Chapter 1

Treatment Engagement: An Introduction

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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

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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,

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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 then 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

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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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