
Janet A. Arida, BSN, MA, Paula R. Sherwood, RN, PhD, CNRN, FAAN, Marie Flannery, PhD, RN, AOCN®, and Heidi S. Donovan, PhD, RN

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.

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 history) 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...