Is Assisted Self-Management a Viable Concept for Individuals With Cognitive Impairment?

Self-management science is one of four key themes within the National Institutes for Nursing Research (access https://www.ninr.nih.gov/aboutninr/ninr-mission-and-strategic-plan/themes-self-management#.UyNMhM7N4f_). The science of self-management examines ways to help individuals with chronic conditions, their families, and caregivers manage their illness and enhance their health behavior. The science of self-management has advanced our understanding of the behaviors that individuals can use to influence their health; the processes of acquiring the requisite knowledge and skills to enact behaviors; and the contextual factors that can influence self-management behaviors. Self-management theories focus on cognitively intact individuals who can problem solve, make decisions, collaborate with their health care provider, and access resources that will optimally meet their needs (Grady & Gough, 2014).

But what about individuals with cognitive deficits and their family caregivers? In this issue of Research in Gerontological Nursing (RGN), a team from the Netherlands reports on how and by whom family caregivers want to be supported in their self-management when caring for a relative with dementia (Huis in het Veld et al., 2018). We are pleased to publish this article, which is a beginning step in understanding important elements of self-management support for caregivers of individuals with dementia. This editorial will explore the self-management that even those with substantial cognitive impairment (CI) may be able to accomplish and make suggestions for broadening the scope of current theoretical models to include the self-management of individuals with CI.

SELF-MANAGEMENT BEHAVIOR AND COGNITIVE IMPAIRMENT

Individuals with CI use a variety of behaviors in different situations to feel well and reduce stress. Although some of these behaviors may be dysregulated and mal-adaptive, others represent a healthy, constructive way of regulating mood and stress levels. Self-soothing behaviors commonly observed are rocking, pacing, and ruminating (Kong, Evans, & Guevara, 2009). Oxytocin release from the paraventricular nucleus in response to such sensory stimulation is a mechanism that has linked self-soothing behaviors to positive effects (Uvnäs-Moberg, Handlin, & Petersson, 2015). Exiting behavior by individuals with dementia is often an attempt to escape pain or relieve discomfort from a full bladder (Kovach et al., 2012). The view that individuals with dementia who resist being moved have problematic psychological behavior has been replaced by the view that resistance to movement is actually an adaptive response to being undertreated for musculoskeletal pain that worsens with movement (Kovach et al., 2012). A pilot study of a mindfulness intervention, also reported in this issue of RGN, provides evidence that emotion regulation through mindfulness activities may positively affect short-term mood and behavior of those with CI (Kovach, Evans, Sattell, Rosenau, & Gopalakrishnan, 2018).

DYSREGULATED SELF-MANAGEMENT BEHAVIORS

Unlike the neonate or comatose person, individuals with CI do not need caregiving for every need. But adaptive self-management behaviors can become dysregulated and maladaptive in the extreme. Individuals who pace to self-soothe may become exhausted and unable to meet caloric needs. Individuals who withdraw to decrease stimulation that has exceeded their stress threshold may become socially isolated. Hyperorally behaviors may lead to ingesting unsafe substances. Similar to cognitively intact adults who have difficulty regulating health behaviors, such as dietary intake or physical activity, assistance is needed to bring these dysregulated self-management behaviors into adaptive thresholds.
EXPANDING THEORETICAL MODELS OF SELF-MANAGEMENT

Although cognitively intact individuals and those with CI can become dysregulated in their self-management, what differs between them may be the mechanism by which self-management interventions help them engage in behaviors that manage their need or condition. Lorig’s work on self-management posits that self-efficacy is the mechanism by which self-management interventions work and emphasizes decision making as a critical self-management skill (Lorig & Holman, 2003). Individuals with mild CI may still be able to have belief in their abilities strengthened, but those with more severe deficits have a more limited ability to engage in the reflective thinking needed to enhance self-efficacy or self-regulate. Many individuals with CI can make decisions regarding their daily life activities when provided choices from a limited number of simple options (Brownie & Nancarrow, 2013).

Ryan and Sawin’s (2009) Individual and Family Self-Management Theory emphasizes knowledge, beliefs, self-regulation, and social facilitation as processes of self-management. In individuals with Alzheimer’s disease and other dementias, long-term memory is severely compromised and knowledge acquisition limited, but cueing can still be effective for some short-term directions (Bourgeois, 2014; Nugent et al., 2011). Self-management interventions for individuals with dementia often involve external assistance from a family or professional caregiver. For example, a caregiver may provide a cue, environmental change, or stimulus that facilitates an individual’s behaviors to a more regulated state. Providing finger foods to an individual who has a need to pace may allow him/her to continue the self-soothing pacing behavior while also meeting caloric and nutritional needs. Providing wayfinding signs allows individuals with dementia to self-navigate the environmental space without getting lost. Reflective thinking and problem solving are limited, but social facilitation, which includes social support and negotiated collaboration, may still be used. A caregiver may negotiate removing an agitated individual’s table knife by exchanging it for a more desirable object.

CONCLUSION

The current editorial has made the case that assisted self-management is a viable concept for individuals with CI. Models of dementia care have been criticized for being overly problem-focused (Hill, Kolanowski, Milone-Nuzzo, & Yevchak, 2011). Self-management models provide an opportunity to cast the care of individuals with CI within a perspective that draws on remaining capacities, environmental modifications, social supports, and resources to enhance behavior and outcomes. If the science of self-management is to move toward inclusion of individuals with substantial CI, there needs to be more effort to develop the components of self-management processes, interventions that facilitate regulated self-management, and mechanisms of action by which interventions regulate behavior of individuals with CI. Including those with CI into models and the science of self-management will only occur if the scientific community is open to broadening the scope of current theoretical explanations for enhancing self-management behaviors. Failure to consider individuals with CI through the lens of self-management models at best reflects a restricted view of self-management, and at worst is a form of scientific nihilism in which individuals who are not cognitively and functionally meeting a certain standard are excluded from an entire body of nursing science.

REFERENCES

Bourgeois, M.S. (2014). Memory and communication aids for people with dementia. Towson, MD: Health Professions Press.


Christine R. Kovach, PhD, RN, FAAN, FGSA
Editor
Jewish Home and Care Center Distinguished Research Professor in Aging

Julie L. Ellis, PhD, RN, GCNS-BC
Assistant Professor

Rachel F. Schiffman, PhD, RN, FAAN
Professor and Associate Dean for Research
Director, Self-Management Science Center at UWM

University of Wisconsin-Milwaukee
Milwaukee, Wisconsin

The authors have disclosed no potential conflicts of interest, financial or otherwise.

doi:10.3928/19404921-20180413-01