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The need for a social revolution in residential care

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ABSTRACT

Loneliness and depression are serious mental health concerns across the spectrum of residential care, from nursing homes to assisted and retirement living. Psychosocial care provided to residents to address these concerns is typically based on a long-standing tradition of 'light' social events, such as games, trips, and social gatherings, planned and implemented by staff. Although these activities provide enjoyment for some, loneliness and depression persist and the lack of resident input perpetuates the stereotype of residents as passive recipients of care. Residents continue to report lack of meaning in their lives, limited opportunities for contribution and frustration with paternalistic communication with staff. Those living with dementia face additional discrimination resulting in a range of unmet needs including lack of autonomy and belonging—both of which are linked with interpersonal violence. Research suggests, however, that programs fostering engagement and peer support provide opportunities for residents to be socially productive and to develop a valued social identity. The purpose of this paper is to offer a re-conceptualization of current practices. We argue that residents represent a largely untapped resource in our attempts to advance the quality of psychosocial care. We propose overturning practices that focus on entertainment and distraction by introducing a new approach that centers on resident contributions and peer support. We offer a model—Resident Engagement and Peer Support (REAP)—for designing interventions that advance residents' social identity, enhance reciprocal relationships and increase social productivity. This model has the potential to revolutionize current psychosocial practice by moving from resident care to resident engagement.

Introduction

Vera is an 82-year old widow living with early-stage dementia, newly admitted to a residential care home. Until her diagnosis five years earlier she loved volunteering and playing violin in her community orchestra. Now, no longer able to play her violin, Vera spends her time alone listening to classical music on the radio. She has little interest in the activities provided, is not able to find a way to continue volunteering and is having difficulty connecting with others.

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During an interview Vera shared her loneliness and sense of loss at how her life has changed—from doing so much to doing so little. Asked how she is adjusting to living at the home, Vera responded: "I think my room is at the end of the world." (Theurer et al., 2012). We will return to Vera towards the end of the article.

Vera's failure to find meaningful connections exemplifies growing concerns about the critical rates of loneliness in residential care (Bekhet & Zauszniewski, 2012; Brownie & Horstmanshof, 2011; Prieto-Flores et al., 2011). Residential care is defined as congregate living with various levels of support including long-term care or nursing homes as well as assisted and retirement living (Schafer, 2014), and loneliness is present across this spectrum of care. A study of residential care homes in northern Sweden and western Finland revealed that 55% of residents in care homes experienced loneliness (Nyqvist et al., 2013). Assisted living residents are at high risk for loneliness and social isolation (Tremethick, 2001) and a descriptive comparative study examining loneliness in elders living in retirement homes found that among the total sample (N = 314), nearly 29% (n = 91) reported feeling lonely (Bekhet & Zauszniewski, 2012). Loneliness is linked with depression (Bekhet & Zauszniewski, 2012; Cacioppo et al., 2006; Hagan et al., 2014; Heikkinen & Kauppinen, 2004) and impaired mental health among older persons (Wilson et al., 2007). Indeed, longitudinal studies of loneliness and depression suggest that they are associated yet separate constructs, which have a reciprocal relationship (Barg et al., 2006; Cacioppo et al., 2006).

Although most residential settings provide programming such as social gatherings designed to address psychosocial needs (Evans, 2009; Ice, 2002; Knight & Mellor, 2007; McCann, 2013), there is little evidence for the effectiveness of these activities to remediate loneliness (Victor, 2012) and interventions for depression which simply increase social interaction have produced mixed results (Cruwys et al., 2014a). Many residents have trouble making meaningful social connections without support (Cipriani et al., 2006) and those living with dementia may have additional challenges due to increased difficulties in communication (Alzheimer Disease International, 2013). This paper investigates the troubling underpinnings of the social environment fostered in residential care. The aim of the article is three-fold: (1) to explore the need for change in current psychosocial approaches and examine the impact of these approaches on residents identity and well-being; (2) to examine the potential of using social identity theory, social productivity and peer support to enhance our understanding; and (3) to offer a re-conceptualization of the role of psychosocial care and a revolutionary model for designing interventions to advance residents social identity, enhance reciprocal relationships and increase social productivity and well-being.

Exploring the need for change in psychosocial care

The need for change in psychosocial care within residential settings is long-standing as reports of loneliness and depression have not improved in over 50 years. In the late 1950s and early 1960s, Townsend (1962) conducted an extensive survey of residential institutions and homes for the aged in England and Wales. He described a variety of negative effects associated with institutional relocation including loss of occupation, isolation from family, friends and community, tenuousness of new relationships, loneliness, loss of privacy and identity and the collapse of self-determination. The same concerns are still prevalent today and in some ways have become magnified within institutionalized settings with the increasing frailty and chronic health conditions of residents (Baumbusch, 2008). Residents report frustration around their lack of influence and independence (O'Dwyer, 2013; Timonen & O'Dwyer, 2009), and paternalistic communication styles among staff (Baur & Abma, 2011).

We are proposing that conditions for a social revolution continue to grow in response to the psychosocial care provided in residential settings. A social revolution has been described as 'a dramatic and wide-reaching change in the way something works or is organized or in people's ideas about it' (Revolution, 2015). A social revolution is a change process that can happen on different levels (Duthel, 2008). An example of this is the many innovations within the current culture change movement in the United States set up to improve quality of life in elder care (Weiner & Ronch, 2003). By social revolution in residential care we mean an overturning the long-standing tradition of psychosocial care that is centered on superficial social programming—a move from providing 'recreation' to providing opportunities for emotional and meaningful social engagement. A social revolution in residential care could be akin to the civil rights movement in mental health, which rejected the basic premise of traditional care within the medical model, seeing it as a broken system that fostered stigma and discrimination (Adame & Leitner, 2008). This social revolution is a response to the pervasive influence of this deeply entrenched biomedical model (Doyle & Rubinstein, 2013) which negatively impacts residents' social identity (Ferrand, Martinent, & Durmaz, 2014; Shulman, 2014).

Current approaches to psychosocial care

Current psychosocial programming provided in residential settings is a concern for a number of reasons. Many disciplines are involved informally in socially supportive care, but therapeutic recreation is specifically mandated to maintain or improve physical and mental health status, functional capabilities and psychosocial quality of life (Leitner & Leitner, 2011). In the United States, the Centers for Medicare and Medicaid Services include recreational therapy in the mix of treatment and rehabilitation services necessary for skilled nursing and residential care facilities (American Therapeutic Recreation Association, 2009). However due to a combination of heavy workloads for staff (Knight & Mellor, 2007), pervasive stereotyping (Sherwin & Winsby, 2011), and the complex health conditions of residents (Alzheimer Disease International, 2013) recreation programming is frequently inappropriate or inaccessible and activity participation rates are low. For example, a study in the United States found that 45% of residents with dementia participated in few or no activities, 20% participated occasionally and 12% attended activities that were inappropriate to their functioning levels or incongruent with their interests (Buettner & Fitzsimmons, 2003). Another study found that aside from time spent receiving care, residents spent only 2 minutes within a six-hour period interacting with other residents or staff (Alzheimer Society, 2007).