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GUEST EDITOR'S MESSAGE

Relational Fragility and the Isolational Trajectory in the Latter Stages of Life

Lenard W. Kaye, DSW, PhD

In the Spring of 2017, the U.S. Senate Special Committee on Aging held a hearing on the risk of isolation for older adults who are aging under conditions that separate them from their communities. I was honored to have the opportunity to present testimony on the impact that living in small towns and rural communities can have on the integrity of one's relationships in later life with family, friends, neighbors, and the residents of the larger community.

My testimony (Kaye, 2017), and the others testifying that day in April, underscored the alarming rates of social isolation and loneliness confronting older adults in today's world. In part, fueled by a 40% increase in the number of individuals living alone between 1980 and 2010, it has been estimated that the prevalence of social isolation and loneliness may be as high as 43% among older adults living in the community (Nicholson, Molony, Fennie, Shellman, & McCorkle, 2010).

The escalating risk of isolation

The escalating risk of isolation has put too many older adults on a troubling trajectory with potentially life threatening consequences.

has put too many older adults on a troubling trajectory with potentially life threatening consequences. For that reason, the National Institutes of Health, AARP, the World Health Organization, and the American Academy of Social Work & Social Welfare, have announced social isolation to be a major universal challenge and threat to social

and community health and well-being (Lubben, Gironde, Sabbath, Kong, & Johnson, 2015).

Closely associated with the downward isolational trajectory that too many older adults find themselves moving along, are the increasingly fragile relationships that exist between them and family, friends, neighbors, and other members of the communities in which they reside. The threat posed by the weakening of one's social network cannot be overstated. Social relationships provide not only social support but increase our access to resources, create a buffer against stress, and served as a trusted social influence. Research suggests that social relationships have as much influence on our health as a number of lifestyle factors including obesity and smoking.

Older adults at greatest risk of becoming socially isolated are LGBTQ elders, those with physical, sensory, and functional impairments, who live alone, are 80 years of age and older,

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are geographically isolated, living on limited income, lacking instrumental supports (access to transportation, the internet, telephones, etc.), with poor mental health, weak social networks, and facing critical life transitions (i.e., divorce, death of a spouse, an abrupt retirement, a health crisis, children moving out, etc.) (Lubben, Gironda, Sabbath, Kong, & Johnson, 2015). As well, the high risk pool includes those residing in small towns and rural communities and older men who have fragile and rather anemic social support networks and engage in significantly less social exchange with informal support networks.

Social isolation can be life threatening. Socially isolated individuals have both higher morbidity and mortality rates including increased rates of disability, dementias, hospitalizations, falls, poor health practices, psychological distress, neglect and exploitation, and lower self-reported health and well-being (Lubben, Gironda, Sabbath, Kong, & Johnson, 2015). Social isolation was found to increase the relative risk ratio of being a current smoker compared to have never smoked by 67% and this risk was found to be greatest among males and non-Hispanic whites. Similarly, social isolation was also found to increase the relative risk ratio of being depressed by 13% (Choi & Dinitto, 2015).

In this Issue

In this issue of JALC we address the issue of social isolation from multiple perspectives. Cliff Singer, a geriatric neuropsychiatrist, reviews the research on social isolation, loneliness, and health, and considers the implications for more informed professional practice. Pepper Schwartz and Nicholas Velotta at the University of Washington consider the changing nature of sexuality and intimacy in later life and its impact on relationships. Jen Crittenden then explores the notable phenomenon of grandparents raising grandchildren in rapidly increasing numbers and the special challenges

that can pose for both the grandparent and the grandchild. Doug Kimmel considers how one's sexual orientation and gender identity can have dramatic effects on the quantity and quality of relationships in later life. Finally, Jim Ellor explores the influence that religiosity and spirituality can have on shaping our late life relationships and interactions with others. Taken together, I hope readers come away from this issue of JALC with a greater appreciation for the significance and undeniable complexity that social interaction brings to our ability to thrive in later life.

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Dr. Kaye's academic career, spanning 35 years, has been dedicated to gerontological and geriatrics health care and services research, evaluation, and education. He founded and directs the University of Maine Center on Aging charged with maximizing the health and well-being of older adults and their families in the state of Maine and beyond. Common themes running through all of his research include: recognition of the important influence of informal supports (family, friends, and neighbors) in the lives of older adults and their use of community-based services; gender differences in geriatrics health services access and utilization; the special challenges facing mid-life and older men in their response to assuming the responsibilities of caregiving; the influence that rural residence has on older adult health service consumption patterns; and the implications of research and evaluation findings for improving the efficacy and efficiency of aging services provision.



Health Effects of Social Isolation and Loneliness

Clifford Singer, MD

ABSTRACT: Human beings are social animals and our biological, psychological, and social systems evolved to thrive in collaborative networks of people. In many societies, social networks are likely to thin as people age, leading in many cases to isolation and loneliness. In this article we review the evidence that social isolation affects health and mortality, whether or not the isolation is accompanied by subjective loneliness. Some studies suggest that the impact of isolation and loneliness on health and mortality are of the same order of magnitude as such risk factors as high blood pressure, obesity, and smoking. We also review what is known about the mechanisms underlying the effects of isolation and loneliness on health. Cardiovascular, inflammatory, hormonal, sleep-related, and emotional factors are all relevant. Finally, we look at the preliminary evidence that interventions to address social isolation and loneliness may improve health outcomes. Throughout all the research referenced in this review are cautions that it can be difficult to isolate cause and effect in these studies, since people with pre-existing health conditions may be prone to social isolation, and many chronic health conditions make socialization more challenging. We must also remember that not all who are isolated are lonely and not all who are lonely are isolated. Being in unhealthy relationships can be more stressful than being alone. Nevertheless, we conclude that efforts to address social isolation in older adults, including those relying on remote technologies, are likely to be cost-effective for health care systems, and are, at the very least, humane approaches to a very common form of distress in older adults.

Health Effects of Social Isolation and Loneliness

We are a social species. Our social networks (families, tribes, communities, etc.) enabled us to survive and thrive. Our survival was served by the evolutionary development of behaviors and physiologic mechanisms (neural, hormonal, cellular, genetic) that support social interactions (Cacioppo et al., 2011). But as with all human traits, there is variation in our social behaviors and needs. The fact is, most of us are psychologically and biologically “programmed” to need social networks. It is logical that social isolation may impose stress on our minds and bodies that has a significant impact on health.

Since social isolation and loneliness are common in older adults, much attention has been paid to clarifying their adverse effects on health in old age.

Since social isolation and loneliness are common in older adults, much attention has been paid to clarifying their adverse effects on health in old age. However, it is surprisingly difficult to study these effects and to distinguish the effects of social isolation and loneliness on health when pre-existing health conditions, such as immobility and depression, can themselves both contribute to ill health as well as increase isolation and loneliness. It is also challenging to distinguish social isolation and loneliness from one another;

not all who are isolated are lonely and not all who are lonely are alone. In this article, we review what is known on this topic.

not all who are isolated are lonely and not all who are lonely are alone. In this article, we review what is known on this topic.

Defining social isolation and loneliness

Not all people experience “aleness” in the same way. Social scientists who study isolation and loneliness have attempted to define these terms in specific ways, since a person is considered socially isolated if they live alone, have less than monthly contact with friends or family, and don’t belong to a group (religious congregation, club, work or volunteer organization, etc.). Of course, some choose isolation as a preferred lifestyle. Others, likely far more in number, have isolation imposed on them through the death of loved ones, family and friends moving away, remote rural housing, recent moves to an unfamiliar city, impaired mobility, and other situations leading to depleted social networks and isolation. People in these situations may be more likely to experience loneliness and to feel isolated (perceived isolation). There are validated research instruments that quantify social isolation and loneliness primarily in terms of number and frequency

of social contacts. However, defining isolation in quantitative terms may not always be valid. Research, as well as our own experience, tells us that the quality of our social interactions, more than the number of our relationships, determines loneliness.

Researchers have also approached these issues using qualitative methods. Cornwell and Waite (2009) use terms such as “social disconnectedness” and “perceived isolation” to define social isolation and loneliness using the objective and subjective nature of these states. Social disconnectedness is defined as lack of contact with others. Perceived isolation is defined as the subjective experience of lack of companionship and support. Loneliness may be part of that, although people can still experience subjective isolation around others. The assumption is that social disconnectedness without perceived isolation (i.e. isolation without loneliness) would be more “ego syntonic” and less stressful than states of loneliness and depression, therefore having less impact on health. Research has not always supported this assumption (Cornwell & Waite, 2009). Social isolation, with or without loneliness, can have as large effect on mortality risk as smoking, obesity, sedentary lifestyle and high blood pressure (Cacioppo et al. 2011).

Associations of isolation and loneliness on health

Several indicators of social isolation have been associated with poor health. There is a vast literature on this topic that is beyond the scope of this article, but several studies can help us better understand the relationships of social networks, perceived isolation, health, and mortality. From a methodological perspective, these studies assume that health status contributes to one’s ability to be socially engaged. Therefore, health status can contribute to loneliness and isolation, thereby creating a “cause and effect” dilemma when attempting to define the relationships between loneliness, social isolation, health, and mortality. Investigators must control for baseline health status in the design of their studies and in the analysis of their data. Despite this, the effects of social isolation and

loneliness on health are a strong enough force that they consistently emerge as unambiguous risk factors for ill health and mortality in the many studies that have examined these relationships through various methodologies, including longitudinal cohort studies and meta-analyses (quantitative analysis of the combined results of carefully selected studies).

An older, but large and well-designed prospective study over four years looked at total mortality in a group of men for whom social networks were known. Some 32,624 healthy men were followed and 511 deaths occurred. Socially isolated men (not married, fewer than six friends or relatives, no memberships in religious or social organizations) had a 90% increased risk of cardiovascular death and more than double the risk of death from an accident or suicide. They also had double the risk of non-fatal stroke. They had no increased risk from non-fatal MI in this study, raising the question of whether or not social isolation contributes to either the severity or survivability of cardiac events (Kawachi et al., 1996). These investigators did not look at loneliness versus social isolation as relative risk factors.

It is natural to assume that loneliness has a greater effect on health and some studies support that conclusion. Adverse effects on health from loneliness are seen at every stage of the lifecycle (Hawkley & Capitanio, 2014). But the elderly are at particular risk both for loneliness and the health consequences of loneliness. For example, in a questionnaire study involving a large number of older adults in Finland, 39% suffered loneliness at least some of the time; 5% often or always. Loneliness was statistically associated with several demographic variables, including rural living, older age, living alone or in residential care, widowhood, low level of education, and low income. Subjectively, the people in this study attributed their loneliness to illness, loss of spouse, and lack of friends. Poor health status and poor functional status were also associated with greater feelings of loneliness (Savikko et al., 2005). A study done by Cacioppo and Cacioppo (2014) found loneliness to be associated with ill health to a greater degree than just social isolation. They examined two ele-

ments of social isolation independently (social disconnectedness and perceived isolation) on both physical and mental health. Stronger relationships were shown between loneliness and worse health, including cardiovascular disease, inflammation, and depression, than social isolation itself. Loneliness in older adults was shown to significantly increase risk of functional decline and death in a recent longitudinal cohort study of 1604 followed over six years. Some 43% of the cohort reported loneliness and they were at higher risk for both functional decline (ADLs, mobility) and death. The authors of this study found that loneliness was associated with these poor outcomes even after adjusting for baseline health status and depression, but did not compare those who were isolated to those who were lonely (Perissinotto et al., 2012).

On the other hand, many investigators have found social isolation itself to be a risk factor for ill health. In a meta-analysis of studies examining the magnitude of effect of social isolation and loneliness on mortality in which important baseline health variables were controlled in the analysis, Holt-Lunstad and colleagues (2015) found a 29% increased risk of mortality over time from social isolation and 26% increase in mortality risk from loneliness. Interestingly, they found a 32% increased risk from just living alone, independent of social isolation. That is, they found no correlation of objective versus subjective social isolation. This finding is counter-intuitive, in that we would think that the stress of loneliness would be a driving factor for ill health, yet “aleness” seems to be at least as strong, if not a stronger influence on health. Steptoe et al. (2013) investigated whether the health impact of social isolation was “caused by loneliness” in 6500 men and women more than 52 years of age participating in the English Longitudinal Study of Aging. They quantified contact with family, friends, and community organizations and administered a loneliness questionnaire. They monitored mortality for an average of 7.25 years per subject. After adjusting for demographic variables, social isolation

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increased mortality whereas loneliness did not. Those with the highest social isolation (least social contact) had an even higher risk. It is very important to note that although there was an increased mortality risk in lonely people, they also had higher baseline mental and physical health problems that may have accounted for the increased risk over the period of observation. That is, loneliness in this study was association with high baseline levels of depression, arthritis, and mobility impairment than the social isolation without loneliness cohort. So, when baseline health variables were factored out, the loneliness cohort did not seem to have as high a mortality rate. In reality, both social isolation and loneliness are associated with increased mortality rates (Steptoe A et al. 2013).

Whether or not the impact of social isolation and perceived isolation (i.e. loneliness) on health are comparable remains unclear, but the evidence seems to be leaning towards the conclusion that both pose risks to health. In an effort to clarify the relative effect of loneliness and social isolation on cardiovascular mortality risk, Valtorta et al. (2016) conducted a meta-analysis of 11 cardiac and eight stroke studies. Poor social relationships in general (social isolation and loneliness) were associated with a 29% increase in risk of coronary heart disease and 32% increase in stroke risk. This increased risk is comparable to the risk of obesity and lack of physical activity and whether isolated people were lonely or not did not appear to make a difference.

Potential mechanisms

Many potential mechanisms have been proposed to account for the relationships between social integration, perceived social support, and health outcomes. First of all, spending time with people who exhibit healthy habits may reinforce healthy behaviors, improve access to health-related information, better nutrition, more physical activity, transportation to health care providers, and even increase financial resources. Of course, peer relationships can easily lead to unhealthy behaviors or interpersonal stress as well, but

in the literature pertaining to older adults, the health-promoting benefits of social relationships seems to outweigh the negative effects. (Cornwell & Waite, 2009) But changing health behaviors is likely not the only mechanism by which social contacts protect health and well-being.

Loneliness is known to be a major risk factor for depression, which itself accelerates functional decline and increases mortality rate. (Mehta et al., 2002) Even sub-clinical depression may increase risk of all-cause mortality. (Culjpers & Smit, 2002), so depression may have contributed to the increased mortality and cardiovascular diseases found in the loneliness cohorts of those studies cited previously. Depression may increase mortality and illness through several mechanisms. Depression can increase platelet aggregation through diminished serotonin function and thereby increase risk for myocardi-

Whether or not the impact of social isolation and perceived isolation (i.e. loneliness) on health are comparable remains unclear, but the evidence seems to be leaning towards the conclusion that both pose risks to health.

al infarction and stroke. There may also be increased heart rate variability (unstable autonomic nervous system) and increased release of adrenaline, both leading to increased risk of cardiac arrhythmia (Seymour & Benning, 2009). Whatever the mechanism, the effect of depression on mortality is significant in size. In a large cohort study (Cardiovascular Health Study), investigators found that depression increased mortality risk by 24% when they accounted for all important co-variables (Schultz et al., 2000).

Social isolation can have direct effects on cardiovascular disease risk factors. Perceived isolation and loneliness are associated with increased sympathetic nervous system activity, increased inflammation, and decreased sleep, all of which can accelerate brain and cardiovascular aging (Cacioppo, et al., 2011). Loneliness increases risk for dementia, likely through these mechanisms, however the absence of social interaction itself may also be a primary factor in that social stimulation can help maintain brain health (Cacioppo & Hawkley, 2009; Cacioppo et al., 2014). Grant and colleagues examined key metabolic risk factors for cardiovascular mortality, looking at blood pressure, lipids, and cortisol responses to stress. Using a measure of social integration (Close Persons Questionnaire), they found dysregulated blood pressure and cortisol responses to acute stress in people (238 middle-aged men and women) with few close friends. They also saw increased cholesterol in the socially isolated men, but not women. These physiologic changes increase risk of heart attacks and stroke. The authors note that these changes in cardiovascular risk factors in isolated individuals were independent of whether they expressed feelings of loneliness (Grant et al., 2009).

Finally, there is some evidence that loneliness can affect immune function, increasing susceptibility to infection (Cohen S et al., 1997). Loneliness is also associated with disrupted sleep. Insomnia affects immune function, glucose regulation, cardiovascular risk, dementia risk, mood, and daytime function (Hawkley et al., 2010).

Interventions

We do not yet know whether efforts to reduce isolation and loneliness can actually improve health. Despite this, Valtorta et al. (2015) note that the evidence linking social isolation in old age with poor health is strong enough that efforts to reduce cardiovascular disease need to consider social interventions aimed at reducing isolation (Valtorta NK et al., 2015). While this claim may be premature, there are studies that do suggest increasing social networks can improve health. In one such study, conducted over a

10-year period of follow-up, men (aged 42-77) with lower levels of "social integration" (by a standard social network index) were, as expected, found to be at greater risk of total mortality than those with more social connections. What was surprising in this study was that in a sub-analysis of the older men of the sample who showed increasing social network size over the 10-years of study, an increased number of close friends or increased attendance at religious services were both associated with a reduced risk of death. The effect size was robust. Those reporting having more friends over time, showed a reduction of 29% in mortality risk per year (Eng et al., 2002). This doesn't prove causality; perhaps improvements in health for other reasons promoted behaviors that lead to more friends. Nevertheless, the finding is encouraging.

Although the stress of being a caregiver to a disabled family member is not the same kind of stress as social isolation, caregivers consistently describe the isolation of the caregiver's role as one of the most stressful aspects of the caregiving role. Caregivers consistently report higher levels of stress than non-caregivers and chronic stress is associated with poorer health outcomes and higher rates of mortality. But caregivers overall have a lower mortality rate. The important factor is stress. Not all caregivers experience significant stress, and those that don't may experience health benefits from the caregiving relationship. In fact, in one study, non-stressed caregivers had 43% lower rates of mortality relative to non-caregivers. In previous studies, caregivers experiencing significant emotional stress showed a 60% increase in mortality rate (Fredman L et al., 2010). These findings are relevant to considerations of interventions for social isolation. Non-stressed caregivers are more likely to experience positive emotions from the person they are providing care for and to gain strength from having a vital role to play in another person's life. To be a caregiver and not feel some reciprocal caring from your partner is a special form of isolation that is particularly demoralizing, stressful, and unhealthy. Even small efforts to make isolated people feel appreciated and useful may reduce the stress of loneli-

ness and thereby improve health.

Innovative ways to help depressed, isolated people may also have positive effects on health. In a twelve-month multi-modality, home-based intervention, randomized controlled trial for older adults with depression, those receiving a home-based (as opposed to usual, office-based) treatment had significantly better responses. The home-based treatment group were more likely to be in remission from depression, had greater quality of life improvements, and greater gains in functional well-being and emotional well-being (Ciechanowski et al., 2004).

Given the mobile nature of our society, social relationships frequently are maintained at a distance through telephone contact, email, and social media when physical contact is not practical. Interventions relying on technology to reduce isolation may be better than no intervention at all, but they are not the same as in-person visits. A large cohort study has recently revealed that different methods of contact are not equal in reducing feelings of loneliness and depression. These investigators found a higher risk of depression in those with less than once-a-month face to face contact with children, family, or friends. People with once or twice-a-week contact had the lowest rates of depression. However, older age, interpersonal conflict, and depression at baseline decreased the effect of physical contact. That is, if a person is prone to depression, is physically frail, or the relationship causes tension, a phone call may be as good (or better) than in-person contact (Teo et al., 2015).

There is an increasing amount of evidence that pets, especially dogs and cats, are associated with health benefits and reduced mortality. Research into whether animal companions can offset the deleterious effects of social isolation on health is needed.

Implications for Aging Life Care / care management:

Aging Life Care / care managers may be in a better position than any other member of the health care team both to recognize social isolation and to organize interventions. Based on current evidence, they can justify in-

creased focus on social relationships in the multidisciplinary health care treatment plan and in their individual efforts to reduce isolation in their clients. An understanding that social isolation is a significant risk factor to health, of similar magnitude to obesity and diabetes, may be persuasive for some of their clients who are able to increase social contact with others, either in person or through social technologies.

Summary

We have reviewed studies examining the complex relationships of health, mortality and social isolation in old age. There is strong evidence that many older adults feel isolated, and that loneliness is associated with poor health and higher rates of mortality. There is also evidence that social isolation even without subjective loneliness increases risk. The effect of social isolation on health appears to be of a similar magnitude to other risks to health, such as high blood pressure, smoking and obesity. Whereas these health risk factors have stimulated major public health interventions in recent decades, efforts to reduce isolation and loneliness have not been made on a level of population-health. Some authors, however, warn that such large-scale efforts based on health risk may be premature. They say that increased risks to health from isolation and loneliness are actually "modest" in magnitude and that the strong associations found in many studies are due to failure to control for baseline health status (Corman et al., 2003). We also have to keep in mind that being in toxic relationships may be even more stressful and unhealthy than loneliness. Nevertheless, there is enough evidence to consider social isolation and loneliness among older adults a significant public health issue. There are also compelling hypotheses and some experimental data to explain the physiologic mechanisms by which social isolation drives disease. And perhaps more importantly, we are starting to see evidence that interventions to reduce loneliness may provide health benefits. I have not offered simple prescriptions to address isolation and loneliness. That is not the purpose of

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this review, which is meant to offer evidence that population-health authorities should take this issue as seriously as other known health risk factors. While we don't have definitive evidence at the present time, it is very likely that social interventions provided at relatively modest costs will have very significant cost savings in public health. Much more research is needed for intervention trials, including those employing social media and telephone contacts. At the very least, such efforts provide a safe, humane approach to a common cause of suffering in older adults.

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The Changing Nature of Intimate and Sexual Relationships in Later Life

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ABSTRACT: Studies regarding sexuality have generally overlooked the growing population of older adults over 50. In this article, we discuss and elaborate on what information we do have regarding intimacy and sexuality post-50 including sexual behaviors, sexual satisfaction ratings, and how the policies within long-term care facilities (LTC's) and elderly housing impact sexual expression later in life. All these facets of aging and sexuality are also examined in the context of aging LGBT individuals who often benefit from specialized methods of treatment by their healthcare professionals.

One of the most common comments today about people over 50 is that each decade is somehow ten or more years younger now than it used to be. It is not our task here to marshal evidence to the truth or fiction of this assertion, but intuitively, it seems right. As we look at aging today, it does appear true that age is enacted differently than it was in previous older generations and that vitality—asserted in longer careers, second and third marriages, and late child rearing—has changed the face and felt experience of the last quartile of life.

One cannot discount the impact of culture and cohort. Much of what we have to say will hinge on the fact that the Baby Boom generation, born between 1945 and 1964, have reinvented each phase of their lives. Being the largest generation, they turned the

spotlight on themselves in adolescence and at every phase thereafter. It is not surprising then that the leading edge of this group (now in their early 70s) have remained a center of attention, refusing to retire to previous stereotypes of aging such as being content to center their lives purely around their grandchildren, serving as handmaidens to their adult child's needs. They are not only working longer -- either because of economic need or professional fulfillment -- they are changing the way they use their recreational time, even opting for world travel or discovering new interests, and perhaps even building new careers (see Miller, 2017). They are also researching supplements and healthy foods, using creams that promise rejuvenation, lifting weights, and dressing in contemporary modes. Gyms are now full of exercising oldsters doing Yoga and Pilates. A generation whose parents would never have been caught anywhere but on a farm in jeans, wear leggings and work-out clothes on the street. Elderly men and women are frequently doing a number of things out of with sync with "traditional" values and behaviors. For example, having multiple marriages (many in old age), living together without getting married, and being open and proud of their sexual identity—often declaring late in life that they are gay, lesbian, or transsexual.

The ubiquitous media in our culture supports and celebrates youthfulness but is beginning to integrate more and more programs featuring older actors retaining their vitality. Dating sites show large numbers of people over 60 in their membership with some sites such as SeniorFriendFinder and How-AboutWe openly recruiting older men

and women as their clientele. Pharmaceutical ads show youthful retirees, workers, and grandparents enjoying life in physically demanding ways and, of course, ads for Viagra and Cialis are predicated on older men wanting, as well as needing, medications for sexual intercourse.

Here, however, we come to a point that has been much less discussed or changed in the reframing of a more vital longevity: the role sexuality plays in

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the revitalization process. As a nation that would much rather have sex than talk about it, there is precious little discussion about a particularly squeamish subject, sex among the aging and elderly. But despite the awkwardness surrounding the subject of sexuality in later years, we know that sexuality continues to play a part in people's lives at any point in the life cycle. This is something we want to address so

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that we all can be more knowledgeable about people's needs and desires. Though there is much to be said about the topic, in our brief coverage we will address key aspects of aging and sexuality such as the frequencies of sexual encounters, how satisfying sex can be in later life, the influence that having an intimate relationship can have on this population, which major illnesses or physical impairments have the potential to dampen sexuality, especially for seniors, and how long-term care facilities (LTC's) can both promote and interfere with resident's sexual longevity. It is worth noting that this is not a complete picture, but rather a review of curated information. Because of this, we emphasize the need to take the findings presented as a partial contribution in a complex narrative.

A (Sexually) Active Population

There is certainly evidence that older and elderly people have liberalized their ideas about sex. An AARP study (Fisher et al., 2010) showed that attitudes about sex among older populations have continually gotten more accepting and approving. Whereas 73% of people affirmed the statement "there is too much emphasis on sex in our culture today" in 1999, by 2004 only 65% of respondents felt that way. We believe this shows an increasing comfort with and desire for sexuality as a core ingredient to happiness in later life as well as in young adulthood and middle age. Even with the tabooed nature of elderly sexuality, many Baby Boomers refuse to be inhibited.

Part of this may be due to a reluctance to give up on any of the joys and perks of their youth but it also may be part of their attachment to healthy living. There is certainly some evidence that exercise helps people connect to their bodies, and allows more use of those bodies longer. Pilates, for example, strengthens the core and pubic muscles and has even been suggested as a way of strengthening orgasms (see Herbenick, 2015). Additionally, research shows that having a sexual life is correlated with many components of leading a healthy lifestyle including

(but not limited to) relationship satisfaction, overall happiness, and mental health (Blanchflower & Oswald, 2004; Fisher et al., 2010; McFarland, Uecker, & Regnerus, 2011; Schwartz & Velotta, 2018; Zeiss & Kasl-Godley, 2001)—and so, the re-emergence of sexuality as a positive good for older people could have important ramifications for health and happiness.

Given that the preponderance of sexuality research focuses on the desires, frequencies, and satisfactions of heterosexual men and women in their reproductive years, there have been few reviews and studies that tap into the over-50 population. Even so, there are some that reveal quite a bit about this growing populace. In the 2009 AARP study mentioned earlier, for example, 75% of respondents believed "a satisfying sex life is important". A recent literature review found that the older population is very interested in remaining sexually viable even with harsh social barriers impeding access to this desire (Schwartz, Diefendorf, & McGlynn-Wright, 2014). Whether that attitude comes from being more active in general, feeling more entitled to have a thriving sexual life, or liberalized notions of masturbation (with more access via online to vibrators or sex aides) is not clear, but there certainly has been more conversations about sex among the elderly. AARP has published columns on sex for the last few decades and movies and TV programs like Netflix's *Grace and Frankie* (starring Lilly Tomlin, Jane Fonda, Martin Sheen, Sam Waterston, and Tom Selleck), Amazon's *Transparent* (with Jeffrey Tambor as a transwoman), *It's Complicated* (with Meryl Streep, Alec Baldwin, and Steve Martin), and *Mamma Mia!* (with Julie Walters, Stellan Skarsgård, and Meryl Streep again) are rare but still support the theme that having sex, passion, and romance over 60 is not ridiculous.

It's not just a Hollywood fantasy, however. The current literature confirms this message of sexual and romantic engagement at older ages. Men and women over 60 continue to live sexual lives with or without partners (Schwartz & Velotta, 2018). According to a 2009 AARP survey on midlife and older adults, nearly 40%

of married older adults are having sex at least once a week, and 60% of partnered older adults report sex at least once a month (Fisher et al., 2010). The survey also found that almost 50% of older singletons who are dating or engaged reported having sex once a week. So, although it is true that sexual frequency reduces over time—both with older age and longer duration of relationships—much of what determines sexual activity has to do with psychosocial factors like internalized ageism and stigma, poor body image, poor relationship quality, or absence of a partner (these last two are especially true for women). Thus, the reduction in sexual frequency is not as closely linked to the biological effects of old age as many people may think.

If we look not just at frequencies but also at sexual satisfaction, the data show that a high percentage of older people are enjoying their sexual lives. There are many factors that make sexual satisfaction fluctuate, but the potential for pleasure from sexual activity does not diminish with age (Penhollow, Young, & Denny, 2009). In his study with older adults currently in relationships, Gillespie (2016) found that sexual communication (partners speaking about their needs from sex) and more variety in sexual encounters (e.g. trying new positions, locations, or sex toys) were major predictors of both high sexual satisfaction and high sexual frequency. For older adult partners who are married or cohabitating, sexual satisfaction ratings remain around the 50% mark (Fisher et al., 2010). Unfortunately, it does seem that individuals post-45 have a harder time remaining sexually satisfied if they are not paired, or do not actively date. AARP's data showed only 10% of older men and women who are single and are not currently dating report being sexually satisfied (Fisher et al., 2010). More encouraging, that number jumps to 60% for those over 45 who are actively dating.

Research on older people makes it clear that having some kind of relationship, however casual, is closely tied to having any sexual activity and increasing both sexual and personal satisfaction. However, the research literature notes that younger adults

often see romance among the elderly—and especially among postmenopausal women—as unnatural or unnecessary (Bouman, Arcelus, & Benbow, 2007; Hinchliff & Gott, 2008). In the senior author's large university class on human sexuality, sex education videos showing older men and women often get reactions of disgust and discomfort. If the senior men and women are merely holding hands or kissing, they receive a more positive reception but this reception seems to categorize the couple as "adorable" or "cute". Both response types dehumanize men and women over a certain age who are genuinely interested in love, romance, and yes, sex. Older adults are, of course, quite capable of finding love, enjoying one-night flings, or reigniting the flame with a high school sweetheart at a 50th reunion, and take umbrage at not being taken seriously. If professionals in the helping and medical specialties who work with older populations show that they do not think these men and women have sexual thoughts or urges or behaviors, it follows that their clients, advisees, or patients will feel that the full scope of who they are is unseen and denigrated.

LGBT Sexual Activity

We also think it is important to include the special needs of older LGBT population in our discussion. Though the data is sparse (almost non-existent for bisexual and transsexual individuals) we will briefly touch on these populations' frequencies and satisfaction ratings. Before continuing it is important to note that in combining several types of sexual minorities into one section we are not attempting to portray homogeneity in their needs or behaviors. Our more general approach to these populations is simply due to the paucity of scholarly data on older sexual minorities.

Regarding gay male sexuality post-50, we find that having a stable partner does not impact sexual frequency nearly as much as it does for heterosexuals. When asking gay men ($n = 24,787$) about their most recent sexual encounters, Rosenberger et al. (2011) found that the majority of sexual acts in all age brackets surveyed were with a partner that participants

labeled an acquaintance. About 30% of sexual encounters in the 60-year-old-and-up brackets were with a boyfriend, significant other, or someone the respondent was dating. Over 60% of sexual encounters happened within the past week for this population. And with around half the gay population post-40 reporting that they are currently partnered (Lyons, Pitts, & Grierson, 2013) it is likely that many of these frequent acquaintance hook-ups reflect a non-monogamous culture among gay men—something that has been observed in other literature (Lyons et al., 2013; Northrup, Schwartz, & Witte, 2012). Alongside their high frequency rates, gay men over 60 also have relatively high sexual satisfaction ratings, with around 40% saying they are "very satisfied" (Lyons et al., 2013). Overall the older gay male population, when given the right environment, seem very capable of maintaining long-term sexual functioning and satisfaction.

Factors that are influential for female sexuality such as: relationship quality, presence of a partner, and emotional fulfillment are especially vital for lesbians. Perhaps the most significant predictor of sexual longevity in the partnered lesbian population is relationship quality which is positively correlated with arousal, sexual functioning, pleasure, and satisfaction (Henderson, Lehavot, & Simoni, 2009; Tracy & Junginger, 2007). Some early literature on the sexual frequencies of older lesbians found that there is a decline over the course of their relationships (Blumstein & Schwartz, 1983; Loulan, 1987). Unfortunately, we simply lack empirical, contemporary evidence on average lesbian sexual frequencies as they stand today. Some have explored whether the parameters used to measure such frequencies should be modified for lesbian samples in order to reflect the fluid, less episodic nature of lesbian sexuality (Meana, Rakipi, Weeks, & Lykins, 2006). It is important to observe, however, that lesbians value the companionate qualities of their partnerships, and do not necessarily feel that the relationship is less intimate if they have low sexual frequency (Averett, Yoon, & Jenkins, 2012). That said, lesbians engage in more masturbatory behavior than their

heterosexual female counterparts and are more inclined to integrate masturbation into partnered sex (Hurlbert & Apt, 1993; Laumann, Gagnon, Michael, & Michaels, 1994) as well as have more positive attitudes towards masturbation in general than heterosexual women (Writer, 2012).

The most unstudied sexual minority group, especially in terms of sexuality in old age, is bisexuals. From the sparse data we have, it appears that older bisexual men are very likely to have had their last sexual encounter with an acquaintance rather than a partner (Rosenberger et al., 2011) and may be more generally cut off from positive social or intimate relationships. Some indication that this is true is that research has shown higher rates of internalized stigma and smaller social networks for male bisexuals and a higher likelihood for them to live alone (Fredriksen-Goldsen et al., 2013). Additionally, because bisexuals are seen as emotionally or sexually dangerous by both heterosexuals and homosexuals, bisexuals are likely to keep their sexual lives private, undiscussed or remain "in the closet". They may only identify by their current sexual behavior, which may give less than the whole picture to professionals trying to help them or place them in a comfortable housing or community environment. We feel this is a very under-researched population and therefore our understanding of what this population needs later in life is very limited.

Illness, Impairment, And Sexuality Later In Life

Even with many older adults living longer, more sexually fulfilling lives, sundry health-related conditions impact the ability of some seniors to perform sexual acts. Here we have devoted space to discuss a few select ailments that are known to effect sexuality for older men and women.

Cancer

Though technological advances and increased awareness have allowed many cases of cancer to be detected earlier than in previous generations, breast and prostate cancer remain a prevalent

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problem for many older individuals.

Breast Cancer

Breast cancer is a serious risk for women post 40 who comprise around 95% of those diagnosed, with older age brackets experiencing an even higher risk of developing the disease (American Cancer Society, 2016a; National Cancer Institute, 2015). Chemotherapy, which is still regularly used in the treatment of breast cancer, has a host of negative physiological side effects that are temporary, but many effects can be quite severe and carry on months after ending chemo (Biglia et al., 2010; Boswell & Dizon, 2015; Malinowszky et al., 2006). Reported sexual consequences include reductions in: sexual desire or interest, arousability, sexual functioning, and the overall quality of relationship with partner (Biglia et al., 2010; Knobf, 2001). Another treatment method, radiation therapy (RT), has shown less clear links between onset of treatment and sexual dysfunction (it is often used in conjunction with other techniques, making it difficult to isolate how RT specifically affects sexual health). That said, Boswell and Dizon (2015) suggest that the locoregional impairments that RT can cause (e.g. pain in breasts and loss of flexibility) could contribute to the reductions in sexual functioning we see in women exposed to it.

The most severe of treatment for breast cancer is surgical removal of tissue. There are various types of breast surgery, ranging from mastectomy-only (with no following breast reconstruction) to lumpectomy (removal of only cancerous tissue) and mastectomy with reconstruction, but a common theme in literature suggests that mastectomy-only (MO) patients have worse sexual consequences than patients who elect for the other surgeries.

Studies find that those treated with MO operations are more likely to experience low levels of sexual desire, arousal, perceived sexual attractiveness, sexual functioning, and encounter greater difficulties in achieving orgasm (Aerts, Christiaens, Enzlin, Neven, & Amant, 2014; Al-Ghazal, Fallowfield, & Blamey, 2000). And yet another aspect that MO patients have to face is the loss of their breasts—something that can alter body

image significantly. Of those women who get any of the three cancer removing surgeries listed, MO patients report significantly worse body image than their peers (Engel, Kerr, Schlesinger-raab, Sauer, & Hölzel, 2004; Markopoulos et al., 2009). This low body image implies that even for those with high sexual functionality after surgery, some older women may feel too self-conscious to engage sexually, a disappointing finding to discover.

Prostate Cancer

For men, the risk of developing prostate cancer increases exponentially with age and about one in seven men is diagnosed in their lifetime (American Cancer Society, 2016b; Prostate Cancer Foundation, 2016). And along with concern for one's survival, prostate cancer can have devastating effects on sexual functioning and satisfaction.

As is the case for breast cancer, most male cancer patients must undergo radiation therapy to treat their prostate. This technique, though effective for treating prostate cancer, has been associated with low levels of sexual desire, decreased frequency of erections, lowering importance of sex life post treatment, reduced orgasm intensity, and an uptick in ejaculation dysfunctions (e.g. no ejaculate during orgasm or pain during ejaculation) (Helgason, Fredrikson, Adolfsson, & Steineck, 1995; Incrocci, 2002, 2006, 2015; Incrocci & Slob, 2002; Incrocci, Slob, & Levendag, 2002; Olsson, 2015).

For patients with worse prognoses, doctors may choose to perform a radical prostatectomy and that procedure results in erectile dysfunction for 60-70% of patients (Chung & Gillman, 2014). Some additional post operation difficulties with radical prostatectomies include: incontinence during sexual activity, less or no sperm emission at orgasm, changes in penile appearance (e.g. length and curvature), and decreased pleasure during orgasm (Ambruosi et al., 2009; Chung & Gillman, 2014; Dubbelman, Wildhagen, Schröder, Bangma, & Dohle, 2010). And although Dubbelman et al. (2010) found there are nerve-sparing procedures that doctors can follow in order to reduce damage to orgasmic functioning, being over the age of 60 was

one of the strongest predictors associated with the inability to achieve climax post-radical prostatectomy.

There are various treatment methods that can help men who experience difficulty after their prostate cancer treatment, ranging from highly effective sildenafil citrate (i.e. Viagra) (Incrocci, Koper, Hop, & Slob, 2001) to intracavernosal injections administered into the base of the penis prior to sex. Other non-pharmaceutical methods are discussed by authors Canalichio, Jaber, and Wang (2015) in their review of hormonal and non-hormonal based treatments for sexual functioning post-prostate cancer surgery.

Diabetes

The Centers for Disease Control and Prevention's National Diabetes Statistics Report: Estimates of Diabetes and Its Burden in the United States (2014) found that 25.9% of Americans 65 years of age and up were diabetic, men making up a significant majority of this population. Erectile dysfunction (ED) is commonly comorbid in male patients with diabetes due to a combination of various blood circulation difficulties and can often be alleviated with the use of oral medications such as Viagra (Hatzimouratidis & Hatzichristou, 2014). With treatment for diabetes induced ED available, it is somewhat surprising that men with diabetes are more likely to see their ED as severe and permanent when compared to their non-diabetic counterparts (Eardley, Fisher, Rosen, Nadal, & Sand, 2007). Perhaps showing the value of a medical staff who can initiate conversations about sexual functioning with their diabetic male patients.

The effects of diabetes on older women is relatively unclear. The disorder impacts vascular and neurogenic functioning which may be associated with lowered desire and reduced lubrication but these symptoms are also present in many non-diabetic post-menopausal women, making it harder to discern if the root cause is diabetes or other, more general aging processes (Zeiss & Kasl-Godley, 2001).

Depression

Of the 35 million-plus Americans over 65, more than 6.5 million are impacted by depression (Reyers, 2013). We do not have room in this paper to

discuss all the concomitants of this all too common problem, but suffice it to say that depression can, and frequently does, wipe out both the desire for sex and arousal when having sex. Often patients are so severely impacted that a medical professional will not think twice about giving a high dosage anti-depressant or anti-anxiety medication that affects sexual functioning since they are far more worried about their patient's mental state than their sexual life. Still, this disregard for the concomitant impact of anti-depressives and anxiolytics can worsen the situation for the suffering patient. Often patients are not even told about the impact the medication will have on their sex life or simply don't bring up the sexual side effects they are experiencing when with their prescribing doctor (Ferguson, 2001). This dynamic impedes possible discussion on how a lower dosage or a different drug might affect their sexual life less. As important, there may also be an impact of these drugs on the patients ability to love and feel affectionate (Marazziti et al., 2014). This, of course, complicates the couple's life together and may result in a partner feeling unloved or appreciated, not realizing that some of the flat affect is drug induced.

Long-Term Care Facilities

One of the most important decisions that older people (and often their families) must make is whether or not they will require long-term caregiving in a facility or home. As we have illustrated, sexual activity remains an important aspect of many aging men and women's quality of life. However, the facility and policies of nursing homes often contain negative views toward sexual behavior in the aging population (Bauer, McAuliffe, & Nay, 2007; Bouman et al., 2007; Hinrichs & Vacha-Haase, 2010; Parker, 2006). Desexualization of this population may serve as a convenience for caretakers, allowing them to escape uncomfortable and complex discussions about elderly sexuality. They may also simply lack knowledge and feel unqualified to speak with residents. Issues such as these are especially poignant for LGBT individuals who find it difficult to express their sexuality in LTC settings due to assumed heterosexuality and homophobic dispositions within the staff

(Hinrichs & Vacha-Haase, 2010).

LGBT residents may conceal their sexual orientation as well as other pertinent information (e.g. HIV status) to reduce stigmatic treatment by health workers (Griebing, 2016). A recent study using lesbian transgendered participants found that although this population felt that they had aged successfully, major concerns still plagued them about late-life events and legal difficulties (Witten, 2015). Given that many in the LGBT community rely on "chosen families" for social support (networks of non-biological family members), when judgments must be made on whether someone is capable of giving sexual consent (for example, when a person has fading cognitive abilities or has dementia), a lack of proper documentation of who is entitled to claim a family or spousal relationship, may make it difficult for those closest to the client to protect his or her interests. Legal complications and negative attitudes found in caregivers and family members, surely contribute to LGBT nervousness in regards to their sexual freedom being honored when living under institutional care in hospitals, long-term care facilities, or other kinds of senior communities.

One solution for older LGBT patients nervous about sexual restrictions imposed within heterosexual LTC communities are homes built exclusively for sexual minorities which have staff trained in facilitating the specialized needs of its members. In addition to expanding LGBT-specialized communities, a broader message to healthcare providers treating LGBT patients can be to develop a strong sense of trust with minority clients. Trust often enables LGBT patients to be open and honest about personal matters pertaining to their sexuality (Dibble, Eliason, De-joseph, & Chinn, 2008) and will likely increase sexual liberties for minority members within primarily heterosexual facilities. This is especially important for less experienced and younger staff members who show higher rates of sexual restrictiveness towards patients than more experienced, senior faculty (Bouman et al., 2007).

Regardless of sexual orientation, the recognition of sexual rights within LTC's is meaningful to many. Unfortu-

nately, residents have reported feeling that their providers care little about fostering an intimate environment for couples and few facilities even permit double-beds (Bouman et al., 2007). Additionally, the atmosphere of nursing homes can be quite open and indirectly oppose residents' desires to have private moments with partners (Frankowski & Clark, 2009). It is not difficult to imagine how unlocked-door policies, community-based activities, and restrictions on sharing sleeping quarters may negatively impact tenants' ability to engage in sexual activities.

Roach (2004) describes the conduct and actions that caregivers and staff take to restrict sexual contact between residents as the guarding discomfort paradigm. This is because the incentive for preventing such behaviors is to "guard" against the discomfort that seeing older men and women in sexual or intimate situations would cause staffers. After her interviews with nursing and LTC staff, Roach concluded that the staff's restrictive actions are not only a product of their individual predispositions towards sexuality but also a product influenced by the general "ethos of an organization" (p. 174).

Should a resident have a cognitive disability, the nursing home's restrictiveness may be even more inhibiting. Individuals who display inappropriate sexual behavior (ISB), for example, are regularly removed from ISB-triggering stimuli or given distractive tasks. And—in cases where such actions do not reduce patients' ISB—practitioners may medicate the individual often with prescriptions used off-label (Dominguez & Barbagallo, 2016). Some research on inappropriate sexual behavior among the cognitively impaired indicates however that ISB is rarely motivated by sexual urges. Usually the patient's intentions are to communicate something entirely appropriate, but their actions are observed as a sexual act (Dominguez & Barbagallo, 2016).

Conclusion

In our brief review on aging and sexuality we have drawn a problematic picture that indicates that western culture still stigmatizes and/or ignores sexual desire and sexual relationships

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among older men and women. A review of the literatures available, indicates that there is a lack of recognition of older people's sexual needs, and that professionals who are supposed to be working in behalf of people in late middle or old age as caretakers, medical and mental health professionals, or as social workers and para-professionals, may not accord older people the same sexual rights as they do to younger populations. This may be especially true for older gays, lesbians, bisexuals, and transsexuals. Older men and women trying to stay vibrant as an individual, and sexually attentive to them self or with a partner, deserve more conscious concern and support for their sexual lives.

However, translating research findings into useful policies and practices can be quite complicated for the administrator overseeing a large residence community or the clinician cycling through many patients a day. Therefore, we would like to offer some of the more pragmatic steps that professionals who work with older individuals may take in order to reduce potential barriers to their clients' ability to enjoy thriving sexual lives well past the age of 50. Firstly, care facilities may want to review their unlocked-door and single-bed policies which can be clear obstacles for the residents looking to enjoy private, intimate time with one another. Having activities where residents can partake in pairs (as opposed to as a group) is another measure that can enable more opportunities for residents to experience intimate, romantic connections with one another. For the LGBT population, facilities may explore having staff specialized in serving older LGBT residents. This could enable their clientele who are in the sexual minority to develop more trusting bonds with a group of care staff that is specifically trained for providing aide to their unique concerns later in life.

For clinicians who require knowledge about sexual activity, conscious efforts to assess implicit biases could be helpful in reducing issues related to assumed heterosexuality (for LGBT patients) and presumptions of sexual inactivity later in life (for all older

patients). For example, Aging Life Care Professionals may want to ask whether their patient has a male or female partner prior to discussing any sexual activity to avoid the use of inaccurate pronouns or non-applicable sexual behaviors that may make their patient uncomfortable to answer (e.g. asking a gay male how frequently he engages in vaginal intercourse with his partner). It may also benefit practitioners to foster open dialogs about their patients' sexual frequencies and satisfaction—topics often left untouched by doctors treating older patients who are also less likely to seek help with sexual needs when their doctors do not ask about their sexual behavior during visits (Hinchliff & Gott, 2011). Doctors and medical professionals should consider administering an annual questionnaire during their patients' check-ups that covers sexual issues as areas that the patient might like to discuss. Among the potential areas of concern, patients could answer items (as appropriate) about: the presence of erectile dysfunction, pain during intercourse or other penetrative sexual behaviors, genital pain in the absence of sexual behavior, undesired loss of sexual interest or arousal, and the desire to hear about medications that affect sexual behavior or get a referral to see a doctor who specializes in sexual medicine. Of course, there are many more actions that care workers can take to better their clientele's sexual autonomy later in life, but these are a few good starting points. With the recent medical innovations in sexual health it is important to keep the above-50 population informed as to what their options are to increase their sexual longevity, and in so doing increase their sexual agency for the rest of their life.

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Supporting Grandfamilies: Common Relational Issues and Support Needs Faced by Grandparents Raising Grandchildren

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SUMMARY: As the number of grandparents who are raising grandchildren increases in the U.S., so too does the need for Aging Life Care Managers who are aware of the special needs of these families. Transitioning to a custodial grandparenting arrangement often presents emotional, relational, and financial hardships for grandparents and their grandchildren. This article discusses the common challenges and relational issues faced by grandfamilies and strategies that practitioners can use to support them effectively.

Grandparents hold a special place in the hearts of their grandchildren. Often seen as guiding forces in their families, grandparents bring extra energy, wisdom, and new perspectives to the lives of their young kin. Now, more and more grandparents are taking on additional responsibilities in their families, serving as primary custodial guardians and parents to their grandchildren. The numbers of grandparent-headed households, sometimes called kinship families or grandfamilies, is growing in this country with more than 2.5 million children being raised by approximately 2.7 million grandparents and other relatives (Generations United, 2016). Stepping into the role of primary caregiver can be difficult for the grandparent and requires the family to adapt and adjust to new roles -- not just for the grandparent, but also for the adult child, and grandchild.

While the reasons that children come into kinship care can be as diverse as the families themselves, the most common reason for this arrangement is tied to the growing drug epidemic in the U.S. With over a third of children placed into foster care as a result of parental substance abuse, this epidemic is having a widespread effect on families. The fallout from the grow-

ing heroin and opioid crisis can lead to kinship care when there is incarceration of one or both parents, the death of one or both parents, and/or the absence of one or both parents due to participation in substance use disorder treatment (Generations United, 2016). Additional circumstances that may lead to a kinship arrangement beyond substance abuse include physical or mental illness of the parent, child abuse and neglect, or the voluntary choice to relinquish custody to the grandparent (Child Welfare Information Gateway, 2016).

While kinship care arrangements often bring a new-found stability to the family, they create challenging dynamics and changing relationships. Practitioners serving grandfamilies need to possess knowledge of a myriad of resources and systems including aging services, child welfare, education, and social services in a time when our service systems have not kept pace with the complex needs of these families (Baker, Silverstein, and Putney, 2008). This article will touch upon some of the common issues faced by grandfamilies and how practitioners can best support this growing cohort of older adults who are pulling double duty as "grandma" or "grandpa" and "mom" or "dad."

Relationship Dynamics of Grandfamilies

While all points in the caregiving trajectory are important, the transition point into caregiver has been identified as critical for grandparent health and well-being. Recent research shows that when compared to other grandparents, custodial grandmothers are more likely to experience stress, poor self-rated health, and depression and less likely than their non-custodial peers to have support in their caregiving. Custodial grandmothers also report lower levels of perceived rewards connected with their kinship caregiving duties. These effects are magnified for grandmothers as they transition into caregiving roles over time (Musil et al., 2010). The implications for this study suggest that the transition point is an important one for caregivers and one where practitioners can provide support and guidance to address potential negative effects for grandparents.

The changing dynamics of transitioning to a kinship care arrangement may provide emotional challenges for all involved. As relationships between grandparents and their adult children, grandchildren, and others in the family change, the family unit is

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challenged to accommodate these new arrangements. One common occurrence in these families is a sense of ambivalence, or conflict, among family members. Conflicts may arise between grandparents and their adult children over issues such as visitation with the child(ren), different parenting approaches, or long standing relationship issues between parent and adult child. Part of this conflict derives from role ambiguity when grandparents now hold more than one role and the adult child may be challenged to maintain their role within the family. To address role conflict and ambiguity, practitioners are encouraged to help the family facilitate discussion around changing roles and expectations first through "joining" or bonding with the family and then exploring whether or not the family is at a point where it is seeking to reestablish old family structures or if new family role and expectations will be built together (Leticq, Bailey & Dahlen, 2008). Helping grandparents to express these sources of ambivalence and work through them is an important step to addressing relationship changes.

Grief and loss is a prevalent experience among grandparent caregivers. Sources of grief and loss often center around changing roles within the family, the timing of caregiving activities, and specific circumstances that brought about the transition to kinship caregiving. The type of grief and loss experienced by grandfamilies is distinctly different from the loss experienced by the death of a friend or loved one. Instead, many grandparent caregivers experience what is referred to as ambiguous loss. Ambiguous loss is the experience of loss that does not bring with it a sense of closure, and can create confusion and distress for those who are experiencing the loss. Boss (2010) outlines the two types of ambiguous loss that can be experienced. The first is a loss where there is physical absence but psychological presence of a loved one. This may occur when the adult child is incarcerated, staying in a residential treatment facility, or living out-of-state but still maintains some psychological presence in the family

and stays connected to their parenting role.

The second type of ambiguous loss experienced in grandfamilies occurs when a loved one is physically present but psychologically absent. This type of loss is most common with families where addiction or mental illness has led to the kinship caregiving arrangements. Both grandchild and grandparent may feel the effects of these ambiguous losses. Ambiguous loss, because of its lack of closure and the confusion it brings to families, may lead to ambivalence surrounding the kinship caregiving arrangement. The key to managing ambiguous loss and resulting ambivalence is to provide an opportunity for caregivers to discuss their experiences, feelings, and conflict in a non-judgemental setting (Boss, 2010).

From a life course perspective, grandfamily arrangements may be seen as disrupting retirement and other life plans which will require coping strategies and retooling for the grandparent. As with grief and loss, there is no one right or wrong way that grandparents experience custodial grandparenting. While some grieve the loss of their retirement years others may enjoy the new focus and activities that the parenting arrangement brings to their lives. Supporting grandfamilies requires both a recognition of loss but also celebrating the positive aspects of such arrangements for children and caregivers. Along these lines, Servaty-Seib and Wilkins (2008) suggest a gains/loss framework when working with custodial grandparents. Using this perspective, grandparents can be encouraged to articulate the gains and losses they have experienced, aiming to increase the perception of gains while decreasing the perception of losses. This perspective allows for an individualized approach to assessment and intervention. For example, you may discuss the role of grandparent that is lost in the custodial grandparent arrangement but also the new role of parent/caregiver that is gained. A grandparent may lose their opportunity for traditional retirement activities but gain a new and deeper sense of purpose that comes with caring for their grandchild. This approach can

help grandparents to more accurately assess their personal circumstances and intentionally focus on the positive aspects of caregiving.

Another important consideration is the circumstances that have led to the grandfamilies arrangement. With a significant portion of children in kinship foster care placements placed due to substance use disorders within their families, it is important to recognize that many grandfamilies are affected by substance abuse. This substance use reverberates throughout the whole family as it affects not only the adult child but the grandchild and ultimately the grandparent who assumes care. Children who have been raised in homes affected by substance abuse are more likely to have special cognitive and physical needs of their own, especially if they were exposed prenatally to drugs or alcohol. Children affected by substance abuse may have also experienced abuse and neglect or other family trauma related to their parent's substance use disorder. These special considerations place additional stress on the grandparent caregiver and require services and education to support the grandparent. As such, grandparents parenting a child affected by substance abuse should be encouraged and supported to learn more about substance use and its effect on children to ultimately enhance the parenting they are able to provide to the children in their care and navigate the relationship with their adult child. Community support groups that are tailored to support families affected by substance abuse, like a Nar-Anon or Al-Anon family group, can be valuable sources of emotional support and education for grandparents caring for children affected by substance use.

Importance of Caregiver Self-Care and Setting Boundaries

The grandparents who are raising grandchildren face their own challenges with as many as 1 in 4 grandparents managing their own disability in addition to the needs of the children in their care. In addition, about a third of such caregivers live in poverty (Generations United, n.d.a). With 58% of

grandparent caregivers filling the roles of both worker and caregiver, juggling time commitments is an additional challenge to be faced. Lozier (2015) suggests the following strategies for caregiver self-care which can help to combat the additional stressors and time commitments: 1) prioritize obligations and time commitments by learning to say “no” to non-essential tasks; 2) reduce or limit exposure to technology (computer screens, phones, televisions) to limit stress; 3) turn to faith-based endeavors if that is a source of comfort; 4) schedule free time in the day if even only for small increments of time; and 5) get organized using lists and tools that help you prioritize (Lozier, 2015).

As new roles are established, grandparents should be encouraged to develop practical strategies for managing the new relationship dynamics between themselves and their adult child. Proactively setting boundaries will help to facilitate the relationship between grandparent and adult child. These strategies include thinking through how they can allow adult children to be involved in some aspects of the parenting work, even if that involvement is limited. Grandparents should also be encouraged to identify manipulative behavior on behalf of the adult child and be prepared to address it proactively. Grandparents will also need to increase their comfort level in decision making for their grandchild when their adult child is not able to do so (Smith & Dannison, 2015).

Navigating Service Systems

Grandfamily familial arrangements include both families where children are placed into formal and informal kinship care arrangements. Formal kinship care is care provided by a relative that is arranged and formalized through a foster home licensure process facilitated by the state-level child welfare system. Informal kinship care, on the other hand, is care that is arranged when a grandparent or other relative steps in to provide care to a child without any formal child welfare involvement. Estimates suggest that for every child in a formal kinship placement there are 20 children who are being raised in informal kinship

care arrangements (Generations United, 2016). This distinction is an important one for practitioners to recognize as informal kinship care families often lack access to the resources and support provided through state foster care systems. A first step to supporting grandparent caregivers is to identify their family arrangement and understand the potential service gaps that may exist for informal families.

Dolbin-MacNab and Targ (2002) developed a framework that professionals from any field can use to guide their practice with grandfamilies. Three of the tenets within this framework include being prepared to consider the multiple and complex issues that grandfamilies face, networking with other professionals to stay abreast of new programs and services available, and removing barriers that may keep grandparents from seeking and obtaining the help they need through advocacy. Using this framework, aging practitioners may find themselves with new and strange bedfellows such as child welfare service providers and those who work within educational and legal systems. Supporting grandfamilies will require new networks and connections be formed to address emerging needs faced by grandparent caregivers. To guide this work, Generations United (n.d.b) has created a taxonomy of needs presented by grandparent caregivers which crosses into areas beyond aging services and include the categories of housing, education, health, legal and financial challenges. Specific challenges faced by grandfamilies include:

- **Housing:** residing in inadequate housing for children due to lack of space or housing configuration, living in senior housing that does not allow children to live with the grandparents, and a lack of household funding to handle extra housing and utility expenses related to having an additional child under your roof.
- **Education:** barriers to enrolling children in school, especially when the grandparent does not have legal custody or guardianship; lack of familiarity with special education services that the child may need; lack of household funding to provide

school supplies and necessities for the child.

- **Health:** a caregiver’s own health challenges which may need to be met; lack of financial resources to cover additional medical expenses for themselves and/or their grandchild; lack of access to insurance when the grandparent does not have legal custody or guardianship; inability to make medical decisions on behalf of the child without appropriate legal arrangements; and lack of knowledge of health programs, such as Medicaid and Children’s Health Insurance Program (CHIP), that can assist in meeting medical needs.
- **Legal:** Legal issues for grandfamilies tend to focus on issues related to formal custody and guardianship arrangements for the child. An additional legal consideration includes setting up a will and making other legal arrangements that can assist in providing care and support for the grandchild in the event that a caregiver dies or is no longer able to assume the role of kinship caregiver.
- **Financial:** Financial supports needed by grandfamilies center on programs and services that can reduce financial burden for families. These include obtaining access to programs like child-only Temporary Assistance for Needy Families (TANF) benefits, Supplemental Nutrition Assistance Program (SNAP), Supplemental Security Income (SSI); obtaining subsidized guardianship, adoption payments, or other forms of child support; access to emergency food cupboards and clothing exchanges; connecting with heating assistance programs; and learning about and accessing local programs through churches and civic groups that provide individual assistance and support.
- **Additional needs:** While the full range of needs is likely to vary from family to family, additional needs may include the need for learning or re-learning child development knowledge and parenting skills; staying connected socially with other kinship caregivers through support

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groups; finding relief from caregiving and an opportunity for self-care through the use of respite services; and obtaining special needs services for the children in their care.

It is important to note that some states also have kinship navigator programs, programs that are specially designed to meet the service needs of kinship families. More information can be obtained about these programs and other resources for grandfamilies at www.grandfamilies.org

Continuing Education is Key for Practitioners

Research points to a need for practitioners who work with children and older adults to be educated about the special needs of grandfamilies (Fruhauf, Pevney, & Bundy-Fazioli, 2015). There are recent national programs developed to help retool practitioners for assisting these families, including the online Certificate Program in Grandfamilies Leadership facilitated by the UMaine Center on Aging (www.kinshipcert.org) which features online content tailored to a wide variety of professionals in the field. Additional resources that may be helpful to practitioners include Generations United (GU) (www.gu.org), a national organization that works to "improve the lives of children, youth, and older people through intergenerational collaboration." GU offers policy and practice resources that can assist those who serve grandfamilies. The GrandFamilies journal, a publication from the National Research Center on Grandparents Raising Grandchildren, is a new open access publication in the field that features peer-reviewed research and practice articles specific to issues faced by grandfamilies.

In summary, assisting grandparents who are raising their grandchildren necessitates an individualized approach to meet the complex and ever changing needs of these families. Successfully engaging custodial grandparents requires a practitioner to understand the special needs of this population including family dynamics, grief and loss, coping strategies, and where families can turn for help. Aging Life Care Managers are

encouraged to seek out continuing education and training and collaborate across disciplines on grandfamilies issues in order to connect with programs and services across aging, child welfare, education, and legal systems.

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The Effect of Sexual Orientation and Gender Identity on Relationships in Later Life

Douglas C. Kimmel, PhD

Overview

The goal of this article is to provide some useful resources for understanding the special issues of aging lesbian, gay, bisexual, and transgender (LGBT) older adults, especially related to isolation. This article includes: 1) a summary of the support and advocacy issues from the National SAGE website; 2) focused discussion on home care, housing issues, and growing older with HIV/AIDS; 3) examples of specific programs focused on older LGBT concerns; and 4) a list of a number of publications available directed at the special problem of isolation for older persons who are LGBT. All of these resources are readily available on-line by searching the associated links, or on the original website.

Services for Advocacy for Gay, Lesbian, Bisexual, and Transgender Elders (SAGE) was founded in 1978 to reach out to the isolated gay men and lesbians in New York City who were among the most vulnerable members in the emerging gay community forty years ago. It began offering friendly visiting, brunches, dances, and social events. It drew attention to sexual orientation and ageism and the myth that gay people do not grow old. SAGE has become a major national aging organization and prominent voice of advocacy for older LGBT individuals. This article relies on the pioneering work of SAGE and draws heavily on materials it provides online. We summarize some key points with links for the quotations as well as for additional resources at the end of this article.

Background Information

One obstacle facing all aging

The hardships associated with being a caregiver can also place the caregiver at risk for social isolation, yet few supports for caregivers consider the unique needs of LGBT families. Major life transitions such as the death of a loved one or the loss of a job can also disrupt an elder's stability and lead to social isolation.

Americans is the risk of social isolation. As adults near retirement age, they may become isolated over time from their broader communities (places of worship, work settings, etc.), as well as from friends and family. This phenomenon means, among other consequences, smaller and lower quality support networks, debilitating feelings of loneliness and depression, and at its worst, an estranged life where one's physical and mental health deteriorates (<https://www.sage.org/issues/isolation.cfm>).

Social isolation affects many LGBT older people around the country as they deal with stigma and discrimination in their daily lives and in our country's aging system. The primary risk factors for social isolation affect LGBT older adults

in unique and disproportionate ways. For example, one primary risk factor is living alone. LGBT older people are twice as likely to live alone, twice as likely to be single, and three to four times less likely to have children—and many are estranged from their biological families.

Other risk factors for social isolation include mobility or sensory impairments, socio-economic status, and psychological or cognitive vulnerabilities. The research shows that LGBT elders face higher disability rates, struggle with economic security and higher poverty rates, and many LGBT elders deal with mental health concerns that come from a lifetime of discrimination that has had psychological and materials costs.

The hardships associated with being a caregiver can also place the caregiver at risk for social isolation, yet few supports for caregivers consider the unique needs of LGBT families. Major life transitions such as the death of a loved one or the loss of a job can also disrupt an elder's stability and lead to social isolation.

Location-related barriers, coupled with stigma and discrimination, can make it difficult for LGBT elders in many parts of the country to find the community supports they need to age successfully and avoid social isolation (<https://www.sageusa.org/issues/isolation.cfm>).

Home Care and Housing

In April of 2014, The National Resource Center on LGBT Aging highlighted the need for LGBT-Inclusive housing and care for LGBT older adults.

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Secure, stable, and affordable housing is a necessary component for healthy aging. In practical terms, a home is a physical shelter from the elements. However, people also feel a powerful emotional connection to their homes—it is a place where they can feel safe to be themselves, free from intimidation, harassment or discrimination. Research has consistently shown that LGBT older adults are less likely to have children to care for them, less likely to have someone to call on in time of need, and are at much greater risk for social isolation than their heterosexual peers. Therefore, many of them have created strong social networks and families of choice within the LGBT community. LGBT older adults in a San Diego study stated the desire to age at home rather than move, but when asked about options, over 90 percent indicated a preference for LGBT-specific housing if it were available, and 94 percent of the same cohort reported a preference to live alongside other LGBT adults. For LGBT older adults, who came of age during a time before people began living openly and being LGBT was often misunderstood and grounds for fear and harassment, safe homes are especially important.

Unfortunately, this security is denied to many LGBT older adults. Many LGBT older adults experience fear, intimidation and harassment in their private homes as well as in nursing homes or assisted living facilities, making their living situations physically and emotionally unhealthy. In addition, due to higher levels of financial insecurity and lack of affordable housing, many LGBT elders find that they cannot afford homes in the communities they may have lived in for years (<https://lgbtagingcenter.org/resources/resource.cfm?R=339>).

A recently-published, groundbreaking report—LGBT Older Adults in Long-Term Care Facilities: Stories from the Field—highlights the mistreatment that some LGBT elders may encounter (<https://lgbtagingcenter.org/resources/resource.cfm?r=54>). A broad coalition of LGBT groups led by the National Senior Citizens Law Center released the report. The groups included the

National Center for Lesbian Rights (NCLR), Lambda Legal, the National Center for Transgender Equality (NCTE), the National Gay and Lesbian Task Force (NGLTF), and Services & Advocacy for GLBT Elders (SAGE). The report collected information and stories from 769 individuals who responded to an online survey.

Of the total respondents, 328 people reported 853 instances of abuse, including:

- Harassment by residents and staff
- Refusal by staff to accept a medical power of attorney
- Refusal by staff to use preferred name and/or pronoun
- Refusal to provide care
- Wrongful transfer or discharge

Nearly nine in 10 respondents said that they thought long-term care staff would discriminate against someone who came out as LGBT in a facility; eight in 10 responded that they would expect mistreatment or bullying from nursing home residents; one in 10 reported that nursing home staff had disregarded a medical power of attorney when it was assigned to a resident's partner. Transgender elders in particular reported that they experienced isolation and staff refusal to recognize their gender identities (<http://www.lgbtagingcenter.org/resources/resource.cfm?R=64>).

Older People Living with HIV/AIDS

Social isolation, loneliness, stigma and discrimination may be particularly challenging obstacles for those aging with HIV/AIDS. In a 2011 research report by Mark Brennan-Ing and Steven R. Karpiak (2011), it was found that: social isolation and resultant loneliness are endemic among OPLWHA [older people living with HIV/AIDS]. Fewer than 20% have a partner or spouse, and they are about half as likely to have a living child as adults 65 and older. Approximately 70% live alone, which is nearly twice the rate of other older adults. OPLWHA tend to have friend-centered networks that we have typically associated with the LGBT community, yet two-thirds of

these adults identify as heterosexual. And while friends do provide needed support, many also have HIV. Also, OPLWHA do not disclose their serostatus to many friends.

Beyond the high rates of loneliness and poorer quality-of-life, social isolation also points to an impending shortfall of the support these older adults will need now and as they grow older and confront multiple health issues. Caregivers are derived from these social networks. Without caregivers, OPLWHA will need to increasingly turn to supports that are medically based, as well as formal community-based social services that address their treatment and care needs. However, AIDS service organizations and other HIV service providers are not experienced in the domain of aging. Conversely, most aging service providers have little knowledge of HIV.

Research is needed to better understand the causes of social isolation among OPLWHA, as well as studies that examine dynamics of social support among this population to better understand their needs and how they are met. We need to develop and test interventions that can serve to reduce social isolation and increase available levels of support. Furthermore, we need research on the service utilization patterns and associated factors (i.e., needs, service barriers) that can provide an evidence base for policy makers and program planners to address the growing needs of this aging HIV population. Lastly, we need to better understand how to better integrate HIV and aging services with research targeted at understanding how we can best leverage the resources available from these providers (<http://www.lgbtagingcenter.org/resources/resource.cfm?R=324>).

Current Efforts for Targeted Support

There are several agencies and programs across the country that have adopted programs dedicated to supporting the needs of LGBT elders and their caregivers. The following are a few of those efforts.

Boulder Area Agency on Aging, Boulder, CO

<https://www.bouldercounty.org/families/seniors/services/lgbt>

In a 2012 interview, Nancy Grimes and Emily Lewis of the Boulder County Area Agency on Aging outlined the LGBT-specific support programs they host. In 2000, they created the Rainbow Elders, a social support group for LGBT seniors; a group of 10–20 folks who met monthly for about eight years. “They currently maintain a mailing list of area residents who have self-identified as Rainbow Elders, and they send a monthly newsletter of social events of interest to this population.” When their agency held its first focus groups with LGBT seniors in the early 2000s, many fears about aging were raised, such as:

- Where am I going to live?
- How will I be treated in a nursing home if I am ‘out’?
- Who are safe providers in the county?

These questions led to the creation of the “Silver Lining Directory: A Resource Guide for the LGBT Elder Community in Boulder County,” which is published bi-annually and distributed to area senior residences and service providers. A non-discrimination policy that includes sexual orientation and gender identity/expression is required for inclusion. The focus groups and subsequent Directory led to a much more ambitious project: Project Visibility. This cultural competency training was launched in 2004 and includes a film in which local elders and area providers voice their concerns about the aging services network; a 40-page manual of definitions, cultural competency tips, and LGBT history accompanies the film.

Lastly, since 2000, the Boulder County Area Agency on Aging has hosted an annual Lavender Gala to reduce social isolation during the holidays. They also hold at least one educational activity, such as an estate planning workshop, for the community. The Agency hosts a booth at the local pridefest to remind their elders that the Boulder County Area Agency on Aging is LGBT friendly. The Boulder

County AAA also collaborates with Out Boulder, the local LGBT center, to encourage elders to participate in activities such as an intergenerational film project, in which youth and elders’ shared stories were captured on film (<http://www.lgbtagingcenter.org/resources/resource.cfm?r=438>).

Center on Halstead, Chicago, IL

<http://www.centeronhalsted.org/senior.html>

In 2014, Britta Larson, Senior Services Director at the Center on Halstead was interviewed about their innovative housing program for LGBT older adults. Homesharing is a shared housing program where compatible matches are facilitated between a renter and a Homesharing provider who has an extra bedroom in their apartment, condominium, or house. Although each participant has their own bedroom, common areas of the home, such as the living room and kitchen, are shared between them.

Homesharing providers, who are generally LGBT older adults, establish the amount of rent they are looking to receive, which is usually around \$500 and includes all utilities. In some cases, renters provide household assistance in exchange for reduced rent. Types of assistance that may be offered include housekeeping, laundry assistance, grocery shopping, and meal preparation (<https://www.lgbtagingcenter.org/resources/resource.cfm?R=401>).

Larson points out several of the unique needs of LGBT older adults that make this program so important. First, he states, LGBT older adults are twice as likely to be single and three to four times more likely to be without children than their heterosexual counterparts. In addition, most senior living communities are not LGBT affirming and many LGBT older adults fear discrimination in this setting. The household assistance that renters can provide to LGBT older adults through this program can help them remain in their own home and age in place.

Second, he posits that after a lifetime of unequal treatment under the law, many LGBT older adults are experiencing financial hardships. The

additional revenue that the Homesharing provider receives from the rent can be tremendously beneficial for seniors on a fixed income.

Lastly, Larson informs that social isolation among LGBT older adults is common as their support systems dwindle as they age. The companionship they receive from their renter can reduce loneliness and isolation.

Although there are a number of other Homesharing Programs in existence, this Homesharing Program, which began in July 2010, is the first program in the nation that has been designed to meet the unique needs of LGBT older adults (<https://www.lgbtagingcenter.org/resources/resource.cfm?R=401>).

The SAGE Program

www.sageusa.org

SAGE’s innovative services around the country help LGBT elders address employment barriers as they age, and provide LGBT-friendly supports, such as those offered at The SAGE Center throughout New York City (<https://www.sageusa.org/issues/isolation.cfm>). SAGE has a growing network of SAGE affiliates who are meeting these needs in various parts of the country, and their online resources help reach LGBT elders in every part of the country.

SAGE Maine – An Example of SAGE in Action

www.sagemaine.org

SAGE Maine, a state-wide affiliate of Services & Advocacy for GLBT Elders (SAGE), has a particular focus on the effects of sexual orientation and gender identity (SOGI) on relationships in later life. The following are some anecdotal examples from three years of experience in this rural and relatively politically conservative state.

A Drop-In Center opened in Bangor, Maine. On the first day the intern was greeted by two women who did not know each other. One had recently been bereaved after a 40-year relationship with a same-sex partner and was coping with the attitudes of friends and colleagues who did not recognize

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that this grief was equivalent to that of a married couple, not just two roommates or friends. The second lived down a long dirt road several miles from Bangor and did not know another lesbian. After an article appeared in the Bangor Daily News about the group, two other women who had been together for over 30 years and had just retired, and a male neighbor they thought might be gay, arrived; they did not know any other lesbian or gay people in Bangor either. Currently, the group has grown to include a monthly luncheon that attracts as many as 21 people (with two service dogs). Last month Sage Maine invited students from the Bangor High School "Pride" group to come for a potluck; seven came and were engaged in wonderful intergenerational conversations around small tables. Many of the Sage Maine staff felt as if they were acting as kind of "grandparents" for these kids, some of whom identified as transgender or gender nonconforming (TGNC). At the recent Pride Festival, many of these pot-luckers met and greeted each other, as the two retired women helped staff the table along with three other Drop-In folks. Although previously isolated, these students are no longer disconnected and are part of a supportive community. We have invited one new member to the state-wide SAGE Maine Board and in her biographical sketch she wrote: "Finding SAGE meant everything ... After her partner's death: understanding, support, and companionship. She feels honored to be considered for this opportunity to give back to SAGE and help others, as she has been helped."

In the bigger city of Portland, SAGE Maine has had an even larger effect with its monthly dinner which is subsidized by the Southern Maine Area Agency on Aging and hosted by St. Luke's Episcopal Cathedral. Middle-aged volunteers from a local insurance company help serve the meals to over 80 participants. This year there was not only a contingent of walkers in the Pride Parade, but SAGE Maine was able to use a tourist trolley to bring those who did not walk to the large festival in the park, where we provid-

ed seating in the shade for all older participants.

One unique service SAGE Maine provides is a "Virtual Drop-In Center" where folks connect by telephone across the state. The calls are arranged by the Executive Director at the request of the participants who provide a phone number for the call to be received; there is also a toll-free number with no code needed if they wish to connect without providing their phone number, or are calling from a different number. At the designated time (4 pm on Tuesdays for the Lesbian, Gay, & Bisexual - LGB - folks; 4 pm on Wednesdays for the Transgender - T or TGNC - folks), the phone rings and they are invited to join the conversation. Some typical comments on the LGB conversation is the fear of disclosure in the rural community, concern about anti-gay attitudes if they need home health or physical therapy, and worry about housing if one can no longer live at home. The TGNC group, which is made up primarily of individuals who have never identified as LGB and have been, or still are married, have different concerns.

For example, one person had to visit the emergency room late at night and felt the attending staff was uncomfortable with treating her, despite the fact that she has been regularly seen at the hospital for many years. Another participant lives in a very rural part of the state and no one knows he was not born male. He is very careful to avoid "having a target on his back" and so avoids any LGBT gathering or group; the telephone group is the only place where he feels able to talk openly and, in fact, may be the only social contact he has during the week. Another TGNC participant, still living with a wife, has to take our calls out in the barn on her cell phone, as the wife is unaccepting of living with someone who thinks of herself as a woman.

SAGECAP: Innovative LGBT Caregiving Program

[<https://sageusa.org/programs/sagecap.cfm>]

SAGE's SAGECAP program offers critical supports for LGBT caregivers in New York City and around the country.

SAGECAP offers a host of caregiving services to provide comprehensive support to caregivers. These services include: weekly caregiver support groups, one-on-one and group counseling services, educational seminars, bereavement group referrals, and development of caregiving plans. In addition, SAGECAP works with caregivers to prepare for their own aging needs by offering informational workshops on topics such as long-term care, financial and legal planning, and referrals to planning professionals with expertise in LGBT aging issues. By offering a comprehensive menu of counseling supports and educational resources, SAGECAP supports the caregiver with their current reality as well as preparing them for a supportive aging future. Additionally, SAGECAP promotes LGBT caregiving issues through education and outreach both locally and nationally through ad campaigns, presentations and partnerships with aging service providers to increase the ability of the aging services, and LGBT services network to meet the needs of the growing numbers of caregivers. [<http://www.lgbtagingcenter.org/resources/resource.cfm?R=45>]

Conclusion

These support and housing programs are shining examples of what is being done and what can be done to better help LGBT elders face their unique aging experience. As Aging Life Care Managers, it is vitally important we pay special attention to the risk factors for social isolation and loneliness in our aging LGBT clients and that you encourage your local providers and facilities to do the same. It is even more important to let the LGBT community know about services that are affirming by advertising, signs in waiting rooms, and by the use of LGBT-friendly forms. One cannot tell who is LGBT by looking, nor can an LGBT person tell which services or facilities are affirmative by guessing.

As providers, we need to recognize the subtle and significant unique needs of isolated older individuals because of long-standing attitudes regarding sexual orientation and gender identity. These gender-based attitudes

are often deeply ingrained in the fabric of society and in the psyche of individuals. Only by calling attention to them, and seeking out available resources, especially including training and certification from organizations such as SAGE (<http://sageusa.care>), can we address the problems of isolation and relationship deficits in the later years.

Resources

SAGE LGBT Elder Hotline

Now, no matter where they live, LGBT elders have a place to call when they need peer counseling, information, and local resources. The SAGE LGBT Elder Hotline is live and ready to take your calls at 1-888-234-SAGE. The hotline is open Monday through Friday from 4pm - midnight, Eastern Time and on Saturday from noon to 5PM Eastern Time. Prefer to use email? Reach out at SAGE@glbthotline.org.

LGBT Aging Center

Another website that also has a rich set of resources about LGBT isolation is the National Resource Center on LGBT Aging: <http://www.lgbtagingcenter.org>. This resource center is supported by SAGE and several other organizations and was created with a federal grant. Here are some of their current resource publications:

SAGE PUBLICATIONS

[<http://sageusa.org/results.cfm?Keywords=isolation>]

- A Guide to LGBT Caregiving - Spanish Edition (Una guía para el cuidado de personas LGBT)
- Act now! OAA reauthorization must include services for LGBT elders
- Advancing an LGBT Agenda: Guide to Aging Topics at Creating Change 2014
- Eight Policy Recommendations for Improving the Health and Wellness of Older Adults with HIV
- Gaining Visibility: The Challenges Facing Transgender Elders
- Health Equity & LGBT Elders of Color

- How Health Care Reform Will Help LGBT Elders
- Improving the Lives of LGBT Older Adults
- Improving the Lives of LGBT Older Adults - Abbreviated Version
- Improving the Lives of LGBT Older Adults - Large Font
- Improving the Lives of Transgender Older Adults
- Improving the Lives of Transgender Older Adults: Executive Summary
- In Their Own Words: A Needs Assessment of Hispanic LGBT Older Adults
- Inclusive Questions for Older Adults: A Practical Guide to Collecting Data on Sexual Orientation and Gender Identity
- Inclusive Services for LGBT Older Adults: A Practical Guide to Creating Welcoming Agencies
- Infographic: Federally-Supported Services for LGBT Elders
- Know Your Rights! LGBT Older Adults & Older Adults Living with HIV
- Lesbian, Gay, Bisexual Older Adults & Medicare Fraud Prevention
- LGBT Older Adults and Exclusion from Aging Programs and Services
- LGBT Older Adults and Falling Through the Safety Net
- LGBT Older Adults and Inhospitable Health Care Environments
- LGBT Older Adults and Reauthorization of the Older Americans Act: A Policy Brief
- Opening Doors: An Investigation of Barriers to Senior Housing for Same-Sex Couples
- Out & Visible: The Experiences and Attitudes of LGBT Older Adults, Ages 45-75
- Planning With Purpose
- Public Policy & Aging Report: Integrating LGBT Older Adults into Aging Policy & Practice

One webpage on the SAGE site is devoted to isolation; reviewing the comments and resources, it is clear the mission of SAGE is both service and advocacy for LGBT elders.

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Late Life Relationships in Spiritual Perspective

James W. Ellor, PhD, DMin

SUMMARY: Late Life Relationships in Spiritual Perspective is a review of the research around the impact of religion and spirituality on relationships. Late life relationships often involve a foundation in religion and/or spirituality particularly when the individuals involved view God as still very active in the world. This article begins by talking about definitions of religion and the challenge of defining spirituality and moves onto discuss basic concepts of intrinsic/extrinsic religion, coping, marriage and family, and social networks involving faith communities. This article explores these concepts as they are reflected in the research over the past 30 years.

Late Life Relationships in Spiritual Perspective

The important role of religion and spirituality in the lives of those over the age of 65 has been long documented (Maves, & Cedarleaf, 1949; and Gray & Moberg, 1962). Research has been conducted into the impact of religion since before the 1920's. Since that time, researchers have addressed many important questions about the impact of religion on late life relationships. We begin our discussion by examining how researchers have defined religiosity and how this has led them to determine the importance of religion and/or spirituality for individual older people.

Cohort Effects and Changes

One of the critical research questions was whether one becomes more religious as one ages. Prior to 1969, research largely found that older adults attend religious services more than successive younger generations suggesting that the older one gets, the more likely she/he is to become more religious.

However, as a result of the Duke Longitudinal Study of Aging (1955-1969) a new perspective was offered (Blazer & Palmore, 1976, p. 85). This study found that religion was not a reflection of aging, but rather a cohort effect. In other words, even though data

suggests that older persons are more likely to attend church, synagogue, temple or mosque, this reflects the life experience of their cohort, rather than a reflection of aging. This view of religion continued through the 1980's into the 1990's even as religious research embraced the idea of spirituality and became largely inseparable.

However, today we are seeing a very new picture. There has been a shift, particularly with younger persons, to embrace spirituality, rather than religion. Even though studies suggest that attendance at religious organizations has not radically changed, even those who attend religious congregations identify themselves more with spirituality (Ellor & McGregor, 2011). Whether or not this shift will affect attendance in future cohorts of elders is unclear. However, what is clear is that any evaluation of how religion affects late life relationships must include an investigation of both religion and spirituality.

Sorting out Religion and Spirituality

The terms religion and spirituality, while often used together, can be understood as distinct concepts. Numerous efforts to offer definitions for these concepts are found in the literature. Taken together, religion generally

refers to faith traditions, congregations, and dogmas. Spirituality, on the other hand, seems to be defined more along the lines of individual beliefs and relationships with the spiritual. For example, Koenig, King, & Carson (2012) offer the following two definitions: "Religion, involves beliefs, practices, and rituals related to the sacred, (p. 37)" whereas here spirituality is generally more challenging to define. They suggest "the word spirituality has none of the baggage; it has come to mean whatever people wish and has wide applicability and appreciation in this age of individualism (p. 38)." The challenge that Koenig and Associates are pointing out is that spirituality is more likely to reflect individual preferences and each person has his or her own perceptions or nuances as to what this should mean. For this reason, spirituality can be much more difficult to define.

Relationships, when traced back to religion, tend to suggest an institutional context. Bible studies, friends from synagogue, temple as a place to meet new friends, or rituals in which all the members of the mosque participate all contribute to relationships. While the institutions may be context that brings people together, relationships are still maintained by individuals. Thus, spirituality may best capture the connection between people, whether it reflects a relationship to the

divine or between two persons with something in common. Regardless, an older persons' beliefs, whether based in religious dogma or spiritual ideas, are likely to have a significant impact on their relationships in later life.

Intrinsic/Extrinsic Religion

Another way to think about how important religion is for an older person is to consider what motivates a person to embrace religion or faith. Gordon Allport, seeking to clarify religious orientations, developed the concept of intrinsic/extrinsic religion (Allport & Ross, 1967). He integrated this concept into a 20-point scale that sorts individuals into two groups, 1) those with an intrinsic sense of religiosity and 2) those with an extrinsic perspective. This index has frequently been used as a "religiosity scale," or a measure that determines religiousness.

Extrinsic

Allport explains persons with extrinsic orientation are "...disposed to use religion for their own ends." He states the term extrinsic is borrowed from axiology in order to "designate an interest that is held because it serves other, more ultimate interests" (Allport & Ross, 1967, p. 434). While this has been interpreted in other contexts since the work of Gordon Allport, for the most part, definitions seem to rely on the idea that people with extrinsic leanings have some type of motivation that does not reflect their faith for coming to church, synagogue, temple, or mosque. For example, a person who sees their social standing enhanced by stating that they are a member of 1st Church.

Intrinsic

On the other hand, the intrinsic believer is there to worship God, however she or he perceives God. Allport defines the intrinsic person as one who finds their "master motive in religion." The intrinsic believer will regard other needs as less significant and attempt to bring these needs into harmony with religious beliefs and prescriptions, (Allport & Ross, 1967, p. 434).

This concept holds a long history in the research field, but is important

to direct practice as it signals information about the type of relationship one's client might have with their religious congregation. Intrinsically oriented individuals seem to see their congregation and faith as a source of support and assistance, where this may not be as true for a person with an extrinsic orientation. This research also seems to suggest the importance of their religion or faith to that individual. This was not the original intent from Gordon Allport, but anecdotally seems to be helpful.

Intrinsically oriented individuals seem to see their congregation and faith as a source of support and assistance, where this may not be as true for a person with an extrinsic orientation. This research also seems to suggest the importance of their religion or faith to that individual. This was not the original intent from Gordon Allport, but anecdotally seems to be helpful.

The literature throughout the 1960s and 1970s often used this idea of intrinsic vs. extrinsic religion as a primary religiosity factor. It seemed as if this was somewhat abandoned for the next 20 years, but has returned in more recent years. More recent researchers see this distinction as the difference between a person committed to their religion or faith and someone who is not. This distinction seems to sort persons who have a personal faith rather than someone who treats it more like a club.

For care providers, it is important to utilize both of these concepts in determining the impact religion and spirituality has for your individual clients.

In religious research, this concept of intrinsic vs. extrinsic religion reflects the essential motivations for embracing religion, but does not necessarily reflect the spirituality of the person. Care providers need to examine both the nature of their client's beliefs (religious, spiritual, or both) and what motivates them to be involved with a religious organization (intrinsic vs. extrinsic). Understanding the foundation of client's beliefs will inform the care provider about how much these beliefs can be leveraged for maintaining or gaining new relationships and supports as they age.

Relationships & Religion

There are several important ways that religion and spirituality impact relationships in later life.

Religion as a source of Relational Values

The literature on older adults suggests that religious organizations are an important source of values. These shared values offer both the basis for mutual relationships as well as guidance as to how relationships should be conducted. Often defined by sacred texts with the concurrence of religious leaders, values reflected by religion are often one reason why young families join religious institutions, to bring up their children (Balboni et. al., 2017).

Marriage

Religious beliefs may also help strengthen and fortify marital relationships. Research into older couples' relationships suggest that religion can have a buffering effect between partners. "Associations between religiosity and marital outcomes...specifically increased church attendance and personal religiousness have been linked to lower risk of divorce and increased marital satisfaction" (Mahoney, Pargament, Tarakeshwar and Swank, 2001 p. 559). This is an important finding; however, other studies suggest that this is truer for women than in men within the relationship (Yorgason, 2015).

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Religious Coping

A critical part of human relationships involves what psychologists would refer to as “coping.” Developing good coping mechanisms is key to addressing stressful situations and maintaining healthy relationships. Numerous studies have shown that one of the most important coping mechanisms can be religious coping. However, religion may not always have a positive effect on coping. For example, when faced with a major trauma, persons with an intrinsic faith may turn to their faith for support in coping whereas persons with an extrinsic faith will turn away from their faith.

Positive Religious Coping

Religion has been emerging as a primary coping device since the early 1990’s (Koenig, 2004). It has been suggested that religious coping can be the “strongest predictor of positive psychological changes in the aftermath of extremely stressful events” (Krumrei & Rosmarin, 2012, p.246). Kenneth Pargament (1998) suggests that “religious coping is multipurpose. It may provide comfort, stimulate personal growth, enhance a sense of intimacy with God, facilitate closeness with others, or offer meaning and purpose in life” (p. 116).

There are several different ways of employing religion in coping such as: spiritual support, congregational support, and benevolent religious reframing (Pargament, 1998).

Spiritual Support

Spiritual support suggests a partnership with God where the individual turns to God for help and support in challenging times. When this person prays he or she believes that God will respond and be supportive of whatever concern is being brought up (Pargament, 1998).

Congregational Support

The inter-human support from fellow believers can be uplifting both as the result of common values and beliefs as well as simply the nurturing that comes from people who care. While not every congregation is able to

provide this for every individual, it is a common goal or aspiration of most congregations to offer this type of support to its members.

Benevolent Religious Reframing

Another way of employing religion in coping, referred to as benevolent religious reframing, suggests that religion allows the individual to reframe a painful event from being a human tragedy to become God’s will. By doing so, the individual is no longer alone in their suffering and may even find a companion in God to absorb some of the guilt or blame for the situation. This reframing allows the individual to feel the support of God rather than the alone feeling of working through a challenge by themselves.

Together, these three positive uses of religious coping suggest a relationality that is critical to finding the support that many people need at times of a crisis. However, researchers working in coping have found that any coping mechanism can be employed either positively or negatively.

Negative Religious Coping

Pargament, in his research, is quick to note that there are some harmful uses of religion. Religious institutions are composed of human beings, and not always as supportive of their members as one might hope. Negative responses to either God or a congregation can include dissatisfaction with a congregation or even a sense that either God or the congregation have abandoned them in their time of need. Not unlike the figure of Job in the Bible, people can feel abandoned or forgotten by God, particularly when they expect God to prevent something from happening and yet it happens anyway. Further, instead of reframing a human hurt into some type of support from God, an older person could assume that God has either actively attempted to harm them or at least simply ignored their pain (Pargament, 1997). Pargament concludes, “religious coping appears to affect the outcomes to negative

life events. Sometimes it is helpful and other times it may be harmful” (Pargament & Brant, 1998, p. 124).

Caregiving Relationships – a demonstration of religious coping

One powerful example of the effect of religious coping is its impact on family relationships and caregiving. One of the most challenging times for relationships in later life comes when an older family member is faced with caregiving needs. A person’s religious beliefs impact their values and offer rules for how we respond to the needs of a family member. Religious coping offers a rich environment for practical application in this situation.

For example, when examining motivations for families to offer care for older adults, many religious traditions suggest that it is important to “Honor thy father and their mother” (Exodus 20:12) as found in the 10 Commandments. This can be interpreted as a commandment to care for aging parents that may also be reinforced by congregations and clergy as a value that is right to do. During employment of this commandment, the same individual may then feel that it is God’s will that she or he is engaged in what is often the hard work of family caregiving. In this process, the congregation may well offer considerable support for these activities.

However, as demonstrated in the discussion above on coping, there can be both positive as well as negative aspects. Epps’ 2015 study examines African American, Hispanic, as well as Caucasian families and challenges the assumption that religion is always a positive factor. Some approaches to religion and faith are more prone to bring out guilt as much as support for either the caregiver or the person in need of care. This guilt can lead to negative feelings and even resentment among family members who are asked to play the caregiving role.

Social Networks, Social Services, and Faith Communities

In addition to providing a framework and support for late life relation-

ships, religious organizations also provide practical support for relationships to develop. Faith communities provide significant social networks. These communities not only provide a place for people to join together, but also encourage socialization and support relationships.

Older persons involved in a faith community start with their faith tradition in common. Often this will include cultural variables as well, as many religious communities reflect a wide variety of cultural orientations. Having religious beliefs in common is especially important for an older person who is attempting to develop new relationships. For example, an older person moving to a new location can start with a local religious community and automatically have relationships with people they have something in common with.

It is not uncommon to find small groups within religious communities that are made up of older adults. In Christian Churches, often women's groups, for example, will be largely made up of older women. The group may not be called a senior citizen group, but will function in that capacity (Tobin, Ellor, Anderson-Ray, 1986). Frequently, widows and widowers will also come together in congregational contexts, sitting together at meetings or worship and even offering rides to events for each other. Many religious communities and faith traditions have groups that expand beyond the local congregation. Lutheran church women, or Presbyterian men, for example, have national organizations that link the groups in local communities together for events, reading material, and other social functions. These groups can be an essential support for elders as they prevent social isolation and provide community and social interaction.

Faith communities may also serve as hosts for outside groups that provide social networks for older people outside of their worshipping congregation (Tobin, Ellor and Anderson Ray, 1986). Many non-faith-based services have found a home in religious organizations. For example, there are numerous religious congregations that have large rooms with a kitchen at one end

that make attractive meal sites. Often an external group, often associated with the Area Agency on Aging, will run a meal site in the faith community's kitchen. This way, the church is providing yet another opportunity for older adults to engage in social interactions and develop relationships.

In addition to serving as a host for social networks, religious organizations also play other important roles in supporting relationships for older adults. In their mixed methods saturation sample study of six communities ranging from urban to rural, Tobin, Ellor and Anderson Ray (1986) found that religious organizations also provide three other types of programs or services for older adults:

- Providing religious programs
- Providing pastoral care programs
- Providing formal social services (p.32)

While the value of religious programs for promoting late life relationships seems obvious, the impact of formal and informal services on relationships is not as widely acknowledged. These programs and services play an important role in encouraging relationships with church members, as well as the Pastor of the church. Through these programs, church members are not only providing essential support, but also responding to the emotional and spiritual needs of the older adult.

Pastoral Care Programs

Pastoral care programs vary widely in religious congregations. They can be used to refer to any informal service found in a religious congregation including: rides to the doctor, informal counseling services of various types, or home visits by both clergy and lay persons. Any type of service that supports the person for socialization or connects them with others would all be included in this category. Often this type of support is set up in an informal way: If Mrs. Smith needs a ride to the doctor, she need only call Pastor Jones who will call Mr. Lang who will pick up Mrs. Smith and take her to the doctor. While this can be referred to as providing transportation services, there is no means

test, no case file, no service agreement, but a vital service is provided to the older adult. In this way, religious groups are not only providing a needed service, but also creating positive relationships with church members.

Formal Social Services

Religious groups also function as formal service providers. Services might include: child and adult day care centers, senior centers, multi-purpose case management, and a variety of other formal services. Cnnan, Boddie, Handy, Yancey, and Schneider (2002) further found that religious organizations create agencies that assist in social welfare activities, especially in cities. In some cases, religious organizations have created services that have eventually separated from the church. Tobin, Ellor and Anderson-Ray (1986) observed that frequently when a religious congregation helps to create a social service, it is quickly spun off as its own 501c3 organization. If such agencies are staffed by clergy or visible laity from the sponsoring church(s), they tend to stay close to these organizations. However, when this bond is broken, it is not uncommon for the agency to drift away from the congregation to be anchored within the formal social service system.

Summary

Throughout the long history of research into the various impacts of religion on aging, there is considerable evidence to suggest that religion offers positive support for human interaction in later life. The trend in family research around religion and/or spirituality is that religion and spirituality enhance relationships (Epps, 2015).

In general, religion and spirituality, when shared, offer rules for how to get along with one another as well as external guidelines that can be turned to without invoking the other person in the relationship. If religion offers these rules or areas of agreement in a socially acceptable context, it serves a useful purpose. While these rules have historically been clear, religious research has

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become more of a challenge as more recent cohorts have shifted toward the concept of spirituality rather than religion. Because of the individual nature of spirituality, it is essential for care providers to understand their client's beliefs and how these beliefs affect their relationships.

Religious institutions can be strong support networks that create community and foster relationships, especially for older people. However, the impact that religious and/or spiritual beliefs have on relationships in later life varies greatly depending on the individual. It is important for care providers to have a clear understanding of how to evaluate the importance of religion and spirituality and how these beliefs may have both positive and negative effects on relationships for older people.

For the current cohort of older adults, religious rules can often be viewed as spiritual support for relationships. However, as future generations embrace spirituality without always grounding it in the institutional, religious congregation's greater disparity is likely to occur. Future research in this field may change as views become more individualized and less likely to be leveled by religious values.

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