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Applying a Trauma-Informed Perspective to Loss and Change in the Lives of Older Adults

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Abstract

Traumatic events are widely acknowledged to have long-term impacts on individuals, yet only recently have health care professionals begun to assess for and gain an understanding of trauma in the lives of older adults. For many older adults, trauma is often disenfranchised and overlooked as being either a distant past event (e.g., child abuse) or a normal part of aging (e.g., widowhood). Trauma informed care, on the other hand, calls for health care professionals to acknowledge that past and recent events may have been traumatic for older adults and to assess and care plan to reduce or prevent re-traumatization. In this paper, we explore the impacts of trauma in later life through a case study of a patient admitted to a long-term care facility. Analysis of this case study suggests several important implications for social work practice in long term care and the use of person-centered care practices in the care of older adults in general.

Keywords: Psychological trauma, trauma informed care, nursing home

Introduction

Over the past 10 years trauma informed care has proliferated as an important approach in health and human service delivery systems. Trauma informed care constructs service delivery systems that acknowledge the possibility that everyone who comes into contact with those systems may have been exposed to traumatic events and creates services that attempt to avoid re-traumatization (Fallot & Harris, 2008). The prevalence and long term impacts of trauma were first described in the ACEs Study, conducted at Kaiser Permanente Health System in the late 1990's (Felitti et al., 1998). By collecting information on childhood experiences and long term health outcomes in adult health care recipients (Felitti et al., 1998), the ACEs study raised awareness of both the widespread prevalence of potentially traumatic experiences and the long term impacts of trauma exposure (Muskett, 2014). The effects of trauma are magnified in health and human service settings as individuals with trauma histories are disproportionately likely to need these services. While often clustered with trauma treatment, trauma informed care is different because it is applied to all individuals in contact with a setting (Fallot & Harris, 2008).

A systematic review about trauma informed care research describes positive impacts such as decreased use of restraints, decreased reports of distress, and higher rates of participation and compliance with treatment (Muskett, 2014). Critics of trauma informed care are concerned that the focus on trauma classifies all stressful events as trauma, de-emphasizing coping and resilience. Not all of those who experience traumatic events have negative outcomes (Bonanno, 2004). Positive outcomes are often seen in cases when a traumatic event is a discrete, isolated experience in an otherwise supportive and nurturing environment (Muskett, 2014). However, trauma informed care may also be a part of that supportive, nurturing environment.

Trauma informed care was first used in inpatient mental health settings and residential treatment for children and youth. It has been discussed in health care settings (Reeves, 2015) but seldom in long term care (Kusmaul & Waldrop, 2015; Anderson, Fields, & Dobb, 2011). In the United States, the Centers for Medicare and Medicaid Services (CMS) released new nursing home regulations in October 2016 that included the need to incorporate trauma informed principles in patient-centered care (CMS, 2016), with a focus on nursing home residents who are Holocaust survivors and survivors of childhood sexual abuse. The authors of this paper believe that the regulatory definition of trauma that would warrant trauma informed care is limited, so this paper uses the broader view of trauma, which includes but is not limited to physical, emotional, and sexual abuse, neglect, serious illness, forced displacement, traumatic grief, and experiencing or witnessing various types of violence (SAMHSA, 2016b). We apply this definition of trauma to long term care through the lens of a case study and the multiple stressful events potentially experienced by a new nursing home resident. We use this case study to support the need for trauma informed care in long term care settings. This case study is an amalgamation of many real patients that the authors saw while working in health care settings. While not an actual ‘case study’, the characteristics of the actors and situations are not uncommon in long-term care settings.

Literature Review

Trauma and Theory

Trauma theory has evolved over time and is rooted in developmental theories. Freud first considered the impact of trauma on development when he observed a patient’s re-experiencing a previously repressed anxiety provoking memory (Lynch, 2012). He and Josef Breuer concluded that external events were capable of producing lasting hysterical symptoms (Brandell, 2012).

They defined trauma as any event, thought, or feeling that was capable of creating sufficient intrapsychic conflict that it could produce an intolerable level of anxiety (Lynch, 2012, pp. 90).

Repression was considered to be an important skill for coping with traumatic experiences.

Lazarus & Folkman (1984)'s seminal work defines coping as the thoughts and behaviors that help an individual manage the demands of an experience that exceeds their resources. The trauma coping mechanisms people develop are a combined result of individual characteristics (Piers, 1998) and how they interpret the situation (Lazarus & Folkman, 1984), which ultimately determines how they incorporate the experience into their persona, which is why traumatic experiences impact different people in different ways. Modern trauma theory distinguishes between Freud's concept of repression and dissociation, in which the individual unconsciously stores the traumatic experience away from other life experiences (Lynch, 2012). People with dissociated traumatic memories are vulnerable to trigger events, when external stimuli resemble previous experiences that are not in conscious memory (Lynch, 2012). Through this theory, we can understand how nursing home care functions such as bathing and dressing could inadvertently trigger a reaction in a dissociated patient.

Trauma informed care is based in trauma theory. It considers how trauma impacts the developmental process of an individual that experiences it (Lewis, 2012). This parallels why trauma is important for social work. Social workers approach individuals with a life course, person in environment perspective which would include the long term impacts of traumatic experiences. Trauma includes a range of experiences that threaten death, bodily harm, or violence (American Psychiatric Association, 2013). Long term consequences seem to be related to the individual's reaction to the event, including feelings of fear, helplessness, and horror

(Stamm, 1999, p.4). These consequences may be pervasive and may include unhealthy coping behaviors and avoidance (Rayburn et al., 2005).

Stress, Coping

While trauma is a significant problem, not every stressful event is traumatic (Larkin, Felitti, & Anda, 2014). Even when something is traumatic, not everyone has the same reaction. Some losses may be traumatic for some people, yet for others these events can be portrayed in a nexus of stress, coping and even resilience. Positive outcomes are most often associated with discrete events and a supportive environment. Yet, we also need to consider the experiences of loss, sudden loss, unexpected loss, and multiple losses at the same time which can overwhelm previously adequate resources (Bonanno & Kaltman, 2001). Older adults who move into nursing homes often experience multiple losses, either in the time leading up to nursing home admission, resulting in the need for nursing home care, or as a result of nursing home placement itself (Choi, Ransom, & Wylie, 2008). Events that are seen as potentially traumatic in earlier life, such as loss of a spouse, forced relocation, and acquired disability may be dismissed as normal parts of aging. While older adults cannot be incarcerated in a nursing home against their will, older adults are often compelled by a nexus of care needs, cognitive status, financial resources (or lack thereof), and caregiver circumstances into a long term care institution.

Each of these potentially traumatic events has been individually linked to negative outcomes such as depression, uncertainty (Dorsett, 2010), disconnection, loss of pride in one's self and accomplishments (Nuttman-Shwartz, 2007). Forced relocation in particular disrupts connections to place and sense of belonging, particularly when the new location is more crowded and lacks distinct boundaries (Roos, Kolobe, & Keating, 2013). These may occur separately or

together for older adults. Semi-private nursing home rooms, for example, may be crowded and lack boundaries and also result in loss of belongings and independence.

Social Work Approach/Strengths Perspective

The trauma informed care perspective is useful for social work practice, and indeed incorporates many principles that may already be employed in nursing home social work. The trauma informed care principles of choice, collaboration, and empowerment (Fallot & Harris, 2008) are described in nursing home regulation as being a required part of person centered care. The October 2016 nursing home regulations specifically require including the resident's perspective in care planning. Trauma informed care is rooted in shifting the question of "What's wrong with you?" to "What happened to you?" (SAMHSA, 2016a). *This shift changes the asker's perception from the person in front of them being the problem to the person in front of them having a problem.* Applying this perspective across a long term care organization brings all staff to this viewpoint. Trauma informed care creates a person-centered environmental culture that treats all individuals in ways that protects trauma survivors from re-traumatization, much like universal precautions in health care presumes that all human blood and body fluid might contain a blood borne disease (OSHA, n.d.), or universal design in architecture that makes products and environments accessible and usable by all (University of Missouri, 2017).

Trauma-Informed Perspective

A person centered intake process considers the person in environment, including all the environments they have lived in throughout their lives. Potentially traumatic events happen at high rates in our communities (Bloom & Farragher, 2010; Larkin, Felitti, & Anda, 2014) and thus chances are high that a new client may have a traumatic event in their past. Traumatic reactions occur when internal and external resources are not able to react to an experience

(Bloom & Farragher, 2010) which is how different individuals have different reactions to potentially traumatic events. When traumatic events occur to individuals whose resources are inadequate for whatever reason, trauma may have a long term impact on perceptions. Trauma informed service systems acknowledge the universal potential for these impacts and deliver services in ways that take care not to re-traumatize (Bloom & Farragher, 2010).

Trauma informed care is a broad concept. SAMHSA (2016a) says a trauma informed organization recognizes the pervasiveness of trauma, responds to the signs and symptoms of trauma in all members of the system, and seeks to avoid re-traumatization by its actions. Service delivery systems should encompass principles of safety, choice, collaboration, trustworthiness, and empowerment in their approaches to clients (Harris & Fallot, 2001). Trauma informed care implementation includes a combination of workforce education, and organizational practices that reflect the Fallot & Harris (2008) principles (Hanson & Lang, 2016). It is important to assess past trauma using evidence based assessment tools, to understand recovery models, and refer to trauma specific services if warranted (Hanson & Lang, 2016). Trauma informed care is different from trauma treatment services, but may include them (SAMHSA, 2016a). Discussions of trauma informed care in residential settings for older adults have been absent. A literature search on trauma informed care and residential settings produced only discussions of juvenile and adult residential mental health treatment. This paper seeks to address that gap. Since a lack of trauma informed systems may inadvertently exacerbate previous trauma symptoms or cause new ones, we consider the potentially traumatic experience of nursing home admission in the “case study” of Lucia, and discuss her losses and changes from a trauma informed perspective. As previously stated, Lucia is not an actual case, but a collection of characteristics and situations common to nursing home patients and their families.

Case Study

Lucia is a 72-year old woman who recently relocated to a nursing home in Baltimore, Maryland, from her private home in New Jersey. She is of Puerto Rican descent, has an Associate's degree, and worked for 40 years as an administrative assistant for an automotive company until her retirement at age 70. She has a daughter who lives out of state and a son who lives locally. Lucia's husband of 52 years died 10 months ago and since that time her physical, emotional, and cognitive health have declined significantly. She has congestive heart failure and osteoporosis and three months ago she was diagnosed with Alzheimer's disease. The precipitating event to her placement in the nursing home was a fall resulting in hip replacement. Lucia did not regain her ability to walk despite the efforts of physical therapy and she now uses a wheelchair for mobility. Upon admission to the nursing home, Lucia presents with a flat affect and appears to be confused and afraid of the new environment. Lucia's son is present during the admission process and states, "My mother has never been the same since dad died." He serves as her power-of-attorney for health care and financial decisions and feared for her safety living alone at home. Lucia's involvement in the decision to move to the nursing home was limited, but she agreed that she was afraid of having another fall. Lucia will be living in a double-occupancy room since there are no single-occupancy rooms available.

Application of Literature and Theory to Case Study

In this case study Lucia has experienced multiple potentially traumatic events in the months leading up to and including her admission to the nursing home. While we are unable to determine the specific impacts of these events, we will explore each event, and discuss trauma informed ways to mitigate the potentially negative impact on Lucia. We will examine the process of institutionalization and reflect upon the factors in our case study that may impact Lucia's life during this transitional phase.

Loss – Nursing Home Placement

While 1% of adults age 65 to 74 reside in nursing homes, this number climbs to 8% for those age 75 and older. While these percentages are low, they translate into approximately 1.4 million individuals. This number is expected to rise in the next two decades with the growth of the older adult population and continued high rates of chronic illness and disability (Congressional Budget Office, 2013). Institutionalization or 'nursing home placement' is a

complex and stressful event for older adults and their families, marked by emotional issues, social losses, tangible losses, loss of independence and autonomy, and family conflict and strain (Brownie, Horstmanshof, & Garbutt, 2014; Ellis, 2010; Nikzad-Terhune, Anderson, Newcomer, & Gaugler, 2010). Long term care is associated with rates of post-traumatic stress disorder from 9-22% (Moye & Rouse, 2014).

The decision to institutionalize is typically arrived at via two avenues, either after months or even years of consideration and deliberation or after a catastrophic event (e.g., injurious fall, stroke) (Johnson & Bibbo, 2014). The first avenue to relocation may afford individuals and families with the time needed to emotionally process the meaning and consequences of the move (Bern-Klug, 2008). The second avenue may be more challenging given the lack of time to prepare emotionally and logistically for the move. In our case study, Lucia suffered a catastrophic fall resulting in the inability to walk and subsequent nursing home placement.

While care needs and professional advice are certainly factors (Mason, Auerbach, & LaPorte, 2009), ultimately the decision lies with the older adult and the family. In many cases family members decide based on their ability to provide the needed care. In this case, Lucia reportedly had little input into this decision and this can be problematic. A recent integrative review on relocation found that older adults with less participation in the decision-making process “experienced prolonged adjustment periods, dissatisfaction with the facility and staff, and hesitancy to participation in the social activities of the community” (Gilbert, Amella, Edlund, & Nemeth, 2015, p. 766). Lucia also has a diagnosis of dementia and studies have found nursing home placement can result in increased behavioral problems, increased depression, decreased cognition, increased falls, and in some cases decreased overall quality of life (Beerens et al., 2014; Sury, Burns, & Brodaty, 2013). The road ahead for Lucia and her

family may be difficult based upon the sudden decision to relocate to the nursing home, the limited role that Lucia played in this decision, and her diagnosis of dementia.

Loss – Death of a Partner/Spouse

Except in rare cases of simultaneous death, widowhood is an inevitability for partnered and married individuals. Among older adults, the loss of a spouse is considered one of the most distressing yet one of the most common transitions (Carr, 2006). Research on the impact of widowhood is rich and deep, and explores both the experience of losing a spouse and the specific experience of losing a spouse in late life. Despite the extensiveness of the research, consistent conclusions are hard to find (Wolff & Wortman, 2006).

Carr (2006) identifies several of the many methodological challenges to conducting research on bereavement and widowhood. Cross sectional research requires accurate recall of events before, during, and after the target death yet when recruiting widowed persons, events are viewed retrospectively through the lens of the loss (Carr, 2006). Cross sectional research that recruits individuals who have experienced loss also faces challenges around identification and recruitment of subjects, as well as ethical issues on subject vulnerability and length of time since the death (Adamson & Holloway, 2012), which may lead to a less-than-representative sample that does not contain all groups of interest. Oversampling and targeted recruitment techniques may address some of this, but they may not be able to overcome all of the structural barriers to accessing diverse populations (Caserta, Utz, Lund, & DeVries, 2010).

Longitudinal research captures events as they change over time, but it is difficult to predict who will become widowed during the study period to ensure an adequate sample of widowed individuals (Carr, 2006). Existing longitudinal studies of populations present some opportunities here, but they must contain questions or areas of interest (Martin-Matthews, 2011).

Current data sets such as the Health and Retirement Survey or the Changing Lives of Older Couples (CLOC) study focus on particular age groups (Martin-Matthews, 2011). Further, even if the study contains older and younger samples, since widowhood is an unusual event in young and middle adulthood, prospective studies are unlikely to capture equivalent comparison groups (Carr, 2006).

Despite these methodological challenges, existing research attempts to characterize the similarities and differences between the experiences of younger and older widowed individuals. Across age groups, the loss of a partner can reverberate across the emotional, social, physical, and spiritual domains of life and grief reactions can be intense. For those who lose a spouse, “the experiences of widows and widowers are linked inextricably to how, when, and where their spouses died” (Carr, Wortman, & Wolff, 2006, p 49). So while the depth of the experience may be similar, the details are different. Age and life stage can shape the grief reactions and the support that widows receive. Younger widows are faced with specific realities that older widows typically do not have to address, such as raising children alone, addressing the grief reactions of their young children, loss of income, loss of social identity, and loss of long-range plans, hopes, and dreams (Parkes & Prigerson, 2010; Taylor & Robinson, 2016). Older widows, such as Lucia, face different realities, such as simultaneously confronting the compounded losses associated with aging, losing the support necessary to maintain independence, and missing a relationship that may have spanned many decades (Naef, Ward, Mahrer-Imhof, & Grande, 2013). Older widows are less likely to re-partner than younger widows contributing to social isolation. Finally, older widows have been found to have higher rates of complicated or prolonged grief compared to younger widows and have a higher morbidity and mortality rates than married older adult counterparts (Ott, Lueger, Kelber, & Prigerson, 2007; Sullivan &

Fenelon, 2014; Supiano & Luptak, 2014; Vable, Subramanian, Rist, & Glymour, 2015). Elderly widowed individuals who had happy marriages to previously healthy spouses are the most likely to develop chronic grief reactions (Wolff & Wortman, 2006), putting Lucia at high risk.

Some research articulates the opposite. The anachronous nature of losing a partner in younger adulthood typically casts such deaths as “tragic” while the loss of a partner in later life is generally considered to be “normative”. Older adults who lose a spouse may have undergone more anticipatory grieving either due to age, an extended illness, or witnessing friends losing spouses (Wolff & Wortman, 2006). Older adults also have more experience in managing the many challenges of life (Wolff & Wortman, 2006). Ageism may also play a role as society tends to devalue older adults and view them as having limited futures and therefore less to mourn (Bevan & Thompson, 2003; Croxall, 2016). These disparate societal views can effectively enfranchise or disenfranchise the grief experienced by these two groups of widows. Grief can become disenfranchised when losses are not fully recognized, acknowledged, and validated resulting in a lack of emotional and instrumental support (Doka, 1989).

The social work perspective of person, place, and time supports the idea that the context of a loss is a significant factor in how the loss is incorporated into an individual’s life structure (Stamm, 1999). Despite this, health care professionals, including social workers, may be among those who disenfranchise the grief of older widows by failing to recognize the depth of these losses. In our case study, Lucia recently lost her husband of over five decades. As she moves into the nursing home, few staff will recognize that she is a recent widow as she joins a legion of other widowed residents. Nursing home social workers may assess for losses during an intake interview, but once widowhood is a box that is checked on an intake form, they may not have the time to follow up to assess for grief reactions (Bern-Klug & Kramer, 2013). Disenfranchising

her grief, as with disenfranchising trauma, may compromise Lucia's quality of life as she deals with multiple losses and change. A trauma informed environment would create a safe space for Lucia to address her grief.

Loss – Physical abilities/health

In this case, Lucia is coping with two chronic diseases and a new diagnosis of dementia. Professionals rarely label cases such as Lucia's as traumatic; however, there is evidence to suggest that these diagnoses and the impact of these diseases on Lucia could result in traumatic reactions. Chronic illnesses can affect the physical, functional, social, and emotional aspects of an older adult's life. Older adults may experience frightening or disruptive physical symptoms, such as chronic fatigue, pain, weakness, difficulty breathing, insomnia, incontinence, and weight changes. These symptoms can impact functional ability (e.g., ambulation, continence) and the ability to complete basic and instrumental activities of living (e.g., bathing, housekeeping). Emotionally, people with chronic conditions experience higher rates of distress, depression, and loneliness than those without chronic diseases. Chronic health conditions can also decrease an individual's social interactions with others and with the world (for a review, see National Institutes of Health, 2016). In sum, chronic conditions can have a devastating impact on life and quality of life for older adults.

Specifically, Lucia is faced with congestive heart failure, osteoporosis and Alzheimer's disease. Congestive heart failure is associated with an array of debilitating and problematic symptoms and effects, such as difficulty breathing, fatigue, fear, role failure, social isolation, cognitive impairment, and feeling trapped or imprisoned by the illness (Falk, Ekman, Anderson, Fu, & Granger, 2013; Jeon, Kraus, Jowsey, & Glasgow, 2010; Yu, Lee, Kwong, Thompson, & Woo, 2007). Not being able to breathe, in particular, has been associated with high levels of

anxiety, at times resulting in anxiety and terror attacks (Dekker et al., 2014). Osteoporosis can negatively affect someone's physical, emotional, and social life. Osteoporosis may bring pain and decreased mobility. Individuals with osteoporosis are at increased risk of severe injury with falls which may lead to greater fear with ambulation, which increases the risk for falls. Once a fall with injury has occurred, as in Lucia's case, recovery is often prolonged and an individual may not return to prior level of physical functioning. Decreased mobility may decrease socialization and interaction with others.

As Lucia struggles with the physical challenges of living with congestive heart failure and her newly acquired disability related to her fall, she is also faced with a recent diagnosis of Alzheimer's disease. The process of receiving a dementia diagnosis and finding information and support can be incredibly difficult for older adults and their families. The process has been characterized as "negotiating a labyrinth" (Gibson & Anderson, 2011; Robinson et al., 2011; Samsi et al., 2013). The diagnosis can cause emotional challenges as well. While some older adults find relief in finally receiving a diagnosis and learning the cause of their problems, others experience shock at the idea of facing one of the most dreaded disease progressions, the process of losing one's memory and self. Alzheimer's disease may also be associated with shame and stigma. People with Alzheimer's disease are stigmatized by the symptoms of the illness that result in losses of self-esteem, control, and ability (La Fontaine, Buckell, Knibbs, & Palfrey, 2014; Mitchell, McCollum, & Monaghan, 2013). While many older adults are able to effectively cope with chronic illness, even with diseases such as Alzheimer's disease, for those older adults whose buffering resources are not available or have been compromised, chronic illnesses may have traumatic consequences (de Ridder, Geenen, Kuijer, & van Middendorp, 2008).

Loss – Independence

The ability to live independently and make one's own decisions is the hallmark of the achievement of adulthood in American society. It is interesting to note that independence as a loss is a particularly western construct. In cultures where being cared for by your children promotes status, dependence can be a point of pride (Secker, Hill, Villeneuve, & Parkman, 2003). For many older adults in the United States, the loss of independence is the most feared loss of later life. Independence is tied to concepts such as autonomy, dignity, and self-worth. Many older adults feel conflicted by their increasing need for assistance. Older men are given particularly mixed messages in this area, as they are told independence is a part of aging successfully, yet are criticized by society for not seeking health care and assistance when needed (Smith, Braunack-Mayer, Wittert, & Warin, 2007).

Older adults can lose their independence in many different ways, often in combination. Chronic illness and increasing physical frailty can lead to the need for assistance with activities of daily living and physical dependence on others. This loss of independence often leads to the loss of dignity, as help is provided with previously intimate tasks such as bathing, dressing, and toileting. Stopping driving is also associated with losing independence. Older adults perceive that losing the ability to drive results in losing independence in other aspects of life such as socialization and engagement. Research has shown this to be partially true. While driving cessation is related to a decrease in paid work and volunteerism, it is not associated with decreases in socialization (Curl, Stowe, Cooney, & Proulx, 2013). Despite this, many Americans live in areas not reasonably covered by public transportation. In those cases, it is true that losing the ability to drive does result in increased dependence on others. In cases where stopping driving co-occurs with increased physical dependence, the ability to travel without assistance may be lost entirely.

Older adults can also become cognitively dependent. Decision making is a significant point of contention with adult children often taking over decision making. In some cases, like Lucia's there is a diagnosis of dementia. Family members may take over decision making because they believe that the diagnosis of dementia means that they are no longer able to make their own decisions and fear for their safety. In other cases, family members assume control over some aspect, such as the checkbook, in an attempt to be helpful and in doing so inadvertently disempower their parent. Lack of control over decisions, particularly those involving relocation, is tied to worse adjustment and greater depression (Gilbert et al., 2015).

Older adults often link independence to living in one's own home. They presume that living in an institutional setting of any kind is the first step towards dependence. Having a personal dwelling is associated with autonomy and choice. As a result, older adults will often choose to remain in the community without services or longer than practicable, for fear that giving up that home or control of that home will result in the loss of all control. There are cases where some benefits would be obtained from a communal setting such as having help available if needed, companionship, and activity (Hillcoat-Nallétamby, 2014). However, these are often outweighed by the larger fears: of institutionalization, of losing control, of being a burden, and of being perceived as not being able to handle one's own activities (Hillcoat-Nallétamby, 2014).

When someone comes into a nursing home, the loss of independence is felt acutely. People enter nursing homes because they need physical or mental assistance, or a combination thereof. Staff see them from time of admission as someone who needs help. Other parts of their previous identity are lost in the frame of dependence. In many settings, residents lose control over routines, choices, and control that are most associated with independence. Others decide when and what they eat, where they sleep, when they shower, and other daily decisions that are

taken for granted. This loss of independence is often not acknowledged, as the new resident is seen as someone who has come where the help they need is being provided. Within a nursing home, where everyone has some level of dependence, the stigma of dependence is often not recognized, yet at the same time, many older people in nursing homes have few visitors from community dwelling peers and become disconnected from more abled friends. Dependence is a form of helplessness caused by one's need to rely on another, and feelings of helplessness are associated with traumatic reactions (Stamm, 1999).

Loss – Home and neighborhood

The image of home invokes more meaning than simply the four walls of a house or apartment or the roof over one's head. Homes may hold memories of departed loved ones or past times, represent achievement and success, or embody feelings of safety and security (Perry et al., 2015). In light of other losses, the home may be the last remaining connection to lost loved ones. Items within the home may also contain memories. Relocation to a long term care facility often results in the need to divest of many or all possessions, as few personal items fit into the shared space of a nursing home (Ekerdt, Sergeant, Dingel, & Bowen, 2004; Luborsky, Lysack, & Van Nuil, 2011).

For people who have lived in the same home for decades attachment to the community and its social structures are as important as the home itself (Wiles, Leibing, Guberman, Reeve, & Allen, 2011). Older people have characterized their communities as places of social connection and interaction, with this connection being related to both physical structures and neighbors (Wiles et al., 2011). Home is also perceived as a refuge, providing a sense of safety and security from threat, not because of actual threat, but because of the familiarity of the environment (Wiles et al., 2011). Social integration into the larger community has benefits including role fulfillment,

self-esteem, social recognition, and self-efficacy (Scharlach & Lehning, 2013). The theme of safety also relates to how individuals perceive the transfer into long term care, with mixed results. In one study, some respondents felt safer in the long term care facility because of physical deterioration of their previous homes and changes in the neighborhood. Others found the lack of freedom more restrictive than the added safety it provided (Johnson & Bibbo, 2014). The home situation prior to admission and the events that preceded the admission provide the context for how someone might perceive the environmental aspects of the admission.

Psychological adjustment to a long term care facility occurs in stages (Ellis, 2010). New residents face many negative stages, including anxiety, fear, depression, disillusionment, hostility, and denial (Ellis, 2010). Patients who feel that they are involuntarily admitted to institutions experience negative emotions such as helplessness, insecurity, humiliation, and vulnerability (van den Hooff & Goossensen, 2014). Patients reported a lack of control and not being listened to or heard (van den Hooff & Goossensen, 2014). Staff reactions and structural adaptations can ease the psychological adjustment (Ellis, 2010). A trauma informed approach including the trauma informed care principles “safety, trustworthiness, choice, collaboration, and empowerment (Fallot & Harris, 2008, p.6) would directly addresses some of these issues.

Trauma- Fall with Injury

In addition to many losses, Lucia experienced a common late life event, a fall with life changing injury. A fall with injury is a significant physical event that causes physical harm, may threaten death, and may increase feelings of powerlessness and vulnerability. Psychological distress is a fairly common reaction to a physical injury (Richmond & Kauder, 2000). Despite a reluctance to label the impacts of a physical injury as trauma, there are documented effects that meet the criteria of posttraumatic stress (Jayasinghe, Sparks, Kato, Wyka, et al., 2014).

A significant minority of older adults who sustain falls that result in injury develop diagnosable post-traumatic stress disorder (PTSD) or related symptoms such as depression and anxiety (Chung, et al., 2009). Multiple medical conditions are associated with the subsequent development of PTSD, and falls have one of the highest rates of PTSD development among four different types of medical events (Moye and Rouse, 2014). The level of PTSD is not specifically related to the severity of the injury. Older adults in the study reported life disruption from the PTSD over and above life disruption from the injury (Chung et al., 2009). Post-fall emotional distress can interfere with tasks of healing and recovery from an injury, such as physical rehabilitation and resumption of previous activities. It can also reduce engagement with informal support systems on which the injured individual may need to rely for instrumental and emotional support (Jayasinghe, Sparks, Kato, Wilbur, et al., 2014). Even those who do not experience immediate PTSD may experience increased anxiety, which is associated with the subsequent development of PTSD related to the fall with injury (Bloch et al., 2014).

Fewer older individuals who sustain unexpected injuries report distress than younger injured individuals. Researchers believe this is related to both a lifelong accumulation of coping skills to allow them to cope with new stressors and a more realistic view of future functional status (Richmond & Kauder, 2000). However, like younger individuals, they do still have a risk, ageism may prevent providers from recognizing this distress. Evidence based interventions are available to address these post fall emotional barriers to recovery, but the distress needs to be recognized as an issue in order to be addressed (Jayasinghe, Sparks, Kato, Wilbur, et al., 2014). A trauma informed approach would operate under the assumption that all residents might have experienced past trauma and would address any post-traumatic symptoms that developed as a result of Lucia's fall with injury.

Implications for Social Work Practice

Federal regulation requires social work services to be provided in nursing homes, but they do not require social workers to provide the services. Only facilities with greater than 120 beds are required to employ a full time social worker, and the qualifications to serve as a nursing home social worker do not require a degree in social work. Generally nursing homes use one of the following models of social work service delivery: a qualified social worker, paraprofessional social work staff, or an interprofessional team that includes social workers (Roberts & Bowblis, 2016). As a result, social work practice in long term care can be disjointed. Social work is a unique field, with a clinical focus that requires a practicum prior to graduation. The revised nursing home regulations released in October 2016 have further deprofessionalized the role of social work in long term care by adding to the degrees that would qualify someone to practice social work in long term care and not addressing the 120 bed rule (Bern-Klug et al., 2016). Social workers are also not required to be part of the interdisciplinary team (CMS, 2016).

While not promising for the profession, there are currently many degreed and, in some cases, licensed social workers employed in long term care. These professionals will play an important role in the implementation of both person-centered care and trauma-informed care. Interestingly, the 2016 revised nursing home regulations added mandates for trauma-informed care in the care planning, quality care, and behavioral health categories. However, CMS limits this to nursing home residents who are veterans, survivors of disasters, the Holocaust, or abuse (CMS, 2016). This article finds significant support for assessing for trauma in all older adults who enter long term care, especially considering the range of potentially traumatic events residents may have experienced.

Returning to the case study presented earlier, we can see how the skills of the social work profession could play a key role in providing quality care to Lucia and her family. Person-centered care and trauma-informed care begin by obtaining a deep and rich understanding of a resident's life through a detailed psychosocial history. Lucia has experienced multiple significant losses in a short time period and her 'presenting problem' is more than simply her diminished levels of cognitive and physical functioning and her medical diagnoses. Lucia's voice should be heard, as well as the voices of her family members. Earlier in this article, we speculated on the impact of Lucia's life events and impact that they could have on her well-being. While this is useful in this discussion, understanding Lucia's lived experiences and reactions to these events are key and social workers are well-trained and positioned to conduct detailed psychosocial histories (Milner, Myers, & O'Byrne, 2015). The psychosocial history should be used to inform follow up evaluations and to formulate a person-centered (and trauma-informed, if warranted) care plan.

Nursing home residents are subject to a lengthy battery of assessments, but evidence of trauma in a psychosocial history warrants formal follow-up. The PTSD Checklist may be effective in determining the impact of trauma on well-being and may be a useful assessment tool (Cook, Elhai, & Arian, 2005). In Lucia's case, depression and grief scales, such as the Geriatric Depression Scale (Sheikh & Yesavage, 1986) and the Inventory of Complicated Grief (Prigerson et al., 1995), may also be useful in assessment and monitoring well-being. Lucia's social worker and the interdisciplinary team in the nursing home should then care plan to reduce stress and retraumatization. Lucia has lost much of her independence in the move to the nursing home. Nursing home staff should preserve as much of Lucia's independence as possible and include her in decision-making and in formulating her care plan. Lucia has also experienced fear due to

COPD and past falls. Fear can also be an issue for persons with dementia, as cognitive perceptions and abilities change. Staff should work to allay these fears and reassure Lucia that they are present to help her at anytime. Lucia may also be at risk of social isolation due to the loss of her husband and the move to a foreign environment. The social worker should make a concerted effort to introduce Lucia to other residents and to encourage and facilitate participation in social activities. Finally, the social worker should pay careful attention to Lucia's reaction to having a roommate. Lucia may appreciate having a new friend in her roommate and there is evidence to suggest that these living arrangements are not uniformly negative, especially if choice is provided (Abbott et al., 2017). However, the social worker should look to match Lucia with another resident or transfer her to a single room if there are indications of problems. As Lucia's life evolves in the nursing home, care plans should be adjusted according to her preferences and abilities with an understanding that emerging developments (e.g., progression of dementia, additional falls) have the potential to introduce trauma and traumatic reactions.

The culture change movement has been in long term care for more than 30 years. This person-centered perspective advocates for nursing homes to be more home-like and less clinical, and to make the resident the center of decision making (Koren, 2010). Essential features in culture change mirror those of trauma informed care, with foci on relationships, empowerment of direct care staff and residents, choices, and collaborative decision making (Koren, 2010). Social workers are also trained in macro and policy practice and an ethical framework which supports advocating for vulnerable persons (Bern-Klug et al., 2016). This professional position allows them to challenge the ageist assumptions that lead to the under recognition of trauma in older adult populations, particularly in long term care. Ageism contributes to society's attitudes of old age being associated with loss, and the belief in the futility of increasing services to older adults

because it will not improve things (Achenbaum, 2015). Ageism plays a central role in society's failure to view losses and changes that may occur for people who are admitted to nursing homes as potentially traumatic in the lives of older adults. Social workers are trained to advocate for underrepresented groups and to fight for social justice. Changing long term care delivery systems to be more person centered will create an appropriate response to the biopsychosocial impacts of trauma (Larkin, Felitti, & Anda, 2014) in the lives of older adults and lead to better quality of care and quality of life. Despite the narrow focus taken by the revised long term care regulations, it is important to consider trauma for all long term care residents as part of good person centered care and good clinical practice. We hope that this paper has shown that despite the many losses that often do occur in late life, a trauma informed perspective can mitigate these challenges and improve quality of life in long term care.

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