Stotts, Kroon, & Janson, 2011). The way information is being conveyed and received determines patient's view of their diabetes at diagnosis and beyond (Lawson et al., 2008). Good relationships and therapeutic alliance between patients and clinicians is integral to diabetes treatment (Furler et al., 2008).

Attitude, Beliefs, and Knowledge

One in five healthcare professionals in the DAWN-2 study never had any postgraduate level of diabetes education or training (Holt et al., 2013). The various level of knowledge on diabetes management influences healthcare professionals' confidence to support people with diabetes and work with other diabetes care team member (Blackberry et al., 2013). Clinicians' attitudes and beliefs at diagnosis directly influence how patients perceive the seriousness of their disease and how patients engage with their diabetes treatment regime (Dietrich, 1996; Puder & Keller, 2003). Clinicians' attitudes and beliefs also influence how they manage their diabetes patients (Nam et al., 2011).

Motivational Interviewing (MI) Approach

The Motivational Interviewing (MI) approach refers to "*a directive, client-centered counseling style for eliciting behavior change by helping clients to explore and resolve ambivalence*" (Miller & Rollnick, 2002). The MI provides a framework for clinicians to build rapport and support people with diabetes to be in control, to be empowered, and to choose their own goals (Carrier, 2009). Training for clinicians is available; however, practice and feedback are as important to embed the delivery of MI approach in routine practice (Miller & Rollnick, 2002). MI has been shown to be effective in promoting patient-centered care and improving health outcomes in diabetes including glucose level, self-efficacy, physical activity, diet, and body weight are also reported (Martins & McNeil, 2009).

Stages of Change/Transtheoretical Model (TTM) of Behavior Change

The TTM has six stages of change including pre-contemplation, contemplation, preparation, action, maintenance, and termination (Prochaska, DiClemente, & Norcross, 1992). This model has been widely applied in behavior change research

and offers framework to match treatment according to the individual's stages of behavior change (Prochaska & Velicer, 1997). Evidence from a systematic review shows that behavior interventions, including those moderated by behavior change theories or models, are effective in improving glycated hemoglobin, objective and self-reported physical activity and body mass index among people with type 2 diabetes (Avery, Flynn, van Wersch, Sniehotta, & Trenell, 2012; Guicciardi et al., 2014). The TTM model of change intervention also reduces smoking rates among people with diabetes in primary care by 26% over 12 months (Perez-Tortosa et al., 2015).

Collaborative Care

Quality of relationships between patients and their healthcare providers is key; however, collaboration between multiple healthcare providers to better meet patients' needs as their care becomes progressively complex is just as important (Funnell, 2006). There are several ways to integrate collaborative care in usual practice. For example a psychologist within a comprehensive multidisciplinary care team provides psychological services to support overall health and well-being of patients and their carers (Kichler, Harris, & Weissberg-Benchell, 2015). Evidence on the significant benefits of collaborative care among patients with coexisting depression on reduced depressive symptoms, enhanced self-management, and satisfaction with care and glycemia is emerging (Atlantis, Fahey, & Foster, 2014; Coventry et al., 2015; Johnson et al., 2014; Richards et al., 2013). While what constitutes collaborative care model varies, common factors include case management or care coordination, behavioral activation, treat to target, regular monitoring, and individualized patient-centered care. Training, ongoing support, professional and personal qualities of the case manager and preexisting relationships facilitate successful delivery of diabetes collaborative care models (Wozniak et al., 2015)

Patients' Factors

Every patient reacts differently upon receiving a diabetes diagnosis hence there is no one strategy that is superior or more effective than others. Treatment engagement should be individualized based on patient's health literacy, coping skills, and support services.

Health Literacy

There is a strong evidence on the positive association between health literacy and diabetes knowledge particularly in the US primary care (Al Sayah, Majumdar, Williams, Robertson, & Johnson, 2013; Bailey et al., 2014; van der Heide et al., 2014). People with high levels of health literacy are more likely to self-manage their

diabetes (van der Heide et al., 2014) while those with low literacy levels develop more diabetes complications and hypoglycemia (Bailey et al., 2014). The relationship between health literacy and other outcomes including glycemic control, quality of life, health care utilization, or patient–provider interaction is less clear (Al Sayah et al., 2013; Bailey et al., 2014).

Healthcare professionals always need to assess their patients' health literacy level when conveying diabetes diagnoses or treatment plans and adjust their communication level accordingly (Parker, 2000). Some practical ways clinicians can engage patients with limited health literacy include using visual materials, avoid jargon or complex medical terms, simple instructions, and involving care givers or family members in the discussion. It is important to check patients' understanding of the diagnosis and treatment plans by asking them to repeat and demonstrate.

Attitude, Beliefs, Culture, and Knowledge

Apart from health literacy level, attitude, beliefs, culture and knowledge influence patients' ability to accept diabetes diagnoses and undertake self-management (Nam et al., 2011). Misconceptions and stigma regarding diabetes still exist widely in the community. Despite global health promotion and awareness on diabetes, public understanding of the etiology of type 1, type 2, gestational diabetes, and other type of diabetes is still poor. The lack of knowledge often influences public beliefs and attitudes that diabetes regardless of its type is caused by overeating, obesity, and sedentary lifestyle (Vishwanath, 2014). Likewise diverse cultural factors can play a pivotal role in forming people's perception on how or why people have diabetes. In some cultures, people believe that type 2 diabetes is caused by emotional distress and trauma rather than poor lifestyle choices (Furler et al., 2008; Stuckey et al., 2014). Cultural beliefs are commonly shaped by patients' personal experience with diabetes in their family and local community.

Illness beliefs including how patients view the seriousness of diabetes and perceived impact of diabetes on their lives are developed early and these beliefs remain for at least 3 years after diagnoses are made (Skinner et al., 2014). Personal models of diabetes including beliefs about symptoms, treatment effectiveness, consequences, and emotional responses to possible complications are influenced by the way the diagnosis is communicated by healthcare professionals rather than patient's personality traits (Lawson et al., 2008). Illness beliefs are associated with the development of psychological distress and depression (Skinner et al., 2014). Understanding patients' culture, beliefs, and knowledge about diabetes at diagnosis enhance patient-centeredness to diabetes treatment engagement.

Psychosocial and Peer Support

Findings from nearly 9000 adults with type 1 diabetes and type 2 diabetes in the DAWN-2 study reported psychosocial issues such as anxiety, fear, worry about hypoglycemia and complications of diabetes, depression, and negative moods or

hopelessness. The study also found that discrimination at work and public misunderstanding about diabetes exist (Stuckey et al., 2014). For example, in the workplace the study found people with diabetes were dismissed because of their diminished capacity to perform or do shift work; or taking medical leaves which could be costly to the employer. Participants reported resilience and being positive as a coping mechanism. Moreover, receiving psychosocial support through a caring and compassionate family, caregivers, healthcare professionals, and peers are regarded as important. There is emerging evidence that peer support programs such as Peer for Progress benefits people with diabetes by offering psychosocial support (Fisher et al., 2015).

Patient Education and Self-Management

Evidence shows that group-based structured diabetes self-management education or training (DSME) in people with type 2 diabetes has favorable effects in clinical, lifestyle, and psychosocial outcomes (Steinsbekk, Rygg, Lisulo, Rise, & Fretheim, 2012). There are various DSME programs with contents covering diabetes disease progression, lifestyle modification, diabetes treatment options, blood glucose monitoring, identifying diabetes complications, and personal goals/targets to achieve (Haas et al., 2012). DSME should be offered to people being newly diagnosed with diabetes (American Diabetes Association, 2015). Yet only half of the Australian National Diabetes Support Scheme (NDSS) members with type 2 diabetes were offered structured DSME (Speight et al., 2011). In the US, less than 7% of privately insured patients with new diabetes diagnosis completed DSME within 12 months of diagnosis (Li et al., 2014). The low proportion of people receiving structured education is alarming given that illness beliefs form early following diagnosis and impact on health outcomes as diabetes progresses (Skinner et al., 2014).

During the Initiation of Diabetes Treatment

The ADA and the European Association for the Study of Diabetes (EASD) have made a joint position statement and guidelines on the best practice management of diabetes (Inzucchi et al., 2012). Multiple dose insulin or continuous subcutaneous insulin infusion is the recommended therapy for type 1 diabetes (American Diabetes Association, 2014). Unlike type 1 diabetes, gestational diabetes, or Latent Autoimmune Disease of Adults (LADA), there is less sense of urgency to initiate and intensify treatment in type 2 diabetes. Disease severity at diagnosis can also vary greatly between one person to another as diagnosis can be made early through health screening or later in the disease progression when symptoms are more pronounced or diabetes complications have emerged. Lifestyle modification with metformin is commonly the first line therapy with step by step clinical guidelines leading to insulin therapy in type 2 diabetes (Inzucchi et al., 2012).

Lifestyle modification is an integral part of type 1 and type 2 diabetes care regardless of pharmacological regime. Research evidence shows that lifestyle modification on diet, exercise, and body weight as well as getting interpersonal support from family and friends remains challenging for people with diabetes (Schroeder et al., 2015). In addition, there is often a mismatch between the healthcare professionals' perception and the actual ability of the patient to undertake self-care activities (Peyrot et al., 2005). This section describes strategies to engage all patients with diabetes to make lifestyle changes and self-care activities as well as to initiate glucose lowering agents.

Stepped Care to Engage Patients Upon Initiation and Intensification of Diabetes Treatment

Cognitive, behavioral, and emotional dimensions each play a part in forming patients' experience to living with diabetes on a day to day basis and the way they manage their diet, physical activity, therapy, and patient–doctor relationship (Graffigna et al., 2014). Patients who have limited understanding of the rationale of therapeutic regime and ineffective support from healthcare professionals, tend to avoid healthcare encounters and a review of their diabetes therapy. Over time patients become ambivalent about their diabetes and disconnected with their healthcare professionals. Assessing and monitoring individual patient experience enables healthcare professionals to engage with their patients during their diabetes treatment.

Person-Centered Care

Person-centered care (PCC) is the underlying strategy to engage patients in their diabetes treatment, individualized treatment to reach normoglycemic target and prevent micro and macrovascular complications according to their individual circumstances. PCC needs to take into account factors such as age, gender, education, life experience, socioeconomic, cultural diversity, social support, environment, communication skills, relationships with healthcare professionals, and coping behavior. PCC requires clinicians to express genuine concern and empathy towards patients.

In type 1 diabetes, the three key elements underpinned PCC include forming long-term relationships with patients and their families; setting up multidisciplinary team care arrangement; and maintaining records of how care is delivered over time (Wigert & Wikstrom, 2014). Training for healthcare professionals, patients, and their families is vital to ensure PCC is embedded in the delivery diabetes care because soon after diagnosis, treatment options need to be discussed and treatment decisions made. Patients and their families require significant support from healthcare professionals to understand what the diagnosis means for them psychologically, to manage the demand of insulin regime and monitoring as well as to learn to adjust their lifestyle (Malik & Taplin, 2014).

In a large cohort of people with newly diagnosed type 2 diabetes in the US, an oral hypoglycemic agent was introduced within a year of diagnosis in younger population while among people aged 65 years and over it took in excess of 2 years (Zhang et al., 2012). The significant time difference to the initiation of treatment also reflected in almost two thirds of younger patients as opposed to less than half of older people were on treatment 2 years post diagnosis. The study also found that older people were less likely to receive antihyperglycemic therapy. Similar findings were found in the UK that at 2 years post diagnosis only one in two patients with newly diagnosed type 2 diabetes was prescribed hypoglycemic agents. Initiation of therapy was associated with younger age at diagnosis and worse glycemic control (Sinclair, Alexander, Davies, Zhao, & Mavros, 2012).

Delay in intensification of therapy after the initiation of oral hypoglycemic agents also occurs in type 2 diabetes. The addition of the second or third oral agents ranged from 1.6 years to over 7 years despite elevated glycemia (HbA1c $\geq 7.0\%$ or ≥ 53 mmol/mol) (Khunti, Wolden, Thorsted, Andersen, & Davies, 2013). Furthermore, a significant proportion, of the 80,000 UK patients with type 2 diabetes, never had their treatment intensified during the 7 years study follow-up period. Overall, the studies highlight *clinical inertia*, a failure to intensify treatment despite persistent hyperglycemia, as well as a substantial lack of ongoing patient engagement to achieve optimal glycemia in type 2 diabetes once the diagnosis was made.

Shared Decision-Making

Shared decision-making (SDM) is a partnership between patients and clinicians to achieve agreement on an evidence-based treatment option that suits patient's circumstances and preferences (Tamhane, Rodriguez-Gutierrez, Hargraves, & Montori, 2015). Patient-centered care is the underlying principle of SDM.

SDM facilitates exchange of information between clinicians on the risks and benefits of treatment and patients to express their values and preferences (Barry & Edgman-Levitan, 2012). SDM relies on clinicians' communication skills to respond to patient's health literacy level. The end result is a shared responsibility of the decision being made. SDM becomes more prominent in healthcare policy although yet to be part of routine clinical practice (Barry & Edgman-Levitan, 2012).

Diabetes is a chronic but progressive condition that necessitates patient to constantly juggle diabetes care with other life demands and other competing comorbidities. SDM in diabetes care enables patients to be the main player to adjust and prioritize their diabetes management with help from their clinicians (Frosch, 2015). Adults with late onset type 1 diabetes report having to make decisions very rapidly after diagnosis occurred. The diagnosis made a significant impact on their lives. To enable people to have SDM, they need knowledge, respect from others on their individual choices and support to make decisions on day to day basis (Jull, Witteman, Ferne, Yoganathan, & Stacey, 2016).

The Patient Health Engagement is a new model of consumer engagement based on patient's own experience with their health management to facilitate shared a

decision making process regarding available health services and sustainable engagement in preventive action and healthy behaviors (Graffigna et al., 2014). Discussion between prescribing clinicians and patients about the choice of diabetes treatment and therapeutic regime needs to occur soon after diagnosis. Once prescribing is completed, it is far too late to engage patients in their therapy. Even multiple follow-up from pharmacists or nurse-directed outreach service makes no difference in improving primary medication adherence (Fisher et al., 2015).

Psychological Barriers

Almost half of people with diabetes participated in the DAWN study reported poor psychological well-being that has negative impact on their ability to self-manage their condition (Peyrot et al., 2005). Despite clinicians recognizing this issue, only one in ten patients received psychological therapy with lack of resources in clinical practice cited as the most common reason (Peyrot et al., 2005). Identifying and addressing the underlying psychological barriers after diagnosis is made and factors that may attribute to the effectiveness of therapy is therefore essential.

Health Illness Beliefs

Education enhances knowledge and training improves skills in self-management. Yet for many people with diabetes continues to struggle with adhering to diabetes self-care behaviors and treatment recommendations. Health illness beliefs influence patients' adherence to self-care and diabetes treatment (Harvey & Lawson, 2009). There are many models and theories to explore the relationship between health beliefs and behaviors. One model that has been widely developed to understand and predict health behaviors is Leventhal's Self-Regulatory Model (also called the Illness Perceptions Model, the Illness Representations Model, the Parallel Process Model, or the Common-Sense Model) that takes into account patients' dynamic and parallel processes of emotional and cognitive response to illness such as how patients make sense of their diabetes and how they develop their coping mechanism (Leventhal, Brissette, & Leventhal, 2003). Perceived threat on the severity and vulnerability to complications as well as belief in treatment effectiveness and the value of care from healthcare professionals play a major part on optimal diabetes outcomes (Harvey & Lawson, 2009). Psychological theory-based interventions offer healthcare professionals the greatest prospect to engage their patients in diabetes self-care behavior and treatment (Harvey & Lawson, 2009).

Treatment Goals and Goal Setting

There are various clinical (blood glucose control, blood pressure, weight loss, exercise) and psychosocial (quality of life, depression, self-efficacy, satisfaction, knowledge) outcomes in diabetes treatment; however, most research regardless of the type

of intervention and clinical practice focus on blood glucose control as the primary outcome. Indeed, glycemic control is important in diabetes for improving health outcomes. Hyperglycemia causes vascular complications through glycation and oxidation of proteins, and lipids, inflammation and disturbed angiogenesis. A period of poor glycemic control can cause tissue and organ damage well past the period of hyperglycemia, well recognized as the *legacy effect* (Holman, Paul, Bethel, Matthews, & Neil, 2008). For every 1% reduction in HbA1c, the relative risk for microvascular complications, diabetes-related mortality, and myocardial infarction decreased by 37%, 21% and 14% respectively over the course of the disease (Holman et al., 2008; Stratton et al., 2000).

In a systematic review of comprehensive behavioral intervention trials incorporating problem solving, goal setting, and health promotion, only a modest improvement of glycosylated hemoglobin (HbA1c) is observed (Medical Advisory Secretariat 2009). Similarly, clinicians often measure their treatment's effectiveness only on clinical parameters with little regards to patients' own treatment goals and how they would like to achieve treatment goals given their capacity, circumstances, and priorities in their life (Frosch, 2015). For example a nurse continued coaching a patient according to the coaching intervention schedule to achieve optimal diabetes control despite the patient experiencing bereavement (Walker et al., 2011).

Motivational Interviewing

MI principles and techniques underpin clinical encounters between clinicians and their patients. MI is proposed as one effective method to engage patients in diabetes therapy (Martins & McNeil, 2009). Yet evidence from real-world clinical practice remains inconclusive. Integration of MI principles within structured nurse-led diabetes care was ineffective in improving glycemic control or lifestyle modification among people with type 2 diabetes (Jansink et al., 2013). Better outcomes on MI were generally associated with longer consultation time with MI-trained nurses, greater opportunity to discuss lifestyle modification and increased patients' readiness to change. However, introduction of MI to intensify therapy among people with out of target glycemia and lipids had little effect. In fact, patients randomly allocated to the MI intervention group were less engaged in the study compared to usual care (Pladevall, Divine, Wells, Resnicow, & Williams, 2015). These findings raise doubts whether MI principles are appropriate, or clinicians' failure in properly implementing MI principles attributed to the lack of success (Jansink et al., 2013).

Patient Education and Self-Management

Patient education on self-management needs to be considered as part of an ongoing diabetes therapy. Data from US Commercial and Medicare payer-derived claims showed that participation in diabetes self-management education or training within accredited or recognized programs by diabetes educators reduced healthcare costs.

Furthermore, multiple and ongoing attendance produced better quality of care and adherence to medication regime (Duncan et al., 2011).

In parents and young people with type 1 diabetes, higher knowledge, understanding, confidence, and motivation were associated with attendance in group-structured self-management education program delivered by trained members of pediatric diabetes services (Christie et al., 2014). However the program was ineffective in improving glycemia over 2 years. Despite evidence on the benefits of self-management education, integrating self-management programs into routine care and engaging people with diabetes and their families to participate in the program remains a challenge. Low uptake in type 1 diabetes program has been attributed to difficulties juggling other life demands or finding suitable time to fit the group education schedule (Christie et al., 2014). Training multidisciplinary team to support patients with type 1 diabetes and their families is key. Establishing a transitional care between pediatric and adult diabetes services is vital to ensure the continuity of care given that older teenagers are more likely to disengage in their healthcare and the alarming rate of complications under 40 years of age (Winocour, 2014).

In type 2 diabetes, self-management education motivates people to continue their self-care activities and engagement with their healthcare professionals. Reasons for participation in self-management programs include desire to stay healthy, being independent, achieve better quality of life, avoid complications, and reduce utilization of health services (Newton, Asimakopoulou, & Scambler, 2015). There are various types of programs available to meet the needs of people with type 2 diabetes. This includes programs for people with newly diagnosed, within few years of being diagnosed and longstanding duration. There is also generic self-management support that takes into account the presence of multimorbidity and support in chronic diseases in general. The Stanford Chronic Disease Self-Management Program developed by Lorig is one example. The program is available in various format, delivery, and adaptation to various cultures and languages (Lorig, 2015). The Peer for Progress is another form of self-management support that was originated in the US and have been adapted globally (Fisher et al., 2015). In the UK, the Diabetes Education and Self-Management for ongoing and newly diagnosed type 2 diabetes (DESMOND) program has been running for the past decade (Davies et al., 2008; Skinner et al., 2014).

Stepped Care to Engage Patients During Transition to Insulin Therapy

A decision to commence insulin often produces negative psychological impact such as grief, loss of independence, stress, blame, and anger. Strategies discussed in the previous section when initiating and intensifying treatment are relevant and can be applied. This section elaborates some areas that are pertinent to how patients deal with the decision to commence insulin. A particular focus is for healthcare professionals to receive adequate training to support patients psychologically and to

dedicate sufficient time to engage patients to safely and independently administered and titrate their insulin regime.

In type 1 diabetes, transition to insulin occurs soon after diagnosis. Ensuring children/adolescent and their families are able to cope and make an adjustment is important. Stigma, communication, disclosure, balancing the children's feeling of being different to their peers and restriction to normal daily activities needs to be addressed (Lambert & Keogh, 2015). Stress, burnout, time pressure, social support, parental autonomy support, and stigma influence glycemic control (Mulvaney et al., 2011). Patient-centered care principles need to underpin care as each patient will have various psychosocial circumstances, health literacy, and maturity. To successfully engage patient and their families in treatment, healthcare professionals also need to explore barriers stem from complex insulin initiation and adjustment regimens. Simplifying therapy as well as close support and monitoring how the patients and their families respond to prescribing regimens and adjust therapy accordingly are necessary (Santer, Ring, Yardley, Geraghty, & Wyke, 2014). Collaborative and integrated pediatric care by trained multidisciplinary team is warranted.

Use of insulin is critical in achieving glycemic control but often delayed in type 2 diabetes. While patient-centered education and self-management are important (Norris, Lau, Smith, Schmid, & Engelgau, 2002), pharmacotherapy is a key aspect of type 2 diabetes therapy. There are increasing pharmacological options, including GLP-1 agonist therapy; however, insulin remains the most efficacious medication to achieve glycemic target. Despite the importance of tight glycemic control and strong evidence of the use of insulin, *clinical inertia* remains an issue particularly in primary care (Khunti, Wolden, Thorsted, Andersen, & Davies, 2013). This may stem from misunderstanding the benefits of tight glycemic control, lack of confidence about insulin initiation and up-titration, or problematic interpretation of blood glucose patterns. Concerns about hypoglycemia and confusion about target levels for HbA1c also may play a role. Barriers also exist at the health or practice system and patient level (Kuritzky, 2009). Healthcare professionals may set unrealistic goals (Wolpert & Anderson, 2001) or neglect discussing insulin in ways that engage patients (e.g. improve energy, better quality of life, reduce complication risk). Given the epidemic of type 2 diabetes, the majority of cases and initiation of insulin will need to be managed in primary care.

Initiation and intensification of insulin regime in type 2 diabetes is often delayed particularly in primary care. Patients reported having “*psychological insulin resistance*”, worry that insulin will make life inconvenient and less flexible, and feelings of being failure and self-blame (Holmes-Truscott, Pouwer, & Speight, 2014). The average HbA1c level prior to insulin initiation range between 8.3% or 67 mmol/mol (Best et al., 2012) and 9.4% or 79 mmol/mol (Davis, Davis, & Bruce, 2006). A large clinical practice data from 11,696 patients with type 2 diabetes in the UK showed that between 2004–2013 only one in three had their basal insulin regime intensified within a median time of 4 years (Khunti et al., 2016). Clinical inertia was attributed to older age, longer duration of diabetes, use of oral antihyperglycemic agent and presence of comorbidities. The same study also found that a third of patients with out of target glycemia ceased their insulin therapy. Guidelines and clinical algorithm

to initiate insulin in primary care is available. However increased primary care-based insulin initiation remains a challenge that requires greater clarification of the role of each interdisciplinary team member, integration into routine care, and ongoing quality assurance (Sunaert et al., 2014). A model of care, of primary care physician and nurse team with training and mentoring support from a diabetes educator and a diabetologist, embedded within the primary care systems with simple algorithm and education for patients may facilitate uptake of insulin (Furler et al., 2014).

Monitoring

Monitoring is essential in diabetes care to review the effect of therapy and to examine disease control and progression. Blood glucose monitoring include patient's self-monitoring of blood glucose (SMBG), HbA1c, point of care testing, and continuous glucose monitoring (Standards of Medical Care in Diabetes-2016: Summary of Revisions, 2016). Clinicians should consider the rationale for testing blood glucose using each of these options, and review the result based on the individualized target and recommended clinical guidelines.

Evidence around the benefits of glucose monitoring in patients on insulin therapy is robust while it is less clear for patients with type 2 diabetes not on insulin (Standards of Medical Care in Diabetes-2016: Summary of Revisions, 2016). In type 1 diabetes, a large proportion of adult patients and caregivers of children reported only 20–40% downloaded their SMBG data four times or more in the past 12 months (Wong, Neinstein, Spindler, & Adi, 2015). Furthermore, less than a third reviewed their SMBG data. Those who regularly reviewed their SMBG data had significantly better glycemic control. Meanwhile a review of people with type 2 diabetes over 12 months duration who were not on insulin found that SMBG had no effect on glycemia, patient satisfaction, well-being, or health-related quality of life (Malanda et al., 2012).

Continuous glucose monitoring (CGM) examines instantaneous real-time or retrospective glucose level and glycemic variability. The CGM technology has improved significantly in the past few years to enable online data sharing. Overall CGM is underutilized in clinical practice mainly due to lack of affordability. CGM is primarily used in type 1 diabetes together with an insulin pump and is essential for a closed-loop artificial pancreas (Rodbard, 2016). CGM is particularly useful for patients with a history of hypoglycemia or hypoglycemia unawareness. Among patients with type 2 diabetes on insulin, CGM can be a powerful educational and motivational tool for both patients and their healthcare professionals (Blackberry et al., 2014).

HbA1c is generally reviewed twice yearly; however, when patients are out of glycemic target or have their therapy modified, HbA1c tests are performed every 3 months. HbA1c level is strongly related with risks of developing diabetes complications. Apart from monitoring blood glucose level, ADA recommends regular screening and treatment of macro- and microvascular complications in routine clinical care (Standards of Medical Care in Diabetes-2016: Summary of Revisions, 2016).

The Role of Technology in Patient Treatment Engagement

There have been massive technological advances in diabetes care besides CGM and insulin pumps. Various types of eHealth interventions are available to improve clinical outcomes and patient engagement. Online patient self-management and support tool has the potential to supplement the traditional one-on-one patient clinical encounter (Kaufman, 2010). Web-based tools enable healthcare professionals to service a large number of patients in glucose monitoring, medication review, lifestyle counseling, and social support as well as promoting greater partnerships between patients and their healthcare professionals. Some of the functionalities that have been found useful in engaging people with diabetes include:

- Online self-management support where patients can input and monitor their lifestyle modification, blood pressure, mood, blood sugar against their individualized goals
- Web-based learning, sharing of online information between patients and their healthcare professionals and remote monitoring can facilitate more efficient and timely review and individualized actions
- A “virtual coach” or monitor “virtual support groups or chat rooms or blogs” to offer round the clock support.

Evidence on the use of eHealth in facilitating better health outcomes, capacity of self-manage diabetes, or health service utilization is unequivocal (de Jongh, Gurol-Urganci, Vodopivec-Jamsek, Car, & Atun, 2012). A review of 16 trials covering clinic-based, Internet-based, and mobile phone-based interventions found that mobile phone-based performed better than computer based self-management interventions in improving HbA1c (Pal et al., 2013). However overall benefits in clinical outcomes, mental health, quality of life, health behavior, and resource utilization is limited.

Despite showing great potential to complement or enhance current diabetes care, evidence on how technologies can be used as a patient engagement tool is lacking (Barello et al., 2015). User experience and functionality of the technologies are rarely evaluated in research to date (Lyles, Sarkar, & Osborn, 2014). Furthermore, there is often a mismatch of expectations between patients and their healthcare professionals. For example, patients found Personalized Decision Aid (PDA) to be simple and can offer practical information in their diabetes management. Meanwhile, healthcare professionals viewed PDA as too complex and burdensome for patients (Lee et al., 2016).

A recent study highlights the importance of healthcare professionals’ perceived ability in motivating, engaging, and activating patients in their self-management using mHealth and eHealth devices. Patient engagement is a mediator of healthcare professionals’ ability to motivate patients with type 2 diabetes and patients being activated or taking actions. The ability to motivate patients’ autonomy is also a much stronger predictor of treatment adherence than increased frequency of mHealth and eHealth use (Graffigna, Barello, Bonanomi, & Menichetti, 2016).

Conclusions

Diabetes is a metabolic as much as a psychological disease. It is a progressive disease that requires lifelong commitment to a therapeutic regime and significant lifestyle modification. There is often a mismatch between clinicians focusing on diabetes treatment solely to achieve glycemic targets and patients' dealing with psychosocial issues and competing life demands. The Chronic Care Model provides a useful framework for clinicians to deliver comprehensive and holistic diabetes care.

“...resources (should be) allocated to proactive psychological care that encourages (diabetes) patients to be engaged and goal orientated” (Kirby, 2015).

One strategy does not fit all in people with diabetes. Patient engagement in diabetes treatment needs to start early in the course of the disease and be maintained across life span. Treatment approaches should be individualized and based on patient-centered care particularly given that the bulk of the care lies with the patient. Successful patient treatment engagement requires ongoing support, monitoring, and review. Different types of interventions should be offered at various stages of the disease progression and be adjusted to patients' individual circumstances. Support from trained healthcare professionals and accredited programs are widely available. Additionally, support and networking opportunities online and face-to-face with peers exist and should be recommended. Clinicians need to be responsive to enhanced standards of medical care in diabetes, healthcare system reform, new therapies, and more importantly greater complexity in the disease profile as people with diabetes live longer.

“It must be emphasized that clinical evidence and expert recommendations alone cannot improve patients' lives, but must be effectively translated into clinical management” (American Diabetes Association, 2014).

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Chapter 13

Engaging Trauma Survivors in Treatment

Cassandra Snipes

Introduction

Traumatic events are often devastating. Many survivors suffer incredible physiological, psychological, and psychosocial disability. These experiences most often affect younger persons and traumatic sequelae can interrupt what should be the most generative time of life. Yet we far too often leave survivors to pick up the pieces and work towards recovery on their own. We do not adequately engage them in care. The current system requires survivors to notice signs that follow-up care is indicated, know how to access such care, and know how to navigate potential barriers to care. The ability to meet these demands is influenced by intrapersonal (e.g., coping repertoire and health literacy) and systemic factors (e.g., natural support system and availability of providers). It is estimated between 70% and 90% of children are exposed to at least one traumatic event prior to reaching adulthood and approximately 90% of adults report exposure to at least one traumatic event, as classified by DSM-% criteria (Cohen, Kelleher, & Mannarino, 2008; Kilpatrick et al., 2013). Unsurprisingly only a small proportion of trauma survivors receive adequate follow-up care, this despite enormous need.

This is an unforgivable failure of the health care system. Posttraumatic problems are unique in that the precipitating factor of dysfunction is identifiable. For example, an assault (trauma) may result in a liver laceration (injury), whereas the moment someone develops Congestive Heart Failure (CHF) cannot be pinpointed. The discrete event of trauma is a unique opportunity for engagement, as it often results in survivors' contact with at least one care professional. In the case of sexual abuse a

C. Snipes, Ph.D. (✉)

Department of Psychology, University of Nevada, Reno, 1664 N. Virginia Street/Mail Stop 298, Reno, NV 89557, USA

e-mail: snipes.cassandra@gmail.com

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W. O'Donohue et al. (eds.), *Practical Strategies and Tools to Promote Treatment Engagement*, DOI 10.1007/978-3-319-49206-3_13

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survivor may interact with the police and or a victims' advocate agency. Military members may receive in-theater screening, or be treated by a medic and or psychologist on the battlefield in the case of a traumatic event such as the death of a fellow service member. They may be transferred to a military hospital or they might have contact with veterans' health care upon leaving the service. Civilian survivors of traumatic injury may require emergency services and a hospital admission. Despite these initial contacts with the health care system the opportunity for engagement in appropriate follow-up care is missed all too often.

This failure occurs for a myriad of reasons; however, all are solvable. This chapter first provides the reader with an understanding of the magnitude of unmet need in trauma survivors. This is not meant to be an exhaustive review of all potential deleterious effects of trauma but intended to communicate the general scope of the problem. Barriers to engagement are identified. Finally, application of specific treatment engagement strategies across a variety of contexts are presented, couched in an example of a trauma survivor's care journey.

Consequences of Trauma

Physiological Consequences

Perhaps the most salient consequence of trauma is injury that occurs either via direct insult (e.g., gunshot or assault) or natural disasters such as earthquakes. These injuries are unfortunately not infrequent—traumatic injury amounts to 41 million emergency room visits and 2.3 hospital admissions annually in the USA alone (National Trauma Institute, 2014). Survivors may undergo emergency surgery, may be paralyzed, or may require amputation. The recovery from such injuries certainly persists beyond the acute hospitalization phase and complications may be enduring. Traumatic brain injury such as a subarachnoid hemorrhage or diffuse axonal injury may cause lasting cognitive deficits. Survivors may also suffer complications such as Multi Organ Dysfunction Syndrome, which can occur after the acute injury phase. Moreover, studies have demonstrated 40–50% of trauma patients experience clinically significant persistent pain 1 year after injury (Browne et al., 2013; O'Donnell et al., 2013). The direct physiological impact of trauma is immense and can notably disrupt the lives of survivors.

Survivors may also have indirect physiological complications. For example, childhood sexual abuse is associated with a threefold increase in occurrence of non-epileptic seizures and increased risk of chronic noncyclical pelvic pain in adulthood (Maniglio, 2009). Traumatic experiences and chronic stress can also result in acute immune peripheral inflammatory responses. These inflammatory responses have been shown to persist beyond the acute post-injury phase in individuals with complicated injuries and these processes have been shown to increase risk for chronic

health conditions such as cardiovascular disease (Baker, Nievergelt, & O'Connor, 2012; Heath, et al., 2013; Toledo, 2012). Childhood trauma contributes to an increased prevalence of inflammatory health outcomes such as allergies, asthma, headaches, and gastrointestinal tract problems (Cohen et al., 2008). The direct physiological burden of trauma is immense and these experiences can have longstanding secondary effects.

Psychological Consequences

The psychological cost of trauma is staggering. Initial reactions to trauma include sadness, agitation, nervousness, jumpiness, upsetting memories, disturbing dreams, and anger (U.S. Department of Veterans Affairs, 2015). These responses are normative when experience for a brief period of time; however, when these reactions persist behavioral health disorders may manifest. This risk is particularly attenuated in the case of Posttraumatic Stress Disorder (PTSD), Major Depressive Episode (MDE), and exacerbation of preexisting substance abuse problems (Bonanno, Brewin, Kaniasty, & La Greca, 2010; U.S. Department of Veterans Affairs, 2015); however, the risk of developing a psychiatric disorder post-trauma is increased relative to community norms across most diagnostic categories.

Posttraumatic Stress Disorder and Major Depressive Episode

Experience of traumatic events leaves individuals vulnerable to the development of PTSD and MDE at relatively similar rates. After direct insult injury the risk of development of PTSD has been found to be between three and ten times greater than community norms (Kessler, Berglund, Demler, Jin, Merikangas, Walters, 2005; O'Donnell et al., 2008). Risk of experiencing a MDE 1-year post injury is approximately doubled relative to community norms (Center for Behavioral Health Statistics and Quality, 2015; O'Donnell et al., 2008). Natural disasters also result in increased prevalence of depression and PTSD—a meta-analysis revealed approximately 30% of survivors met criteria for severe psychological dysfunction related to PTSD and or MDE (Norris, Friedman, & Watson, 2002). Women who have suffered abuse have been shown to have slightly more than a twofold increase in risk of PTSD and MDE, relative to community samples (O'Campo et al., 2006). Finally, approximately 30% of asylum seekers who have been displaced from their home country meet criteria for these disorders (Ryan, Kelly, & Kelly, 2009). Trauma undoubtedly increases vulnerability to both PTSD and MDE, and although there is some variability depending on the study population, generally no more than 30% of trauma survivors will develop these conditions (Bonanno et al., 2010; Zatzick et al., 2004).

Substance Abuse

Substance abuse can certainly exacerbate trauma risk; however, the relationship between trauma and onset of substance abuse disorders is less clear. Substances can increase risk of trauma by impairing judgment and increasing disinhibition—alcohol is responsible for approximately half of all trauma deaths and nonfatal injuries in the USA (Soderstrom, Gentilelo, & Ivatury, [year unknown](#)). Trauma can increase the use of substances as tobacco, alcohol, and drugs but evidence shows this occurs only in people who used these substances prior to the occurrence of trauma (Bonanno et al., [2010](#); Breslau, Davis, & Schultz, [2003](#)). Substances may function to numb the intense emotional experiences that often follow traumatic experiences and may provide an “escape” from emotional processing. However, this is an ill-advised coping strategy as evidence demonstrates preexisting alcohol abuse or dependence leads to heightened deterioration of emotional and behavior function in the posttraumatic injury phase (Robinson, [2006](#)). Although new onset substance use disorders may not be of particular concern following a traumatic event, substance users are more likely to experience certain types of trauma and are at risk of exacerbation of their substance abuse problems.

Other Behavioral Health Disorders

Childhood trauma leaves survivors vulnerable to most behavioral health disorders, including those that are more likely to be treatment resistant than PTSD and MDE. Survivors of childhood abuse and maltreatment are more likely to develop Borderline Personality Disorder and Paranoid Personality Disorder (Golier et al., [2003](#); MacIntosh, Godbout, & Dubash, [2015](#); Maniglio, [2009](#)). Childhood sexual abuse has also been shown to increase risk a wide range of psychiatric disorders including psychotic symptomatology, complex PTSD, dissociation, eating disorders, and somatization (Cohen et al., [2008](#); Maniglio, [2009](#)). Traumatic experiences early in life attenuate risk of serious behavioral health problems.

Suicide

The most devastating behavioral health consequence of trauma is the increased risk of completed suicide. There are a number of potential pathways by which this risk may be elevated. Robust data has found childhood abuse to be an independent predictor of suicide (Cohen et al., [2008](#); Roy, Gorodetsky, Yuan, Goldman, & Enoch, [2010](#)). Traumatic brain injury (TBI) has also been found to independently risk of suicide and there appears to be a dose-response—repeated TBIs were associated with increased risk in military personnel when controlling for TBI and psychiatric

symptom severity (Belik, Stein, Asmundson, & Sareen, 2009; Bryan & Clemans, 2013). However, Wilcox, Storr, and Breslau (2009) also found PTSD to be an independent predictor of attempted suicide and demonstrated that exposure to trauma alone, the absence of PTSD, does not increase risk of suicide. PTSD has been shown to contribute to an almost 90% increased risk of suicide in individuals that have suffered traumatic injury. This increased risk may also be in part due to exacerbation of substance use disorders, as positive alcohol toxicology has been found to be a significant predictor of suicide following severe injury (Ryb, Soderstrom, Kufera, & Dischinger, 2006). Trauma exposure certainly increases risk of completed suicide; however, the pathway(s) from time of exposure to suicidal behavior remain controversial.

Psychosocial Consequences

Trauma exposure is associated with a number of poor psychosocial outcomes that are influenced by both physical and mental health concerns. For example, 40% of survivors of traumatic injury suffer disability so great that they do not return to work within 12 months post traumatic injury (Browne et al., 2013). This is certainly influenced by injury severity; however, psychiatric symptoms have been found to account for the largest proportion of the variance in disability at 12 months (Michaels et al., 2000; O'Donnell et al., 2013). Untreated behavioral health problems following trauma also lead to school failure, marital instability, and violence (Cohen et al., 2008; National Institute of Mental Health, 2005). Childhood sexual abuse specifically increases the likelihood of engagement in high-risk sexual behaviors, social impairment, interpersonal problems, and learning impairment (Maniglio, 2009). These are not insignificant derailments given that trauma most often occurs early in life and can have a longstanding impact. Trauma-related psychosocial impairment is also associated with significant societal cost. In the USA alone, \$585 billion a year is spent on trauma-associated health care costs and lost productivity (National Trauma Institute, 2014). Traumatic experiences are associated with great psychosocial burden with longstanding individual and societal impact.

Unmet Need

Many survivors of trauma do not receive appropriate medical and behavioral health care despite the fact trauma is often an identifiable event associated with substantial trauma-related disability. We leave survivors to navigate a complex health system primarily on their own. This is at least part of the reason that there are significantly higher rates of behavioral health problems and disability in the year following trauma.

A high level of unmet need has been demonstrated in survivors of trauma. Need for services range from basic necessities such as food and to primary health care. Between 70% and 80% of victims of violent crime were found to have approximately eight unmet needs on average post injury, ranging from housing to mental health care (Boccellari et al., 2007). Sabin, Zatzick, Jurkovich, and Rivara (2006) demonstrated 40% of adolescents reported no source of primary care posttraumatic injury. Over a 12-month recovery period a substantial proportion of severe lower extremity injury survivors had vocational (33%), mental health (35%), financial (41%), legal services (45), and home nursing (48%) needs (Archer, Castillo, MacKenzie, & Bosse, 2010). Although these findings are largely specific to traumatic injury, the level of physical, psychological, and psychosocial suffering post-trauma suggests a significant amount of unmet need across different types of trauma—if we were able to properly address the needs of survivors the impact of these experiences would not cause rates of dysfunction to soar above community norms. Presently survivors are sent home after horrific traumatic experiences without the resources to feed and house themselves, let alone obtain proper physical and mental health care.

Treatment Engagement Barriers

Systemic and intrapersonal barriers maintain a health care environment in which the needs of trauma survivors are not properly addressed. These obstacles are not necessarily specific to trauma survivors but are particularly problematic in this vulnerable population. Furthermore, systemic barriers (e.g., living as a member of a traditionally underserved group) interact with intrapersonal barriers (e.g., compromised health literacy) to create especially challenging contexts for survivors of trauma.

Underserved Groups

Trauma does not impact all groups at the same rate. Individuals of low socioeconomic status from urban areas experience a higher incidence of violent crime and injury (Breslau, Kessler, Chilcoat, Schultz, Davis, & Andreski, 1998; Boccellari et al., 2007). These individuals are also more likely to be victims of sexual abuse (Douglas & Finkelhor, 2005). Individuals of low socioeconomic status are also more likely to suffer greater and prolonged loss after natural disasters—there is a higher likelihood of mortality, and they are more likely to suffer injuries, and encounter greater obstacles in the recovery and reconstruction (Masozera, Bailey, & Kerchner, 2007). Membership in a marginalized group is associated with an increase of traumatic experiences and this contributes amplified unmet need.

These traditionally underserved groups have the greatest overall unmet need for treatment (Ngui, Khasakhala, Ndetei, & Roberts, 2010). This is influenced by factors such as financial constraints, living in an area with a low number of medical providers, and lack of insurance. These barriers associated with underserved group membership are compounded in survivors of trauma—experience of trauma often creates a considerable need in those that already have trouble accessing services.

Evidence does demonstrate significant unmet need in trauma survivors of underserved populations. For example, being black, being younger, and having no spouse or partner is associated with higher unmet need in trauma survivors (Archer et al., 2010). Moreover, rehabilitation need 1-year posttraumatic injury is influenced by insurance status and education level (Castillo, MacKenzie, Webb, Bosse, & Avery, 2005; Greene et al., 2010). Uninsured and publicly insured pediatric trauma survivors have a greater risk of mortality when controlling for a priori confounders (Rosen, Saleh, Lipsitz, Meara, & Rogers, 2009). Finally, approximately 28% of those trauma survivors in need of behavioral health treatment report cost and 19% report “not knowing where to go” as a reason for lack of engagement in care (Archer et al., 2010). Globally underserved groups are more likely to experience trauma and still have substantial barriers to quality care despite magnified need.

Health Literacy

Health literacy, the ability to understand and utilize basic health information to inform appropriate health decisions, universally impacts treatment engagement (U.S. Department of Health and Human Services, 2016). Unsurprisingly, groups at highest risk for trauma are the most likely to display compromised health literacy. Populations most likely to experience low health literacy are individuals of low socioeconomic status and racial or ethnic minorities (Ginde, Weiner, Pallin, & Camargo, 2008; U.S. Department of Health and Human Services, 2016). Education and access to health care resources also impact the prevalence of compromised health literacy. Furthermore, refugees and asylum seekers have been shown to have compromised health literacy which negatively impacts access to health care resources (Boateng, 2015). Several studies demonstrated low health literacy in trauma survivors. For example, 25% of patients in the emergency room were found to have difficulty understanding basic health materials (Ginde et al., 2008). Kadakia et al. (2013) found orthopedic trauma patients had limited comprehension of their injuries, surgeries, and postoperative instructions. Health literacy is not only more prevalent in populations vulnerable to traumatic events but also is associated with higher mortality rates in children and adults after traumatic injury (Greene et al., 2010; Rosen et al., 2009). Health literacy is an intrapersonal factor, created by systemic influences, that critically impacts engagement in care after trauma.

Shame and Stigma

Shame and stigma often occur in the context of trauma (Fallot & Harris, 2002) and these sequelae negatively impact treatment engagement (Corrigan, Druss, & Perlick, 2014). Feelings of shame and perceived stigma can lead to nondisclosure of trauma (e.g., in the case of sexual abuse) and this undoubtedly decreases the likelihood an individual will receive appropriate posttraumatic care (Holm & Hansen, n.d.). Additionally, even when the traumatic experience is “disclosed,” as in the case of traumatic injury, shame and stigma can also play a role in restricting treatment engagement. Some populations are more vulnerable to these effects than others. Minority populations are more likely to endorsed perceived stigma and shame, possibly due to the fact that they do not adhere to mainstream understanding of illness (Corrigan et al., 2014). Both active duty service members and veterans identify perceived stigma as a barrier to initiating needed medical or behavioral health care (Zinzow, Britt, McFadden, Burnette, & Gillispie, 2012). Refugees have also demonstrated stigma as a barrier to seeking mental health help (Vincent, Jenkins, Larkin, & Clohessy, 2013). Shame and stigma are culturally influenced intrapersonal factors that heavily impact likelihood of seeking health care, particularly for susceptible populations.

Lack of Continuity of Care

Lack of continuity of is dangerous in any population but is particularly problematic post-trauma. A lack care continuity can be a direct result of a failure to properly engage individuals in follow-up care after initial trauma-related care. When survivors are in the hospital are they provided with assistance in obtaining insurance? Are they informed of other avenues of care beyond following with hospital responsible for acute care (i.e., community mental health, housing assistance, etc.)? This lack of continuity of care can also be a result of inadequate care systems. In order for trauma survivors to receive follow-up care there must be a place to go to receive care. Is there a community resource for sexual abuse survivors? Are there a sufficient number of primary care physicians in the area that adept at caring for patients with pain-related disability? Are there pain management specialists available? Does the hospital provide outpatient behavioral health services to trauma survivors or must they find care elsewhere? Lack of continuity of care is both a systemic lack of resources and a failure to properly engage patients in treatment.

Strategies for Engagement

The immense burden of posttraumatic complications and the existent treatment engagement barriers warrant a novel response to trauma survivors. Relying on current systems is simply inadequate especially for underserved groups that are most

likely to experience traumatic events. Focus should be placed on initial engagement immediately following traumatic experiences in order to funnel individuals to appropriate care avenues. Strategies to promote engagement post-trauma are presented below in a stepped-care manner—with the least invasive interventions discussed first.

Level 1: Public Health Prevention and Intervention

The lifetime prevalence of trauma is quite high and many of those exposed to trauma go on to suffer associated disability. However, there is very little public education regarding what to do in case of posttraumatic dysfunction. School children are taught to hide under desks in the case of an earthquake and to talk to someone they trust if someone hurts them. However, once children achieve greater autonomy as adolescents there is no education regarding what to do in the case of a prolonged reaction to a traumatic event, despite high incidence of trauma. These children mature into adults without an understanding of how to help themselves or navigate the health care system. Imagine the case of Michael, an African American high school senior who lives in a neighborhood with a high rate of violent crime. Neither of his parents graduated from high school and he does not have health insurance. He has never been hurt and has had very little interaction with the health care system. Michael has never received any education regarding response to trauma from his family nor from school. Should Michael suffer trauma he would not have been provided the resources to effectively engage in care. The impact of lack of trauma-specific education is attenuated in populations exposed to repeated traumatic events (e.g., areas of high rates of violent crime) and those with compromised health literacy.

School-based education or public service campaigns (e.g., billboards and websites aimed at raising community awareness) may be effective at increasing rates of engagement after trauma. These avenues may serve to increase health literacy regarding posttraumatic complications and offer an understanding of when to seek care. In fact, creating effective health educated curriculums in school is a Centers for Disease Control and Prevention (CDC) objective (CDC, 2016) and programs to increase knowledge of behaviors such as safe sex and health eating are commonplace. However, some school-based preventative efforts have been found to be iatrogenic (i.e., D.A.R.E.) and there is conflicting evidence regarding whether similar public service campaigns are helpful. An Australian campaign regarding raising awareness of depression and anxiety demonstrated enhanced understanding of the benefits of treatments such as psychotherapy and psychotropic medication (Corrigan et al., 2014). In the USA, it is difficult to determine the magnitude of similar campaigns. The SAMHSA What a Difference a Friend Makes campaign resulted in a median of approximately 64,000 visits to the website each month over the course of 2 years. The SAMHSA Erase the Barriers campaign had somewhat dismal results—only .0006 % of the population in targeted states visited the website and only 30 % of those returned to the website a second time (Corrigan et al., 2014). Although

effective school-based and public health campaigns are in infancy we must work towards effectively apply these strategies to increase trauma-specific community health literacy. Take the above example of Michael and hypothesize that he received an afternoon of education on normal reactions to trauma and how to access health care resources in his community. Envision that he sees billboards in his neighborhood normalizing engaging with community mental health in the case difficulty after a traumatic experience. These strategies have the potential to make a significant impact in underserved communities or in the case of large scale disasters in which there are not enough providers to deliver individualized health education.

Level 2: Peer Support

Peer support is a critical component of any trauma treatment program. In fact, peer support has been identified as a central feature of many behavioral health (e.g., the skills group component of Dialectical Behavior Therapy) and dual diagnosis treatment modalities (Fallot & Harris, 2002). This is largely due to the fact that deterioration of social support leads to difficulty in coping across a range of disorders, including posttraumatic maladjustment (Heber, Grenier, Richardson, & Darte, 2006). Peer support also has the potential to target drivers of disparities in health care. Evidence also shows individuals fail to engage in treatment because they do not adhere to the same values or cultural background as providers from the majority culture (Corrigan et al., 2014). Peer support may bridge this cultural gap.

Consider that Michael, the young man in the above example, suffers a gunshot wound during the course of his senior year of high school. He is rushed by EMS to the emergency room and undergoes trauma resuscitation. Michael is then hospitalized for 6 days. In the case of treatment as usual, surgeons, physicians, and mid-level providers treat his medical problems. These providers are older than Michael and are not part of the cultural group he most identifies with. He is then sent home with instructions to follow-up in several weeks with his primary care doctor. He has a difficult time understanding how to follow-up with care but does not feel comfortable asking questions of his medical team. Michael's family is not at bedside during this admission. Now picture during Michael's hospitalization he is visited by a peer—someone of his cultural group who also suffered a gunshot wound in the past. This peer provides the emotional support and understanding of someone "who's been there." He provides education about normal reactions to trauma and how to identify dysfunction. The peer tells Michael where to go for help and reminds him that it is normal to seek help in times of need. Envision that this peer support person calls Michael after his discharge from the hospital to provide to remind him of any follow-up appointments. Michael still has not obtained health insurance and states this is keeping him from engaging in follow-up care. The peer support provides Michael a referral to patient advocate who can help him obtain Medicaid. The peer support then visits Michael in his home several months post-discharge from the hospital and facilitates Michael's family's engagement in his recovery plan.

This peer model has been successfully applied to survivors of trauma—for example, the Trauma Recovery and Empowerment Model (TREM) utilizes groups to target shame and loneliness in female survivors of trauma (Fallot & Harris, 2002). The Canadian military also developed a model in which Peer Support Coordinators provide individual as well as group support (Heber et al., 2006). Finally, patients with TBI in a peer support program reported enhanced knowledge of TBI and better overall quality of life (Hibbard et al., 2002). Peer support has an enormous potential to contribute to treatment engagement post-trauma.

Level 3: Critical Incident Stress Debriefing and Psychological First Aid

Behavioral health first aid, such as Critical Incident Stress Debriefing (CISD) and Psychological First Aid (PFA), are structured models of peer support aimed at enhancing knowledge to promote treatment engagement (Corrigan et al., 2014). CISD consists of a supportive and focused discussion of a traumatic event (Mitchell, n.d.). Evidence regarding this approach has been mixed. CISD has been shown to exacerbate risk of dysfunction following trauma in a civilian population (Roberts, Kitchiner, Kenardy, & Bisson, 2009). This is thought to be due to discussion of heterogeneous traumatic events during sessions of CISD. There is some evidence to support use of CISD in the military due to the fact that the intervention is usually delivered in groups that have experienced the same traumatic event (Adler, Bliese, McGurk, Hoge, & Castro, 2009). PFA is another form of first aid and is fundamentally different than CISD. This approach delivers information, peer support, and instrumental support to trauma survivors (Varker & Devilly, 2012). PFA is a popular programmatic response to trauma which can be implemented on a large scale. This method is promoted by both the World Health Organization and the Department of Veterans Affairs (World Health Organization, 2011; U.S. Department of Veterans Affairs, 2016). However, several important reviews note that a lack of empirical evidence makes it impossible to ascertain whether or not this intervention is effective (Bisson & Lewis, 2009; Dieltjens, Moonens, Van Praet, De Buck, & Vandekerckhove, 2014). That is not to say that PFA is ineffective, but rather there is insufficient evidence to conclude effectiveness. CISD and PFA are possible avenues by which to promote population-based treatment engagement after traumatic experiences.

Level 4: Integrated Care

Integrating behavioral health services into primary care is a feasible strategy by which to better engage those in need of services (World Health Organization, 2008). Overall health outcomes are enhanced and the stigma associated with behavioral health care is reduced (Zeiss & Karlin, 2008). Application of integrated care to

achieve enhanced treatment engagement amongst trauma survivors may occur in both inpatient and outpatient settings.

Inpatient primary care settings offer an unparalleled context for treatment engagement. Trauma survivors are primarily hospitalized for physical injury and these patients represent a wide spectrum of precipitating traumatic events. Patients may have suffered interpersonal violence such as a gunshot wound, sexual and or physical assault, a motor vehicle accident, or a traumatic fall, to name a few. These hospitalizations provide an opportunity to screen for risk of prolonged trauma-related disability, provide preventative psychoeducation and brief intervention, and possibly positively impact dysfunction during hospitalization (i.e., nightmares, difficulty in communicating with the treatment team, etc.).

Again consider the example of Michael. Visualize the peer support person visiting him in the hospital under the guidance of a health psychologist. The health psychologist conducts assessment, delivers the educational content to the peer support, and also visits with Michael to answer questions he might have, in addition to teaching distress management skills. This psychologist is integrated into the trauma service primary care team and alerts the providers, per screening, Michael has compromised health literacy. She recommends Michael be provided health information at a junior high level of understanding. The health psychologist also asks that the medical team remind Michael to use distress management skills during difficult and or painful aspects of his treatment, such as removal of chest tubes. Michael implements these skills and is effective at managing the stress he experiences in the hospital. He avoids respiratory distress and subsequent intubation, in addition to avoidance of benzodiazepines to manage his emotions.

The care trajectory described in this example is a relatively novel perspective of treatment engagement and empirical support is in its infancy. An exposure-based brief intervention delivered to survivors of trauma in the emergency room was found to be feasible and effective at reducing posttraumatic maladjustment (Rothbaum et al., 2012). Next, Zatzick et al. (2014) found a brief motivational interviewing intervention to be successful in moderately reducing alcohol use in survivors of traumatic injury in an inpatient setting. Finally, a collaborative cognitive behavioral treatment implemented by a psychologist on an inpatient trauma service was shown to reduce dysfunction 1 year post-hospitalization (Peris et al., 2011). Although this literature suggests inpatient integrated care for trauma is effective further empirical work is necessary.

Integrating trauma-informed care into primary care outpatient settings is perhaps less unique than the aforementioned hospital-based integration. In fact, SAMHSA and HRSA recommend screening for traumatic experiences, PTSD, substance use, and depression during all outpatient primary visits (please visit www.integration.samhsa.gov/clinical-practice/screening-tools#TRAUMA for an excellent screening measure resource; SAMHSA-HRSA SAMHSA-HRSA Integrated Health Solutions, 2016). Individuals may then receive a brief intervention (i.e., motivational interviewing for substance abuse) and or be referred to specialty behavioral health.

Consider the scenario in which Michael remains engaged with his physical rehabilitation care. He feels lonely at times and often finds himself thinking of the moment

he was shot, despite his best efforts to ignore these memories. However, Michael elects to manage these problems on his own. He goes to his primary care physician (PCP) for an annual health maintenance visit 7 months after his initial injury. Upon screening, Michael's PCP notes that he endorsed moderate symptoms of depression. His PCP discusses his depression symptoms with Michael and a behavioral health consultant meets with Michael during this visit. This professional coaches him on the importance of behavioral activation and refers Michael to outpatient behavioral health. Michael's example illustrates the potential impact integrated trauma-informed outpatient services this care delivery model is now a national standard.

Discussion

We will all likely experience a potentially traumatic event during our lifetime. Most of us will be able to manage the initial associated distress. However, approximately 30–50% of survivors will endure disability 1 year post-trauma. This is simply an unacceptable level of suffering and his burden is disproportionately shouldered by marginalized populations. Underserved groups are more likely to be traumatized and barriers such as lack of financial resources and compromised health literacy restrict their ability to properly engage in services after trauma.

The entire system of care must change in order to address the problem of post-traumatic unmet need. The example of Michael is illustrative. Treatment as usual without a doubt leaves Michael ill-prepared to successfully manage the aftermath of trauma. He is a member of a vulnerable population with low health literacy and no insurance. Michael is naïve to common emotional reactions to trauma and does not know whom to turn to in the case of maladjustment. Michael is treated in the hospital but is sent home with little understanding of his goals of care. He has no transportation to follow-up medical appointments and is lost to follow-up. Michael becomes known in the local emergency room for frequent presentations related to pain. In the alternative version of Michael's story, he is given the necessary resources to support his recovery at *every step of the way*. Even when Michael struggles (i.e., does not seek behavioral health care in the context maladjustment) the system is there to catch him (e.g., outpatient primary care screening and referral to treatment). This level of systemic change will transform the magnitude of disability we now associate with traumatic events.

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Chapter 14

Engagement of Patients in the Self-Management of Pain

Akiko Okifuji and Dennis C. Turk

Chronic Pain and Its Impacts

Chronic pain is a prevalent physical condition that presents serious public health concerns (Institute of Medicine, 2011). A large multinational study (Tsang et al., 2008) found that chronic pain is present in about 40% of adults. Similarly, a recent large scale analyses of the US adults reports that 47% of American adults report persistent pain (Brown, 2012). Furthermore, the prevalence of chronic pain appears to be on a rise. For example, chronic low back pain has increased by 64% between 2000 and 2007 (Smith, Davis, Stano, & Whedon, 2013). It is further expected to grow as the population ages; with more than 50% of respondents in a large population-based sample of Medicare beneficiaries reported “bothersome” pain (Patel et al., 2014).

The adverse impact of chronic pain is pervasive. Chronic pain disturbs sleep (Onen, Onen, Courpron, & Dubray, 2005) and can compromise physical ability to function (Duque, Parra, & Duvallet, 2011; Latorre-Roman, Santos-Campos, Heredia-Jimenez, Delgado-Fernandez, & Soto-Hermoso, 2014), and affects emotional health (Fishbain et al., 2015; Gerrits et al., 2014), frequently leading to diminished enjoyable life activities (Gatchel & Schultz, 2014), and reduced life expectancy (Andersson, 2009; McBeth et al., 2009; Torrance, Elliott, Lee, & Smith, 2010). But chronic pain does not only impact on patients themselves but their significant others by its effect on social and family relationships causing significant emotional distress

A. Okifuji, Ph.D.

Pain Research & Management Center, Department of Anesthesiology, University of Utah,
615 Arapeen Drive, Suite 200, Salt Lake City, UT 84108, USA
e-mail: Akiko.Okifuji@hsc.utah.edu

D.C. Turk, Ph.D. (✉)

Department of Anesthesiology and Pain Medicine, University of Washington
School of Medicine, Box 356540, Seattle, WA 98195-6540, USA
e-mail: turkdc@uw.edu

in these supporters and caregivers (Ojeda et al., 2014; Schwartz, Slater, Birchler, & Atkinson, 1991).

Chronic pain is costly to the society not only due to health care expenditures and disability compensation but also related to loss of productivity and subsequent tax loss. The Institute of Medicine (Institute of Medicine, 2011) estimates that chronic pain, costs the nation up to \$635 million annually.

Chronic Pain as a Multifactorial, Biopsychosocial Phenomenon

Historically, pain is assumed to directly reflect tissue damage; that is, the presence and extent of pain should be highly correlated with and explained by the degree of identifiable pathology. When pain cannot be adequately explained by tissue damage, the pain is often considered as “functional” or “psychological,” with the nuances that the pain is a result of either deliberate malingering, drug-seeking, achievement of secondary gains (e.g., attention, avoidance of undesirable activities and responsibilities), or unconscious expression of psychological illness. However, with the advancement of imaging technology, it became abundantly clear that radiographically observed pathology does not necessarily correlate with pain complaints (e.g., Baranto, Hellstrom, Cederlund, Nyman, & Sward, 2009; Blankenbaker et al., 2008; Borenstein et al., 2001; Carragee, Alamin, Miller, & Carragee, 2005; Dunn et al., 2014; Jarvik et al., 2005; Link et al., 2003). In contrast, research has repeatedly demonstrated the significant role of the cognitive, behavioral, affective, and contextual factors in the development and maintenance of chronic pain (Flor & Turk, 2011; Okifuji & Turk, 2012). This has led the field to widen its view on pain as a complex biopsychosocial phenomenon where neurophysiology reciprocally interacts with a range of psychological and social variables (Gatchel, Peng, Peters, Fuchs, & Turk, 2007).

Treatment of Patients with Chronic Pain

There are a wide range of treatment options available for chronic pain. It may involve a single modality focusing on medication management, intervention (surgery, nerve block), exercise, and complimentary therapy (e.g., massage, yoga). Although a single modality may effectively reduce pain in a minority of chronic pain patients they rarely completely eliminate pain and many require more comprehensive approach that addresses the relevant biopsychosocial factors (Turk, Wilson, & Cahana, 2011). Such comprehensive approach typically assumes that (1) patients are autonomous and active participants to their own rehabilitation and (2) the ultimate benefit of the treatment comes from patients’ acquiring skills and concepts of

self-management to regulate their symptoms, stress, mood, and health-related quality of life. Such comprehensive approaches often require consolidated efforts by multiple clinicians with expertise in medicine, exercise, psychology, nursing, and pharmacy (Loeser & Turk, 2004). It has been repeatedly shown that although the comprehensive pain programs treat more complicated and treatment resistant patients, they are more cost-effective than unimodal medical management or intervention treatment (Gatchel & Okifuji, 2006; Kamper et al., 2014; Turk, 2002).

In contrast to traditional pharmacological and medical interventions, comprehensive biopsychosocial interventions emphasize self-management and involve skill-training and activation therapy. Since the primary focus of these programs is on rehabilitation rather than cure, they require active patient participation. In order for patients to enjoy the long-term benefit of such programs, they need to internalize what they learn, integrate it as a new habit in their daily lives, and continue their efforts at self-management for extended periods of time. However, failure to adhere with regimen and premature termination of rehabilitative treatments are common, and present significant barriers to successful treatment (Turk & Rudy, 1991). Unfortunately, research addressing adherence in chronic pain treatments is scarce. In the following section, we will review the available data on adherence with medical management, exercise, and multimodal approaches.

Adherence

Analgesic medications are one of the most commonly provided treatment approach for treating chronic pain (White, Arnold, Norvell, Ecker, & Fehlings, 2011) and has grown significantly in recent years (Vowles et al., 2015). Nonadherence with opioid analgesics, in particular, is a serious concern because this class of drugs can produce significant adverse physical effects as well as the potential for misuse and abuse which appear to be prevalent (e.g., Chou, Fanciullo, Fine, Passik, & Portenoy, 2009; Hojsted, Ekholm, Kurita, Juel, & Shogren, 2013; Vowles et al., 2015).

Recent reports show that self-reported adherence with medication regimen in chronic pain is disappointingly low, about 38–52% (Broekmans, Dobbels, Milisen, Morlion, & Vanderschueren, 2010a, 2010b). In the elderly for whom polypharmacy tends to be more common due to the presence of a number of medical diagnoses, non-adherence can be as high as 75% (Salzman, 1995). Rosser, McCracken, Velleman, Boichat, and Eccleston (2011) found that although 76% of their patients with chronic pain reported to yes to the question “do you take your medication exactly as prescribed?” the patients admitted that nonadherence was greater in response to more specific questions; for example, 52% reported that they “sometimes miss doses” and 30% reported that they “sometimes take an extra dose.” Moreover, when addressing the question of what might be underlying the nonadherence; their results suggest that the actual pain level may not direct the under- or overuse of medications, but rather, it was associated with certain beliefs about with-

drawal (underuse) and about need for further analgesics (overuse). Of course, we should not be surprised by the high prevalence of non-adherence by chronic pain patients. Non-adherence is high for treatments of most medical problems as lifestyle modification programs (Meichenbaum & Turk, 1987).

For comprehensive, rehabilitation programs, adherence rates may vary greatly depending upon the type, intensity and complexity of the treatment demands. Typically, the greater the efforts expected from patients, the poorer the patient adherence. In an early study, Lutz, Silbret, and Olshan (1983) found that at 8-month follow-up fewer than 13% of patients successfully treated in a rehabilitation program indicated on mailed questionnaires that they continue to practice all of the recommended self-management behaviors prescribed (e.g., relaxation, activity pain, exercise). A more recent report found self-reported adherence report suggests that although patients are fairly adherent to taking new medications and returning to the clinic for follow-up visits (93–99%), others including discontinuing medications, physical therapy, and home programs generally yielded much poorer adherence rates (39–48%) (Robinson et al., 2004). A regimen that requires patients to exert effort and spend time tends not to fare well. For example, minutes engaged in aerobic and stretching exercise decline linearly with time following the treatment (Dobkin, Abrahamowicz, Fitzcharles, Dritsa, & da Costa, 2005).

Similarly, attrition rates in clinical trials examining the efficacy of exercise and/or multimodal pain treatment tend to be high. Reviews on the effect of exercise programs (by itself as well as in combination with other modality) (Busch, Schachter, Overend, Peloso, & Barber, 2008; Jones, Adams, Winters-Stone, & Burckhardt, 2006) suggest a wide range of attrition rates, from 0% to 67%, with the average rate of 20–27%. A systematic review of the mindfulness- and acceptance based intervention, focusing on stress reduction and acceptance commitment therapy for chronic pain patients show a wide range of attrition rates, from 0% to 49% (Veehof, Oskam, Schreurs, & Bohlmeijer, 2011). Of course, we should not be surprised by the high prevalence of non-adherence by chronic pain patients. Non-adherence is high for treatments of most medical problems as lifestyle modification programs (Meichenbaum & Turk, 1987).

Adherence clearly has an impact on treatment outcomes. Poor adherence may lead to minimize the clinical benefit and increase the chance of relapse (Turk & Rudy, 1991). On the other hand, good adherence may have benefit enhancing effects for the treatment. For example, a study following the 2435 patients undergoing multimodal therapy (Curran, Williams, & Potts, 2009) showed that multi-aspects of adherence to exercise, behavioral, and cognitive treatment skill training appeared to have small, but significant contributing factors for greater sense of well-being at 1-month follow-up; however, the relationship was greatly enhanced when adherence was combined with treatment outcomes at the post-treatment. A recent study evaluating the effects of the structural, multimodal day program in over 550 patients (Nicholas et al., 2012) demonstrated the incremental benefit of adherence for improving pain, disability, and mood.

Approaches to Enhance Patients' Engagement in Treatment

Given the serious impact of chronic pain on overall quality of life, one may assume that all treatment-seeking patients should have strong motivation and intention to commit to treatment. Poor adherence that is commonly seen in chronic pain treatments might appear to be contradictory. It is often assumed that having a strong intention leads to successful execution of the behavior (goal attainment) (Ajzen, 1991). Intention to perform a behavior is the decision to act in a particular way and an indication of how much effort people are willing to exert to perform the behavior. Intention is typically expressed: "I intend to do X." However, having a good intention on its own often fails to produce successful goal attainment. The degree to which strength of intention leads to successful goal attainment is quite modest: it typically explains 20–35% of the variance in goal achievement (Gollwitzer & Sheeran, 2006). The common wisdom of the past behaviors predicting the future goal attainment is similarly modest, about 26% (Sutton & Sheeran, 2003). The failure to attain a goal is usually not due solely to the lack of strong intention but failure to act on it (Sheeran, 2002). Variables other than the strength of goal intention affect the intensity of goal striving behaviors and attainment. A longitudinal study (Reuter, Ziegelmann, Lippke, & Schwarzer, 2009) following individuals undergoing orthopedic rehabilitation, for instance, showed that intention to engage in physical regimen shows a slight decline in the first 6 months but stays constant afterwards, whereas actual behavioral engagement shows initial increase followed by a decrease after 6 months. Thus, when significant behavioral change and maintenance is the goal (e.g., exercise), we need to consider factors that may strengthen the relationship between the intention and goal attainment.

What may be the potential factors weakening the relationship between intention to engage in treatment and goal of actually engaging in therapeutic behaviors? There are several studies trying to delineate factors contributing to poor adherence or attrition. As was the case with adherence with medical management regimen, patients' thinking patterns seem to be an important factor in achieving high level of adherence with self-management. In particular, a sense of self-efficacy, a personal conviction that the person can effectively do something to produce a desired outcome in a given context, appears to contribute to the person's ability to maintain efforts to acquire such self-management skills (Thompson, Broadbent, Bertino, & Staiger, 2015). Similarly, predictors for long-term exercise adherence appear to include belief about the health benefit of the regimen (Burton, Shapiro, & German, 1999), self-efficacy belief to continue the regimen (Litt, Kleppinger, & Judge, 2002), and in-treatment efforts (Dobkin et al., 2005). Interestingly, symptom severity of chronic pain at the pretreatment per se seems to have very little to do with how patients adhere or stay on with the treatment. Analyses of the dropouts in a trial evaluating the cognitive-behavioral treatment (CBT) for chronic pain (Glombiewski, Hartwich-Tersek, & Rief, 2010) revealed that contributing factors of attrition were not related to pretreatment pain level or disability factors, but rather, those with high level of psychological distress tended to drop out. Pain response to treatment (i.e., exercise) however

may influence adherence. A number of studies suggest that symptom flare in response to exercise leads to nonadherence (e.g., Richards & Scott, 2002; Schachter, Busch, Peloso, & Sheppard, 2003; van Santen et al., 2002).

There are other barriers that may contribute to nonadherence with physical regimen. According to the CDC report (Centers for Disease Control and Prevention, 2011), the most commonly reported barriers to physical activity include perceived lack of time, fear of injury, limited or unfamiliarity with resources, lack of motivation, lack of enjoyment with exercise, low self-efficacy for exercising, and lack of support. For people with chronic pain, additional pain-related factors such as fear of pain exacerbation and perceived physical limitation may need to be considered (Bair et al., 2009; Vlaeyen & Linton, 2000). Incorporation of treatment approaches that address these factors that seem to lead to compromise patient adherence are needed to improve patients' engagement in therapies and improve outcomes of chronic pain treatments. We will now review three types of approach that can improve treatment engagement of chronic pain patients: Education, Implementation Intensions, and Motivation Enhancement Therapy (MET).

Education

Active participation in treatment process required in chronic pain rehabilitation is quite different from the general medical care, where patients tend to be a passive recipient of treatment. Thus, it is perhaps not surprising that some patients hold an expectation that treatment should consist of something being *done to them* by clinicians, rather than *their taking initiative* to acquire skills and actively engage in the therapeutic process. This paradigm shift is critical in fostering patients' willingness to commit and actively engage in the treatment program. Such chronic pain education includes a range of materials but it generally targets (1) pain and related symptoms are not something to be cured but to be managed, (2) "hurt" is not the same thing as "harm" (i.e., tissue damage), and (3) self-management approach is effective. Clinicians can present research findings in layman's terms to help patients understand how chronic pain differs from acute pain. In particular, many patients (the lay public, and many health care providers as well) believe that pain reflects the presence and progression of physiological damage. It may be particularly helpful for patients to learn that pain severity and degree of structural damage are not necessarily correlated (Baranto et al., 2009; Blankenbaker et al., 2008; Borenstein et al., 2001; Carragee et al., 2005; Dunn et al., 2014; Jarvik et al., 2005; Link et al., 2003). Establishing appropriate expectations and goals provided through information serves as a foundation of successful pain rehabilitation. Some examples of educational materials for chronic pain patients are listed in Table 14.1.

Research evaluating the effect of patient education for improving treatment engagement by chronic pain patients is limited, because education is typically a part of the more comprehensive rehabilitation program. However, available evidence is encouraging for education helping adherence in chronic pain patients. For example,

Table 14.1 Educational components

• Concept of chronic pain
– What is chronic pain?
– How is chronic pain different from acute pain?
– “Gate control model”: Pain isn’t just one thing!
– Hurt vs. Harm
– Common myths about chronic pain
• Treatment options for chronic pain
– Medications
– Procedures
– Information
– Exercise
– Coping skill training
– Rationales for multimodal approaches
– How effective are they?
– Can we “cure” chronic pain?
• Strategies to cope
– “but I hurt too much” what to do?
– Pain vs Suffering
– Habit change
Goals
What to expect

an education program that aimed to help patients understand their pain condition and “demedicalize” their pain has been found to reduce pain-related fear and catastrophizing tendency (de Jong et al., 2005). When patients with neck and low back pain received information regarding nonpharmacologic information, they showed greater adherence with physical regimen (Escolar-Reina et al., 2009). Setting expectations and goals prior to starting exercise program for low back pain patients also appears to promote adherence with the regimen (Coppack, Kristensen, & Karageorghis, 2012). Further studies are needed to delineate the effects of provider-patient collaboration in setting expectation of active engagement on treatment adherence.

Volitional Approach: Implementation Intentions (IIS)

The idea of implementation intentions (IIS) aims to address how to fill the gap between peoples’ intentions and goal attainment, that is, the imperfect relationship between intentions to perform a certain behavior and actual behavioral engagement (Gollwitzer, 1993). The gist of IIS is that successful goal achievement is facilitated

by a second act of willing that furnishes the goal intention with an if-then plan specifying when, where, and how the person will instigate a response that promotes goal realization. Stated in another way, IIS involves action plans with practical “if-then” contingencies that spell out in advance how one may strive for attaining the behavioral goal. Thus, IIS encompasses a process of identifying potential barriers and situations and planning potential responses via resource findings and problem solving (Gollwitzer & Sheeran, 2006).

Implementation intentions are not the same as goal intention; goal intention is the focal point of the pre-decisional phase (e.g., “I want to do physical exercise”), whereas implementation intentions refer to the action and the post-decisional phase (Gollwitzer, 1993). IIS typically involves two types of planning: action and coping (Belanger-Gravel, Godin, & Amireault, 2013). Action planning involves determining when, where, and how to do the target behavior, and coping planning offers a series of problem-solving exercises that work by teaching common barriers, identifying potential barriers to maintain the physical activity, and then explore options to overcome them. As noted earlier, common barriers that lead to poor engagement in becoming more active include (Centers for Disease Control and Prevention, 2011) (1) beliefs that there is not sufficient time, (2) pain flares up after exercising, (3) family/friends are viewed as not understanding or are not supportive, (4) exercise is boring, and (5) no resources are available to perform exercise. IIS can utilize the problem-solving strategies or skill trainings that are commonly provided in the CBT aspect of the rehabilitation.

As a first step, patients can learn a general strategy pattern of problem-solving (Nezu & Perri, 1989) by addressing some simple example problems. In this exercise, patients are asked to specify and clarify specific problems. For each problem, patients are asked to generate as many potential options as they can, no matter how implausible or ridiculously impossible they may seem. Then the patient in collaboration with the therapist can systematically evaluate the feasibility and potential consequence of each approach. Based upon the evaluation, the patient rank orders the options and is encouraged to start trying one at the time from the highest ranked solution.

Similarly specific behavioral skill training may help address barriers. For example, self-management skill training for pain flare-ups, communication, and social skills training, and stress management are commonly provided as a part of the multimodal pain rehabilitation (Okifuji & Turk, 2013). IIS can take advantage of such skill training by helping patients to apply them to specific barriers by adding the skills to develop various if-then scenarios, using the problem-solving approach, and developing action plans.

Knowing available resources and feeling comfortable using them also may aid expanding patients’ ability to engage in activation. Therapist and patient can work together to identify what resources are available and accessible for the patient. Then, various if-then situations can be applied to help the patient develop action plans; for example, patients may develop a plan for going to a certain indoor facility to walk when it is snowing, or ways to combining chores and walking to save time.

Table 14.2 Examples of IIS Outlines for specific barriers to activation therapy

Barriers	Outline
Time Management	<ul style="list-style-type: none"> • Clarifying values of exercise • If-then problem solving and action plans <ul style="list-style-type: none"> – If there is not enough time to exercise because... – Apply problem solving – Develop action plans • Combating procrastination <ul style="list-style-type: none"> – How procrastination happen – Apply problem solving – Develop action plans
Flare-ups	<ul style="list-style-type: none"> • Flare-up Management <ul style="list-style-type: none"> – What can we do – Skill training for flare-up management – If-then exercise – Develop action plans
Support from others	<ul style="list-style-type: none"> • Interpersonal Effectiveness <ul style="list-style-type: none"> – Effective communication training – Interpersonal effectiveness to improve relation with others – If-then exercise – Develop action plans
Resource management	<ul style="list-style-type: none"> • Available Resources <ul style="list-style-type: none"> – What are available within 10 min from home Parks, Recreation centers, Shopping area, Trails • Things that make difficult to stick with regimen <ul style="list-style-type: none"> – Weather, Pain, Stress, Time, Low motivation – If-then exercise • Develop action plans using available resources

Each person likely has unique barriers to his or her situation. Those unique barriers also need to be identified and addressed in advance, anticipating the most likely difficulties they will encounter in trying to implement planned behavior. Clinicians should work collaboratively with patients to explore emotional, cognitive, and physical cues that are associated with barriers. Examples of IIS outlines are described in Table 14.2.

IIS: Outcomes

The IIS approach has been used to promote the patient engagement to achieve better management in various health-relevant behaviors including eating habits (Adriaanse, Vinkers, De Ridder, Hox, & De Wit, 2011), addictive behaviors (Webb, Sniehotta, & Michie, 2010), smoking (Armitage, 2008), cancer screening behaviors (Browne & Chan, 2012), vaccination (Milkman, Beshears, Choi, Laibson, & Madrian, 2011), and dental flossing (Schuz, Wiedemann, Mallach, & Scholz, 2009). A meta-analysis of 94 studies (Gollwitzer & Sheeran, 2006) found that implementation intention formation had a medium-to-large effect on goal attainment ($d = .65$). IIS have also

been incorporated in a number of trials aiming to activate people with or without health concerns. IIS has been shown to be effective for improving physical activity levels in healthy young adults (Prestwich, Perugini, & Hurling, 2010), sedentary women (Arbour & Martin Ginis, 2009), obese elderly people (Belanger-Gravel, Godin, Bilodeau, & Poirier, 2013), cardiac patients (Sniehotta, Scholz, & Schwarzer, 2006), and diabetic patients (Thoolen, de Ridder, Bensing, Gorter, & Rutten, 2009). The meta-analytic review of the implementation intentions on physical activity from 24 studies shows encouraging results with a pooled effect of .31 at post treatment and .24 for follow-up visit with a higher effects shown with a program involving specific barrier management (Belanger-Gravel, Godin & Amireault, 2013).

An interesting question is then, what is it about planning that helps patients to actively engage in therapeutic effort? The studies investigating this question, in regard to physical activity, consistently suggest that improved self-efficacy for the target behavior is one of the most critical factors (Barg et al., 2012; Darker, French, Eves, & Sniehotta, 2010; Fleig, Pomp, Schwarzer, & Lippke, 2013; Koring et al., 2012; Lippke, Wiedemann, Ziegelmann, Reuter, & Schwarzer, 2009). Additionally, IIS also seems to aid in making the target behaviors more habitual (Verplanken & Faes, 1999). When behaviors are newly adopted, it requires active monitoring and regulation; if a behavior is performed frequently, then its execution becomes less resource intensive (Verplanken & Melkevikb, 2008). Being able to problem-solve barriers seems to increase the habit strength, thereby enabling people engage in the target behaviors more frequently. Although there is no study yet to show the effectiveness of the IIS approach for chronic pain patients, the available evidence strongly suggests that the approach should be beneficial for improving their ability to actively engage in the treatment and maintain their effort to perform self-management skills and is worth systematic investigation.

Motivation Enhancement Treatment

Motivation Enhancement Therapy (MET) is a therapeutic method that targets patients' motivation, originally developed by William Miller and his colleagues (Miller, 1983) for treating people with problem drinking to enhance their motivation to change their problem behaviors. MET is a problem-focused, therapist-directed approach aiming to help patients enhance their commitment and motivation for treatment. MET offers a collection of therapeutic techniques to help patients (1) clearly recognize their problems, (2) perform a personal cost-benefit analysis of their therapeutic or counter-therapeutic behaviors, (3) develop consistency between their therapy goals and motivation, and (4) internalize motivational thoughts via improved self-efficacy. Indeed, that self-efficacy beliefs play an important role in motivation is not new. Over 30 years ago, Bandura and Cervone (1983) demonstrated that greater self-efficacy led to greater efforts for goal attainment. The improvement in self-efficacy for the target behaviors appears to play a key role in

promoting behavioral change via MET (Chariyeva et al., 2013; Walpole, Dettmer, Morrongiello, McCrindle, & Hamilton, 2013).

A major goal of MET is to help patients attain a self-driven motivation to commit and engage in treatment. The primary steps of the MET include (1) clarification of problems and goals, (2) understanding of the pro vs con balance in their choices, and (3) development and internalization of self-motivational statement. These steps will be provided in the supportive and empathetic therapeutic environment. MET is broadly grounded in the Rogerian tradition of psychotherapy (i.e., empathy, reflection, therapist unconditional positive regard) in conjunction with behavioral analyses. It is inherently patient-centered, requiring clinicians to maintain nonjudgmental, nonconfrontational demeanor. Clinicians create the empathetic therapeutic environment where patients feel that they are heard and understood. It is important to define empathy here, as empathy is sometimes misunderstood as having to agree at all cost. Empathy should be expressed as understanding and acceptance without any influence of clinicians' own view on the matter. Empathetic listening, one of the most important approaches for MET, is achieved with reflective comments to patients' thoughts and feelings, even if they reflect maladaptive behaviors and cognitions. Value judgment by clinicians often leads to defensive responses from patients who may discount the importance of their problems. When patients cannot appreciate the need to do something about their problems, it is impossible to motivate them to engage in necessary treatment process. It is worth considering each of the MET steps and expand our discussion of approaches to create a productive therapeutic environment.

Step 1. Recognition of problems and clarification of goals: Patients' expectations for pain treatment vary greatly. Some people may have unreasonable expectation, for example, to have a complete resolution of pain that they have lived with for decades. Some hope to manage pain reasonably so they can do things they have not been able to, or participate in life activities they would like to. Some are not sure what to expect. Although expectations may differ from person to person, most people commonly have very little idea of what should happen to fulfill their expectation. Thus, in this step, clinicians guide patients to understand their current status and what they expect to achieve via treatment. Such directed questions can help them see the discrepancy between how they are now and what they want. For example, a patient may want to feel better by becoming more able to do housework, whereas he spends most of his day reclining and resting because he is afraid of making his pain worse. Realizing that there is a gap helps patients start thinking what they need to do to achieve what they want. Furthermore, it provides an opportunity to develop a specific plan. It is not uncommon to see patients, after years of deactivated lifestyle and disability, feel helpless and not know what they can do. Clarification of expectation and goals help explore options as to what can possibly be done.

It is important to note that open-ended questions are much more effective in highlighting the individualized phenomenology of chronic pain and their goals. Although open-ended questions are more time consuming than pointed yes/no questions, the former tend to help patients to have deeper understanding of the issues at hand. Examples of questions to address problems and goals are listed in Table 14.3.

Table 14.3 Example questions to help patients identify problems and goals

Problems
• How is your life now different from your life you had before your pain began?
• How is your pain impacting your ability to do things you want and enjoy life?
• What do you miss most about your life before the pain began?
• What change would you like to see most?
Goals
• What are you doing now that may help you make things better for you?
• What do you think you or others could do to help your goals come true?
• What change would you like to see most?
• What would your life look like if your pain is managed better?

Step 2. Decisional Balance: Understanding the need for behavioral change does not necessarily lead to the willingness to commit oneself to do the necessary things. It is particularly difficult for patients with chronic pain facing the multimodal, interdisciplinary rehabilitation. Activating rehabilitation requires acquisition of various pain management skills that needs to be practiced daily. This further requires modification of lifestyles and habits; it takes a lot of time and effort; despite an onerous “investment,” improvement is typically slow and gradual. Thus, a sense of frustration that treatment requires the upfront “cost” with very little immediate return is common and can reduce the initial excitement that patients may have had for the treatment. The decisional balance is an exercise in which patients explore “all sides of the story” by developing a personal “balance sheet” comparing both advantages and disadvantage of committing to therapy as well as not committing. Each therapeutic activity has both pros and cons; for example, activating exercise can help one become stronger, toner, and fitter, although it takes time and effort and may make one feel sore afterwards. So there are both pros and cons of committing to exercise. How about not doing exercise? The advantages of not doing exercise would include being able to rest more, not having to take time, and not having to worry about a flare-up in response to exercise. They may also identify some “cons” of not doing exercise, such as not gaining health benefit and maintain body weakness (see Table 14.4 for more comprehensive example). The decisional balance can be extended for a range of life domains that are affected by chronic pain and benefit from change. By clarifying the pros and cons of their own therapeutic efforts vs not putting efforts can help diminish the sense of ambivalence about their commitment. Furthermore, understanding the “cons” aspect, can help the clinician to identify their particular needs and weakness and see what areas of coping and other supportive care may be necessary to help patients achieve their goals.

Table 14.4 Decisional balance

Not trying to become active (status quo)		Trying to stay active (treatment engagement)	
Good things	Not so good things	Good things	Not so good things
<ul style="list-style-type: none"> • I won't get tired or sore • I don't have to spend time 	<ul style="list-style-type: none"> • I don't feel that good anyway even if I don't exercise • I may get even more deconditioned • I will have greater chance of staying disabled • Can't participate in social things • More depression • May gain weight • Will never be able to go back to work 	<ul style="list-style-type: none"> • I will gain physical strength • The stronger I get, the more I can do things with friends and family • I feel better about myself • I feel more independent • I may become less disabled and less burden on family • I may be able to lose weight • Eventually, it will help my pain 	<ul style="list-style-type: none"> • Pain may get worse right after • I may feel time pressure

Step 3. Eliciting Self-Motivational Statements: Self-motivational statements are statements prompted from patient, helping them reflect on their intention to commit to action. They act as a consistent match between their predetermined goals and their motivation to engage in needed tasks to achieve the goals. Developing this consistent pattern can be a big challenge particularly for chronic pain patients whose dysfunctional cognitive and behavioral styles have become habitual as their standard mode due to the chronicity of the problem. For those people, it is important that therapy guide them first to start seeing the connection between engaging in treatment and therapeutic benefit. For example, a question like “What will make engaging in exercise easier for you?” “What do you think would work for you if you decide to try the therapy?” may serve as the beginning point. Additionally, therapists can direct patients’ attention to the past achievement in successfully committing themselves to engage in something—by asking them “What was it like when you tried?” “What do you remember when you were able to?”

Negative thinking is common in chronic pain patients who may devalue the importance of their past accomplishment. Playing up the value of past success with positive reinforcement can be a powerful tool to foster self-efficacy for greater engagement in self-management of pain. Similarly, it is important that any statement relevant to the self-motivational framework, however trivial it may be, is recognized and reinforced. Questions to elaborate further such as “How were you able to do that?” “How did you overcome...?” can be asked to provide the basis of reinforcing the past success whereas questions such as “How do you think you could start trying...?” “How do you think you can enjoy this commitment?” can further clarify the motivational statement. It is also important to remember that clinician’s encouraging responses can significantly impact patient’s motivation.

Simple comments such as “I think it’s a wonderful idea,” “I see how important this is to you,” and “You have a point there,” can help the process of eliciting self-motivational statements conclude in a positive and productive manner.

Developing and Maintaining Productive Therapeutic Environment for MET

As we discussed above, supportive and empathetic environment is critical to succeed in MET. However, such environment should not be mistaken as a synonymous to blindly supporting patients’ wishes and beliefs. Rather, such an environment should serve as a basis to help patient argue for engaging in therapeutic effort. It is unfortunately too common to see that clinicians argue for the importance of their committing in therapy whereas patients resist by presenting excuses or arguing why it should not work. Although well intended, arguing against patients for therapy rarely works. The critical stance of MET therapist is that he or she stands on the same side of the argument, thereby supporting patients’ motivation to get better.

To reiterate, engaging in the rehabilitative effort for chronic pain patients is not easy. It requires a lot of time commitment, conscious effort to change the way they appraise the pain and associated dysfunction, maintenance of exercise, and repeated practice to develop adaptive coping skills. Sometimes, the program may involve tapering of medications that patients relied on for many years, leading to increased anxiety. Thus it should not be surprising to see patients’ resistance to treatment. Such resistance may come in many forms. Examples of common forms of resistance are listed in Table 14.5.

Table 14.5 Examples of resistance presentation

Presentation	Examples
Arguing	Challenges the validity of information or therapist’s expertise “Every physical therapy I did made my pain worse, so it can’t possibly help. You are a psychologist, so you can’t really know if it works”
Denying	Denys or refuse to admit problems “I don’t know why you think I can’t relax. I lay down on a sofa and watch TV all day”
Minimizing	Minimizes the benefit of engaging treatment “I can now walk 15 minutes in the water but my pain is still awful and I can’t do anything”
Blaming	Blames others for the problem and does not acknowledge any responsibility for him/herself “My sister just stressed me out so bad that I felt totally sick. I couldn’t do anything for 3 days”
Disagreeing	Disagreeing with a treatment direction with “yes, but” response “Yes I know I should practice the skill, but it’s just so boring”

One of the hallmarks of MET is that a clinician does not fight resistance but rolls with it. There are several specific techniques that a clinician can employ to work with resistance.

Reflection

When using the reflection technique, clinicians express their acknowledgement of the patients' comments that reflects resistance in a nonconfrontational manner. The simplest way is to rephrase what the patient said in a way that assures the patient that she is heard and understood without any value judgment. For example, a patient may argue that she is too tired to do the home exercise program after coming home from work, the clinician may simply responds "It is hard for you to work out after a long day."

Alternatively, the clinician may use the exaggerated form of reflection by intensify the hardship of the comment to help her reevaluate her own statement. For example, the clinician may respond to the above comment, "I understand that you feel it is absolutely impossible to do the exercise after work." One must note a caution here; such amplification may, depending on how it is said, sound ridiculous or sarcastic criticism ("Geez, you really can't do it, can you?"). If the patient cannot feel the empathetic support from the clinician about her struggle, the amplified reflection will simply encourage further resistance and be counterproductive.

Another way to use the reflection technique is to present two sides of the difficulty raised. The assumption here is that the patient's statement represents the conflicting feeling that the patient has trouble engaging in treatment effort even though he or she really wants to get better. Double-sided reflection points to both of these underlying feelings with one ends of the reflection to support the motivational side. With the example above, the clinician may respond, "On one hand, you find it very difficult to do the exercise after work, and at the same time, it's frustrating because you really want to do it."

Clinician may also use the reflection technique and then add a little twist by reframing the patient's statement. Initial reflection is typically presented as an empathetic agreement, affirming that the patient is well heard. Then the clinician offers a reframed perspective on the same subject in a non-threatening manner. For example, the clinician may respond to the above statement: "You have a point there. It is really hard to work out after a long day. It's so frustrating for you not to be able to do the exercise, even though you want to find a way to do it and move forward with your program." This subtle change in the direction can help the patient move further towards change while maintaining the therapeutic relationship.

Such twist can be applied to defuse a focus on non-self-efficacious belief that is common in chronic pain patients. Often times, those patients feel helpless, overwhelmed, and demoralized by perceived demands made by the treatment program. When this happens, they tend to magnify the difficulties of treatment engagement

which become their sole focus when they think about their rehabilitation. Shifting focus can provide the opportunity to defuse such intense focus and start thinking more flexibly about options and being more resourceful and resilient in contrast to being passive, reactive, and helpless in the face of their symptoms and life circumstances. For example, the therapist may respond to the above statement, “I see that it has been very difficult for you. Pain and low energy really impact you there. Tell me more about things you wish to be able to do in your life.”

Emphasis on Personal Choice and Control

In addition to the supportive empathy, respecting personal choice and control for patients is critical in the MET approach. The literature suggests that patients resist therapy when they perceive a loss of, or a threat of losing, personal choice and control (Brehm & Brehm, 1981). Resistance further intensifies as the importance of the threatened freedom is greater, often leading patients to engage in something counteractive to sabotage the therapeutic effort. Needless to say, it is basically up to each patient whether or not he or she wants to take an advantage of therapeutic opportunity. However, it is not uncommon that well-meaning clinicians push the therapeutic agenda and demand their compliance. This approach unfortunately reinforces the passivity of the patient, rather than helping them actively engage in treatment effort. In MET, it is essential that the affirmation of personal choice and control be reminded throughout the course of treatment that it is ultimately their choice to follow through the treatment recommendation. For example:

Patient: All of you keep telling me to do the home program, even though I keep telling you it’s just too hard to do it after a long day at work.

Clinician: It is your choice, of course. It is your health after all. We can only make the recommendations and the rest is up to you.

Such interaction can help the patient understand that the choice is theirs; at the same time, it fosters a sense of responsibility for the patient to commit to the treatment regimen.

MET Outcomes

The accumulated evidence suggests that MET facilitates change to reduce a range of problem behaviors that are chronic and requires self-motivated engagement in treatment, such as smoking (Burris, Perez, Evans, & Carlson, 2013), problem drinking (Foxcroft, Coombes, Wood, Allen, & Almeida Santimano, 2014; Vasilaki, Hosier, & Cox, 2006), problem gambling (Grant, Donahue, Odlaug, & Kim, 2011), eating disorders (Weiss, Mills, Westra, & Carter, 2013), and high-risk sexual behaviors (Rongkavilit et al., 2014). MET has also been shown to help people with

various health conditions engage in greater physical activities for their health; the populations include those with heart failure (Brodie & Inoue, 2005), diabetes (Chlebowy et al., 2014), and spinal cord injury (Latimer-Cheung et al., 2013). A recent systematic review (O'Halloran et al., 2014) indicates that the MET approach results in significant improvement in physical activity levels in people with chronic health conditions, reflecting its effect on treatment engagement.

MET is often not a stand-alone treatment but an introduction and motivational facilitator for more intensive rehabilitative treatments. MET principles can be incorporated with more traditional rehabilitative programs. A number of studies have shown that when MET is incorporated into a multimodal rehabilitative program, patients tend to improve their pain and functional status, suggestive of improved treatment engagement (Ang et al., 2013; Tse, Vong, & Tang, 2013; Vong, Cheing, Chan, So, & Chan, 2011). Research specifically investigating adherence in chronic pain treatment is scarce at this time. However, the available evidence suggests that MET helps opioid adherence and reduce the risk of opioid misuse in elderly chronic pain patients (Chang, Compton, Almeter, & Fox, 2015). The results from two studies evaluating the benefit of combining MET with activation exercise therapy for low back pain (Friedrich, Gittler, Halberstadt, Cermak, & Heiller, 1998; Vong et al., 2011) also suggest that it improved exercise compliance and attendance to sessions. There are other trials ongoing that plan to specifically examine adherence with the regimen in various chronic pain conditions (Ang et al., 2011; Mertens, Goossens, Verbunt, Koke, & Smeets, 2013).

Conclusions

Chronic pain is a significant public health problem that adversely impacts millions of people and at huge societal costs. Chronic pain is a complex multifactorial phenomenon that often requires multimodal approach to address the biomedical, psychosocial, and physical domains that interact with one another. One of the critical requirements of such treatment is patients' active engagement in therapy. The paradigm shift from being passive recipients of treatment to active participants in their own self-management is a key for the treatment success; yet it is difficult to achieve. Adherence with treatment self-management regimens in chronic pain is generally poor.

As a means to improve treatment engagement for chronic pain patients, we reviewed education, IIS, and MET. The empirical evidence supporting those approaches in improving treatment engagement is quite promising but still at the preliminary stage. The field is still young and there are a many research needs to better understand the mechanisms underlying these approaches and the characteristics of patients who are most likely to benefit. Furthermore, future research needs to investigate how improving treatment engagement impacts overall clinical benefit. This line of research should help us ultimately develop the optimal clinical strategies to help patients manage their pain effectively.

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Chapter 15

Anxiety

Allison J. Ouimet and Andrea R. Ashbaugh

Anxiety disorders are characterized by fear or anxiety in excess of what most individuals would experience in the same situation, which leads to significant distress or impairment in functioning. With the introduction of the fifth edition of the Diagnostic and Statistical Manual (DSM; American Psychiatric Association, 2013) the following are currently classified as anxiety disorders: panic disorder, agoraphobia, social anxiety disorder, specific phobia, separation anxiety disorder, selective mutism, and generalized anxiety disorder (GAD). Previous iterations of the DSM also classified obsessive compulsive disorder (OCD) and posttraumatic stress disorder (PTSD) as anxiety disorders, though they are now each classified within their own separate sections. Given the prominent role of anxiety in both of these disorders, we will include them in our discussion.

Anxiety disorders can be chronic and debilitating and affect a significant proportion of the population. Epidemiological studies estimate the lifetime prevalence of all anxiety disorders combined to be between 18.8 and 28.8% (Kessler, Chiu, Demler, & Walters, 2005; Kessler et al., 2005). It is estimated that in the 1990s the annual cost of anxiety disorders was approximately \$42.3 billion, with about 85% of those costs attributed to non-psychiatric and psychiatric treatment costs (Greenberg et al., 1999). It has further been estimated that nearly 50% of the cost associated with lost productivity due to mental health problems is attributable to anxiety disorders (DuPont et al., 1996). Beyond the economic burden, anxiety disorders are associated with significant societal costs, including lower educational attainment and marital instability (Lepine, 2002).

A.J. Ouimet, Ph.D. (✉) • A.R. Ashbaugh, Ph.D.
School of Psychology, University of Ottawa, Vanier Hall, 136 Jean Jacques Lussier,
Ottawa, ON K1N 6N5, Canada
e-mail: Allison.Ouimet@uOttawa.ca; Andrea.Ashbaugh@uottawa.ca

Stepped-Care Treatment of Anxiety

According to several consensus panel recommendations, cognitive behavioral therapy (CBT) is a first-line treatment for anxiety disorders (e.g., Institute of Medicine, 2014; National Institute of Health and Clinical Excellence, 2011). Indeed, multiple reviews and meta-analyses have demonstrated its efficacy compared to wait-list, placebo, and in some cases alternative therapies in reducing anxiety and related symptoms (e.g., Butler, Chapman, Forman, & Beck, 2006; Tolin, 2010). CBT has been demonstrated to be at least as effective as pharmaceutical treatment, and substantially more cost-effective (e.g., Van Apeldoorn, Stant, van Hout, Mersch, & den Boer, 2014). Additionally, pharmacological treatment has demonstrated high potential for negative side effects, further supporting CBT for anxiety disorders as best practice (Hunsley, Elliott, & Therrien, 2013). Before discussing treatment engagement, we briefly review the evidence for the primary CBT modalities.

Self-Help

Overall, self-help CBT is more effective than wait-list or placebo in the treatment of anxiety disorders (with an advantage noted for computer-based modalities compared to book-based modalities), but less effective than face-to-face psychotherapy (Haug, Nordgreen, Öst, & Havik, 2012). Importantly, although computer- and/or Internet-assisted therapies appear to be efficacious, attrition rates are substantial, and increase as level of therapist contact decreases (e.g., Twomey et al., 2014).

Group CBT

Group treatment packages exist for several anxiety disorders (e.g., Heimberg & Becker, 2002). Although the research is mixed with regards to whether group treatment is as efficacious as individual treatment (Stangier, Heidenreich, Peitz, Lauterbach, & Clark, 2003; Whittal, Robichaud, Thordarson, & McLean, 2008), the ability to treat several clients simultaneously may reduce treatment cost and increase treatment availability.

Individual CBT

With increasingly fine-grained and symptom-specific cognitive models (e.g., Moscovitch, 2009; Radomsky, Shafran, Coughtrey, & Rachman, 2010), there has been a gradual movement towards individualized case conceptualization as the “gold standard” of CBT (e.g., Kuyken, Padesky, & Dudley, 2009; Persons, Beckner,

& Tompkins, 2013). It is unclear, however, whether individualized CBT offers any incremental efficacy over a more manualized approach (e.g., Chadwick, Williams, & Mackenzie, 2003; Mumma & Smith, 2001).

Treatment Engagement in CBT for Anxiety Disorders

Unfortunately, a substantial proportion of individuals with any mental health issue either delay or fail to seek treatment (e.g., Wang et al., 2005), and of those who begin individual psychotherapy, 20–70% terminate therapy early (Gearing, Townsend, Elkins, El-Bassel, & Osterberg, 2014). Research has also demonstrated that “dose” of therapy can predict therapeutic outcome (Craske et al., 2006), highlighting the importance of increasing treatment engagement as soon as possible during treatment for anxiety disorders. As such, the current chapter focuses on strategies to improve treatment engagement both prior to treatment-seeking and during treatment with respect to CBT for anxiety. Additionally, given research suggesting that stepped-care may increase the number of clients achieving remission (e.g., Tolin, Diefenbach, Maltby, & Hannan, 2005), we have attempted to propose a framework wherein clients are offered the least invasive, most cost-effective treatment first, moving on to more intensive modalities as necessary.

The Disorder–Treatment Gap

As reviewed by the Anxiety Disorders Association of Canada (ADAC; 2003), the economic burden of anxiety disorders is largely attributable to individuals who do not receive treatment. The worldwide treatment gap for GAD, panic disorder, and OCD has been estimated to be greater than 50% (Kohn, Saxena, Levav, & Saraceno, 2004). Moreover, among people who do seek treatment, the estimated median duration of delay between disorder onset and treatment contact varies from 9 to 23 years, depending on the disorder (Wang et al., 2005). This research suggests that improving access to and engagement with early intervention is a potentially powerful step in reducing the impact of anxiety disorders.

Several factors are believed to contribute to this gap including systemic barriers (e.g., funding), practitioner training/expertise, and stigma (ADAC, 2003). For example, research has demonstrated that primary care physicians fail to detect anxiety disorders in the majority of sufferers (e.g., Lecrubier, 2001). Importantly, this underdiagnosis and misdiagnosis may be related to the tendency for individuals to present physical, rather than psychological complaints (see Lecrubier for a review). Moreover, when disorders are recognized by general practitioners, there is a 59% chance treatment will be offered, suggesting that avenues for improving initial access and engagement with mental health services include education of both sufferers and health practitioners.

Indeed, Gulliver, Griffiths, and Christensen (2010) reported in their review that adolescents and young adults indicate stigma/embarrassment, difficulty recognizing symptoms, and wanting to “do it themselves” as the greatest barriers to seeking mental health services. Moreover, a recent review demonstrated that the relationship between concerns about stigma and reduced help-seeking was small to moderate, and that the most endorsed stigma-related concern was related to disclosure (Clement et al., 2015). Considering the nature of anxiety disorders, fears about the negative consequences of disclosure may lead to avoidance of treatment-seeking.

What Predicts Dropout and Treatment Refusal in CBT for Anxiety?

Across treatment outcome studies, dropout rates among individuals with anxiety range from 5.6% to 27% (e.g., Issakidis & Andrews, 2004; Keijsers, Kampman, & Hoogduin, 2001). Dropout rates are fairly consistent across anxiety disorders, with most studies examining dropout from CBT after therapy has begun. Relatively few studies have examined treatment refusal rates—being offered treatment but declining. One study found that approximately 30% of individuals offered CBT decline it, and another 10% drop out once treatment has begun (Issakidis & Andrews, 2004). Additionally, at least one study documented that dropout is more likely to occur after the first session than later sessions (Bados, Balaguer, & Saldaña, 2007). Dropout rates following pharmacological treatment appear to be similar to rates following CBT, ranging from 6% to 38% for panic disorder (Bakker, Van Balkom, & Spinhoven, 2002), about 10.58% for obsessive compulsive disorder (Kobak, Greist, Jefferson, Katzelnick, & Henk, 1998), and 16–23% for social phobia (Federoff & Taylor, 2001).

Relatively few studies have examined factors that predict dropout or treatment refusal. Characteristics that have been examined include demographic characteristics, symptom severity, and treatment-related factors such as perceived efficacy, motivation and treatment expectations. In general, the research is inconsistent with some studies finding certain variables to be predictive of dropout and other studies finding the same variables to be unrelated to dropout. With regards to demographic variables, research suggests that socially disadvantaged individuals, such as those with lower education, ethnic minorities, children living in single-parent households, parents, and lower household income, are more likely to drop out (Grilo et al., 1998; Keijsers et al., 2001). Additionally, several studies indicated that individuals with less severe anxiety are more likely to drop out of treatment (e.g., Issakidis & Andrews, 2004). Furthermore, one study found that the presence of depressive symptomatology was a predictor of both treatment refusal and drop out (Issakidis & Andrews, 2004). Poor treatment motivation, negative attitudes towards treatment, and poor therapeutic alliance also predict dropout (Bados et al., 2007; Grilo et al., 1998; Keijsers et al., 2001). Finally, at least one study has found that individuals

offered group rather than individual therapy also are more likely to dropout (Issakidis & Andrews, 2004). One common belief, even among trained therapists is that engaging in exposure can be extremely stressful and aversive (Becker, Zayfert, & Anderson, 2004). However, dropout rates do not appear to be higher for treatments that use exposure based strategies (Hembree et al., 2003).

When clients have been surveyed about their reasons for dropping out, about 50% indicate dissatisfaction with treatment as the reason for terminating early (Bados et al., 2007; Keijsers et al., 2001). Other reasons include inadequate self-perceived symptom improvement and personal reasons, such as work conflict or relocation. Based on these findings, factors that appear particularly relevant to improving treatment engagement include therapeutic alliance, beliefs about therapy, symptom severity, and ambivalence. Below follows a description on how each of these factors can be addressed to increase treatment engagement. Where appropriate we will describe how these factors can be addressed within a stepped-care model.

Strategies for Increasing Treatment Engagement

Improving Access to Care

Considering the impact of barriers to mental health care, interventions designed to increase both help-seeking in anxiety sufferers and recognition of need by primary care physicians are warranted. Specifically, interventions designed to increase mental health literacy as well as treatment literacy (e.g., confidentiality during treatment) in the population at large may be particularly important for increasing awareness of symptoms and decreasing worries about stigma. In particular, given the observed gap in recognition of anxiety disorders and appropriate referral to treatment in primary care, public education about the psychological symptoms of anxiety and how to report these to primary care physicians and to request psychotherapeutic referrals may be particularly important.

Indeed, several organizations provide detailed and evidence-based information on their websites for the public. For example, the Canadian Psychological Association has published several online “Fact Sheets” describing different psychological disorders and their evidence-based treatments (<http://www.cpa.ca/psychologyfactsheets/>), the Association for Behavioral and Cognitive Therapies (ABCT) provided a detailed description of what to expect in CBT, including a brief discussion of recent controversies (<http://www.abct.org/Help/?m=mFindHelp&fa=psychoTreatments>), and the American Psychological Association directly addressed concerns about disclosure by describing a client’s right to and limits of privacy during psychological treatment (<http://www.apa.org/helpcenter/confidentiality.aspx>). These efforts to provide accurate information are an important step in increasing mental health literacy and decreasing concerns about the potential negative consequences of seeking help. It is important to note, however, that although interventions

designed to increase health literacy have led to improved help-seeking attitudes among individuals with psychological distress, no effect of such interventions on help-seeking behavior has been observed (for a review, see Gulliver, Griffiths, Christensen, & Brewer, 2012). That being said, it is possible that improved help-seeking attitudes may lead to increased help-seeking behaviour over time, rather than soon after the intervention (in the review noted, only one study looked at follow-up data). More research into effective interventions for increasing access to care is certainly warranted.

With respect to accurate diagnosis and referral by primary physicians, research has demonstrated that standardized screening measures are easy and brief to use, and can drastically increase recognition of mental health problems. For example, Spitzer et al. (1994) demonstrated that use of the Primary Care Evaluation of Mental Disorders (PRIME-MD), a standardized diagnostic interview for which the mean administration time was 8.4 min, resulted in an 86% diagnostic accuracy rate. To further reduce clinician administration time, a self-report version, the Patient Health Questionnaire (PHQ; Spitzer, Kroenke, & Williams, 1999) was developed and validated in a large primary care sample, demonstrating similar diagnostic validity to the original interview-based version. It is therefore critical for primary care physicians to consider incorporating standardized mental health screening instruments into their practice, and referring those with positive results for more specialized assessment, diagnosis, and/or treatment by mental health care practitioners.

As such, a particularly important role for mental health care practitioners is to participate in education of primary care physicians, whether through public lectures, consultation, or perhaps more simply, by regularly communicating with physicians through brief intake, progress, and therapy termination reports of their clients. Indeed, this practice may increase physicians' awareness of the prevalence of anxiety symptoms, how they may present in different individuals, and how effective evidence-based treatment by trained practitioners can improve the care of their patients.

Beginning Treatment

Efficient clinical practice. As mentioned previously, research suggests that a large number of individuals simply do not attend their first session (Issakidis & Andrews, 2004). Therefore, one of the first steps in establishing good treatment engagement is to maximize the probability that the client will be able to attend the first session. When clients initially seek treatment, it is frequently because their symptoms have reached a point where they believe help is warranted and they are likely highly motivated to begin treatment. Long wait times between initial telephone contact to set an appointment time and the first session increase the likelihood that symptoms may change and motivation to seek help may diminish (Carroll, 1997). Minimizing the interval between initial phone contact and the first session can help increase retention (Stark, Campbell, & Brinkerhoff, 1990). Providing flexible appointment

times may also increase treatment engagement for individuals with busy schedules, such as people who work full time or individuals with children. Finally, a reminder call before the initial appointment may also help ensure that the client engages in treatment from the beginning.

Maximizing therapeutic alliance. It has long been theorized that a key element in successful therapeutic outcome is a strong therapeutic alliance (i.e., the relationship between the therapist and the client). Though there are various definitions of what constitutes the therapeutic alliance, much research has used Bordin's (1979) conceptualization. This model suggests that the alliance comprises three components: (1) agreement on therapeutic goals; (2) agreement on therapeutic tasks; and (3) an emotional bond between the therapist and client.

Most research examining the role of the therapeutic alliance in therapy has focused on its relationship to treatment outcome. Several meta-analyses across different treatment modalities and diagnoses suggest that the therapeutic alliance accounts for approximately 10% of the variance in treatment outcome (Crits-Christoph, Connolly Gibbons, Hamilton, Ring-Kurtz, & Gallop, 2011; Fluckiger, Del Re, Wampold, Symonds, & Horvath, 2012). Research specific to anxiety disorders has been mixed. Weiss, Kivity, and Huppert (2014) found that the therapeutic alliance did not significantly predict treatment outcome in the treatment of anxiety disorders, though they noted that the magnitude of the variance accounted for was 13.54%, which was consistent with previous meta-analyses. However, this study only examined individuals who completed treatment and therefore it is unclear whether the therapeutic alliance might predict treatment retention. At least two other studies have also found that the therapeutic alliance was unrelated to outcome in the treatment of panic disorder (Casey, Oei, & Newcombe, 2005; Ramnero & Ost, 2007). In contrast, others have found that the therapeutic alliance significantly predicts treatment outcome in CBT for panic disorder and social anxiety disorder (Huppert et al., 2014; Mörtberg, 2014).

Though the research is inconsistent with regards to whether the therapeutic alliance is directly related to outcome in the treatment of anxiety, several findings suggest that the therapeutic alliance may be important for treatment engagement. For example, Ramnero and Öst (2007) found that the therapist's perception of the client showing active participation and goal direction was positively correlated with treatment outcome for panic disorder. Furthermore, therapeutic alliance predicted greater cognitive change in the treatment of panic disorder (Casey et al., 2005). These findings suggest that strengthening the therapeutic alliance may help increase treatment engagement.

Crits-Christoph et al. (2006) provide specific recommendations on how to improve the therapeutic alliance. First, to enhance goal agreement, they suggest that the therapist establish explicit goals at the outset of therapy and regularly review treatment goals with the client to ensure agreement. Consistent with CBT, we recommend that this been done collaboratively with the client. Within the context of CBT for anxiety disorders, this is likely particularly important in the development of explicit and realistic behavioral goals (e.g., give a speech in class).

Second, to increase task agreement, Crits-Christoph et al. (2006) suggest ensuring clear understanding of the therapy process and regular review of therapeutic tasks. It may be particularly important at the beginning of therapy to spend adequate time describing the CBT model of anxiety, including a rationale for both the cognitive and behavioral elements of therapy. Indeed, one study demonstrated that a treatment rationale may increase engagement in exposure exercises (Ahmed & Westra, 2009). Discussing the rationale for all components of therapy, from social skills training and cognitive restructuring to exposure, should be done routinely. Extra attention, however, to ensure the client understands the rationale may be more important for components of therapy that can be especially difficult and stressful, such as exposure therapy, as the client may be more willing to engage in exposure if they understand its purpose. Regular review of these rationales prior to task engagement (e.g., before exposure; see below) is also recommended.

Finally, to enhance the therapeutic bond, Crits-Christoph et al. (2006) recommend examining the client's motivation for change (described below), being empathic, using a conversational style, ensuring the client is being heard, and using nonverbal behaviors appropriately. Within the context of the treatment of anxiety disorders this may mean empathically responding to the clients' level of anxiety. Clients often acknowledge that their anxiety is extreme, yet experience tremendous difficulty coping with the intensity of their anxiety. Acknowledging that given the client's particular constellation of beliefs or developmental history it is understandable that they experience anxiety in a particular context may be helpful in enhancing empathic responding and ensuring the client feels heard. In addition, techniques, described in detail below, including assessing an individual's stage of change and using motivational interviewing techniques may be particularly helpful in enhancing the therapeutic bond and making the client feel understood.

Comprehensive and accurate assessment. We believe that a thorough assessment is integral to maximizing treatment engagement. In addition to the obvious purpose of assessment—establishing a diagnosis and understanding of the client—assessment is the first opportunity to engage the client, develop the therapeutic relationship, and identify barriers to treatment.

Establishing an accurate diagnosis using well-validated measurement tools is crucial. Semi-structured interviews, such as the Structured Clinical Interview for DSM-5 (SCID-5; First, Williams, Karg, & Spitzer, 2015) and the Anxiety Disorders Interview Schedule (ADIS-5; Brown & Barlow, 2014) may be especially useful. Because there is substantial symptom overlap across anxiety disorders, a thorough assessment to consider various differential diagnoses is important. The establishment of an accurate diagnosis ensures that the treatment plan is consistent with the needs of the client and also offers the opportunity for the client to feel understood by the therapist. For example, if an individual experiences panic attacks in social situations because of fear of humiliation or embarrassment (e.g., consistent with a diagnosis of social anxiety disorder) but is given a diagnosis of panic disorder, she may feel misunderstood by the therapist and be less engaged in interoceptive exposure techniques, used in the treatment of panic disorder, as they do not address her core fears.

In addition to establishing an accurate diagnosis, treatment engagement may also be enhanced by collaboratively developing an idiographic case conceptualization of the client's problem with the client. Collaborative case conceptualization involves working with the client to understand their unique problem within the context of theory and research of their presenting problem. The therapist brings with them their expertise and knowledge about anxiety disorders and the client brings with them their personal knowledge of their issues and history (Kuyken, Padesky, & Dudley, 2008). Collaboratively working towards an accurate case conceptualization can also help enhance the bond between therapist and client, and inform mutually agreed upon goals and tasks for therapy. It should be noted, however, though guidelines towards evidence based assessment promote the use of collaborative case conceptualization (e.g., Christon, McLeod, & Jensen-Doss, 2015), there is surprisingly little empirical research examining the scientific validity of case conceptualization (Bieling & Kuyken, 2003).

A thorough assessment should also include evaluation of potential predictors of dropout and treatment interfering beliefs such as treatment ambivalence and maladaptive beliefs about therapy (reviewed in detail below). Predictors of dropout that should be assessed include potential obstacles to treatment, including scheduling issues, such as working full-time or having children, and time-management problems. The therapist can then use this information to either adapt to the needs of the client or help the client problem solve potential barriers.

Because less severe symptoms appear to be related to higher rates of dropout among individuals with an anxiety disorder, we suggest that clinicians administer validated self-report measures of symptom severity (see Antony, Orsillo, & Roemer, 2001 for a review) to help provide the appropriate intensity of treatment. For example, a client who reports mild social anxiety may begin with self-help resources (including clinician contact where appropriate), whereas a client with severe social anxiety will likely require weekly individual therapy.

Given the importance of attendance, adherence, and homework completion (i.e., treatment engagement) on the efficacy of CBT, we recommend highly that clinicians assess for markers of resistance. Therapists can ask questions about the client's thoughts and motivations for change. Questions might include "What prompted you to seek treatment now?" "How do you think your life will be different if your anxiety was less intense?" and "What barriers do you see that might make it difficult to change?"

To assess beliefs about treatment itself, therapists can inquire about previous treatment experiences and their outcome, as well as the client's thoughts about what treatment will entail, and expectations for the outcome of treatment. If treatment interfering beliefs, such as "treatment will never work" or "treatment will be too difficult for me," are identified, the therapist can spend extra time providing psychoeducation about the nature of treatment and exploring the client's beliefs and expectations about therapy using the strategies described below. Additionally, validated questionnaires assessing change expectancy and treatment-interfering beliefs can also be administered (see Appendix).

Motivational Interviewing

Motivational Interviewing (MI) is a collaborative therapeutic communication style designed to enhance motivation for change by “rolling with resistance” rather than by convincing clients they need to change (Miller & Rollnick, 2009). In the context of anxiety disorders, it has largely been explored as a “pretreatment” to CBT. Many individuals presenting for treatment of anxiety disorders endorse at least some therapy-related reluctance, resistance, or fear (e.g., Dozois, Westra, Collins, Fung, & Garry, 2004; Rowa et al., 2014), which can predict reduced engagement/adherence (Dozois et al., 2004).

Although MI has only recently been investigated in the treatment of anxiety disorders, it appears to be a promising intervention, particularly for clients at risk for dropout or reduced engagement. MI has been demonstrated not only to improve treatment outcome (for a detailed review, see Westra, 2012), but to improve treatment resistance, ambivalence, low motivation, or reduced engagement. For example, four sessions of pre-CBT for GAD MI led to large reductions in resistance compared to no pretreatment and to four sessions of CBT (Aviram & Westra, 2011). Additionally, pre-CBT MI has been shown to increase commencement of Exposure Therapy (ET) in a small sample of previously treatment-refusing individuals with OCD (Maltby & Tolin, 2005).

Following comprehensive assessment, we recommend that clinicians adopt an MI style prior to beginning CBT for those individuals demonstrating reluctance or ambivalence. With respect to self-help resources, many books and computerized interventions begin by asking clients to assess their own reluctance and motivation for change. Considering the research demonstrating higher rates of early treatment termination when clinician contact is minimal or nonexistent, it may be particularly important to supplement self-help near the beginning of treatment to make sure that reluctance and/or therapy-interfering beliefs are targeted. Similarly, adding an MI component prior to group CBT for anxiety may be warranted as standard practice.

Although a detailed description of MI is outside the scope of this chapter, we recommend that clinicians consult the list of resources below, attend workshops when available, and seek supervision when necessary.

Targeting Treatment Related Beliefs

In addition to increasing motivation, it may be important to target therapy related beliefs prior to beginning CBT for anxiety disorders. Indeed, a recent review of predictors of dropout reported that only expectations and opinions about therapy emerged as consistent predictors of engagement (Fontenelle & Santana, 2011). In particular, pretreatment expectancy (i.e., the extent to which clients believe treatment will help improve their symptoms) predicts improved outcomes following CBT for anxiety, potentially because of its tendency to increase therapeutic alliance and homework completion (e.g., Price & Anderson, 2012).

Furthermore, research suggests it may be particularly important, prior to commencing CBT, to increase treatment credibility (e.g., Ahmed & Westra, 2009) and to increase the extent to which clients with anxiety believe it is their efforts towards change (rather than the power of the therapist) that will help alleviate their symptoms (Delsignore, Carraro, Mathier, Znoj, & Schnyder, 2008). A recent pilot intervention demonstrated that targeting therapy-interfering beliefs (e.g., *Going to treatment means I cannot handle my problems; treatment will not reduce my symptoms*) via CBT increased intent to seek treatment in Veterans with mood and anxiety symptoms (Stecker, Fortney, & Sherbourne, 2011).

As CBT practitioners treating anxiety disorders, we are fortunate to be able to rely on a wealth of data to explain to our clients why and how our treatment plan is likely to work. We strongly recommend that early in therapy, clinicians provide their clients with psychoeducation not only about their particular disorder, but also about the ways in which CBT has been shown to be helpful. Sharing evidence related to the impact of factors such as homework completion, regular attendance, and in-session engagement may be particularly useful in increasing clients' sense of control and agency over their own recovery. Moreover, Socratic questioning and behavioral experiments can be employed very early on to target potential treatment-interfering beliefs. Rather than waiting to see whether certain beliefs may get in the way at different points of therapy targeting therapy interfering beliefs early on may increase the likelihood that clients *show up* at the beginning, work towards some early change, and feel encouraged to *continue* attending. Similar to MI, we believe these strategies can be implemented in all modalities and recommend that some clinician contact be offered during this stage, if self-help is the first step.

During Treatment

Collaborative Empiricism

Collaborative empiricism (CE) has been proposed as the optimal therapeutic “style” that differentiates CBT from other forms of therapy (Beck, Rush, Shaw, & Emery, 1979). It refers to “shared work” between client and therapist through which a case conceptualization is developed collaboratively, and beliefs (about behavior, emotions, coping ability, etc.) are tested empirically. For example, rather than “assigning” a thought record as “homework,” the clinician may use Socratic questioning to guide clients toward considering monitoring their beliefs in situations in which they tend to feel anxiety, and then work with the client in session to develop a worksheet which would monitor thoughts, emotions, behaviors, and physiological sensations in particular situations.

As mentioned previously, research has demonstrated that goal consensus early in therapy can contribute to improved outcome (e.g., Tryon & Winograd, 2011). It goes without saying that successful outcome is contingent upon showing up in the first place. Because CE likely contributes to goal consensus, we strongly recommend

clinicians adopt this collaborative (as opposed to didactic) style early in therapy, to enhance the development of therapeutic alliance, client willingness/openness to share, client sense of agency for change, and ultimately, client engagement in therapy.

Treatment contracting may be a particularly helpful tool to arrive at goal consensus early in treatment (e.g., Otto, Reilly-Harrington, Kogan, & Winett, 2003). By formalizing treatment goals collaboratively, and signing documents indicating agreement to pursue such goals, clients may feel more engaged in the therapeutic process. This process may also open the door for discussion of treatment interfering beliefs. For example, if clients are hesitant to agree to (or even consider!) treatment goals related to Exposure Therapy (ET), clinicians become aware of potentially problematic beliefs such as “*I won’t be able to tolerate my own discomfort*” and can begin addressing these early in therapy, hopefully increasing engagement and attendance.

Enhancing Acceptability of Exposure Therapy (ET)

Exposure Therapy (ET) is often an important component of CBT for anxiety, and has received robust support regarding its efficacy (Olatunji, Cisler, & Deacon, 2010; Ougrin, 2011). Traditionally, ET consists of gradual exposure to feared stimuli or situations (e.g., spiders, enclosed spaces, contaminants, social interactions, physical sensations) without using compensatory or safety behaviors, such as escape, “safe people,” carrying medications, avoiding eye contact, or hand washing. Gradual exposure likely functions in several ways, including fostering habituation to physical symptoms or feared stimuli, violating erroneous expectations about negative consequences, and increasing self-efficacy and/or distress tolerance.

Despite its well-known effectiveness, particularly for anxiety disorders, there are two important barriers to engaging clients in ET. First, dropout or treatment refusal rates prior to beginning exposure can be substantial (e.g., Foa et al., 2005; McDonagh et al., 2005). For example, although intent-to-treat analyses from a randomized controlled trial comparing ET to medication alone and a combined treatment demonstrated 62% of participants in the ET condition and 70% of participants in the combined condition were classified as “treatment responders,” an examination of dropout rates at random assignment and during treatment, resulted in an overall dropout rate of 43% across both conditions that included ET (Foa et al., 2005). Second, therapists’ negative beliefs about ET (e.g., that it is unethical, intolerable, unsafe, or unhelpful) may reduce their likelihood to use it, or to use it at an effective dose without incorporating stress-reduction techniques (e.g., controlled breathing) concurrently (Deacon, Lickel, Farrell, Kemp, & Hipol, 2013; Farrell, Deacon, Kemp, Dixon, & Sy, 2013; Van Minnen, Hendriks, & Olf, 2010). Further, although some organizational barriers (e.g., lack of appropriate clinical supervision) reduce use or proficiency of ET with anxious clients, therapist characteristics (e.g., high

anxiety sensitivity, negative beliefs about ET) appear to be the primary barriers to adoption of ET (Harned, Dimeff, Woodcock, & Contreras, 2013).

Expectations about ET, both on the part of the client and the therapist appear, therefore, to be a particularly important target area for treatment engagement. As already noted, treatment expectancy and credibility are consistent predictors of both dropout and treatment outcome. As such, if a therapist holds negative beliefs about ET, it is unlikely that a client will develop helpful expectancy or credibility beliefs. Moreover, if a client begins therapy with negative beliefs about ET that are not addressed early on the likelihood they will stay in therapy is reduced. In other words, although not tested empirically, it is possible that therapists' beliefs about ET actually lead to increased treatment refusal and/or decreased treatment engagement. Moreover, clients who endorse reluctance to participate in ET are more likely to be excluded from ET by exposure therapists (Meyer, Farrell, Kemp, Blakey, & Deacon, 2014). In other words, there appears to be a feedback loop wherein negative beliefs about ET by either the client or therapist contribute to behaviors in each other that reduce its use and efficacy. To this end, we offer recommendations related to both therapist and client beliefs about ET.

Therapist beliefs about ET. Similar to a CBT protocol, assessment of negative beliefs about ET is an important first step in examining whether there are barriers to its successful delivery. Recently, the self-report *Therapist Beliefs About Exposure Scale* (TBAES; Deacon et al., 2013) was found to predict cautious use of ET. We recommend clinicians consider using this self-assessment tool to examine the nature and extent of their beliefs about ET when treating anxiety.

Clinicians who attended a day-long didactic workshop related to the use of ET in the treatment of anxiety disorders exhibited a significant decrease in negative beliefs about ET (Deacon, Farrell, et al., 2013). Additionally, an online ET training program increased the adoption of ET and the proficiency of its delivery among non-exposure therapists (Harned et al., 2013). We therefore recommend clinicians considering incorporating ET into their practice seek psychoeducation through evidence-based treatment manuals, workshops, and clinical supervision by seasoned exposure therapists. Some research has demonstrated that regular delivery of ET following didactic training occurs only following successful treatment efforts using this type of therapy, and that use of ET may diminish as clinical supervision is reduced over time (McLean & Foa, 2013; Ruzek & Rosen, 2009). Indeed, where face-to-face supervision is not accessible, clinicians may benefit from "distance-supervision" either via internet, videoconference or other methods (e.g., Schnurr et al., 2007), and are strongly encouraged to seek this out as needed.

Farrell, Deacon, Dixon, and Lickel (2013) proposed several suggestions for maximizing the development of positive beliefs about ET among therapists. In brief, they suggest that training in ET should include: (1) experiential exercises designed to create and/or strengthen automatic associations in memory between ET and "tolerable," "safe," "ethical"; (2) psychoeducation which provides both empirical evidence and emotional appeals; and (3) activities which require advocating for the use of ET. To this end, psychoeducation for clinicians, whether in primary care or otherwise, may be most effective when they include information

about the brevity of distress associated with ET, the contribution of this treatment to lower relapse rates than medication, and case examples documenting its efficacy. Moreover, to the extent that this information can be disseminated to the public to increase mental health literacy, access and engagement with care may be improved. Specifically, clinicians have a responsibility, when providing informed consent, to include information about the negative consequences of *not* pursuing treatment (i.e., the likely persistence/worsening of symptoms, vulnerability to the development of other psychological disorders, etc.), research-based advantages of CBT over other approaches such as medication or other types of therapy, and options for managing increased distress during some portions of therapy (e.g., increased anxiety when beginning ET).

Client beliefs about ET. Whether clients are being prepared for ET alone, or for an exposure component of CBT, this intervention is helpful only if clients participate actively. It may be particularly important to ensure that ET exercises are collaborative and have goals shared by the client and therapist. Several client beliefs may interfere in ET engagement (Clark, 2013). For example, clients may either refuse or be reluctant to engage in ET because they believe they will be unable to tolerate the physiological symptoms, that their symptoms will worsen, that there will be a catastrophic consequence (e.g., heart attack, lose control), that it will be unhelpful, or that they will be unable to complete the task without compensatory or safety behaviors.

Safety behavior (SB) refers to any type of behavior that may function as overt or covert avoidance of anxiety or another feared outcome in a particular situation (Salkovskis, 1991). Examples of SBs include avoiding eye contact in social anxiety, washing hands after touching a contaminant in OCD, seeking reassurance in GAD, only leaving the house with a “safe person” in panic disorder, or maintaining barriers between the self and a feared stimulus (e.g., only looking at spiders in cages). SB, similar to avoidance, contributes to the perpetuation and exacerbation of anxiety symptoms likely because it prevents individuals from obtaining disconfirmatory evidence related to their feared outcomes (see Helbig-Lang & Petermann, 2010, for a review).

Despite evidence that SB tends to maintain anxious symptoms, recent research has focused on the *judicious* use of SB during ET, suggesting that it may increase the acceptability (i.e., engagement) of exposure exercises, without decreasing therapeutic effects (e.g., Hood, Antony, Koerner, & Monson, 2010; Milosevic & Radomsky, 2013). It is particularly important to note that the studies that have shown equivalent effects of ET with or without SB use have emphasized the *judicious* use of SB. The judicious use of SB refers to the “careful use of safety behavior, with an emphasis on the early stages of treatment” (Rachman, Radomsky, & Shafran, 2008, p. 169). Indeed, a primary goal of such use is to allow for greater disconfirmatory learning by more rapid progression of ET (e.g., “Wow! I actually can tolerate being closer to that contaminant”), with eventual “phasing out” of SB use to avoid the development of problematic beliefs (e.g., “I was safe only because I was wearing gloves”). Rather than simply allowing clients to use whatever SB they typically rely on to tolerate anxiety-provoking situations, clients and clinicians

work together to include specific SB in specific contexts with the goal of eliminating them gradually over time. Indeed, collaborative goal-setting is inherent to successful ET, specifically during the construction of *exposure hierarchies*, a series of avoided situations ranked from least (e.g., walking to the end of the driveway) to most fearful (e.g., taking the bus to the mall), which are then gradually approached as therapy progresses. Indeed, virtually all self-help CBT for anxiety books include this type of hierarchy as a guide to completing ET.

Although there has been considerable controversy in the literature related to the theoretical and clinical implications of incorporating judicious SB use into ET, the practice is conceptually indistinguishable from “traditional” ET, wherein earlier steps on the hierarchy are less fear-provoking. For example, Katerelos, Hawley, Antony, and McCabe (2008) provided a sample pretreatment exposure hierarchy for an individual undergoing group CBT for social anxiety disorder, which included two related items as follows: “*Walk past strangers in a public place without making eye contact*” and “*Walk past strangers in a public place and making eye contact*” (p. 509). In essence, the avoided situation is *walking past strangers* with, and then later without, the SB *avoid eye contact*.

Studies have generally demonstrated that ET with judicious SB use is at least as effective as ET with no SB use (e.g., Milosevic & Radomsky, 2013; Sy, Dixon, Lickel, Nelson, & Deacon, 2011). Moreover, research examining client preferences has shown that ET with SB use is at least as acceptable as traditional ET (Deacon, Sy, Lickel, & Nelson, 2010), and may be considered *more* acceptable by clients (e.g., Levy & Radomsky, 2014; Milosevic & Radomsky, 2013), a factor which would likely increase treatment engagement. As such, it is likely not the use of SB, per se, which is helpful or harmful, but rather the *function* of the SB during ET (see Parrish, Radomsky, & Dugas, 2008). Specifically, SB use may be recommended over no SB use to the extent that it (Parrish et al., 2008):

1. increases self-efficacy and/or confidence (e.g., in ability to tolerate distress, approach feared stimulus);
2. includes a moderate amount of attention on the feared stimulus;
3. enables clients to approach their feared stimulus more closely, thereby increasing the opportunity to encounter and incorporate disconfirmatory evidence; and
4. does not contribute to beliefs about the safety of objects (e.g., antianxiety medication) or behaviors (e.g., distraction) rather than the safety of the feared situation or the ability of the client to cope.

We recommend therefore, especially for clients showing reluctance to engage in exposure, that exposure tasks be developed collaboratively, and that clinicians consider incorporating the *judicious* use of SB, with the goal of fading SB use as therapy progresses. Collaborative treatment planning may be more readily accomplished by using a cognitive rationale (e.g., belief disconfirming rationale) rather than a habituation rationale. Both undergraduate students and individuals diagnosed with an anxiety disorder rate descriptions of CBT with a cognitive rationale as more acceptable and easier to adhere to than CBT with an extinction-based rationale (Milosevic & Radomsky, 2013).

Using a Belief Testing Rationale

Research directly comparing components of CBT (e.g., behavioral vs. cognitive vs. cognitive-behavioral techniques and/or packages) has generally found equivalent effects (see Longmore & Worrell, 2007, for a review). There is some evidence, however, that using a cognitive (i.e., belief disconfirmation) rationale for exposure tasks leads to greater improvements in symptoms, beliefs, and/or behavior than does a habituation/extinction rationale (e.g., Kim, 2005; Salkovskis, Hackmann, Wells, Gelder, & Clark, 2007). Importantly, in Salkovskis et al.'s (2007) study, the exposure intervention, which produced significantly greater improvements in the cognitive rationale condition (compared to the habituation rationale), lasted only 3.25 h. Additionally, clients who improve early in treatment are less likely to drop out (Lutz et al., 2014), and sudden gains have been preceded by cognitive change (Norton, Klenck, & Barrera, 2010), suggesting that a cognitive rationale may increase treatment engagement by producing symptom changes earlier in therapy.

Behavioral experiments (BEs; see Bennett-Levy et al., 2004) represent a cognitive technique that may be particularly important to increasing treatment engagement, though the research examining this hypothesis, to our knowledge, is limited. Essentially, BEs consist of using empirical methods to test a potentially problematic belief through an experiential activity. These activities can include surveys, tests of feared consequences or ability to tolerate anxiety through exposure to the situation, examination of the effects of reducing vs. increasing safety behavior, etc.

A recent review of studies comparing cognitive vs. behavioral rationales for ET demonstrated that, although more rigorous research is needed, there was an advantage for activities similar to BEs compared to “standard” ET (McMillan & Lee, 2010). Interestingly, BEs may also offer some advantage over “standard” cognitive techniques, such as automatic thought records (ATRs). One recent experiment demonstrated that whereas both ATRs and BEs were equally efficacious, BEs led to earlier changes on the target belief (McManus, Van Doorn, & Yiend, 2012).

Of particular importance to treatment *engagement*, one study that asked clinicians in training to develop and practice BEs and ATRs related to their own problematic behavior demonstrated superior ratings for BEs on belief and behavior change (Bennett-Levy, 2003). Moreover, qualitative data indicated that clinicians experienced the BEs as more powerful and compelling methods of cognitive change than ATRs, and as impacting them at an implicit and emotional level (i.e., at the “heart level”; Teasdale, 1999). This finding lends support to the idea that clients may perceive BEs as more acceptable and impactful than other methods, such as ET and ATRs. Additionally, it may be the case that clinicians trained in BEs will have higher treatment expectancy, and therefore be able to impact treatment expectancy and/or engagement in therapy.

Given the limited amount of research in this area, we are cautious with our recommendations. However, we suggest that especially for clients who are demonstrating reluctance to participate in certain aspects of CBT such as ET (e.g., because of fear of anxiety or discomfort) or ATRs (e.g., because they do not believe it “in their

heart”), clinicians consider increasing their use of BEs to test problematic beliefs and behavioral patterns. It would be particularly interesting to investigate whether incorporating BEs into self-help versions of CBT would increase engagement and/or outcomes. Moreover, we strongly encourage all clinicians to obtain training in this methodology through self-directed reading, workshops, or clinical supervision.

Concluding Remarks

As reviewed above, CBT is a highly effective treatment for anxiety disorders. However, any therapy is useful only if clients agree to engage in it! We have attempted to provide evidence-based suggestions for the implementation of CBT to increase the likelihood that clients will attend therapy, participate actively, and continue attending. We have also made some suggestions related to clinician training, which we believe are particularly important. The ability, for example, to adopt an MI style whenever necessary likely contributes greatly to engagement at all stages of therapy. Moreover, evaluating the way our own beliefs about specific interventions (e.g., ET) may interfere with client engagement is particularly important. Finally, we have made some recommendations related to stepped-care of anxiety, with the goal not only of decreasing cost and increasing efficiency, but of meeting the client’s needs.

Clients whose symptoms are mild may feel overwhelmed if proposed a 20-week intensive treatment plan and choose not to attend. Similarly, clients with severe symptoms may feel dismissed or invalidated if given a self-help book and asked to return in 3 weeks. Tailoring the intensity of treatment, while incorporating the suggested strategies (e.g., increasing clinician contact when engagement is at risk) may be particularly important. Finally, efforts to increase treatment engagement will likely be unsuccessful if the client feels misunderstood in the first place, highlighting the importance of “starting off on the right foot” with an accurate and comprehensive assessment.

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Chapter 16

Exercise as a Behavioral Health Intervention in Primary Care Settings

Eric Reinhart, Melissa Keller, and Larry James

Several authors (Cummings, Cummings, & Johnson, 1997; Frank, McDaniel, Bray, & Heldring, 2004; James & Folen, 2005; James & O'Donohue, 2009; O'Donohue, Byrd, Cummings, & Henderson, 2005) have posited the theory motivating the paradigm shift that has led to many psychologists and other behavioral health professionals providing mental health services in the primary care setting. These authors have identified an increased access to mental health services, improved outcome efficacy, more efficient feedback to the referring physicians, decreased costs, and stigma as the primary reasons for offering behavioral health interventions in primary care. The primary care integration model not only enhances outcome, but it also reduces costs and medical utilization (Cummings, 1991; Von Korff et al., 1998; Young, Bradley, & Turner, 1995).

James and O'Donohue (2009) not only provide a theoretical argument for integrating behavioral health interventions within the primary care setting, these researchers illustrate models, techniques and clinical applications that can be conducted all within a traditional 30 min primary care follow-up appointment. Over the past decade, as the primary care behavioral health integration paradigm shift expanded, so did the idea that exercise can be employed as a treatment modality to better manage anxiety and depression. The present chapter builds upon the foundation of primary care behavioral health integration research cited above and offers models and intervention strategies to utilize exercise as an intervention in the primary care setting.

E. Reinhart, Psy.D. • M. Keller, Psy.M. • L. James, Ph.D., A.B.P.P. (✉)
Department of Psychology, Wright State University,
2595 Leawood Road, Dayton, OH 43123, USA
e-mail: reinhart.2@wright.edu; keller.122@wright.edu; Larry.James@wright.edu

Physical activity has been linked to several health benefits and exercise has been shown to be effective in preventing, treating, and recovering from a variety of chronic diseases including cardiovascular disease, diabetes, and cancer (Josefsson, Lindwall, & Archer, 2014). Researchers have also been able to link physical activity to improved mental health and psychological well-being (Josefsson et al., 2014). Exercise has been found to be as effective as cognitive, behavioral, and pharmacological interventions, with similar response and remission rates (Daley, 2008).

With the introduction of selective serotonin reuptake inhibitors, recognition and treatment of depression by primary care physicians has risen from 5% to 50% (Hirschfeld, 2001). Given this rise in care, it is important for professionals within a primary care setting to be aware of nuances within the literature that affect validity of the studies, hypotheses of why exercise works, as well as factors that affect outcomes, how exercise compares to other interventions, and problems and implications associated with exercise. It is also important to understand special populations and patient variables that impact adherence to prescribed exercise routines.

Several reviews of the literature suggest that many studies have problems with their face validity due to methodological problems (Daley, 2008). Prior reviews of the research suggest that many studies are not adequately randomized. Researchers may have relied on volunteers, particularly in studies trying to identify factors affecting adherence (Guillot, Kilpatrick, Hebert, & Hollander, 2004; Patel, Keogh, Kolt, & Schofield, 2013). In addition to randomization, there may be a lack of blinding when conducting outcome assessment, follow-up is conducted briefly shortly after the intervention is completed, and often nonclinical samples are used. These methodological problems have led to the exaggeration of results in favor of the intervention (Daley, 2008).

How researchers operationalize terms like physical activity and exercise also require consideration. Exercise typically implies a regular, structured, leisure-time pursuit whereas physical activity is associated with tasks that take place at home or in the workplace (Salmon, 2001). The interventions used to explore the impact of exercise and its effect on depression and anxiety also vary. Interventions may be high or low intensity, anaerobic versus aerobic, or vary in duration and frequency (Daley, 2008; DeBoer, Powers, Utschig, Otto, & Smits, 2012). The bulk of research conducted is focused on formal exercise programs and aerobic exercise (Salmon, 2001).

Accounting for these problems, many reviewers have concluded that exercise has broad effects and can be utilized as a preventive measure for physical and psychological problems (Smith, 2006). The mechanisms leading to the alleviation of symptoms associated with depression and anxiety are not well understood. There are several physiological and psychological hypotheses as to how exercise impacts mood and anxiety (Daley, 2008; DeBoer et al., 2012; Wipfli, Landers, Nagoshi, & Ringenbach, 2011).

The major physiological hypotheses and mechanism of action include: the release of endogenous opiates, like beta-endorphins and plasma endorphins, the monoamine hypothesis which posits there is an increase in availability of brain neurotransmitters, like increases in serotonin and norepinephrine, as well as the opponent's process model and the thermogenic hypothesis (Daley, 2008). The opponent's process model posits the activation of sympathetic nervous system acts as a catalyst for parasympathetic activity, thereby releasing acetylcholine and metabolization of cortisol (Callaghan, 2004). Although considered a viable at one time, the thermogenic hypothesis posited that increased body temperature would reduce muscle tension and alter neuron activity; however there is no clear empirical support for this theory. The results of several studies suggests that mood may be decreased and anxiety raised immediately following rigorous exercise (DeBoer et al., 2012). Stathopoulou, Powers, Berry, Smits, and Otto (2006) also posit that exercise improves the sleep cycle and helps regulate daily lifestyles, which improves mood.

The major psychological hypotheses include: distraction, improved self-esteem and self-efficacy, behavioral activation, and extinction learning. One possible explanation is that when individuals are engaged in exercise, they are simply distracted from their depressing thoughts and worries (Daley, 2008). Successful adherence to exercise regimens also contributes to one's sense achievement, control, and mastery. Development of these qualities builds a sense of efficacy positively impacting as self-esteem (Daley, 2008; DeBoer et al., 2012). Stathopoulou et al. (2006) also suggest that exercise promotes adaptive action and is a form of behavioral activation for individuals with depression. Exercise also facilitates extinction learning which is the reduction of fears and avoidance of anxiety-related sensations or anxiety sensitivity. Anxiety sensitivity is an enduring fear of anxiety and anxiety-rated sensations, including increased heart rate, respiration, and perspiration, as well as chest pain and shortness of breath (Broman-Fulks, Berman, Rabian, & Webster, 2004; DeBoer et al., 2012; Stathopoulou et al., 2006).

Within a primary care setting, 10–20% of adults will visit their primary care physician during an episode of mental illness; however often the visit is not due to the episode itself (Hirschfeld, 2001). The fifth edition of the Diagnostic and Statistical Manual (DSM-5) suggests the prevalence rate of major depression in the USA is 7%. The prevalence of major depression in individuals between the ages 18–29 is three times higher than individuals age 60 and older. The prevalence of major depression in women is 1.5–3 times higher than for men. The prevalence for generalized anxiety in the USA is 2.9% in adults and .9% among adolescents. Prevalence peaks in middle age and declines in later years. Women are twice as likely to experience generalized anxiety disorder. Individuals of European descent and individuals from developed countries are more likely to experience and reports more symptoms of generalized anxiety disorder (American Psychiatric Association, 2013).

The presence of depression and anxiety contribute to primary care visits and often lead to high medical utilization. Depression and anxiety are also associated with greater chronicity, slower recovery, increased rates of recurrence, as well as

greater psychosocial disability (Hirschfeld, 2001). Presenting complaints of depression and anxiety are likely to be more somatic and include back pain, chest pain, shortness of breath, heart palpitations, problems with sleep or appetite, and fatigue, to name a few (Hirschfeld, 2001).

Many studies have demonstrated links between the prevention of depression as well as the reduction of depressive symptoms in both clinical and non-clinical populations (Josefsson et al., 2014). Similar links to exercise and the reduction of symptoms of anxiety have also been made (Broman-Fulks et al., 2004). There are several factors that can affect the outcome of exercise as an intervention. Whether the patient presents with clinical or nonclinical depression and/or anxiety will affect the impact of exercise. The presence of negative affect, which is common in people experiencing depression or anxiety, affects motivation and adherence (Smits, Tart, Presnell, Rosenfield, & Otto, 2010). The degree of anxiety sensitivity will also impact outcome as people with higher levels of sensitivity will have more fear to overcome to initiate and persist with an exercise program (Broman-Fulks et al., 2004). Smits et al. (2010) also suggest that social physical anxiety, the fear of one's body being judged in public also plays a role in motivation and adherence to an exercise program.

The intensity of the exercise will impact outcomes. Effects on anxiety have been found with both low and high intensity exercises (Daley, 2008). Individuals with anxiety sensitivity have shown decreased sensitivity with high-intensity exercise (Broman-Fulks et al., 2004). However people with sedentary lifestyles may initially be opposed or intimidated by high intensity exercise (Callaghan, 2004). Outcomes tend to improve with tailored exercise programs as opposed to generic prescriptions for exercise. Healthcare professions need to consider what benefits are most salient to the patient, what would most benefit the patient's symptoms, the patient's current level of activity, as well as what is preventing them from being more active. The patient should be active in the process and questioned about what would help them incorporate more activity (Seime & Vickers, 2006). When an exercise program is prescribed by a physician, printed motivational messages are available, and face-to-face counseling occurs, outcomes are improved (Daley, 2008).

Modality and the dose-response relationship are also key factors in outcomes. Typical modalities include walking, running, resistance training and their implementation based on ability and symptom set (DeBoer et al., 2012). Yoga and Tai Chi have also been implemented for symptom reduction and improved cognitive functioning (Callaghan, 2004). Analysis of the literature suggests the recommended duration for exercise prescription is 10 weeks to reduce anxiety and should be performed 3-4 times per week. Regimens with higher and lower frequencies did not have as high anxiolytic effects. Regimens 20-30 min in length were also recommended; however exercise could be executed in 10 min increments have accumulated effects on symptoms (DeBoer et al., 2012).

Jayakody, Gunadasa, and Hosker (2014) conducted a systematic review of randomized controlled studies of exercise as an intervention for anxiety and found that exercise helped reduce anxiety symptoms in participants with panic disorder, but not as well as antidepressant medication. Individuals with social phobia also

benefitted from exercise when coordinated with group cognitive behavioral therapy. There was no difference in effect between aerobic or anaerobic exercise and it was also unclear whether moderate to heavy or very light to light exercise was more effective in reducing anxiety symptoms.

Exercise, as opposed to drug therapies, has few negative side-effects and some physicians have noted patients engaged in exercise may require lower doses of antidepressants (Callaghan, 2004; Patel et al., 2013). In fact, adherence to exercise prescriptions is comparable to medication trials (Daley, 2008). Secondary benefits are also present with exercise. Those benefits include improved cardiovascular health, reducing the risk or impact of cardiovascular diseases, weight management, reduced fatigue, and improved cognitive functioning (Callaghan, 2004). There are broad effects realized by exercise, which may also be a preventative measure for physical and psychological problems (Smith, 2006).

Despite the multitude of benefits to be gleaned from physical activity and exercise, the attitudes of primary healthcare and mental health professionals may impact incorporation of exercise as an intervention (Albright et al., 2000). Professionals may lack exercise counseling skills and confidence in the effectiveness of their advice. Institutional support and referral options may also be lacking or unavailable. In a primary care setting, time pressures also present problems, as a tailored program may require more time than is typically allotted for an appointment. Lastly, there may be no reimbursement for preventative care (Albright et al., 2000).

In addition to provider limitations, adherence to exercise interventions also impacts the utilization of exercise and is affected by many factors. Energy, motivation, and commitment are required to maintain an exercise program. Individuals with negative affect tend to be less physically active. Negative affect is also predictive of adoption of an exercise program, Remission of symptoms may reduce to inclination to exercise and require regular monitoring. The attitudes and knowledge about exercise of primary healthcare and mental health professions will also impact the utilization of exercise (Albright et al., 2000; Daley, 2008).

Krogh, Lorentzen, Subhi, and Nordentoft (2014) found adherence to exercise interventions was dependent on age and satisfaction with the intervention. Higher age was positively correlated to attendance and satisfaction; therefore consideration of motivation levels and factors influencing satisfaction should be considered when working with younger patients (Krogh et al., 2014). A fear of risk of falling or getting hurt also needs to be addressed with older patients, as their fear affects their motivation level and adherence (Cheung et al., 2007). Smits et al. (2010) suggest that patients who have elevated Body Mass Indexes (BMI) or who are obese may have higher anxiety sensitivity, which makes attempts at exercise more aversive. This relationship was not confirmed in their study, but their results suggested this may be a factor. The authors were also clear that the aversion to exercise was modifiable with cognitive-behavior therapy, by increasing the acceptability of exercise and exertion related sensations (Smits et al., 2010).

Patel et al. (2013) conducted a study, in New Zealand, with community-dwelling older adults utilizing the Green Prescription program to see whether an increase in physical activity would decrease depression. The Green Prescription is a prescription written out by a primary care physician in the same format as a drug treatment

would be. The type, intensity, and frequency of the physical activity, tailored to the patient is written down as a prescription. The patient then receives monthly telephone-based support that focused on time-related goals for physical activities. The prescription program was found to be effective in increasing activity and decreasing reported symptoms of depression. Participants also perceived an increase in their health-related quality of life. Of note, the participants in this study had chronic health problems; however they were not clinically depressed.

Guillot et al. (2004) noted that cardiac rehabilitation patients were three times more likely to drop out of an exercise program if they lacked spousal support and a lack of spousal support was the single most predominant factor in predicting non-compliance. They found that cognitive and behavioral processes increasing activity, greater self-efficacy, and perceptions of social support and advantages of the exercise program were linked with treatment adherence. Daley (2008) noted that women with postnatal depression also has substantial barriers to overcome which included childcare responsibilities, fatigue, interrupted sleep, and breastfeeding. Hayes et al. (2013) noted that with breast cancer patients exercise did not impact mood or anxiety levels, but it did increase the patients reported quality of life and helped prevent fatigue.

Stathopoulou et al. (2006) proposed recommendations for the implementation of an exercise program. They first recommend screening of patients to evaluate whether cardiovascular or acute infectious diseases were present. The training mode must consider the patient's age, gender, exercise experiences, and any location-specific exercise circumstances. As mentioned earlier, workout sessions should be reach moderate to high intensity and last approximately 30 min and completed approximately three times a week. Stathopoulou et al. (2006) suggest that a heart rate monitor be utilized to monitor exercise intensity and the first week of exercise could be substituted with something easier, like walking, so that motivation and efficacy may be preserved and adherence increased. The exercise program should last approximately 4 weeks to ensure the habit is developed. Written materials, like the treatment dose and suggestions for anticipated barriers, be provided to the patient for referral and as a cue to practice. The primary care provider should also help the patient plan for continued maintenance of the health behaviors (Stathopoulou et al., 2006).

A Framework for the Delivery of Exercise in Primary Care

As the third author of this chapter travels around the country and lectures on primary integration, the question “how do I talk with the patient about this?” appears to be the most common question. Also, “what should I say, how can I get it all in thirty minutes, how do I prepare the patient and/or what test should I use” are common theme questions. Rowan and Runyan (2005) described the 30 min follow-up session for the average primary care consultation and follow-up session. The authors in this chapter assert that the model suggested by Rowan and Runyan (2005) is not only currently relevant but is ideal to introduce exercise as an intervention to a patient. In their work, Rowan and Runyan (p. 16) provided the *Introduction, Assessment and Intervention phases* as the primary component of the 30 min session.

In the *introduction phase* patients are “prepped” and told that each session is for 30 min, the patient’s goals and question will be addressed and the intervention is tailored to the individual needs of each patient. Here, exercise is defined and examples are provided for each patient. Actually defining exercise with concrete examples is of pivotal importance because many sedentary patients will view doing the laundry, cleaning the house, walking the dog, driving the car as equal to walking on a treadmill for 30 min as equal. This phase last approximately 5 min. In Fig. 16.1, a model template for the introduction session is provided. In Fig. 16.1, the third author of this chapter prepares a patient for exercise as an intervention.

In the *assessment phase*, target symptoms are identified and how symptoms will be assessed each week upon follow-up is discussed with the patient. Examples would be weight, blood pressure, caloric intake, heart rate, distance (running, walking swimming, cycling, etc.). It is suggested that the psychologists assess measures such as the OQ-45 or other quantifiable measures as part of each follow-up session to document mood, quality of life, suicidal ideation, and overall mood improvement. It is highly recommended that measures such as blood pressure, weight, cholesterol, and pulse are included as part of the assessment phase.

The final phase is the *Intervention phase*. The focus of the intervention phase as described by Rowan and Runyan (2005) is on designing a treatment that reduce symptoms. Thus, to this end, one would assist the patient in identifying an exercise routine that reduces depression and anxiety and enhances relaxation for the patient. Once the patient is cleared by their primary care provider, a consultation with exercise specialists and/or physical therapists assist in identifying the ideal exercise for the patient. At many large health care systems, a variety of daily group based programs are offered. Programs such as low intensity walking, jogging, swimming, and yoga are common. As part of a holistic approach, it is also recommended that each patient is evaluated by a registered dietitian to evaluate the patient’s meal plan.

Hi Ms. Smith, I am Doctor _____ . I am a psychologist here and part of the primary care treatment team. How are you doing today? Well Ms. Smith before we get going too far, I would like to discuss with you how we’re going to use exercise to help manage you depression and anxiety. Is that o.k.? I will see you each week for about thirty minutes and during each session we will review what the previous week’s exercise was like, how you did, what worked for you and what are some concerns or room for improvement you might have. What do you think about this so far Ms. Smith? Very well, let’s talk about your depression and anxiety symptoms. What seems to be bothering you the most and can you tell me why? What type of exercise do you think would be best for you on the list we have for you to take a look at? O.K. Walking appears to be your choice and that is fine. Here is a handout for you on healthy, low intensity walking and how to get the best health benefits out of walking. I would like for you to do a couple of things to help track how you’re doing. I have a mood chart that is easy to use and it will track your mood before and after exercise each day. When you come back each week, the nurses will weigh you, take your vitals and then we’ll get started and review your progress each week. Also when you come in each week the clerks will set you up to take 1 or 2 quick test on the computer to just see how you’re doing. Is that O.K.? Well, Ms Smith, do you have any questions? O.K. I will see you next week.

Fig. 16.1 Introduction of the exercise intervention

Exercise as an intervention in primary care can be either an individual intervention or a group based intervention. The decision to choose either approach typically will be decided by available resources and the patient's preference. James, Folen, Page, Noce, and Britton (1998), offered a more robust group model as he and his colleagues partnered with a family medicine department and provided inpatients with intensive group based exercise supervision 7 days a week. Although their results were impressive, costs alone would perhaps yield a program as such in today's insurance market as unfeasible.

Case Illustrations of Exercise as an Intervention in Primary Care

Case 1. John is a 48-year-old, white, married, male executive who is self referred for the treatment of anxiety. He does not want to be seen going into the mental health clinic so he spoke with his doctor about "getting help" in his family medicine department. John was referred by his PCM after basic labs were assessed by his medical team. When John presented to the psychologist's office John asserted that he was motivated to try something new because he did not want to discuss "personal stuff" but rather wanted alternative interventions to treat his anxiety. His symptoms were insomnia, trouble concentrating at work, anger outbursts, weight loss, and a general sense of nervousness. John was screened and he was diagnosed with an adjustment disorder with anxious mood and referred to the psychologist office. John described his sense of being "always over worked and stressed." John was not motivated to receive psychiatric medications but rather was interested in using exercise as an intervention. Baseline OQ-45 measure were taken and John chose to participate in a morning swim club at nearby YMCA five mornings a week. John was given a mood log to document his mood before and after his exercise session. He was also referred to a dietitian to determine if his meals were related to his increased anxiety levels. Within 3 weeks, after swimming 5 days a week, John reported was losing weight, reported a decreased level of anxiety, improved sleep and his anxiety outbursts decreased as well.

Case 2. Mary is a 60-year-old African-American, divorced female who was referred by her doctor because Mary was depressed, angry at life and did not want to be seen by a psychiatrist again. She was tried on Prozac and Paxil a year ago and Mary reported that she "hated it." When asked why she said "that medication is for crazy people and I didn't want it but my doctor told me to try it ... I just stopped taking it after a while." At the introduction and the first meeting Mary described her feelings of "being all alone" after her children went away to college. Mary reported that her routine was to work, eat, sleep, eat and/or just lay on the sofa when she was at home. She felt empty with "nothing to look forward to at all." Although Mary had not exercised in years, and was approximately 30 pounds overweight she expressed a desire to exercise and "get going again in life." We agreed that walking would be the best choice for her and also that a group model would also serve to build support for her.

Mary was given a list of exercise programs in her community with all available contact information. Mary lab work and vitals were collected as well as baseline tests by the psychologist. Mary found a walking club at a nearby church in her community. Diligently she documented her mood before and after her walk each day after work. By week three Mary began to exchange phone numbers and e-mail contact information with other female participants in the church's walking club. She presented each week for follow-up and at week 10 Mary had lost 10 pounds coupled with a decrease in her blood pressure and improvements in her depressive mood.

Case 3. Kerry was a 40-year-old, married, white female who had three children, ages 5, 8, and 10. Kerry arranged to see her primary care manager (PCM) because she felt that her and her family's lives were out of control. She told her PCM that her hair was falling out because she was "so stressed" and depressed. Kerry felt that because of "life taking over" she had little time with her husband and her children and that they rarely ate together or spent time together as a family. Kerry's cholesterol and blood pressure were described by her PCM as dangerously high and she wanted to begin an exercise routine to manage her stress, depression and "get healthier."

During the introduction phase Kerry felt that she needed to do something not only for her but an exercise routine that she could do with her children and her husband. Given that Kerry resided in a warm climate, she believed that a combination of two to three different types of exercises would be ideal. All baseline measure was taken and reviewed. Kerry felt that cycling and walking would be a good starting place because her "kids already had bikes." Her family would walk on Monday, Wednesday, and Friday for 30 min and use the bikes on a trail near their home on Tuesday and Thursday. Kerry encountered some resistance from her two oldest children but by the weeks end all family actively participated. Kerry documented her mood before and after each exercise session and her progress was charted each week during the follow-up session. Her moods, "stress," and life began to return to a healthy level.

Case 4. Tim, a 45-year-old, married, self-employed business man was diagnosed with bipolar disorder when he was 35. He believed, looking back that he had this disease for many years but was self-medicating himself with alcohol. He was now alcohol free but struggled with depression on occasion even though he was taking his lithium for his bipolar disorder as prescribed by his psychiatrist. Over the years he had gained 50 pounds and was now on additional medications for type II diabetes. Tim talked with his PCM about additional non-medical interventions he could try in addition to the lithium to "help manage" his depressed mood.

Tim was motivated to exercise and he did not want to be involved in any group activities. He was provided with a handout that identified the numerous walking and biking trails near his home. He believed that walking out on a tree lined country trail would "mellow" his moods and sooth him. Tim began walking with his wife every day after work on a variety of country trails. Even though he did not lose weight, he was pleased that his weight gain had stabilized. His extreme depressive episodes became more infrequent and Tim began to report that he felt better about himself.

Case 5. Kendra was a 29-year-old, single, Hispanic American female accountant. She was referred by her PCM and she was not motivated to try exercise as an

intervention to help manage her depressed affect and anger outbursts at work. Her experience with exercise was limited to her High School P.E. which she reportedly “hated every minute of it.” During the introduction phase Kendra was asked to express her reservation about exercise. The benefits of exercise related to mood improvement and the reduction of stress and anxiety symptoms were explained to the patient. Kendra remained unimpressed but she agreed to try aerobics classes which she actually enjoyed. Initially Kendra agreed to participate in only one aerobics class and would “take it from there and see how it goes.” She signed an adherence contract (see Table 16.1) and began to increase the classes to three times a week. Her mood improved as her anger outbursts began to decrease.

Summary of Exercise Interventions: Why Were the Exercise Interventions Effective?

Often, behavioral health care providers lament about their unsuccessful attempts to increase healthy exercise in their patients. PCM, nurses, psychologists, and the collective health care team typically direct their patient “exercise for thirty minutes,

Table 16.1 Exercise contract

I _____ am interested in
 using exercise as a way to improve

I agree that I will do the following exercise

at the following days/times each
 week _____

and I will keep a mood and feelings log before and after I exercise.

Name Date

three times a week.” But we find that these professionals are chagrined when the patients retorts “but doctor I wasn’t able to do any workouts this week.” The PCM or health care professional, sighs, and scratches his or her head and ask quietly to him or herself “why won’t she just workout a little?” Or “I’ve told John over and over to exercise, but he just won’t . . . I don’t get it.”

In Table 16.2, the authors have highlighted some “tips” to getting patients in the primary care clinic. As discussed in this chapter, it is well documented that exercise alone can reduce anxiety and depressive symptoms as well as manage type II diabetes, high cholesterol, and essential hypertension. Not only do help care professionals very mindful of this but so are the patients who present in the primary care clinics. Why then is it so difficult to get patients to exercise?

1. **Be realistic.** Most of the patients seen in primary care are there because they were never a disciplined and serious athlete. Thus, setting up an initial goal of asking an obese patient who is depressed and has chronic pain to “work out for 45 minutes every day” is setting that patient up for failure and the PCM for disappointment. Set small and obtainable goals that the patients can reach early on in the program.
2. **Try just walking.** If done correctly walking rather than jogging can be very efficacious and it is less painful on the back and joints. The older, heavier, and more diseases a patient has, the less likely jogging will be effective because of pain.
3. **Don’t be a lone wolf.** Building social support with exercise is critical. The more you can include a workout partner the chances increase that that patient will continue to exercise.
4. **Do what’s easy first.** Patients should be encouraged to do an exercise that is very easy for them to do first in order to getting them going in the right direction.
5. **Use a mood log before and after exercise.** This step will “connect the dots” for patients and allow them to see in a concrete way how their mood improves after exercise.
6. **Keep it close.** The closer the place where a patient will exercise, the higher the likelihood he/she will actually work out. In other words, do not ask patients to drive 45 min to an hour to go exercise. Keep it simple and find nearby resources for your patients.

Table 16.2 Tips to improve exercise compliance

1.	Be realistic
2.	Try just walking
3.	Don’t be a lone wolf
4.	Do what’s easy first
5.	Use a mood log before and after exercise
6.	Keep it close
7.	Include the family
8.	Tie exercise to mood and health
9.	Build in healthy rewards
10.	Do some form of exercise every day

7. **Include the family.** The more you can build family support for your patient, the more you will enhance a positive outcome.
8. **Tie exercise to mood and health.** Regularly discuss with your patients not only how their mood has improved but discuss how their blood pressure, weight, glucose levels, etc. have improved. This will magnify the power of the exercise intervention.
9. **Build in healthy rewards for the patient.** Most of these patients will only know how to use food or alcohol as a reward for achieving a goal. At the onset of treatment assist the patient in selecting frequent and healthy rewards for continued exercise.
10. **Do some form of exercise every day.** The “experts” say exercise three times a week. The reality is that this does not work for most patients. To be effective, exercise should be built into one’s daily life and seen as something we do every day much like taking a shower. For example just because John took a shower yesterday does not mean that John does not have to take a shower today. Ideally, the type and intensity of the exercise should be varied. But the goal is encourage patients to be active and do healthy exercise each day.

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Chapter 17

Promoting Active Treatment Engagement in Child and Family Therapy

Michelle R. Byrd, Rachel Kentor, and Megan Perez

The past decade has seen a proliferation of evidence-based practices in the sub-discipline of child and family therapy, with upwards of 250 therapies and techniques having some level of empirical support (e.g., Chorpita, Bernstein, & Daleiden, 2011). However, despite the existence of myriad efficacious therapeutic techniques, there remains a vast chasm between children in need of care and those actually receiving adequate psychological services. Research indicates only an estimated 25% of children are receiving the level and/or type of care clinically indicated (Manion, 2010; NIMH, 2001). To this end, it is estimated that fewer than 50% of children with existing mental health diagnoses receive any form of mental health care (Costello, Mustillo, Erkanli, Keeler, & Angold, 2003; Merikangas et al., 2010). Alarming, the extant literature suggests that children who may be the most vulnerable by virtue of family circumstances or presenting diagnosis may also be those least likely to receive adequate care (e.g., Bell & Doucet, 2003; Gopalan et al., 2010; Snell-Johns, Mendez, & Smith, 2004). For example, one study showed that in cases of families receiving treatment related to child abuse and neglect, upwards of 70% of families dropped out of treatment prematurely (Meezan & O'Keefe, 1998). Although there are many points of failure in the current prevailing system of behavioral healthcare, one obvious barrier to families receiving the care they need is failure to engage in treatment at several key junctures.

The concept of treatment engagement in child and family psychotherapy is, by definition, more complex than individual adult psychotherapy given the unique nature of the therapeutic relationships forged between therapist, parents or other

M.R. Byrd, Ph.D. (✉) • R. Kentor, M.S. • M. Perez, M.S.
Department of Psychology, Eastern Michigan University,
301E, Mark Jefferson Science Complex, Ypsilanti, MI 48197, USA
e-mail: mbyrd@emich.edu; rkentor@emich.edu; mnperetz7@gmail.com

caregivers, and the identified child or adolescent client themselves. Moreover, it is not uncommon to have other adults who are important in the child's life be invested and sometimes directly involved in the treatment as well, such as grandparents or teachers. In addition, in many states, adolescents of a certain age may seek treatment on a limited basis independently and without parental knowledge or consent; these clients may be uniquely naïve to the process of appropriate treatment engagement because of their developmental stage and relative inexperience in active help-seeking. Because of the multiple constituents involved in this intricate and often evolving web of treatment provision, therapists must be particularly mindful of whom the key decision-makers are with regard to initiating and continuing treatment and take care to manage the demands of each of these interested parties adequately and appropriately.

Defining Treatment Engagement in Child and Family Therapy

Several researchers have attempted to identify key markers of treatment engagement. In their seminal early review of the behavioral pediatric treatment engagement literature, McKay and Bannon (2004) outlined the general milestones of a child entering traditional outpatient mental health treatment as being: (1) the recognition of a problem either by the child's parents or other invested adults (i.e., grandparents, teachers, coaches, etc.); (2) the family learning of specific available mental health resources in the form of a direct referral or individual research on available providers; (3) a parent or other caregiver making contact with the potential agency or provider, though this is sometimes done by the client themselves, in the case of a mature adolescent; (4) parents or other caregivers presenting the child for an intake appointment; and (5) relevant family members maintaining ongoing appointments as long as clinically necessary.

These events should be viewed as necessary but insufficient markers of treatment engagement, as they represent a minimal or superficial level of engagement (Staudt, 2007), however, these are useful data points in that these are readily and objectively measured and failure to reach any of these milestones should serve as a clinical "red flag" to therapists. If a family misses any one of these steps, they are, by definition, disengaged. Moreover, providers must remember that these steps are not necessarily linear and that significant disruptions may occur at any phase of treatment seeking. Staudt (2007) proposed a more complete model of treatment engagement that builds upon the behavioral markers described by McKay and Bannon but also emphasizes attitudinal markers of engagement.

Staudt (2007) defines the attitudinal component of engagement as being, "the emotional investment in and commitment to treatment that follow from believing that it is worthwhile and beneficial," (p. 185). Families who have this level of engagement perceive the potential benefits of therapy to outweigh any potential costs or drawbacks and embody an "all in" level of involvement in the therapeutic process. Yatchmenoff (2005) developed a helpful self-report assessment tool to

determine a family's level of attitudinal engagement that can be used by clinicians to gauge a family's attitudes and beliefs in order to have the opportunity to improve motivation for treatment before offering the evidence-based treatment protocol itself and having a higher probability of treatment failure. Toward this goal of understanding and intervening upon attitudinal factors related to resistance, it is useful for clinicians to understand the predominant theory of help-seeking, the Transtheoretical Model of Behavior Change (Prochaska & DiClemente, 1983).

Stages of Change

Parents' initial decision to seek service is profoundly influenced by their beliefs about the child's problem, perceived value of treatment, perception of barriers, and past experiences in service systems (Kerokian, McKay, & Bannon, 2006; Owens et al., 2002; Raviv, Sharvit, Raviv, & Rosenblat-Stein, 2009). For example, the odds of a child being brought in for an initial appointment decreases if parents report skepticism about the helpfulness of treatment (McKay, Pennington, Lynn, & McCadam, 2001). The Transtheoretical Model of Behavior Change first introduced by Prochaska and DiClemente (1983) maps on well to the child treatment engagement processes outlined by McKay and Bannon (2004) and Staudt (2007) and provides a framework for understanding some of the barriers with regard to treatment engagement described above, particularly within a stepped care model of care, as we discuss in detail below.

The transtheoretical model outlines the stages of change individuals attempting to engage in behavior change proceed through at differing rates. Research has analyzed the relationship of these stages to behavior change, as well as identified successful interventions designed to improve commitment to therapy for each stage (Norcross, Krebs, & Prochaska, 2011; Prochaska & DiClemente, 1983). Throughout the process of change, therapists should assess for the client or family's stage in order to best match the intervention and recognize the potential for relapse (Norcross et al., 2011). Five stages are now included in the model: precontemplation, contemplation, preparation, action, and maintenance (Norcross et al., 2011). This chapter will utilize this theory as a means of helping therapists conceptualize how to best assist children and families engage optimally in treatment in order to achieve maximal therapeutic benefit.

Precontemplation, the first stage of treatment seeking in the transtheoretical model, represents a time in which clients, in this case children or families, are not yet ready to make a change, moreover, families may not even recognize that a change in their behavior is necessary. Instead, they may view the problem being exogenous, context-specific, or transient, and thus assume that others or factors in the environment need to change; however it is likely that family, friends, or teachers recognize a problem as being within the family system at this stage, as they have the benefit of perspective being outside of the immediate family along with peer comparisons, in the case of teachers, pediatricians, etc. (McConaughy, DiClemente,

Prochaska, & Velicer, 1989; Norcross et al., 2011). The goal of moving parents and children through this phase of help-seeking is to help them make an educated decision about whether or not behavioral care would likely be helpful to a given child at this moment in time.

In the context of child and family therapy, it is at this stage that invested adults other than the child's parents may bring their concerns to the primary caregivers. For example, in the case of ADHD, it is commonly the case that teachers and/or school counselors express concern about a child's abilities before parents are themselves actively thinking about having their child tested or treated. Many parents describe these conversations as "reality checks" from their trusted support network that validate suspicions that parents may have had that their child is falling outside of expected norms on some attribute. Sometimes, particularly in families who already have a history of successful help-seeking, prospective clients will seek the opinion of a mental health professional to determine whether the identified problem(s) is considered within clinical range and, if so, if treatment is indicated. However, when parents receive feedback about their child's behavior from sources that are either not trusted and/or the feedback itself is perceived as unsolicited, ignorant, critical, or judgmental, this may create more resistance and stall the help-seeking process.

Contemplation is the stage in which clients are now aware of a problem, and are considering changing in the future or within the year, however the family has yet to take any action or make changes (McConaughy et al., 1989; Norcross et al., 2011). It is at this stage of change when it seems that cognitive or perceptual barriers to engaging in treatment are most likely to become significant impediments. Parental perceptions of barriers to receiving care beyond simple logistics, including beliefs about the therapeutic process and expectations for therapy, have been shown to increase the amount of time that families delay actually getting care (e.g., Garcia & Weisz, 2002; Nock & Kazdin, 2001). This stage can be characterized as "watchful waiting," and appears to be a stage at which many families stagnate in the help seeking process as they wait to see if their child's concerns resolve as a result of normal development or relevant changes in the environment. For example, many families will wait to seek treatment if a problem is brought to light during the Spring months with the notion of seeing if the problem is alleviated during the Summer months when many schools are out of session and stress is perceived to be lowered for children in the USA. However, we know anecdotally that this pattern results in a surge in child referrals to outpatient clinics in late September/early October when evidence emerges that problems did not spontaneously remit over the summer nor were the concerns the unique opinion of the child's teacher from the previous year.

Children and families within the third stage of *Preparation* have made a decision to change in the near future and, in fact, may have started to make small changes on their own in an attempt to reduce symptomatology or suffering (Norcross et al., 2011). It is common in the preparation stage that families are directly seeking referrals for behavioral health specialists and evaluating the feasibility of various help seeking methods. Oftentimes, logistic concerns play a significant role in determining whether families are able to successfully engage treatment at this juncture. For example, if

clinics prove inaccessible due to location or office hours, these barriers may prove sufficient to inhibit treatment initiation, particularly in low-resource families who cannot afford transportation or childcare for other children in order to receive care for a target child. Related, many clinics have a substantial waitlist, which can be an additional impediment to “striking while the iron is hot,” particularly for the most vulnerable of families.

Action represents a stage in which the family ideally fully engages care to address behavioral health concerns, often involving making an intake appointment and attending initial treatment sessions either within an existing care network (such as a primary care office) or in a specialty mental healthcare setting (Norcross et al., 2011). This phase of change occurs within the first 1–6 months of initiating contact with a mental health provider, in which the client’s actions are effortful and hopefully lead to a reduction in suffering. This is the extended phase of therapy in which the majority of interventions should be engaged and the most change should occur, concluding with successful termination of regular treatment as indicated by improvement in independent functioning (Norcross et al., 2011; Prochaska & DiClemente, 1983). When the concept of traditional psychotherapy is brought to mind, it is the action phase that is the primary point of reference.

The *action* stage of change also most closely resembles traditional psychotherapy within a stepped care model (O’Donohue & Draper, 2011). However, it is much more likely within stepped care that traditional psychotherapeutic services will be delivered in novel ways, such as via HIPAA-secure internet server, within an integrated care practice, or in group vs. individual formats.

It is at this stage of change that an extraordinary proportion of families either fail to fully engage or disengage from treatment. Ongoing attrition rates as treatment progresses have been shown to be correlated with parents feeling overwhelmed, experiencing multiple stressors (Friars & Mellor, 2009; Harrison, McKay, & Bannon 2004), and other family difficulties (Gopalan et al., 2010). Johnson, Mellor, and Brann (2008) found the highest levels of dropout occurred for families with higher levels of psychosocial difficulties and problems involving family dynamics. Only about half of families who make an initial contact with a behavioral health provider ever begin treatment (Pellerin, Costa, Weems, & Dalton, 2010) and the “no-show” rate at intake appointments is very high, ranging from 48 to 62 % of appointments (Harrison, McKay, & Bannon, 2004; McKay, McCadam, & Gonzales, 1996). Moreover, even once families initiate treatment and attend their first session, if a sufficient therapeutic alliance is not forged quickly, treatment engagement will not continue (Kerokian et al., 2006; Robbins et al., 2006). When attrition occurs, it tends to happen within the first few sessions (Masi, Miller, & Olsen, 2003). In fact, when therapeutic alliance is not achieved and parents feel disrespected by their child’s therapist, they are not only more likely to drop out of therapy prematurely, but are also six times more likely to doubt the utility of future attempts at behavioral interventions (Kerokian et al., 2006).

Further, evidence also suggests that low-income urban families are less likely to initially engage and/or be retained in treatment services (McKay, Stoewe, McCadam, & Gonzales, 1998; Snell-Johns, Mendez, & Smith, 2004). The vulnerability of these

families is amplified by interrelated adversities in their broader social ecology including issues such as poverty, social isolation, community violence, racism, and lack of access to resources (Attar, Guerra, & Tolan, 1994; Bell & Doucet, 2003; Coulton & Pendey, 1992; Gustafsson, Larsson, Nelson, & Gustafsson, 2009; Ingoldsby & Shaw, 2002; Stern & Smith, 1995; Stern, Smith, & Jang, 1999; Tolan & Henry, 1996). One study found the average length of treatment being as low as a mean of 3.5 sessions in urban low-income populations (McKay, Harrison, Gonzales, Kim, & Quintana, 2002) with only 9% of cases persisting in treatment for 12 weeks, considered to be the minimum length of treatment in most treatment outcome studies (McKay, Lynn, & Bannon, 2005). In more socioeconomically diverse samples, children have been found to receive significantly more sessions, an average of 13.8 (Brookman-Frazee, Haine, Gabayan, & Garland, 2008). Independent of demographic predictors, children who exhibit more externalizing disorders are more likely to drop out of treatment prematurely than are children who are anxious or depressed (Baruch, Vrouva, & Fearon, 2009; Burns, Cortell, & Wagner, 2008).

In highlighting these treatment engagement issues related to the *action* stage of change, two patterns emerge. First, children and families are very likely to dropout as a result of the same types of problems which likely gave rise to treatment seeking in the first place. Secondly, some of the barriers that families face in seeking and maintaining treatment are difficult systemic problems to address that are outside of the scope of psychotherapy, such as poverty, racism, and community violence. Several researchers have attempted to identify evidence-based strategies to improve engagement during the active phase of treatment, as will be illuminated later in this chapter.

Lastly, the *Maintenance* phase of change represents the stage at which the child and family continue to maintain the behavior changes, beyond 6 months, while actively trying to avoid relapse (McConaughy et al., 1989; Norcross et al., 2011). In this final stage of therapy, the therapist acts as a consultant, allowing the client to lead the process (Norcross et al., 2011). It is common in traditional psychotherapy as well as in stepped care models to taper down frequency of sessions and, in the stepped care model, even the duration of sessions. Many client families will benefit from “booster” or “check-in” sessions planned for months after the formal cessation of an episode of care in order to crystallize gains and prevent recurrence of previous concerns and/or new problems from arising. Within a model of intermittent treatment throughout the lifespan, once a person has established a therapeutic relationship with a given behavioral health specialist, they may reenter treatment for even briefer episodes of care (1–2 sessions, phone consultation, etc.) as needed for years to come, still within the maintenance phase of change.

To summarize the implications and application of the transtheoretical model, interventions should be tailored to match the client’s current stage of change; resistance is said to occur when the therapist is working at a different stage than that of the client. It is not until the client is in the *action* stage that evidence-based interventions such as contingency management and stimulus control should be implemented (Prochaska & DiClemente, 2005). The stages which occur before action are thought to bring the client and family to a level of readiness for treatment in order to optimally benefit and the maintenance phase is thought to preserve treatment gains with the option of moving back into the action phase if clinically indicated.

Unfortunately, clinicians aren't always afforded the opportunity to gradually move with clients along the continuum of change. As a result, interventions are sometimes implemented despite clients' unpreparedness for change. In an integrated care setting, for example, parents might be ready to receive components of parent management training (PMT) upon the first patient encounter with a behavioral health specialist because they already feel comfortable in the setting and are directly asking for assistance. However, in a traditional outpatient mental health setting, it may take many sessions before the same treatment components to be delivered, as clients and their parents may not hold the same expectation for immediate prescription for change in this context. Likewise, we would anticipate resistance, if not attrition, if clients' families were ready for the action phase of treatment and their therapist was engaging as though the family was still in precontemplation or preparation stage.

Another common source of resistance according to the transtheoretical model is a mismatch of stages of change between clients. In marital therapy, for instance, one spouse is often in the *contemplation* stage while the other is in *pre-contemplation* (Prochaska & DiClemente, 2005). The same discord can often be noted between parents and children. When treatment is initiated due to child oppositional behavior, parents are likely several stages ahead of their children in respect to readiness for change. The reverse may be true in some cases of internalizing disorders. When an adolescent is being treated for depression and/or anxiety in the context of familial discord or environmental stressors, for example, the child may themselves be in the *preparation* or *action* phase despite parents' *pre-contemplative* state. The latter of these two situations is arguably a greater obstacle to treatment, given that environmental control is largely—and often, exclusively—parental responsibility.

Although these mechanisms of resistance do frequently infiltrate clinical practice, we should be wary to consider this resistance to be inherently problematic. Patterson and Chamberlain (1994) posit that resistance is an inherent component of treatment, and reflects the inability of individuals to change their own behavior, a natural occurrence that permeates human existence. In treatment, this resistance serves to change the behavior of the therapist, whose response can, in turn, modulate the resistance to alter treatment outcomes. In a process referred to as the *struggle hypothesis*, teaching or confronting behaviors of the therapist are predictive of a subsequent resistant reaction by parents during parent management training (PMT), widely considered to be one of the most empirically robust treatment programs for children and their families (Patterson & Chamberlain, 1994). This resistance reflects that which is predicted by the stages of change model. However, this resistance is thought to then stabilize or decrease, presumably due to parents' recognition of treatment gains as treatment progresses and the interventions prove successful. Therapists, both in traditional settings as well as in stepped care models, can enhance parental recognition of treatment progress by implementing ongoing assessment with feedback during each contact with client. Improvement in child behavior serves as the most powerful reinforcer of parent behavior and engagement in treatment. These changes in resistance, then, are postulated to be "an indirect determinant for successful treatment, and changes in parenting practices are considered to

be a direct cause” (Patterson & Chamberlain, 1994, p. 53). It is additionally important to note that a dose-response curve is evident for the relationship between parental resistance and treatment outcome. If no struggle exists, then there is likely to be little-to-no change; however, resistance levels that are too high or continuously increasing will likely result in similarly unsuccessful treatment.

Interventions to Increase or Improve Treatment Engagement with Children and Families

Several major reviews of the treatment engagement in child and family therapy have been undertaken (e.g., Gopalan et al., 2010; McKay & Bannon, 2004). While we applaud the good work of both the researchers who conducted the individual studies as well as those who provided competent reviews, this body of work is limited in that virtually all of the interventions that have been evaluated focus solely on the action phase of change. This emphasis neglects the continuum of help-seeking and the opportunity for mental health professionals to affect change leading to productive therapeutic work. As such, we have attempted to not only review the relevant studies, but also to suggest some ideas for improving engagement at stages other than action phase of change. The next section of this chapter will review the most commonly utilized and evidence-based strategies to improve treatment engagement at all phases of the change process.

As elucidated by the transtheoretical model, treatment engagement begins way before clients ever meet with a therapist, particularly in a stepped care model. We must be mindful that public awareness of mental health issues and, very importantly, the availability of evidence-based techniques and treatments, may very well be critical factors in moving children and families through the stages of change optimally.

Treatment engagement truly begins before families ever fully recognize their need for treatment in the precontemplation and contemplation stages of change. For clinicians working within a context that offers the financial and creative support for such endeavors, media campaigns are an effective means of changing peoples’ beliefs and attitudes about seeking behavioral care, as well as conveying information with regard to when treatment is warranted. While this public marketplace is dominated by drug companies, our own code of ethics does not prohibit this form of information dissemination, psychologists have simply been limited by access to resources. Public service announcements should serve to provide accurate information about various common diagnoses, as well as the availability of efficacious treatments while decreasing misconceptions and stigma about these domains.

When families present for treatment in the *precontemplation* phase, therapists are well advised to use methods to increase awareness and knowledge of the potential problem area while focusing on building rapport (Norcross et al., 2011). Parents will frequently benefit from psychoeducation at this stage of change, particularly aimed toward understanding the distinction between clinical and nonclinical levels

of behavior (indicative of treatment response) and relevant etiological information in an effort to reduce the shame and blame sometimes associated with the discovery of a potential problem. Clinicians may find referring parents to particular vetted websites or self-help books a useful adjunct to treatment in precontemplation to assist in building a family's fund of knowledge in a particular area and with regard to mental health services more generally. Children must not be left out of this information loop, as some research has indicated that children harbor many misconceptions about mental health problems and treatment which cause them to be more resistant to and even afraid of psychotherapy (e.g., Byrd & Nix, unpublished manuscript). As such, it is important to offer developmentally appropriate psychoeducational materials either via television ads, regular mail, or websites. In addition, clinicians may choose to offer informational informal training opportunities in their respective communities on particular topics such as distinguishing normative vs. clinical anxiety or managing behavior problems. These opportunities not only provide a great educational service to the community, but also help to build familiarity with that therapist in particular and potentially clinicians more generally for an unexposed population.

Often times in traditional models of therapy, parents presenting their child for a psychological assessment or with blatant ambivalence about initiating therapy will be encouraged to keep a diary card or engage in another form of tracking the behavior of interest over a specified period of time and then return to the therapist in 1–2 weeks to review and further assess the necessity of treatment at that time. Within a stepped care model, it is very likely that at this stage parents and children may not be in direct contact with a specialty behavioral health provider, but, should be exposed to information about mental health concerns and normative psychosocial development within their naturalistic environment, such as through their relationships with primary care providers and teachers. To this end, the model calls for a cultural shift of increased public health awareness of mental health, including educating our nation's children about this aspect of their overall well-being such that they will be more likely to recognize and report concerning symptoms when they arise, much the way children are already taught to recognize and report physical complaints to their parents, teachers, and other caregivers.

Related, it is important that healthcare providers and educators well known to potential clients and their families are knowledgeable about markers of behavioral concerns and trained to both make meaningful observations about potentially problematic child behavior but also to be able to have conversations with families about these concerns in a way that is non-stigmatizing and supportive. The attitudes and beliefs of these helping professionals likely influence those held by children and caregivers (though this has not been directly studied to our knowledge), so it is critical that the messages conveyed are accurate and promotional in nature.

In stepped care and, specifically, in integrated care, it is important that primary care providers and treatment extenders are able to either provide directly or provide a bridge to behavioral interventions as quickly following the discovery process as possible. This may necessitate having behavioral health resources available online through the trusted portal of the primary care office or patient-centered medical

home, having an accessible and well-stocked lending library of evidence-based psychoeducational and self-help materials, and will likely also mean having a member of the in-house multidisciplinary team who is a mental health professional.

If families are already familiar at some level with a behavioral health provider at the point at which they are contemplating care and the family schedules a consultation or intake appointment, it is recommended that the clinician further focus on increasing awareness, but this method can be more Socratic in nature (Norcross et al., 2011). This stage is an opportunity to begin or enhance client education, involving both children and parents as developmentally appropriate, as they are likely more willing to accept information directed toward change (Prochaska & DiClemente, 1983). This is a critical phase of treatment seeking within the stepped care model, as many families can benefit from self-directed psychoeducational resources provided through web-based or traditional print formats. As such, it is important that helping professionals such as teachers, nurses, and clergy have knowledge of accurate and accessible resources to which to direct families who are questioning the need for more intensive services. Moreover, providers within the primary care environment may prove valuable to answer simple questions the family may have about developmental appropriateness of particular behaviors and clinical thresholds for help-seeking.

Likewise, as parents and children move into the contemplation and preparation stages, it is important that they are able to find competent mental health professionals either within institutions already known to them or easily accessed. In planning where to set up mental health resources, location is a critical factor to promote treatment engagement. For example, many university training clinics offer low or no fee clinical care. However, they are also commonly housed in the heart of campus, sometimes inside academic departments, which may be a significant barrier to treatment for families who may be intimidated by the academic environment. Even more practically, parking in these environments is notoriously bad and expecting families to pay for parking on top of payment for treatment may well be unfeasible.

Increasingly, behavioral health providers are housed outside traditional clinic settings and instead ensconced in other community-based settings that have less stigma attached. For example, some clinicians have begun to rent space within community or women's centers that also offer adjunctive case management and financial support services with which families are already engaged, thus providing a version of wraparound care that aims to decrease barriers to access for some of the most vulnerable families. Some progressive school districts have even extended beyond traditional school psychological offerings and have created quasi-clinics serving both children and their parents within the school setting and have demonstrated up to 25% enhanced treatment engagement at initiation and vastly reduced ongoing attrition by doing so (Atkins et al., 2006).

From a technology standpoint, as families consider their options for behavioral care, having an engaging web presence is critical to creating reasonable and accurate beliefs and expectations about treatment. Transparent information is key in helping families build a relationship with a practice before ever stepping foot inside its walls, so having up-to-date photos of clinicians, the clinic building, and the interior of the

clinic (e.g., waiting room, treatment rooms, etc.) may be helpful in putting families at ease by giving them accurate expectations about what they will see upon arrival. In addition, practices should take care to describe services rendered in the context of the evidence base for their model of care. As a move toward helping families engage treatment at the level most appropriate for their needs (consistent with a stepped care model), psychoeducational and appropriate self-help materials should also be made available on the clinic website. Parents and children should feel that they have been provided with sufficient information about the intervention process to make an educated decision prior to moving toward the action of seeking psychological services for their child.

In a stepped care model, this stage of help-seeking would be an opportunity for existing helping professionals, such as pediatricians, to refer parents and children to behavioral health professionals within an integrated system (i.e., a patient-centered medical home), preferably within the same appointment as the decision is made to pursue some form of treatment. Doing so has the potential to improve engagement at this stage of change as the family does not need to go outside of its existing network of care in order to begin the process. For families who already have a relationship history with a mental health provider (as in the case of intermittent therapy throughout the lifespan), they may be ready to write and tailor a treatment plan with guidance from the therapist (Norcross et al., 2011).

As families take the steps to garner care by moving into the action stage of change, whether that be introducing the problem within the context of a primary care pediatric visit or seeking specialty behavioral healthcare services, there are data to suggest that therapists and clinic administrators should be using specific techniques to improve engagement as soon as the family enters the system. Within the first phone call to make an appointment, it is important that the family representative making the call feel understood and not judged, as well as having any logistic barriers addressed (e.g., McKay et al., 1996). Related, telephone reminder calls and automated systems that allow clients to confirm, modify, or cancel appointments have been shown to lead to increased rates of attendance at first therapy appointments (Tambling, Johnson, Templeton, & Melton, 2007). The “next frontier” in technological engagement before the first session and in-between subsequent sessions is the use of automated text messaging, which has been already tested and proven effective in primary care settings but has yet to be investigated in the context of specialty mental health (Downer, Meara, Da Costa, & Sethuraman, 2006).

Several studies have found decreased rates of attrition by directly addressing engagement with child clients and their caregivers within the first sessions. Prinz and Miller (1994) compared two parent management training (PMT) protocols, one of which was enhanced by the inclusion of in-depth discussions of parental expectations for treatment, reactions to being in treatment, and other personal stressors not typically addressed in PMT. The enhanced family treatment model had almost 20% less attrition than the standard version and this difference became more pronounced among families considered to have “high adversity,” with a 50% difference in attrition rates. Similarly, McKay and colleagues conducted a series of studies (1996, 1998) aimed at improving engagement through the use of a specific interviewing

strategy employed either within the first session of care or on the phone prior to the first session. More specifically, McKay et al. focused their efforts on providing psychoeducation about the function of therapy and the respective roles of clients and therapists while clarifying any client misperceptions of these concepts. In their 2014 intervention study, Warnick, Bearss, Weersing, Scahill, and Woolston demonstrated a statistically significant decrease in attrition in early sessions by improving early identification of target problems through improved assessment, encouraging active and collaborative treatment planning that included both parents and youth, and patient-centered prioritization of these treatment targets such that the problems most pressing to the child/adolescent and/or parent were treated first, rather than relying on clinician judgment, as would be traditional. Although additional study of these techniques is needed, they are consistent with a cognitive-behavioral approach to treatment and may be considered a useful bridge to evidence-based practice, much like Motivational Interviewing (Miller, 2004). Moreover, these strategies are particularly amenable to a stepped care model which would emphasize targeted intervention driven by client complaints, rather than a lengthy rapport-building phase.

In the *Maintenance* phase of change, although clinicians no longer have regular or ongoing contact with their clients, they may still schedule booster sessions for weeks or months in the future and there are still useful mechanisms for maintaining engagement even beyond that time frame. At the time of termination, clients and families should have full knowledge of clinically relevant cues to return to treatment, including both symptoms and potential major stressors. From the perspective of the child or adolescent, termination should feel more like saying, “So long, see you later!” rather than, “Goodbye-forever.” This phase of care is also an opportunity for therapists to contact other members of their client’s multidisciplinary team, including primary care providers, to summarize the episode of behavioral care and indicate when/if the client should return to receive more services. Doing so helps to maintain a systemic web of care and allows for expedited future contact when the need arises. Some therapists will also maintain their relationship with their client’s family by sending birthday or holiday cards, a strategy often employed in longitudinal research to prevent long-term attrition.

Special Considerations for Treatment Engagement with Adolescents

While the majority of this chapter has focused on engaging treatment with children and their caregivers, these data and strategies do not necessarily generalize to older children and teenagers. Data from the 2014 National Comorbidity Survey, a national sample of over 10,000 adolescents ages 13–17, revealed that 64% of teens have utilized mental health services in the past 12 months, 43% of whom hold at least one psychiatric diagnosis (Costello, He, Sampson, Kessler, & Merikangas, 2014). The most frequented service providers were schools (24%) and specialty mental health providers (23%), with a minority of adolescents receiving services in a

general medical setting (10%). These data suggest that although teens are accessing services at much higher levels than their younger counterparts, there are aspects of stepped care that are clearly failing to meet the needs of this population. More specifically, while it is consistent with a stepped care model that teens are accessing some type of care within the school setting, they are not viewing their physical care provider's office as another alternative mechanism for behavioral health needs.

As with younger children, treatment for adolescents is frequently initiated by another party (i.e., parents, school, or juvenile courts). However, adolescents are generally expected to be much more active participants in their treatment than are younger children, the latter of whom are often "treated" by working primarily with their parents. The expectation, then, for adolescents to participate in a process into which they may have been coerced is a complicated one. Accordingly, initiation (i.e., attendance at the initial appointment) and retention rates are markedly lower among adolescents than in younger children (Gopalan et al., 2010), despite the fact that a larger proportion of teens are receiving services overall. This is because adolescent patients often do not understand or agree with the need for services. Indeed, adolescents are significantly more likely to attend treatment when they agree that their mental health and/or behavior is problematic, and agree on at least one treatment goal (Gopalan et al., 2010), consistent with what we would expect in the context of the stages of change. In addition to the lack of self-initiated treatment, there are a number of factors hypothesized to contribute to adolescents' reticence to engage with mental health services.

Treatment may be perceived as conflicting with the primary developmental goals of adolescence: *competence*, due to perception of treatment as an inability to manage one's own health and behavior; *social acceptance*, associated with fear of stigma should peers become aware of treatment; and *autonomy*, as treatment may be considered continued dependence on adults (Gopalan et al., 2010). As such, it is critical that clinicians engaging with adolescent clients take care to use psychoeducation early on in therapy to decrease or manage stigma associated with psychological concerns and help seeking as well as adopting a skills-based approach consistent with many cognitive behavioral treatment modalities that offers a sense of control to the emerging adult.

Kim, Munson, and McKay (2012) made several specific suggestions to improve engagement with teenagers and emerging adults. They particularly recommend the use of Motivational Interviewing (MI) with adolescents to help reduce resistance to treatment. MI has been implemented with adolescents suffering from serious psychiatric illness, substance abuse, and injurious behaviors, and been demonstrated to increase the likelihood of active participation in treatment (Gopalan et al., 2010). Kim, Munson, and McKay also emphasized considering the ecological point of view of adolescents, given its supposition that poor treatment engagement reflects treatment barriers within and across levels of an individual's ecosystem. Because adolescents may encounter more logistical barriers than either children or adults seeking therapy, consideration of these very practical barriers makes some sense. Stepped care models speak specifically to reducing these logistic barriers to effective engagement. Home-based therapy, for example, has been found to increase attendance and participation by bringing mental health services into patients' homes, circumventing practical barriers of transportation (e.g., Gopalan et al., 2010). Thompson, Bender,

Windsor, and Flynn (2009) found that adolescents and their family members who received home-based therapy that emphasized experiential activities aimed at strengthening their intrafamilial relationships through improved coping and communication had significantly lower attrition rates than those receiving similar programs within outpatient treatment settings. For adolescents presenting with disturbances of behavior characterized by oppositional behavior, Brief Strategic Family Therapy has been shown to increase retention rates for adolescents in treatment by facilitating whole family treatment engagement (Staudt, 2007).

Kim et al. (2012) conducted a systematic review of interventions targeting adolescent engagement in mental health services, such as those described above. Interventions were stratified into one of three levels: individual (i.e., targeting specific client behavior change or individual barriers), family (i.e., enlisting parents as collaborators in care and targeting parental barriers), and service delivery (i.e., therapist engagement strategies, varying delivery approaches). Both individual- and family-level interventions increased initial attendance and engagement, though did not continue to promote ongoing engagement. Service delivery levels, in contrast, effectively improved ongoing engagement (including promptness, proportion of appointments kept, and retention). The latter two levels were identified as more commonly implemented with adolescents. Of note, these interventions were delivered to a variety of diverse patient populations and service providers, suggesting high generalizability of results.

Summary and Conclusions

As evidence-based practices for children and adolescents proliferate, we must take care as clinicians to be mindful that treatment success is contingent upon treatment engagement throughout the stages of change. This issue is particularly critical in light of the fact that a person's first episode of behavioral care, regardless of the form that this contact takes within a stepped care model, will likely provide a template for treatment throughout the lifespan. As such, we, as mental health professionals, must seize this opportunity to dispel misconceptions and stigma and to socialize our clients and their families to become empowered collaborators in their own care.

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