Chapter 17
Is Aging a Disease? Mental Health Issues and Approaches for Elders and Caregivers

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The real adventure is, and always has been, your whole life.

Kabat-Zinn, 2013, p. xxix

Introduction

We are all aging, moment by moment. How we perceive aging creates our experience of it. Do we regard our aging as part of the natural trajectory of life, as an adventure, as a tragedy, or as a pathological medical condition? Ageism, as described by Robert Butler (1980), is the stereotyping of and prejudicial attitude toward older adults. Similar to other "isms," ageism includes external bias and discrimination and the internalization of the stereotypes. If we have internalized bias, we may regard our aging as a tragedy or ailment to be remedied. Mindfulness, the nonjudgmental awareness of the present moment (Kabat-Zinn, 2013), offers new perspectives, reacquainting us with the adventure of our lives. The practices of mindfulness hold a wide range of promise for the aging, including new viewpoints, holistic connection, and empowerment.

Complex psychosocial factors such as loss, pain, and loneliness impact elders more frequently and routinely than other age groups. In addition, we are living longer, but with more disabilities. Currently, 62 % of US citizens over 65 have two or more chronic conditions, and this number is expected to rise significantly (Vogeli et al., 2007). Mindfulness is a 2500-year-old Buddhist practice and is one of many mind/body approaches to health and healing that view and treat the mind, body, and spirit holistically. A small but significant study by Creswell et al. (2012) nicely

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E. Shonin et al. (eds.), *Mindfulness and Buddhist-Derived Approaches in Mental Health and Addiction*, Advances in Mental Health and Addiction,
DOI 10.1007/978-3-319-22255-4_17

illustrates the multifaceted nature of issues facing elders and the benefits of holistic, wellness-centered programs such as mindfulness-based stress reduction (MBSR) and other mindfulness-based interventions (MBIs). Following an MBSR class with non-frail elders, these researchers found that participants self-reported less loneliness (an emotional state elders often face and that is associated with health problems) and also had reduced pro-inflammatory gene expression (inflammation is increasingly associated with chronic conditions, including Alzheimer's, heart diseases, and stress).

Conventional medical approaches treat individual diagnoses separately, often with specialists. For elders, this approach has increased the likelihood of polypharmacy and even potentially inappropriate medicine use especially for elders with cognitive loss (Lau et al., 2010). In addition, conventional medicine tends to focus on pathology, while MBIs focus on abilities, not disabilities.

Mental health conditions in elders are also complex and multifaceted. Physical illness may systemically impact mental and emotional health. Distressing symptoms, such as pain, may lead to mental and emotional suffering. Chronic conditions are associated with an increased risk of major depression and substantial disability (Moussavi et al., 2007). Healthcare professionals routinely screen elders for depression before a diagnosis of dementia because depression is common among elders and may cause confusion and memory loss (Rodda, Walker, & Carter, 2011). In one scenario, an elder admitted to the emergency room for confusion became increasingly verbally and physically agitated. She was temporarily restrained, sedatives were administered, and she was scheduled for admission to the psychiatric unit when her caregiver arrived with her hearing aids. Once she could hear, this elder's agitation vanished, and she was able to communicate her complaints and needs (McBee, 2008, p. 74).

Frail elders experience multiple losses, and the loss of meaning and control in life has profound effects (Krause, 2004). Mindfulness practice can be adapted and taught to elders and provides tools to cope with these challenges. While frail elders may be dependent on others for their basic needs, they may realize they have choices in how they respond to dependency. Mindfulness practice also reminds us of our basic interconnectedness and that we all have meaning in the web of life.

In this chapter, we will describe the most common mental health problems for elders and adaptations to MBIs to provide relief. We will also describe why caregivers are an integral component of mental health for elders, the common emotional suffering and mental health problems experienced by family and professional caregivers, and how MBIs can be best offered to this population.

Despite the complexities of conditions, mindfulness holds a promise of preventing the major ailments facing elders and caregivers, as well as treating distressing symptoms and improving quality of life. A primary tenet of mindfulness-based approaches is health, rather than disease. Or, as Jon Kabat-Zinn writes in *Full Catastrophe Living*, "as long as you are breathing, there is more right with you than there is wrong with you" (2013, p. xxvii).

Reflection

Step back and consider how aging is viewed in the media and culture. How have I internalized these views?

Practice

Start with yourself. Contemplate your body. How has it changed over time? How might it change more as you age? What thoughts and feelings arise? How might you cope with limitations to your life and lifestyle? Can you accept that it is challenging, but perhaps the ultimate practice of our life?

Mindfulness as a Prescription for Preventing and the Ameliorating of Age-Associated Diseases

> Old age is not a diagnosis.
>
> Gawande (2014, p. 27)

Many adults over 65 are healthy, and their mental health/addiction problems are similar to those of their younger peers. In this chapter, we will include the spectrum of aging, with a particular focus on frail elders and adaptations of MBIs for this underserved population. More than 75 % of US adults over age 65 suffer from at least one chronic medical condition that requires ongoing care and management (Institute of Medicine (IOM) of the National Academies, 2008). Pain and disability clearly impact mental as well as physical health. Older adults who adopt the proactive stance of preventing, or at least delaying, the onset of age-associated diseases may find mindfulness practice beneficial in either avoiding or reducing the symptom burden of the major categories of age-associated diseases and mental health conditions.

Older adults are at particular risk of stress-related illness. The top three causes of mortality with aging are heart disease, cancer, and stroke (Sahyoun, Lentzner, Hoyert, & Robinson, 2001). Heart disease and stroke are clearly stress-related while the role of stress is less clear with regard to cancer (Sapolsky, 2004). A recent review by Carlson (2012) illustrated strong evidence in multiple studies for the emotional and mental, as well as physical benefits of MBIs for mixed-age adults with medical conditions. A meta-analysis by Goyal et al. (2014) found that meditation programs can reduce multiple negative dimensions of psychological stress with no reported harm. Given the strong evidence that meditation programs and MBIs reduce both physical and psychological suffering, as well as offer preventative value, clinicians need to make their patients aware of mindfulness and meditation in an array of recommended best practices. The challenge for clinicians working with frail older adults is identifying methods of teaching or conveying the essence of mindfulness practice to this population.

Mental Health

> Some people feel the rain. Others just get wet.
>
> Miller, R. (January 1, 1973)

Mental health problems in older adults reflect the general population and are specific to aging. According to a review (Goodwin, 1983), the four most prevalent

psychiatric disorders specific to elderly persons are dementia, depression, alcoholism, and paranoia. The sections below will review the first three of these in detail, and the forth – paranoia – will be encompassed in the section on dementia.

Ageism, the stereotyping and discrimination toward older adults, was first labeled in 1980 by Robert Butler and continues to negatively impact elders. While the negative impact of discrimination is clear, internalization of the ageist stereotype has been linked to detrimental physical and cognitive outcomes (Levy, 2009). Mindfulness teaches us how much our perceptions of life impact our emotions and understanding. A holistic perception of well-being would include a true sense of mental wellness, not simply an absence of mental health problems. For elders, this perception itself may be empowering.

Reflection

How do I view/perceive aging? Do I focus on illness or the worst case scenario? When I look at frail elders, do I see the whole person behind the frailty?

Practice

Practice taking slow, long, deep belly breaths. When you do this exercise, feel your breath filling your torso, your whole body. After you feel comfortable with this practice, teach it to an elder. If the elder cannot follow your instructions, just practice the deep breathing in their presence. Notice what happens.

Cognitive Decline

> The mind can go in a thousand directions, but on this beautiful path, I walk in peace. With each step, a gentle wind blows. With each step, a flower blooms.
>
> Thich Nhat Hanh (1990, p. 376)

Loss of cognitive function is one of the most feared experiences of aging. Alzheimer's disease (AD), the most common cause of chronic dementia, is the sixth leading cause of mortality in the United States; a recent article in a leading neurology journal gives evidence suggesting that it is actually the third leading cause of death (James et al., 2014). Lesser manifestations of cognitive dysfunction with aging include mild cognitive impairment (MCI) and age-associated memory impairment (AAMI). And, as the population ages worldwide, the prevalence of Alzheimer's disease and other dementias increases exponentially (James et al., 2014).

In view of the projected epidemic of Alzheimer's disease and other forms of age-related cognitive impairment, as well as the as yet lack of a good pharmacological intervention, a technique that has been shown to be feasible and acceptable to older adults and possibly efficacious in altering the course of cognitive changes with aging is of major interest. Even a small shift in the inexorable trajectory of the Alzheimer's disease process would manifest major economic and social benefits.

In recent studies, mindfulness and MBIs demonstrate a moderate to strong effect in improving brain elasticity and function, while reducing emotional stress and

disability. A review article by Newberg and colleagues (2014) found that meditation can change both brain structure and function, improve cognitive function, enhance memory, and protect against age-related and high stress-related cognitive decline. One of the highest profile articles in this area of inquiry demonstrated that the traditional MBSR 8-week course in healthy, meditation-naïve, mixed-age adults resulted in significant increases in the density of the brain in areas related to learning and memory (Holzel et al., 2011). An analysis of the link between aging and cerebral gray matter suggested a slower decline in gray matter with aging among long-term meditators (Luders, Cherbuin, & Kurth, 2015). A systematic review of meditation on cognition and age-related cognitive decline found meditation both feasible and effective for older adults (Gard, Holzel, & Lazar, 2014). An article in the Spanish medical literature attributed stabilization of global cognitive function, functional status, and behavioral symptoms to a mindfulness intervention involving 127 probable Alzheimer's patients over a two-year follow-up period, compared with progressive muscle relaxation and cognitive stimulation experimental groups (Quintana Hernandez et al., 2014). Recent small studies demonstrate promising evidence for teaching elders in supportive housing/assisted living. Elders were able to participate in MBSR groups and reported decreased anxiety and stress (Sasi, Ramesh, & Anice, 2014; Moss et al., 2014)

Often, behavioral problems accompany dementia, resulting in frustration, anger, and disinhibition regardless of the person's previous nature and customs (Cohen-Mansfield, 1997). Dementia can produce behaviors ranging from mild agitation to spitting, hitting, kicking, biting, cursing, and elopement. (Cohen-Mansfield, 1997). These behaviors lead to suffering and injury for both the care receiver and care provider and are a leading cause of institutionalization or hospitalization (Phillips & Diwan, 2003). Here, also, mindfulness may benefit by addressing these painful and often escalating behaviors. With modifications, mindfulness can be taught in groups or individually to those with cognitive loss. While carryover benefits are limited and quantitative research difficult, anecdotally, elders with dementia are able to benefit from simplified meditation and mindfulness (Lantz, Buchalter, & McBee, 1997, McBee, 2008). Environmental and, specifically, caregiver interactions may also serve to escalate or de-escalate challenging situations. For this reason, this chapter will include information on working with both family and paid caregivers, describing research on mindfulness interventions and offering general tips on teaching mindfulness to caregivers.

Reflection

How do I identify myself? Am I my body? My history? My material or scholarly acquisitions? What if I lost the ability to access memory?

Practice

Consider the image of ourselves as a wave. We believe we are the wave, but often forget the wave is only a temporary manifestation of the ocean. Do you view your thinking mind as "you?" Is there a bigger "you?" Without expecting answers, walk with this question. Feel the ground, smell the wind, taste your life.

Depression

> Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure.
>
> Oliver Sacks, The New York Times Opinion Page, 2/19/2015, My Own Life: On learning he has terminal cancer

Depression in older adults is associated with medical illness, disability, and death, and medical illness and disability are associated with higher levels of concomitant depression (Murrell, Himmelfarb, & Wright, 1983). Incidence of depression in persons with Alzheimer's disease may be as high as 86 %, indicating the importance of this issue (Rodda et al., 2011). Mindfulness-based cognitive therapy (MBCT), an offshoot of MBSR formulated by Segal, Williams, and Teasdale (2002) as an intervention for recurrent depression, has demonstrated significant positive results. A meta-analysis commissioned by the US Agency for Healthcare Research and Quality (AHRQ) on the efficacy of programs for psychological stress and well-being concluded that mindfulness meditation had moderate evidence of both short- and long-term improvement in depression (Goyal et al., 2014). A few studies have targeted MBCT and MBIs specifically for older adults with depression. Results included improvements in anxiety, depression, and "purpose in life" and no relapse after 6 months (Meeten, Whiting, & Williams, 2014; O'Connor, Piet, & Hougaard, 2013; Smith, Graham, & Senthinathan, 2007). A retrospective review of 141 older adults who had taken MBSR found a >50 % reduction in the number reporting clinically significant depression and anxiety (Young & Baime, 2010). MBIs appear to be acceptable and efficacious in treating elders for both the symptoms of depression and the root causes.

While MBIs may clearly translate for an older population with minimal disability, many elders suffer from multiple disabilities, including those that require modification in teaching mindfulness practices. In institutional or other group settings, one author (LM) taught mindfulness skills to elders with a wide range of physical and cognitive disabilities, described in greater detail below in: Teaching Mindfulness. MBI groups for elders served to connect an often disconnected population and also to empower a disempowered population. Elders reported benefiting from the group connection and significantly improved in their sense of well-being. Or as one group participant observed, "(Mindfulness) makes me feel at peace with the world. It helps my whole body and spirit. I forgot all my troubles" (McBee, 2008).

Reflection

How do I respond to challenges? Physically, emotionally, mentally? Can I step back and observe?

Practice

A fellow teacher and friend describes how he works with frail elders. "You enter a space with people who are in that way of being in the world and work from there." When you are with an elder, can you step into their space?

Alcoholism and Substance Abuse

> But I would not feel so all alone, everybody must get stoned.
>
> Dylan (1966)

Alcoholism and substance abuse are largely undiagnosed and studied in older adults (Benshoff, Harrawood, & Koch, 2003). Alcohol abuse is often associated with self-treatment of depression, sadness, loneliness, and dysphoric moods, conditions disproportionately impacting elders (Gupta & Warner, 2008; Goodwin, 1983). Diagnosing alcohol and other substance abuse in elders is challenging, partly due to age bias but also due to the different metabolism of alcohol in aging bodies and its effects on the aging brain. Alcohol-related dementia may not be appropriately diagnosed, leading to treatment error (Ridley, Draper, & Withall, 2013). Ultimately, the complicated medical and social etiology and diagnosis of older adult alcoholism may lead to poor or no treatment. The legalization of marijuana and growing acceptance of it as a treatment for disease and end-of-life suffering will also present potential areas for discussion. In addition, certain pain medications carry risk for addiction and misuse, compounded by elders with confusion (Malec & Shega, 2014).

Unfortunately, there are few studies to recommend specific treatment for elders with a substance abuse problem. The aging population is increasing, and older addicted adults are unlikely to decrease usage or become abstinent (Patterson & Jeste, 1999). Problematic substance abuse in elders is predicted to increase considerably in the near future, creating an urgent need for treatment models specific to this population. One study projects a 70 % increase in US older adults needing treatment for substance abuse by 2020 (Gfroerer, Penne, Pemberton, & Folsom, 2003). Mindfulness-Based Relapse Prevention (MBRP), an MBI targeting substance abuse in the general population, has proved promising (Witkiewitz, Marlatt, & Walker, 2005). With modifications for elders such as those described elsewhere in this chapter, this treatment may offer one model for addressing the upcoming epidemic and warrants further study. For the frail elders unable to participate in the cognitive/behavioral aspects of MBIs, mindfulness treatments for distressing behaviors may offer relief.

Family caregivers are at risk for substance abuse as a maladaptive response to stress and substance abuse often leads to elder abuse (Homer & Gilleard, 1990; Gordon & Brill, 2001). Healthcare workers are also at risk for substance abuse problems. In a 2001 review of the literature, Bennett and O'Donovan (2001) describe the risk of substance misuse in healthcare workers related to the high-stress environments and relative ease of access to pharmaceuticals. This report also reviewed the personal and professional negative effects of substance abuse in this population. As above, both MBRP and other MBIs may offer partial solutions to substance abuse in caregivers, with possible adaptations of time and locations as described elsewhere in this chapter.

Reflection
Do I use behaviors or substances to find relief from suffering?
Practice
Sit. Practice. Stay with whatever comes up: pleasant, unpleasant, boring, painful, distressing, no matter how strong the call, sit. Notice where you wish to go, what you wish to do. Is it habitual? Is it an addictive response?

Quality of Life: Pain, Insomnia and End of Life

As previously described, elders face complex and interdependent issues. While pain, insomnia, and end of life are not considered mental health problems, problems in these areas are common to elders and in the clinical experience of the authors often lead to mental and emotional distress.

> Your suffering is not you.
>
> Kabat-Zinn (2013, p. 411)

Pain

Pain is one of the biggest causes of reduced quality of life for older adults. Up to 50 % of community-dwelling older adults and 85 % of nursing home residents experience persistent pain (Cavalieri, 2007). Pain is often untreated or undertreated in older adults for a variety of reasons, from mythologies concerning pain being a part of the aging process to lack of expertise on the part of healthcare professionals. Undertreatment of pain has numerous mental health consequences, including anxiety, depression, cognitive impairment, insomnia, loss of mobility, and social isolation (Zeidan, Grant, Brown, McHaffie, & Coghill, 2012).

Much pain, especially if it is chronic, has an element of "secondary pain." This secondary pain is a reaction to the perception of pain and may include anxiety, fear, anger, and frustration, resulting in a physiologic response that can exacerbate the perception of pain, including muscle contraction and other "fight-or-flight" reactions (Kabat-Zinn, 1982; Kabat-Zinn, Lipworth, & Burney, 1985). In addition, chronic pain is increasingly being recognized as a phenomenon of the central nervous system, in which previously inadequately treated pain may cause the imbedding of the neural circuitry of pain perception in the brain, which is subsequently initiated by minimal stimuli, a sort of broken record repeating itself. It is thought that mindfulness practice, by strengthening certain regions of the brain, overrides and creates new circuits that diminish the prominence of the pain circuitry (Grant, 2014; Zeidan et al., 2012). Goyal et al. (2014), in a meta-analysis commissioned by the AHRQ, found that meditation reduced pain by one third in the general population. Two large recent meta-analyses found that mindfulness did not statistically significantly

diminish pain but did positively impact mental health and quality of life in a general population of those who suffer from pain (Rajguru et al., 2014; Song, Lu, Chen, Geng, & Wang, 2014). Studies of mindfulness for chronic low back pain in older adults reported improved disability, pain, and psychological function (Morone, Rollman, & Moore, 2009) and improved pain acceptance and physical function (Morone, Greco, & Weiner, 2008). These findings are consistent with the author's own small study with older nursing home adults (McBee, 2008). In this group, frail elders reported a trend toward less pain and a statistically significant reduction in feelings of sadness, or as one member reported: "I feel uplifted. I realize we all have pain." These findings clearly reflect that perception of an experience is the experience.

Insomnia

Sleep-related disorders are common in older adults; 25 % of American adults 50 and older self-report a sleep "problem" (Gallup Poll, 2005). This high level of sleep disruption, contrary to popular myth, is not an inevitable concomitant of aging but reflects the prevalence of medical and psychological morbidities in this population. There is a bidirectionality involved: older individuals with sleep disorders are more likely to develop multiple medical problems, and those with medical problems are more likely to develop sleep disturbances. Increased morbidity and mortality accompany all manifestations of these interrelated problems (Bloom et al., 2009).

Mindfulness for sleep problems has not been adequately studied in older adults, but it has been shown in studies to benefit other patient groups with insomnia (Carlson, Speca, Patel, & Goodey, 2003; Gross et al., 2010). Black and colleagues (2015) recently reported a randomized clinical trial of mindful awareness practices for older adults with sleep disturbances which found improvements in sleep quality superior to results in the control sleep hygiene education group (Black, O'Reilly, Olmstead, Breen, & Irwin, 2015).

A Good Death

> Everything is changeable, everything appears and disappears; there is no blissful peace until one passes beyond the agony of life and death.
>
> Kyokai (2006, p. 123)

While mindfulness and meditation are often taught without reference to their spiritual roots, the essence of these practices is grounded in the teachings of the Buddha. At times, it is helpful to reflect on these core teachings, which some view as philosophical and could align with most religions.

The practice of being "with dying" is considered the most important of practices. The natural affiliation of mindfulness practice and dying and end-of-life care has been embraced by ancient texts (Coleman & Thupten, 2006) as well as by modern meditation teachers (Levine & Levine, 1989, Rosenberg & Guy, 2000). Although the usage of mindfulness and meditation practices at the end of life is increasing, scientific research evidence concerning the use of mindfulness and dying is limited. Ball and Vernon (2014) elucidate these limitations and suggest areas to be researched. At the end of life, mindfulness can benefit the dying and also their caregivers (Mackenzie & Poulin, 2006). Currently, many hospice and palliative care movements, such as the New York Zen Center for Contemplative Care, teach mindful presence to end-of-life care doctors, nurses, chaplains, medical students, and other healthcare professionals (www.zencare.org). As one 93-year-old MBSR participant reported in a group run by one of the present authors (PB), "I have come to understand and embrace the concept of impermanence."

Reflection

How comfortable am I with death? Could I allow the idea of my own death to be a mindfulness practice?

Considerations for elders and caregivers

Remember that hearing is the last sense to leave us. Be mindful of what is said around the dying person. Even if there is no response, offer comforting words, music, prayers. If no words come, use the breath as a teaching. How is the dying person breathing?What does this tell us about her/him? Can we sync our breathing to him/her as a way of relating?

Caregivers may be suffering more than the dying patient. How can mindfulness practice offer relief?

Suggestions for Teaching Mindfulness to Frail Elders

> We are always the same age inside.
>
> Stein (1955, p. 946)

Mindfulness practices may be helpful for all of the above mental health problems and physical symptoms. Elders with few or no physical and cognitive limitations would be appropriate for mixed-age groups of MBSR and MBCT. Mindfulness may also be taught to elders with a range of limitations, with teaching modifications addressing communication, physical, and cognitive frailties. The teacher's authentic respect and conviction will convey the essential qualities of mindfulness – awareness and compassion – for all sentient beings. If we as teachers accept that there is more right with us than wrong with us, how do we convey this essential "rightness and intrinsic wisdom" to elders?

The authors have taught mindfulness to elders with a range of abilities and disabilities, in a variety of environments. The grounding of all adaptations and training

of both teachers is in Mindfulness-Based Stress Reduction, the 8-week, 2–2 ½-hour class with homework and an all-day retreat, developed by Kabat-Zinn (2013). This class includes the formal practices of meditation, yoga, mindful walking, and loving-kindness, as well as informal inquiry and awareness of everyday events. These practices are based on, but not limited to, the stricter interpretations of mindfulness. For example, deep breathing is included in MBSR, while more traditional mindfulness might instruct participants to only observe, rather than direct the breath. Also, guided imagery could be viewed as distancing oneself from the present. In MBSR, guided imagery, such as the mountain meditation, is used as a metaphor to assist in deepening practice (Kabat-Zinn, 2013). In working with frail elders and caregivers, the authors taught the formal and informal practices listed above with some adaptations. For example, the all-day retreat and homework expectations would be shortened or eliminated. For the mindfulness-based elder care program developed by McBee, these modifications also included use of music and aromatherapy as a way of creating a calming milieu in a sometimes chaotic institutional environment (2008). Other adaptations for frail elders included mindful hand massage as one way of connecting with elders with cognitive loss (2008).

Guidelines below describe some teaching modifications. While these methods include adaptations from traditional mindfulness teaching, the core teaching of awareness and compassion remains. As mindfulness teaching expands, there have been, and will continue to be, discussions on the integrity of teaching. The teacher emerges as a key component of teaching, or "The work ultimately depends on you, on who you are as a person" (McCown, Reibel, & Micozzi, 2010, p. 91). What the teacher ideally conveys is authenticity, compassion and presence, and teaching via embodiment as well as words. In working with frail elders, mindfulness teachers are encouraged to be especially aware of conveying these qualities nonverbally, communicating through body language, facial expression, hand gestures, hands-on guidance as well as tone and cadence of voice.

It is impossible to offer detailed guidelines here for teaching mindfulness to frail elders due to the wide range of abilities and disabilities. Some common themes include:

Communication

Elders often experience communication limitations including hearing and vision loss. Identifying this in advance is helpful. In a group, teachers can sit near those with more profound hearing or vision loss to repeat or communicate the instructions or feedback. Demonstrating instructions through dramatic gestures or hands-on instruction in the case of mindful movement is another suggestion. Elders with cognitive limitations will benefit from repeated, simple, concrete instructions, with nonverbal cuing.

Adapting Formal Practices

Meditation times may be shorter, and instructions repeated more frequently. Allow time for participants to settle in and understand the instructions. Physical exercises can be adapted for seated or prone participants. For example, if a group member could only lift one arm, she was encouraged to do so, focusing on remaining abilities rather than disabilities. Mindful walking may become mindful wheeling (in wheelchairs). Some group members may be passive participants and yet still may benefit from the experience of participating in a mindfulness group.

Adapting Informal Practice and Group Discussion

Group discussion may focus on complaints about physical ailments or care providers. This can be an excellent opportunity to encourage group members to use mindfulness skills during challenging moments. For example, if a participant is upset about having to wait for a caregiver, they can practice deep breathing or mindful movement. If concerned about pain, a breath awareness meditation can be suggested.

Caregivers and Mental Health

> Three things in human life are important: the first is to be kind; the second is to be kind; and the third is to be kind.
>
> James (in Edel, ed.) (1972)

Caregivers are integral to the frail elders' physical and mental well-being, and healthier elders may stay well longer with the support of an involved caregiver. Absence of a family caregiver has been linked to hospital readmissions, and caregiver stress is linked to institutionalization of frail elders, demonstrating the overall importance of the caregiver role (Schwartz & Elman, 2003; Spillman & Long, 2009).

The complex and multifaceted medical conditions of elders present challenges for caregivers, especially when combined with cognitive decline, impaired judgment, and even combative behavior. Caregiving is provided by family, friends, volunteers (informal or unpaid), and professionals (formal or paid), often a combination of them. Each of these caregiving groups has unique benefits and stresses associated with the caregiving experience. The sections below will review the research on informal and formal caregivers as well as benefits and options for MBIs. While caregiving can be stressful and lead to physical and emotional challenges for the caregiver, 83 % of caregivers report that the experience is positive (National Opinion

Research Center, 2014). And, perceiving the benefits of caregiving is correlated with lower levels of reported depression (Haley, LaMonde, Han, Burton, & Schonwetter, 2003).

Informal Caregivers

> As desire abates, generosity is born. When we are connected and present, what else is there to do but give?
> Kornfield (2015)

Overview

Informal caregivers, unpaid family and friends, provide the majority of assistance for frail elders. Exact numbers are varied, but most estimates are in the tens of millions. The survey "Caregiving in the US" (2009) found that 65 million individuals, or approximately 29 % of the US population, were providing informal care for a disabled friend or family member (National Alliance for Caregiving &AARP, 2009). The majority of care recipients are elders, and their main problems, as reported by their caregivers, are "old age" and dementia. In addition, the average age of both those who give and receive care is increasing, and caregivers may have their own age-related conditions. While all figures cited here are from a US study, they reflect global trends, where developed and less-developed countries also face the complex problems of an aging population.

Engaged informal caregivers have a critical effect on those they care for. Caregiver involvement has been shown to improve outcomes in dementia (Mittelman, Haley, Clay, & Roth, 2006; Vickrey et al., 2006) and to postpone institutionalization (Miller & Weissert, 2000). Caregiver duties may be as basic as a daily phone call but ultimately are unpredictable and may become continuous round-the-clock care. Caregivers may be unable to leave the recipient alone and often neglect their own physical illness or impairments to provide assistance. This situation may affect the caregiver in various ways, including disrupted sleep, emotional and financial difficulties, and physical strain (Wolff, Dy, Frick, & Kasper, 2007). The impact of caregiver stress is so pervasive that a recent article in the Journal of the American Medical Association cautioned physicians to assess caregivers for their level of "caregiver burden" when providing care for frail elders (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). While not a diagnosis, caregiver burden is defined as the perceived negative effect of caregiving on the caregiver's life and ability to function (Zarit, Todd, & Zarit, 1986). Approximately 30 % of caregivers report that caregiving is highly stressful (National Alliance for Caregiving & AARP, 2009). Supporting this, research strongly correlates links between informal caregiving and elevated stress hormones (Kiecolt-Glaser et al., 2003; Vitaliano, Zhang, & Scanlan, 2003).

Caregivers are also more susceptible to physical illness and psychological distress (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Pinquart & Sorensen, 2006; Sörensen, Duberstein, Gill, & Pinquart, 2006) and even elevated mortality rates (Christakis & Allison, 2006; Schulz & Beach, 1999). Multiple studies have found that long-term informal caregiving is associated with increasing depression (Burton, Zdaniuk, Schulz, Jackson, & Hirsch, 2003; Cannuscio et al., 2002).

Caregiver mental and physical illness will have obvious tangible effects on their ability to assist care recipients. Less tangible, but equally potent, are the emotional contagions of stress and depression (Goodman & Shippy, 2002; Joiner & Katz, 1999). No matter how frail, cognitively impaired, and/or noncommunicative they are, elders receiving care may perceive the emotional distress of their caregiver and may become distressed as a result. In a French study of 100 community-dwelling informal caregivers and care receivers diagnosed with Alzheimer's disease (AD), Thomas et al. (2006) found that the caregiver's depressive symptoms and quality of life correlated with the care receiver's depressive symptoms, quality of life, and behavior problems.

MBIs for Informal Caregivers

In a meta-analysis of evidence-based practices for caregiver distress, Gallagher-Thompson and Coon (2007) identified key elements of successful interventions as skill building, education, and support. MBSR and MBIs more generally include these elements and show strong evidence in reducing caregiver stress. Pilot studies have demonstrated that teaching MBSR, or modified MBIs, benefitted AD caregivers. Following an 8-week MBSR course one author (LM) offered for informal caregivers at a nursing home, participants reported decreased stress, anxiety, grief, and caregiver burden. After a 4-week follow-up, they reported further reduction in all measures except depression. Participants also expressed greater satisfaction in the caregiving role and found the group discussions focused on reducing stress while caregiving (Epstein-Lubow, McBee, Darling, Armey, & Miller, 2011). Other pilot studies have found that AD caregivers participating in mindfulness training improved psychological symptoms compared to control participants (Franco, Sola Mdel, & Justo, 2010; Ho et al., 2011; Norouzi, Golzari, & Sohrabi, 2013; Oken et al., 2010). In two randomized controlled studies for family AD caregivers, an MBSR group was compared with a matched control support group. Participants in both groups showed reduced stress and depression (Coogle, Brown, Hellerstein, & Rudolph, 2011; Whitebird et al., 2012).

MBSR and MBIs more generally hold significant potential for mitigating caregiver stress and increasing a sense of self-efficacy. Unfortunately, while caregivers are at high risk for stress and stress-related problems, there are realistic practical and emotional obstacles to providing needed self-care. The majority of caregivers are also employed, and many report juggling work schedules as well as sacrificing time with friends and other family members for caregiving (National Alliance for

Caregiving & AARP, 2009). There may also be underlying resistance to self-care or to viewing oneself as vulnerable. Moreover, a frequent symptom of depression is a lack of motivation, decreasing the likelihood of seeking support. Modifications of mindfulness teaching may increase participation in either brief MBI programs or traditional MBSR for this busy and stressed population. To begin, it may be helpful to consider adapting time commitment expectations for meeting and practice, accessibility of location of classes, and highlighting applicability to caregiving. Dosage and effect of mindfulness teaching and practice is a focus of current and ongoing studies, with some targeting caregivers. Carmody and Baer (2009) reviewed published standard and shortened MBSR programs and found no significant correlation between mean effect size and number of in-class hours. In one study for caregivers, a yogic form of meditation, Kirtan Kriya, was assigned for 12 minutes per day for 8 weeks. Participants in the experimental Kirtan Kriya group improved in mental health and cognitive functioning, psychological distress, and telomerase activity as compared to controls (Lavretsky et al., 2013). Another study found that a 4-hour mindfulness training offered to caregivers increased acceptance, presence, peace, and hope, as well as decreased reactivity and caregiver burden (Hoppes, Bryce, Hellman, & Finlay, 2012).

Research conducted with caregivers and populations with intellectual disabilities (ID) and developmental disabilities (DD) holds implications for AD caregivers, since both cope regularly with behavioral challenges. Singh et al. (2004) found that when ID caregivers received mindfulness training, their patients were happier. In another study, he and colleagues found that when ID parents received mindfulness training, their children showed greater positive and less aggressive behaviors (Singh et al., 2007). Research increasingly points to the benefits of learning stress reduction skills for both caregivers and care receivers. Harmell, Chattillion, Roepke, and Mausbach, (2011) analyzed key characteristics of resilience in caregivers for persons with dementia and found higher levels of personal mastery and self-efficacy and increased use of positive coping strategies appear to have a protective effect on various health outcomes. In addition, Lewallen and Neece (2015) found family caregiver stress was reduced following participation in an MBSR class and that this was also associated with improved behavior and social skills for their developmentally delayed children with DD.

Reflection

How do I feel about caregiving? Do I view it as a burden? Am I bringing a light heart to the experience? How would I feel if I were dependent on others for my basic needs?

Practice

Can I find ways to bring lightness and joy to caregiving? Remember, "we don't stop playing because we grow old; we grow old because we stop playing."- George Bernard Shaw

How am I cared for in less obvious ways by others? How would I feel if my needs increased?

Smile, fake it if you have to. Laugh. Smile and laugh with the person(s) you care for.

Paraprofessional and Professional Caregivers

> We cannot cure the world of sorrows, but we can choose to live in joy.
>
> Campbell (2011)

Medical professionals working with frail elders are under increasing pressure due to changing reimbursement systems, managed care, challenging end-of-life decision-making, and treating simultaneous chronic conditions, many of which are drug resistant. Job stress directly impacts patient care. Doctors experiencing burnout, a result of long-term stress, report giving less than optimal patient care (Shanafelt, Bradley, Wipf, & Back, 2002). Geriatric healthcare workers may be especially vulnerable to "burnout," the emotional exhaustion experienced by those who work with people (Freudenberger, 1974). Both nurses and nursing assistants studied in a long-term care facility linked a significant correlation between stress and inadequate preparation to meet the emotional needs of clients and perform job duties (Kennedy, 2005).

Professionals, such as doctors, social workers, nurses, and therapists, all deliver care to frail elders, but paraprofessionals, or nursing assistants, provide 70–80 % of the basic, life-sustaining personal care. This direct-care workforce is currently the largest US occupational group and the fastest growing (Paraprofessional Healthcare Institute (PHI), 2013, Bureau of Labor Statistics (BLS), 2007). The aging population with multiple chronic conditions will require exactly the personal care provided by paraprofessionals, over longer and longer periods. US paraprofessionals are overwhelmingly female; many are of ethnic minority and/or foreign born, and most have a high school diploma or less (Figueiredo, 2010). They are at physical risk due to disease exposure and the physical demands of direct care with often confused and combative patients (Bureau of Labor Statistics (BLS), 2008). The work is high risk, yet poorly paying, leading to significant job stress (Figueiredo, 2010). Unsurprisingly, more than one in ten paraprofessionals have reported depression lasting 2 weeks or longer, the highest rates of any occupation (Mental Health Services Administration & Office of Applied Studies (October 11, 2007)). Paraprofessional stress results in high job turnover and unsatisfactory communication (DHHS and DOL U.S. Department of Health and Human Services and U.S. Department of Labor (DHHS and DOL), 2003).

MBIs for Formal Caregivers

A recent study found that burnout was significantly associated with suboptimal self-reported patient care (Shanafelt et al., 2002). In 2009, the *Journal of the American Medical Association* published a study by Krasner and colleagues (2009) reporting reductions in burnout and improvements in mood and professional behavior following an 8-week MBSR course with 10-month follow-up for physicians. Additional studies also demonstrate that mindfulness-based programs for healthcare professionals are feasible and effective for reducing burnout and improving patient care (Beckman et al., 2012; Irving, Dobkin, & Park, 2009; Schenstrom, Ronnberg, &

Bolund, 2006). In addition, a doctoral study found that professional dementia caregivers who participated in an 8-week mindfulness class that included information on dementia and challenging behaviors showed improvements in staff well-being and adaptive attitudes toward people with dementia (Clague, 2010). One author (LM) experimented with a wide range of formats, locations, timing, and other teaching adaptations of mindfulness for staff at a large nursing home. All models were found to have some success and created a broader facility awareness of the personal and professional benefits of mindfulness for self-care [see below and McBee, 2008]. Finding time to attend stress reduction classes, either by taking time on or off the job, was the most challenging obstacle. In a shortened (4-week) class based on MBSR and MBCT offered to nurses and nursing assistants in a geriatric hospital, researchers found that participants demonstrated significant improvements in symptoms of burnout and increased relaxation and life satisfaction when compared to a similar wait-listed group (Mackenzie, Poulin, & Seidman-Carlson, 2006).

Cognitive problems, including dementia and intellectual disability, often lead to challenging behaviors as a result of frustration and lack of inhibition, causing distress and injury to both patient and staff (Ozga, M. (November 3, 2011); Rymer et al., 2002). Pilot studies offering mindfulness-based programs to staff caring for people with intellectual disabilities(ID) report promising results, including increased awareness of stress and reductions in psychological distress as well as improvements in self-care and interactions with peers and clients (Bethay, Wilson, Schnetzer, Nassar, & Bordieri, 2012; Brooker et al., 2012; Noone & Hastings, 2010). Studies have also shown a correlation between mindfulness programs for staff and improved patient/client care (Singh et al., 2004). One meta-analysis reviewed 11 studies and found mindfulness programs offered to persons with ID improved behaviors, and that mindfulness programs offered to family and professional caregivers improved relationships and job satisfaction (Chapman et al., 2013). Following a 7-day intensive training of mindfulness-based positive behavior support (MBPBS) for staff caring for those with developmental disabilities (DD) in three residential group homes, staff stress level improved, resident restraints were discontinued, and staff and peer injuries ceased (Singh et al., 2014). Byron, Ziedonis, McGrath, Frazier, and Fulwiler (2014) also found that residential staff caring for adolescents with DD reported an MBI program provided an environmental shift that increased focus and increased cohesion on the unit.

Suggestions for Teaching Mindfulness to Informal and Formal Caregivers

> It is relationality above all else… that is at the heart of mindfulness.
>
> Kabat-Zinn (2013, p. 265)

The range of those who receive care and those who give care, as well as their environments, additional support or lack thereof, financial resources, and other essential factors, are as varied as the general population. Despite some differences, the overwhelming majority of caregivers readily assert a need for stress reduction in

the experience of these authors. The major obstacles for caregivers are time limitations; inability to leave care receiver and/or find backup care; and resistance to, or postponement of, self-care. Thus, the primary challenge to teaching mindfulness to caregivers may be to get them in the room.

Educating caregivers on the causes and effects of chronic long-term stress on their emotional and physical well-being may be an incentive. One author (LM) offered a one hour in-service for all nursing home staff that included this information followed by mindful meditation and gentle stretching. Family and professional caregivers may also benefit from a discussion on the contagious nature of emotions (see description above under Caregiver/Overview). Family caregivers for noninstitutionalized elders may need respite arrangements and even transportation to attend mindfulness groups. Groups held in nursing homes or hospitals could include both caregivers and care receivers, modifying instructions and programs as appropriate. Holding classes in locations convenient for caregivers is also helpful.

Once recruited, groups or individual classes for caregivers may need to be briefer. One author (LM) visited nursing units during times when not providing direct care (charting time) and offered simple skills training on breath awareness or mindful movement. Both family and professional caregivers anecdotally report benefiting from skills that they could use in the midst of their busy lives (Author LM). Caregivers used diaphragmatic/deep breathing when in challenging situations and practiced standing or seated mountain pose throughout the day. In addition to teaching these practices, suggesting practical applications helps. For example, caregivers can be encouraged to stop and take a deep breath before encountering a challenging situation or to stand in mountain pose while waiting in line. These pauses with intentional awareness on physical sensation lead to more habitual poses and perhaps an ability to respond, rather than react, to stressful situations.

Teacher presence is also an important factor. Caregivers may miss classes or spend class time complaining about the challenges of caregiving. If classes are missed, the teacher can call the absent participants with encouragement and support. When caregivers complain, the teacher may find this an excellent teaching opportunity. With curiosity and compassion, the discussion can reframe the conversation as inquiry. Inquiry into the caregivers' subjective experience, as described by McCown, Reibel, and Micozzi (2010), is "'cultivating observation' and 'moving towards acceptance'" (p. 127) that honors the individual wisdom held by all.

Conclusion: Cultivating Equanimity

In 2008, the Institution of Medicine described the "impending crisis" in healthcare provision for older adults. Aside from workforce shortages, recommendations for fundamental changes include promoting new models of care, increased training and support for family and professional caregivers, and a comprehensive view of health for older adults and inclusion of patients and families in decision-making. Mindfulness practices might offer key benefits for this aging population and their

caregivers. Cultivating awareness and compassion may provide frail elders and caregivers with equanimity in the face of mortality, illness, loss, and frailty. Equanimity, an attitude of openness and acceptance, has not previously been regarded as a quantifiable outcome in mindfulness research, but a leading group of scientific mindfulness researchers has reviewed the psychological, physiological, and neuroimaging assessments that have been applied in measuring equanimity and also endorses this outcome measure as potentially the most important element in reflecting the ability of mindfulness to improve overall well-being (Desbordes et al., 2014).

Mindfulness practices promote our ability to view aging holistically, not pathologically. Increasing evidence supports the preventative benefits of mindfulness on our brain and body. Recent studies also link mindfulness and measures of psychological well-being, including self-reported depressive symptoms, quality of life, and stress profile (Fiocco & Mallya, 2015). Anecdotally, and through various studies, both authors (LM and PB) have found mindfulness not only teachable to elders and caregivers but also overwhelmingly well received and profoundly informative for the challenges of aging. One author (LM) found in groups in the nursing home that included residents, staff, and family/friend caregivers, the lines between teacher and taught diminish, and all learned from one another. Following many mindfulness groups, elders report increased acceptance, quiet, and peace. One informal caregiver found: "I feel less anxious about stresses than I formerly did. I think about 'riding the waves' instead of getting anxious about them or 'fighting' the waves. I feel less responsible for my husband's well-being." Both formal and informal caregivers report increased self-efficacy as well as a deeper understanding described by this formal caregiver, "I remember thinking many times during the class that this work has a way of bringing us all to a common denominator. We all have bodies, breath, and thoughts." One family caregiver even stated "she no longer felt she ever had to be alone again" (McBee, 2008).

Ultimately, the true practice for teachers and clinicians is to work with our own perceptions and beliefs on aging, limitations, dependency, and dying. Embodiment of the practice of awareness and compassion is conveyed verbally and nonverbally by the teacher. As mindfulness teachers, practitioners, and clinicians, we can teach mindfulness practices with adaptations to frail elders and caregivers. However, the most important skill/intervention/knowledge we bring to frail elders and their caregivers is our presence, who we are in each moment.

> Within each health care practitioner lives the Wounded One; in every patient, every sick and suffering human being, abides a powerful Inner Healer.
>
> Santorelli (1990, p. 15)

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