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Title Page**Full title**

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Concise Title

Cancer related fatigue

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Introduction

This paper explicates how Orem's Self-care Deficit Theory of Nursing (Orem, 1995) was selected to guide a study to explore and measure cancer related fatigue (CRF), and determine the most effective self-care strategies used to combat CRF in a cohort of patients with a diagnosis of cancer (breast cancer, colorectal cancer, Hodgkin's and Non-Hodgkin's lymphoma). The secondary aim was to explore self-care agency and its relationship to CRF.

Nurse theorists have strongly advocated the use of conceptual models of nursing to guide nursing practice (Timmins and Horan, 2007; Fawcett and Desanto-Madeya, 2012). Melnyk and Fineout-Overholt (2011) highlight that conceptual frameworks and models guide the planning and implementation of care in a purposeful way, and thus are beneficial to nursing practice. In the last decade a number of different disciplines most notably nursing, psychology and the social sciences have introduced a number of theories and conceptual models pertaining to the concept of self-care.

Symptom management is a core aspect of cancer and its subsequent treatments, especially in relation to the management of problematic CRF. There are many interrelated features of symptom management and self-care or self-management. Symptom management has been conceptualised as self-monitoring, self-care, self-regulation, and self-management (Fu, Lemone and McDaniel, 2004; Ream and Richardson, 1997; Teel, Meek, McNamara and Watson, 1997). According to Fu et al. (2004) and Kidd (2007), five theoretical or conceptual models have been used to describe symptom management: These models include the Self-care Deficit Theory of Nursing (Orem, 1991; Orem, 1995, 2001), the Symptom Management Theory (Dodd et al., 2001, Humphreys et al, 2008), the Common Sense Model (Leventhal Brissette and Leventhal, 2003), Theory of Unpleasant Symptoms (Lenz, Pugh, Milligan, Gift and

Suppe, 1997; Lenz and Pugh, 1998), and the Symptom Interpretation Model (Teel et al., 1997). The following section will outline four of these theoretical frameworks: the Symptom Management Theory (Dodd et al., 2001, Humphreys et al, 2008), the Common Sense Model/Self-Regulation Model (Leventhal Brissette and Leventhal, 2003) and the Symptom Interpretation Model (Teel et al., 1997) and the Self-care Deficit Theory of Nursing (Orem, 1991; Orem, 1995, 2001) and offer some discussion regarding their use in nursing practice and detail the description of self-care provided by each theory. However, the main focus will be in reviewing Orem's (1995) self-care deficit theory of nursing as is it considered most appropriate to this study.

Symptom Management Theory

The University of California, San Francisco (UCSF) School of Nursing's Symptom Management Theory is a generic, patient focused symptom management theory which is designed to be used by nurses to promote patients' symptom management abilities (Dodd et al., 2001; Humphreys et al, 2008). The theory is based on the patient's perceptions of symptoms as this is described by Dodd et al (2001) as the gold standard of symptom reporting, i.e. that a patient knows best what they are experiencing. Although a single symptom can occur in patients with cancer, according to Dodd et al (2001) multiple symptoms often are experienced simultaneously. These symptoms are a major problem for patients, as well for their family caregivers, because the management of these symptoms is often the responsibility of the patients themselves (Dodd and Miaskowski, 2000). This theory highlights that a symptom does not need to be experienced before symptom management strategies are implemented, it therefore promotes both self-care and preventative self-care and decreases the risk of developing a symptom. The goal of symptom management is therefore

to avert or delay a negative outcome through biomedical, professional and self-care strategies.

The component of symptom management includes the person who manages the symptom, how and where the symptom is managed, and the recipient of the intervention. Outcomes lead back to the symptom experience as management strategies are revised as needed. The theory also takes into account the fact that symptom-management strategies fail when it is difficult for the individual to adhere to them (Dodd et al., 2001). Lenz et al (1997) highlights that the theory is based on the premise that effective management of any given symptom or group of symptoms demands that all three dimensions be considered. However, the interrelatedness of these three dimensions of symptom management is rarely taken into account in research, though its importance is acknowledged.

The symptom management theory has been developed and tested using a wide range of symptoms, including cancer and cancer-treatment related symptoms (Lubkin and Larsen, 2006; Wells, 2007; Landers, Livingstone, McCarthy & Savage, 2014). The Symptom Management Theory is a useful tool that and researchers can use (a) to help them understand the symptom experience, (b) to evaluate symptom-management strategies, and (c) to evaluate the outcomes of these management strategies (Dodd et al., 2001; Humphreys et al, 2008). According to Fu et al (2004) symptom management often requires changes in strategies over time or in response to acceptance of a strategy. Symptom management is therefore a dynamic process, often requiring changes in strategies over time or in response to acceptance or lack of acceptance of the strategies devised. The symptom management theory has its merits in that it is patient focused – prioritising symptoms from the patient’s perspective and it stresses the importance of preventative self-care. However, as it primarily focuses on symptom

clusters and does not incorporate the construct of self-care agency, it was not considered suitable for this research study.

The Common Sense Model / Self-Regulation Model

The common sense model (CSM) focuses on the patients' perceptions of control on behaviour, it is also known as the Leventhal's self-regulation model (Leventhal, Nerenz and Purse, 1984; Leventhal, Benyamini, Brownlee, Diefenbach, and Leventhal, 1997). In the CSM, the individual is an active problem solver who selects coping strategies to control perceived risks (Leventhal, Diefenbach, and Leventhal, 1992). The CSM originated from studies of compliance behaviour in patients with hypertension (Keller et al., 1989). This theory, previously referred to as the theory of self-regulation, has been refined and widely studied from the perspective of many disciplines over the past two decades (Diefenbach and Leventhal, 1996; Johnson, 2002; Hale, Treharne and Kitas, 2007; Kaptein, Bijsterbosch, Scharloo, Hampson, Kroon and Kloppenburg, 2010). The main focus of this model is that individuals are motivated to construct meanings for body sensations to engage in self-regulating behaviours. Self-regulatory capability allows a person to have control over his or her thoughts, feelings, motivations, and actions (Baumeister and Vohs, 2007). Leventhal et al. (1984) highlight that the CSM provides an overall framework for describing health-related behaviours as it integrates social and contextual factors with an individual's cognition and affect (emotions). Fu et al (2004) outlines that there are three phases involved in the process of the model, these are: representation, coping, and appraisal. In this model, health and illness behaviours are the product of the combined action of the illness representation, of specific illness threats, and of the coping processes used in the situation (Brownlee, Leventhal and Leventhal, 2000).

There are many uses of the CSM in nursing, and to an extent self-care. By assessing the individual's cognitive and emotional representations of the illness, the nurse practitioner will be able to use the CSM to establish interventions and action plans that will be helpful in decreasing the patient's distress in the management of symptoms (Fowler, Kirschner, Van Kuiken, and Baas, 2007). Hagger and Orbell (2003) in a meta-analysis of 45 empirical studies using this model concluded that there was consistent support for its use. The model has also been tested in patients with cancer (Kidd, 2007; Llewellyn, McGurk, and Weinman 2007; Costanzo, Lutgendorf, and Roeder 2011). While the Common-sense Model of Self-Regulation Model provides a useful explanation how patients respond to the threat of experiencing a symptom, it does not allow for an investigation of the most effective self-care strategies used to combat CRF. Neither does it allow for an exploration of self-care agency and its relationship to CRF.

The Symptom Interpretation Model

The Symptom Interpretation Model (SIM) is based on the illness representation model, knowledge structures theory, and propositions about reasoning (Teel et al., 1997). Individuals name and assign meaning to environmental stimuli based on this interpretation and behaviours are selected for symptom management. The SIM postulates a cognitive process of decision making (Teel et al., 1997). This model addresses the multidimensionality and individuality of symptom management in terms of different experiences of a symptom (Fu et al., 2004). It assumes that interactions between internal and external environments have to reach sufficient magnitude to have an impact before awareness is awakened that something is wrong. This pre recognition phase is based primarily on knowledge about symptoms (Benner and Wrubel, 1989). This has implications for patients self-caring for cancer related symptoms

such as fatigue, and reiterates the importance of patients availing of knowledge and information about their CRF, or any other cancer symptoms.

In the SIM, a symptom is an integrated response to stimuli. Three major constructs in the model are (a) input –recognizing a disturbance in the human system; (b) interpretation – naming the sensation and attaching meaning to the symptom by activating stored information and reasoning about the symptom; and (c) outcome - making decisions and either doing something or nothing. Acquisition of expertise with the symptom experience increases through the course of one’s life. Over time, similarity between symptom events is recognized. For example, people living with a chronic illness become familiar with the symptoms associated with the illness and usually develop a repertoire of responses designed to alleviate negative sensations (Teel et al., 1997). However, in critique of this model, and as already highlighted if patients firstly receive knowledge and education about the likely impact of CRF and self-care guidelines for symptoms such as CRF, they are more likely to recognize symptoms at an earlier stage and thus initiate self-care measures. They will also be more motivated to have involvement in preventative health promotion practices such as maintaining optimum nutrition and exercise to decrease the frequency of symptoms such as CRF. While there is a lot of merit in this model, it was not deemed as suitable as Orem’s (2001) theory for this research study as the model primarily focuses on the individual’s beliefs or perceptions about their illness which was not the focus of the study.

Orem’s Self-care Theory

Orem first used the construct of self-care in her 1956 definition of nursing and later in her 1959 expression of when and why persons require care, and can be helped through, nursing

(Orem, 1995, pp. 7, 433). Orem's (2001) overall self-care deficit theory, is a grand theory composed of three inter-related theories, 1) the theory of self-care which describes why and how people care for themselves; the theory of self-care deficit which describes and explains why people can be helped through nursing; and 3) the theory of nursing systems, relating to nursing requirements (Berbiglia, 2014).

The theory of self-care involves a number of key concepts; self-care, self-care agency, basic conditioning factors and therapeutic self-care demand. Self-care is defined as the practice of activities by individuals, which they personally initiate and perform on their own behalf in maintaining their own life, health, development, and well-being (Orem and Vardiman, 1995). Orem et al. (2001) describes how self-care is based on deliberately performing actions that regulate and maintain health, functioning, and optimal wellness. It is not a behaviour people are born with, but a learned behaviour produced by active participation in caring for oneself (Orem, 2001).

People on a daily basis identify threats to well-being, seek and use information to make decisions, and initiate activities to maintain life, health, functioning, and well-being, all of which comprise the self-care process (Orem, 1995). Orem developed her theory by delineating a clear distinction between the perceptions of human beings held by physicians and nurses (Fawcett, 2017). Her work questioned "What condition exists in a person when judgements are made that a nurse should be brought into the situation – which a person should be under nursing care?" This idea evolved into her concept of "self-care", that is, "when they are able individuals, care for themselves" (Foster and Bennett, 2002, pg. 125). Each individual is viewed as a self-care agent who possesses capabilities termed self-care agency that is essential to performing self-care actions. Deliberate action is undertaken to

meet the therapeutic self-care demand arising out of known needs for care, this varies throughout life. If this demand is not met, a self-care deficit exists, which denotes the need for nursing (Orem, 1985; Hartweg, 1991; McBride, 1991, Banfield, 2011).

Orem's (2001) second constituent theory, the self-care deficit theory, is central to her general theory of nursing. This theory describes when nursing may be necessary to assist the person with their self-care needs. In order for nursing to be legitimate, a self-care deficit must exist. If through thorough assessment a deficit is observed, and assistance is deemed necessary, the nurse should provide an appropriate level of assistance (Orem, 2001). Thus, nursing may be essential for effective self-care in individuals who are incapable of meeting required self-care demands. The self-care deficit of nursing theory posits that individuals learn and deliberately perform for themselves, or have performed for them (dependent care) on a continuous basis those actions that are necessary to protect human integrity, physical and mental functioning, and development within norms essential for promoting life, health, and well-being. Self-care is a learned behaviour, deliberate action for some purpose; it is practical work requiring energy expenditure. Self-care consists of the action systems performed by individuals in time and in conformity with healthcare requirements that are associated with growth and development, their state of health and health-related conditions, the environment, and other influencing factors. Orem's self-care theory supports the establishment of a contractual relationship with patients as major emphasis is placed on what the patients are going to do to change themselves (Fawcett, 2012). Nursing may be needed when the individual needs to incorporate newly prescribed, complex self-care measures into their self-care systems, the performance of which requires specialized knowledge and skills (Orem, 2001, pg. 283). Orem (2001) referred to this as the nursing agent, the nurse meeting patient's self-care

therapeutic demands while simultaneously assisting patients in developing their self-care agency.

The concept of SCA has three requisites: (a) foundational capabilities and dispositions (not being measured in this study) (b) power components (also referred to as the enabling traits) and (c) self-care operations (also referred to as operational traits). The latter is separated into 1) the ability to know self-care requisites and 2) means of meeting them (estimative self-care operation) i.e. the ability to make judgements and decisions about self-care (transitional self-care operation) and the ability to perform actions to meet self-care requisites (productive self-care operations) (Orem, 2001). Basic conditioning factors are variables that influence a person's requirements for self-care and their self-care agency such as age and health state (Baker and Denyes, 2008). These basic conditioning factors (age, gender, and developmental state, socio-cultural factors, state of health, family systems factors, health system factors, environmental factors, resource availability and adequacy) as well as the three levels of requisites impact an individual's ability to perform self-care. Therefore, the consequences of self-care agency are (1) appropriate performance of self-care actions, and (2) achievement of a desired outcome (Sousa, 2002).

Orem's third constituent theory, the theory of nursing systems focuses on the concept of 'agency'. Nursing agency is operationalised into the three nursing systems: (a) the wholly compensatory system, (b) the partly compensatory system, and (c) the supportive- educative system. The wholly compensatory nursing system takes place when the patient is unable to engage in effective self-care activities. Finally, the partly compensatory nursing system occurs when the patient is able to participate in self-care activities, however, is not able to

meet all self-care demands. The supportive-educative system takes place when the patient is able to perform self-care therapeutic demands, however, to be effective, the patient needs nursing assistance; therefore, the nurse 'promotes the patient as a self-care agent (Orem, 2001).

Although Orem's Self-care Theory has been widely acknowledged for its beneficial use in both the organization of nursing care and education, some limitations have also been noted. George (2002) critiqued Orem's theory as simple yet complex. In George's view states the term self-care is used with numerous configurations. This multitude of terms, such as self-care agency, self-care demand, self-care premise, self-care deficit, self-care requisites, and universal self-care, can be very confusing initially until the essence of each concept is understood. It must be stressed that for a novice to be introduced to this theory, understanding each of Orem's concepts is difficult, time consuming and complex. However, this theory is considered most apt for the present research because as highlighted by Fu et al. (2004) the application of the theory to symptom management includes awareness of new needs in the presence of the symptom experienced, the response of the patient to these new needs, and the patient's capability for performing the required actions.

Sousa (2008) outlined how self-care agency has been used widely in nursing research to examine its relationship with conditioning factors and other concepts from within Orem's (2001) Theory of Self-Care. Researchers have reported significant relationships between 1) self-care agency and specific conditioning factors developed by Orem (2001), (i.e. age, gender, marital status, ethnicity, available resources, income and education) (Ailinger and Dear, 1993; Mapanga and Andrews, 1995; Wang and Laffrey, 2001; Sousa and Zauszniewski, 2005), and 2) self-care agency and self-care activities (i.e. identifying and

managing symptoms, seeking appropriate health care advice, choosing and performing exercise, adhering to a dietary regimen, and monitoring the progress of diseases) (Sousa et al., 2004; Sousa et al., 2005). In addition, researchers have studied and found significant relationships between self-care activities, health, and well-being (Sousa et al., 2008).

According to Timmons & Horan (2007) & Timmons (2008), although empirical testing of Orem's (1971; 1980; 1985; 1991; 1995; 2001) conceptual theories of nursing is relatively rare, they stress that a number of studies have indicated a significant benefit of using the theory in the care of cardiac patients. Lukkarinen and Hentinen (1997) measured self-care agency in a cohort of patients with coronary heart disease (n=250), patients with higher levels of "power components" were directly related to higher self-care. These include abilities such as attention, use of energy, movement, knowledge and decision-making (Orem, 2001). More recently, Afrasiabifar, Mehri, Sadat, and Ghaffarian (2016) investigated the impact of Orem's self-care theory on fatigue in patients with multiple sclerosis. These researchers concluded that the application of Orem's theory was associated with a lower levels of fatigue in the intervention group.

Overall, it must be highlighted that the review of the literature revealed that by enhancing an individual's self-care agency, one can promote better engagement in self-care activities. Orem's (1995) self-care theory, is the most well-known and utilised theory of self-care and in reviewing the literature, the most frequently applied to nursing research. The concept of self-care is mainly known through Orem's (1971) theory and is associated with a desire to enable and allow people to take the initiative in being responsible for their own health. This is why it is the theory of choice in this thesis.

Conclusion

This study is guided by the Theory of Self-care. Self-care is defined as “the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being” (Orem, 2001, pg.104). This is pivotal in this study, as one of the key study objectives is to ascertain how patients with cancer care for themselves when they are experiencing CRF. In this theory, self-care occurs when the individual takes a deliberate action to meet known self-care requisites. The overall goal of self-care is the self-monitoring and promotion of the individual’s health and well-being.

The self-care deficit theory of nursing was the theory of preference for the study. An important aspect of the science of self-care is that it views the individual person as the agent of self-care in regard to their own health and well-being. The study advances theoretical and conceptual understandings, since previous research to explore and measure cancer related fatigue (CRF), and determine the most effective self-care strategies used to combat CRF in a cohort of patients with a diagnosis of cancer has been largely atheoretical.

Prior to this study, there have been no attempts to examine the relationships between self-care agency and its relationship to CRF. By including the concepts of self-care and self-care agency in her theory, Orem has made a lasting and notable contribution to the development of disciplinary nursing knowledge. The inclusion of these concepts is an important feature of the current study as it allowed for an investigation of the relationship between cancer related fatigue levels; self-care and self-care agency between a number of cancer population groups. Interestingly, in this study higher levels of self-agency were linked to statistically lower levels of fatigue.

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