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Help Seeking for Cancer Symptoms: A Review of the Literature

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Although much progress has been made in reducing mortality rates and improving survival, cancer still accounts for more deaths than heart disease in people younger than 85 years in the United States (Jemal et al., 2008). At the Sixth International Cancer Conference held in Ireland in 2008, Scott Lipman, MD, reported that a great challenge of cancer research is to detect cancer at an early stage (Healy, 2008). Early detection can improve patient outcomes in terms of survival rates and more effective treatments (American Cancer Society, 2000; Campo, Comber, & Gavin, 2004). For self-discovered cancer symptoms, early detection depends on patients promptly seeking help from a healthcare professional. However, evidence shows that many people delay help seeking for self-discovered cancer symptoms (Bish, Ramirez, Burgess, & Hunter, 2005; Cockburn, Paul, Tzelepis, McElduff, & Byles, 2003; Corner, Hopkinson, & Roffe, 2006; Facione & Giancarlo, 1998; Howell, Smith, & Roman, 2008; Mason & Strauss, 2004a; Meechan, Collins, & Petrie, 2002; Ristvedt & Trinkhaus, 2005; Scott, Grunfeld, Main, & McGurk, 2006). Help seeking is a ubiquitous term used in many different contexts. *Helpseeking*, *help-seeking*, and *seeking help* are used interchangeably throughout the literature and often are discussed in the context of health-seeking behavior. This article aims to delineate how help seeking and related concepts are used in the literature and define help seeking in the context of cancer symptom discovery. In addition, theoretical literature that assists in understanding the concept of help seeking will be explored.

Literature Search

A literature search was conducted with CINAHL®, EBSCO, and PubMed databases. The search was limited to articles published in English from 1998–2008 to focus the review and retrieve the most current literature (apart from seminal work by Facione, 1993; Facione & Dodd,

Purpose/Objectives: To define help seeking and identify a theoretical framework to explain the help-seeking process of patients with self-discovered cancer symptoms.

Data Sources: Literature published in English from 1998–2008.

Data Synthesis: Findings highlighted gender's role in help-seeking behavior. Delayed help seeking for cancer symptoms was common, with many associated influencing factors. To date, research on intentions to seek help has facilitated the development of health-promotion programs that target those who are likely to delay.

Conclusions: Help seeking was defined as a response to health changes as well as a part of the broader process of health-seeking behavior. Reviewed frameworks and models provided knowledge and understanding about help-seeking behavior in various contexts. However, an all-encompassing framework explaining the entire process was not identified.

Implications for Nursing: Nurses are in a unique position to promote prompt help seeking for patients with self-discovered cancer symptoms. Gaining clarity on the concept and identifying a theoretical framework may help nurses understand the complex nature of help seeking in patients with self-discovered cancer symptoms.

1995; Facione & Giancarlo, 1998; Facione, Giancarlo, & Chan, 2000; Facione, Miaskowski, Dodd, & Paul, 2002). Inclusion criteria were articles with *cancer* and at least one of the following key words in the titles or abstract: *help-seeking*, *help seeking*, *help-seeking*, and *help-seeking behavior*. When pertinent, articles on help seeking related to other diseases or conditions were reviewed to further clarify the term. In total, 50 relevant articles were retrieved from the databases; additional articles were located using the reference lists of the literature reviewed. The review sought to determine how authors conceptually, operationally, and theoretically defined help seeking and identify factors that influence the help-seeking behavior of patients with self-discovered cancer symptoms. Thematic analysis of the literature revealed two key themes: “help seeking

and gender” from a general health perspective and “help seeking for cancer symptoms” from a general and specific viewpoint. The review particularly draws from the work of de Nooijer, Lechner, and de Vries (2001a, 2001b, 2002a, 2002b, 2003) for a European perspective and from Facione et al. for an American perspective.

Help Seeking and Gender

The literature review showed that help seeking and gender have been the focus of studies in many areas of health care, including general health (Smith, Braunack-Mayer, & Wittert, 2006), urologic (prostatic) health (George & Fleming, 2004), and cardiovascular health (Higginson, 2008; Lefler & Bondy, 2004; Moser, McKinley, Dracup, & Chung, 2005). Studies reviewed have been conducted with quantitative methodologies (Moser et al.) as well as qualitative methodologies, including focus group interviews (O'Brien, Hunt, & Hart, 2005), phenomenology (George & Fleming), and grounded theory (Higginson). Other literature included position papers (Smith et al.) and a meta-analysis (Lefler & Bondy).

Men's underuse of the healthcare system has been clearly constructed as a social issue (O'Brien et al., 2005). In general, women appear to seek help or visit a healthcare professional on a more regular basis than men (George & Fleming, 2004; O'Brien et al.; Smith et al., 2006). The femininity of seeking help and masculinization of delay as well as reasons why men and women decide to delay are evident in studies by George and Fleming, Masson and Strauss (2004b), O'Brien et al., and Smith et al. The issue of being a burden to others was relevant for men and women (George & Fleming; Higginson, 2008; Moser et al., 2005), with some men expressing guilt about using an under-resourced health service (George & Fleming). The media's role in raising awareness about health issues was apparent, but the emphasis on breast cancer was sometimes detrimental to other health issues (e.g., prostate cancer in men, acute myocardial infarction in women) (George & Fleming; Higginson). Two groups of men in O'Brien et al.'s study believed help seeking was “preserving or restoring their masculinity” as opposed to “unmasculine.” The men were fire fighters or had sexual health issues that they believed interfered with their masculinity. Men and women emphasized the importance of remaining in control at the onset of symptoms and when accessing healthcare professionals (George & Fleming; Higginson). The need to gain more holistic views on help-seeking behavior with the development of more individualistic and multifaceted approaches to health education for men and women remains crucial (George & Fleming; Higginson; Lefler & Bondy, 2004; Moser et al.; Smith et al.). In addition, help seeking often is viewed as nonmasculine, apart from situations in which men's sexuality could be negatively affected by delayed treatment. However, delayed help seeking occurs for similar reasons among men as

well as women. Therefore, gender should be considered in relation to help seeking.

Help Seeking for Cancer Symptoms

The presentation of cancer symptoms varies according to the site and extent of disease. The situation is complicated further in that cancer is a life-threatening condition, which may foster distress and potentially delay help-seeking behavior. Studies on help seeking and cancer provide insights into the broad spectrum of help-seeking behaviors from the perspective of those with no symptoms who seek help (de Nooijer et al., 2001a), those with symptoms who seek help (de Nooijer et al., 2001a, 2001b), those with symptoms who delay (de Nooijer et al., 2001a, 2001b; Smith, Pope, & Botha, 2005), and those who are symptom free (de Nooijer et al., 2002a, 2002b, 2003; Sheikh & Ogden, 1998). The role of knowledge, interpretation of symptoms, fear, and gender were emphasized (de Nooijer et al., 2001b; Sheikh & Ogden). Smith et al. (2005) also discussed sanctioning, that is, legitimizing or justifying help seeking by “raising issues when consulting a healthcare provider for another symptom” (Smith et al., 2005, p. 829). In addition, de Nooijer et al. (2001b) identified knowledge, social support, and being ashamed and embarrassed as issues for patients with cancer symptoms. The studies provide important insights into the complex process of symptom recognition, appraisal, interpretation, and subsequent decisions to seek help for men and women with cancer symptoms.

Studies of intentions to seek help emphasized the importance of knowledge, beliefs, and emotions (de Nooijer et al., 2002a, 2002b; Sheikh & Ogden, 1998). De Nooijer et al. (2002a) asserted that “intention is generally one of the most significant predictors of behavior” (p. 368), and although help seeking may be expected in certain situations, it will not always occur in reality.

De Nooijer et al. (2003) studied the social-psychological correlates of passive detection (paying attention to cancer symptoms) and help-seeking intention among asymptomatic Dutch women. The study aimed to identify factors that explained paying attention to cancer symptoms and intentions to seek help within an appropriate time frame. The study used a social cognition model based on the theory of planned behavior (Ajzen & Madden, 1986) and Bandura's (1977) self-efficacy construct. The model includes concepts such as “anticipated regret” and “moral obligation,” which are of value in secondary cancer prevention. A convenience sample (N = 618) was taken from a larger longitudinal study by the Dutch Cancer Society on the early detection of cancer among asymptomatic Dutch adults. Data were collected with two researcher-developed questionnaires. The first assessed determinants of paying attention to cancer symptoms and seeking medical help; the second assessed passive detection and the intention to seek help within an appropriate time

for possible cancer symptoms. The sample was mostly women (77%), with a mean age of 47 years. Nine percent had a personal history of cancer, and 92% knew someone with cancer. The study found that knowledge, advantages of help seeking, moral obligation, anticipated regret, social norms, and self-efficacy were correlated with the intention to seek help. The authors concluded that intentions to seek help can be encouraged by providing knowledge about cancer symptoms and addressing the importance and moral obligations of seeking help. In addition, the authors noted that regret may occur in the absence of help seeking, and barriers to help seeking should be discussed with patients (de Nooijer et al., 2003). The findings suggest that researchers should be sensitive to issues surrounding delay when studying help-seeking behavior.

Specific Cancer Symptoms

Studies on help seeking for specific cancers emphasized that delayed help seeking for cancer symptoms is an issue given the benefits of early detection. Studies reviewed were quantitative as well as qualitative and were conducted in Europe and the United States, with one study from New Zealand (Meechan et al., 2002). Lack of knowledge leading to uncertainty and minimization of symptoms are associated with delayed help seeking for symptoms of bowel cancer (Cockburn et al., 2003), rectal cancer (Ristevdt & Trinkhaus, 2005), breast cancer (Bish et al., 2005; Facione & Giancarlo, 1998; Meechan et al., 2002), testicular cancer (Mason & Strauss, 2004a, 2004b), lung cancer (Corner et al., 2006), oral cancer (Scott et al., 2006), and lymphoma (Howell et al., 2008). In addition, the aging process is mistakenly linked to symptoms for testicular cancer, lymphoma, and lung cancer, thus leading to the assumption that symptoms are harmless (Corner et al.; Howell et al.; Mason & Strauss, 2004b). In some cases, relaxed health behaviors might include a general tendency not to worry, thus leading to delayed help seeking (Ristevdt & Trinkhaus). Failure to recognize symptoms of lung cancer and the media's overwhelming bias toward breast cancer with an absence of recognition of lung cancer as a common disease entity were acknowledged (Corner et al.). The bias was supported in a study of testicular cancer in which men viewed breast cancer as socially acceptable versus the taboos surrounding genital health and help seeking (Mason & Strauss, 2004b). Mason and Strauss (2004b) reiterated the issues of stigma and embarrassment associated with help seeking for genital health. Future researchers should consider the pejorative implications of delayed help seeking and possibly use another term, such as "lag time" (de Nooijer et al., 2003; Mason & Strauss, 2004a).

Breast cancer is the most common malignancy among women in the developed world (Ferlay et al., 2007; Grunfeld, Hunter, Ramirez, & Richards, 2003; Jemal et al., 2008). In the United States, help seeking for self-discovered breast cancer symptoms has been studied since 1993 (Fa-

cione), with research focusing on help seeking, delayed help seeking, and intentions to seek help. In the literature, a complex array of factors (facilitators and barriers) influence women in seeking help. Such factors range from sociodemographics (e.g., age) to women's knowledge and beliefs, social and psychological factors, health service issues, health-seeking habits, and symptom discovery matters (Arndt et al., 2002; Bish et al., 2005; Burgess, Hunter, & Ramirez, 2001; Burgess, Ramirez, Richards, & Love, 1998; Facione & Dodd, 1995; Facione & Giancarlo, 1998; Meechan et al., 2002; Meechan, Collins, & Petrie, 2003; Nosarti et al., 2000; O'Mahony, 2001; Ramirez et al., 1999).

Some research has focused on predicting delay and women's intentions to seek help (Facione et al., 2000, 2002; Grunfeld et al., 2003; Hunter, Grunfeld, & Ramirez, 2003). The studies suggest the behavior can be prevented by identifying women who may delay by using various models, such as the Judgement to Delay Model (Facione et al., 2002), the Self-Regulation Model, and Theory of Planned Behavior (Hunter et al., 2003). Women may be encouraged to seek help early through breast health-promotion programs targeting those who are likely to delay. An enhanced understanding of help-seeking behaviors will assist healthcare professionals in identifying these women.

Theoretical Perspectives on Help Seeking

Some literature focused on help seeking from a theoretical perspective (see Table 1). The studies were useful in developing an understanding of the process of help-seeking behavior. In relation to help seeking for urinary incontinence, Shaw (1999) provided a detailed framework for the study of coping, illness behavior, and outcomes. Theories used in the development of the framework were the Theory of Reasoned Action and the Theory of Planned Behavior (Ajzen & Fishbein, 1980), the Transactional Stress Model (Lazarus & Folkman, 1984), and the Model of Illness Representation (Leventhal & Nerenz, 1985). Shaw's (1999) framework demonstrated that symptoms are appraised by individuals as either threatening or nonthreatening and, based on this appraisal and coping resources, individuals adopt a particular coping strategy, such as active health behavior or passive avoidance. The framework suggests that appropriate appraisals and choice of actions will result in adaptation (health and well-being) or maladaptation (illness and distress). The model is described as dynamic and changing over time with variables. The framework provides theory-based guidelines for identifying which psychological concepts and constructs to measure and could be used to explore help seeking in a variety of conditions and situations.

Shaw (2001) further discussed the psychosocial predictors of help-seeking behavior and their effect on

Table 1. Regional Perspectives on Help Seeking

Author	Region	Focus	Relevant Theories and Frameworks	Views on Help Seeking
Bish et al., 2005	United Kingdom	A systematic literature review to improve understanding of why women delay in seeking help for breast cancer symptoms	Self-Regulation Theory (Leventhal et al., 1984) Theory of Planned Behavior (Ajzen, 1991) Theory of Implementation Intentions (Gollwitzer, 1993)	An explanatory model describing the process of help seeking is proposed.
Burgess et al., 2008	United Kingdom	Development of a psycho-educational intervention promoting early help seeking by older women with breast cancer symptoms	Self-Regulation Theory (Leventhal et al., 1984) Theory of Planned Behavior (Ajzen, 1991) Theory of Implementation of Intentions (Gollwitzer, 1993) Social Cognitive Theory (Self-Efficacy) (Bandura, 1977)	Early presentation of breast cancer to a healthcare professional
Dodd et al., 2001	United States	Symptom Management Model (general symptom perspective)	Self-Care Model (Orem, 1971, 1980, 1985) Model of Symptom Self-Care (Sorofman et al., 1990)	The model describes symptom experience, symptom management strategies (including help seeking), and symptom outcomes.
Shaw, 1999	United Kingdom	Describes a framework for the study of coping, illness behavior, and outcomes; relates to urinary incontinence	Theory of Reasoned Action and Theory of Planned Behavior (Ajzen & Fishbein, 1980) Transactional Stress Model (Lazarus & Folkman, 1984) Model of Illness Representation (Leventhal & Nerenz, 1985)	Help seeking is not the only health behavior possible, with some people choosing to self-manage.
Shaw et al., 2008	United Kingdom	Qualitative descriptive study on how people decide to seek health care in general from a sample who had sought help for urinary symptoms (N = 33)	Andersen's Behavioral Model (1968) Health Belief Model (Becker, 1974) Framework of Health Behaviors (Shaw, 1999)	"Healthcare consultation is dependent on individuals' decisions to seek help" (p. 1517). The help-seeking decision relies on "an individual's knowledge of what might be considered a medical problem, awareness of possible causes, and potential severity of such symptoms and knowledge of treatments available" (pp. 1520–1521).
White et al., 2006	United States	Quantitative: testing a proposed help-seeking framework applied to infertility (n = 580)	Empirical work of Mechanic (1968) and Zola (1973) Shaw's (1999) framework	Symptom salience, life-course variables, individual and social cues, and predisposing and enabling factors affect perceptions of a health issue and directly and indirectly affect medical help seeking.

an individual's quality of life in patients with urinary incontinence. Shaw (2001) sought to determine how far the earlier framework could explain findings related to incontinence. The Theoretical Frameworks of Help-Seeking Behavior and Outcome (Shaw, 1999), the Model of Illness Representation (Leventhal & Nerenz, 1985), and the Transactional Model of Stress (Lazarus, Cohen, Folkman, Kanner, & Schaefer, 1980) were reviewed. Shaw (2001) concluded that Leventhal and Nerenz's Model of Illness Representation was useful because it addresses the reasons people do not seek help for urinary incontinence. In addition, Lazarus's Transactional Model of Stress was considered useful to increase understanding of how people cope with urinary incontinence. Shaw (2001) concluded that his own framework could identify the predictors of behavior, coping, and the effect of symptoms in relation to urinary incontinence. However,

he proposed that additional research exploring other factors within the model was warranted.

Shaw, Brittain, Tansey, and Williams's (2008) grounded theory study described the decision-making processes involved in help seeking among middle-aged and older adults with urinary storage symptoms. Thirty-three participants (18 men and 15 women) who had sought medical care for urinary symptoms were interviewed. The study aimed to identify an appropriate explanatory theoretical framework for the decision-making process regarding help seeking for a variety of conditions in individuals older than age 40 who have sought help for urinary symptoms. The steps in the decision-making process derived from the data were (a) identification of a symptom, (b) identification of the cause of symptoms, and (c) the costs and benefits of symptoms and treatments. The authors concluded that a decision would be

made concerning the seriousness of the health threat based on the individuals' appraisal of the situation. Study findings were discussed in the context of Andersen's (1968) Behavioral Model, the Health Belief Model (Becker, 1974), and Shaw's (1999) Proposed Framework of Health Behaviors. The authors concluded that many factors identified in the study related to psychosocial issues (e.g., knowledge, previous experience, information seeking, social context) that were not addressed in Andersen's Behavioral Model. The authors maintained that although the Health Belief Model focuses on threat perception and behavioral evaluation, it does not consider the individual's experience of symptoms or the resultant effect on quality of life because its original focus was to explain preventive behavior, not responses to illness situations (Shaw et al.). Finally, although Shaw's (1999) framework has some relevance to the study, the authors concluded that it also must address the experience of symptoms rather than just focus on preventive health behavior to be useful in a help-seeking context. The apparent deficit in the Shaw model may be addressed by the Symptom Management Model (Dodd et al., 2001), which draws on Orem's (1971, 1980, 1985) Self-Care Model and Sorofman, Tripp-Reimer, Lauer, and Martin's (1990) Model of Symptom Self-Care. Dodd et al.'s model includes the domains of nursing science (person, health and illness, and environment) as contextual variables influencing all three aspects of the model (i.e., symptom experience, symptom management strategies, and symptom outcomes). The authors propose that the individuals' symptom experiences encapsulate their perception, evaluation, and response to symptoms. Dodd et al.'s model could be said to depict the core principles of Shaw's framework in a more succinct and user-friendly format.

Drawing on the work of Mechanic (1968), Shaw (1999), and Zola (1973), White, McQuillan, Greil, and Johnson (2006) hypothesized that symptom salience, life-course factors, individual and social cues, and predisposing and enabling factors affect perceptions of infertility and directly and indirectly affect medical help seeking in a sample of 196 women in the Midwestern United States. Findings demonstrated that the perception of a fertility issue played a key role in women's help seeking and that symptom salience had a significant direct effect on the process. The study supports the central role of cognitive appraisal in the help-seeking process, as well as the importance of symptom salience, comorbidity, and attitudes toward medical treatment. White et al.'s model may be used to explore help seeking for self-discovered cancer symptoms, although it does not explicitly consider delay, as suggested in Shaw's (1999) outcome of maladaptation.

In an effort to understand why women delay in seeking help for self-discovered breast cancer symptoms, Bish et al. (2005) proposed an explanatory model that described

the process of help seeking. The model draws on self-regulation theory (Leventhal, Nerenz, & Steele, 1984), the Theory of Planned Behavior (Ajzen, 1991), and the Theory of Implementation of Intentions (Gollwitzer, 1993). Bish et al.'s model was developed further by Burgess et al.'s (2008) in the development of a psychoeducational intervention to promote early detection of breast cancer in older women. Burgess et al.'s (2008) theoretical framework draws on Bish et al.'s theories as well as social cognitive theory (self-efficacy) (Bandura, 1977). The framework outlines how, in the discovery of a breast cancer symptom, sociodemographic factors (e.g., age, socioeconomic status, ethnicity) affect women's knowledge of symptoms, knowledge of personal risk, and confidence in detecting a breast change and, therefore, influence the decision to seek help. Additional factors that may affect a woman's likelihood to delay help seeking include her attitude toward seeking medical help in general, whether she reveals the symptom to somebody close, and her beliefs about cancer and its management (Burgess et al., 2008).

Defining Help Seeking

Help seeking is described in many different ways throughout the literature (see Table 2). In relation to rectal cancer symptoms, delayed help seeking is indicative of a person's general pattern of health-related behavior (Ristvedt & Trinkaus, 2005). In a study on medical care seeking and health-risk behavior in patients with head and neck cancer, Tromp et al. (2005) suggested that care seeking and help seeking are components of health-seeking behavior. Tromp et al. asserted that health behavior is crucial in the development, detection, and course of cancer of the head and neck and that relevant health behaviors include prompt medical care seeking. Howell et al. (2008) described help seeking in patients with lymphoma as the first step in diagnosis. However, in the context of help seeking for urinary incontinence, Shaw (1999) stated that help seeking is one possible health behavior, with some people choosing to self-manage. Therefore, help seeking is a response to health changes and part of the broader process of health-seeking behavior.

Conclusion and Recommendations

This article reviewed current literature on help seeking to delineate how it and related concepts are used and identify a definition for the term. In addition, literature was reviewed to identify a theoretical framework explaining the process of help seeking in patients with self-discovered cancer symptoms. Studies on gender differences highlighted the role that gender plays in health- and help-seeking behavior. Studying help seeking for cancer symptoms from generic as well as specific perspectives showed that delay is a common phenomenon with many influencing factors, particularly symptom appraisal.

Table 2. Defining Help Seeking for Cancer Symptoms

Author	Region	Research Design	N	Definition or Views
de Nooijer et al., 2002a	The Netherlands	Quantitative, descriptive	1,530	Help seeking is "seeking medical help within one week for symptoms such as swelling or thickening" (as in breast cancer) and within four weeks for symptoms such as "changes in bowel habits and unusual weight loss" (p. 363).
Facione & Dodd, 1995	United States	Qualitative analysis of narratives of women with breast cancer undergoing chemotherapy	39	Linked help seeking to seeking evaluation from a healthcare professional
Howell et al., 2008	United States	Grounded theory	32	Help seeking is "the first step on the pathway to diagnosis" (p. 532).
Ristvedt & Trinkaus, 2005	United States	Quantitative, correlational	69	Help-seeking behavior may be part of health-related behavior.
Tromp et al., 2005	The Netherlands	Quantitative, descriptive	264	"Relevant health behavior includes prompt medical care seeking" (p. 665).

Knowledge of intentions to seek help can facilitate the development of health-promotion programs that target people who are likely to delay.

The reviewed frameworks and models related to help seeking for urinary incontinence, infertility, and breast cancer symptoms. However, an all-encompassing framework that explained the entire help-seeking process was not identified. Shaw's (1999) framework and Dodd et al.'s (2001) model on symptom management complement each other in addressing the complex nature of symptom appraisal and outcomes and may be useful in additional study of help-seeking behavior.

Prompt help seeking and early detection of cancer are key to improving patient outcomes. Research emphasizes that healthcare providers, particularly nurses,

should continue encouraging individuals to seek help promptly for self-discovered cancer symptoms. Therefore, additional development of theoretical knowledge about help seeking to enable providers to be more responsive to the needs of individuals who discover a potential cancer symptom is warranted.

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