# Antecedents and Outcomes of Uncertainty in Older Adults With Cancer: A Scoping Review of the Literature

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**Problem Identification:** Uncertainty is a major source of distress for cancer survivors. Because cancer is primarily a disease of older adults, a comprehensive understanding of the antecedents and outcomes of uncertainty in older adults with cancer is essential.

Literature Search: MEDLINE<sup>®</sup>, PsycINFO<sup>®</sup>, Scopus, and CINAHL<sup>®</sup> were searched from inception to December 2015. Medical Subject Headings (MeSH) terms and free text words were used for the search concepts, including *neoplasms*, *uncertainty*, and *aging*.

**Data Evaluation:** Extracted data included research aims; research design or analysis approach; sample size; mean age; type, stage, and duration of cancer; type and duration of treatment; uncertainty scale; and major results.

Synthesis: Of 2,584 articles initially identified, 44 studies (30 qualitative, 12 quantitative, and 2 mixed-methods) were included. Evidence tables were developed to organize quantitative and qualitative data. Descriptive numeric and thematic analyses were used to analyze quantitative results and qualitative findings, respectively. Outcomes were reported under four main categories: antecedents of uncertainty, outcomes of uncertainty, management of uncertainty, and the experience of uncertainty.

**Conclusions:** Uncertainty is an enduring and common experience in cancer survivorship. Uncertainty is affected by a number of demographic and clinical factors and affects quality of life (QOL) and psychological well-being.

Implications for Practice: Uncertainty should be considered a contributing factor to psychological well-being and QOL in older adults with cancer. Nurses are in a unique position to assess negative effects of uncertainty and manage these consequences by providing patients with information and emotional support.

ncertainty is defined as a "period of anticipation prior to confrontation with a potentially harmful event" (Monat, Averill, & Lazarus, 1972, p. 237) and is a common experience in cancer (Applebaum et al., 2014; Gil et al., 2006; Maher & De Vries, 2011). The unknown etiology and unpredictable future of cancer can prompt a sense of sustained uncertainty lingering throughout the cancer journey (Mishel, 1981; Wright, Afari, & Zautra, 2009). Lack of ability to define and classify illness-related events (Mishel, 1988) and predict treatment outcomes can provoke an apprehensive feeling of uncertainty (Penrod, 2001) that can adversely affect patients' psychosocial well-being (Ferrans, 1994; Gotay & Muraoka, 1998; Henderson, 1997). The cancer survivorship literature frequently locates uncertainty within the stress and coping model and suggests that uncertainty surrounding cancer can impair coping and adaptation through intensifying negative effects of stress and paralyzing anticipatory coping mechanisms (Lazarus & Folkman, 1984; Mishel, Hostetter, King, & Graham, 1984; Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000). Higher levels of uncertainty have been shown to be associated with poorer quality of life (QOL), greater levels of emotional distress, higher levels of anxiety and depression, and

more relationship issues with family members (Braden, 1990; Christman, 1990; Mast, 1995; Mishel, 1984).

Because cancer is primarily a disease of older adults (Hurria et al., 2014), a need exists for a better understanding of potential influences of uncertainty on adjustment outcomes in older adult cancer survivors. To date, no review has been conducted. Therefore, the objective of this review is to provide an overview of existing literature on uncertainty in older adults with cancer. The overall aim is to develop a better understanding of the role of uncertainty in coping and adaptation to facilitate the development of age-specific interventions. Current gaps in the existing body of knowledge will be identified to inform future research studies. The research question for this review is the following: What are uncertainty antecedents and outcomes in older adults with cancer?

## Methods

A scoping review was conducted using the methodologic framework developed by Arksey and O'Malley (2005) and later refined by Levac, Colquhoun, and O'Brien (2010) and Daudt, van Mossel, and Scott (2013), in which a systematic review appeared ineffective because of a dearth of intervention studies of high methodologic quality. A scoping methodology is a systematic approach to guide a comprehensive search of existing evidence on a particular topic, summarize and synthesize findings, identify knowledge gaps, and inform future studies (Arksey & O'Malley, 2005; Colquhoun et al., 2014). The six steps of a scoping review are the following: (a) identifying the research question; (b) identifying relevant studies; (c) selecting studies; (d) extracting and charting data; (e) collating, summarizing, and reporting results; and (f) optional consulting with stakeholders (Arksey & O'Malley, 2005). Employing this framework, published research was analyzed to delineate the breadth, depth, and nature of evidence on the concept of uncertainty in older adults with cancer and identify the areas for future research inquiries. The sixth step, consulting with stakeholders, was omitted because the results of the review did not specify any particular theme germane to stakeholders necessitating consultation.

# Identifying Relevant Studies and Search Strategy

Four electronic databases were searched using appropriate search terms as advised by a librarian. Medical Subject Headings (MeSH) terms and free text words were used for the search concepts of *neoplasms*, *uncertainty*, and *aging*. The three terms were combined with a Boolean "AND." The search was limited to the English language. Articles in MEDLINE<sup>®</sup>, PsycINFO<sup>®</sup>, Scopus, and CINAHL<sup>®</sup> were searched from inception to December 2015. The search was not limited by publication year because the review was the first one in this area, and the objective was to identify the extent of the existing evidence, highlight well-established findings, and identify the gaps in the body of knowledge. Reference lists were verified for potential studies. A two-phase process was employed to select eligible articles. First, titles and abstracts were reviewed to detect relevant articles. Second, full texts of selected citations were reviewed to identify articles meeting inclusion criteria. Review of the abstracts and full-text manuscripts and data abstraction were conducted by one person.

Eligible studies were quantitative, qualitative, or mixed-methods. Articles were included if the mean or median age of participants was 65 years or older (or if the results were reported for subgroups with a mean or median age of 65 years or older) and if the focus was on uncertainty in cancer. Studies that focused on psychometric evaluation of uncertainty measures and commentaries were excluded from the review because they did not contain any information to answer the review question.

### **Data Extraction, Analysis, and Synthesis**

Extracted data included research aims; research design or analysis approach; sample size; mean age; type, stage, and duration of cancer; type and duration of treatment; uncertainty scale; and major results. Evidence tables were developed to organize quantitative and qualitative data separately. Quantitative results and qualitative findings were analyzed by descriptive numeric or thematic analyses, respectively (Levac et al., 2010). Outcomes were reported under four main categories: antecedents of uncertainty, outcomes of uncertainty, management of uncertainty, and the experience of uncertainty.

## Results

The initial search yielded a total of 2,584 studies. Based on screening titles and abstracts, 1,688 studies were excluded. The most common reason for excluding articles was that the primary focus was not on uncertainty in cancer (n = 1,269). Full-text article review resulted in excluding an additional 852 studies that did not meet the inclusion criteria. A total of 44 articles were selected for data extraction and analysis (see Figure 1).

## **Description of Included Studies**

Thirty of 44 studies used a qualitative design guided mainly by phenomenology (n = 12) or grounded theory (n = 6). Of the 44 total studies, 12 were quantitative, and 2 studies used a mixed-methods design. The majority of quantitative studies (n = 10) used



a cross-sectional design with the uncertainty in illness theory (Mishel, 1988) (n = 11) as the underlying conceptual framework and the Mishel Uncertainty in Illness Scale (Mishel, 1981) (n = 10) as the uncertainty measure. Seven quantitative studies used small samples from 9–43 participants. Studies were conducted in the United States (n = 15), Sweden (n = 10), the United Kingdom (n = 7), Australia (n = 4), Canada (n = 3), Norway (n = 2), Germany (n = 1), Israel (n = 1), and Taiwan (n = 1). Studies were conducted from 1995–2015 and encompassed individuals with multiple types of cancer (n = 12), prostate cancer (n = 11), breast cancer (n = 6), gastrointestinal cancer (n = 6), lung cancer (n = 1), and renal cancer (n = 1).

#### Antecedents of Uncertainty

Six studies reported data on the antecedents of uncertainty (see Table 1). Given the nature of the antecedents, they were categorized under two subheadings: demographic and clinical.

**Demographic antecedents:** Age, sex, and educational levels were the demographic variables studied in relation to uncertainty. A positive correlation (when two variables move in the same direction) between age (in years) and uncertainty was reported in a cross-sectional study on predominantly Caucasian (91%) and married (60%) older adults with breast cancer (Sammarco, 2003). However, no significant difference in uncertainty levels was reported when a cohort of mixed ethnicity and mostly married (56%) older adult breast cancer survivors were compared with their

younger counterparts (Sammarco, 2009). Similarly, no relationship was found between age and uncertainty in a prospective study with survivors of colon cancer (Galloway & Graydon, 1996). The relationship between sex and uncertainty was examined in only one study, and no significant relationship was reported (Galloway & Graydon, 1996). Higher levels of education were negatively correlated (when two variables move in the opposite directions) with uncertainty in men with prostate cancer undergoing watchful waiting (Wallace, 2005). However, survivors of colon cancer (male and female undertaking surgery) with higher levels of education reported significantly higher uncertainty than those with lower education (Galloway & Graydon, 1996).

**Clinical antecedents:** Time since diagnosis, stage of cancer, symptom pattern, symptom distress, and comorbidities were the clinical antecedents studied in relation to uncertainty. Time since diagnosis was identified as a significant predictor of uncertainty in a prospective study with men undergoing active surveillance for prostate cancer (Parker et al., 2015). In that study, longer time since diagnosis was associated with lower levels of uncertainty. However, two studies with participants undergoing active surveillance for either prostate cancer or small renal tumors found no significant association between time since diagnosis and uncertainty (Parker et al., 2013; Wallace, 2005). The length of hospitalization, however, was shown to be positively correlated with uncertainty in older adults with colon cancer (Galloway & Graydon, 1996). In addition, uncertainty was found to vary with cancer stage in older adult patients undergoing surgery so that a significant decrease in uncertainty was only reported by patients at stages 0 and I (Lien, Lin, Kuo, & Chen, 2009). No relationships were found between uncertainty and symptom pattern and symptom distress in two small studies with survivors of prostate or colon cancer (Galloway & Graydon, 1996; Wallace, 2005). The role of comorbidities was examined in only one cross-sectional study, and it showed that the levels of uncertainty increased significantly in the presence of coexisting health conditions (Sammarco, 2003).

#### **Outcomes of Uncertainty**

Seven studies reported data on the outcomes of uncertainty. QOL was the most commonly researched outcome (Bailey, Mishel, Belyea, Stewart, & Mohler, 2004; Kazer, Bailey, Sanda, Colberg, & Kelly, 2011; Parker et al., 2013, 2015; Sammarco, 2003, 2009; Wallace, 2003). Other studied outcomes included anxiety (Lien et al., 2009; Parker et al., 2015), depressive symptoms (Galfin & Watkins, 2012; Lien et al., 2009), intrusive thoughts and avoidance behavior (Parker et al., 2013), abstract thinking and rumination (Galfin & Watkins, 2012), and fear of cancer progression (Parker et al., 2015).

| Study   | Aim(s)  | Sample and Design   | Results  |
|---|---|---|--|
| Bailey<br>et al.,<br>2004<br>(United<br>States)     | To examine the effec-<br>tiveness of a five-week<br>telephone-delivered<br>intervention on improv-<br>ing ability to manage<br>and cognitively reframe<br>uncertainty                         | Cross-sectional study with<br>39 patients with prostate<br>cancer treated with watch-<br>ful waiting aged a mean of<br>74.5 years using GTUS<br>(RR = 75%)  | Significant improvements in current QOL (Wilks'<br>lambda F[1, 37] = 8.6, p = 0.006), better expectations<br>of QOL in six months (F[1, 37] = 7.4, p = 0.01), higher<br>improvement in disease-related confusion (Wilks'<br>lambda F[1, 37] = 4.3, p = 0.04), and more positive<br>perception of future (Wilks' lambda F[1, 37] = 5.82,<br>p = 0.02); no significant improvements in cognitive<br>reframing ability, mood state, and growth through<br>uncertainty   |
| Boyes<br>et al.,<br>2015<br>(Australia)             | To describe the preva-<br>lence of and factors<br>associated with unmet<br>supportive care needs<br>among patients with<br>hematologic cancer   | Cross-sectional design with<br>311 patients with leukemia,<br>lymphoma, myeloma, and<br>other cancers treated with<br>chemotherapy and other<br>treatments (58%) aged 55–<br>74 years using SCNS-SF34<br>(RR = 90%)   | Uncertainty about the future was among the<br>moderate- to high-level unmet needs (21%, 95% Cl<br>[16, 25]).   |
| Galfin &<br>Watkins,<br>2012<br>(United<br>Kingdom) | To examine whether<br>two specific psychologi-<br>cal processes—patho-<br>logic rumination and<br>increased abstract-<br>ness—are involved in<br>psychological distress<br>in palliative care | Cross-sectional, multi-<br>method study with 36 pa-<br>tients with various cancers<br>treated with palliative care<br>aged a mean of 68.3 years<br>(SD = 10.09) using rumina-<br>tive interview   | More uncertainty, abstract thinking, and rumination<br>were found with patients in palliative care than an<br>age-matched control group. Uncertainty was signifi-<br>cantly and positively correlated with abstract thinking<br>( $r = 0.32$ , $p < 0.01$ ), anxiety ( $r = 0.53$ , $p < 0.01$ ), de-<br>pression ( $r = 0.51$ , $p < 0.01$ ), frequency ( $r = 0.43$ ,<br>p < 0.01), and duration ( $r = 0.55$ , $p < 0.001$ ) of ru-<br>minative thinking, and distress ( $r = 0.49$ , $p < 0.001$ ).<br>More uncertainty and abstractness were associated<br>with more depression in patients in palliative care. |
| Hegarty &<br>Wallace,<br>2008<br>(Ireland)          | To explore uncertainty<br>and QOL of American<br>and Irish men with<br>prostate cancer  | Cross-sectional study with 29<br>patients with prostate cancer<br>treated using active surveil-<br>lance (19 from United States,<br>10 from Ireland) aged a<br>mean of 58.8 years (SD =<br>12.5) for American men and<br>53.7 years (SD = 13.3) for<br>Irish men using MUIS | Slightly higher levels of uncertainty were seen in<br>American participants. American and Irish partici-<br>pants were fairly consistent in affective and HRQOL,<br>as well as primary, opportunity, and danger ap-<br>praisal.  |
| Kazer<br>et al.,<br>2011<br>(United<br>States)      | To evaluate the effects<br>of a five-week, Internet-<br>based intervention on<br>uncertainty, self-<br>efficacy, and QOL  | Cross-sectional study with<br>nine patients with prostate<br>cancer treated with active<br>surveillance for a mean of<br>three years aged a mean of<br>72 years (range = 66–79)<br>using MUIS (RR = 66%)  | Slight increase in uncertainty levels; slight and tem-<br>porary improvement in QOL; slight and temporary<br>decrease in self-efficacy   |
| Lein<br>et al.,<br>2009<br>(Taiwan)                 | To examine the re-<br>lationships among<br>uncertainty, social sup-<br>port, and psychological<br>adjustment for older<br>adult patients with can-<br>cer undergoing surgery                  | Longitudinal study with 43<br>patients with stages III and<br>IV cancers (44%) treated<br>with surgery (90%) aged a<br>mean of 75.6 years<br>(SD = 5.01) using MUIS<br>(RR = 74%)   | Uncertainty levels varied with cancer stages. Moder-<br>ate levels of uncertainty were reported at the time<br>of surgery. Significant decrease was seen in the<br>levels of uncertainty for patients at stage 0 or I af-<br>ter surgery. Nonsignificant decrease in the levels of<br>uncertainty was seen after surgery for participants<br>at stages II, III, and IV. Significant relationship was<br>found between uncertainty and anxiety (r = 0.48, p <<br>0.01; r = 0.411, p < 0.01) and depression (r = 0.386,<br>p < 0.05; r = 0.376, p < 0.05) before and after sur-<br>gery, respectively.                 |

Continued on the next page

| Study   | Aim(s)  | Sample and Design   | Results   |
|---|---|---|---|
| Parker<br>et al.,<br>2013<br>(United<br>States) | To examine the influ-<br>ence of uncertainty on<br>distress and QOL dur-<br>ing two years   | Prospective, observational<br>study with 100 patients with<br>small renal tumors treated<br>with watchful waiting aged<br>a mean of 72.5 years (SD =<br>9.9) using MUIS   | No significant change was found in uncertainty levels<br>over time. Uncertainty was associated with poorer<br>general QOL scores in physical domain (p = 0.008),<br>worse cancer-related QOL in physical (p = 0.001),<br>psychosocial (p < 0.001), and medical domains (p =<br>0.034). Uncertainty predicted intrusive thoughts and<br>avoidance behaviors ( $\beta$ = 0.55, p < 0.001).  |
| Parker<br>et al.,<br>2015<br>(United<br>States) | To evaluate the as-<br>sociation between<br>illness uncertainty,<br>anxiety, fear of progres-<br>sion, and general and<br>disease-specific QOL;<br>to examine whether<br>anxiety mediates the<br>association between<br>uncertainty and QOL | Prospective study with 180<br>patients with prostate can-<br>cer at cT1c clinical stage<br>(85%) treated with active<br>surveillance aged a mean of<br>67.2 years (SD = 8.9) using<br>MUIS  | Mean of baseline uncertainty scores were similar to other cancer populations. Time was a significant predictor of uncertainty, with scores being significantly lower than baseline starting from 12 months until 2.5 years. Uncertainty was significantly and negatively associated with all of the EPIC summary scores (physical: $\beta = -0.099$ , mental: $\beta = -0.128$ ). Uncertainty was significantly and positively associated with fear of progression ( $\beta = 0.072$ ). Mediation analysis was negative for the mediating role of anxiety for association between uncertainty and all QOL summary scores. |
| Sammar-<br>co, 2009<br>(United<br>States)       | To examine the differ-<br>ences between older<br>and younger breast<br>cancer survivors in<br>perceived support, un-<br>certainty, and QOL  | Cross-sectional study with<br>292 patients with breast can-<br>cer treated with various treat-<br>ments (163 younger than<br>age 50 years, $\overline{X} = 44.3$ , SD =<br>4.4; 129 older than age 50<br>years, $\overline{X} = 66.7$ , SD = 10.3)<br>using MUIS (RR = 31%) | Moderate levels of uncertainty were reported by older<br>and younger participants. No significant difference in<br>uncertainty levels of younger and older participants was<br>reported. Uncertainty was a significant predictor of QOL<br>(explained 19% of variance). Significant negative as-<br>sociation was found between uncertainty and QOL ( $\beta$ =<br>-0.135, t = -6.32, p < 0.001).   |
| Sand<br>et al.,<br>2008<br>(Sweden)             | To explore the percep-<br>tion, experiences and<br>significance of power-<br>lessness and hopeless-<br>ness in dying patients<br>with cancer; to examine<br>triggering factors and<br>make qualifications                                   | Cross-sectional, mixed-<br>methods study with 103<br>patients with various can-<br>cers treated with palliative<br>care aged a median of 67<br>years (range = 40-91) using<br>researcher-developed ques-<br>tionnaire (RR = 58%)  | Uncertainty was a triggering factor to provoke power-<br>lessness and hopelessness, and was described as a<br>feeling that anything can happen at any time and as<br>living without normal time references.   |
| Wallace,<br>2003<br>(United<br>States)          | To assess the associa-<br>tion among uncertainty,<br>anxiety, danger ap-<br>praisal, and QOL; to<br>examine the mediating<br>role of anxiety and<br>danger appraisal in the<br>relationship between<br>uncertainty and QOL                  | Cross-sectional study with<br>19 patients with prostate<br>cancer treated with watchful<br>waiting aged a mean of 76<br>years (SD = 6.7) using MUIS<br>(RR = 90%)   | No significant relationships were found between<br>uncertainty, anxiety, danger appraisal, and HRQOL.<br>Uncertainty significantly explained 36% of the variance<br>in affective health functioning domain of QOL. Interac-<br>tion term of uncertainty, anxiety, and danger appraisal<br>explained 72% of the variance in health functioning<br>domain of QOL. Danger appraisal was a mediator<br>between uncertainty and affective health functioning<br>domain of QOL.   |
| Wallace,<br>2005<br>(United<br>States)          | To explore the anteced-<br>ents of uncertainty  | Cross-sectional study with<br>19 patients with prostate<br>cancer treated with watchful<br>waiting aged a mean of 76<br>years (SD = 6.7)  | Significant negative correlation was found between<br>education and uncertainty (r = $-0.78$ , p < $0.001$ ). Edu-<br>cation explained 52% of the variance in uncertainty.<br>Significant negative correlation between duration of<br>illness and uncertainty (r = $-0.55$ , p = $0.02$ ) but not a<br>significant predictor of uncertainty. No significant cor-<br>relation was found between uncertainty and symptom<br>pattern (r = $-0.063$ , p = $0.8$ ), social support (r =<br>-0.005, p = $0.983$ ), cognitive capacity, and relationship<br>with healthcare providers (r = $0.29$ , p = $0.26$ ).                |

Cl—confidence interval; EPIC—Expanded Prostate Cancer Index Composite; GTUS—Growth Through Uncertainty Scale; HRQOL—health-related quality of life; MUIS—Mishel's Uncertainty in Illness Scale; QOL—quality of life; RR—relative risk; SCNS-SF34—Supportive Care Needs Survey Short Form 34

Quality of life: A significant negative association between uncertainty and QOL was reported consistently. Uncertainty was found to be significantly and negatively correlated with QOL in older adults with breast cancer, and it was the most influential variable on QOL after controlling for surgery, mastectomy, age, comorbidity, and social support (Sammarco, 2003, 2009). Comparable results were reported for patients with small renal tumors and prostate cancer undergoing watchful waiting and active surveillance (Parker et al., 2013, 2015; Wallace, 2003). Uncertainty and social support together were found to explain a significantly greater variance in QOL than either variable alone (Sammarco, 2003). To understand the process through which uncertainty affects QOL, Parker et al. (2015) conducted a mediating analysis exploring whether the relationship between uncertainty and QOL was mediated by anxiety and found no significant results.

Stress indicators: The positive associations between uncertainty and (a) intrusive thoughts and avoidance behavior and (b) fear of cancer progression were supported by two longitudinal studies (Parker et al., 2013, 2015). In addition, uncertainty was found to be significantly and positively associated with abstract thinking, anxiety, depression, frequency and duration of ruminative thinking, and distress of eccentric rumination in participants receiving palliative care (Galfin & Watkins, 2012). Greater uncertainty and abstract thinking were positively linked to psychological distress and depression induced by rumination (Galfin & Watkins, 2012). The impact of uncertainty on anxiety and depression was further supported in a prospective study of uncertainty, social support, and psychological adjustment in older adult patients with cancer undergoing surgery (Lien et al., 2009). Uncertainty was shown to be significantly and positively correlated with anxiety and depression before and after surgery (Lien et al., 2009).

## **Management of Uncertainty**

Two intervention studies (Bailey et al., 2004; Kazer et al., 2011) reported data on the influence of uncertainty management interventions on psychological well-being and QOL. Kazer et al. (2011) conducted a pilot, pre-/post-test intervention study with nine older adults undergoing active surveillance for prostate cancer to evaluate the influence and durability of a five-week, Internet-based cognitive reframing and self-management intervention on uncertainty, self-efficacy, and QOL. The results of this study were mixed, and no effect sizes were reported (Kazer et al., 2011).

Bailey et al. (2004) examined the effect of a fiveweek watchful waiting intervention on cognitive reframing and uncertainty management ability in a convenience sample of 39 men with prostate cancer at stage T1 or T2 and found that those receiving the intervention had greater improvement in current and expected QOL compared to those receiving usual care (Bailey et al., 2004).

## **Experience of Uncertainty**

Table 2 illustrates the main findings of the included qualitative studies. The findings of reviewed literature were thematically analyzed and classified under five subheadings: (a) perception of uncertainty, (b) temporal pattern of uncertainty, (c) uncertainty and treatment decision making, (d) uncertainty and emotional well-being, and (e) coping with uncertainty.

Perception of uncertainty: Uncertainty about medical conditions and the future was one of the most common concerns expressed by older adults at different stages of cancer from diagnosis to terminal phases (Arber & Spencer, 2013; Banning, Hafeez, Faisel, Hassan, & Zafar, 2009; Gardner, 2008; Grimsbø, Ruland, & Finset, 2012; Guilhot et al., 2013; Halldórsdóttir & Hamrin, 1996; Larsson, Hedelin, & Athlin, 2007; Oliffe, Davison, Pickles, & Mróz, 2009; Persson & Hallberg, 1995; Saeteren, Lindström, & Nåden, 2011; Sandeman & Wells, 2011). Uncertainty was described as being in a state in which it is hard to cope (Berterö, Vanhanen, & Appelin, 2008; Kasper, Geiger, Freiberger, & Schmidt, 2008; Kuzari, Biderman, & Cwikel, 2013; Sharf, Stelljes, & Gordon, 2005) and ranked in the moderate to high level of unmet needs (Boyes et al., 2015). A variety of phrases, such as "not sure," "left in limbo," "what happens now?", "I do not know," and "I am waiting," were used by older adults to describe their perception of uncertainty across the cancer trajectory (Arber & Spencer, 2013; Berterö et al., 2008; Jonsson, Aus, & Berterö, 2010). Three main sources of uncertainty were not knowing (Andreassen, Randers, Näslund, Stockeld, & Mattiasson, 2006; Jonsson et al., 2010; Winterling, Wasteson, Glimelius, Sjödén, & Nordin, 2004), waiting (Berterö et al., 2008; Kuzari et al., 2013; Larsson et al., 2007), and unpredictable future (Jonsson et al., 2010; Karlsson, Friberg, Wallengren, & Öhlén, 2014; Saeteren et al., 2011). Ambiguity and complexity of cancer diagnosis and treatment were the key contributing factors to patients' lack of ability to understand events and interpret situations (Berterö et al., 2008; Fried & Bradley, 2003; Gardner, 2008; Jonsson et al., 2010; Oliffe et al., 2009). Waiting was commonly linked to difficult situations, such as pending diagnostic test results (Larsson et al., 2007; Oliffe et al., 2009) and delay in receiving information and treatment (Kuzari et al., 2013; Mazor et al., 2013). Unpredictable future was frequently linked to the possibility of death (Gardner, 2008; Grimsbø et al., 2012; Jonsson et al., 2010; Winterling et al., 2004). Related subthemes identified in the literature are listed on Figure 2.

| TABLE 2. Characteristics of Quantative Studies included in the Review |   |   |  |  |
|---|---|---|--|--|
| Study   | Aim(s)  | Sample and Design   | Results  |  |
| Andreassen<br>et al., 2006<br>(Sweden)                                | To describe patients'<br>experiences of liv-<br>ing with esophageal<br>cancer and their ap-<br>proaches for seeking<br>information  | Content study with 13 pa-<br>tients with esophageal can-<br>cer treated with surgery plus<br>curative and palliative treat-<br>ment aged 44–77 years  | Enduring uncertainty was related to the ambigu-<br>ous nature of cancer and not knowing about the<br>effectiveness of treatment. Uncertainty about the<br>future kept the patients from planning for the fu-<br>ture and intruded upon the patients' daily lives.<br>Uncertainty was occasionally emotionally devas-<br>tating.  |  |
| Arber &<br>Spencer,<br>2013<br>(United<br>Kingdom)                    | To explore patients'<br>experiences during<br>the first three months<br>following a diagnosis<br>of malignant pleural<br>mesothelioma   | Grounded theory study with<br>10 patients with pleural me-<br>sothelioma aged a mean of<br>70.3 years (range = 56–82)<br>(20% female)   | High levels of uncertainty were reported by all<br>patients. High levels of uncertainty, together with<br>feeling lack of control, resulted in psychological<br>distress. Uncertainty was related to progression of<br>disease, treatment schedule, medical system, and<br>the rate of physical decline; was communicated<br>using phrases like "not sure," "left in limbo," "what<br>happens now?", "I do not know," and "I am wait-<br>ing"; and was associated with loss of control and<br>insecurity about how to live and who can possibly<br>help. CAM, support groups, and referral to pallia-<br>tive care were used to facilitate coping with uncer-<br>tainty and lack of control. |  |
| Bailey et al.,<br>2007<br>(United<br>States)                          | To explore uncertainty<br>and problems experi-<br>enced by men under-<br>going watchful waiting<br>for prostate cancer;<br>to describe common<br>strategies adopted<br>by men to manage<br>uncertainty related to<br>watchful waiting | Content analysis study with<br>10 patients with prostate<br>cancer treated with watchful<br>waiting aged 64–88 years  | Three domains of concerns were uncertainty,<br>danger appraisal, and opportunity appraisal.<br>Sources of uncertainty were lack of physical<br>symptoms, ambiguous tests, and misattribution<br>of symptoms. Sources for danger appraisal were<br>many treatment options and lack of clear treat-<br>ment guidelines to support appropriateness of<br>watchful waiting over traditional treatment mo-<br>dalities. Sources of opportunity appraisal were<br>having an opportunity to manage uncertainty<br>through work, self-care, keeping options open,<br>and use of alternative medications and<br>prayer.   |  |
| Banning<br>et al., 2009<br>(United<br>Kingdom)                        | To explore factors that<br>influence the lived<br>experience of breast<br>cancer in Pakistani<br>Muslim women   | Thematic study with 36 patients with breast cancer aged 22–76 years   | Long-term uncertainty was reported by participants who had cancer recurrence.  |  |
| Berterö<br>et al., 2008<br>(Sweden)                                   | To explore the impact<br>of inoperable lung<br>cancer on life situa-<br>tion and QOL from the<br>perspective of patients  | Hermeneutic phenomenol-<br>ogy study with 23 patients<br>with lung cancer aged a<br>median of 67 years (range =<br>36–86) (48% female)  | It was hard to come to terms with uncertainty.<br>The source of uncertainty was questions about<br>diagnosis, treatment, and outcomes of treat-<br>ment, as well as waiting for the diagnosis and<br>treatment and not knowing if cure is possible.<br>Uncertainty caused anxiety for the patients and<br>decline in QOL.  |  |
| Clayton<br>et al., 2005<br>(Australia)                                | To explore various<br>stakeholders' views on<br>the content and phras-<br>ing of information<br>when discussing life<br>expectancy with termi-<br>nally ill patients  | Qualitative study with 19 pa-<br>tients with various advanced<br>cancers treated with pallia-<br>tive care for a median of 12<br>weeks (range = 3 weeks to 2<br>years) aged a median of 68<br>years (range = 36–83) (58%<br>female) | Most patients were aware of the uncertainty in-<br>herent in predictions about life expectancy.<br>Patients expected to be provided with informa-<br>tion about uncertainties and limitations in the<br>form of general indication of what to expect in<br>the future. Some patients liked to be given a time<br>frame to have a rough range of life expectancy or<br>the longest possible period of time that they may<br>live.   |  |

Continued on the next page

| TABLE 2. Characteristics of Qualitative Studies Included in the Review (Continued) |  |   |  |  |
|--|--|---|--|--|
| Study  | Aim(s)   | Sample and Design   | Results  |  |
| Denberg<br>et al., 2006<br>(United<br>States)                                      | To explore the contrib-<br>uting factors to treat-<br>ment decision making<br>in patients with pros-<br>tate cancer                                    | Thematic study with 20 pa-<br>tients with localized prostate<br>cancer treated with radical<br>prostatectomy, brachyther-<br>apy, external beam therapy,<br>watchful waiting, cryother-<br>apy, and hormonal ablation<br>aged a mean of 65 years<br>(range = 54–80) | Marked and enduring uncertainty about the future<br>was reported by two-thirds of participants after<br>learning about the diagnosis. Uncertainty was a<br>contributing factor to treatment decision making.<br>Delay in treatment could increase uncertainty.<br>Uncertainty contributed to the desire for rapid<br>treatment. Surgery was identified as the best treat-<br>ment because it was the most certain and rapid<br>approach, which could give the patients a sense of<br>finality.   |  |
| Fried &<br>Bradley,<br>2003<br>(United<br>States)                                  | To explore patients'<br>perspective on impor-<br>tant aspects of end-of-<br>life treatment decision<br>making  | Constant comparative study<br>with 23 patients with various<br>types of advanced cancer<br>(44%) aged a mean of 70<br>years (range = 60–84) (35%<br>female)   | Most patients were aware of the uncertainty sur-<br>rounding the treatment outcomes. Patients did not<br>talk spontaneously about the role of uncertainty<br>in their treatment decision making. The possibility<br>of a given outcome influenced patients' treatment<br>preferences.  |  |
| Gardner,<br>2008<br>(United<br>States)   | To explore the ways in<br>which older couples<br>negotiate uncertainty<br>and collaborate to<br>search for and create<br>meaning at the end<br>of life | Systematic coding study<br>with 35 patients with various<br>stage III or IV cancers in ac-<br>tive treatment aged a mean<br>of 66 years (range = 56–81)<br>(29% female)   | Dealing with uncertainty and ambiguity associated<br>with the medical condition and the future was one<br>of the most common concerns among older adults<br>with advanced cancer. The sources of uncertainty<br>were future of the cancer, effectiveness of treat-<br>ment, dealing with changing medical status, com-<br>plexity of treatment and healthcare system, and<br>possibility of death. Many patients reported feeling<br>unsure how to act and how to define their roles<br>when nothing is certain or familiar. Uncertainty<br>and concerns about the future had a negative<br>effect on couples' relationships. Trying to make<br>sense of situations, faith, maintaining hope, and<br>optimism were common coping strategies to deal<br>with uncertainty.                                     |  |
| Grimsbø<br>et al., 2012<br>(Norway)  | To explore emotional<br>cues and concerns of<br>patients expressed in<br>email communication<br>with oncology nurses                                   | Verona coding study with<br>60 patients with breast and<br>prostate cancer (first-time<br>diagnosis, no metastasis:<br>87%) aged a mean of 65<br>years (SD = 7.6) for men<br>and 59 years (SD = 7.9) for<br>women (63% female)                                      | Uncertainty was frequently expressed and was<br>commonly related to the future, spread of disease,<br>treatment, daily life activities, and death.   |  |
| Guilhot et al.,<br>2013<br>(United<br>States)                                      | To assess the impact<br>of diagnosis and treat-<br>ment on patients with<br>CML on TKIs  | Ethnographic study with<br>50 patients with CML for a<br>mean of seven years treated<br>with TKIs for 18 months aged<br>21–80 years   | All patients with CML experienced some uncertain-<br>ty. The majority of uncertainty-provoking events<br>were disease-related, such as drug resistance,<br>disease progression, poor test results, persistent<br>adverse events or occurrence of new adverse<br>events, and limitation in access to therapy. Anxiety<br>was experienced by patients who had uncertainty.<br>In a five-stage, patient-centered model of per-<br>sonal experience with diagnosis, treatment, and<br>management of CML (crisis, hope, adaptation,<br>new normal, and uncertainty), uncertainty was<br>experienced after establishing a new normal. Pa-<br>tients with uncertainty tended to move backward<br>to adaptation or new normal stages once they<br>received information about the next step in testing<br>or therapy. |  |

| TABLE 2. Characteristics of Qualitative Studies Included in the Review (Continued) |  |   |   |
|--|--|---|---|
| Study  | Aim(s)   | Sample and Design   | Results   |
| Halldórsdóttir<br>& Hamrin,<br>1996<br>(Sweden)                                    | To explore the lived<br>experience of having<br>cancer   | Phenomenologic study with<br>nine patients with various<br>cancers aged 38–69 years<br>(56% female)   | All patients experienced uncertainty. Uncertainty<br>was experienced at different stages of cancer, in-<br>cluding diagnosis, treatment, post-treatment, and<br>terminal phase. Uncertainty and lack of control<br>were experienced simultaneously.   |
| Hedestig<br>et al., 2003<br>(Sweden)   | To describe the mean-<br>ing of living with an<br>untreated localized<br>prostate cancer   | Phenomenologic study with<br>seven patients with prostate<br>cancer treated with watchful<br>waiting aged 62–69 years   | Cancer was described as a threat to life. Partici-<br>pants felt ambivalent about whether to share the<br>illness experience with others, experienced a<br>change in life and masculine identity from pros-<br>tate cancer, were uncertain about the impact of<br>cancer on length of life, felt increased uncertainty<br>at the time of physician visits related to being<br>informed about worsening cancer, and developed<br>personal strategies to manage uncertainty.  |
| Jonsson<br>et al., 2010<br>(Sweden)  | To explore the impact<br>of prostate cancer on<br>men's daily lives two<br>years after diagnosis   | Hermeneutic phenomenol-<br>ogy study with 22 patients<br>with localized or advanced<br>prostate cancer treated for<br>18-24 months aged a me-<br>dian of 68 years (range =<br>50-85)        | Uncertainty was related to the nature of prostate<br>cancer; its causes; the potential preventive mea-<br>sures; effectiveness of treatment; and not knowing<br>how long life will be, what is going on, and what<br>could happen. Uncertainty was associated with<br>ambiguity. Knowledge about cancer and health was<br>essential to decrease uncertainty.  |
| Karlsson<br>et al., 2014<br>(Sweden)   | To interpret meaning<br>of existential uncer-<br>tainty and certainty<br>for people diagnosed<br>with advanced gastro-<br>intestinal cancer and<br>receiving palliative<br>treatment | Phenomenologic study with<br>14 patients with advanced<br>gastrointestinal cancer treat-<br>ed with palliative care aged<br>49–79 years (50% female)  | Present was more certain as compared to future.<br>Thinking about the future could provoke great<br>uncertainty for patients. Involvement in planning<br>important activities for the future, having a goal<br>to look forward to, having something meaningful<br>ahead, and ability to trust people around them can<br>provide patients with a greater sense of certainty.   |
| Kasper et al.,<br>2008<br>(Germany)  | To explore the dis-<br>tinctive qualities of<br>decision-related uncer-<br>tainty in cancer  | Grounded theory study with<br>six patients with various can-<br>cers aged 45-77 years (50%<br>female)   | Management of uncertainty was a significant<br>challenge in coping with decisions regarding can-<br>cer diagnosis and treatment. Uncertainties were<br>likely to be expressed as their opposite. Expressed<br>uncertainties were about disease-related issues<br>(diagnosis, prognosis, and treatment), risk com-<br>munication issues (deciphering information, role in<br>the medical dyad, physicians' trust ability), and as-<br>pects of coping with life (mastering requirements,<br>social integration, causal attribution). |
| Kidd, 2014<br>(United<br>Kingdom)  | To examine the cues<br>and barriers to peo-<br>ples' engagement in<br>self-management dur-<br>ing chemotherapy for<br>colorectal cancer  | Framework analysis, longitu-<br>dinal study with 11 patients<br>with colorectal cancer treat-<br>ed with chemotherapy aged<br>a mean of 65.5 years<br>(range = $49-76$ ) (28% fe-<br>male)  | Uncertainty was an important aspect of control-<br>lability. Uncertainty about when and how best to<br>engage in recommended self-management activi-<br>ties tended to prevent patients from taking part in<br>self-management.   |
| Klafke et al.,<br>2014<br>(Australia)  | To explore how men<br>with cancer integrate<br>and maintain CAM in<br>everyday life  | Thematic study with 24<br>male patients with vari-<br>ous cancers treated with<br>chemotherapy, radiation<br>therapy, hormone therapy,<br>and surgery aged a mean of<br>68 years (SD = 9.9) | CAM provides men with certainty and control<br>and assists with defining events and countering<br>cancer-related fear and uncertainty.  |
|  |  |   | Continued on the next page  |

| Study  | Aim(s)  | Sample and Design   | Results  |
|--|---|---|--|
| Larsson<br>et al., 2007<br>(Sweden)          | To enhance under-<br>standing of the experi-<br>ence of daily life of pa-<br>tients with head and<br>neck cancer during<br>the trajectory of care,<br>with a focus on eating<br>problems                              | Phenomenologic study with<br>nine patients with head<br>and neck cancer treated<br>with surgery and radiation<br>therapy aged a median of 70<br>years (range = 52–86) (22%<br>female) | Uncertainty and waiting were commonly experienced<br>by patients during the cancer trajectory. Waiting for<br>diagnosis was a period filled with uncertainty. Uncer-<br>tainty was provoked by many questions, including<br>the following: "What was going to happen? Who was<br>responsible for care? Where and to whom should<br>they turn to get practical and emotional support?<br>How would the future be?" The state of uncertainty<br>prompted patients to feel vulnerable and insecure.     |
| Mazor et al.,<br>2013<br>(United<br>States)  | To explore patients'<br>perspective on com-<br>munication during<br>cancer care; to iden-<br>tify aspects of com-<br>munication that were<br>significant  | Grounded theory study with<br>120 patients with various<br>cancers (breast and colorec-<br>tal most common) aged<br>37–81 years (88% female)  | Experience and management of uncertainty was<br>strongly associated with information. Common<br>sources of uncertainty included delay in providing<br>information or instruction, the potential progression<br>of care, and what should be expected. Less frequent<br>sources of uncertainty were related to recurrence of<br>cancer and the probable length of survivorship.  |
| Oliffe et al.,<br>2009<br>(Canada)           | To describe self-<br>management strate-<br>gies to control uncer-<br>tainty of living with<br>prostate cancer and<br>undergoing active sur-<br>veillance  | Interpretative description<br>study with 25 patients with<br>prostate cancer treated with<br>active surveillance aged a<br>mean of 68 years (range =<br>48-77)                        | Uncertainty was reported by all the patients under-<br>going active surveillance. Three common reasons<br>for uncertainty were mortality and cancer spread,<br>imminent need for treatment, and impending<br>diagnostic test results and follow-up visits. Two self-<br>management strategies were identified: living a<br>normal life and doing something extra. Self-<br>management strategies were used to reduce com-<br>plexity and ambiguity of the illness- and treatment-<br>related issues. |
| Pascal &<br>Endacott,<br>2010<br>(Australia) | To explore cancer sur-<br>vivors' view on the ethi-<br>cal and existential chal-<br>lenges associated with<br>a cancer diagnosis  | Phenomenologic study with<br>15 patients with various can-<br>cers aged 32–85 years (73%<br>female)   | Uncertainty about cancer recurrence or metastasis<br>was a part of the existential challenge experienced<br>by cancer survivors. latrogenic uncertainty was<br>related to tests and treatment regimen. Medical<br>check-ups could provoke uncertainty.   |
| Persson<br>& Hallberg,<br>1995<br>(Sweden)   | To describe the pa-<br>tients' experience of<br>physical and mental<br>issues during the<br>active phase of can-<br>cer treatment, their<br>measures to deal with<br>these issues, and their<br>views on nursing care | Phenomenologic study with<br>five patients with acute leu-<br>kemia and malignant lym-<br>phoma aged a mean of 70.4<br>years (range = 60–77) (20%<br>female)                          | Participants described living in uncertainty and<br>were uncertain whether they would be alive tomor-<br>row. Uncertainty prevented participants from mak-<br>ing plans for the future or having expectations for<br>future events.  |
| Saeteren<br>et al., 2010<br>(Norway)         | To understand pa-<br>tients' experience of<br>health and suffering in   | Hermeneutic phenomenol-<br>ogy study with 15 patients<br>with various advanced can-   | The life situation was full of uncertainty because<br>of unpredictability of cancer and loss of ability to<br>plan for the future. Uncertainty was related to loss   |

cers treated with palliative

Phenomenologic study with

10 patients with stage III or

IV lung cancer treated with

tive radiation therapy aged a

mean of 70.1 years (range = 46-82) (60% female)

chemotherapy and pallia-

female)

care aged 47-76 years (40%

| TABLE 2. Characteristics of | <b>Qualitative Studies</b> | <b>Included in the Review</b> | (Continued) |
|-----------------------------|----------------------------|-------------------------------|-------------|
|-----------------------------|----------------------------|-------------------------------|-------------|

Continued on the next page

of control and feeling inner ambivalence.

completing treatment.

Uncertainty about living with lung cancer and

progression of the disease was frequently brought

tients. The impact of uncertainty was greater after

to the follow-up consultation sessions by the pa-

the context of severe

To explore the experi-

ence of patients with

lung cancer attending

routine follow-up

cancer

Sandeman &

Wells, 2011

(United

Kingdom)

| TABLE 2. Characteristics of Qualitative Studies Included in the Review (Continued) |  |   |   |  |
|--|--|---|---|--|
| Study  | Aim(s)   | Sample and Design   | Results   |  |
| Sharf et al.,<br>2005<br>(United<br>States)  | To explore the reasons<br>why patients decline<br>doctors' recommenda-<br>tions for further diag-<br>nosis or treatment for<br>lung cancer | Grounded theory study with<br>nine patients with non-small<br>cell lung cancer aged 48–80<br>years  | Decisions made by the patients served as strate-<br>gies for reducing, maintaining, and increasing un-<br>certainty. Management of uncertainty was a hard<br>task once the assessment and cancer outcomes<br>and treatment recommendations were conflicting.<br>A small number of participants chose to live with<br>uncertainty as a way of maintaining optimism.  |  |
| Truant &<br>Bottorff,<br>1999<br>(Canada)  | To explore the process<br>of decision making in<br>women with breast<br>cancer related to us-<br>ing complementary<br>therapies            | Grounded theory study with<br>16 patients with breast can-<br>cer from early diagnosis to<br>palliative care treated with<br>surgery and adjuvant therapy<br>aged 39–71 years   | Uncertainty about the effectiveness of traditional treatment modalities served as the main reason for using complementary therapy at two distinct points across the breast cancer trajectory: (a) in the time period between diagnosis and surgery and (b) at the time of diagnosis of cancer recurrence. Uncertainty and feeling loss of control over life and future were experienced simultaneously. Complementary therapy was used by patients to maintain hope and reduce uncertainty.                                   |  |
| Winterling<br>et al., 2004<br>(Sweden)   | To explore the percep-<br>tion of change in life<br>among patients newly<br>diagnosed with an<br>advanced gastrointes-<br>tinal cancer     | Phenomenologic study with<br>14 patients with advanced<br>colorectal, gastric, pancre-<br>atic, and biliary cancers<br>treated with palliative care<br>(64%) aged a median of 67<br>years (range = 52–80) (50%<br>female) | Uncertainty was a category of mental change<br>experienced by patients receiving a diagnosis<br>of advanced cancer. Perceived uncertainty was<br>related to not knowing what would happen, how<br>the illness would develop, for how long the patient<br>would live, what the physical consequences of the<br>disease would be, and what would happen at the<br>end of life and after the patient's death. Patients<br>receiving radiation therapy were uncertain about<br>the side effects and effectiveness of the therapy. |  |
| Worster &<br>Holmes,<br>2008<br>(United<br>Kingdom)                                | To enhance under-<br>standing of patients<br>experience postdis-<br>charge for colorectal<br>surgery                                       | Phenomenologic study with<br>20 patients with colorectal<br>cancer treated with surgery<br>aged 50–82 years (50%<br>female)   | Diagnosis of cancer provoked uncertainty for pa-<br>tients. After learning about the diagnosis, patients'<br>questions and uncertainties should be addressed<br>by physicians through providing related informa-<br>tion.   |  |

CAM-complementary and alternative medicine; CML-chronic myeloid leukemia; QOL-quality of life; TKI-tyrosine kinase inhibitor

**Temporal pattern of uncertainty:** Feelings of uncertainty peaked at certain points in time, including the time of initial diagnosis (Worster & Holmes, 2008), after completing treatment (Sandeman & Wells, 2011), at periodic medical check-ups, and at follow-up visits (Oliffe et al., 2009; Pascal & Endacott, 2010).

**Treatment decision making:** Treatment decision making was a unique state of uncertainty predominantly experienced by older adults with prostate cancer (Bailey, Wallace, & Mishel, 2007; Denberg, Melhado, & Steiner, 2006; Oliffe et al., 2009). The main reason was the multiple therapeutic options available for localized prostate cancer in older adults with no convincing evidence to inform the choice of optimum treatment to prolong life (Bailey et al., 2007; Oliffe et al., 2009). Active treatments, either surgical or nonsurgical, could offer the potential for cure. However, these were associated with significant risks and negative consequences (Berry et al., 2003; BillAxelson et al., 2005; Steineck et al., 2002). Nonactive treatments (watchful waiting and active surveillance) were described as reasonable alternatives to manage indolent prostate cancer but were linked to a sense of living with untreated cancer (Hedestig, Sandman, & Widmark, 2003) and delay in treatment (Denberg et al., 2006). As such, constant uncertainty about the best possible treatment was a common experience among older adults with prostate cancer.

**Emotional well-being:** Uncertainty was commonly linked to undesirable emotions, such as persisting threat, fear and worry (Hedestig et al., 2003), powerlessness and hopelessness (Sand, Strang, & Milberg, 2008), anxiety (Berterö et al., 2008; Guilhot et al., 2013), insecurity (Arber & Spencer, 2013; Larsson et al., 2007), and vulnerability (Larsson et al., 2007). In addition, uncertainty was identified as an essential aspect of controllability (Kidd, 2014). Loss of control and uncertainty were described as concurrent unpleasant feelings across the cancer trajectory (Arber & Spencer, 2013; Halldórsdóttir & Hamrin, 1996; Kidd, 2014; Klafke, Eliott, Olver, & Wittert, 2014; Saeteren et al., 2011; Truant & Bottorff, 1999). Likewise, less engagement in self-management activities (Kidd, 2014), difficulty in defining roles and maintaining family relationships (Gardner, 2008), and trouble with planning for the future (Andreassen et al., 2006) were reported as the most important consequences of uncertainty. The perception of uncertainty in those undergoing active surveillance and watchful waiting for prostate cancer was reported to contribute to desire for surgery as a rapid treatment (Denberg et al., 2006).

Coping with uncertainty: A wide range of coping strategies were reported to deal with uncertainty and loss of control. Gaining knowledge about cancer and health (Jonsson et al., 2010), cancer-related limitations, and possible events in the future (Clayton, Butow, Arnold, & Tattersall, 2005; Worster & Holmes, 2008) was a commonly used strategy. Complementary and alternative medicine (Guilhot et al., 2013; Klafke et al., 2014; Truant & Bottorff, 1999), support groups, and palliative care (Arber & Spencer, 2013) were also used frequently to make sense of cancer-related events and situations (Gardner, 2008). Further coping strategies included denying, minimizing, or redefining the cancer; keeping undesirable feelings out of mind; avoiding information and relying on physicians for treatment decision making; living a normal life; faith and prayer (Bailey et al., 2007; Oliffe et al., 2009); planning important activities for the future; having a goal to look forward to and something meaningful ahead (Karlsson et al., 2014); and maintaining hope and optimism (Gardner, 2008).

## **Discussion**

The results of this review show that uncertainty is a common experience among older adults with cancer. Uncertainty persists across the cancer trajectory, affects emotional well-being, and activates a range of coping strategies. The reviewed studies identified a number of demographic and clinical antecedents of uncertainty and described psychosocial outcomes of uncertainty.

Evidence on demographic and clinical antecedents of uncertainty was mixed and limited. Some studies reported a positive association between age, education levels, and uncertainty (Galloway & Graydon, 1996; Sammarco, 2003), whereas others found negative or nonsignificant relationships (Galloway & Graydon, 1996; Sammarco, 2009; Wallace, 2005). Several studies reported a significant relationship between time since diagnosis and uncertainty (Parker et al., 2015), but others found no association (Parker et al., 2013;

#### **Not Knowing**

- Cancer state and progression because of poor or ambiguous test results (Bailey, Wallace, & Mishel, 2007; Guilhot et al., 2013)
- Treatment schedule, complexity (Arber & Spencer, 2013), and effectiveness (Gardner, 2008)
- Drug resistance, side effects, and adverse events (Guilhot et al., 2013)
- Meaning of cancer-related events because of limitations in access to therapy (Guilhot et al., 2013)
- Daily life activities and social integration (Grimsbø et al., 2012; Saeteren et al., 2011)
- The extent to which the physicians can be trusted (Saeteren et al., 2011)
- Rate of physical decline, disease progression (Arber & Spencer, 2013; Guilhot et al., 2013; Mazor et al., 2013), spread (Grimsbø et al., 2012), metastasis, and recurrence (Pascal & Endacott, 2010)

#### Waiting

- · Waiting for diagnosis and treatment (Larsson et al., 2007)
- Delay in providing information and instructions (Mazor et al., 2013)
- Delay in treatment (Denberg et al., 2006; Kuzari et al., 2013)

#### **Unpredictable Future**

- Length of life (Jonsson et al., 2010), thinking about the future, and planning for the future (Grimsbø et al., 2012; Saeteren et al., 2011)
- Possibility of death (Gardner, 2008; Grimsbø et al., 2012), end-of-life and afterlife events (Winterling et al., 2004)

FIGURE 2. Major Themes and Subthemes Reported in the Original Studies

Wallace, 2005). The conflicting results may be because of the methodologic limitations of the studies, including frequent non-probability sampling, small sample sizes, and potential bias in sample selection. In addition, several demographic and clinical factors were included in only one study. These factors included sex (Galloway & Graydon, 1996), length of hospitalization (Galloway & Graydon, 1996), stage of cancer (Lien et al., 2009), symptom pattern (Wallace, 2005), symptom distress (Galloway & Graydon, 1996), and comorbidity (Sammarco, 2003). Therefore, it is unclear which demographic and clinical variables should be taken into consideration in future research studies and planning uncertainty management interventions for older adults with cancer.

The conflicting results with regard to the relationships between demographic (age and education) and clinical characteristics (time since diagnosis) and uncertainty in older adult cancer survivors are in line with the results of similar studies with younger adults with cancer (Jeon, Choi, Lee, & Noh, 2016; Kim, Lee, & Lee, 2012; Lin et al., 2013). Evidence suggests that the role and significance of demographic and clinical antecedents of uncertainty might vary across the cancer trajectory (Kim et al., 2012). However, the results of studies with younger cancer survivors may not be directly comparable to the findings of studies with older adults because the type and nature of stress, appraisal process, and coping efforts may change with age (Aldwin, Sutton, Chiara, & Spiro, 1996; Diehl, Coyle, & Labouvie-Vief, 1996; Molton et al., 2008; Moos, Brennan, Schutte, & Moos, 2006).

A solid understanding of antecedents of uncertainty is important because these factors may be essential in structuring a cognitive schema and decreasing uncertainty (Mishel, 1988). Therefore, studies of higher methodologic quality with populations other than Caucasian patients with breast and prostate cancers, who had been overrepresented in the reviewed studies, are warranted to develop a better understanding of the contributing role of demographic and clinical factors to uncertainty in older adults with cancer.

Despite the discrepancy in the literature regarding the antecedents of uncertainty, results on the outcomes of uncertainty were converging. A significant negative association between uncertainty and QOL was consistently supported in the reviewed studies (Parker et al., 2013, 2015; Sammarco, 2003, 2009; Wallace, 2003). In addition, the negative relationship between uncertainty and QOL has been extensively supported in studies with younger cancer populations (McCorkle et al., 2009; Sammarco & Konecny, 2008; Somjaivong, Thanasilp, Preechawong, & Sloan, 2011; Suzuki, 2012; Wonghongkul, Dechaprom, Phumivichuvate, & Losawatkul, 2006). However, it is important to note that the sample sizes of some studies with older adults were too small for the applied statistical analyses, and few studies controlled for potential confounding variables, such as comorbidities, stage of cancer, type and intent of treatment, and cancer prognosis. Therefore, it is unknown whether uncertainty is an independent factor in predicting QOL in older adult cancer survivors. Future research should address this gap and explore how and to what extent uncertainty can affect QOL.

Positive relationships between uncertainty and anxiety and depression were reported in the reviewed studies (Galfin & Watkins, 2012; Lien et al., 2009). However, these results may not be generalizable because the samples were limited to those undergoing surgery or receiving palliative care. There is a large body of evidence explaining how uncertainty can provoke anxiety and depression (Baas, De Dreu, & Nijstad, 2011; Dugas, Gagnon, Ladouceur, & Freeston, 1998; Fresco, Frankel, Mennin, Turk, & Heimberg, 2002). One explanation is that uncertainty about the occurrence or nonoccurrence of adverse events can intensify and prolong emotional reactions (Grupe & Nitschke, 2011; Nitschke et al., 2009; Wilson, Centerbar, Kermer, & Gilbert, 2005) and cause people to overestimate negative outcomes (Grupe & Nitschke, 2011). Individuals dealing with un-

# **Knowledge Translation**

- Uncertainty is linked to negative emotions, such as anxiety and depression, in older adult cancer survivors.
- Uncertainty adversely affects quality of life, with higher levels of uncertainty associated with poorer quality of life.
- Uncertainty management interventions, such as cognitive reframing, can help cancer survivors change their view of illness and related uncertainties, and may enable them to integrate uncertainty into their lives to enhance quality of life and emotional well-being.

certain situations may tend to regain a sense of order and control through engagement in ruminative thinking characterized by repetitive, monotonous, negative, and self-focused thoughts (Baas, de Dreu, & Nijstad, 2012; Baas et al., 2011; Watkins, Moberly, & Moulds, 2008; Segerstrom, Tsao, Alden, & Craske, 2000). Ruminative thinking has been suggested as the core construct of anxiety and depression disorder (Baas et al., 2011; Fresco et al., 2002). Because of the prevalence and significance of anxiety and depression (Alici, Weiss, Holland, Nelson, & Roth, 2011; Fann, Fan, & Unützer, 2009; Weiss Wiesel et al., 2015) in older adult cancer survivors and the substantial impact of emotional distress on survival rate and QOL in this population, more research is needed to explain and clarify the association between uncertainty and emotional distress in older adults with cancer.

The reviewed intervention studies did not provide generalizable findings related to management of uncertainty because of methodologic weaknesses, small and nonrandomized samples, and lack of control groups. No randomized, controlled trials have been conducted. Consequently, little is known about the impact of uncertainty management programs on important health outcomes in older adults with cancer. This area should be targeted with intervention studies.

Findings of qualitative studies showed that uncertainty was commonly experienced by older adult cancer survivors regardless of the type or stage of cancer. More importantly, uncertainty and controllability were strongly linked, with increased perception of uncertainty associated with a greater sense of loss of control. Participants described a wide range of strategies to manage uncertainty and improve the sense of controllability.

To the authors' knowledge, this is the first review on the concept of uncertainty in older adults with cancer. The significant strength of this review lies in using a systematic approach to search multiple databases and analyze and synthesize data, and including studies of quantitative and qualitative designs. However, this review has limitations. First, the conducted search may not have been exhaustive despite employing comprehensive search strategies, including multiple databases, and consulting with a librarian. Second, as in any review, the results are limited by the methodologic quality of the included studies.

# Implications for Nursing

Uncertainty about cancer diagnosis, treatment, and prognosis is a common experience in older adult cancer survivors (Arber & Spencer, 2013; Guilhot et al., 2013). Uncertainty may result in anxiety, depression, and poorer QOL in this population (Lien et al., 2009; Parker et al., 2013). Cancer-related uncertainty is related partly to lack of knowledge about the diagnostic and therapeutic procedures (Arber & Spencer, 2013) and partly to the unpredictable future of living with cancer (Grimsbø et al., 2012). Nurses are in a unique position to assess the source and extent of uncertainty in older adult cancer survivors and provide them with appropriate information, education, and support to cope with uncertainty. Similarly, nurses need to be aware of the potential role of uncertainty in provoking emotional distress and should be able to identify patients who are at higher risk for developing anxiety and depression under conditions of uncertainty. Nurses can use therapeutic communication to encourage patients to express their feelings and adopt the best strategies to deal with negative emotions. Communication techniques and strategies can help nurses establish and maintain therapeutic communication (Bramhall, 2014). Nurses can create a trusting environment by respecting patients in the context of their age and culture, applying active listening techniques, showing empathy for patients' concerns, and explaining procedures in a way that patients can understand (Bramhall, 2014; Wooten, 2013). Likewise, nurses should target this area with intervention studies and randomized, controlled trials to examine which interventions are feasible, effective, and efficient to manage uncertainty in this population. Nurses can also play a role in enhancing QOL in older adults with cancer through designing, implementing, and evaluating uncertainty management interventions.

# Conclusion

Uncertainty is a common and persistent experience in older adults with cancer that can affect their psychosocial well-being and QOL. However, existing evidence is not sufficient to develop a solid understanding about the antecedents and outcomes of uncertainty in this population. Further studies are required to identify the most essential factors contributing to uncertainty. In addition, large-scale, high-quality studies are needed to explore the mechanism underpinning the effect of uncertainty on QOL and emotional distress.

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