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THE EXPERIENCE OF BEING AWARE OF DISEASE STATUS  
IN WOMEN WITH RECURRENT OVARIAN  
CANCER: A PHENOMENOLOGICAL  
STUDY

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## **Dedication**

This work is dedicated to all my patients and to the twelve women who made this study possible.

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Where does one even begin to thank all of those who have supported and guided me throughout this process? I had a sense when I began this journey how difficult it would be on me, I had no idea how much support I would need in order to be successful. None of this would have been possible without the wisdom of Dr. Mei R. Fu. Her dedication to my scholarship, professional and personal development is unparalleled. I am eternally grateful to all of your work on my behalf. You pushed me to be the best, and I am so thankful you did! I would also like to thank the two Allison's! Dr. Squires and Dr. Applebaum have been continued source of assistance and encouragement. I am so thankful to have such brilliant, strong and caring women on my committee. I would also like to thank Dr. Janet Van Cleave who has always been a cheerleader for me and her guidance has been an invaluable to me. Dr. Judith Haber, thank you for your time and feedback.

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## **ABSTRACT**

**Background:** In the United States, each year about 22,440 women are diagnosed with ovarian cancer, the deadliest gynecological cancer - with an estimated 14,080 deaths each year. Patients with recurrent ovarian cancer have more options today due to advances in treatments, and specifically, with the advent of immunotherapies. Many have to make many treatment decisions throughout the disease trajectory and awareness of disease status is one of the factors of the treatment decision making process in the ovarian cancer population. To date the literature has generally conceptualized and operationalized awareness of disease status in cancer patients from the health care provider's perspective. It is not well understood, however, as to how women with ovarian cancer perceive their disease and their process of treatment decision-making.

**Purpose:** The purpose of this phenomenological study was to understand the lived experience of women with recurrent ovarian cancer and how they understood their disease and made their treatment decisions.

**Methods:** Two in-depth interviews were conducted with 12 women over a 15 month period, with the digitally recorded interviews lasting approximately 60 minutes. Each participant had recurrent ovarian cancer and had received multiple chemotherapy treatments. Interviews focused on patients' understanding of their disease, factors that impacted their understanding, how patients participated in treatment decisions as well as the impact of being diagnosed with, and in treatment for, recurrent ovarian cancer. After professional transcription of the recordings, Colaizzi's method of phenomenological reduction guided the data analysis.

**Results:** Three themes were intuited to describe the phenomenon of being aware of disease status: 1) Perceiving recurrent ovarian cancer as a chronic illness; 2) Perceived inability to make treatment decisions; and, 3) Enduring emotional distress. Each of these twelve women had

different personal journeys of being diagnosed with and treated for recurrent ovarian cancer. Yet there were shared essential experiences of how they understood their disease status, the process of making treatment decisions and the emotional distress of managing recurrent ovarian cancer. Within the context that more treatments were available for managing recurrent ovarian cancer, participants did not associate their disease with imminent death and instead they viewed their disease as a chronic illness and focused on “stabilizing” their disease with available treatments.

**Conclusions and Implications:** The findings of this study revealed how twelve women, with recurrent ovarian cancer, experienced being aware of their disease status. The participants conceptualized recurrent ovarian cancer as a chronic disease in the context of having more treatment options available to them. They perceived an inability to make treatment decisions due to lack of information and professional qualifications, which resulted in enduring emotional distress. These results provided insight into how patients with recurrent ovarian cancer understand their disease. In addition, it highlights the difficulty patients may have making treatment decisions. Future research should replicate the study to confirm the persistence of the themes for racially, ethnically, and religiously diverse patient samples and to improve understanding of the role of care contexts in shaping awareness of disease status and decision making processes of patients. Current findings may also be useful for informing intervention design.

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**Chapter 1 – A Proposal for::**

The Experience of Being Aware of Disease Status in Patients with Recurrent Ovarian  
Cancer: A Phenomenological Study

Catherine S. Finlayson

## **Background and Significance**

In 2014, 1.6 million Americans were diagnosed with cancer. Over 60% of those diagnosed will reach five-year survival due to newer and more effective treatment choices for patients with cancer (NCI, 2014). With the advent of newer and more effective cancer treatments, patients with metastatic cancer now have the opportunity to make more decisions about life prolonging and life improving treatments. Patients' awareness of disease status has emerged as an important factor in the process of making treatment and end-of-life decisions (Alaka Ray et al., 2006; Baek et al., 2011; Donovan et al., 2002; Weeks et al., 1998; Yun et al., 2011), but this phenomenon is not well understood overall.

In the United States, each year about 21,980 women are diagnosed with ovarian cancer, the deadliest gynecological cancer - with an estimated 14,270 deaths each year (ACS, 2014; Ozols, 2005). The majority of women diagnosed with ovarian cancer present with advanced-stage disease (stage III and IV), due to lack of effective early screening measures (Ozols, 2005). The first line treatments for advanced ovarian cancer are surgical cytoreduction and platinum- and taxane-based chemotherapy (Ozols, 2005). Recent advances in ovarian cancer treatment provide more choices even for patients who fail the first line of treatment or have recurrent disease. After receiving first line treatment, however, approximately 75% of advanced-stage ovarian cancer patients will have disease recurrence within five years, which will ultimately cause their death (Ozols, 2005). These treatments may negatively impact quality of life with minimal effect of the progression of disease (Donovan, et al, 2002). Therefore, recurrent ovarian cancer patients with progression of disease through first line treatments have to decide about treatment and quality of life.

It is unknown whether women with recurrent ovarian cancer are aware of their disease

status and its potential impact on treatment decisions. Thus it is important to understand the lived experience of being aware of disease status among women with recurrent ovarian cancer.

To understand this phenomenon, this proposal establishes a plan to conduct research with ovarian cancer patients in order to improve our understanding out how their awareness of disease status influences their treatment decision making processes. Chapter 1 provides the justification for the study, provides a detailed review of the relevant literature, and briefly discusses the three research papers that form the exploration of this phenomenon. Chapters 2 to 4 represent each of the studies completed for this dissertation and includes the journals where, at the time of submission, they are currently under review. Chapter 5 synthesizes the findings from the three studies and makes recommendations for developing the science around understanding awareness of disease status in ovarian cancer patients.

### **Review of the Literature: Awareness of Disease Status in Adult Cancer Patients**

A systematic review demonstrated that the current scientific literature lacks consistent conceptual or operational definitions for the concept of patients' awareness of disease status nor were there valid or reliable instruments to measure patients' awareness of disease status (Finlayson, 2014). Therefore, a broader search was needed to understand the concept of awareness of disease status in adult cancer patients.

A keyword search and terms were generated based on the concept of awareness of disease status, prognosis, diagnosis, and cancer. Subsequently, additional search terms were identified using the MeSH (Medical Subject Heading) database. In addition, multiple consultations with the health librarian were conducted to ensure the reliability, thoroughness, and accuracy of key search terms.

The final keywords used were: awareness, perception, truth disclosure, diagnosis,

prognosis, terminal illness, status, neoplasm and metastasis. Using various combinations of the key terms, the following databases were searched: PubMed, CINAHL, Embase, PsycINFO, Web of Science, and SCOPUS. All searches were limited to English language and there was no date restriction in order to understand the evolution of the phenomenon. Also, searches were limited to adults because the issues surrounding childhood cancer are different from the adult patient.

The results from the above search method were 5,436 articles. An additional 23 articles were identified through ancestry searching. From those 1,185 duplicate articles were removed, 4,274 articles were screened. Another 4,080 articles were removed due to lack of relevance to the topic, leaving 194 articles. Of the 194 studies, 47 focused on awareness of disease status or a related topic in the cancer patient and thus were included in this review.

Articles were analyzed to determine how authors described, defined, used, and conceptualized “awareness of disease status” in their studies. Studies were evaluated for their strengths and weaknesses to determine the state of the science around awareness of disease status in adult cancer patients.

### **Summary of the Literature Review - Awareness of Disease Status in Adult Cancer Patients**

Different definitions of awareness of disease status are used in the literature (Andrucciolo et al, 2007; Chochinov, et al., 2000; Corli et al, 2009; Germino & McCorckle, 1985). A definition often used to define “awareness of disease status” is “the patient’s real understanding and level of consciousness about the type of disease, the prognosis, and life expectations” (Corli et al., 2009, p. 355). The operational definitions of awareness of disease status varied from whether the patient: understands his or her illness (Chochinov et al., 2000), has been told their diagnosis by their health care providers (Lheurex et al., 2003; Montazeri, 2004), can say the word “cancer” or “tumor” (Chandra et al., 1998; Iconomou et al., 2002; Montazeri et al., 2009)

or can estimate life expectancy (Weeks, et al., 1998). Researchers argue that disclosure of diagnosis and prognostic information does not necessarily mean that the patients are automatically aware of their disease status (Chochinov et al., 2000; Hoff & Hermerén, 2008, Temel et al., 2011).

Since researchers have defined awareness of disease status differently, consequently; they have different operational definitions of the concept. For example, Chandra et al., determined patients had awareness of disease status if the participants would use the terms “malignancy” and “cancer” in the interviews (1998) and Weeks, et al. operationalized awareness of disease status if a patient could successfully estimate their chances of survival in six months (1998). Based on these two examples of operational definitions, the researchers measured the concept of awareness of disease status differently. Subsequently, no reliable or valid instrument was identified to measure awareness of disease status in any of the remaining forty-five articles. This is a limitation of the literature where the concept of awareness of disease status has yet to be quantitatively measured. These findings were consistent with another systematic review of prognostic awareness in advanced cancer patients which reported that there was a lack of reliable and valid instrument to quantitatively measure the concept as a construct (Applebaum et al., 2013).

Regardless of the aforementioned findings, there are still some important findings from analysis of the literature. Notably, research reveals that that 44-77% of cancer patients are unaware of their disease status (Alaka Ray et al., 2006; Atesci et al., 2004; Baek et al., 2011; Bozcuk et al., 2002; Chandra et al, 1998; Fan et al., 2011; Iconomou et al., 2002; Lee et al., 2011; Montazeri et al., 2004; Roll et al., 2009; Tang et al, 2008; Yun et al., 2011). Other studies reported that among patients already in hospice, 62% of patients had no prognostic awareness

(Andruccioli et al., 2007) and 58% of patients receiving palliative care were not aware of their disease status (Corli et al., 2009). These results highlight that patients often do not have awareness of their disease status, which is problematic when patients must make treatment decisions that may affect their quality of life.

Studies further identified communication between patient and health care professionals as one of the most important factors that affect patients' disease awareness status (Andruccioli et al, 2009; Clarvino et al, 2003; Corli et al, 2009; Hoff & Hermerén, 2008). In particular, many studies conducted in Asia and Eastern Europe discuss how it is common practice in these societies for health care providers to not directly communicate with the patients, but to communicate instead with the patient's family (Atesci et al., 2004, Baek et al., 2012, Bozcuk et al., 2002, Fan et al., 2011, Kao et al., 2013, Lee et al., 2013, Leung et al., 2006, Montazeri et al., 2009, Roll et al., 2009, Tang, 2006) . If the patient is not present for conversations about plans of care then it would logically result that the individual would not be aware of their disease status. Other factors that influence patients' awareness of disease status include: patients' denial; coping mechanisms; lack of understanding of medical terminology; culture; education; age; race (Atesci et al., 2004; Chandra et al., 1998; Chochinov et al., 2000; Corli et al., 2009; Germino & McCorkle, 1985; Helft, et al., 2003; Hoff et al., 2008;).

Further complicating the issue of awareness of disease status is the lack of in-depth analyses examining the experience of having a cancer like ovarian cancer, which has strong potential for metastasis. Before a poorly understood phenomenon can be quantified, it is vital to enhance our understanding of the experiences of those undergoing it. As a result, there is much to learn about how patients with metastatic cancer conceptualize and experience awareness of disease status. Therefore, a qualitative study would aid our understanding of the experience of

patients with cancers that could become metastatic.

### **Purpose of the Study and Research Questions**

The primary purpose of this phenomenological study is to understand the lived experience of being aware of disease status among women with recurrent ovarian cancer. This study seeks to answer the following questions: (1) What is “disease status” from the perspective of patients with recurrent ovarian cancer?; (2) What is “being aware of disease status” from the perspective of patients with recurrent ovarian cancer? and, (3) How does “being aware of disease status” shape patients’ life and treatment decisions?

Findings from the proposed study will contribute to current knowledge and science in two distinct ways. First, by exploring how women with recurrent ovarian cancer experience and conceptualize the concept of awareness of disease status. Second, it will contribute to the science by shedding light on how the participant’s awareness of disease status influences their treatment and end-of-life decision.

### **Methods**

The format of this dissertation consisted of three papers that aimed to examine different aspects of the phenomenon of awareness of disease status in ovarian cancer patients. The first paper is a systematic review of the literature. The reason to complete this paper was the initial investigation into the phenomenon. The second paper evolved from the initial literature review and attempts to improve the conceptualization of “awareness of disease status” and provide operational definitions that can guide future research studies. The final paper consists of the main research project for this dissertation, a phenomenological study of adult ovarian cancer patients’ awareness of disease status.

Qualitative research approaches vary and not all approaches are appropriate to answer

the research questions of the proposed study. The literature on awareness of disease status in cancer patients has demonstrated that there is no consistent operational definition for the phenomenon. If there is no consistent operational definition, then the science is far off from understanding the experience of having awareness of disease status. Therefore, to advance the science surrounding awareness of disease status in cancer patients, there needs to be a more in-depth understanding of the phenomenon. Phenomenology is the best approach for this proposed study because the primary purpose is to gain an in-depth understanding of a phenomenon (Holloway & Wheeler, 2010; Nelms, 2015; Porter, 1998; Wojnar & Swanson, 2007). Other methodologies such as narrative analysis, focus groups, grounded theory, etc., would not provide the methodological framework necessary to gain the in-depth understanding necessary to answer the research questions. Narrative analysis' purpose is to tell the "story" of the participants using various different forms of analysis like thematic, structural, dialogic, and visual techniques to capture individual experiences (Holloway & Wheeler, 2010). Narrative analysis is not an appropriate methodology for the proposed study because the purpose is not to tell the stories of the participants, but to gain an in-depth understanding of their lived individual experience.

Focus groups, by contrast, are a data collection method used to gain an understanding of a phenomenon by having a group interview for "eliciting ideas, thoughts and perceptions about a specific topic" (Holloway & Wheeler, 2010, p.125). Given the sensitive nature of this topic and the limitations of focus groups—including one or two persons dominating the conversation therefore not allowing for each individual experience to come out—would limit the richness of the data. In addition, other members of the group may influence the other participants, resulting description of an experience biased by others in the group (Holloway & Wheeler, 2010). An additional consideration is the nature of the topic being discussed is a private and personal

experience and it remains unknown if the group dynamic would bring more stress to the population.

Due to the lack of theories about awareness of disease status and the impact on patient decision making, grounded theory may seem like another plausible approach for this study. However, the purpose of grounded theory methodology is “the systematic generation of a theory from the data collected by the researchers” (Holloway & Wheeler, 2010, p.175). This methodology would not be appropriate because the purpose of the proposed study is to have a deeper understanding of the phenomenon which may help generate a theory in the future.

### **Phenomenology - Philosophical Underpinnings**

Phenomenology is the result of a philosophical movement which arose in early twentieth century Germany. Edmund Husserl is considered by many as the founding father of phenomenology (Nelms, 2015; Wojnar & Swanson, 2007). Husserl’s philosophical underpinnings are that reality is experiential, the experience is intentional, and the experience can be described (Husserl, 1931). Husserl’s brand of phenomenology became known as descriptive phenomenology (Porter, 1998). A primary goal of the researcher conducting the phenomenological study is “to overcome personal biases, which stand in the way of achieving the state of pure consciousness” (Wojnar & Swanson, 2007). A core strategy to overcome ones “personal bias” is through the process of bracketing. During the process of bracketing, Husserl proposes that one can put aside ones preconceptions to ensure that the approach to the phenomenon of interest remain objective (Nelms, 2015; Wojnar & Swanson, 2007).

A fellow colleague and student of Husserl in Germany, Martin Heidegger, was also a phenomenologist, but his philosophical approach differed in many ways from Husserl’s phenomenology. Heidegger thought that human experience could not be removed from the

context of their environment (Nelms, 2015; Wojnar & Swanson, 2007). As a result, Heidegger did not think that it was possible for an individual to “bracket” him or herself completely, therefore, the notion of interpretative phenomenology (Nelms, 2015; Wojnar & Swanson, 2007). However, not all phenomenological methods use the same approach, therefore, one must choose which approach is consistent with their methodological beliefs and scientific aims.

### **Rationale for Colazzi’s Method**

The process of choosing a phenomenological method should not be arbitrary; the researcher must acknowledge their own perspectives and worldviews. I am an oncology nurse with over a decade of experience caring for cancer patients in acute care settings. I also have a masters degree in public policy, an education which allows me to see the constant intersections of policy in health care and the impact on patients. These aspects of my identity have created a worldview that understands the inherent subjectivity of human beings. In essence, the following statement summarizes my worldview: “subjectivity operates during the entire research process” (Peshkin, 1998, p.17). In the forefront of my mind at all times is the question: Is it possible for a researcher to be completely objective during the data collection and analysis process?

In consideration of these aspects of my identity and worldview, a pure Husserlian approach to this study would not fit. Therefore, I needed a phenomenological approach that would account for researcher subjectivity, while allowing for the participants’ experience to dominate the research.

For this reason, Colazzi’s method was most appropriate for me as I undertook this work. His methodology is based on this notion that the human experience cannot be objectively measured and that no researcher’s approach to a research project is without preconceived notions and ideas. In his 1978 essay he asks the question “How can human experience be

investigated objectively if the objectivity has traditionally meant the elimination of human experience?” (Colaizzi). Through the delineation he states: “Simply stated, experience is there, for all of us, and it cannot be objectively eliminated” (Colaizzi, 1978).

Another philosophical foundation for Colaizzi’s phenomenological method is his belief that research can objectify human experiences in order to measure them. Colaizzi further purports that by doing this, that the individual experience is lost. Therefore, “objectivity resides wherever experience is not” (p. 51, 1978). He claims that this is done through the use of operational definitions. Colaizzi defines operation definitions as “a means of defining a psychological phenomenon by having as little recourse as possible to human experience, and by designating that phenomenon strictly in terms of measurable, observable, and readily duplicable observations” (p.51, 1978). Once there is an operational definition, then it can be measured, understood, and compared. This approach helps provide further justification for paper 2, which will create operational definitions.

### **Preliminary Work**

To prepare to undertake this study, the preliminary work completed consisted of research methods coursework and a pilot study of the interview guide. Since the initial review of the literature revealed that there was no reliable or valid instrument for my phenomenon of interest, I was lead toward qualitative methods . I spent my final year of course work studying qualitative methodologies. I took two courses titled Approaches to Qualitative Inquiry and Case Study and Ethnographic Inquiry. In addition, I took an independent study practicum focused on Phenomenology.

During my journey towards an understanding of qualitative research and phenomenology I learned that I needed to transform my methodological assumptions about what can be known

and how it can be known. Quantitative research assumes that there are universal truths and that if one person performs a study, then the results should be the same even in a different population. That is the opposite for qualitative research; the underlying assumption is that there are no universal truths, and, therefore, no specific hypothesis to test. I discovered that I think that all persons come from a specific worldview, which is shaped by my culture and life experiences. In addition, it is impossible for persons to completely remove themselves from the context of their lives.

During my Case Study/Ethnography class (IRB Exempt Research X14-013), I conducted a pilot study of my interview guide (also known as a qualitative instrument). I interviewed three women with stage IV ovarian cancer using an interview guide and techniques learned in the class and drawing from previous coursework. Each interview was tape recorded, transcribed, and analyzed. The results (which cannot be discussed here as per IRB exemption) showed the women's understanding of their disease and decision-making was so vastly different between them. After this preliminary study there was no doubt that the topic is appropriate for phenomenological methodology and that the lived experiences of these women would provide rich data for analysis. Nonetheless, there were many important lessons that I learned in the preliminary work. The biggest was that all of these women were towards the end of their disease trajectory. When developing my data collection protocols, I realized that follow-up interviews and member checking would not be possible because the participants might die or could be too sick to participate further. Their unpredictable health status refined my inclusion criteria for participants to have a life expectancy of six months to one year. In addition, data transcription and analysis of the pilot data brought three important lessons for my interview techniques: 1) the importance of allowing the participant to speak without interrupting them; 2) using prompts are

extremely important to allow the participant to speak about all the details regarding the experience; and, 3) transcribing is more difficult than it seems, to ensure the accuracy of the participants words takes a trained ear and patience.

### **Participant Population**

The sample size for paper 3 was estimated to be 10-14 participants, but was ultimately determined by data saturation. Data saturation occurs when “no new concepts or dimensions for categories can be identified which are important for the study” (Holloway & Wheeler, 2010, p.145). Therefore, enrollment ended once new themes emerged from interviewing additional participants.

### **Sampling & Criteria**

Purposive sampling is essential in phenomenological research. In order to capture the experience of the phenomenon under investigation, participants are selected based on “experience with the investigated topic and articulateness suffice as criteria for selecting subjects” (Colaizzi, p. 58, 1978). Inclusion criteria for the study’s participants were: 1) diagnosed with recurrent ovarian cancer; 2) already received two chemotherapy regimens; 3) are/were receiving late line chemotherapy or are transitioning to end of life care; 4) able to communicate effectively in English; 5) patients oriented to person, place, and time; and, 5) and able to physically/mentally withstand over an hour long interview.

### **Procedures**

The following paragraphs describe the procedures involved with conducting the main research study for this dissertation.

Preparation for Research. Prior to conducting data collection, the researcher must go through phenomenological reduction. Based on Colaizzi’s philosophical underpinnings, it is not

possible for a researcher to completely “bracket” oneself and look at the topic objectively (1978). By undertaking a specific research topic, a researcher is already coming from a specific perspective. Colaizzi thinks the first question should be “Why am I involved in this phenomenon” (p.55, 1978)? Based on my “presuppositions” about what the experiences of being aware of disease status in women with recurrent stage IV ovarian cancer, it will guide me in the development of my research questions and how I conduct my research.

I am involved in this phenomenon because I have been a nurse taking care of the patient population for over eight years. During that time I have worked with many women who have recurrent ovarian cancer (and many other types of cancers) and have struggled with awareness and decision-making. My work with these women sparked my interest in the phenomenon of awareness of disease status in cancer patients. Through my systematic review, concept analysis, and pilot project I have formed the following presuppositions about the phenomenon of awareness of disease status in women with recurrent ovarian cancer. First, this is an extremely complicated topic with many factors and the conventional knowledge is not adequate at this time to measure it quantitatively. Second, I expect that there will be differences among participants in how they describe their disease. However, I do believe that there are common experiences across cases that I will be able generate themes. Third, I think that awareness is a fluctuating phenomenon and that the experience that I capture with participant will most likely change and that I am only able to ascertain their experience at that specific point in time. Regardless of my subjectivity on the phenomenon, I will try to set aside these presuppositions to allow for the participant’s experience to come through.

Recruitment. Participants were patients of three attending physicians of the Gynecologic Medical Service at Memorial Sloan Kettering Cancer Center. Participants were identified by

physicians and nurses who thought they were well enough and willing to participate in the study. Initial approach of the prospective participant was through the physician or nurse. If the patient agreed to learn more about the study, their contact information was forwarded to the researcher for follow up.

Consent. IRB approval was granted from New York University and Memorial Sloan Kettering Cancer Center. Upon the IRB approval, recruitment began. Potential participants were explained all the details about the study, especially that participation in the study is absolutely voluntary and has no impact on the care they receive from the center. In addition, it was emphasized that all information will be confidential and no patient identifiers will be placed in any research documents. It was also explained to the potential participants that there might be an emotional discomfort during the interview and they have the choice not to participate in the study. If potential participants agree to participate in the study, then they will sign the written consent.

Data Collection. All interviews took place in a private location of the participants' choice to ensure the comfort of the participant, such as private office or private conference room. All interviews were digitally recorded to ensure accuracy of each participant's experience. A journal was kept after each interview to note observations. All interviews were professionally transcribed.

### **Data Analysis**

Colaizzi's method has seven steps for data analysis. These steps are not linear and the process of data analysis overlaps and repeats the steps defined below.

1. Read and re-read all the transcribed interviews, which Colaizzi terms protocols, "in order to make sense of them" (p.59, 1978).

2. Return to the original protocols and begin to extract significant statements. These are “phrases or sentences that directly pertain to the investigated phenomenon” (p.59, 1978).
3. After significant statements are extracted, then comes the process of giving meaning to the statements. Formulating meanings is when the researcher “must leap from what his subjects say to what they mean” (p.59, 1978). Colaizzi, notes that this is a “precarious” process, but necessary to provide greater meaning to the significant statements. The meaning given must never be too far away from what is stated in the original protocol.
4. Repeat steps 1-3 for each protocol, then the researcher can begin to create themes based off the formulated meanings. These themes are then compared to the original protocol to ensure that they can be validated by the data. This is done through the process of “asking whether there is anything contained in the original protocols that isn’t accounted for in the clusters of themes, and whether the clusters of themes propose anything which isn’t implied in the original protocols” (p.59, 1978).
5. Compile an “exhaustive description” of everything generated in steps 1-4.
6. Summarize the ‘exhaustive description” so that there is an identification of the “fundamental structure” of the phenomenon.
7. Validate the information by member checking. Going back to the participants and asking them if the findings match up with their experiences.

### **Establishing Trustworthiness**

Trustworthiness is “the ways we work to meet the criteria of validity, credibility, and believability of our research” (Harrison, 2001, p.323). First, the proposed study was approved by the IRB, to ensure protection of human subjects. Second, all participants consented to be interviewed, understanding that the interviews were digitally recorded and that no personal

health information would be disclosed. Third, reflection is very important to ensure trustworthiness. As a result, phenomenological reduction will be done by the researcher in order to understand her own subjectivity and how that shapes her interpretation of the data. Fourth, data reliability was demonstrated through the emergence of similar data in the first and second interviews.

### **Limitations**

There are limitations inherent in this approach. Deeper understanding is the aim, not generalizability. Meaning that the results of this study are only applicable to the population interviewed, one can not make general statements that all patient with recurrent ovarian cancer will have the same experience. For example, patients treated in different hospitals may have different perceptions regarding the phenomenon of being aware of disease. In addition, it will be difficult to know if the essences discovered in this study would be applicable to other people with other types of cancers.

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**Chapter 2:**  
The Impact of Patient's Awareness of Disease Status  
on Treatment Preferences and Quality of Life among Patients with Metastatic Cancer: A  
Systematic Review from 1997-2014.

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## **ABSTRACT**

**Introduction:** Advances in cancer treatment present challenges to patients with metastatic cancer who have to make treatment decisions in the face of newer and more effective treatments. Patients' awareness of disease status has been an important factor in making treatment choices. We conducted a systematic review of the published literature from 1997–2014 to evaluate the evidence of the impact of patients' awareness of disease status on treatment preferences and quality of life among patients with metastatic cancer.

**Methods:** Nine major electronic databases were searched and 490 articles were retrieved; 15 met the inclusion criteria. An established quality assessment tool was used to assess the quality of the included studies.

**Results:** The overall quality of the included 15 quantitative studies was adequate. A critical limitation of current literature is the lack of consistent conceptual or operational definitions for the concept of patients' awareness of disease status. The included studies conceptualized patients' awareness of disease status either as being informed or understanding one's disease prognosis. Significantly more patients who were aware of their disease status were less likely to choose life-extending treatment or measures. Mixed findings were shown regarding the impacts of patients' awareness of disease status on quality of life. Absence of qualitative studies limited the review's ability to critically synthesize the concept of awareness of disease status.

**Discussion:** Well-designed qualitative studies are needed to shed light on the conceptualization and operationalization of the concept to better capture the impact of patients' awareness of disease status on treatment preferences and quality of life. These studies will strengthen the measurement of the phenomenon in future quantitative studies and enhance the quality and viability of interventions.

## **Introduction**

Approximately 12.7 million people have been diagnosed with cancer worldwide and these numbers are expected to increase each year.<sup>1</sup> In 2014, among 1.6 million Americans who are diagnosed with cancer, more than 60% will reach the 5-year survival because of newer and more effective treatment choices for patients with metastatic cancer.<sup>2,3</sup>

Historically, and still in some cultures, health care providers were and remain reluctant to tell their patients about the diagnosis of cancer or when cancer was metastasized because of the high mortality rate, fear of losing hope, or limited treatment choices for patients with metastatic cancer.<sup>4,5</sup> As a result prior to 1997, there was an absence of research that examined the impact of patients' awareness of disease status on treatment preferences. With the advent of newer and more effective cancer treatments, researchers and clinicians since have made efforts to conduct research to explore the impact of the patients' awareness of disease status. Studies have shown that the majority of patients diagnosed with cancer desire prognostic information.<sup>6,7</sup> In conjunction with the increased treatment choices, patients' awareness of disease status emerges to be an important factor that influences cancer treatment decision-making.<sup>8-11</sup>

With the advances in cancer treatment and increased cancer survival, experiencing cancer is increasingly about quality of life. Prior to 1997, research showed conflicting findings regarding the impact of awareness of disease status on the emotional aspect of the quality of life. One study showed that patients' awareness of disease status significantly increased psychiatric disorders such as depression and anxiety.<sup>12</sup>

However, some research revealed that awareness of disease status helped to decrease depression and anxiety among patients with end-of-life cancer.<sup>13</sup> Conflicting findings of patients' awareness of disease status on the emotional aspect of quality of life and the absence of

research on the impact of patients' awareness of disease status on overall quality make it difficult to discern whether patients' awareness of disease status have different impact on patients' quality of life at different disease stages throughout the cancer trajectory.

Different definitions have been used to define the construct of awareness of disease status.<sup>14-19</sup> One often-used definition states that patients' awareness of disease status is: "the patient's real understanding and level of consciousness about the type of disease, the prognosis, and life expectations"<sup>17</sup> (p335). The operational definitions of awareness of disease status vary in existing research from whether the patients understand their illness,<sup>16</sup> the patients have been informed about their diagnosis by their health care providers,<sup>20, 21</sup> the patients are able to name the word "cancer" or "tumor,"<sup>22-24</sup> or the patients are able to estimate their life expectancy.<sup>10</sup> However, some researchers argue that disclosure of diagnosis and prognostic information may not elicit patients' automatic awareness of disease status.<sup>16, 25, 26</sup>

Known factors that may influence the impact of patients' awareness of disease status include communication between the patient and health care professionals, patients' denial, coping mechanisms, lack of understanding of medical terminology, culture, education, age, and race.<sup>14, 15, 17-19, 25, 27, 28</sup> Yet, the use of different conceptual and operational definitions in the existing research makes it difficult to draw conclusions concerning the impact of patients' awareness of disease status on treatment preference and quality of life among patients with metastatic cancer.

This systematic review aimed to evaluate the level of evidence of peer-reviewed literature published from January 1997 to January 2014. Specifically, this review sought to answer the following questions: (1) What is the definition and operationalization of patients' awareness of disease status in the existing body of literature? and (2) What is the impact of patients' awareness

of disease status on treatment preference and quality of life among patients with metastatic cancer?

## **Methods**

### ***Preparation for Literature search***

The review was conducted in two phases. The initial phase consisted of a thorough literature search and review by the first author to generate key search words or terms based on the concept of awareness of disease status, treatment preferences, and quality of life. Subsequently, additional search terms were identified using the MeSH (Medical Subject Heading) database. The database identifies the appropriate subject headings to enable more precise searches. In addition, multiple consultations with the health librarian were conducted to ensure the reliability, thoroughness, and accuracy of key searching terms.<sup>29</sup> Consulting a health librarian who has expertise in databases and key search terms used in different databases is an effective way to ensure reliability, accuracy of search terms, and exhaustion of the search.<sup>29</sup> The key terms utilized for this systematic review included: awareness, truth disclosure, health status, disease status, prognosis, neoplasm, metastasis, advanced cancer, quality of life, treatment preferences, decision making, patient preference, and choice behavior. Using various combinations of the key terms, the following databases were searched: PubMed, Medline, CINAHL, Embase, PsycINFO, Web of Science, Cochrane Library databases (Systematic Reviews and Controlled Trials Register), and SCOPUS.

### ***Inclusion and exclusion criteria***

The following inclusion criteria were used to optimize appropriate selection of articles: (1) written in the English language, (2) articles that explored the concept of awareness of disease status among patients with metastatic cancer, (3) articles that explored the impact of disease

awareness on treatment preferences or quality of life, and (4) articles that were published in the past 17 years (1997–2014) because this line of research started to arise after 1997.

The following exclusion criteria were used: (1) articles that focused on childhood cancer because the issues surrounding childhood cancers are different from those of the adult patient; (2) articles that focused on the ways of how health care professionals communicate with patients; (3) articles that focused on health care professionals' views on prognostic awareness since the focus of this systematic review was on patients' awareness of disease status; and (4) articles that did not focus on the concepts or the constructs of awareness, quality of life, or treatment preferences.

### ***Data extraction***

In the first phase, the key terms was applied to the 8 databases that were searched and yielded a total of 745 articles. After removal of 255 duplicates, 490 remained. Inclusion and exclusion criteria were applied to the 490 articles; 70 abstracts were deemed relevant. An independent search by a health librarian validated the search results. Upon further examination of the 70 abstracts, 38 articles were excluded because they did not meet the inclusion criteria, leaving 32 articles selected for full-text review. Of those 32 articles, 17 were excluded based on the inclusion and exclusion criteria, leaving a total of 15 articles that were selected for the systematic review (Fig. 1).

The authors reviewed and evaluated each article independently. An evaluation tool was used to quantitatively assess overall quality of each study (Table 1).<sup>29</sup> In addition, the Critical Appraisal Skills Programme (CASP) method was used. CASP is an international consortium that has developed reliable and valid measures to critically appraise, organize, and categorize data ([www.caspinternational.org](http://www.caspinternational.org)). Using the CASP tool, we developed a data analysis chart to assess

each study (Table 2). After completing the evaluation of all 15 articles by the authors independently, the authors achieved consensus by discussing the results and resolving any discrepancies. This process of consensus building ensures reliability and validity of evaluation of the selected studies.

## **Results**

This systematic review consisted of 15 studies. The overall quality of the literature is adequate. The quality of the literature was quantitatively determined using an established tool.<sup>29</sup> Eight of the 15 studies scored 10–12 of a possible total score of 14, indicating high research quality.<sup>8, 10, 11, 20, 24, 30-32</sup> Four studies scored 7–9, indicating adequate research quality.<sup>9, 23, 33, 34</sup> Three of the studies had poor research quality scores of 4–6 (Table 1).<sup>21, 22, 35</sup> Of the 15 studies only 2 were conducted in the United States.<sup>8, 10</sup> The rest of the studies were conducted in the following countries: Turkey,<sup>33, 35</sup> Korea,<sup>9, 11, 31</sup> India,<sup>22</sup> China,<sup>30</sup> Greece,<sup>23</sup> France,<sup>20</sup> Scotland,<sup>21</sup> Iran,<sup>24</sup> Cuba,<sup>32</sup> and Taiwan.<sup>34</sup>

### ***Awareness of Disease Status***

Different definitions and operationalization concerning the concept of the patients' awareness of disease status were used in the reviewed studies. For example, the concept of awareness of disease status was assessed by the patients' ability to name “malignancy” or “cancer”; patients' acknowledgement of the diagnosis of terminal illness; admission of the diagnosis of incurable diseases; the patients' ability to state disease stages; and the patients' ability to estimate their survival in the following 6 months.<sup>8-11, 22</sup>

The majority of the reviewed studies developed their own instruments to measure patients' awareness of disease status and never tested reported reliability or validity of the instruments. Without testing the reliability and validity of instruments, it is difficult to determine

whether the instruments used in these reviewed studies measured the true construct of the concept of patients' awareness of disease status, thus, it is also uncertain whether the research was able to fully capture the impact of patients' awareness of disease status on treatment preferences and quality of life. Twelve articles in this review reported that 44%–77% of their participants were unaware of their disease status.<sup>8, 9, 11, 21-23, 30-35</sup>

### ***Impact of awareness of disease status on treatment preferences***

Four studies reported that patients who were aware of their disease status were less likely to choose aggressive life-sustaining treatments.<sup>8-11</sup> These four studies utilized a prospective cohort study design and convenience sampling. However, none of the four studies defined the construct of patients' awareness of disease status and all used different operational definitions: terminal illness acknowledgement,<sup>8</sup> awareness of incurable disease status,<sup>9</sup> the patients' estimation of 6-month survival,<sup>10</sup> and the patients' ability to state disease stage.<sup>11</sup>

The four studies measured treatment preferences by assessing whether the patients signed a do-not-resuscitate (DNR) order or completed an advance directive,<sup>8</sup> acknowledged the decisional conflicts or verbalized treatment satisfaction,<sup>9</sup> accepted life-extending therapy or comfort care,<sup>10</sup> and used palliative care or intensive care.<sup>11</sup> Patients in the four studies who had the awareness of disease status were less likely to opt for aggressive life-sustaining treatment.<sup>8-11</sup>

### ***The impact of awareness of disease status on quality of life***

Of the 15 studies reviewed, 11 articles examined the impact of patients' awareness of disease status on quality of life. Four instruments were used to assess quality of life: the European Organization for Research and Treatment of Cancer's core quality of life questionnaire (QLQ-C30), the Hospital Anxiety and Depression Scale, Palliative Care Outcome Scales, and the McGill Quality-of-Life Scale. Four studies reported no statistically significant impact of patients'

awareness of disease status on quality of life.<sup>21-23, 35</sup> Three of the four studies conducted in Turkey, India, and Greece did not provide any information regarding the translation and testing of instruments utilized to assess quality of life.<sup>21-23</sup>

Five studies reported that the patients' awareness of disease status had a negative impact on quality of life.<sup>20, 24, 30-33</sup> Two prospective cohort studies reported statistically significant positive impact of the patients' awareness of disease status on quality of life.<sup>31, 34</sup> These two studies used appropriate instruments to measure quality of life (psychometrics reported and appropriate translation). However, both had problems with the sample size, high attrition,<sup>31</sup> and problems with recruitment.<sup>34</sup>

## **Discussion**

This review of studies published between 1997 and 2014 that examined the impact of patients' awareness of disease on treatment preference and quality of life identified 15 relevant studies from 10 countries while only 2 were conducted in the United States. All 15 studies used quantitative approach. The overall quality of the included 15 studies was adequate.

The major limitation of the current literature includes the inconsistency of defining and operationalizing the concept of patients' awareness of disease status and using untested instruments to measure the concept of patients' awareness of disease status. This review revealed that more than 50% of patients were unaware of their disease status.<sup>8, 9, 11, 21-23, 30-35</sup> This finding is comparable to other studies in which the study population was patients receiving hospice and palliative care.<sup>14, 17</sup>

Despite the limitations of the existing literature, with regard to the impact of patients' awareness of disease status on treatment preference, a critical contribution of the existing literature is that patients who were aware of their disease status are less likely to choose life-

extending treatment. To ensure that patients have informed decision on treatment in face of metastatic cancer, such as whether to choose life-extending or palliative treatment, this review underscores the importance of patients' awareness of disease status in this decision making process. In the light of this finding and the fact that more new and effective treatments are available for patients with metastatic cancer, future research should focus on effective ways to ensure that patients are aware of their disease status.

Conflicting findings concerning the impact of patients' awareness of disease status on the patients' overall quality of life were revealed in this review. Such conflicting findings might be because different instruments were used in the studies. Future research should evaluate and identify the most adequate quality-of-life instruments that accurately assess the impact of patients' awareness of disease status on the patients' quality of life.

In addition, as a subjective and multidimensional construct, quality of life is: “an individual's perception of his or her position in life in the culture and value systems in which he or she lives, in relation to his or her goals, expectations, standards, and concerns.”<sup>36</sup> Thus, cultural and societal norms may be important confounding factors for the impact of patients' awareness of disease status on quality of life. Yet, there was no assessment on cultural impact on patients' awareness of disease status in these 15 studies under review.<sup>9, 11, 30-35</sup> Cultural and social factors should be considered in future research on the impact of patients' awareness of disease status on quality of life.

### ***Future recommendations***

Little consistency exists in the current literature in defining, operationalizing, and measuring the impact of patients' awareness of disease status on treatment preferences and quality of life. None of the included 15 quantitative studies provided conceptual or operational

definitions for the concept of patients' awareness of disease status. The lack of instruments to assess the concept of patients' awareness of disease status, and patients' treatment preferences may be one of the most important factors contributing to the conflicting and insufficient data in quantitative research.

The absence of qualitative research limits this review's ability to provide recommendations for conceptual definition and detailed operationalization for the concept of patients' awareness of disease status. To address this deficit and advance the science, qualitative research is urgently needed to provide evidence-based conceptualization of the concept, especially when considering conditions and needs specific to patients with metastatic cancer. Qualitative research is needed to provide in depth and insightful understanding of patients' awareness of disease status to accurately define and operationalize this concept for future quantitative research. In addition, more studies are needed to investigate the impact of patients' awareness of disease status in the United States, not only to address the limitations of the current literature but also give insights into current health care for patients with metastatic cancer.

#### **Author Disclosure Statement**

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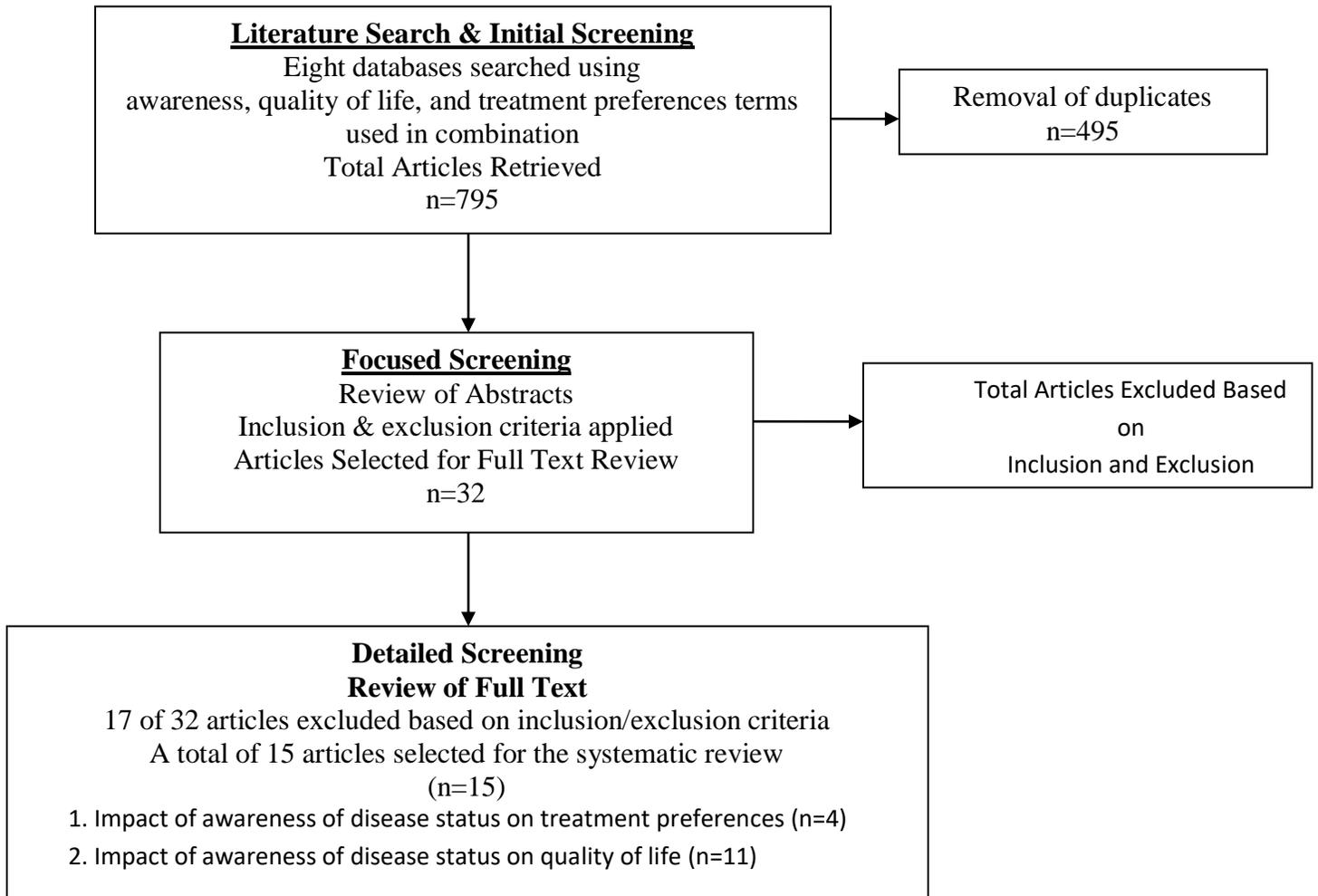
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**Figure 1: Literature Search Flow Chart.** The Impact of Patients' Awareness of Disease Status on Treatment Preferences and Quality of Life among Patients with Metastatic Cancer: A Systematic Review from 1997-2014



**Table 1: Results of Quality Assessment Scores\***

Quality Assessment Criteria	Quantitative (n=15) No. ( %)
Explicit and soundness of literature review	6 (40)
Clear aims and objectives	15 (100)
Clear description of setting	12 (80)
Clear description of sample	15 (100)
Appropriate sampling procedure	4 (26.6)
Clear description of data collection	11 (73.3)
Clear description of setting	14 (93.3)
Evidence of critical reflection (Qualitative Study)	-
Provision of recruitment data	6 (40)
Provision of attrition data	5 (33.3)
Provision of psychometric properties of the measurement instruments (Quantitative Study)	3 (20)
Appropriate statistical analysis (Quantitative Study)	14 (63.3)
Findings reported for each outcome	10(53.3)
Description of validity/reliability of results	1 (9.1)
Sufficient original data (Qualitative Study)	-
Provision of strengths and limitations of the study	11 (73.3)
Quality Scores	Mean 9.07 Standard Deviation $\pm$ 4.79

\*No qualitative studies were identified for this review

**TABLE 2: DATA ANALYSIS CHART**

Author/Year/ Study Origin	Aim/ Design	Sample /Patient Characteristic s	Operational Definition of ADS	Measures/ Instrument	Key Results	Study Strength/ Weakness
Alaka Ray (2006)/ America	Aim: How patients awareness of terminal illness effects mental health and advance care planning, quality of death, and caregiver bereavement outcomes  Design: Prospective cohort study	n=280  54.4% Male  Mean age 57.3 years	Terminal illness acknowledgment	ADS: How would you describe your current health status"?  Options: -relatively healthy -seriously but not terminally ill -seriously and terminally ill Patients who responded to "seriously and terminally ill" were deemed aware	73.3% were not aware of their prognosis Aware patients were more likely to complete advance directives (OR 2.01 v. 0.78 – p<0.05), DNR orders (OR 3.45 v 1.01 – p <0.001) and have EOL conversations with HCP (OR 2.79 v. 0.95 – p < 0.001) Patients who were had ADS had worse QOL (p=0.05)	Sample bias – patients who did not participate were significantly more likely to be in "distress" (p=0.005)
Atesci (2004)/ Turkey	Aim: Does awareness of cancer diagnosis influence psychiatric morbidity  Design: Cross-sectional	n=117  51.3% Female  Mean age 53.7 years	Talk about why they are in the hospital and what they are "suffering from"	"What do you think you are suffering from"?  "Why do you think that you are in the hospital"?  Based on the answers a psychiatrist determined if the patient was aware or not aware	54.7% of patients were considered unaware of cancer diagnosis  Using chi-square psychiatric disorders were statistically more frequent in patients who were aware of their diagnosis (p=0.03)	No concrete measure of awareness, very subjective as to whom is aware  Did not compare ADS to GHQ & HADS scales
Baek (2011)/ Korea	Aim: Examine the effects of awareness of incurable disease	n=98 agreed to participate and completed	Awareness of incurable disease status	Unclear of specific questions asked to determine awareness  Based on results , one question	96% of patients knew that they had cancer, however, 50% did not know their cancer was incurable	High attrition rate – small final sample  Most people enrolled

**TABLE 2: DATA ANALYSIS CHART**

Author/Year/ Study Origin	Aim/ Design	Sample /Patient Characteristic s	Operational Definition of ADS	Measures/ Instrument	Key Results	Study Strength/ Weakness
Bozcuk (2002)/ Turkey	status on satisfaction with treatment choice for palliative chemotherapy among patients with cancer	first survey  n= 62 who completed both parts of the study  68% Male  Mean age was 57.3	Use disclosure of diagnosis to determine awareness	was about expectation of chemo treatment and other if they were informed of their terminal status before chemotherapy began	Based on chi –square those whom had ADS had increased satisfaction with chemotherapy treatment (p=0.02)  In the univariate analysis there was no significant difference between those patients who had ADS and those who did not (p=0.247)	were relatively healthy, biased sample ECOG <2  Unclear about any translation methods for DCS scale – unsure if scale is reliable and valid in Korean population
	Aim: To assess impact of diagnosis on emotional functioning and quality of life  Design: Cross-sectional	n=100  Median age was 54, range was from 16-75  58% male		No mention of specific question of awareness of diagnosis  Patients were either categorized as “knows” or “does not know”	44% of patients were unaware  Using indepent t-test there was no significant difference (no sub-scale had a p <0.05) in QLQ-C30 measures  Logistic regression did not have ADS as a factor that was a determinant of good “emotional functioning” (p=0.164)	No description of methods of recruitment  No description of procedure of interview  No reliability or validity of QLQ-C30 if it was administered  Unaware how awareness of diagnosis was really measured
Chandra (1998)/ India	Aim: Assess awareness of disease status in relation to psychiatric	n=294  51% Women	If patient can use specific terms or answers questions regarding treatment or	Use the words “cancer” or “malignancy” in regards to their disease  “Why do you think you are in the hospital”?	46% were unaware of their diagnosis  72% of the unaware group was unaware if their	No mention of patient recruitment or administration procedures

**TABLE 2: DATA ANALYSIS CHART**

Author/Year/ Study Origin	Aim/ Design	Sample /Patient Characteristic s	Operational Definition of ADS	Measures/ Instrument	Key Results	Study Strength/ Weakness
Fan, (2011)/ China	<p>morbidity</p> <p>Design: Cross-sectional</p> <p>Aim: To evaluate the relationship between the disclosure of cancer diagnosis and QOL in Chinese home care patients with advanced cancer</p> <p>Design: Cross-sectional</p>	<p>Mean age 45 years</p> <p>n=173</p> <p>Mean age 61.13 years</p> <p>54.3% Male</p> <p>88.4% Stage IV Cancer</p>	<p>hospitalization</p> <p>Uses disclosure/ revealing of diagnosis</p>	<p>“What do you think that you are suffering from”?</p> <p>“What are you taking treatment for”?</p> <p>“Have you been told by doctors, relatives, and fellow patients about your disease”?</p> <p>Two psychiatrists then come to a conclusion based on responses</p> <p>“How did you know about your condition?”</p> <p>No specific questions/ language provided</p> <p>Based on all these a determination of “knowledge” was made</p>	<p>treatment was curative or palliative</p> <p>HADS scores were not significantly different between the two groups</p> <p>49.7% aware of their diagnosis</p> <p>After controlling for difference between length of disease – chi-square test showed that patients who were unaware of diagnosis had significantly better physical (p=0.025) and emotional (p=0.020) subscale scores</p> <p>ANCOVA showed that even after controlling for length of disease the physical functioning (p=0.030) and emotional functioning (p=0.016) subscales are still significant</p>	<p>State that 72% of their “aware” group was unaware if treatment was curative or palliative – conflicting results</p> <p>Unaware of instrument psychometrics for populations</p> <p>Hard to determine the difference between aware and unaware based on questions</p> <p>Discusses historical/ cultural context for why patients had not been told about their diagnosis</p>
Iconomou (2002)/	Aim: Assess patient		If patients can name the disease	Open ended question “if the patient could name the illness	59% were unaware of their diagnosis	Good literature review

**TABLE 2: DATA ANALYSIS CHART**

Author/Year/ Study Origin	Aim/ Design	Sample /Patient Characteristic s	Operational Definition of ADS	Measures/ Instrument	Key Results	Study Strength/ Weakness
Greece	preferences for information and to see which patients were aware of their diagnosis and to see if it effected QOL  Design: Cross-sectional	n=100 Mean age 59 years  53% Female	that they were being treated for	for which they were receiving this treatment?"  The primary HCP and primary caregiver were asked to come to a consensus for those patients whom they could not figure out	According to the ANOVA the following two variables impacted if a patient had ADS: younger age (p < 0.001) and higher education p <0.001)  ADS was not a significant variable in predicting QOL	Unsure if it is the appropriate QOL measure  Did not report out all the stats  Convenience sample
Lee (2011)/ Korea	Aim: How awareness of disease status influence QOL  Also looked at factors that effect awareness of disease status  Design: Prospective Cohort Study	122 patients qualified – 98 patients agreed to participate  At 4-6 weeks, 75 remained (23.5% attrition)  2-3 month follow up (32.7%) attrition n=66  Mean age 57.3 years	Knowing if their cancer is advanced	ADS: "Do you know your disease stage"?  Response choices: advanced, locally advanced, early, and I don't know  Advanced = awareness Locally advanced, early, and I don't know = lack of awareness	At the beginning of study, 50% aware of disease status, by the end 48.5% of patients are aware  ANCOVA showed that ADS had significant improvement in QOL over time- in particular, improved role (p=0.004) and reduction in anxiety (p=0.0003) and stress (p=0.042)  Attrition was attributed to older age and higher ECOG score	Detailed statistical analysis of all items  High attrition  Small final sample n=66  Relatively healthy sample from beginning ECOG <2

**TABLE 2: DATA ANALYSIS CHART**

Author/Year/ Study Origin	Aim/ Design	Sample /Patient Characteristic s	Operational Definition of ADS	Measures/ Instrument	Key Results	Study Strength/ Weakness
Lheureux (2003)/ France	Aim: To determine if there is an effect of disclosure of lung cancer diagnosis on QOL  Design: Prospective Cohort Study	68.4% male  n= 70 Mean age was 61.7 years  87.1% Male	Disclosure of Lung cancer diagnosis by a physician	It was assumed that once the information was disclosed by HCP  No discussion what type of information and at what depth information was given	There were significant negative differences between the time before diagnosis and the time after diagnosis in the following subscales: physical(p=0.03), role (p=0.002) , emotional (p=0.0001) and social functioning (p=0.014)	Does not discuss how diagnosis was revealed to patients are of their prognosis  Patient’s with ECOG >2 were excluded which made this a “healthier” cohort  Too many exclusion criteria which limited sample size
Montazeri (2004)/ Scotland	Aim: To examine if knowledge of lung cancer diagnosis effects QOL  Design: Prospective cohort study	n=129 Mean age 67.5 years  60% male	Knowledge of cancer diagnosis	A patients was deemed to have knowledge after “formal disease disclosure” by team of HCPs  Not knowing group was those that were interviewed before “diagnosis”	Of the lung cancer patients -77% were unaware of their diagnosis  According to the Mann-Whitney test patients that knew their diagnosis had significantly more sleep difficulties (p=0.02)  No other significant differences between groups in terms of QOL measures	Discrepancy between size of comparable groups – issues of power  Unclear how patients were determined to have knowledge of their diagnosis  Collection of extraneous data that was never analyzed
Montazeri	Aim: Compare		Knowledge of cancer diagnosis	Initially family was asked if	52% did not know their	First study in Iran

**TABLE 2: DATA ANALYSIS CHART**

Author/Year/ Study Origin	Aim/ Design	Sample /Patient Characteristic s	Operational Definition of ADS	Measures/ Instrument	Key Results	Study Strength/ Weakness
(2009)/ Iran	QOL in patients who knew their diagnosis and those who did not  Design: Cross-sectional	n= 142  Mean age was 54.1 years  56% Male		patients knew diagnosis. Then patients were asked if they could tell the interviewer what was wrong with him/her  If patients could use the terms “cancer” or “tumor” then these patients were considered to have knowledge of their disease	diagnosis  Patients with knowledge of diagnosis had significantly better physical ( $p=0.001$ ), social ( $p=0.014$ ), and emotional ( $p<0.0001$ ) QOL subscales  In the ANOVA ADS was a significant variable in each of the subscales: physical ( $p=0.01$ ), emotional ( $p=0.02$ ), social ( $p=0.03$ )  59% were not aware of their diagnosis	looking at issue  Method of determining knowledge of cancer diagnosis is subjective  Patients who were deemed “too sick” were excluded, bias the results
Roll (2009)/ Cuba	Aim: Two purposes: First, to evaluate the needs of patients with advanced malignant disease using the Palliative Outcome Scale (POS) Second, to look at these needs in comparison with demographic data and patient awareness of their diagnosis  Design: Cross-	n=91  Mean age was 54  57.1% Male	Knowledge of their disease  QOL: None	“What do you know about your condition?”  Based on their answer they coded it into a binary (Y/N) variable	When using the Mann-Whitney test to compare the POS scale items for those with ADS and those with ADS  Those with ADS had less problems with “other symptoms” ( $p=0.011$ ), decrease in anxiety ( $p=0.03$ ), obtaining information ( $p=0.028$ ) and support (0.005)	First article to look at metastatic cancer patient’s needs in Cuba  The measure for awareness was subjective  POS Argentinean version may not be appropriate scale because Cuba is a very different country and the language and concepts may vary

**TABLE 2: DATA ANALYSIS CHART**

Author/Year/ Study Origin	Aim/ Design	Sample /Patient Characteristic s	Operational Definition of ADS	Measures/ Instrument	Key Results	Study Strength/ Weakness
Tang (2008)/ Taiwan	sectional  Aim: Examine awareness of patient's prognosis, evaluate patient/caregiver agreement of end-of-life care, and QOL  Design: Cross-sectional	N= 1108  Median age is 61 years dyads  59.5% Male	Being able to name the disease and then be able to discuss the prognosis	Patients were first asked if they knew their diagnosis  Then they were asked about their prognosis  Asked if the patient could name the disease and determine if it was curable or not	73.8 % of patients were unaware of their prognosis  According to the multiple regression the following variables had a significant positive impact on QOL: ADS (p=0.001), were older (p<0.0001), financially secure (p<0.0001), and congruence between family and patient on place of death (p<0.0001)	Did not show individual results of the MQOL  Unsure how the aware and the unaware group differ in QOL scores or treatment preferences
Weeks (1998)/ America	Aim: Two purposes: 1)If patients estimates of life expectancy effect treatment preferences 2)If patients and HCP's estimates are in alignment  Design: Prospective cohort study	n=917  Mean age 62 years  62% Male	Patient's estimates of their 6 month survival	"What are the chances that you will live for 6 months or more?  Choices: 90% or better About 75% About 50-50 About 25% 10% or less	Patients who had a 90% estimation that they would be alive in 6 months were more likely to favor life extending therapy (2.6 odds ratio)  Patients were less accurate about their survival time than their HCP  57% of patients who thought they had a 90% chance of surviving 6 months died at the six month mark	Large part of the potential sample frame did not have responses – were out of the study  Using estimate of survival time may not be easy for patients to do

**TABLE 2: DATA ANALYSIS CHART**

Author/Year/ Study Origin	Aim/ Design	Sample /Patient Characteristic s	Operational Definition of ADS	Measures/ Instrument	Key Results	Study Strength/ Weakness
Yun (2011)/ Korea	<p>Aim: To evaluate the impact of cancer patients awareness of their terminal disease status and the use of palliative care or ICU use on survival</p> <p>Design: Prospective cohort study</p>	<p>n=619</p> <p>481 completed the questionnaire</p> <p>70.3% &lt;65 years old</p> <p>56.9% Men</p>	<p>Ability of patient to state stage of disease at diagnosis</p> <p>After death, the family member was asked undisclosed questions about the patients awareness at time close to death</p>	<p>Do you know your disease stage?"</p> <p>Answer choices: I don't know, early stage, advanced stage, terminal stage, other.</p> <p>Also, other "end of life issues" were evaluated, but they are not clear as to what they are</p> <p>TP: Use of ICU versus palliative care</p>	<p>41.6% of patients were not aware of their terminal status at beginning of study</p> <p>82.9% were aware at time of death</p> <p>37.9% utilized palliative care</p> <p>13.2% admitted to the ICU</p> <p>Patients who were aware of prognosis were significantly (p=0.019) more likely to use palliative care (70.6%) and less likely to use ICU (50%)</p>	<p>Measure of awareness is unclear</p> <p>Treatment decisions and measure of awareness are being measured post-mortem by family member using undisclosed questions, reliability is questionable</p>

**Chapter 3:**  
Conceptualization and Operationalization of Awareness of Disease Status in Cancer Patients

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Title: Conceptualization and Operationalization of Awareness of Disease Status in Cancer Patients

Article Type: Integrative Review

Keywords: awareness of disease status, neoplasm, cancer, understanding, diagnosis, prognosis, operationalization, conceptualization nursing, integrative review

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## **ABSTRACT**

**Background:** Cancer patients today have more treatment options and therefore, it is important that patients are active partners in treatment decisions. Although awareness of disease status has been investigated in the literature, it has not been consistently conceptualized or operationalized.

**Aim:** The aim of this integrative review is to develop a conceptual definition, conceptual model and to make recommendations for conceptualization and operationalization of the concept of awareness of disease status in cancer patients.

**Method:** Wittemore and Knafel's integrative review methodology guided this paper. The process of problem identification, data evaluation, data analysis resulted in the development of a conceptual definition, model and recommendation for operationalization. Data was obtained through a systematic search of six databases. The key terms utilized were awareness, perception, truth disclosure, diagnosis, prognosis, terminal illness, status, neoplasm and metastasis. All dates through 2017 searched to capture all relevant articles. Sixty-two articles met criteria for inclusion.

**Conclusions:** The concept of awareness of disease status defined in this analysis is “the individual patient’s understanding of being diagnosed and treated for cancer based on the multi-factorial components of individual patient characteristics and contextually driven communication practices of health care providers. It is dynamic and changing throughout the disease trajectory.” The development of a conceptual definition, model and recommendation for operationalization will help develop consistency for future research.

## **Introduction**

Patients with cancer are living longer lives due to advances in treatment (National Cancer Institute, 2017). Cancer, in many cases, has evolved to resemble a chronic disease with all the associated quality of life challenges and comorbidities that accompany it. This results in patients having to make many treatment decisions throughout the course of the disease trajectory.

One factor that has shown to have an impact on cancer patient's treatment decisions is awareness of disease status (Ahn et al., 2013, Aoki et al., 1997, Baek et al., 2012, Burns et al., 2007, Kao et al., 2013, Tang, 2006, Tang et al., 2016, Weeks et al., 2012). While two studies found there was a lack of consistent conceptual and operational definitions for the concept of patient awareness of disease status in cancer patients (Applebaum et al., 2014, Finlayson et al., 2015).

Due to the lack of consistency in how the phenomenon is defined, it is evident that there is no one way to measure awareness of disease status in cancer patients. Therefore, in order to advance the science so that it can more effectively assist cancer patients in coping with the longer term effects of cancer care, the purpose of this integrative review was to examine how researchers operationalized and conceptualized the concept of awareness of disease status in the literature. The result of this integrative review was the development of a conceptual definition, model and recommendations for operationalization.

## **Methods and Data Sources**

Whittemore and Knafl's integrative review methodology guided this paper (CITE). An integrative review approach was the best method to satisfy the aim of the study because implicit in its methodology is to improve the conceptualization of a concept of phenomenon (Whittemore and Knafl, 2005). Whittemore and Knafl's steps for an integrative review include: literature

search, data evaluation and data analysis (2005).

### ***Literature Search***

Data collection began with a thorough literature search and review to generate key words or terms based on the concept of awareness of disease status in patients with metastatic cancer. Additional search terms were identified using the MeSH (Medical Subject Heading) database, which identifies the appropriate subject headings in order to conduct searches that are more precise. Additionally, there were multiple consultations with the health librarian to ensure depth and accuracy of key searching terms.

The key terms utilized for this concept analysis included: awareness, truth disclosure, health status, disease status, prognosis, neoplasm, metastasis, advanced cancer. Using various combinations of the key terms, the following databases were searched: PubMed, Medline, CINAHL, Embase, PsycINFO, Web of Science, Cochrane Library databases [Systematic Reviews and Controlled Trials Register], and SCOPUS.

To identify all the aspects of the concept of awareness of disease status in cancer patients, articles were included: (1) articles that focused on patients with cancer at any point of the disease trajectory; (2) all pertinent articles through 2017 with no limit of search dates; and (3) articles in English language.

The search method initially yielded 6,691 articles. An additional 29 articles were identified through ancestry searching. From those, 1,596 duplicate articles were removed and 5,124 articles were screened. Another 4,696 articles were excluded due to lack of relevance. Of the remaining 428, 62 articles focused on awareness of disease status or a related topic in the cancer patient and thus were included in this review. Figure 1 illustrates the search methodology.

### ***Data Evaluation***

The Critical Appraisal Skills Programme (CASP) method guided the data evaluation. CASP is an international consortium that has developed reliable and valid measures to critically appraise the data ([www.caspinternational.org](http://www.caspinternational.org)). Based on the CASP method to evaluate evidence, data analysis charts were created to assess the appropriateness of the aim, method of sample recruitment and selection, how the concept of awareness of disease status was conceptualized and operationalized, factors that impact awareness, results of being aware, key results of the paper and the strengths and weaknesses of each article. Table 1 summarizes the critical appraisal of the research studies while Table 2 summarizes the various conceptualizations of awareness of disease status found in the studies. The following sections summarize the broader trends seen in the studies.

### ***Data Analysis***

Data extracted from each article included: aim, sample characteristics, definition of the concept of awareness of disease status (if available), operationalization of the concept, factors that impact awareness, consequences of awareness of disease status, key results of the study and study strengths and limitations. General thematic analysis techniques were utilized to examine the content and context of the articles, an approach formulated by Miller and Alvarado's recommendations about the use of documents as "data" in research syntheses (Miller and Alvarado, 2005). The combined approach also allowed for the development of a conceptual model as an additional product of the study.

### **Results**

#### ***Conceptualization of Awareness of Disease Status in the Literature***

Only nine of the sixty-two articles provided conceptual definitions for the concept of awareness of disease status. The following dimensions of awareness were defined: illness

awareness (Corli et al., 2009, Morasso et al., 1996, Moses and Cividali, 1966) acknowledged awareness (Germino and McCorkle, 1985) awareness of diagnosis (Caruso et al., 2000) and awareness of progression (Hoff and Hermeren, 2008). Three articles used other author's conceptual definitions (Andruccioli et al., 2009, Clavarino et al., 2003, Johnston and Abraham, 2000). These definitions described the patient's perception, understanding and acknowledgment of information they received and the meaning of the information (Andruccioli et al., 2009, Caruso et al., 2000, Clavarino et al., 2003, Corli et al., 2009, Germino and McCorkle, 1985, Hoff and Hermeren, 2008, Johnston and Abraham, 2000, Morasso et al., 1996, Moses and Cividali, 1966). Please see table two for each definition.

### ***Operationalization of the Concept***

The concept of awareness of disease status in patients with cancer was operationalized into four categories: Understanding of cancer diagnosis (13 articles), knowledge of prognosis, combination of diagnosis and prognosis (8 articles) understanding of curability (7 articles) and survivability (6 articles). The following sections illustrate the operationalization of each measurement category.

#### ***Understanding of Diagnosis***

The most common term used in the literature was "awareness of diagnosis" (Atesci et al., 2004, Baek et al., 2012, Bozcuk et al., 2002, Brokalaki et al., 2005, Caruso et al., 2000, Chandra et al., 1998, Corli et al., 2009, Fan et al., 2011, Iconomou et al., 2002, Lheureux et al., 2004, Montazeri et al., 2004, Montazeri et al., 2009, Nord et al., 2003). Awareness of diagnosis was operationalized differently and measured inconsistently throughout. In some publications, researchers considered patients aware of diagnosis if they could identify their disease with the word "neoplastic" (Andruccioli et al., 2007); if patients could name the disease they were being

treated for (Ardestani et al., 2015, Iconomou et al., 2002, Tang, 2006) or if they could use the words “malignancy”, “cancer”, “tumor” (Chandra et al., 1998, Montazeri et al., 2009, Papadopoulos et al., 2011). One article deemed patients to have awareness of diagnosis if they could answer yes to the following question “Do you have or have you had cancer” (Nord et al., 2003, p. 313). Three articles considered patients as automatically aware of their diagnosis based upon the delivery of diagnostic information from the health care provider (Aggarwal et al., 2016, Lheureux et al., 2004, Montazeri et al., 2004). Therefore, awareness was limited to what had been communicated by the health care provider.

### *Knowledge of Prognosis*

There are eight publications that use a combination of the diagnosis and prognosis to determine patient awareness of disease status (Ahn et al., 2013, Andruccioli et al., 2007, Aoki et al., 1997, Barnett, 2006, Hoff and Hermeren, 2008, Mackillop et al., 1988, Pronzato et al., 1994, Tang, 2006). One study defined prognosis as “Awareness of the type and stage of the disease relates to the image of his/her current health status” (Caruso et al., 2000, p. 200). Another study defined prognosis as the “accurate perception of prognosis” and operationalized the concept as patients' ability to report their expected survival length as “less than 2 years for stage IV lung cancer and less than 5 years for stage IV colorectal cancer” (Liu et al., 2014, p.674). While these two studies defined prognosis, their measurement or assessment of it was limited. For example, another study asked the patients if he/she could name the disease and determine if it was curable or not (Tang, 2006). Dichotomizing patient responses in this way is an act of reductionism that belies the complexity of understanding one’s fate.

### *Understanding of Disease Curability*

The operationalization of curability applies to all patients with cancer, and is an important part of prognostication. This attribute becomes especially important in the context of metastatic or recurrent disease. Curability was examined in two ways: if the patient with cancer understands if their disease is curable or if the intent of treatment is to cure or palliate.

Chochinov's study of 200 advanced cancer patients receiving palliative care defined awareness of disease status as if a patient knew he/she was not curable. "Full awareness" was considered if "the patient had a full understanding of the gravity of the illness and the imminence of death" (2000, p.501). Conversely, he defined if "the patient believed the illness to be curable then the patients were deemed to have "no acknowledged awareness", with no acknowledgement of terminal prognosis (2000, p.501). In a study conducted in Australia of 181 terminal cancer patients and their caregivers, "full awareness of disease status" was determined if "both participants understand that the treatment was not intended to cure" (Burns et al., 2007, p.189). In a 2006 study conducted in Taiwan, patients deemed to have the awareness of disease status "if patients understood that they had an incurable cancer, death was unavoidable, and their lifespan was very limited" (Leung et al., 2006, p.451). One study examined if patients, who oncologists estimated would die within a year, and health care providers could have "concordance" in terms of likelihood of cure. Concordance was determined if patients were in multiple categories (0%, 1-10%, 11-20% etc.) of the oncologist estimates, which was measured via survey after appointments (Robinson et al., 2008).

Another facet of curability described in the studies was if the treatment that the patient is receiving is curative or palliative. In a 2011 study of 151 metastatic non-small cell lung cancer patients, participants were asked the following yes/no questions: "My cancer is curable;" "The goals of my therapy are to 'help me live longer;'" "try to make me feel better;" or "get rid of all

my cancer” (Temel et al., 2011, p.2321). One of the major findings of this study was that patients exhibit discordance between answers - patients were aware that their cancer was not curable but many still believed the purpose of chemotherapy was curative (Temel et al., 2011). Similarly, another study assessed curability of treatment by asking the following question: “After talking with you doctors about chemotherapy, how likely do you think it was that chemotherapy would...help you live longer, cure your cancer, or help you with problems you were having because of your cancer” (Weeks et al., 2012, p.1617). Patients had the options – “very likely, somewhat likely, not at all likely, don’t know. Of the 1193 stage IV cancer patients, 69% of the lung cancer patients and 81% of the colorectal patients were not aware that their chemotherapy was not curative (Weeks et al., 2012). A similar method of operationalization utilized with 262 cancer patients, 93 of them with metastatic disease, using a Likert Scale to answer the following question: “How much do you think your illness is curable”? Options “1=very difficult to cure to 10=very easy to cure” (Costantini et al., 2015). These studies are additional examples of how researchers adopt reductionist techniques that mask complexity when trying to understand this concept.

### *Survivability*

Survivability looks at a patient’s ability to approximate life expectancy and report if they will survive their disease. Six articles evaluated survivability by asking patients to estimate their survival time until death (Lambden et al., 2016, Robinson et al., 2008, Weeks et al., 1998). One of these three articles asked the participants: “What are the chances that you will live for 2 months or more if current care remains the same?” and “How about 6 months or more?” (Weeks et al., 1998, p.1710). Patients had the following response choices: “90% or better,” “about 75%,” “about 50-50,” “about 25%,” “about 10% or less,” or “don’t know” (Weeks et al., 1998,

p.1710). Fifty-seven percent of the patients who thought they had a 90% chance of surviving 6 months died at or before the six-month mark (Weeks et al., 1998). In this study, a consistent trend was that patients were more likely to overestimate their life expectancy than their health care providers. Another study mirrored this approach, but through qualitative interviews (Cartwright et al., 2014). Another example of survival estimates was if terminal cancer patients could report that their cancer would cause their death (Enzinger et al., 2015, Epstein et al., 2016).

### ***Factors That Determine Awareness***

All studies identified factors that impact a patient's awareness of disease status. These factors were categorized into contextual and individual patient characteristics. Contextual characteristics of the health care environment where patients receive care include characteristics of the health care providers (HCPs) and environment of the hospital (urban and non-teaching hospital). Organizational culture and provider responses to it also influence contextual characteristics. Individual patient characteristics include the culture of the patient, coping mechanisms, education, age, gender, type of cancer, and presence of metastasis.

### ***Contextual Characteristics of Health Care Environment***

Unsurprisingly, the most common precursor of awareness of disease status cited was communication with HCPs. How can patients be aware of their disease if they have not had effective communication with their HCPs? Thus, thirty-two articles considered communication with HCPs as a factor that impacts awareness of disease status, however, this factor was not statistically measured in all of the articles (Ahn et al., 2013, Andruccioli et al., 2007, Aoki et al., 1997, Ardestani et al., 2015, Atesci et al., 2004, Baek et al., 2012, Cartwright et al., 2014, Chandra et al., 1998, Clavarino et al., 2003, Corli et al., 2009, Derman and Serbest, 1993, Enzinger et al., 2015, Epstein et al., 2016, Hoff and Hermeren, 2008, Johnston and Abraham,

2000, Kao et al., 2013, Lee et al., 2013, Leung et al., 2006, Lheureux et al., 2004, Liu et al., 2014, Montazeri et al., 2004, Morasso et al., 1996, Moses and Cividali, 1966, Nord et al., 2003, Papadopoulos et al., 2011, Prigerson, 1992, Pronzato et al., 1994, Ray et al., 2006, Robinson et al., 2008, Tchen et al., 2003, Temel et al., 2011, Weeks et al., 1998).

In particular, many studies conducted in Asia and Eastern Europe discussed how it is the cultural practice for HCPs to not communicate with the patients regarding their disease status, but to inform the family (Ahn et al., 2013, Atesci et al., 2004, Baek et al., 2012, Bozcuk et al., 2002, Chou et al., 2013, Fan et al., 2011, Kao et al., 2013, Lee et al., 2013, Leung et al., 2006, Montazeri et al., 2009, Roll et al., 2009, Tang, 2006). In those cultures, family members serve as the bridge of communication between HCPs and patients in order to shield the patient from bad news. If a patient is not present conversations with HCPs, this will certainly affect their awareness of disease status. This example highlights how culture influences the organization of care delivery systems and providers' subsequent communication styles.

For studies conducted in Western Europe and the United States the focus was on communication characteristics of the HCPs. The following characteristics of HCPs were cited as having an impact awareness of disease status: language used (Hoff and Hermeren, 2008); attitude of the HCPs when disclosing information (Caruso et al., 2000, Fried et al., 2006, Liu et al., 2014, Prigerson, 1992, Robinson et al., 2008); and amount of information disclosed by HCPs (Clavarino et al., 2003, Corli et al., 2009, Morasso et al., 1996).

### *The Influence of Organizational Culture*

Characteristics of the hospital and the type of practice were cited as factors that impacted patient's awareness of disease status. For example, patients who were at a teaching hospital were less likely to be told they were dying (Lambden et al., 2016, Prigerson, 1992). Patients

who were in a hospital specialized for oncology (Brokalaki et al., 2005); who had a referral by an oncology department (Chou et al., 2013); or had an early referral to a palliative care program (Temel et al., 2011) were all more likely to report a better awareness of disease status.

### *Individual Patient Characteristics*

Age, gender and education level have been shown to impact a patient's awareness of disease status. The younger a patient is, the more likely he or she is to have awareness of disease status (Ahn et al., 2013, Brokalaki et al., 2005, Caruso et al., 2000, Chou et al., 2013, Corli et al., 2009, Iconomou et al., 2002, Montazeri et al., 2009, Nord et al., 2003, Papadopoulos et al., 2011). This is significant because cancer is typically a disease that comes with advancing age and therefore there is a gap in how this population comprehends their disease and treatment. Females as opposed to males are also more likely to have awareness (Aggarwal et al., 2016, Ahn et al., 2013, Brokalaki et al., 2005, Burns et al., 2007, Chochinov et al., 2000, Costantini et al., 2015, Helft et al., 2003, Nord et al., 2003, Papadopoulos et al., 2011, Pronzato et al., 1994). In addition, patients with higher education levels (typically more than high school) have greater awareness (Ahn et al., 2013, Brokalaki et al., 2005, Corli et al., 2009, Helft et al., 2003, Iconomou et al., 2002, Mackillop et al., 1988, Montazeri et al., 2009, Moses and Cividali, 1966, Papadopoulos et al., 2011, Pronzato et al., 1994).

The physical health and type of cancer have also been shown to impact awareness, including having metastatic disease (Costantini et al., 2015), a worse performance status (Aggarwal et al., 2016, Barnett, 2006, Lambden et al., 2016) and site of the cancer (Chou et al., 2013). Psychological characteristics of patients can also influence their awareness of disease status, including coping mechanisms (Andruccioli et al., 2009, Andruccioli et al., 2007, Hoff and Hermeren, 2008, Liu et al., 2014, Morasso et al., 1996, Nord et al., 2003) such as denial

(Atesci et al., 2004, Chandra et al., 1998, Fried et al., 2006, Germino and McCorkle, 1985, Helft et al., 2003) and maintaining hope (Robinson et al., 2008).

### *Consequences of Awareness of Disease Status*

Twenty articles stated that awareness of disease status had an impact on treatment decisions (Aoki et al., 1997, Baek et al., 2012, Burns et al., 2007, Caruso et al., 2000, Chou et al., 2013, Corli et al., 2009, Enzinger et al., 2015, Helft et al., 2003, Kao et al., 2013, Lambden et al., 2016, Leung et al., 2006, Mackillop et al., 1988, Morasso et al., 1996, Prigerson, 1992, Ray et al., 2006, Tang et al., 2016, Temel et al., 2011, Weeks et al., 2012, Weeks et al., 1998, Yun et al., 2011). Among these, the ones that cited specific treatment decisions all showed that patients were less likely to choose aggressive end-of-life-care when they had greater awareness of disease status. Six articles reported that participants who had awareness of disease status were more likely to sign a Do Not Resuscitate (DNR) order or create a Living Will (Aoki et al., 1997, Enzinger et al., 2015, Kao et al., 2013, Lambden et al., 2016, Leung et al., 2006, Ray et al., 2006). Additionally, eight articles reported that participants who were aware of their disease status were less likely to end up in intensive care (Baek et al., 2012, Tang et al., 2016), use aggressive treatments towards end-of-life (Burns et al., 2007, Chou et al., 2013, Prigerson et al., 1992, Weeks et al., 2012, Weeks et al., 1998), and more likely to use palliative care services (Yun et al., 2011).

There continues to be conflicting reports on the impact of awareness of disease status on quality of life (QOL) and the studies included in this analysis further illustrate these tensions. Researchers used many instruments and measures of quality of life in the included studies. Such difference in measurement alone would yield variation in the responses. Of the twenty-two articles that reported impact on QOL, the results were equally divided. Nine articles reported a

positive impact on quality of life (Ahn et al., 2013, Ardestani et al., 2015, Chochinov et al., 2000, Kao et al., 2013, Lee et al., 2013, Leung et al., 2006, Nord et al., 2003, Roll et al., 2009, Tang, 2006). Another nine reported awareness of disease status had a negative impact of quality of life (Atesci et al., 2004, Barnett, 2006, Fan et al., 2011, Hinton, 1999, Lheureux et al., 2004, Montazeri et al., 2009, Ray et al., 2006, Tang et al., 2016, Thompson et al., 2009). Four reported no statistically significant impact on quality of life (Costantini et al., 2015, Enzinger et al., 2015, Tchen et al., 2003, Wang et al., 2014) Therefore, it is difficult to draw conclusions about the impact of awareness of disease status on quality of life.

### **Definition of Awareness of Disease Status and Adult Cancer Patients and Conceptual Model**

The following definition of awareness of disease status in cancer patients was derived from the results of this integrative review. The concept of awareness of disease status as defined by this analysis is *the individual patient's understanding of being diagnosed and treated for cancer based on the multi-factorial components of individual patient characteristics and contextually driven communication practices of health care providers. It is dynamic and changing throughout the disease trajectory.*

Figure 2 illustrates the relationships of the factors that impact awareness and the subsequent consequences of awareness of disease status identified in this review. Individual patient characteristics (gender, age, education, coping mechanisms, culture of patient and family, and type of cancer) impact awareness of disease status, as does communication with health care providers, language used, culture of the health care provider, and hospital type and location. There are also contextual characteristics of the health care environment that have been shown to

impact communication patterns between health care providers and patients that influence awareness of disease status.

Since the disease trajectory for cancer may be years for many patients, there will be multiple conversations between health care providers and patients that will result in changing levels of awareness throughout the disease journey. Awareness of disease status will impact communication patterns and subsequently, communication patterns impact awareness of disease status. Ultimately, it is the individual's awareness of disease status that will determine treatment decisions

### **Recommendation for Operationalization**

Due to the variations in operationalization of the concept of awareness of disease status, it is pertinent to have guidelines for how to measure the concept throughout the disease trajectory. Table three outlines recommendations derived from the existing literature and deemed appropriate to measure each dimension of awareness of disease status in cancer patients.

### **Discussion**

This paper helps clarify how the concept of awareness of disease status in cancer patients has been operationalized and conceptualized in the literature. Due to the lack of consistency in operationalization in previous research studies, researchers not able to measure the concept accurately and consistently, thereby resulting in a lack of understanding how awareness of disease status affects patients with cancer. In addition, the conceptualization and operationalization of the concept was from the perspective of the researcher; therefore, we still do not understand how the patient conceptualizes awareness of disease status.

Notably, only nine (14.5%) of the articles provided a conceptual definition for awareness of disease status. There are similarities between the referenced conceptual definitions and the

one developed in this paper, such as; the individuals understanding, communication with the health care provider and the nature of the fluctuation throughout. The generated definition differs because it takes into account the individual patient characteristics (gender, age, education, coping mechanisms, culture of patient and family, and type of cancer) and the contextually different communication practices of the health care providers (language used, culture of health care provider, and hospital type and location). This evidence-based definition is an addition to the science.

The resulting conceptual definition and conceptual model of awareness of disease status in cancer patients are a foundation for future research. Given the complexity of the topic, a qualitative approach would be ideal for capturing all the essences and dimensions of the experience. The operational definitions will also help future quantitative studies choose appropriate reliable and valid measures that can represent the operational definitions.

### **Implications for Nursing**

Many nurses have encountered patients that “just don’t get it,” which is often a source of frustration. This article will help nurses to have a better understanding of the multi-factorial components that impact the individual’s awareness of disease status. By gaining an understanding of the concept through the inherent and contextual characteristics captured in this review, nurses can then identify characteristics that may be impacting the patient’s awareness, which can result in a change to communication and education practices.

### **Conclusion**

This paper analyzed sixty-two articles that examine awareness of disease status in cancer patients. It proposes, to the best of our knowledge, the first coherent definition of “awareness of disease status” for adult cancer patients found in the literature. The conceptual model produced

by this study may help structure future research studies, both qualitative and quantitative. In addition, the recommendations for operationalization of the concept aim to help build some consistency in the literature to enhance its generalizability as a concept in future studies.

Nurses and other health care providers can immediately apply the findings from this study to their clinical practice with cancer patients. Policymakers may use the definition to design new quality measures for cancer care. Importantly, this work provides a solid foundation from which to study awareness of disease status in adult cancer patients and develop future interventions.

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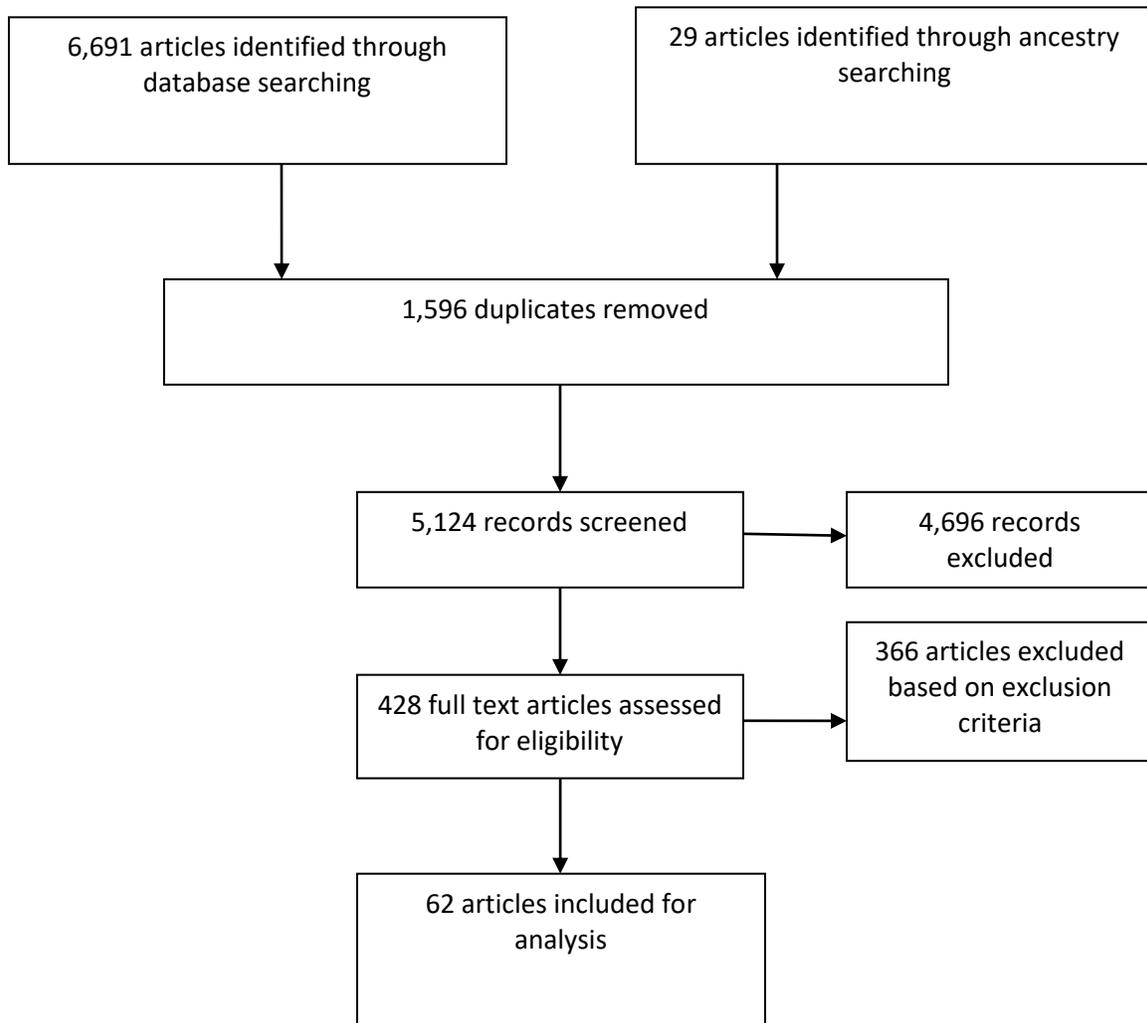
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**Figure 1 – Literature Search Diagram**



**Table 1: Analysis of Individual Articles**

Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
Aggarwal (2016) India	Determine the impact of patients awareness of cancer diagnosis on health related quality of life	n=391 cancer patients  85% male  Mean age 58  77.2% had non-small cell lung cancer	No conceptual definition provided	<b>Awareness of diagnosis</b>  Not all patients were told their diagnosis, if not told researchers “directly inquired if they knew the nature of their disease” It was assumed that if the doctor disclosed the diagnosis then the patient was aware	“Better educated” (p<0.001)  Better ECOG score (p<0.001)	No statistically significant difference in HRQL scores	71.1% were unaware of their diagnosis	Unclear how they are measuring awareness  Cross-sectional
Ahn (2013) Korea	To assess how the awareness of a terminal illness can affect care decision making and the achievement of a good death in advanced cancer patients receiving palliative care services	n=345 terminal cancer patients  53 % male  Mean age 64.58	No conceptual definition provided	<b>Awareness of terminal illness</b>  During initial assessment – a comprehensive interview: - patients expectations of treatment, emotional reaction to disease, and knowledge of their stage  Patients were deemed aware if he/she recognized the anti-cancer treatment was ineffective and that he/she is expected to die in a few months	Younger age (p<0.001)  Married (p=0.0026)  Higher education (p=0.003)  Christian (p=0.024)  Communication with HCP	Higher overall score on the Good Death Inventory (p=0.013)	32% were unaware of their terminal disease	Cross-sectional  Low response rate from large mail survey
Alaka Ray (2006) America	How patient’s awareness of terminal illness effects mental health and advance care	n=280 cancer patients with distant metastasis  54.4% Male	No conceptual definition provided	<b>Terminal illness acknowledgment, Patient evaluation of health</b>  ADS: How would you	None identified	Have a DNR (p<0.001)  EOL conversation (p<0.001)	73.3% were unaware of their prognosis	Sample bias

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	planning, quality of death, and caregiver bereavement outcomes	Mean age 57.3 years		describe your current health status"?  Options: -relatively healthy -seriously but not terminally ill -seriously and terminally ill Patients who responded to "seriously and terminally ill" were deemed aware		Worse QOL (p=0.05)		
Andruccioli (2007) Italy	Assess hospice patients awareness about prognosis and diagnosis	n= 100 cancer patients in hospice  55% male  Mean age 66.25	No conceptual definition provided	<b>Awareness of diagnosis and awareness of prognosis</b>  Diagnosis: 1. Which type of illness have you got? 2. Why are you recovered in this ward? 3. Which are your present and previous treatments?  Prognosis: 1. Which are your plans when you go back home? 2. Which are your wishes for the future? 3. What are you expecting from the hospice?  -Patients were	None identified	None identified	-30% were unaware of diagnosis  62% were unaware of prognosis	Smaller sample size  Cross-sectional

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				<p>considered aware of diagnosis if they could identify their disease as “neoplastic” (did not have to know specifics)</p> <p>-Patients were considered unaware of diagnosis if they could not identify that their disease was cancer or if they thought they have recovered from the disease</p> <p>-Patients were considered aware of their prognosis if they were realistic about goal of hospice care</p> <p>-Patients were unaware of prognosis if they thought that their disease was curable or if there life expectancy was longer than three months</p>				
Andruccioli (2009) Italy	To validate the questionnaire developed in 1994 by Morasso et al.	<p>51 participants with advanced or terminal cancer at two separate hospice facilities</p> <p>23.5% Male</p> <p>Mean age 62</p>	Illness awareness “Dynamic process that changes over time and is influenced by both the quantity and quality of information and by the meaning	<p>6 cognitive factors: type of disease, purpose of therapies, treatment options, prognosis, information seeking, therapeutic iter</p> <p>7 emotional factors: fear for life, vulnerability, emotional change,</p>	Based on Morasso: cultural beliefs, perceived needs, expectations, coping skills, defense mechanisms, locus of illness control	None identified	<p>60.8% unaware of their prognosis</p> <p>Tool was deemed not adequate to determine illness awareness due to high levels of defense mechanisms</p>	Small sample size – possible issues with power

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			that the patient connects to it. In this process, the patient integrates cognitive and emotional aspects" (p.385).	expectations for the future, assertive attitude, communication with family, and non verbal communication	(not measured statistically)			
Aoki (1997) Japan	How disclosure of "diagnosis", "pathology" and "prognosis" affected patients self determination and attitude	N=12 terminal cancer patients  58% Male  Mean age 53.8	No conceptual definition provided	<b>Disclosure of diagnosis, pathology or prognosis</b>  No measure of awareness	Communication with HCP  (not measured statistically)	More likely to sign a DNR (no statistical significance)	All four patients who were told prognosis had a DNR	Small sample size – issues with power  Retrospective chart review  This study just looked at what the patient was told not their understanding
Ardestani (2015) Iran	To investigate the amount of information that Iranian patients have and their preference for the disclosure of a cancer diagnosis	n=126 cancer patients (various types)  55.5% male  79.4% <60 years	No conceptual definition provided	<b>Awareness of diagnosis</b> "The first question regarded his or her disease and type. If the answer was known, patients were given the questionnaire prepared for those aware of their diagnosis"	Conversation with various health care providers (no statistical evidence)	Were not as mentally preoccupied by their condition (p<0.001)  Had less symptoms of anxiety and depression	39.7% unaware of their diagnosis	Unclear what the question is regarding awareness of diagnosis
Atesci (2004) Turkey	To determine if awareness of cancer diagnosis influences psychiatric morbidity	n=117 cancer patients (various types)  48.7% male	No conceptual definition provided	<b>Awareness of diagnosis</b> "What do you think you are suffering from?"  "Why do you think that you	Communication between HCP and patient  Cultural influences such	Awareness may lead to higher levels of psychiatric disorders (p=0.03)	54.7% of patients were considered unaware of cancer diagnosis  Only 14.5% of patients stated that they had been	Subjective determination of awareness  Cross-sectional

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		Mean age 53.7 years		are in the hospital”?  Based on the answers a psychiatrist determined if the patient was aware or not aware	as doctors not providing information to patient but to close relatives  Families not wanting the patient to hear the word cancer  Denial as a defense mechanism  (none of these measured statistically)		informed of their disease by a health care provider	
Baek (2011) Korea	Examine the effects of awareness of incurable disease status on satisfaction with treatment choice for palliative chemotherapy among patients with cancer	n=98 incurable cancer patients  68% Male  Mean age was 57.3	No conceptual definition provided	<b>Awareness of incurable disease status</b>  Unclear of specific questions asked to determine awareness  Based on results , one question was about expectation of chemo treatment and other if they were informed of their terminal status before chemotherapy began	Cultural practice of HCP to only inform family members of incurable disease status (not statistically measured) Patient’s family members forming a “communication barrier” between HCP and patient not statistically measured)  Patients having metastasis (p=0.02)	Hesitant about wanting chemotherapy (p=0.01)  Less likely to choose intensive care towards the end-of-life  (not statistically measured)	96% of patients knew that they had cancer, however, 50% did not know their cancer was incurable  43% thought the intent of chemo was to cure them  In the univariate analysis there was no significant difference between those patients who had ADS and those who did not (p=0.247)	Only two thirds of their sample completed all parts of the study  Cross-sectional

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Barnett (2006) England	Explore patient preferences for information, their satisfaction with the information they had received, and nay outstanding worries or concerns, and to relate this to their understanding of prognosis and psychological wellbeing	n= 106 advanced cancer patients  57% male  Mean age 65		<b>Aware of diagnosis/ prognosis</b> Used open ended questions on “levels of understanding” – at the end of the interview, the interviewer completed an observer rating of patient awareness of diagnosis and prognosis  Awareness was determined if a patient could: “Fully describe condition and treatment –able to separate effects of both” which was direct reference with certainty and realistic timescale	Patients in worse physical health (p=0.036)	Lower anxiety (p=0.012)  Lower depression (p=0.022)	22% unaware of diagnosis and 29% unaware of prognosis	Coding system very subjective – not able to code all participants
Bozcuk (2002) Turkey	To assess impact of awareness of diagnosis on emotional functioning and quality of life	n=100 cancer patients with various diagnosis  58% male  Median age was 54	No conceptual definition provided	<b>Awareness of diagnosis</b> No mention of specific question of awareness of diagnosis  Patients were either categorized as “knows” or “does not know”	Cultural practices in regards to disclosure of diagnosis  Favoring communication with the family as opposed to the patient  (none of these measured statistically)	No significant difference between aware and unaware groups on any of the scales of the QLQ-C30	44% of patients were unaware  Logistic regression did not have ADS as a factor that was a determinant of good “emotional functioning” (p=0.164)	Unclear how they made the determination of how a patient had awareness of diagnosis  Cross-sectional
Brokalaki 2005 Greece	Determine the level of information	n=203 cancer patients	No conceptual definition provided	<b>Awareness of diagnosis</b> Semi-structured interviews: do not relay specific	Being in a hospitalized specialized for	None	59% unaware of their diagnosis	Unclear how they made the determination of

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	provided to Greek cancer patients in regards to diagnosis	49% Female  Mean age 62.3%		language – questions surrounding diagnosis and then subsequent questions about the impact of that awareness and the desire to receive more information	oncology (p<0.001)  Female (p=0.004)  Higher education (p=0.024)  Younger (p<0.001)  Culture and relationship with family (not statistically measured)			how a patient had awareness of diagnosis  Cross-sectional
Burns (2007) Australia	Determine how awareness changes over the “continuum” and if family members have congruence and influence the awareness	n= 117 terminal cancer patients and their caregivers.  47% male  2/3 of the patients were above 60.	Awareness is dynamic over time  Full awareness: “Both respondents understand that the treatment was not intended to cure.”  Partial awareness: One member of the pair correctly understood that the treatment was	Patients and their caregivers were asked if the goal of treatment was:  To monitor illness, to improve quality of life, to control illness, or to cure the disease. Based on the answer to the above question, they dyads were then placed into one of the four categories	Living in an urban environment (p<0.02)  Dyads with female patients (p<0.03)	Potential for hospice care (not measured statistically)	37.6% of the dyads were unaware at the beginning of the study  Increased full awareness in the last six months of life (At least one member of the dyad had awareness 89%).	Longitudinal study Interview of patient and care giver – get a sense o how family influences awareness

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			not curative.”  Non- awareness: “both members of a pair believed that the treatment would cure the disease (misperception) or both members would not know whether treatment aimed to cure of not (confused).”					
Cartwright (2014) USA	To determine how cancer patients understand and discuss prognostic information	n=39 cancer patients with various diagnosis  46.2% male  Mean age -52.3	Patient’s conceptualized prognosis in terms of months or years for survival	N/A	Conversation with health care providers	Negative connotation with prognostic information	“Despite a wide range of experiences, diagnoses and stages, how participants discussed prognosis was the same across groups”  Misuse of medical jargon could mask underlying confusion	Qualitative – focus group bias  Different stages – would have different idea of prognosis
Caruso (2000) Italy	To determine the effect of physicians attitudes towards disclosing the	n= 403 cancer patients with various diagnosis  31% male	“Awareness of the type and stage of the disease refers to the patient’s ability to relate	<b>Awareness of diagnosis</b>  Based on a semi- structured interview: Aware of diagnosis: -“I am affected by	Younger age (p=0.05)  Disclosure of information by physician	Useful in making treatment decisions (not measured statistically)	22% of the adults and 41% of the elderly were not aware of their diagnosis  56% of adult patients	Different interviewers – different opinions on awareness

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	diagnosis of cancer and disease progression on patients awareness of their disease condition	311 adults (<64 years) and 92 elderly(>64 years)	to the image of his/her current health status" (p.200).	cancer" -I have a malignant tumor" -"I know I have cancer or I know I have a malignant tumor" Aware of prognosis: -"I know that my cancer is advancing" -I know I have metastasis"	(p=0.003)		and 59% were not aware of the progression	
Chandra (1998) India	Assess awareness of disease status in relation to psychiatric morbidity	n=294 primarily head and neck cancer patients  49% male  Mean age 45 years	No conceptual definition provided	<b>Awareness of cancer diagnosis</b>  Interviews with patient and relative: Use the words "cancer" or "malignancy" in regards to their disease "Why do you think you are in the hospital"? "What do you think that you are suffering from"? "What are you taking treatment for"? "Have you been told by doctors, relatives, and fellow patients about your disease"? Two psychiatrists then come to a conclusion based on responses	Communication with health care providers  (not measured statistically)	No statistical difference between aware and unaware group on depression and anxiety	46% were unaware of their diagnosis  72% of the aware group were unaware if their treatment was curative or palliative	Unclear the nature of the interviews
Chochinov (2000) Canada	To examine the relationship between	n=200 hospitalized adults with	No acknowledged	<b>Prognostic awareness</b>  Interview: -"What do you	Female (p=0.011)	Less likely to have depression (p=0.029)	9.5% with no awareness	Good discussion of conceptualizatio

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	prognostic awareness, demographic and social characteristics and psychiatric morbidity	advanced cancer receiving palliative care  Mean age 71	awareness: “the patient believed the illness to be curable, with no acknowledgment of terminal prognosis”  Limited awareness: “the patient reported an understanding that the illness is terminal but had unrealistic expectations of the time remaining (more than 6 months)”  Full awareness: “the patient had a full understanding of the gravity of the illness and the imminence of death” (p.501).	understand of your illness”?  “How serious do you believe things are”?  “What have you been told”?  -“Do have a sense of how much time might be left for you”?  Based on interview patients were placed in 1 of three categories: No acknowledged awareness, limited awareness, full awareness	Not being married (p=0.04)  Less personal contacts with family members – 8 or less per week (p=0.007)		17% with limited awareness	n of awareness
Chou (2013) Taiwan	To determine the effect of palliative care consultation service (PCCS) on disease awareness in terminally ill cancer patients	n=2,887 terminally ill cancer patients  At baseline 31% did not have disease awareness  Leaving n=895 patients without	No conceptual definition provided	<b>Awareness of disease</b> Interview with a nurse practitioner – patients were deemed aware if they could describe the following:  Name of disease  Stage of disease  Acknowledgement of the	Longer duration from admission to PCCS (p=0.02)  Male (p=0.012)  Divorce (p=0.035)	More time for EOL planning  Less aggressive EOL care  (not measured statistically)	31% unaware of their disease status prior to PCCS intervention  50% became aware after PCCS intervention	Retrospective review  Unclear how they made the determination of awareness

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		awareness		incurable nature of the disease	Family having awareness (p=0.001)  Cancer site  Being younger than 75 (p=0.012)			
Clavarino (2003) Australia	Determine the effect of medical "truth-telling" on the patient's will to live, perceptions of the curability of their cancer and their subjective well- being in patients with metastatic cancer	46 metastatic cancer patients with a life expectancy between 3 months and two years  59% Male  70% over 50 years old	Do not specifically choose one, but refer to Kellehear's definition: "Patient awareness of dying on the ways in which patients referred to their condition and to their future prospects. He argued that use of words to do with death and dying, for example, 'terminal' or "I'm going to die' or 'my illness is incurable' were indicative of awareness of dying" (p.4).	<b>Beliefs about the curability of their cancer</b>  Semi-structured interview:  "I believe that my cancer is curable" -Likert scale 1=strongly agree, 5= strongly disagree  "Which of the following statements best describes what your doctor has told you about your cancer"?  "My doctor says that my cancer is curable or not curable"  "I am not certain what my doctor has told me about cure"  "My doctor has said nothing to me about cure"	Information given by HCP  Personal qualities  (not measured statistically)	Preparing for death  (not measured statistically)	54% patients did not believe that their cancer was incurable, despite being told by their HCP  Over the three time periods: t1-50%, t2-56.8%, t3-40.9% believed that their cancer was curable	Small sample size, but longitudinal  Qualitative and quantitative analysis  Not all the patients are at the same point in their disease trajectory
Corli,	To explore the	550 advanced	"The patient's	<b>Illness awareness</b>	Increased level	Treatment	45% not aware of their	Did not do a

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(2009) Italy	level of illness awareness in terminal cancer patients	cancer patients and 594 of their caregivers  54% men  Median age 74	real understanding and level of consciousness about the type of disease, the prognosis, and life expectations, which come from the personal rework he/she does with information he/she has eventually been provided with" (p.355).	Checklist/structured interview: "What is the current patient's opinion/awareness of his disease"?  He thinks he has no disease  He thinks he as another disease, not a cancer He thinks he had cancer in the past, but now has another kind of disease  He knows that he has a cancer and that he is suffering for this  I don't know	of education  Currently receiving treatment  More "visible cancers" (skin, breast, GU)  Younger age  Information from HCP  Caregivers attitudes  (measured but only variance – not statistically significant)	decisions  (not measured statistically)	cancer diagnosis: 32% thought they had another disease, 10% was cancer but not now  59.2% of caregivers thought the patients were aware  The older the patient was the less likely they were to have ADS	more sophisticated statistical analysis, unclear if the factors listed are truly significant
Costantini (2015) Italy	To examine awareness of cancer diagnosis and prognosis and the relationship with distress and QOL	262 patients 93 metastatic disease  34% men  Mean age 58	No conceptual definition provided	<b>Awareness of cancer diagnosis and prognosis</b>  <b>Prognosis is operationalized by curability and severity</b>  Diagnosis – open ended question  "What is the nature of your illness and why are you being treated in the	Female (p<0.01)  Metastatic cancer (p<0.001)	No statistical impact on QOL	Only 16% not aware of their diagnosis  Of the metastatic patients – 49% were deemed not to have good awareness of prognosis	Cross-sectional

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				<p>hospital”?</p> <p>Prognosis- Likert scale</p> <p>“How much do you think your illness is curable”?</p> <p>“1=very difficult to cure to 10 = very easy to cure”</p> <p>“How much do you think that your illness is severe”?</p> <p>“1=very serious to 10=not serious at all”</p>				
Derman (1993) Turkey	To determine what percentage of patients know their diagnosis and to what extent, and whether the source or the degree of information differed according to the patient’s general education level	n=45 cancer patients (22 with lower and 23 with higher education)	No conceptual definition provided	<p><b>Awareness of disease</b></p> <p>Used 45 question interview – but does not reveal what the questions were</p>	Communication with HCP (not statistically measured)	None	<p>23% knew diagnosis and “probable” prognosis</p> <p>61% knew diagnosis but had “optimistic information” about prognosis</p> <p>Unclear if there is a difference between the education levels</p>	<p>Unclear how they made the determination of awareness of diagnosis and prognosis</p> <p>Small sample size</p>
Enzinger (2015) USA	To reveal percentage of patients who wanted to know	n=590 metastatic cancer patients	No conceptual definition provided	<p><b>Prognostic understanding</b></p> <p>To assess prognostic understanding, patients</p>	Prognostic disclosure (p<0.001)	<p>No statistical impact on QOL</p> <p>More likely to</p>	86.5% of the 252 patients willing to give a life expectancy – overestimated their	Patients may not have recalled prognostic discussions due

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	<p>their life expectancy and who recall having a discussion about prognostic estimates with their physician. To test the hypothesis that prognostic disclosure by physician is associated with more accurate patient perceptions of life expectancy and more frequent advanced care planning</p>	<p>50.6% male  Mean age 59</p>		<p>asked to estimate their own LE. Also asked to describe current health status as: (1) relatively healthy, (2) relatively healthy but terminally ill, (3) seriously but not terminally ill, or (4) seriously and terminally ill. Patients with 2 or 4 were considered to acknowledge their terminal illness</p> <p>If patients chose the answer; (2) relatively healthy but terminally ill or (4) seriously and terminally ill when asked to describe current health status, they were considered to acknowledge their terminal illness</p>		<p>have a DNR order (<math>p &lt; 0.001</math>)</p>	<p>survival</p>	<p>to denial, (Recall bias)</p> <p>This study did not capture prognostic conversations that occurred after the baseline assessment</p>
Epstein (2016) USA	To evaluate the effects of recent and past clinical discussions about prognosis on change in illness understanding by patients with advanced cancer	<p>n=178 incurable cancer patients</p> <p>32.8% male</p> <p>Mean age 59.7</p>	No conceptual definition provided	<p><b>Terminal illness acknowledgement</b></p> <p>“How would you describe your current health status?”</p> <p>“Which of the following best represents what your oncology providers have told you about a cure for your cancer?”</p> <p>“What stage is your cancer?”</p>	Recent communication with health care providers ( $p=0.002$ )	Better able to make treatment decisions  (not statistically measured)	<p>Pre-scan: 0: 32 (18%) 1: 48 (27%) 2: 47(26%) 3: 42 (24%) 4: 9 (5%)</p> <p>Post-Scan: 0:26(15%) 1: 46(26%) 2: 49(28%) 3: 44(25%) 4: 13(7%)</p> <p>69% had limited terminal</p>	<p>Prospective study</p> <p>Recall bias of patients discussion with health care providers</p>

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				<p>“Many patients have thoughts about how having cancer might affect their life expectancy...when you think of this, do you think in terms of?” (p.2399)</p> <p>Answers to questions coded as 1 or 0 to indicate presence or absence of each indicator. Scores added to construct summary score of 0 to 4 to reflect illness understanding</p>			illness acknowledgment	
Fan (2011) China	To evaluate the relationship between the disclosure of cancer diagnosis and QOL in Chinese home care patients with advanced cancer	n=173 advanced cancer patients  54.3% Male  Mean age 61.13 years	No conceptual definition provided	<p><b>Awareness of cancer diagnosis</b></p> <p>“How did you know about your condition?”</p> <p>No specific questions/ language provided</p> <p>Based on all these a determination of “knowledge” was made</p>	<p>Increased time with cancer (p=0.038)</p> <p>Cultural belief to avoid truth telling to patient</p> <p>Family/HCP withholding information from patient</p> <p>(not statistically measured)</p>	<p>Worse physical QOL (p=0.025)</p> <p>Worse emotional QOL (p=0.020)</p>	50.3% unaware of their diagnosis	<p>Cross-sectional</p> <p>Unclear how they made the determination of awareness of diagnosis</p>
Fried (2006) United States	To examine changes in understanding of prognosis by community-dwelling, seriously	n=218 community-dwelling older persons with advanced chronic illness	No conceptual definition provided	<p><b>Life expectancy predictions</b></p> <p>Patients were interviewed initially and every four months up to</p>	<p>Communication with HCP</p> <p>Doctors willing to communicate prognostic</p>	None	55% of patients who died within a year were uncertain of their prognosis at their final interview	<p>Prospective cohort study</p> <p>Unclear how they made the determination</p>

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	ill older persons and their caregivers, particularly as the time before the patients death shortened.	34% with CA 37% with COPD 29% with CHF  56% male  Mean age 72.8		a year:  “If you had to take a guess, how long do you think that you might have to live?”  No response choices were given	information  Denial  Anxiety  (not statistically measured)		There was no difference among diseases in terms of prognostication  19 patients who were interviewed within 30 days of their death – only 31% thought their life expectancy was <1 year	life expectancy predictions
Germino (1985) USA	To describe the acknowledged awareness of diagnosis, prognosis, treatment and treatment goals in lung cancer and MI patients  Determine if there is a relationship between acknowledged awareness levels to disease, time since diagnosis and symptom distress	n=121 56 with lung cancer and 65 with MI  69% Male  55% over 60 years of age	“Acknowledged awareness is conceptualized as the ill individual’s projected definition of the situation, particularly the verbal communications from which his knowledge of the nature and implications of his illness may be directly inferred” (p36).	<b>Acknowledged awareness</b> “Acknowledged Awareness Structured Interview Scale” Looks at the following categories: 1-How subjects referred to their condition 2-How subjects described their treatments 3-How subjects described their future 4-Whether persons referred to their own death during the interviews	Pain (p<0.05)	Symptom distress (p<0.01)	No statistical difference between MI and Lung CA patients in terms of awareness	Good conceptual definitions  One of the few scales that uses a Cronbach’s alfa to determine reliability, still <0.8

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Helft (2003) USA	To determine if there is a relationship between awareness of prognosis, hopefulness and coping in advanced cancer patients	n=179 advanced cancer patients that are enrolled in a phase 1 clinical trial  54% Male  Median age 59	No conceptual definition provided	<b>Awareness of prognosis/ survival estimates</b>  Questions of estimation:  1. Feelings about the chances of death due to cancer 2. Feelings about death due to cancer in the next 5 years 3. Feelings about death due to cancer in the next year  Answers: -It is certain that it will occur -It is probable that it will occur -It is not probable that it will occur -It is not possible that it will occur	Female (p=0.026)  Higher education (p=0.03)  Psychological variables: denial, fear, anxiety, and depression  (not statistically measured)	Decrease in hope (p=0.030)  Treatment decisions  (not statistically measured)	Only 16% could admit that death would be in 1 year, and only one third in five years	Did not include patients who had a prognosis of <6mos  Cross-sectional
Hinton (1999) England	To determine how cancer patients and family members “came to terms” with death and some of the influences of awareness	n=77 terminal cancer patients  56% men  Median age 65	No conceptual definition provided	<b>Awareness of dying</b>  Used a rating tool 1-9 to determine awareness. 1: “feeling certain of recovery” 9: “certain of death”. 5: noncommittal.  Ratings were based on statements made by the participants during the interview	Physical weakness correlated with increased awareness (p=0.01)  Patients who were aware spent a longer time in hospice care had a “marginal change” (p<0.1)	Increased anxiety (p<0.05)	Only 15% of patients had increased awareness of death closer to actual time of death  Relatives were consistently more aware than the patients	Longitudinal study - multiple interviews over time  Quantifying qualitative data  Late recruitment into the study

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Hoff (2008) Sweden	Describe the discrepancy between information patients received and the awareness of their illness	Followed 12 cancer patients 7 with hematological malignancies  5 with non-operable lung cancer	“To acknowledge what patients know in all phases of their disease, regarding their actual condition of health, of progressing disease and approaching death”  “It might also be possible to find a patients who is informed, yet not aware of his or her state of health, or that the patient is aware event though he or she is not informed” (p.2)	<b>Awareness of progressing disease</b>  Qualitative measurement of transcribed interviews  Classification of patients into four categories: informed and aware, not informed and not aware, aware though not informed, not aware though informed	Underlying mistaken beliefs  Language used by medical team is different from layman  “Collusion” between HCP and pt – avoidance of the conversation (on purpose to serve the patients needs?)  Coping ability	None	Obstacles to awareness of patients: obstacles due to physician, coping strategies of the patients, “collusion b/w patient and physician, progression of disease	Qualitative study  Interviewed at multiple time points  However, not able to interview all participants at later time points
Iconomou (2002) Greece	Assess patient preferences for information and to see which patients were aware of their diagnosis and to see if it effected QOL	n=100 cancer patients – 77% with stage III or IV  53% Female  Mean age 59 years	No conceptual definition provided	<b>Awareness of diagnosis/ illness awareness</b>  Open ended question “if the patient could name the illness for which they were receiving this treatment?”  The primary HCP and primary caregiver were asked to come to a	Younger age (p<0.001)  Higher education (p<0.001)  Breast cancer (p<0.05)  Cultural beliefs against disclosure	More dissatisfied with information received (p<0.05)  Care in general (p<0.05)  No statistical difference in	59% were unaware of their diagnosis  According to the ANOVA the following two variables impacted if a patient had ADS: younger age (p < 0.001) and higher education p <0.001)  ADS was not a significant	Assessment of doctors thinking that patients were aware is very subjective  Cross-sectional

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				consensus for those patients whom they could not figure out	of disease status  (not statistically measured)	QOL	variable in predicting QOL	
Johnston (2000) Ireland	Examine how patients “cope and manage their prognosis in interactions with others	n=16 terminal cancer patients and 14 caretakers.  Majority female  Age 43-77	Glasser and Strauss definitions: open awareness: “where the prognosis is openly acknowledged by everyone”	<b>Awareness of impending death</b>  No method just chose patients that were already deemed “aware”	Family relationships  Communication with the health care providers  (not statistically measured)	Communication with family members  (not statistically measured)	Hope remains an important part of the awareness process even knowing that death is close  Conditional open awareness is “a more realistic and perhaps inevitable response to negotiating a terminal prognosis	Qualitative study
Kao (2013) Taiwan	Investigated if telling the truth about terminal prognosis would affect cancer patients’ psycho-spiritual status and DNR consent	n=90 terminal cancer patients  58.9% Male  Mean age of 57.6	No conceptual definition provided	<b>Awareness of disease status/ terminal prognosis</b>  Determination was made after discussion with patients about expectations of their diseases  Patients were aware if they understood their prognosis and knew that death was approaching  Patients were unaware if they only knew their diagnosis	Cultural beliefs “Truth telling” by HCP  (not statistically measured)	More likely to sign a DNR (p=0.04)  Had less uncertainty (p=0.023)  Less anxiety (0.005)	26% were unaware	Small sample size, possible issues with power  Cross-sectional

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Lambden (2016) USA	Determine oncologist accuracy with life-expectancy by advanced cancer patients	n=85 patients terminal cancer patients  55% male  Mean age 60.5	No conceptual definition provided	<b>Survival estimates</b> Patients were asked "Have the doctors talked with you about how much time you have left to live?" Patients who said "yes" were asked to indicate what the estimate was	Old age (p=0.044)  Poor health status (p=0.017)  Community medical centers (p=0.027)  Catholic (p<0.001)	More likely to have a DNR (p=0.04)  More likely to have an end-of-life discussion (p=0.008)	When a patient was given 0-3 months – survival was overestimated by a median of 4.4 months. Most accurate between 9-12 months	Recall bias
Lee (2011) Korea	How awareness of disease status influence QOL	98 cancer patients  At 4-6 weeks, 75 remained (23.5% attrition)  2-3 month follow up (32.7%) attrition n=66  68.4% male  Mean age 57.3 years	No conceptual definition provided	<b>Awareness of advanced stage of illness</b>  "Do you know your disease stage"?  Response choices: advanced, locally advanced, early, and I don't know  Advanced = awareness Locally advanced, early, and I don't know = lack of awareness	Communication with HCPs  Family members as a communication barrier (Korean culture)  (not statistically measured)	Increased QOL (multiple statistically significant measures)  Reduction on anxiety (p=0.0003)  Reduction of depression (p=0.042)	At the beginning of study, 50% aware of disease status, by the end 48.5% of patients are aware	High attrition rate  Cross-sectional
Leung (2006) Taiwan	Determine the relationship between patients' awareness of terminal illness	n=37 terminal cancer patients  59.5% male	No conceptual definition provided	<b>Awareness of terminal illness</b>  Patients were deemed aware:	Culture where family makes decisions not the patient	Making a will (p=0.009)  Greater acceptance of	All patients knew they had cancer, 32.4% were unaware that they were terminal	Surrogate responses about wellbeing  Cross-sectional

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	and spiritual well-being	45.9% older than 65		<p>If they understood that they had an incurable cancer, death was unavoidable, and their lifespan was very limited</p> <p>Patient's were deemed unaware: If they knew nothing about the disease or if the patients only knew the cancer diagnosis, but were unaware of the terminal condition</p>	<p>Communication with HCP</p> <p>(not statistically measured)</p>	<p>death (p=0.02)</p> <p>Better spiritual well being (p=0.027)</p>		A lot of subjectivity in the measures
Lheureux (2003) France	To determine if there is an effect of disclosure of lung cancer diagnosis on QOL	<p>n= 70 lung cancer patients</p> <p>87.1% Male</p> <p>Mean age was 61.7 years</p>	No conceptual definition provided	<p><b>Disclosure of lung cancer diagnosis by a physician</b></p> <p>It was assumed that once the information was disclosed by HCP patient was aware</p> <p>No discussion what type of information and at what depth information was given</p>	<p>Communication with HCP</p> <p>(not statistically measured)</p>	<p>Worse QOL after disclosure of diagnosis</p> <p>Physical (p=0.03)</p> <p>Role (p=0.002)</p> <p>Emotional (p=0.0001) and Social functioning (p=0.014)</p>	No determination of who in the sample was actually aware	<p>Selection bias- healthy population</p> <p>No measure of what the patient's awareness – assumed they knew</p> <p>Pre-post test design</p>
Liu (2014) United States	If patients of physicians who report discussing prognosis earlier have more accurate awareness of their life expectancy	<p>n=686 patients with stage IV lung/colorectal CA</p> <p>51% male</p> <p>Median age 63</p>	No conceptual definition provided	<p><b>Accurate awareness of prognosis</b></p> <p><b>Estimation of survival time</b></p> <p>Patients were asked: "Based on your understanding about what your doctors have told you about your cancer, your health in general, and</p>	<p>Communication with a physicians whom reported discussing prognosis "now" (p=0.006)</p> <p>Patients who were closer to death (p&lt;0.001)</p>	<p>Improve the EOL care experience</p> <p>(not statistically measured)</p>	83.5% did not have accurate awareness	<p>Large sample size</p> <p>Unable to determine the health care provider/patient conversation</p>

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				<p>treatments you are receiving, how long do you think that you have to live?"</p> <p>Relatively "accurate perception of prognosis" was less than two year for stage IV lung CA and less than 5 years for stage IV colorectal</p> <p>Saying in God's hands or don't know were not deemed aware</p>				
Mackillop (1988) Canada	Determine how accurately cancer patients perceive their situation and to define factors which may lead to imperfect communication between doctors and their patients	<p>n=100 cancer patients with various diagnosis</p> <p>56% male</p> <p>82% &gt;50 years old</p>	No conceptual definition provided	<p><b>Awareness of disease and curability</b></p> <p>Patient interviews where the patient's perceptions of the illness, the patient's perceptions of treatment intent and the patient's expectations of treatment outcome</p>	<p>Higher education (p&lt;0.05)</p> <p>Communication with HCP (not statistically measured)</p>	Treatment decisions  (not statistically measured)	<p>33% of the patients with distant metastasis were not aware</p> <p>33% of patients being treated palliatively thought their treatment was curable</p>	<p>Subjective nature of determining awareness</p> <p>Cross-sectional</p>
Montazeri (2004) Scotland	To examine if knowledge of lung cancer diagnosis effects QOL	<p>n=238</p> <p>129 lung cancer patients and 109 with chronic respiratory disease</p> <p>60% male</p> <p>Mean age 67.5 years</p>	No conceptual definition provided	<p><b>Knowledge of cancer diagnosis</b></p> <p>A patients was deemed to have knowledge after "formal disease disclosure" by team of HCPs</p> <p>Not knowing group was those that were interviewed before "diagnosis"</p>	<p>Younger age (p=0.04)</p> <p>Type of lung cancer (p&lt;0.0001)</p>	No statistically significant impact on QOL	<p>Of the lung cancer patients -77% were unaware of their diagnosis</p> <p>No other significant differences between groups in terms of QOL measures</p>	<p>Cross-sectional</p> <p>Assumption that disclosure of diagnosis = awareness</p>

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Montazeri (2009) Iran	Compare QOL in patients who knew their diagnosis and those who did not	n= 142 GI cancer patients  56% Male  Mean age was 54.1 years	No conceptual definition provided	<b>Knowledge of cancer diagnosis</b>  Initially family was asked if patients knew diagnosis. Then patients were asked if they could tell the interviewer what was wrong with him/her  If patients could use the terms “cancer” or “tumor” then these patients were considered to have knowledge of their disease	Younger age (p=0.001)  Higher level of education (p=0.001)  Cancer site (p=0.001)  Culture (not statistically measured)	Worse QOL subscale scores physical (p=0.001) social (p=0.014) emotional (p=<0.0001)	52% did not know their diagnosis	Assumption that disclosure of diagnosis = awareness
Morasso (1996) Italy	To develop a valid and reliable methodology for assessing illness awareness in cancer patients	n=90 cancer patients in Italy First group of 36 was observed by 5 psychologist to “determine the domains of the concept of awareness”  Second group underwent semi-structured interviews  50% Male	“Is a dynamic process that under goes changes during the course of the disease...is affected by the quantity and quality of clinical information given to the patient and by the meaning assigned by each patient to this information”	<b>Illness /patient awareness</b>  6 cognitive assessments  7 emotional assessments  Coding semi-structured interviews  Agreement by 4 psychologists	Quantity and quality of information  Pre-existing characteristic of the patient  Defense mechanisms  Education level  Cultural background	Treatment decisions  (not statistically measured)	27.8% were not aware  They were able to classify patients in one of 7 awareness levels: Completely aware, aware rationalizing patient, aware denying patient, aware introvert patient, aware patient with inconsistencies, not aware informed patient, completely unaware patient	Was able to validate this method to assess awareness

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		Mean average age 57.3	(p.213).		(not statistically measured)			
Moses (1966) Israel	Determine different levels of awareness of illness – if they were related to personal attributes	n=30 cancer patients  76.6% Female  76.6% between the ages of 46- 65	“We viewed our patients as being on a continuum with regard to their conscious knowledge of their illness. This continuum ranged from those who appeared to be quite unaware of being seriously ill to those who clearly knew of their illness and all its implications”  Maximal awareness: complete conscious integration of all pertinent information leading also to appropriate behavioral patterns, such as taking steps deemed necessary when	<b>Awareness of illness</b>  Awareness was determined based on the multiple interviews of the patients by the two authors	Higher education ( $p < 0.02$ )  More likely to seek treatment ( $p < 0.01$ )  Communication with HCP  (not statistically measured)	Increased withdrawal from interpersonal relationships  Acceptance of fate  (not statistically measured)	56% with intermediate awareness  27% with minimal awareness	Unclear of how they quantified qualitative data  Conceptual definitions

Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
			recognizing their imminent death” (p.985).					
Nord (2003) Norway	Determine if patients who had past diagnosis of CA were able to report that they indeed had CA	n=2,697 former/current cancer patients  43% Male	No conceptual definition provided	<b>Awareness of their previous/current cancer diagnosis</b>  -Survey: “Do you have or have you had cancer?” - Yes/No	Female (p<0.001)  Age(very young and old) (p<0.001)  Communication with HCP  Coping mechanisms  (not statistically measured)	None	20% of the patients who participated in the survey were not aware of a cancer diagnosis	Cross-sectional
Papado- poulos (2011) Greece	Explore the influence of disease awareness of HRQOL of both cancer patients and their caregivers while receiving chemotherapy	n=212 cancer patients  56.1% Female  Mean age 57.4	No conceptual definition provided	<b>Disease awareness</b> Interview questions to caregiver:  “Does the patient know he/she has cancer?”  “Does the patient know he/she has metastasis?”  “Does the patient know he/she has relapse”? (if applicable)  “Does the patient know	Being female (p=0.006)  Higher education (p=0.022)  Younger age (p=0.021)  Patients with breast, GU, Lung, head/neck (p=<0.001)  Cultural belief in	Worse HRQOL (p<0.024)	40% were unaware of their disease	Cross-sectional

Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
				about his/her prognosis?"  Patient awareness was assessed in his/her ability to "acknowledge the illness and use the terms 'cancer' or 'tumor'"	non-disclosure  Communication with HCP  (not statistically measured)			
Prigerson (1992) United States	To understand the dynamics of the dying patient/primary care giver/patient to determine if the patient will acknowledge death and what type of treatment the patient will receive	n=76 geriatric patients who have a life expectancy of six months or less/primary caregivers/ physicians  50% Male  Mean age 71.3	No conceptual definition provided	<b>Death acknowledgement</b> Asking patients the following questions:  "How would you define the current condition of your health?"  Patients who responded terminal or seriously ill were "death acknowledgers"  Those who responded that they were relatively healthy or seriously ill but not terminal: "non death acknowledgers"	Communication with HCP (p<0.01)  Caregivers accepting of pending death (p=0.05)  Disclosure of terminal prognosis (p<0.0001)  Non-teaching hospitals (p<0.01)	Receive less aggressive EOL treatment  More likely to receive palliative care  (not statistically significant)	Only death acknowledgement was statistically significant if patient was to receive palliative care  Physicians at teaching hospitals were 17 times less likely to acknowledge that their patients were dying	Small sample size  Cross-sectional
Pronzato (1994) Italy	To determine the awareness, prognosis and meaning of palliative treatment to patients with incurable cancer	n=100 patients with stage IV solid tumors  42% Female  Median age 60	No conceptual definition provided	<b>Awareness of diagnosis and prognosis</b>  Structured interview using a questionnaire  No specific language but aiming at: patient's knowledge of his/her disease and of the prognosis, patient's satisfaction with	Communication with HCP  Cultural beliefs  Female  Higher education  (not measured statistically)	Ability to have informed consent  (not measured statistically)	62% had no awareness of their cancer  46% thought a cure could be achieved  Only 10% could correctly identify the treatment as being palliative	Cross-sectional  Could have done more sophisticated data analysis

Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
				information received, awareness of the aims of treatments				
Robinson (2008) United States	Patient/oncologist pairs to understand concordance of prognosis	n=147 advanced cancer patients & 51 oncologists  53% Female  Mean age 60	No conceptual definition provided	<b>Curability</b>  “Good concordance”:  Patient/oncologist only differ by 0-2 categories (Patient estimated 11-20% chance of a cure and MD had 0% chance of a cure)	Communication with HCP where the HCP made pessimistic statements (p=0.006)  Maintaining hope  (not measured statistically)	None	64% of the sample were treated with the intent to palliate  Statements of pessimism were significantly associated with concordance about chance of a cure (p=0.017)	Tape recording conversations with patient/HCP – determine awareness (no recall bias)  Only measured one aspect of prognosis via estimated chance of cure  Cross-sectional
Roll (2009) Cuba	First, to evaluate the needs of patients with advanced malignant disease using the Palliative Outcome Scale (POS)  Second, to look at these needs in comparison with demographic data and patient awareness of their diagnosis	n=91 cancer patients  57.1% Male  Mean age 59	No conceptual definition provided	<b>Knowledge of their disease</b>  “What do you know about your condition?”  Based on their answer they coded it into a binary (Y/N) variable	Cultural practices that do not inform patient of terminal condition  (not measured statistically)	Less problems with “other symptoms” (p=0.011)  Decrease in anxiety (p=0.03),  More likely to obtain information (p=0.028) And support (p=0.005)	59% were unaware of diagnosis	Cross-sectional  Unclear how they made the determination of patient knowledge  A more healthy cohort

Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
Tang (2008) Taiwan	Examine awareness of patient's prognosis, evaluate patient/caregiver agreement of end-of-life care, and QOL	N= 1108 terminally ill cancer patients and their family caregivers  59.5% Male  Median age is 61 years dyads	No conceptual definition provided	<b>Being able to name the disease and then be able to discuss the prognosis</b>  Patients were first asked if they knew their diagnosis  Then they were asked about their prognosis  Asked if the patient could name the disease and determine if it was curable or not	Cultural practices about disclosure of prognosis  Family allowing patient to have awareness  (not measured statistically)	Improved QOL (p=0.0010)  Congruence between family and patient on place of death (p<0.0001)	63.8 % of patients were unaware of their prognosis	Younger and healthier cohort than those who chose not to participate  Cross-sectional
Tang (2014) Taiwan	Association between accurate prognostic understanding and EOL care preferences and to also identify correlates of accurate prognostic understanding among terminally ill cancer patients	2,452 terminally ill cancer patients (determined by oncologist)  57% Male  88.87% > 65 years	No conceptual definition provided	<b>Accurate prognostic awareness/ curability</b>  First asking if participants knew their prognosis  "If so, whether their disease was (1) curable, (2) might recur in the future, but their life was not currently in danger, and (3) cannot be cured and they would probably die in the near future".  "Participants were recognized as accurately understanding their prognosis only if they indicated that their disease could not be cured and they would probably die in the near future". (p.781)	Male (p <0.001)  Younger age (p=0.002)  Higher education (p=0.007)  Lung Cancer (p=0.020)  Breast Cancer (p=0.001)  Academic Medical Center (p=0.002)	Less likely to want CPR (p<0.001)  More likely to want hospice care (p<0.001)	50.2% did not understand their prognosis  Huge sample from 23 hospitals	Cross-sectional  Large sample from 23 hospitals

Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
Tang (2016) Taiwan	Prospective study to evaluate the associations of accurate prognostic awareness and prognostic acceptance with psychological distress, existential suffering, and QOL	325 terminal cancer patients  57.5% male 32.1% >65 years	No conceptual definition provided	<b>Prognostic awareness and prognostic acceptance</b>  Prognostic awareness: "Asking if they knew their prognosis, and if so, whether their disease (1) curable; (2) might recur in the future, but their life was not currently in danger; and (3) cannot be cured, and they would probably die in the near future. Patients were recognized as accurately understanding their prognosis only if they indicated that they knew that their disease could not be cured and they would probably die in the near future".  Prognostic acceptance: "On a 7-point Likert scale from 1 (not at all accepted) to 7 (complete acceptance). Prognostic acceptance was further dichotomized into high (>5) and low (<5) acceptance (5=median score)". (p.456)	Closer time until death  (not measured statistically)	Prognostic awareness:  Severe anxiety symptoms (p=0.004)  Severe depressive symptoms (p=0.002)  Worse QOL (p<0.001)  Less likely to want ICU care (p=0.001) Intubation (p=0.003) Mechanical ventilations (p<0.01)  Prognostic acceptance:  Severe anxiety symptoms (p=0.003)  Severe depressive symptoms (p<0.001)  Worse QOL (p=0.05)	58.5% with prognostic awareness in the beginning – at the last assessment 69.8%  41.5% without prognostic awareness in the beginning – at the last assessment 30.2% unaware	Longitudinal study  Not every patient was able to be reassessed –the assessment itself impacting the results

Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
Tchen (2003) Canada	To determine if patients who speak English will have a better understanding of their disease than those who speak another language and that those who do have poorer knowledge of their disease will have worse QOL	n=202 cancer patients 52 English speaking, 50 Portuguese, 50 Italian and 50 Chinese speaking	No conceptual definition provided	<b>Awareness of disease/ curability</b>  To name their type of disease, whether it was a particular type, and which parts of the body were affected. It provided a check list of treatments received during the last 3 months and asked if doctors had taken time to explain the nature of disease and the chance that it might be cured (yes/no answers)  “What do you think is the chance that your disease will be cured?”  Circle best estimate (choices from 0-100% in 10% increments) (p.642)	Communication with HCP (not statistically significant)	No statistical significance of patient’s knowledge of stage of disease and QOL  Patients with a more realistic view of cure having better QOL (p=0.005)	All patients estimated their probability of a cure to be higher than that estimated by physicians (p<0.0001)	Cross-sectional  Feasibility study with a convenience sample  Lack of power to detect other variables
Temel (2011) United States	RCT to determine patients perceptions of prognosis and goals of therapy, then to determine	n=151 metastatic NSCLC patients  77 received the intervention and	No conceptual definition provided	<b>Illness perception/ Curability</b>  Self-report items:  “My cancer is curable”	Introduction of a palliative care program early (p=0.02)	Less likely to take chemotherapy (p=0.02)	Initial interviews showed 31.7% thought their cancer was curable  69.4% also reported that the goal of therapy was to	Randomized control trial

Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
	if early introduction of a palliative care programs impacted patient illness perception over a six month period	74 received the control  48% male  Mean age 65		(yes/no)  “The goals of my therapy are to ‘help me live longer’” (yes/no), “try to make me feel better” (yes/no), or “get rid of all my cancer” (yes/no)			get rid of all their cancer	
Thompson (2009) Canada	To explore the issue of prognostic acceptance on the physical, psychological, and existential well- being of patients with advanced cancer and the factors that may contribute to this process	n=381 terminally ill cancer patients	No conceptual definition provided	<b>Prognostic acceptance</b>  “So you feel that you can accept your situation and come to terms with all that is happening?”  Pt were deemed “acceptors” if they scored 0 to 2 on the item, corresponding to “no” to “mild difficulty” with accepting	Older patients (p<0.000)  Less educated (p<0.05)  Bigger social networks (p<0.05)	Less likely to have depression (p<0.01)  Anxiety (p<0.01)	25.7% had minimal – severe difficulty with acceptance	Mixed methods  Cross-sectional  Patients already receiving palliative care
Wang (2014) China	To understand patient’s awareness of their disease with semistructured interviews and then evaluate where there were significant differences in psychological morbidity and HRQoL	252 potential cancer patients  71% with cancer 45.8% early stage 54.2 advanced stage  59.9% male  31.3 =% >60 years	“The patient knowing that his or her illness was cancer...” (p.1192)	<b>Patient’s awareness of cancer diagnosis</b>  “Patients were asked whether and how the patients had been given the information of cancer diagnosis”.  Semi-structured interview – “aim was to elicit patient’s awareness of their disease. If the patients knew that they had cancer they would be asked to describe how they learned of the diagnosis”. (p.1192)	None identified	No difference between groups in anxiety and depression (p=0.572)	Not all patients were aware of their diagnosis and all were awaiting surgery – major confounder	Vague categorization – used rational that patients awaiting diagnosis (without disease) are in a similar position as those who have disease  Cross-sectional

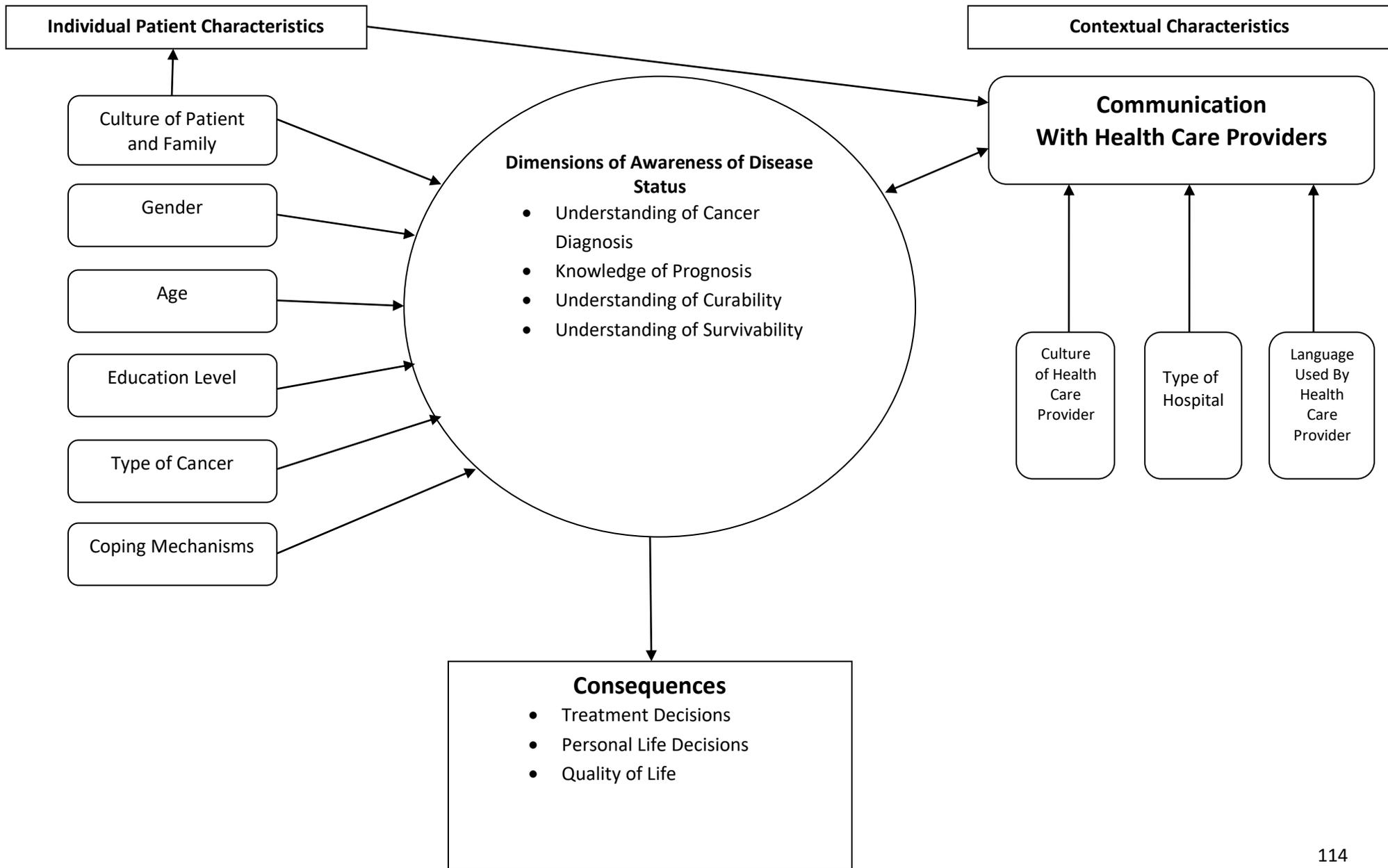
Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
				(From previous manuscript Wang, et al., 2011)				
Weeks (1998) America	If patients estimates of life expectancy effect treatment preferences  If patients and HCP's estimates are in alignment	n=917 cancer patients  39% metastatic colon cancer 61% stage IV lung cancer  62% Male  Mean age 62 years	No conceptual definition provided	<b>Survival estimates</b>  “What are the chances that you will live for 6 months or more?  Choices: 90% or better About 75% About 50-50 About 25% 10% or less	Communication with HCP	Patients who had a 90% estimation that they would be alive in 6 months were more likely to favor life extending therapy (2.6 odds ratio)	Patients were less accurate about their survival time than their HCP  57% of patients who thought they had a 90% chance of surviving 6 months died at the six month mark	Prospective observational study  Low response rate
Weeks (2012) America	To report expectations of patients with metastatic lung or colorectal cancer about the effectiveness of chemo (likelihood of a cure)	n=1193 Stage IV Lung =710 Stage IV Colorectal =483	No conceptual definition provided	<b>Curative intent of treatment</b>  “After talking with your doctors about chemotherapy, how likely did you think it was that chemotherapy would... Help you live longer Cure your cancer Help you with problems you were having because of you cancer”  Response options: “Very likely” “Somewhat likely”	Lung CA (p<0.001)  Identified as white (p<0.001)  Integrated health network (p=0.002)  Perceived negative communication with HCP (p=0.002)	Informed consent of treatment  (not statistically measured)	69% of patients with lung cancer and 81% of those with colorectal cancer gave answers that were not consistent with understanding that chemotherapy was very unlikely to cure their cancer	Cross-sectional  Large sample size

Author/ Year/ Study Origin	Aim	Sample/ Patient Characteristics	Conceptualization of Awareness of Disease Status	Operationalization of Awareness of Disease Status	Factors that Impact Awareness of Disease Status	Results of Having Awareness of Disease Status	Key Results	Strengths/ Limitations
				<p>“A little likely” “Not at all likely” “Don’t know”</p> <p>Participants that stated “was not at all likely” to be curative were considered to have awareness (p.1617)</p>				
Yun (2011) Korea	To evaluate the impact of cancer patients awareness of their terminal disease status and the use of palliative care or ICU use on survival	n=terminal cancer patients  56.9% Men  70.3% <65 years old	No conceptual definition provided	<p><b>Ability of patient to state stage of disease at diagnosis</b></p> <p>Do you know your disease stage?”</p> <p>Answer choices: I don’t know, early stage, advanced stage, terminal stage, other.</p> <p>Also, other “end of life issues” were evaluated, but they are not clear as to what they are (p.2475)</p>	Communication with HCP  (not statistically measured)	More likely to use palliative care (p=0.019)	41.6% of patients were not aware of their terminal status at beginning of study  82.9% were aware at time of death	Selection bias

**Table 2: Conceptual Definitions**

<b>Author and Year</b>	<b>Concept</b>	<b>Definition</b>
Corli, (2009)	Illness awareness	“The patient’s real understanding and level of consciousness about the type of disease, the prognosis, and life expectations, which come from the personal rework he/she does with information he/she has eventually been provided with”
Morasso (1996)	Illness Awareness	“Is a dynamic process that under goes changes during the course of the disease...is affected by the quantity and quality of clinical information given to the patient and by the meaning assigned by each patient to this information”
Moses (1966)	Illness awareness	“We viewed our patients as being on a continuum with regard to their conscious knowledge of their illness. This continuum ranged from those who appeared to be quite unaware of being seriously ill to those who clearly knew of their illness and all its implications”
Germino (1985)	Acknowledged Awareness	“Acknowledged awareness is conceptualized as the ill individual’s projected definition of the situation, particularly the verbal communications from which his knowledge of the nature and implications of his illness may be directly inferred”
Caruso (2000)	Awareness of Diagnosis	“Awareness of the type and stage of the disease refers to the patient’s ability to relate to the image of his/her current health status”
Hoff (2008)	Awareness of Progression of Disease	To acknowledge what patients know in all phases of their disease, regarding their actual condition of health, of progressing disease and approaching death”
Andruccioli (2009)	Illness awareness (Morasso’s definition)	“Dynamic process that changes over time and is influenced by both the quantity and quality of information and by the meaning that the patient connects to it. In this process, the patient integrates cognitive and emotional aspects”
Clavarino (2003)	Awareness of Dying (Kelleher’s definition)	Kellehear’s definition: “Patient awareness of dying on the ways in which patients referred to their condition and to their future prospects. He argued that use of words to do with death and dying, for example, ‘terminal’ or ‘I’m going to die’ or ‘my illness is incurable’ were indicative of awareness of dying”
Johnston (2000)	Awareness of impending death (Glasser and Strauss’ definition)	Glasser and Strauss definitions: open awareness: “where the prognosis is openly acknowledged by everyone”

**Awareness of Disease Status in Cancer Patients Conceptual Model**



**DYNAMIC AND CHANGING THROUGHOUT THE DISEASE TRAJECTORY**

**Table 3: Recommendations for Operationalization**

<b>Operatioanlization</b>	<b>Questions for Measurement</b>
<p>Knowledge of Diagnosis</p>	<p>Open-Ended Questions:</p> <ol style="list-style-type: none"> <li>1. What kind of disease do you have? (Any answer: cancer, tumor, neoplasm)</li> <li>2. Why do you think you are in the hospital?</li> <li>3. What do you think you are suffering from?</li> </ol> <p>Yes/No Questions:</p> <ol style="list-style-type: none"> <li>1. I am affected by cancer</li> <li>2. I have a malignant tumor</li> </ol>
<p>Prognostic Awareness</p>	<p>Open-Ended Questions:</p> <ol style="list-style-type: none"> <li>1. What do you understand of your illness?</li> <li>2. How serious do you believe things are?</li> <li>3. What have you been told?</li> <li>4. What is the stage is your cancer?</li> </ol>
<p>Curability of Disease</p>	<p>Likert-Scale:</p> <ol style="list-style-type: none"> <li>1. I believe that my cancer is curable (1=strongly agree, 5=strongly disagree)</li> <li>2. How much do you think your illness is curable? (1=very difficult to cure, 10=very easy to cure)</li> </ol>
<p>Intention of Treatment</p>	<p>Yes/No Questions:</p> <p>The goals of my therapy are to:</p> <ol style="list-style-type: none"> <li>1. help me live</li> <li>2. try to make me feel better</li> <li>3. get rid of all my cancer</li> </ol>
<p>Survival Estimates</p>	<p>Multiple Choice:</p> <ol style="list-style-type: none"> <li>1. What are the chances that you will live for 6 months or more</li> </ol> <p>Choices:</p> <p>90% or better            About 75%            About 50-50            About 25%            10% or less</p>

**Chapter 4:**

The Experience of Being Aware of Disease Status in Women with Recurrent Ovarian  
Cancer: A Phenomenological Study

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## **ABSTRACT**

**Background:** In the United States, each year about 22,440 women are diagnosed with ovarian cancer, the deadliest gynecological cancer - with an estimated 14,080 deaths each year. Patients with recurrent ovarian cancer have more options today due to advances in treatments, and specifically, with the advent of immunotherapies. Patients who have recurrent disease have to make many treatment decisions throughout the disease trajectory. Awareness of disease status has been noted as one of the factors of the treatment decision making process in the ovarian cancer population. To date the literature has generally conceptualized and operationalized awareness of disease status in cancer patients from the health care provider's perspective. However, it is unknown how patients perceive their disease and their process of treatment decision-making.

**Purpose:** The purpose of this phenomenological study was to understand the lived experience of women with recurrent ovarian cancer and how they understood their disease and made their treatment decisions.

**Methods:** Two in-depth interviews were conducted with 12 women; each participant had recurrent ovarian cancer and had received multiple chemotherapy treatments. Each interview was approximately 60 minutes and was digitally recorded and subsequently transcribed for accuracy. Interviews focused on patients' understanding of their disease, factors that impacted their understanding, how patients participated in treatment decisions as well as the impact of being diagnosed with, and in treatment for, recurrent ovarian cancer. Colaizzi's method of phenomenological reduction guided the data analysis.

**Results:** Three themes were intuited to describe the phenomenon of being aware of disease status: 1) Perceiving recurrent ovarian cancer as a chronic illness; 2) Perceived inability to make

treatment decisions; and, 3) Enduring emotional distress. Each of these twelve women had different personal journeys of being diagnosed with and treated for recurrent ovarian cancer. Yet there were shared essential experiences of how they understood their disease status, the process of making treatment decisions and the emotional distress of managing recurrent ovarian cancer. Within the context that more treatments were available for managing recurrent ovarian cancer, participants did not associate their disease with imminent death and instead they viewed their disease as a chronic illness and focused on “stabilizing” their disease with available treatments.

**Conclusions and Implications:** The results of this study revealed how twelve women with recurrent ovarian cancer experienced being aware of disease status. The participants conceptualized recurrent ovarian cancer as a chronic disease in the context of having more treatment options available to them. They had perceived inability to make treatment decisions due to lack of information and professional qualifications, which resulted in enduring emotional distress. These results provided insight into how patients with recurrent ovarian cancer understand their disease. In addition, the study highlights the difficulty patients may have making treatment decisions. There is opportunity for future research to validate these findings and to do interventional research with the aim of assisting patients with cancer to make treatment decisions.

## **Introduction**

Ovarian cancer claims the lives of fourteen thousand women in the United States each year as another 22 thousand receive a new diagnosis for the same disease.<sup>1</sup> The majority of women diagnosed with ovarian cancer present with advanced-stage disease (stage III and IV), due to lack of effective early screening measures.<sup>2</sup> The first line treatments for advanced ovarian cancer are surgical cytoreduction and platinum- and taxane-based chemotherapy.<sup>2</sup> Patients with recurrent ovarian cancer have more options today due to advances in treatments, specifically, with the advent of immunotherapies.<sup>4</sup> After receiving first line treatment, however, approximately 75% of advanced-stage ovarian cancer patients will have disease recurrence within five years, which will ultimately cause their death.<sup>2</sup> Whereas, there has been an increase in the five-year survival rate, it is still only 46.5%.<sup>1,3</sup>

For those patients who do survive, those who have recurrent disease have to make many treatment decisions throughout the disease trajectory. An important factor that influences treatment decisions in patients with cancer is an individual's awareness of disease status.<sup>6-13</sup> Researchers have noted that awareness of disease status is one of the factors involved in treatment decision making process in the ovarian cancer population.<sup>5</sup>

Two systematic reviews demonstrated that there is a lack of consistency in conceptualizing and operationalizing the concept of awareness of disease status,<sup>42,43</sup> resulting in the inability to compare across cases and a limited understanding of awareness of disease status in patients with cancer. Finlayson et al (Under review) proposed that "awareness of disease status" is defined as the individual patient's understanding of being diagnosed and treated for cancer based on the multi-factorial components of individual patient characteristics and contextually driven communication practices of health care providers. It is dynamic and

changing throughout the disease trajectory. They also provided a conceptual model that captures the different dimensions of the phenomenon so that future research studies can incorporate them simultaneously to full capture its effects on outcomes and experiences.

An important gap in the literature identified by both the systematic reviews and Finlayson et al (Under review) was that only three articles have used qualitative approaches to explore the concept of awareness of disease status in adult cancer patients.<sup>44-46</sup> The aim of these studies varied; one was to understand how patients understood and discuss prognosis,<sup>44</sup> another was to determine the discrepancy between the information patients receive and their awareness<sup>45</sup>, and the last sought to determine how patients cope in relation to their awareness.<sup>46</sup> Each of the studies had participants with various cancer types and prognosis. Two used semi-structured interviews <sup>45, 46</sup> and one used a focus group approach. <sup>44</sup> These studies demonstrated how qualitative approaches can reveal the complexity inherent to patients' perspective of cancer. Due to the variation in objectives of the studies, methodologies and patient populations, no conclusion can be made about a patient centered conceptualization of awareness of disease status from these studies. Even with the addition of these qualitative studies, there is more to be discovered about how patients with cancer articulate awareness of disease status.

## **Aim**

The purpose of this phenomenological study is to understand the lived experience of being aware of disease status among women with recurrent ovarian cancer. This study seeks to answer the following questions: (1) What is “disease status” from the perspective of patients with recurrent ovarian cancer? (2) What is “being aware of disease status” from the perspective of patients with recurrent ovarian cancer? (3) How does “being aware of disease status” shape patients' life and treatment decisions?

## **Methods**

### **Ethical Considerations**

This study was approved by the Institutional Review Board of a large metropolitan cancer center and authors' institution. All participants signed a written informed consent. Confidentiality of the participant was safeguarded by conducting the interview in a private office, using an encrypted digital tape recorder and uploading to a password protected computer. Participants were provided with the contact information for free psychosocial services in the event of potential distress elicited during interviews. All names used in this report are pseudonyms.

### **Design**

Colaizzi's method of conducting a phenomenological study was utilized to gain an in-depth understanding of the phenomenon.<sup>47</sup> Phenomenological qualitative studies involve examining a phenomenon using in-depth techniques.<sup>47</sup> This approach explicitly seeks to capture the experience of living a phenomenon in order to provide an improved definition or conceptualization of it.

### **Recruitment**

Women with recurrent ovarian cancer were recruited from the outpatient gynecological medical service at a large metropolitan cancer center. The inclusion criteria were as follows: a) older than 21; b) diagnosed with recurrent ovarian cancer; c) had received at least two chemotherapy regimens and were currently receiving treatment; d) their primary oncologist had prognosticated that they had at least six months to live; and, e) able to speak and understand English. Participants were excluded if they were a) too sick to participate; b) no longer receiving treatment; or c) not emotionally stable. Fifteen women provided informed consent for the study,

two patients became too sick to participate and one was excluded because she was no longer receiving treatment.

### **Participants and Sample Size**

Purposive sampling was used to capture the experience of the phenomenon under investigation.<sup>47, 48</sup> Sampling occurs until data saturation is achieved, which in phenomenological studies can range from as few as 5 participants to up to 15.<sup>48, 49</sup>

### **Data Collection**

Each of the 12 women in the study were interviewed twice, the second occurring 2-4 weeks after the first. Each interview was approximately 60 minutes and was digitally recorded and professionally transcribed. Data collection for the first interview focused on patients' understanding of their disease, factors that impacted their understanding, how patients participated in treatment decisions as well as the impact of being diagnosed with, and treated for, recurrent ovarian cancer. During the second interview, participants were asked similar questions to clarify or explain in detail certain statements that were not clear or needed more exploration during the first interview. Data was collected from February 2016 through April 2017.

### **Data Analysis**

Colaizzi's seven step method was used for data analysis. It is a non-linear process involving repetition and overlap to ensure no detail of the phenomenon is missed<sup>47</sup>(Table 2, p.59). Data analysis began after the transcription of the first interview. Findings were discussed with a group of experts to ensure proper analysis and interpretation of the data

### *Rigor & Trustworthiness*

Credibility of this study was ensured by adhering to the following procedures. First, the primary researcher (CF) was trained by a phenomenological expert (MF) to conduct the study.

Second, the accuracy of these transcriptions was confirmed by listening to the recording of each interview while checking against the transcripts. Third, the emergence of similar data from interviews #1 and #2 demonstrated strong evidence for dependability. Fourth, inter-rater reliability was determined by using NVivo software between CF and AD. Fifth, a group of experts discussed the analysis and came to a consensus about the results.

## **Findings**

### **The Experience of Being Aware of Disease Status**

The sample size of twelve was determined by data saturation, that is, when no new information were obtained through interviews and no new themes emerged from interviewing additional participants.<sup>48, 49</sup> Data was saturated at ten participants, and an additional two participants were recruited to ensure no new information was missed. A total of n=12 women participated in the study all of whom had a diagnosis of recurrent ovarian cancer and were currently receiving treatment. The mean age of the participants was 58 with a range from 44-74 years and 83% identified as Caucasian and the remainder identified as African-American. There were differences in religious affiliations, marital status, education level, and years with ovarian cancer. Table 1 provides more detailed information. Table 2 gives the specific demographics for each participant.

Each of these twelve women had different personal journeys of being diagnosed with and treated for recurrent ovarian cancer. Despite the differences, there were shared essential experiences of how they understood their disease status, the process of making treatment decisions and emotional distress of managing recurrent ovarian cancer. Within the context that more treatments were available for managing recurrent ovarian cancer, participants did not associate their disease with imminent death, instead they viewed their disease as a chronic illness

and focused on “stabilizing” their disease with available treatments. As such, three themes emerged that describe the phenomenon of being aware of disease status: 1) Perceiving recurrent ovarian cancer as a chronic illness; 2) Perceived inability to make treatment decisions; and, 3) Enduring emotional distress. These three themes comprise the phenomenon of “Being Aware of Disease Status”.

### **Perceiving Recurrent Ovarian Cancer as Chronic Illness**

None of the women felt death was imminent, regardless of a diagnosis of recurrent ovarian cancer, which is currently not curable. The participants believed that there were more treatment options available for recurrent ovarian cancer, and that there was the possibility to keep the disease “stable”. All twelve women recognized that they would “have cancer forever” or “be on chemo” for the rest of their lives. Emily stated: “That is will be just like you have something to help you maintain the disease that you have” or as Melissa remarked: “Something that you’re diagnosed with that there’s no cure for it. But it could be managed clinically.” To expand on the notion of “chronic” many compared their treatment to that of diabetes and hypertension. Fay said: “It’s like me having diabetes, you’re not going to wake up one morning and it’s gone.” In a similar tone, Lindley explains to people “it’s a chronic disease like some people have diabetes or arthritis, and it’s something that cannot be cured. But it can be kept on under control.”

Many of these women acknowledged the precarious nature of their disease, but expressed that there would always be more treatment for managing the disease. Mary compared the management of her recurrent ovarian cancer to mold in the basement: “you know, you’ve got mold in your basement, chemo is the bleach, but if you don’t put a dehumidifier in, you know, after you’ve bleached the place, it just will come back. So his treatments are designed to kind of

help the body be that dehumidifier.” In addition, Jessica died shortly after the interviews were completed said: “I’ll assume that I have treatment options that lead somewhere other than death.” Lindley understood that it was a chronic illness, but did not necessarily think it was going to kill her: “I mean, the message, this is a chronic illness that you can live with, that it’s not going to absolutely kill you.” The words “wishful thinking” were also used to describe hope for more successful treatment by Mary: “there are days when I feel like, yeah, there’s stuff that can be done to knock these tumors out and put me in remission for a while.” Renee also expressed hope for the future: “I understand that this disease is not great. But you know what? I’ve been riding the wave of every new treatment. It’s worked, so I’m being optimistic it will continue.” It was the experience that when one treatment failed, that another would be available or that a novel clinical trial was on the horizon. Melissa mirrored that statement: “It’s like a countdown. I think of that five-year statistic but then I count down and say, okay, but I’m feeling good, I don’t feel sick. And I’m hoping that this clinical trial will get me past the five-year statistic.”

### **Perceived Inability to Make Treatment Decisions**

All the women faced numerous treatment options and felt unable to make their treatment decisions because they did not fully understand the treatment options presented to them. Four categories emerged to describe the phenomenon of perceived inability to make treatment decisions: 1) Inability to fully understand the information on treatment options; 2) Perceived lack of professional training to make treatment decision; 3) Wanting doctors to make treatment decisions; and, 4) Perceived failure as being a real partner in making treatment decisions. These four categories highlight the complexity and multidimensionality of this theme.

#### *Inability to Fully Understand the Information on Treatment Options*

Universally reported was that conversations with their doctors were critical in helping

them understand their disease and treatment options. However, they did not think that they understood everything that was presented to them. Emily stated that: “I wouldn’t say I got – I understood completely everything, but I kind of got the gist of what they were saying about.” Fay felt that she did not understand what was told to her about her treatment: “I think I learned things after the fact, not before. And I’d like to know before, good or bad. At least, I know what’s going on.” When participants felt they did not have enough information, they went on the internet sparingly. Diane stated: “The main reason to look on the internet...you don’t hear everything, like you’re sitting there and like half of it doesn’t register.”

In spite of this, many of the women were not doing online research because it was “depressing”, “disheartening”, “negative” and “scary”. For example, Jessica stated: “I have not been one to research everything and because that to me was extremely depressing. Everything I looked up about ovarian cancer, its viable rates and recurrence rates, I would be in a funk for a week...” Additionally, Patty said: “I never researched anything on the computer. I don’t think I had it in me to do that because I know and, and I don’t mean this way I say it, but I don’t want to hear other people’s bad experiences, their sob story.”

When probed if the supplemental information booklets were helpful in making the decision, all agreed that it was not helpful, even to some it was deemed “overwhelming” and “scary”. When discussing why she does not read the pamphlets, Fay stated: “You know, again, they give you the pamphlets. They give the printout. You read it. Everything is horrible. It means you go through and you read everything and a ‘fatal event can occur’, next line. What is the point? You say ‘why am I reading this? I need it. It has to be done’. So sometimes the less you know the better.” Anne also discussed that she does not read any of the material, because she is not in control over any of her choices: “I just don’t care, because I don’t care, because I

can't control what's going to happen, so I don't even read that stuff. I don't care about it. It's not important to me. I have no control over it."

#### *Perceived Lack of Professional Training to Make Treatment Decisions*

Overall patients expressed their lack of professional qualifications in making treatment decisions. Patty stated that she did not think she was qualified to make the decision: "Well, in the beginning, I was a little surprised. I'm thinking, well, these are my doctors. They should tell me what to do, you know? They're the doctor." Renee agreed that she did not have the credentials: "I don't think so. I mean, they're the experts, not me. And this is not my area of expertise."

#### *Wanting Doctors to Make the Treatment Decision*

The perceived lack of information and qualifications provoked the desires to have their doctor make treatment decisions for them because they trusted their doctors were professionally trained to do so. Having trust in the doctor was one of the most important factors in making treatment decisions. Emily stated: "I trust my doctor...I'm going along with what she said." Heidi mirrored this sentiment: "I was very confident in the – my doctor so if he said okay, you're off this...then we'll try this one. Fine. Fine with me. What do you recommend? Okay, that's it. Then we'll do this one." Again, this was illustrated when Renee stated: "I have a lot of faith with the doctors that I have here, that they're thoughtful about what they're picking for me. It's individualized for my particular cancer." Sarah stated: "If the doctor says it's time for a new drug, then it's time for a new drug. I just go with it."

#### *Perceived Failure of Being a Real Partner in Making Treatment Decisions*

The perceived lack of information and qualifications impacted their perception of themselves as "partners" in decision making. When asked to explain their role in the collaboration, Mary stated: "-- I don't want to feel like I'm in the driver's seat because I just don't

have the knowledge to earn that position on the bus, you know -- but I do feel like it's a partnership..." Heidi, expressed a similar sentiment: "A partner? Well, I'm not a doctor, I don't have a degree and I can read all about it all the time. How can I know that one's better over something else, exactly – you know, the drugs or whatever." Lindley agreed that it was ultimately the doctor's decision: "Okay, doc, what do you recommend? Because I haven't been to medical school."

### **Enduring Emotional Distress**

The presentation of a choice of treatment also became a source of stress and anxiety for many of the participants. This is due to the circumstance in which these participants found themselves, they wanted to be able to make decisions, but feel like they do not have the information and qualifications to do so. Jessica who was faced with a difficult treatment decision stated: "Something that I think, is thoughts would be helpful of giving patient options, it's kind of like, you know, I don't go to the auto mechanic and say, 'Okay, should I use this wrench or that wrench or that wrench?' Like that's your job, which one's going to fix the problem better?" Her frustration was apparent: "Okay here are your choices, your chemotherapy drug choices. There's this, pros and cons. There's this, pros and cons. There's this, pros and cons. How the hell am I supposed to pick which one I should get? Which one is best for me? Its options and more options. I don't know if that's terribly helpful. I don't know per se what the outcomes are." She later explained that: "I felt like there should be somebody that's a lot more qualified than I am to make the choice. Well I see that that's why it is done that way. I get that but I don't know, I guess, it just still seems a little absurd to be a part of that. I think there should be options and a recommendation."

Mary expressed frustrations with the decision making process. However, her source of

stress came from the lack of choice she perceived at times: “Every now and then I have a frustration that when it’s time ... when it’s decision-making time, we don’t sit down and go, okay, here’s all the options, and here’s why I’m recommending this one. He generally comes in with, ‘here’s the situation, I think it’s time to change, and here is my decision about it.’”

Moments later she further explained this point by stating: “Okay, what am I supposed to do, like argue with him about is this one is better than gemcitabine or carboplatin, you know, it’s kind of hard.”

Fay also expressed her stress about making treatment decisions. She feels that she has a lack of control and information, which creates stress. “If I had the information, ‘cause I probably would say, okay, listen this is what it is, you’re an expert, not me. This is what’s working and if it’s not, there’s other things you try. I probably wouldn’t change it, but maybe I would have less anxiety if I knew what the steps were.” Again, not feeling like she has enough information and control, she does not think that she is in “charge of her treatment”. She stated: “I’m not in charge because I don’t think I have enough information about things. It’s limited information. And I don’t feel like I’m being given any options so that I can actually make a decision.”

## **Discussion**

As science continues to advance and more treatment modalities for cancer will continue to develop, patients with recurrent ovarian cancer will be facing the challenge of making more and more treatment decisions along their disease trajectory even in the terminal disease stage. The twelve women discussed their perceived inability to make treatment decisions due to lack of professional qualifications and lack of ability to understand treatment information. The combination resulted in stress and compromised well-being. The women in this study revealed their experience with being aware of disease status within the context that they had options today

due to advances in treatments and can live longer with stable disease. Importantly, the participants conceptualized recurrent ovarian cancer as a chronic disease only in the context of having more treatment options available to them. The participants perceived their disease as chronic and did not think death was imminent, despite being diagnosed with a disease that cannot be cured. Their perceived inability to make treatment decisions due to lack of information and professional qualifications, which resulted in enduring emotional distress.

The aforementioned conceptualizations are a distinct difference from the way awareness of disease status has and is being operationalized and measured in the literature for patients with a terminal illness. The current literature measures awareness of disease status for terminal cancer patients in terms of curability and survivability.<sup>6, 8, 12, 13, 22, 25, 28, 31, 35, 37, 38, 40, 41, 46, 50-52</sup> The concept of cancer as a chronic disease has developed as people live longer with the disease.<sup>53-55</sup> However, none of the current literature uses measures of chronicity in the measurement of awareness of disease status in patients with this type of cancer.

The findings from this study suggest that it would be useful for researchers and clinicians incorporate concepts of chronicity into their work with ovarian cancer patients. Future research would include replication studies in various patient populations and centers to further confirm the consistency and trustworthiness of the findings. More research is also needed to see if this phenomenon exists in other cancer patient populations.

Future research should also help develop and test interventions that would help patients make decisions in ways that would ease distress. For example, a nurse led intervention designed to assist patients become more informed and feel more comfortable with the decision making process through dedicated time with a nurse would present the most efficient option given current constraints on clinical practice. Future studies should also include the development of a

quantitative instrument that measures the concept of awareness of disease status in cancer patients which includes the patient perspective of chronicity and disease management.

Finally, there are limitations inherent in this approach. Deeper understanding is the objective of a phenomenological study, not generalizability. It will be difficult to know if the essences discovered in this study would be applicable to other individuals with metastatic cancers. The participants in this study were also largely white middle class females. More studies with patients from different racial, ethnic, and socioeconomic backgrounds are needed to address this limitation and determine where findings are consistent and diverge based on these factors. Furthermore, patients treated in different hospitals may have different perceptions regarding the phenomenon of being aware of disease due to availability of treatments and clinical trials or culture of each cancer center.

### **Conclusions and Implications**

The results of this study reveal how twelve women, with recurrent ovarian cancer, experience being aware of disease status. The findings will help clarify conceptual and operational definitions of the concept of awareness of disease status in cancer patients. Importantly, this study revealed that patients have difficulty making treatment decisions and despite efforts to promote shared decision making between patients and providers, the work suggests that strategy may need further refinement for cancer patients. In the interim, there is an opportunity for health care providers to ease their distress during a health care encounter and be sensitized to the complexity of an ovarian cancer patient's awareness of disease status.

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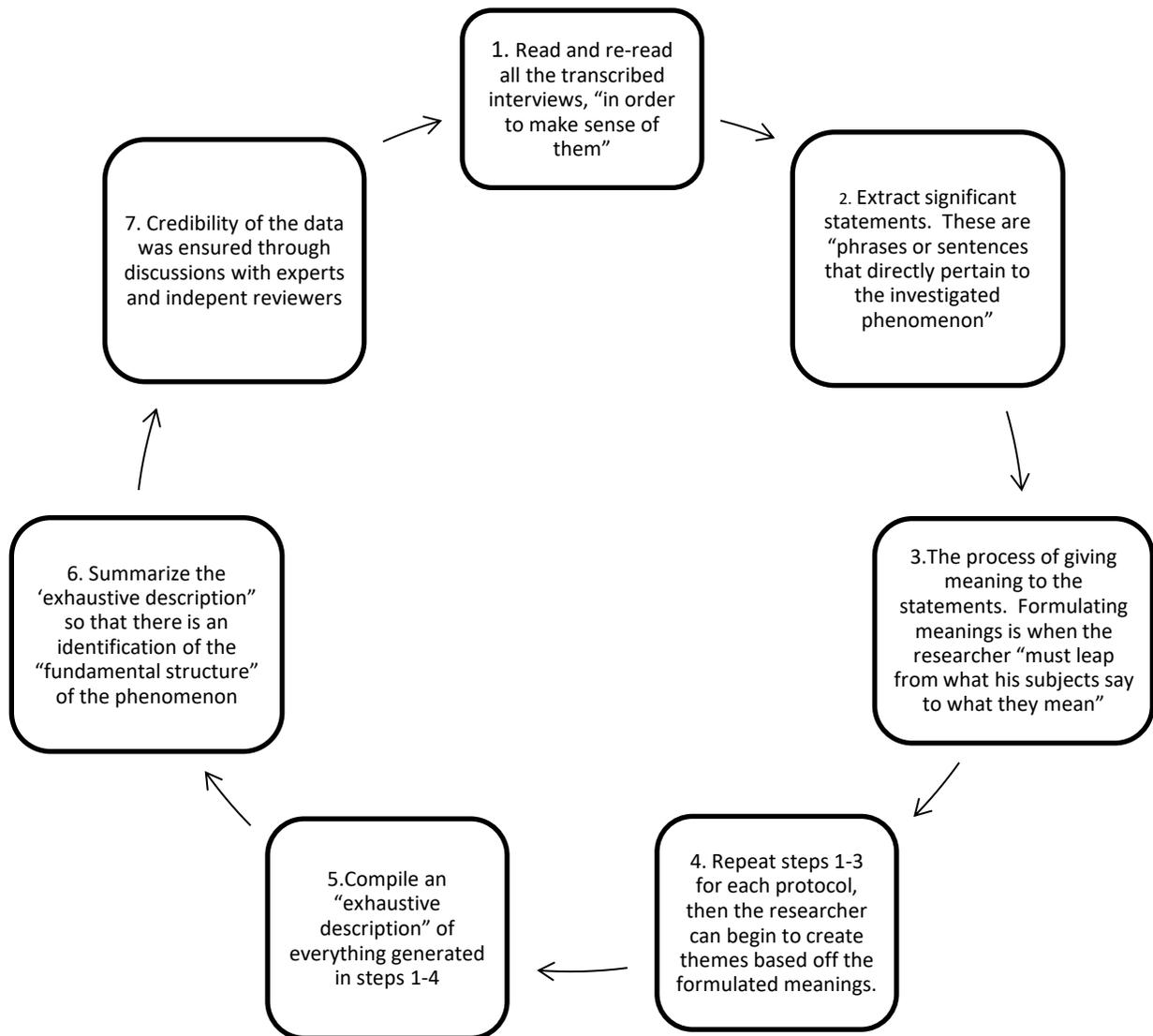
**Table 1 – Demographics of Participants**

<b>Demographics</b>	<b>Number of Participants</b>	<b>Percentage</b>		<b>Demographics</b>	<b>Number of Participants</b>	<b>Percentage</b>
<b>Age</b>				<b>Receiving treatment</b>		
40-49	2	16.67%		Yes	12	100.00%
50-59	4	33.33%		No	0	0.00%
				<b>Number of chemo lines</b>		
60-69	5	41.67%		<3	2	16.67%
70-79	1	8.33%		5	4	33.33%
<b>Race</b>				6	2	16.67%
White	10	83.33%		7+	4	33.33%
African American	2	16.67%		<b>Number of surgeries</b>		
<b>Marital Status</b>				1	3	25.00%
Married	7	58.33%		2	4	33.33%
Divorced	3	25.00%		3	2	16.67%
Widowed	1	8.33%		4	0	0.00%
Single	1	8.33%		5+	3	25.00%
<b>Children</b>				<b>Drains</b>		
Adult	9	75.00%		Yes	2	16.67%
Young	2	16.67%		No	10	83.33%
No	1	8.33%		<b>Working</b>		
<b>Education</b>				Yes	5	41.67%
HS	1	8.33%		No	7	58.33%
Some college	2	16.67%		<b>DNR</b>		
College	4	33.33%		Yes	0	0.00%
Masters	3	25.00%		No	12	100.00%
MD/PhD	2	16.67%		<b>Currently Alive</b>		
<b>Religion</b>				Yes	9	75.00%
Protestant	3	25.00%		No	3	25.00%
Catholic	6	50.00%				
Jewish	2	16.67%				
Spiritual	1	8.33%				
<b>Years with Cancer</b>						
<2 years	1	8.33%				
2-3 years	4	33.33%				
3-4 years	2	16.67%				
4-5 years	1	8.33%				
5+ years	4	33.33%				

**Table 2: Demographics of Individual Participants**

<b>Pseudonym</b>	<b>Age</b>	<b>Ethnicity</b>	<b>Marital Status</b>	<b>Children</b>	<b>Education Level</b>	<b>Religion</b>	<b>Years with Ovarian Cancer</b>	<b>Number of Chemo Lines</b>	<b>Number of Surgeries</b>	<b>Working</b>	<b>DNR</b>	<b>Alive</b>
Anne	61	White	Married	2 adult	College	Catholic	2.7	5	1	N	N	N
Diane	57	White	Married	2 adult	Masters	Lutheran	4.7	6	2	Y	N	
Emily	60	AA	Widowed	2 adult	2 years College	Methodist	2.8	7	1	N	N	N
Fay	61	White	Divorced	2 adult	College	Jewish	1.6	2	2	N	N	
Heidi	65	White	Divorced	1 adult	3 years college	Catholic	3.3	8	2	Y	N	
Jessica	44	White	Married	2 teens	College	Catholic	3.5	7	2	N	N	N
Lindley	74	White	Separated	2 adult	PhD	Jewish	5.2	3	3	Y	N	
Mary	56	White	Married	1 adult	College	Spiritual	2.5	7	1	N	N	
Melissa	45	AA	Married	2 young	DO	Episcopal	2.5	5	5	Y	N	
Patty	50	White	Married	1 adult	HS	Catholic	6.5	5	6	N	N	
Renee	55	White	Married	3 adult	MBA	Catholic	7	5	5	Y	N	
Sarah	65	White	Single	No	Masters	Catholic	8	6	3	N	N	

**Figure 1 – Colaizzi’s Steps for Data Analysis**



**Chapter 5:**  
Discussion and Conclusions

## **Introduction**

This chapter will discuss the collective work of the dissertation entitled: “The Experience of Being Aware of Disease Status in Women with Recurrent Ovarian Cancer: A Phenomenological Study”. The three papers presented in this dissertation are independent publications, but work in tandem to describe the state of the science of awareness of disease status, the development of a definition and conceptual model and finally a phenomenological study to help understand the phenomenon of awareness of disease status in cancer patients. This chapter will discuss the unique contribution each paper made to the science, implications for practice and research and finally recommendations for future research.

### **Paper 1: The Impact of Patient’s Awareness of Disease Status on Treatment Preferences and Quality of Life among Patients with Metastatic Cancer: A Systematic Review from 1997-2014.**

This paper demonstrated that there no consistent operationalization of the concept of awareness of disease status in patients with metastatic cancer (Finlayson, Chen, & Fu, 2015). These results were also found in a systematic review published around the same time (Applebaum et al., 2014). Despite differences in measurement of the concept, this review did show that patients who had awareness of disease status were less likely to choose life-extending treatment. This has broad implications because the incidence of cancer will continue to increase (Institute, 2017b) and that end-of life care continues to be major source of spending for Medicare (J. Cubanski, 2016). Therefore, the recommendation of this review was to have “evidence-based conceptualization of the concept, especially when considering conditions and needs specific to patients with metastatic cancer.” (p.4). Based upon this recommendation, it was concluded that a further exploration was needed into the operationalization and conceptualization of awareness of disease status. Therefore, the second paper looked at all the literature that examined the topic, not just if it had an impact of treatment preferences and quality of life.

## **Paper 2: Conceptualization and Operationalization of Awareness of Disease Status in Cancer Patients**

This study examined how sixty-two peer-reviewed manuscripts operationalized and conceptualized the concept of awareness of disease status in cancer patients. The major contribution of this paper is the development of a working definition, conceptual model and recommendations for the operationalization of the concept of awareness of disease status in cancer patients. These articles identified factors that impact awareness of disease status and it is through the existing literature that this model has its foundation. In addition, the conceptual definition is based off the conceptual model. Due to the lack of consistency in operationalization, researchers are not able to measure the concept accurately and consistently, resulting in a lack of understanding how awareness of disease status affects patients with cancer. Therefore creating the need for recommendation for operationalization of the various dimensions of the concept. Therefore, this paper aims to be a foundation for researchers who want to measure this concept quantitatively in the future.

One of the major results of this paper was that there is a definable and measurable problem of awareness of disease status. Twenty-three out of the 62 articles (37%) reported that often more than 50% of their participants were not “aware.” If this is the reality, how can we ask patients to engage in informed health care decision making if they are not aware of the purpose of treatment, especially in the advanced cancer setting? A study conducted of patients receiving palliative chemo therapy thought the purpose of the treatment was curative (Weeks et al., 2012). This becomes an issue of informed consent: “Patients without a sustained understanding that chemotherapy cannot cure their cancer have not met the standard for true ongoing informed consent to their treatment” (Weeks et al., 2012, p.1621). Not only are there implications in terms

of informed consent, there are also implications for patient autonomy and ethical decision making.

### **Paper 3: Experience of Being Aware of Disease Status in Women with Recurrent Ovarian Cancer: A Phenomenological Study**

The results of this study reveal how twelve women, with recurrent ovarian cancer, experience being aware of disease status. The women conceptualized recurrent ovarian cancer as a chronic disease in the context of having more treatment options available to them. The women in this study revealed their experience with being aware of disease status within the context that they had options today due to advances in treatments and can live longer with stable disease. These women understood their disease as chronic and did not think death was imminent, despite being diagnosed with a disease that cannot be cured. These women had perceived inability to make treatment decisions due to lack of information and professional qualifications, which resulted in enduring emotional distress. This is a distinct difference from the way awareness of disease status is being operationalized and measured in the literature for patients with a terminal illness. The current literature measures awareness of disease status for terminal cancer patients in terms of curability and survivability. (Ahn et al., 2013; Baek, Kim, Heo, Yun, & Lee, 2012; Clavarino, Najman, & Beadle, 2003; Epstein, Prigerson, O'Reilly, & Maciejewski, 2016; Hinton, 1999; Johnston & Abraham, 2000; Lheureux et al., 2004; Liu et al., 2014; Prigerson, 1992; Ray et al., 2006; Robinson et al., 2008; Tang et al., 2016; Tchen et al., 2003; Temel et al., 2011; Weeks et al., 2012; Weeks et al., 1998; Yun et al., 2011) The concept of cancer as a chronic disease has developed as people live longer with the disease. (Anchisi, 2016; Berlinger & Gusmano, 2011; Phillips & Currow, 2010) However, none of the current literature uses measures of chronicity in the measurement of awareness of disease status in patients with cancer.

Given the findings in this study, it would be prudent for future researchers and clinicians

incorporate the perspective of chronicity into their work. Researchers looking to quantitatively measure the concept of awareness of disease status should include some items that measure the concept of chronicity. These items would measure not if the disease is terminal or curable, but does the patient perceive their disease as chronic. Also, an item should be included that examined not if the goal of treatment was curative or not, but if the goal was to maintain disease or keep it stable. These subtle differences in measurement may give a more accurate understanding of the patient's awareness of disease status. Furthermore, for clinicians there are implications for practice. Understanding that your patient's may conceptualize awareness of disease status differently from you may improve communication to ensure that there is a foundation from where you both can work.

Science continues to advance and as more treatment modalities for cancer continue to develop, patients with recurrent ovarian cancer will be facing the challenge of making more and more treatment decisions along their disease trajectory even in the terminal disease stage. The twelve women in the study discussed their perceived inability to make treatment decisions due to lack of professional qualifications and lack of ability to understand treatment information. This resulted in stress and compromised effective well-being. The clear implication for future research is needed to determine interventions that would help patients make decisions, and subsequently ease distress. A proposal for future research is discussed further in this chapter.

### **Limitations of the Study**

There are limitations inherent in this approach. Deeper understanding is the objective of a phenomenological study, not generalizability. It will be difficult to know if the essences discovered in this study would be applicable to different individuals with metastatic cancers. More research is needed to see if this phenomenon exists in other patient populations. Given that

this is the first phenomenological study that looks at this concept, replicating this study in a different population may yield different results. There were measures put in place to ensure objectivity: 1) accuracy of these transcriptions was confirmed by listening to the recording of each interview while checking against the transcripts; 2) the emerging of the similar data from interviews #1 and #2 demonstrated strong evidence for data credibility and validity; 3) inter-rater reliability was determined by using NVivo software between CF and AD; and 4) a group of experts discussed the analysis and came to a consensus about the results. However, even given the rigor of the methods and approach, inherent in this approach is the primary researcher's subjectivity. Colaizzi's method does account for such subjectivity; however, it is possible that if another researcher conducted the same study with the same participants, they may have different results.

The average age of a woman diagnosed with ovarian cancer is 55 and the race with the highest incidence being white, followed by black (Institute, 2017a). The average age of the women in this study was 58 years with a range from 44-74 and 83% identified as white and the remainder identified as black. Whereas, this sample is in rough accordance with national demographics, being treated at Memorial Sloan Kettering Cancer Center (MSKCC), the patient experience may vary than that of a community hospital or a non-academic medical center. Many of the women in this study began their treatment at another hospital, but came to MSKCC to have more options. There may be differences in patients who choose to receive care at a major medical center than those who do not. Additional phenomenological research would determine if the themes revealed in this study emerge in different populations.

### **Additional Themes**

Given the nature of this type of investigation, additional themes emerged that were not

relevant to answer the questions, but were pertinent to the patient experiences. The themes had to do more with the psycho-social aspect of being diagnosed and treated for recurrent ovarian cancer. The following themes were intuited from the data: the impact of the recurrence; goals for the future; impact on life, attitude towards cancer and life and interpersonal relationships. Below are just highlights of each theme, the intent is to publish these findings in additional manuscripts after the completion of the dissertation defense.

### *The Impact of Recurrence*

After receiving first line treatment, however, approximately 75% of advanced-stage ovarian cancer patients will have disease recurrence within five years, which will ultimately cause their death (Ozols, 2005). Whereas, there has been an increase in the five-year survival rate, it is still only 46.5% (Institute, 2017a; Wright et al., 2015). Given these numbers many of the participants in this study were aware that the disease could recur, but they remained hopeful that it would not come back. For example, Anne said: “But it never occurred to me that I was going to be in recurrence at that point. It never entered my mind. Again, maybe because I was being hopeful.” However, there were participants that were unaware that it could recur. Diane stated: “I didn’t know it could keep coming back. So that’s what’s kind of like ‘whoa, I didn’t realize that that’s what could happen.” Regardless of awareness of recurrence, all participants had a shock when the ovarian cancer returned. Mary describes the distress: “...but, it was profound, the shock. And it really made me, it was like the 2x4 that hit me in the head.”

### *Goals for the Future*

In the context of their recurrent ovarian cancer diagnosis, many of the participants had different goals for the future when compared to those prior to the diagnosis. Many of the participants did not even think of the future because it became upsetting to them. For example,

Melissa stated: “I try to live for the present, not to think about what’s going to happen in the future but it still bothers me of the possibilities of what could happen...” Others just hoped to maintain a good quality of life, Heidi said this in response to what her goal for the future was: “My goal? Well, that if it’s going to help me, of course. It’s going to work; it’s going to do something. Give me whatever time or at least a better quality of life.” The most common theme among the participants was the goal for a long life and more treatment. Fay stated: “I can’t say that I have any. To stay alive. That’s my goal. I don’t really have any”.

### *Impact on Life*

Many of the participants discussed their ability to work as a major impact the recurrent ovarian cancer had on their lives. Seven of the twelve participants were not working; all but one were not happy about their inability to work because of their disease. Fay expressed disappointment when she was not able to work: “I was there more than 15 years, so I knew people very, very well. I was there more than I was home. So it’s a big loss when you stop going.” It was many of the participant’s work that really made it easy to get through treatment because it makes their life seem “normal” and “distracts them” from their cancer. Heidi explained that her work was: “Very important. Its cheap therapy, I always said that. It’s a very cheap therapy because you’re there, you don’t have time to think about yourself or dwell on anything...” Many of the women also described the physical toll the recurrent ovarian cancer has taken on their lives, especially the side effects of the medications. Many of the women described feeling tired and not able to do as much as they could in the past. This became a source of frustration, for example Fay: “I want to do things, but the medication makes me very tired, and then I get frustrated because I’m so tired.”

### *Attitude Towards Cancer and Life*

Many of the participants were resilient in the face of a terminal disease. Many discussed maintaining “normalcy” or a “new normal”. Emily discussed normalcy in her life: “Well, the cancer is, you know, 100% what causes the new normal. I think I would have gone, you know, blithely along in my old life, which is radically different. I mean, I shouldn’t say radically, I’m not ... it’s not like I’ve, you know, joined a cult or anything like that or moved to, you know. But it caused my new normal, for sure.” Some even expressed how cancer has been a gift for them, even that “cancer rocks” despite the terrible diagnosis. Mary describes this juxtaposition: “I really, I was perfectly sort of content before I went, but now that I’m sort of loving life so much, I don’t want it to end. So it’s like this blessing/curse, you know, that keeps sort of cycling around. So I just really stay focused on, you know, not just living but thriving every way I can and every day.” Even the ability to maintain strength was a theme that emerged, many of the participants wanted to ensure that they would be around for their family. Melissa stated: “This is the way -- in a nutshell, this is the way I see it. I have two children to raise and I don’t have time to be dead [Laughing] because -- my husband can be crazy sometimes. [Long spell of laughter]”

### *Interpersonal Relationships*

One of the most interesting themes that emerged was the participants discussing how their relationships changed when they did not look “like a cancer patient. Anne struggled with her family when she was still undergoing chemo: “Because I think they think because I look okay, they just assume that I’m better, and I don’t go anymore. They don’t know that the reason I look okay is because I do go.” Diane echoed this sentiment: “And the other thing is I hate when people just kind of look at you and do the whole thing of you don’t look like you have cancer, I’m like no, no, I do.” Heidi also discussed this juxtaposition of looking well, but still

struggling: "...that's why I try and tell them I say look, I may look okay, but my hands do hurt if I have to pick up something and do –bending over."

### **Implications for Policy and Practice**

The purpose of a phenomenological study is not to make broad statements across cases, but to have a deeper understanding of the individual experience. Therefore, it is difficult to make policy recommendations based off this study. However, in the studies included in chapter two and three demonstrated that patients who have awareness of disease status are more likely to sign a do-not-resuscitate (DNR) order or completed an advance directive (Ray et. al, 2006), acknowledge the decisional conflicts (Baek et. al, 2012), accept comfort care (Weeks et. al, 1998) and use palliative care (Yun et. al, 2011). Therefore, given the constraints on the healthcare budget and the expense of end-of-life care, it would be prudent to find ways to reduce cost. By ensuring that patients have a better understanding of their disease and the implications of their treatment there are potential cost savings from minimizing futile interventions towards the end-of-life.

There are direct implications for clinical practice. The twelve women in this study experienced difficulty making treatment decisions. At this juncture, it is unclear if this is a unique experience to the twelve women interviewed or if it is the experience of many cancer patients. Regardless, all patients with cancer will have to make treatment decisions at various points throughout the disease trajectory. There is an opportunity for health care providers to help patients and their care takers better understand the treatment options through individualized communication and education.

### **Proposed Future Research Based upon Results**

The results of this study reveal how twelve women, with recurrent ovarian cancer,

experience being aware of disease status. These women conceptualized recurrent ovarian cancer as a chronic disease in the context of having more treatment options available to them. These women had perceived inability to make treatment decisions due to lack of information and professional qualifications, which resulted in enduring emotional distress. Therefore, there are two paths for future research. The first is the development of an instrument based upon the patient conceptualization of being aware of disease status. The second is an intervention to help aide women with recurrent ovarian cancer to make decisions.

### ***Instrumentation***

As previously noted that there is no consistency in how awareness of disease status in cancer patients is operationalized (Applebaum et al., 2014; Finlayson et al., 2015). Then in the integrative review revealed the many dimensions of and factors that impact awareness of disease status in cancer patients. In addition, the conceptualization and operationalization of the concept has come from the perspective of the researcher. The results of this study provide information for how women with recurrent ovarian cancer understand their disease. In order to develop conceptualization and operationalization from the perspective of the patient, first more research would be necessary to develop instrumentation. Even though two of the participants were African-Americans, more research is needed to understand how other ethnicities undergo the experience of awareness of disease status in recurrent ovarian cancer. In addition, replication of this study in various cancer patients populations to see what the experience of being aware of disease status is for different cancers. After more information is gathered then work could begin in the development of a quantitative instrument to measure the concept of awareness of disease status in cancer patients.

### ***Intervention to Aide Women with Recurrent Ovarian Cancer to Make Treatment Decisions***

Results from my dissertation study reveal that the women who participated the perceived inability to make treatment decisions and subsequent enduring emotional distress. Whereas, these results cannot be generalizable, there is no evidence to suggest that this phenomenon is unique to this population. My recent research demonstrates patients with recurrent ovarian cancer have difficulty making treatment decisions. Therefore, it would be prudent to have an intervention where the goal is to help ease patient's distress when facing treatment decisions. The secondary aim is understand clinician's perceptions of their patient's awareness of disease status and how that impacts their ability to make treatment decisions. The hypothesis is that women with recurrent ovarian cancer will have difficulty making treatment decisions because they will be less likely to have awareness of disease status and understand the implications of treatment.

One example of this type of intervention protocol is The *DecisionKEYS for Balancing Choices* was designed to improve the decision making process specifically for patients with cancer who have to make specific treatment decisions and addresses the stress and conflict surrounding the decision (Hollen et al., 2013; Jones, Steeves, Ropka, & Hollen, 2013). The *DecisionKEYS for Balancing Choices* is a theory based nursing driven intervention where the purpose is to aid patients with their decision making.

## **Conclusion**

The three papers in this dissertation illustrate the journey from initial investigation to the conclusions of the study. The first discovery was that there was no consistent operationalization of the concept of awareness of disease status in cancer patients. This lead to further exploration of how the concept was conceptualized and operationalized throughout the literature, which resulted in the development of a conceptual definition, conceptual model and recommendations

for operationalization in the future. However, these two reviews did not answer the question initially sought out – what do patients truly understand about their disease status? The results of the dissertation study revealed that the participants perceive recurrent ovarian cancer as a chronic disease even though it is currently not curable. In addition, due perceived lack of information and professional qualifications, they have difficulty making treatment decisions, which lead to enduring emotional distress. These findings are a foundation for future research: the development of quantitative instrumentation to measure the concept of awareness of disease status in cancer patients from the patient perspective and intervention research aimed to ease the distress of decision making.

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