

Representational Approach: A Conceptual Framework to Guide Patient Education Research and Practice

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Illness representations are cognitive structures that individuals rely on to understand and explain their illnesses and associated symptoms. The Representational Approach (RA) to patient education offers a theoretically based, clinically useful model that can support oncology nurses to develop a shared understanding of patients' illness representations to collaboratively develop highly personalized plans for symptom management and other important self-management behaviors. This article discusses theoretical underpinnings, practical applications, challenges, and future directions for incorporating illness representations and the RA in clinical and research endeavors.

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Numerous authors have described the content and structure of illness representations, as well as the role they may play in influencing health-related behaviors and outcomes (Donovan, Ward, Sherwood, & Serlin, 2008; Hagger & Orbell, 2003; Leventhal, Diefenbach, & Leventhal, 1992; Leventhal et al., 1997; Rees, Fry, Cull, & Sutton, 2004; Schiaffino, Shawaryn, & Blum, 1998). This article outlines the conceptual underpinnings of illness representation and provides an overview of an intervention theory to patient education, the Representational Approach (RA), based on illness representations.

Illness Representations

Illness representations are mental models or networks of related information, including prior experience, memories, attitudes, and beliefs, on which an individual relies to understand and explain an illness or symptom and its role in his or her life. The Common-Sense Model (CSM) of illness representations (Diefenbach & Leventhal, 1996; Leventhal, Meyer, & Nerenz, 1980) posits that an individual's common sense representations of his or her illness are instrumental in shaping subsequent health-related behaviors. These representations are shaped by internal (genetic, physical, emotional, and psychological factors, as well as personal and familial illness his-

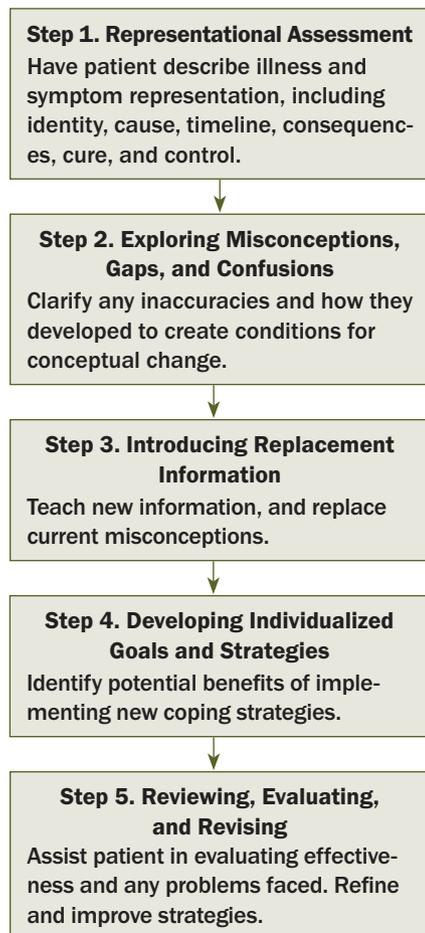
tory) and external (social, cultural) aspects of the individual's experience, and, in turn, they shape appraisal of and coping with illness and symptoms by the individual (Diefenbach & Leventhal, 1996). The CSM conceives of individuals as active problem solvers and posits that recognizing patients' illness representations, including the processes they deploy to identify and meet the challenges of illness, is an essential first step for providers to be able to supply effective, supportive interventions (Diefenbach & Leventhal, 1996; Leventhal et al., 1992). Illness representations consist of a cognitive component (ideas about the identity, cause, timeline, consequences, and controllability of an illness or symptom) and a parallel emotional component (psychological burden or distress related to the illness or symptom) (Diefenbach & Leventhal, 1996; Hagger & Orbell, 2003; Leventhal et al., 1992).

A basic tenet of the CSM is that an individual's cognitive and emotional representations of health problems influence his or her coping and health-related outcomes; therefore, patients and clinicians are wise to make these representations explicit prior to providing novel information, such as education or psychosocial or behavioral interventions (Donovan & Ward, 2001; Leventhal et al., 1997). Illness representations are influenced by a wide range of factors, including traditional, information-based

learning; everyday experiences; cultural beliefs; and stories from influential others. As a result, they may contain misconceptions or may lack important information necessary to guide effective disease management. However, these illness representations play a critical role in influencing the health-related coping behaviors in which people choose to engage. Adequately exploring these representations is essential to effective intervention design and delivery because they form the cognitive and emotional scaffolding through and into which all new information is perceived, understood, and integrated (Diefenbach & Leventhal, 1996; Donovan et al., 2008).

FIGURE 1. Representational Approach to Patient Education

Note. Based on information from Donovan et al., 2007.



Representational Approach to Patient Education

In 2001, Donovan and Ward proposed the RA to patient education, the first intervention theory based on the CSM. The RA has roots in two complementary conceptual traditions: the CSM of coping with health threats, which provides a theoretical basis for understanding illness representations (Diefenbach & Leventhal, 1996; Leventhal et al., 1980), and Hewson's Model of Conceptual Change (Hewson, 1993; Ward et al., 2009), which offers a lens through which to view the process by which individuals' changes in representations lead to behavior changes. Hewson's Model of Conceptual Change asserts that conceptual change emerges when purposeful, deliberate effort is applied toward restructuring existing representations that serve to organize and integrate new information (Hewson, 1993). Hewson observed that many illness representations are characterized by gaps, errors, and confusions, and noted that each of these can serve as potential points of intervention (Hewson & Hewson, 1984; Ward et al., 2009) (see Figure 1).

Current Use in Research and Evolution

Since its inception, the RA has been used to guide the development and testing of interventions for patients and their family caregivers in cancer symptom management (Barsevick et al., 2010; Donovan et al., 2014; Heidrich et al., 2009; Ward et al., 2008, 2009) and end-of-life decision making (Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2010), and to support caregivers of patients with primary malignant brain tumors. In addition, a similar line of illness perception intervention research based on the CSM has evolved simultaneously (Broadbent, Ellis,

Thomas, Gamble, & Petrie, 2009; Petrie, Cameron, Ellis, Buick, & Weinman, 2002; Siemonsma et al., 2013). Findings from these studies have been mixed, with the most positive findings in end-of-life decision making and cardiac rehabilitation and weaker results in the area of cancer symptom management.

A series of studies has been conducted at the University of Pittsburgh using RA as the framework for intervention design and delivery. In the initial study, research nurses delivered the Written Representational Intervention to Ease Symptoms (WRITE Symptoms) to women with recurrent ovarian cancer through Internet message boards and found a significant improvement in symptom-related distress for women receiving the WRITE Symptoms intervention compared to those in the control group (Donovan et al., 2014). In the next study, the researchers compared the nurse-delivered WRITE Symptoms to a computer-mediated WRITE Symptoms in which an Internet-based program led women through the same process without individualization from a nurse (self-directed WRITE). Preliminary analyses suggest that participants desired interaction with an expert who could provide advice and guidance (Hagan, Arida, Hughes, & Donovan, 2016). Current research is testing a caregiver intervention, SmartCare (based on the RA) to address the unmet needs of family caregivers of patients with a primary malignant brain tumor.

Conclusion

The RA to patient education is an existing theory that can serve as the basis for developing theoretically derived interventions to test in research designs. This framework is particularly appropriate to research that includes educational and behavior change components. The concept of illness representations

provides a structured framework for identifying an individual's existing mental model of his or her cancer diagnosis or symptom experience. The use of RA provides direction and rationale for individualized patient-centered assessment and tailoring of individual content. By eliciting and exploring a patient's illness representations, nurses can better understand a patient's illness experiences, identify what additional information is needed or current understandings need to be clarified, and work in a collaborative fashion with patients to help identify highly individualized plans of care. Individualizing interventions in this manner can increase patient investment in health-related behavior change and enhances the likelihood of satisfactory outcomes.

The RA offers a theoretically based, systematic method that can be used clinically to assess a patient's understanding and beliefs about the cause, consequences, ability to control or cure, and emotional burden of cancer, and to plan interventions to help them address their symptoms and other unmet needs to improve health and quality of life. Implicit in the RA is the acknowledgement that engaging patients in planning symptom management strategies based on an understanding of their illness representations respects patients' autonomy and self-determination and maximizes the likelihood of successful outcomes.

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