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# Awareness of Disease Status Among Patients With Cancer

## An Integrative Review

### KEY WORDS

Awareness  
Cancer  
Decision-making  
Disease status  
Health status  
Neoplasms  
Prognosis  
Truth disclosure

**Background:** As the quality of cancer care improves, oncology patients face a rapidly increasing number of treatment options. Thus, it is vital that they are full and active partners in the treatment decision-making process. Awareness of disease status has been investigated in the literature; it has been inconsistently conceptualized and operationalized. **Objective:** The aim of this integrative review was to develop a conceptual definition and model of the awareness of disease status among patients with cancer. **Methods:** Whittemore and Knaff’s integrative review methodology guided this article. We obtained data through a systematic search of 8 databases. Key terms utilized were awareness, perception, truth disclosure, diagnosis, prognosis, terminal illness, status, neoplasm, and metastasis. Dates through January 2020 were searched to capture all relevant articles. Sixty-nine articles met inclusion criteria. **Results:** The integrative review methodology guided the development of a conceptual definition and model. The concept of “awareness of disease status” was defined as the individual patient’s understanding of being diagnosed and treated for cancer based on the multifactorial components of individual patient characteristics and contextually driven communication practices of healthcare providers. This understanding is dynamic and changes throughout the disease trajectory. **Conclusion:** These findings will inform consistency in the literature. Such consistency may improve person-centered clinical communication, care planning practices, and, ultimately, cancer-related outcomes. **Implications for Practice:** With a greater understanding of the complexity of patients’ awareness of

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disease status, nurses will be able to guide their patients to make informed decisions throughout their disease trajectory.

Patients with cancer are living longer because of advances in treatment,<sup>1</sup> leading to an increased number of treatment decisions throughout the disease trajectory. Several studies have shown that patients' awareness of disease status (ADS) is a predictor of treatment decision-making.<sup>2-9</sup> For example, there have been empirical associations between increased ADS and a lower risk of intensive care<sup>4,8</sup> and aggressive treatments toward end of life.<sup>5,9-12</sup> These associations may have significant implications on healthcare and resource utilization, as well as cost. Yet, 2 systematic reviews demonstrate there is no consistent conceptual and/or operational definition for patients' ADS, highlighting the nonlinear nature and cultural variation inherent to understanding this phenomenon.<sup>13,14</sup> In fact, evidence suggests there are multiple approaches to measuring ADS among the oncology population, which may complicate shared decision-making processes and the quality of communication between healthcare providers (HCPs) and patients. We aim to narrow this evidentiary gap. The purpose of this integrative review was 2-fold: (1) to examine how researchers have conceptualized and operationalized patients' ADS using a rigorous integrative review methodology and (2) to synthesize an evidence-informed conceptual definition and theoretical model of ADS that may be applied to future scientific investigations in the field.

## ■ Methods and Data Sources

Whittemore and Knaff's<sup>15</sup> integrative review methodology guided this article. Integrative review is a method that assists researchers to systematically evaluate primary sources with aims to (1) create a foundational understanding of the state of the science related to a given phenomenon and (2) identify patterns, themes, and relationships among sources that meet inclusion criteria. Implicit to Whittemore and Knaff's<sup>15</sup> methodology is to understand how phenomena are conceptualized in the literature. The following steps were utilized: data collection, data evaluation, and data analysis. Data collection consisted of a thorough literature review. During data evaluation, pertinent data from primary sources were extracted and systematically placed into a data extraction table. Data analysis was an iterative process where the researchers identified patterns and themes while also comparing and contrasting relationships between concepts. Although this review was completed for the lead author's dissertation, this review reflects updates to the literature since publication of that work.<sup>16</sup>

### Data Collection

To identify all conceptual aspects of ADS, a thorough search of the literature was conducted. We completed data collection at 2 different time periods (January 2017 and January 2020) to ensure the timeliest inclusion of evidence. Preliminary search terms were identified in previous work.<sup>14</sup> Additional search terms were identified using the MeSH database, which identifies the appropriate

subject headings to conduct searches that are more precise. Multiple consultations with a health librarian ensured accuracy and applicable range of key searching terms.

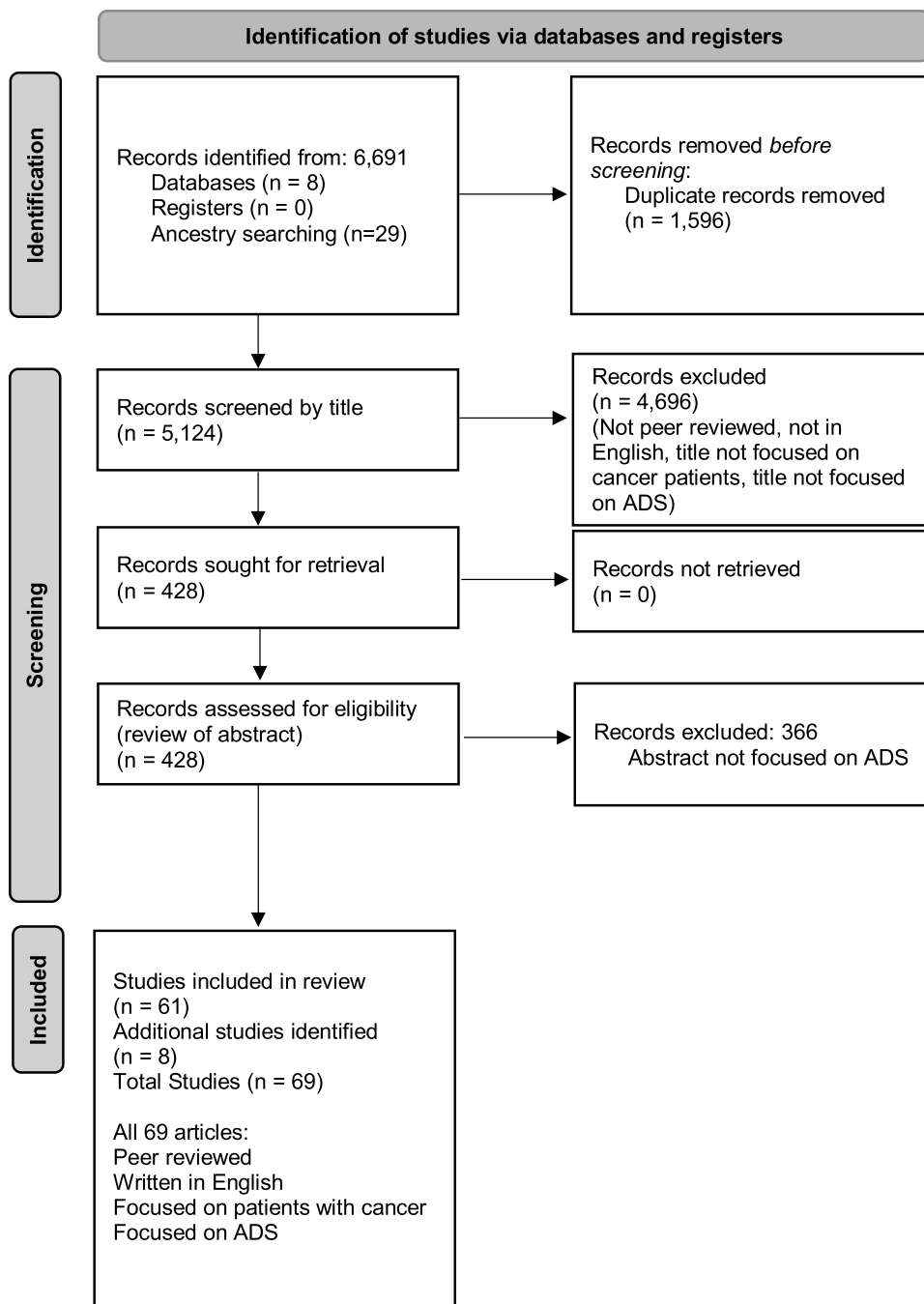
The key terms utilized for this integrative review included the following: "awareness," "truth disclosure," "health status," "disease status," "prognosis," "neoplasm," "metastasis," "advanced cancer." Using various combinations of the key terms, the following databases were searched: PubMed, MEDLINE, CINAHL, EMBASE, PsycINFO, Web of Science, Cochrane Library databases (Systematic Reviews and Controlled Trials Register), and SCOPUS. All articles met the following inclusion criteria: written in English; peer-reviewed empirical articles using either qualitative, quantitative, or mixed-method designs; focused on patients with cancer at any point along the disease continuum; examined the concept of ADS. There was no limit of search dates; all pertinent articles through January 1, 2020, were included; this was to observe how the concept has evolved longitudinally. Articles were excluded if they met the following criteria: not in English, focused on a population other than cancer patients, or did not assess patients' ADS.

The 2017 search method initially yielded 6991 articles. An additional 29 articles were identified through ancestry searching. From those, 1596 duplicate articles were removed, and 5124 articles were screened by title. Another 4696 articles were excluded based on the exclusion criterion: did not focus on cancer or ADS. Of the remaining 428 articles, 61 met the inclusion criteria and were included in the review. Using the same search strategy in January 2020, an additional 8 articles were identified, resulting in a total of 69 articles<sup>17</sup> (Figure 1).

### Data Evaluation

Consistent with the integrative review methodology, we created data evaluation chart (referred to as "data displays" by Whittemore and Knaff<sup>15</sup>). The purpose of the data display is to allow for the "constant comparison across all primary sources."<sup>15</sup> The Critical Appraisal Skills Programme<sup>18</sup> method guided the creation of the data evaluation tables. The Critical Appraisal Skills Programme is an international consortium that has developed reliable and valid measures to critically appraise the data (<https://casp-uk.net/>). Based on the Critical Appraisal Skills Programme cohort checklist, data evaluation tables were created to assess the appropriateness of the aim and method of sample recruitment and selection and track how the concept of ADS was conceptualized and operationalized, factors that impact awareness and their outcomes, and the key results and limitations of each study.

Data extracted from each article included the aim, sample characteristics, definition of the concept of ADS (if available), operationalization of the concept, factors that impact awareness, consequences of ADS, key results of the study, and study strengths and limitations (Appendix). General thematic analysis techniques were utilized to examine the content and context of the articles, an approach informed by Miller and Alvarado's<sup>76</sup> recommendations about the use of documents as "data" in research syntheses.



**Figure 1** ■ PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-analyses) chart.

The combined approach also allowed for the development of a conceptual model as an additional product of our review.

## Data Analysis

Consistent with Whittemore and Knaf’s<sup>15</sup> integrative review methodology, data analysis was an iterative process of identifying patterns and themes in the data evaluation tables. Analysis began with the creation of the first table and was continued after completion of the data analysis chart. It is through the ongoing analysis, comparing, and contrasting relationships that the research team generated the following results that conceptualized ADS: understanding of diagnosis, knowledge of prognosis, understanding of

disease curability, survivability, understanding the disease trajectory, factors that determine awareness, contextual characteristics of the healthcare environment, the influence of organizational culture, individual patient characteristics, and the consequences of ADS.

## ■ Results

### Operationalization of the Concept

The concept of ADS in patients with cancer was operationalized in the following ways: understanding of cancer diagnosis, knowledge of prognosis, combinations of knowledge of diagnosis and

prognosis, understanding the disease trajectory, and understanding of curability and survivability. Both qualitative and quantitative approaches were used to study the phenomenon. 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.”<sup>4,24,26,27,29,30,35,42,49,54,56,58,59,63,77</sup> Awareness of diagnosis was operationalized differently and measured inconsistently. In some publications, researchers considered patients aware of the diagnosis if they could identify their disease with the word “neoplastic,”<sup>21</sup> if patients could name the disease they were being treated for,<sup>7,23,49</sup> or if they could use the words “malignancy,” “cancer,” or “tumor.”<sup>30,59,64</sup> 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?”<sup>63</sup> Three articles considered patients as automatically aware of their diagnosis based on the delivery of diagnostic information from the HCP.<sup>19,54,58</sup> Therefore, the level of ADS or lack thereof was limited to what had been communicated to and remembered by the patient.

## Knowledge of Prognosis

There were many publications that used a combination of diagnosis and prognosis knowledge to determine patient ADS.<sup>2,3,7,19,21,23,25,29,31,32,37,39,44,48,55–57,62,64,65,68–70</sup> One study defined prognosis as “awareness of the type and stage of the disease relate[d] to the image of his/her current health status.”<sup>29(p200)</sup> 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.”<sup>55(p674)</sup> Although these 2 studies defined prognosis, their measurement or assessment of it was limited. For example, another study asked the patients if they could name the disease and determine if it was curable or incurable.<sup>7</sup>

## 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 2 ways: if the patient with cancer understands curability of disease and the intent of treatment (eg, curative or palliative).

Chochin and colleagues<sup>33</sup> study of 200 patients with advanced cancer receiving palliative care defined ADS as the patient’s knowledge of disease incurability. “Full awareness” was considered if “the patient had a full understanding of the gravity of the illness and the imminence of death.”<sup>33(p501)</sup> Conversely, they suggested if “the patient believed the illness to be curable, then the patients were believed to have ‘no acknowledged awareness,’ with no acknowledgement of terminal prognosis.”<sup>33(p501)</sup> In a study conducted in Australia of 181 patients with terminal cancer and their caregivers, “full ADS” was determined if “both participants understand that the treatment was not intended to cure.”<sup>5(p189)</sup>

In a 2006 study conducted in Taiwan, patients were deemed to have the ADS “if patients understood that they had an incurable cancer, death was unavoidable, and their lifespan was very limited.”<sup>53(p451)</sup> One study examined if patients—whom oncologists estimated would die within a year—and HCPs 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 oncologists’ estimates, which was measured via survey after appointments.<sup>66</sup>

Another facet of curability was related to the patient’s knowledge of the intent of the treatment (eg, curative or palliative in nature). In a 2011 study of 151 metastatic non–small cell lung cancer patients, participants were asked to respond to the following questions in a “yes” or “no” format: “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.”<sup>72(p2321)</sup> One of the major findings of this study was that patients exhibited discordance between answers. For example, patients were aware their cancer was not curable, but many still believed the purpose of chemotherapy was curative.<sup>72</sup>

Similarly, another study assessed curability of treatment by asking the following question: “After talking with your 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?”<sup>9(p1617)</sup> Patients were given the following response options: “very likely, somewhat likely,” “not at all likely,” and “I don’t know.” Of the 1193 patients with stage IV cancer, 69% of the lung cancer patients and 81% of the colorectal patients were not aware that their chemotherapy was not curative.<sup>9</sup> A similar method of operationalization was utilized with 262 patients with cancer, 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”).<sup>36</sup> These studies are additional examples of how researchers adopt reductionist techniques that mask complexity when trying to understand this concept.<sup>8,69</sup>

## Survivability

Survivability describes a patient’s ability to approximate life expectancy and report if he/she will survive his/her disease. Three articles evaluated survivability by asking patients to estimate their survival time until death.<sup>12,51,66</sup> One of these studies 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?”<sup>12(p1710)</sup> Patients had the following response choices: “90% or better,” “about 75%,” “about 50-50,” “about 25%,” “about 10% or less,” or “don’t know.”<sup>12(p1710)</sup> Fifty-seven percent of the patients who thought they had a 90% chance of surviving 6 months died at the 6-month mark.<sup>12</sup> In this study, patients were more likely to overestimate their life expectancy compared with their HCPs. Another study mirrored this approach, but through qualitative interviews.<sup>28</sup> Cartwright and colleagues<sup>28</sup> study found that participants’ discussions of their prognoses were similar across groups, despite the differences in experiences, stages of disease, and diagnoses. Another example of survival estimates was whether

patients with terminal cancer could report if their cancer would be a direct cause of their death.<sup>40,41</sup>

## Understanding the Disease Trajectory

Of the articles that offered conceptual definitions of awareness, several discussed how patient understanding fluctuated throughout the disease continuum. There is conceptual inconsistency in the selected studies (eg, using different surrogate terms for this overarching attribute). To illustrate, researchers noted: “The term *awareness* is used to acknowledge what patients know in all phases of their disease, regarding their actual condition of health, of progressing disease and of approaching death.”<sup>48(p2)</sup> Morasso et al<sup>60</sup> also uses the term *illness awareness*, defined as “a dynamic process that undergoes changes during the course of the disease... is affected by the quantity and the quality of clinical information given to the patient and by the meaning assigned by patient to this information.”<sup>(p213)</sup> Awareness was further defined as “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 the information he/she has eventually been provided with.”<sup>35</sup>

These definitions are overarching and multifaceted and describe awareness as not being isolated to a patient’s discussion of diagnosis, prognosis, cure, or survival, but their ability to incorporate these aspects into a holistic perspective. Furthermore, these authors define awareness as something fluid that can change over time as the disease progresses. In addition to the elasticity of the concept, it will be highly dependent on the individual patient characteristics.

## Factors That Determine Awareness

All studies identified factors that impact a patient’s ADS. These factors were categorized into contextual and individual patient characteristics. Contextual characteristics of the healthcare environment where patients receive care include characteristics of the HCPs and environment of the healthcare system. 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 the Healthcare Environment

The most common predictor of ADS cited was communication with HCPs. Thus, 32 articles considered communication with HCPs as a factor that impacts ADS; however, this factor was not statistically measured in all of the articles.<sup>2–4,6,11,12,20,21,23,28,30,34,35,38,40,41,48,50,52–55,58,60,61,63–66,71,72,77</sup>

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 rather to inform the family.<sup>2,4,6,7,10,26,42,52,53,59,67,77</sup> Within these cultural norms, family members served as the bridge of communication between HCPs and patients to shield the patient from bad news.<sup>2,4,6,7,10,26,42,52,53,59,67,77</sup> A patient’s absence from healthcare

discussions with HCPs clearly impacted his/her ADS. This example highlights how culture influences the organization of care delivery systems and providers’ subsequent communication styles.

Studies conducted in Western Europe and the United States focused on communication characteristics of the HCPs. The following characteristics of HCPs were cited as having an impact on ADS: language used,<sup>48</sup> attitude of the HCPs when disclosing information,<sup>11,29,43,55,66</sup> and amount of information disclosed by HCPs.<sup>34,35,60</sup>

## The Influence of Organizational Culture

Characteristics of the hospital and the type of clinical setting were cited as factors that impacted patient’s ADS. For example, patients who were at a teaching hospital were less likely to be told they were dying.<sup>11,51</sup> Patients who were in a hospital specialized for oncology,<sup>27</sup> who had a referral to an oncology department,<sup>10</sup> or who had an early referral to a palliative care program<sup>72</sup> were all more likely to report a better ADS.

## Individual Patient Characteristics

Age, gender, and education level have been shown to impact a patient’s ADS. The younger a patient is compared with older persons in their cohort, the more likely he/she is to have ADS.<sup>2,10,27,29,35,49,59,63,64</sup> 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. Female patients are also more likely to have awareness when compared with male patients.<sup>2,5,19,27,33,36,46,63–65</sup> In addition, patients with higher education levels (typically more than high school) have greater awareness.<sup>2,27,35,46,49,57,59,61,64,65</sup>

The physical health and type of cancer have also been shown to impact awareness, including having metastatic disease,<sup>36</sup> a worse performance status,<sup>19,25,51</sup> and site of the cancer.<sup>10</sup> Psychological characteristics of patients can also influence their ADS, such as coping mechanisms,<sup>21,22,48,55,60,63</sup> denial,<sup>30,43,45,46,77</sup> and a desire to maintain hope.<sup>66</sup>

## Consequences of Awareness of Disease Status

Twenty articles stated that ADS had an impact on treatment decisions.<sup>3–6,8–12,20,29,35,40,46,51,53,57,60,72,75</sup> 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 ADS. Six articles reported that participants who had ADS were more likely to sign a do-not-resuscitate order or create a living will.<sup>3,6,20,40,51,53</sup> In addition, 7 articles reported that participants who were aware of their disease status were less likely to end up in intensive care,<sup>4,8</sup> use aggressive treatments toward end of life,<sup>5,9–12</sup> and were more likely to use palliative care services.<sup>75</sup>

There continue to be conflicting reports on the impact of ADS on quality of life (QOL), and the studies included in this analysis further illustrate these tensions. Researchers used many instruments and measures of QOL in the included studies. Such differences in measurement alone would yield variation in the responses. Yet, of the 37% of articles that reported impact on QOL, the results were equally divided. Nine articles reported a



positive impact on QOL.<sup>2,6,7,23,33,52,53,63,67,70</sup> Another 9 reported that ADS had a negative impact of QOL.<sup>8,20,25,42,47,54,59,73,77</sup> Four reported no statistically significant impact on QOL.<sup>36,40,71,74</sup> Thus, it is difficult to draw conclusions about the impact of ADS on QOL.

## ■ Discussion

Through our integrative review, we sought to fill an evidence gap related to ADS among patients with cancer, a concept that has been inconsistently defined and operationalized by researchers. Of the 69 articles reviewed, individual patient and contextual characteristics emerged as central factors that impact ADS and are associated with significant consequences. Results from this integrative review led to the following definition of ADS among patients with cancer: “the individual patient’s understanding of being diagnosed and treated for cancer based on the multifactorial components of individual patient characteristics and contextually driven communication practices of healthcare providers. This understanding is dynamic and changes throughout the disease trajectory.”

Based on this definition, a conceptual model was created to inform future clinical practice and research initiatives. Figure 2 illustrates the relationships of factors that impact ADS and the subsequent consequences of ADS identified in this review. It is critical to acknowledge that the concept of ADS is not static but rather exists in the context of a dynamic and changing disease trajectory course. The individual patient characteristics (eg, culture of patient/family, gender, age, education level, cancer type, coping mechanisms) inform the many dimensions of ADS, including knowledge of prognosis and an understanding of diagnosis, curability, and survivability. The model illustrates that iterative communication with HCPs will impact ADS over time. In addition, the influence of other contextual characteristics (eg, culture of HCP, hospital type, HCP language) is an invaluable component of the ADS equation. Finally, there are several significant consequences to ADS, such as treatment decisions, personal life decisions, and QOL.

Because of inconsistency in operationalization, research to date has not measured the concept accurately and contributes to the lack of clarity related to how ADS affects patients with cancer. The various operationalizations of the concept in the literature were from the perspective of a research team. This means that, regardless of how various primary sources measured ADS, those measurements were not rooted in the perspective of the patient; they were rooted in how the researchers conceptualized ADS. Therefore, there is still a substantive gap in accurately understanding how the patient conceptualizes ADS. Furthermore, we did not include an exploration of how family caregivers’ ADS impacts decision-making, QOL, and cancer caregiver-related burdens that may impact the experiences and treatment trajectories of patients.

Limiting or categorizing patient responses as a method to glean ADS is an act of reductionism that belies the complexity of understanding one’s fate. There is also an issue of informed consent in the setting of cancer treatment.<sup>9</sup> Without an increased and sustained commitment to enhancing patient ADS, how can we ask patients to engage in informed healthcare decision-making if

they are not aware of the purpose of treatment interventions, especially in the advanced cancer and palliative setting?

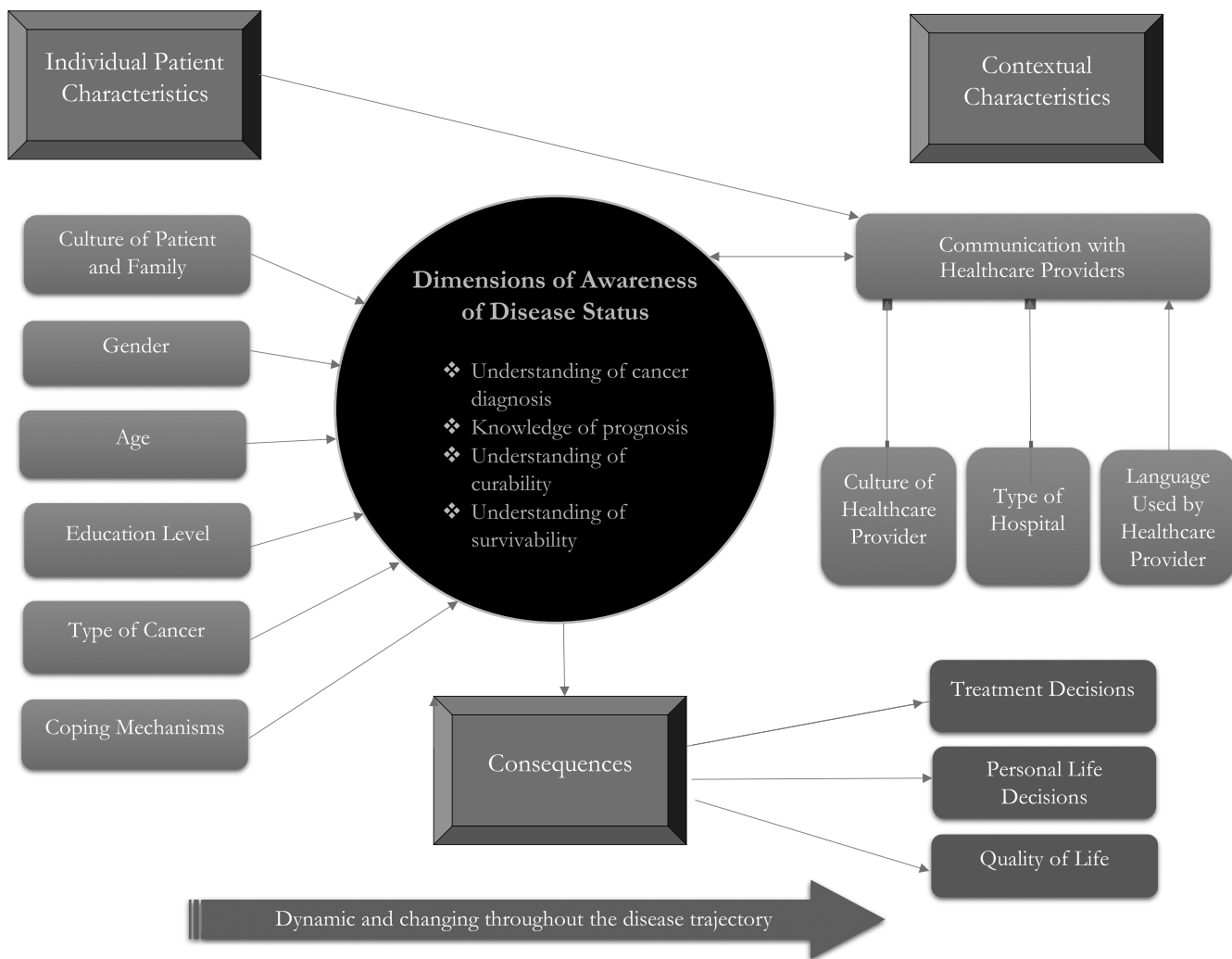
## Implications

There are several clinical implications based on the findings of this review. First, ADS directly informs decision-making related to not only disease-modifying treatments but also readiness to participate in advance care planning and utilization of hospice and palliative care.<sup>75</sup> These patient and clinical outcomes exist in the context of disease and symptom progression, availability of treatment options, and a patient’s adapting needs, values, preferences, and goals, all of which impact an individual’s ADS. The phenomenon of ADS exists on a continuum from diagnosis to end of life and is informed by patient/family and health system factors that impact decision-making and subsequent outcomes. Both the resulting conceptual definition and model (Figure 2) consider the individual and contextual characteristics that impact ADS amid an ever-evolving cancer trajectory.

Second, nearly half of the articles appraised in this review identified that ADS is often established through discussion with HCPs.<sup>2-4,6,11,12,20,21,23,28,30,34,35,38,40,41,48,50,52-55,58,60,61,63-66,71,72,77</sup>

Thus, the value of transparent and truthful communication about disease status, prognosis, and available decisions cannot be overstated. It is imperative that HCPs appreciate the complexity and multifactorial domains that inform ADS (Figure 2) and decision-making to ensure the process is viewed and approached as both iterative and person-centered. In addition, HCPs must reflect on their own assumptions, worries, and concerns about sharing serious news, as well as systemic barriers to creating cancer care environments that leverage shared decision-making in partnership with patients and their families. Communication training that emphasizes empathic, respectful, and inclusive approaches to cancer care delivery is essential for building such capacities. In addition, several experts have recommended that training in primary palliative care (eg, generalist-level palliative care delivered by primary teams) for all HCPs would enhance individualized and holistic care that meets the psychosocial, physical, spiritual, and cultural contexts of patients. A fully integrated model of primary palliative care in cancer settings improves HCP communication that meets patients and families “where they are” in the disease process and may promote accurate ADS.<sup>78-80</sup>

Research implications include but are not limited to the need for (1) more in-depth understanding of the concept and influence of ADS as a predictor of decision-making and other clinical outcomes in the cancer setting, such as intensive care unit and palliative care utilization; (2) more robust investigations of interprofessional HCPs’ and patients’ perceptions of ADS across noncancer illnesses to better identify its role in clinical care delivery; and (3) evaluation of the resulting conceptual model (Figure 2) as applied to various stages of the cancer continuum for ADS instrument development. Future research should also elicit how ADS impacts decisional conflict and decisional self-efficacy, particularly during disease transitions or major decision inflection points that carry potentially substantial, irreversible, or long-term consequences. Our results showed that the effect of ADS on QOL was mixed, suggesting a critical need to explore the relationship



**Figure 2** ■ Conceptual model of awareness of disease status.

more thoroughly between ADS and the different constructs and components of QOL and how those characteristics may change at varying stages of disease.

## Limitations

There are several limitations of this review. First, we sought to explore ADS specific to the cancer population, potentially excluding key references and research from other fields. However, to our knowledge, this the first integrative review that sought to conceptualize a definition of ADS among patients with cancer based on a comprehensive synthesis of the literature. Next, our criteria included only articles in English, limiting our discussion regarding cultural variability of ADS. Yet, we provide a model for other colleagues across cultures and contexts to adapt and use when considering the application and utility of ADS in their settings. Finally, our search strategy included all research prior to January 2020, preventing us from exploring the role of ADS during the COVID-19 pandemic. Patients with cancer have been particularly vulnerable to the impacts of the SARS-CoV-2 virus, and cancer care systems will likely experience long-term conse-

quences.<sup>81</sup> Additional research will be needed to describe the role of ADS at the intersection of cancer, complex decision-making, and this global public health emergency.

## Conclusion

Awareness of disease status is a highly subjective concept and will vary based on inherent and contextual experiences of the individual patient with cancer, as well as the dynamics of the health system and cancer care delivery. The studies included in this integrative review measured ADS from the perspective of the HCP. Therefore, it is vital to understand how patients conceptualize this concept. In the same way that patients must be engaged as equal partners in their treatment decision-making and ongoing communication that informs their ADS, they must also be active participants in the scientific explorations that will guide clinical practice and, ultimately, dictate the quality of their cancer care and subsequent related outcomes. In the end, it is the patient's ADS that will determine treatment and life decisions, as well as the quality of their life and, potentially, the quality of their death.

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## Appendix • Data Extraction Table

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Aggarwal et al <sup>19</sup> (2016) India	Determine the impact of patient's awareness of cancer diagnosis on health-related QOL	n = 391 cancer patients 85% Male Mean age, 58 y 77.2% had non-small cell lung cancer	No conceptual definition provided	<b>Awareness of diagnosis</b> Not all patients were informed of 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" ( $P < .001$ ) Better ECOG score ( $P < .001$ )	No statistically significant difference in HRQOL scores	71.1% were unaware of their diagnosis	Unclear how they are measuring awareness Cross-sectional
Ahn et al <sup>2</sup> (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 y	No conceptual definition provided	<b>Awareness of terminal illness</b> During initial assessment—a comprehensive interview: Patient's 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 ( $P < .001$ ) Married ( $P = .0026$ ) Higher education ( $P = .003$ ) Christian ( $P = .024$ ) Communication with HCP	Higher overall score on the Good Death Inventory ( $P = .013$ )	32% were unaware of their terminal disease	Cross-sectional Low response rate from large mail survey
Alaka Ray et al <sup>20</sup> (2006) USA	How patient's awareness of terminal illness affects mental health and advance care planning; quality of death, and caregiver bereavement outcomes	n = 280 cancer patients with distant metastasis 54.4% Male Mean age, 57.3 y	No conceptual definition provided	<b>Terminal illness acknowledgment</b> <b>Patient evaluation of health</b> ADS: How would you describe your current health status? Options: -healthy -Seriously but not terminally ill -Seriously and terminally ill Patients who responded to "seriously and terminally ill" were deemed aware	None identified	Have a DNR ( $P < .001$ ) EOL conversation ( $P < .001$ ) Worse QOL ( $P = .05$ )	73.3% were unaware of their prognosis	Sample bias
Andruccioli et al <sup>21</sup> (2007) Italy	To 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	None identified	None identified	-30% were unaware of diagnosis 62% were unaware of prognosis	Smaller sample size Cross-sectional

(continues)

**Appendix • Data Extraction Table, Continued**

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Andruccioli et al <sup>22</sup> (2009) Italy	To validate the questionnaire developed in 1994 by Morasso et al	51 participants with advanced or terminal cancer at 2 separate hospice facilities 23.5% Male Mean age, 62 y	Illness awareness “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” (p385)	<p>future? (3) What are you expecting from the hospice? -Patients were considered aware of diagnosis if they could identify their disease as “neoplastic” (did not have to know specifics) -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 -Patients were considered aware of their prognosis if they were realistic about goal of hospice care -Patients were considered unaware of prognosis if they thought that their disease was curable or if their LE was &gt;3 mo</p>	Based on Morasso: cultural beliefs, perceived needs, expectations, coping skills, defense mechanisms, locus of illness control (not measured statistically)	None identified	60.8% unaware of their prognosis Tool was deemed not adequate to determine illness awareness due to elevated levels of defense mechanisms	Small sample size— issues with power
Aoki et al <sup>3</sup> (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 y	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 4 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 (continues)

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Samimi Ardeshani et al <sup>23</sup> (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 (distinct types) 55.5% Male 79.4% <60 y	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 HCPs (no statistical evidence)	Were not as mentally preoccupied by their condition ( $P < .001$ ) Had less symptoms of anxiety and depression	39.7% unaware of their diagnosis	Unclear what the question is regarding awareness of diagnosis
Assaf et al <sup>24</sup> (2017) United Arab Emirates	To explore the experiences of Arab women in the UAE following the diagnosis and treatment of breast cancer	N = 20 Ages 30 to 65 y (mean, 50 y) 14 Had university degrees, 12 married, 17 Muslims, 3 Christians	No conceptual definition provided	<b>Awareness of diagnosis</b> Participants explained that Arab communities viewed cancer as a deadly disease, and no one was allowed to discuss it. "We are not allowed to say it because if you say it, it will also affect you"	Culture	Participants reported that there was nothing to worry about and decided not to talk about it openly	"Upon knowing their diagnosis, the women started to protect themselves by projecting blame not for ignoring the presence of the lump but that on someone else"	Qualitative phenomenological study
Atesci (2004) <sup>17</sup> Turkey	To determine if awareness of cancer diagnosis influences psychiatric morbidity	n = 117 cancer patients (various types) 48.7% Male Mean age, 53.7 y	No conceptual definition provided	<b>Awareness of diagnosis</b> "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	Communication between HCP and patient Cultural influences such 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)	Awareness may lead to higher levels of psychiatric disorders ( $P = .03$ )	54.7% of patients were considered unaware of cancer diagnosis Only 14.5% of patients stated that they had been informed of their disease by an HCP	Subjective determination of awareness Cross-sectional
Baek et al <sup>4</sup> (2012) Korea	Examine the effects of awareness of incurable disease status on satisfaction with treatment choice for palliative chemotherapy	n = 98 incurable cancer patients 68% Male Mean age, 57.3 y	No conceptual definition provided	<b>Awareness of incurable disease status</b> Unclear as to specific questions Based on results, 1 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	Hesitant about wanting chemotherapy ( $P = .01$ ) Less likely to choose intensive care toward the end of life (not	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	Only 2 thirds of their sample completed all parts of the study Cross-sectional

(continues)



Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/Limitations
Barnett <sup>25</sup> (2006) England	among patients with cancer Explore patient preferences for information, their satisfaction with the information they had received, and any outstanding worries or concerns, and to relate this to their understanding of prognosis and psychological well-being	n = 106 advanced cancer patients 57% Male Mean age, 65 y	No conceptual definition provided	<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	“communication barrier” between HCP and patient not statistically measured) Patients having metastasis ( $P = .02$ ) Patients in worse physical health ( $P = .036$ )	statistically measured) Lower anxiety ( $P = .012$ ) Lower depression ( $P = .022$ )	In the univariate analysis there was no significant difference between those patients who had ADS and those who did not ( $P = .247$ ) 22% unaware of diagnosis and 29% unaware of prognosis	Coding system very subjective—not able to code all participants
Bozduk et al <sup>26</sup> (2002) Turkey	To assess impact of awareness of diagnosis on emotional functioning and QOL	n = 100 cancer patients with various diagnosis 58% Male Median age, 54 y	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 regarding 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” ( $P = .164$ )	Unclear how they made the determination of how a patient had awareness of diagnosis Cross-sectional
Brokaki et al <sup>27</sup> (2005) Greece	Determine the level of information provided to Greek cancer patients regarding diagnosis	n = 203 cancer patients 49% Female Mean age, 62.3 y	No conceptual definition provided	<b>Awareness of diagnosis</b> Semistructured interviews: do not relay specific language—questions surrounding diagnosis and then subsequent questions about the impact of that awareness and the desire to receive more information	Being in a hospitalized specialized for oncology ( $P < .001$ ) Female ( $P = .004$ ) Higher education ( $P = .024$ ) Younger ( $P < .001$ )	None	59% unaware of their diagnosis	Unclear how they made the determination of how a patient had awareness of diagnosis Cross-sectional

(continues)

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Burns <sup>5</sup> (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 >60 y	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 not curative.” Nonawareness: “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).”	<b>Understanding of disease curability</b> Patients and their caregivers were asked if the goal of treatment was: To monitor illness, to improve QOL, to control illness, or to cure the disease. Based on the answer to the above question, they dyads were then placed into 1 of the 4 categories	Culture and relationship with family (not statistically measured) Living in an urban environment ( $P < .02$ ) Dyads with female patients ( $P < .03$ )	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 6 mo of life (at least 1 member of the dyad had awareness 89%)	Longitudinal study Interview of patient and caregiver—get a sense of how family influences awareness
Cartwright et al <sup>28</sup> (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 y	Patient’s conceptualized prognosis in terms of months or years for survival	<b>Survivability</b> <b>Contextual characteristics</b> This was determined via focus groups and based off investigators coding	Conversation with HCP’s	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 Distinct stages—would have different idea of prognosis
Caruso et al <sup>29</sup> (2000) Italy	To determine the effect of physician’s attitudes toward	n = 403 cancer patients with various diagnosis	“Awareness of the type and stage of the disease refers to the	<b>Awareness of diagnosis</b> Based on a semistructured interview:	Younger age ( $P = .05$ ) Disclosure of	Useful in making treatment decisions (not	22% of the adults and 41% of the elderly were not aware of	Different interviewers—different (continues)

**Appendix • Data Extraction Table, Continued**

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
	disclosing the diagnosis of cancer and disease progression on patients' awareness of their disease condition	31% Male 311 adults (<64 y) and 92 elderly persons (>64 y)	patient's ability to relate to the image of his/her current health status" (p200)	Aware of diagnosis: "I am affected by 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"	information by physician (P = .003)	measured statistically)	their diagnosis 56% of adult patients and 59% were not aware of the progression	opinions on awareness
Chandra et al <sup>30</sup> (1998) India	Assess ADS in relation to psychiatric morbidity	n = 294 primarily head and neck cancer patients 49% Male Mean age, 45 y	No conceptual definition provided	<b>Awareness of cancer diagnosis</b> Interviews with patient and relative Use the words "cancer" or "malignancy" regarding 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 conclude based on responses	Communication with HCPs (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
Chen et al <sup>31</sup> (2017) Taiwan	To examine the prevalence of advance/terminal cancer patients' accurate PA and differences in accurate PA by publication year, region, assessment method, and service received	N = 34 articles were reviewed	No conceptual definition provided	<b>PA</b> Articles included only that where PA was explicitly defined. Had defined questions for measuring accurate PA or did not appropriately cite an instrument	Accurate PA was higher by clinician assessment than by patient report (63.2% vs 44.5%, P < .001)	None identified	Only 49.1% of advanced/terminal patients understood their prognosis. Accurate PA was independent of service received and publication year, but highest in Australia followed by East Asia, North America, and Southern Europe ad United Kingdom	A systematic review and meta-regression analysis
Chen et al <sup>32</sup> (2019) Taiwan	To explore the joint roles played by symptoms distress and functional	n = 317 terminally ill cancer patients. 57.7% Male	No conceptual definition provided	<b>PA</b> Asking patients "Whether they knew their prognosis and, if so, whether their disease (1) was	Participants in the 4 worst symptom—functional states had a significantly higher	None identified	Most of the participants (76.3%) had accurate PA in	Large sample size Hierarchical generalized linear modeling (continues)

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Chochinov et al <sup>33</sup> (2000) Canada	impairment in association with cancer patients' functional PA	Mean age, 58.73 y n = 200 hospitalized adults with advanced cancer receiving palliative care Mean age, 71 y	No acknowledged awareness: "the patient believed the illness to be curable, with no acknowledgement of terminal prognosis" Limited awareness: "the patient reported an understanding that the illness is terminal but had unrealistic expectations of the time remaining (>6 mo)" Full awareness: "the patient had a full understanding of the gravity of the illness and the imminence of death" (p501)	curable; (2) might recur in the future, but their life was not currently in danger; and (3) could not be cured, or they would probably die soon" Patients were recognized as accurately understanding their prognosis only if they chose option 3	likelihood of reporting accurate PA with aOR (95% CI) ranging from 3.537 (1.761-7.102) to 19,262 (8,101-45,797). Female (P = .011) Not being married (P = .04) Less personal contacts with family members—58 per week (P = .007)	Less likely to have depression (P = .029)	9.5% with no awareness 17% with limited awareness	Good discussion of conceptualization of awareness
Chou et al <sup>10</sup> (2013) Taiwan	To determine the effect of palliative care consultation service (PCCS) on disease awareness in terminally ill cancer patients	n = 2887 terminally ill cancer patients At baseline 31% did not have disease awareness Leaving n = 895 patients without awareness	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 incurable nature of the disease	Longer duration from admission to PCCS (P = .02) Male (P = .012) Divorce (P = .035) Family having awareness (P = .001) Cancer site Being <75 y old (P = .012)	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

(continues)



Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/Limitations
Clavarino et al <sup>34</sup> (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 an LE between 3 mo and 2 y 59% Male 70% over 50 y old	Do not specifically choose 1, but refer to Kellehear’s definition: “Patient awareness of dying on the ways in which patients referred to their condition and to their 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” (p4)	<b>Beliefs about the curability of their cancer</b> Semistructured 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 3 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 et al <sup>35</sup> (2009) Italy	To explore the level of illness awareness in terminal cancer patients	550 advanced cancer patients and 594 of their caregivers 54% men Median age, 74 y	“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” (p355)	<b>Illness awareness</b> 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	Increased level of education Currently receiving treatment More “visible cancers” (skin, breast, GU) Younger age Information from HCP Caregiver’s attitudes (Measured but only variance—not statistically significant)	Treatment decisions (not measured statistically)	45% not aware of their 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	Did not do a more sophisticated statistical analysis, unclear if the factors listed are significant
Costantini et al <sup>36</sup> (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 y	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 hospital?”	Female ( $P < .01$ ) Metastatic cancer ( $P < .001$ )	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

(continues)

Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
de Blacam et al <sup>37</sup> (2017) Ireland	To determine patient awareness and sun protection behavior in patients previously treated for nonmelanoma skin cancer	n = 250 patients who had undergone excision of BCCs between Jan 2011 and Dec 2012 62.8% Male Mean age, 66.35 y	No conceptual definition provided	Prognosis—Likert scale “How much do you think your illness is curable?” “1 = very difficult to cure to 10 = very easy to cure” “How much do you think that your illness is severe?” “1 = very serious to 10 = not serious at all” <b>Awareness of diagnosis</b> Via telephone interview: “Participants were asked a series of questions regarding knowledge of the lesion that they excised, their perceived risk of such a lesion that they had excised, their perceived risk of such a lesion recurring in the next 3 y, their current sun protection behavior and their opinion of UV radiation effect on the skin” Based on their individual responses, and ordinal, Likert-type score for disease awareness (maximum score = 10) was generated for each patient	Women and patients age <65 y were significantly better informed about their diagnosis than men ( $P = .021$ and $0.000$ , respectively)	Participants were more likely to wear skin protection during outdoor activities.	Only 28.8% of respondents knew that the lesion they had excised was a BCC and understood that there was a significant chance of developing another similar lesion in the next 3 y	Telephone administered questionnaire. Potential for observation bias
Derman and Serbest <sup>38</sup> (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	Awareness of disease/prognosis Contextual characteristics Used 45 question interview—but does not reveal what the questions were	Communication with HCP (not statistically measured)	None identified	23% knew diagnosis and “probable” prognosis 61% knew diagnosis but had “optimistic information” about prognosis Unclear if there is a difference between the education levels	Unclear how they made the determination of awareness of diagnosis and prognosis Small sample size
Diamond et al <sup>39</sup> (2017) USA	To measure patient awareness of MG incurability and LE	Adult patients admitted to an in-patient neurology service. N = 50 MG patients and Grades III or IV MG	Full PA was defined as awareness of MG incurability and accurate estimate of LE	<b>Knowledge of prognosis</b> Twenty (40%) patients and 22 (69%) caregivers had full PA. 20% of patients had no PA	No difference in awareness based on age, sex, race, or tumor characteristics. However, 37% of	Patients with memory problems may require more dedicated efforts at prognostic communication and	Twenty (42%) patients and 16 (50%) caregivers desired more prognostic information	Prospective, mixed-methods exploratory study. No a priori hypothesis about frequency of PA ( <i>continues</i> )

**Appendix • Data Extraction Table, Continued**

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Enzinger et al <sup>40</sup> (2015) USA	To reveal percentage of patients who wanted to know their LE and who recall discussing prognostic estimates with their physician. To test the hypothesis that prognostic disclosure by physician is associated with more accurate patient perceptions of LE and more frequent advanced care planning	32 paired caregivers. Age range of patients and caregivers = 18-77 y Education ranged from high school to postgraduate n = 590 metastatic cancer patients 50.6% Male Mean age, 59 y	is defined as a devastating neurological illness leading to progressive functional decline, cognitive impairment and invariably death  No conceptual definition provided	<b>Prognostic understanding/survivability</b> To assess prognostic understanding, patients asked to estimate their own LE. Also asked to describe current health status as: (1) healthy, (2) healthy but terminally ill, (3) seriously but not terminally ill. Patients with 2 or 4 were considered to acknowledge their terminal illness If patients chose the answer; (2) 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	patients with full PA had participated in previous therapeutic clinical trial compared with 60% of those with limited or no PA  Prognostic disclosure ( $P < .001$ )	discussion of treatment preferences and EOL care, reiteration of the information on subsequent encounters, and the provision of written information  No statistical impact on QOL More likely to have a DNR order ( $P < .001$ )	Ten (20%) of patients had no PA Seventeen (57%) of patients with multiple recurrent MG had limited or no PA  86.5% of the 252 patients willing to give an LE—overestimated their survival	Patients may not have recalled prognostic discussions due to denial, (Recall bias) This study did not capture prognostic conversations that occurred after the baseline assessment
Epstein et al <sup>41</sup> (2016) USA	To evaluate the effects of recent and past clinical discussions about prognosis on change in illness understanding by patients with advanced cancer	n = 178 incurable cancer patients 32.8% Male Mean age, 59.7 y	No conceptual definition provided	<b>Terminal illness acknowledgement/survivability</b> “How would you describe your current health status?” “Which of the following best represents what your oncology providers have told you about a cure for your cancer?” “What stage is your cancer?” “Many patients have thoughts about how having cancer might affect their LE...when you think of this, do you think in terms of?” Answers to questions coded as 1 or 0 to indicate presence or absence	Recent communication with HCPs ( $P = .002$ )	Better able to make treatment decisions (not statistically measured)	Pre-scan: 0: 32 (18%) 1: 48 (27%) 2: 47 (26%) 3: 42 (24%) 4: 9 (5%) Post-Scan: 0:26 (15%) 1: 46 (26%) 2: 49 (28%) 3: 44 (25%) 4: 13 (7%) 69% had limited terminal illness acknowledgment	Prospective study Recall bias of patient's discussion with HCPs

(continues)

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/Limitations
Fan et al <sup>42</sup> (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 y	No conceptual definition provided	Operationalization of ADS: Scores added to construct summary score of 0 to 4 to reflect illness understanding <b>Awareness of cancer diagnosis/contextual characteristics</b> "How did you know about your condition?" No specific questions/language provided Based on all these a determination of "knowledge" was made	Increased time with cancer ( $P = .038$ ) Cultural belief to avoid truth telling to the patient Family/HCP withholding information from patient (not statistically measured)	Worse physical QOL ( $P = .025$ ) Worse emotional QOL ( $P = .020$ )	50.3% unaware of their diagnosis Unclear how they made the determination of awareness of diagnosis	Cross-sectional Unclear how they made the determination of awareness of diagnosis
Fried et al <sup>43</sup> (2006) USA	To examine changes in understanding of prognosis by community-dwelling, seriously ill older persons, and their caregivers, particularly as the time before the patient's death shortened.	n = 218 community-dwelling older persons with advanced chronic illness 34% with cancer 37% with COPD 29% with CHF 56% Male Mean age, 72.8 y	No conceptual definition provided	<b>LE predictions/contextual characteristics</b> Patients were interviewed initially and every 4 mo up to 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	Communication with HCP Doctors willing to communicate prognostic information Denial Anxiety (not statistically measured)	None	55% of patients who died within a year were uncertain of their prognosis at their final interview There was no difference among diseases in terms of prognostication 19 patients who were interviewed within 30 d of their death—only 31% thought their LE was <1 y	Prospective cohort study Unclear how they made the determination LE predictions
George et al <sup>44</sup> (2020) USA	Examined if receiving palliative chemotherapy or radiation, and the perception of those treatments as curative or noncurative, is associated with prognostic understanding (PA)	N = 334 patients with advanced cancer refractory to at least 1 chemotherapy treatment 34.2% Male 64.6% of the populations >65 y	No conceptual definition provided	<b>Awareness of prognosis</b> Was evaluated by assessing patient's: (1) terminal illness acknowledgment; (2) recognition of disease as incurable; (3) knowledge of advanced stage of disease; and (4) expectation to live months as opposed to years Responses were coded 0 or 1, representing absence or presence of understanding, respectively, for each item The 4 prognostic understanding item indicators were also summed	Patients receiving chemotherapy or radiation treatment had significantly different prognostic understanding than those not receiving such treatments. PA also depended on whether patients perceived the treatment as curative. Demographics:	Depending on patient perceptions The no-treatment group had higher prognostic understanding scores compared with the treatment group ( $P < .001$ ). However, the accurate treatment perception group had the highest prognostic	Observational study. Cross-sectional analysis.	(continues)



**Appendix • Data Extraction Table, Continued**

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Germino and McCorkle <sup>45</sup> (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 y 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)	(possible 0-4), with higher composite scores indicating greater prognostic understanding  <b>Acknowledged awareness/contextual characteristics</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	black, <65 y, not married, not insured, not recruited at a cancer center, and recruited from the south/southwest were more likely to misperceive intent of treatment  Pain ( $P < .05$ )	Symptom distress ( $P < .01$ )	No statistical difference between MI and lung cancer patients in terms of awareness	Good conceptual definitions One of the few scales that uses a Cronbach’s $\alpha$ to determine reliability, still <.8
Helft et al <sup>46</sup> (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 y	No conceptual definition provided	<b>Awareness of prognosis/survival estimates/contextual characteristics</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 y (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 <b>Awareness of dying/contextual characteristics</b> Used a rating tool 1-9 to	Female ( $P = .026$ ) Higher education ( $P = .03$ ) Psychological variables: denial, fear, anxiety, and depression (not statistically measured)	Decrease in hope ( $P = .030$ ) Treatment decisions (not statistically measured)	Only 16% could admit that death would be in 1 y, and only one-third in 5 y	Did not include patients who had a prognosis of <6mos Cross-sectional
Hinton <sup>47</sup> (1999) England	To determine how cancer patients and family members	n = 77 terminal cancer patients	No conceptual definition provided		Physical weakness correlated with increased awareness	Increased anxiety ( $P < .05$ )	Only 15% of patients had increased awareness of death	Longitudinal study—multiple interviews over time (continues)

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Hoff and Hermeren <sup>48</sup> Sweden	“came to terms” with death and some of the influences of awareness Describe the discrepancy between information patients received and the awareness of their illness	56% men Median age, 65 y Followed 12 cancer patients 7 with hematological malignancies 5 with nonoperable 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 patient who is informed, yet not aware of his or her state of health, or that the patient is aware even though he or she is not informed” (p2)	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 <b>Understanding disease trajectory/ contextual characteristics</b> Qualitative measurement of transcribed interviews Classification of patients into 4 categories: informed and aware, not informed and not aware, aware though not informed, not aware though informed	Patients who were aware spent a longer time in hospice care had a “marginal change” ( $P < .1$ ) Underlying mistaken beliefs Language used by medical team is different from layperson “Collusion” between HCP and patient—avoidance of the conversation (on purpose to serve the patient’s needs?) Coping ability	None	closer to actual time of death Relatives were consistently more aware than the patients Obstacles to awareness of obstacles due to physician, coping strategies of the patients, “collusion b/w patient and physician, progression of disease	Quantifying qualitative data Late recruitment into the study Qualitative study Interviewed at multiple time points However, not able to interview all participants at later time points
Iconomou et al <sup>49</sup> (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 y	No conceptual definition provided	<b>Awareness of diagnosis/illness awareness/contextual characteristics</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 consensus for those patients whom they could not figure out	Younger age ( $P < .001$ ) Higher education ( $P < .001$ ) Breast cancer ( $P < .05$ ) Cultural beliefs against disclosure of disease status (not statistically measured)	More dissatisfied with information received ( $P < .05$ ) Care in general ( $P < .05$ ) No statistical difference in QOL	59% were unaware of their diagnosis According to the ANOVA the following 2 variables impacted if a patient had ADS: younger age ( $P < .001$ ) and higher education ( $P < .001$ ) ADS was not a significant variable in predicting QOL	Assessment of doctors thinking that patients were aware is very subjective Cross-sectional
Johnston and Abraham <sup>50</sup> (2000) Ireland	Examine how patients “cope and manage their prognosis in	n = 16 terminal cancer patients and 14 caretakers.	Glaser and Strauss definitions: open awareness: “where the prognosis is openly	<b>Awareness of impending death/ contextual characteristics</b> No method just those patients that were already deemed “aware”	Family relationships Communication with the HCP’s (not statistically measured)	Communication with family members (not statistically measured)	Hope remains an important part of the awareness process even knowing that	Qualitative study <i>(continues)</i>

Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/Limitations
Kao et al <sup>6</sup> (2013) Taiwan	interactions with others	Majority female Aged 43-77 y	acknowledged by everyone <sup>6</sup>	<p><b>ADS/terminal prognosis/contextual characteristics</b></p> <p>Determination was made after discussion with patients about expectations of their diseases</p> <p>Patients were aware if they understood their prognosis and knew that death was approaching</p> <p>Patients were unaware if they only knew their diagnosis</p>	<p>Cultural beliefs “Truth telling” by HCP (not statistically measured)</p>	<p>More likely to sign a DNR (<math>P = .04</math>)</p> <p>Had less uncertainty (<math>P = .023</math>)</p> <p>Less anxiety (<math>0.005</math>)</p>	<p>death is close</p> <p>Conditional open awareness is “a more realistic and perhaps inevitable response to negotiating a terminal prognosis</p> <p>26% were unaware</p>	<p>Small sample size, issues with power</p> <p>Cross-sectional</p>
Lambden et al <sup>51</sup> (2016) USA	Determine oncologist accuracy with life-expectancy by advanced cancer patients	n = 85 patients Terminal cancer patients 55% Male Mean age, 60.5 y	No conceptual definition provided	<p><b>Survival estimates/contextual characteristics</b></p> <p>Patients were asked “Have the doctors talked with you about how much time you have left to live?”</p> <p>Patients who said “yes” were asked to indicate what the estimate was</p>	<p>Old age (<math>P = .044</math>)</p> <p>Poor health status (<math>P = .017</math>)</p> <p>Community medical centers (<math>P = .027</math>)</p> <p>Catholic (<math>P &lt; .001</math>)</p>	<p>More likely to have a DNR (<math>P = .04</math>)</p> <p>More likely to have an end-of-life discussion (<math>P = .008</math>)</p>	<p>When a patient was given 0-3 mo, survival was overestimated by a median of 4.4 mo.</p> <p>Most accurate between 9-12 mo</p>	<p>Recall bias</p>
Lee et al <sup>52</sup> (2013) Korea	How ADS influence QOL	98 cancer patients At 4-6 wk, 75 remained (23.5% attrition) 2- to 3-mo follow-up (32.7% attrition) n = 66 68.4% Male Mean age, 57.3 y	No conceptual definition provided	<p><b>Awareness of advanced stage of illness/contextual characteristics—consequences</b></p> <p>“Do you know your disease stage?”</p> <p>Response choices: advanced, locally advanced, early, and I don’t know</p> <p>Advanced = awareness</p> <p>Locally advanced, early, and I don’t know = lack of awareness</p>	<p>Communication with HCPs</p> <p>Family members as a communication barrier (Korean culture) (not statistically measured)</p>	<p>Increased QOL (Multiple statistically significant measures)</p> <p>Reduction on anxiety (<math>P = .0003</math>)</p> <p>Reduction of depression (<math>P = .042</math>)</p>	<p>At the beginning of study, 50% aware of disease status, by the end 48.5% of patients are aware</p>	<p>High attrition rate</p> <p>Cross-sectional</p>
Leung et al <sup>53</sup> (2006) Taiwan	Determine the relationship between patients’ awareness of terminal illness and spiritual well-being	n = 37 terminal cancer patients 59.5% Male 45.9% >65 y old	No conceptual definition provided	<p><b>Awareness of terminal illness/contextual characteristics—consequences</b></p> <p>Patients were deemed aware: If they understood that they had an incurable cancer, death was</p>	<p>Culture where family makes decisions not the patient</p> <p>Communication with HCP (not</p>	<p>Making a will (<math>P = .009</math>)</p> <p>Greater acceptance of death (<math>P = .02</math>)</p> <p>Better spiritual well</p>	<p>All patients knew they had cancer, 32.4% were unaware that they were terminal</p>	<p>Surrogate responses about well-being</p> <p>Cross-sectional</p> <p>A lot of subjectivity in the measures</p> <p>(continues)</p>

Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Lheureux et al <sup>54</sup> (2003) France	To determine if there is an effect of disclosure of lung cancer diagnosis on QOL	n = 70 lung cancer patients 87.1% Male Mean age, 61.7 y	No conceptual definition provided	unavoidable, and their lifespan was limited Patients 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 <b>Disclosure of lung cancer diagnosis by a physician</b> <b>Awareness of diagnosis/contextual characteristics</b> It was assumed that once the information was disclosed by HCP patient was aware No discussion what type of information and at what depth information was given	statistically measured) Communication with HCP (not statistically measured)	being (P = .027) Worse QOL after disclosure of diagnosis Physical (P = .03) Role (P = .002) Emotional (P = .0001) and Social functioning (P = .014)	No determination of who in the sample was aware	Selection bias—healthy population No measure of what the patient's awareness—assumed they knew Pretest-posttest design
Liu et al <sup>55</sup> (2014) USA	If patients of physicians who report discussing prognosis earlier have more accurate awareness of their LE	n = 686 patients with stage IV lung/colorectal cancer 51% Male Median age, 63 y	No conceptual definition provided	<b>Accurate awareness of prognosis</b> <b>Estimate of survival time/contextual characteristics</b> Patients were asked: “Based on your understanding about what your doctors have told you about your cancer, your health in general, and treatments you are receiving, how long do you think that you have to live?” Relatively “accurate perception of prognosis” was <2 y for stage IV lung cancer and <5 y for stage IV colorectal Saying in God's hands or don't know were not deemed aware	Communication with a physician who reported discussing prognosis “now” (P = .006) Patients who were closer to death (P < .001)	Improve the EOL care experience (not statistically measured)	83.5% did not have accurate awareness	Large sample size Unable to determine the HCP/patient conversation
Mack et al <sup>56</sup> (2018) USA	To evaluate experiences with prognosis communication among adolescents and young adults (AYAs) with cancer.	n = 203 young adults with cancer 75% <18 y old	No conceptual definition provided	<b>Awareness of disease and curability</b> Patients and oncologists were both asked the following questions: “How likely you think it is that you/this patient will be cured of cancer” with response categories of “extremely likely (>90% chance of cure)”; “very likely (75%-90%)”; “moderately likely (50%-74%)”; “somewhat likely (25%-49%)”;	More extensive prognostic disclosure (P = .003)	Patients who had more extensive prognostic disclosure had higher odds of trust in the oncologist, peace of mind, and hope related to physician communication	62% reported prognostic estimates that exceeded those reported by physician (eg, most overestimate chances of cure relative to oncologists)	High response rate (74%). Bivariable and multivariable logistic regression

(continues)

Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Mackillop et al <sup>57</sup> (1988) Canada	Determine how accurately cancer patients perceive their situation and to define factors that may lead to imperfect communication between doctors and their patients	n = 100 cancer patients with various diagnosis 56% Male 82% >50 y old		“unlikely (10%-24%)”; “very unlikely (<10%)”; or “no chance of cure”	Higher education ( $P < .05$ ) Communication with HCP (not statistically measured)	(OR, 1.30; 95% CI, 1.01 to 1.67; $P = .05$ ).  Treatment decisions (not statistically measured)	Disclosure was also associated with lower distress related to knowing about Prognosis. 33% of the patients with distant metastasis were not aware 33% of patients being treated palliatively thought their treatment was curable	Subjective nature of determining awareness Cross-sectional
Montazeri et al <sup>58</sup> (2004) Scotland	To examine if knowledge of lung cancer diagnosis effects QOL	n = 238 129 lung cancer patients and 109 with chronic respiratory disease 60% Male Mean age, 67.5 y	No conceptual definition provided	<b>Knowledge of cancer diagnosis/contextual characteristics</b> A patient was deemed to have knowledge after “formal disease disclosure” by team of HCPs Not knowing group was those that were interviewed before “diagnosis”	Younger age ( $P = .04$ ) Type of lung cancer ( $P < .0001$ )	No statistically significant impact on QOL	Of the lung cancer patients ~77% were unaware of their diagnosis No other significant differences between groups in terms of QOL measures	Cross-sectional Assumption that disclosure of
Montazeri et al <sup>59</sup> (2009) Iran	Compare QOL in patients who knew their diagnosis and those who did not	n = 142 GI cancer patients 56% Male Mean age, 54.1 y	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 ( $P = .001$ ) Higher level of education ( $P = .001$ ) Cancer site ( $P = .001$ ) Culture (not statistically measured)	Worse QOL subscale scores physical ( $P = .001$ ) social ( $P = .014$ ) emotional ( $P \leq .0001$ )	52% did not know their diagnosis Assumption that disclosure of diagnosis = awareness	
Morasso et al <sup>60</sup> (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 psychologists to “determine the domains of the concept of	“Is a dynamic process that undergoes changes during the course of the disease... is affected by the quantity and quality of clinical information given to	<b>Patient awareness/understanding disease trajectory</b> 6 cognitive assessments 7 emotional assessments Coding semistructured interviews Agreement by 4 psychologists	Quantity and quality of information Preexisting 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 1 of 7 awareness levels: Completely aware, aware rationalizing	Was able to validate this method to assess awareness

(continues)



Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Moses and Cividali <sup>61</sup> (1966) Israel	Determine distinct levels of awareness of illness—if they were related to personal attributes	awareness” Second group underwent semistructured interviews 50% Male Mean average age 57.3  n = 30 cancer patients 76.6% Female 76.6% between the ages of 46-65	the patient and by the meaning assigned by each patient to this information” (p213)	<b>Awareness of illness/contextual characteristics</b> Awareness was determined based on the multiple interviews of the patients by the 2 authors	(not statistically measured)  Higher education ( $P < .02$ ) More likely to seek treatment ( $P < .01$ ) Communication with HCP (not statistically measured)	Increased withdrawal from interpersonal relationships Acceptance of fate (not statistically measured)	patient, aware denying patient, aware introvert patient, aware patient with inconsistencies, not aware informed patient, completely unaware patient  56% with intermediate awareness 27% with minimal awareness	Unclear of how they quantified qualitative data Conceptual definitions
Nipp et al <sup>62</sup> (2017) USA	To explore the relationships among PA, coping, QOL, and mood in patients with newly diagnosed, incurable cancer.	N = 350 Mean age, 64.9 y 46% Female 92.3% white 69.7% married 62.6% educated beyond high	No conceptual definition provided	<b>Awareness of prognosis</b> The Prognosis and Treatment Perceptions Questionnaire Participants were asked to report the primary goal of their current cancer treatment from the following mutually exclusive	Communication with HCP Yet within this subgroup who reported their primary treatment goal was “to cure my	Patients who reported a terminally ill health status had worse QOL ( $P < .001$ ), depression ( $P < .001$ ),	49.4% accurately reported their health status as “terminally ill.”	Homogenous sample Lack of information about patient-clinician communication. No direction of relationship among (continues)

**Appendix • Data Extraction Table, Continued**

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Nord et al <sup>63</sup> (2003) Norway	Determine if patients who had past diagnosis of cancer were able to report that they indeed had cancer	n = 2697 former/current cancer patients 43% Male	No conceptual definition provided	options: "to lessen my suffering as much as possible," "for me and/or my family to be able to keep hoping," "to make sure I have done everything," "to extend my life as long as possible," "to cure my cancer," "to help cancer research," or "other." Participants were asked to describe their current health status by choosing from the following mutually exclusive options: "relatively healthy," "relatively healthy and terminally ill," "seriously ill and not terminally ill," or "seriously ill and terminally ill."	cancer," 44.9% acknowledged that their oncologist's goal was not "to cure my cancer." Among all participants, 22.8% reported that their oncologist's primary treatment goal was "to cure my cancer"	and anxiety ( $P < .007$ )	20% of the patients who participated in the survey were not aware of a cancer diagnosis	variables - Linear regression
Papadopoulos et al <sup>64</sup> (2011) Greece	Explore the influence of disease awareness of health-related QOL of both cancer patients and their caregivers while receiving chemotherapy	n = 212 cancer patients 56.1% Female Mean age, 57.4 y	No conceptual definition provided	<b>Disease awareness/contextual characteristics</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 about his/her prognosis?" Patient awareness was assessed in his/her ability to "acknowledge the illness and use the terms "cancer" or "tumor"	Being female ( $P = .006$ ) Higher education ( $P = .022$ ) Younger age ( $P = .021$ ) Patients with breast, GU, Lung, head/neck ( $P \leq 0.001$ ) Cultural belief in nondisclosure Communication with HCP (not statistically measured)	Worse HRQOL ( $P < .024$ )	40% were unaware of their disease	Cross-sectional

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Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Prigerson <sup>11</sup> (1992) USA	To understand the dynamics of the dying patient/primary caregiver/patient to determine if the patient will acknowledge death and what type of treatment the patient will receive	n = 76 geriatric patients who have an LE of ≤6 mo/primary caregivers/physicians 50% Male Mean age, 71.3 y	No conceptual definition provided	<b>Death acknowledgement/contextual characteristics</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 healthy or seriously ill but not terminal: “nondeath acknowledgers”	Communication with HCP ( $P < .01$ ) Caregivers accepting of pending death ( $P = .05$ ) Disclosure of terminal prognosis ( $P < .0001$ ) Nonteaching hospitals ( $P < .01$ )	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 62% had no awareness of their cancer 46% thought a cure could be achieved Only 10% could correctly identify the treatment as being palliative	Small sample size Cross-sectional
Pronzato et al <sup>65</sup> (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 y	No conceptual definition provided	<b>Awareness of diagnosis and prognosis/contextual characteristics</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 information received, awareness of the aims of treatments	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
Robinson et al <sup>66</sup> (2008) USA	Patient/oncologist pairs to understand concordance of prognosis	n = 147 advanced cancer patients & 51 oncologists 53% Female Mean age, 60 y	No conceptual definition provided	<b>Curability/contextual characteristics</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 ( $P = .006$ ) 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 ( $P = .017$ )	Tape recording conversations with patient/HCP—determine awareness (no recall bias) Only measured 1 aspect of prognosis via estimated chance of cure Cross-sectional
Justo Roll et al <sup>67</sup> (2009) Cuba	First, to evaluate the needs of patients with advanced malignant disease using the Palliative Outcome Scale (POS) Second, to look at	n = 91 cancer patients 57.1% Male Mean age, 59 y	No conceptual definition provided	<b>Knowledge of their disease/contextual characteristics—consequences</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” ( $P = .011$ ) Decrease in anxiety ( $P = .03$ ), More likely to obtain information ( $P = .028$ )	59% were unaware of diagnosis Unclear how they made the determination of patient knowledge A healthier cohort	(continues)

## Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Shen et al <sup>68</sup> (2018) USA	these needs in comparison with demographic data and patient awareness of their diagnosis To examine the association between the main interactive effects of advanced cancer patients and caregiver prognostic understanding on DNR	n = 279 caregiver dyads Mean patient age 60.18 86.1% White 56.9% Female 58% College education or higher Mean caregiver age 54.48 85% White 63.7% Female 59.7% College educated or higher	“As an acknowledgment that the end of their life is near (eg, that patients are likely to have months, rather than years, left to live).”	<b>Prognostic understanding</b> Patients and caregivers were asked, “How long do you think you have [the patient has] left to live?” Responses were given in terms of mo and years. Responses of ≤12 mo were coded as “1” = prognostic understanding and responses of >12 mo were coded as “0” = lack of prognostic understanding 3.6%-38.9% lacked prognostic understanding	Caregiver/Patient Agreement	When both patient and caregiver understood prognosis, 70% of patient completed DNR compared with 31.6%–38.9% when 1 or both lacked prognostic understanding (P = .04)	72.2% of dyads patient, caregiver, or both lacked prognostic understanding Result cannot be generalized. : combined effects of both patient and caregiver were examined. Adequate sample size	The sample was white and highly educated patients and caregivers. Result cannot be generalized. : combined effects of both patient and caregiver were examined. Adequate sample size
Shin et al <sup>69</sup> (2018) South Korea	To evaluate patients' and family caregivers' understanding of the cancer stage, treatment goal, and chance of cure taking their own physician's evaluation as reference	n = 750 patient-caregiver dyads Mean patient age 60.2 y 54.6% Female	No conceptual definition provided	<b>Awareness of prognosis/incurability</b> Patients and caregivers were asked to report their knowledge of patient's cancer stage (localized, regional, distant, or metastatic, and do not know), treatment goal (cure, life-prolonging, and symptom relief), and chance of cure (0%, 1-25%, 26-50%, 51-75%, 75-99%, and unsure	Older age (aOR, 1.05; 95% CI, 1.02-1.08) Optimistic view of treatment goal was associated with regional (aOR, 2.96; 95% CI, 1.17-7.51) or distant stage (aOR, 38.12; 95% CI, 16.12-90.13) Patients of surgical oncologists were less likely to have an optimistic view of treatment goal (aOR, 0.33; 95% CI, 0.15-0.72)	None reported	The agreement rates between patient-physician and caregiver-physician for chance of cure were 41.4% and 45.1%, respectively. The agreement rates between patient-physician and caregiver-physician were 63.0% and 65.9% for disease stage, 69.0% and 70.0% for treatment goal, and 41.4% and 45.1% for chance of cure	Unclear of communication practices

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**Appendix • Data Extraction Table, Continued**

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/Limitations
Tang <sup>7</sup> (2006) 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, 61 y 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 ( $P = .0010$ ) Congruence between family and patient on place of death ( $P < .0001$ )	63.8% of patients were unaware of their prognosis	Younger and healthier cohort than those who chose not to participate Cross-sectional
Tang et al <sup>70</sup> (2008) Taiwan	Association between accurate prognostic understanding and EOL care preferences and to identify correlates of accurate prognostic understanding among terminally ill cancer patients	2452 terminally ill cancer patients (determined by oncologist) 57% Male 88.87% > 65 y	No conceptual definition provided	<b>Accurate PA/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" (p781)	Male ( $P < .001$ ) Younger age ( $P = .002$ ) Higher education ( $P = .007$ ) Lung cancer ( $P = .020$ ) Breast cancer ( $P = .001$ ) Academic Medical Center ( $P = .002$ )	Less likely to want CPR ( $P < .001$ ) More likely to want hospice care ( $P < .001$ )	50.2% did not understand their prognosis Huge sample from 23 hospitals	Cross-sectional Large sample from 23 hospitals
Tang et al <sup>8</sup> (2016) Taiwan	Prospective study to evaluate the associations of accurate PA and prognostic acceptance with psychological distress, existential suffering, and QOL	325 terminal cancer patients 57.5% Male 32.1% >65 y	No conceptual definition provided	<b>PA and prognostic acceptance/contextual characteristics</b> <b>PA:</b> "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 soon. 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." <b>Prognostic acceptance:</b> "On a 7-point Likert scale from 1 (not at all accepted) to 7 (complete	Closer time until death (not measured statistically)	PA: Severe anxiety symptoms ( $P = .004$ ) Severe depressive symptoms ( $P = .002$ ) Worse QOL ( $P < .001$ ) Less likely to want ICU care ( $P = .001$ ) Intubation ( $P = .003$ ) Mechanical ventilations ( $P < .01$ ) Prognostic acceptance:	58.5% with PA in the beginning—at the last assessment 69.8% 41.5% without PA 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

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Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/Limitations
Tchen et al <sup>71</sup> (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	acceptance). Prognostic acceptance was further dichotomized into high (>5) and low (<5) acceptance (5 = median score)" (p456)  <b>Awareness of disease/curability/contextual characteristics</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 mo 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) (p642)	Communication with HCP (not statistically significant)	Severe anxiety symptoms (P = .003) Severe depressive symptoms (P < .001) Worse QOL (P = .05)  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 = .005)	All patients estimated their probability of a cure to be higher than that estimated by physicians (P < .0001)	Cross-sectional Feasibility study with a convenience sample Lack of power to detect other variables
Temel et al <sup>72</sup> (2011) USA	RCT to determine patients' perceptions of prognosis and goals of therapy, then to determine if early introduction of a palliative care programs impacted patient illness perception over a 6-mo period	n = 151 metastatic NSCLC patients 77 received the intervention and 74 received the control 48% Male Mean age, 65 y	No conceptual definition provided	<b>Illness perception/curability</b> Self-report items: "My cancer is curable" (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)	Introduction of a palliative care program early (P = .02)	Less likely to take chemotherapy (P = .02)	Initial interviews showed 31.7% thought their cancer was curable 69.4% also reported that the goal of therapy was to get rid of all their cancer	Randomized control trial
Thompson et al <sup>73</sup> (2009) Canada	To explore the issue of prognostic acceptance on the physical, psychological, and existential well-being of patients with	n = 381 terminally ill cancer patients	No conceptual definition provided	<b>Prognostic acceptance/contextual characteristics—consequences</b> "So, you feel that you can accept your situation and come to terms with all that is happening?" Patients were deemed "acceptors" if they scored 0 to 2 on the item,	Older patients (P < .000) Less educated (P < .05) Bigger social networks (P < .05)	Less likely to have depression (P < .01) Anxiety (P < .01)	25.7% had minimal —severe difficulty with acceptance	Mixed methods Cross-sectional Patients already receiving palliative care

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Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Wang et al <sup>74</sup> (2014) China	advanced cancer and the factors that may contribute to this process To understand patient's awareness of their disease with semi structured 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 y	"The patient knowing that his or her illness was cancer..." (p1192)	<b>Patient's awareness of cancer diagnosis/contextual characteristics—consequences</b> "Patients were asked whether and how the patients had been given the information of cancer diagnosis." Semistructured 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" (p1192) (From previous manuscript Wang, et al., 2011)	None identified	No difference between groups in anxiety and depression ( $P = .572$ )	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
Weeks et al <sup>12</sup> (1998) America	If patients estimate of LE 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 y	No conceptual definition provided	<b>Survival estimates</b> "What are the chances that you will live for ≥6 mo?" Choices: 90% or better About 75% About 50-50 About 25% ≤10%	Communication with HCP	Patients who had a 90% estimation that they would be alive in 6 mo were more likely to favor life extending therapy (OR, 2.6)	Patients were less accurate about their survival time than their HCP 57% of patients who thought they had a 90% chance of surviving 6 mo died at the 6 mo mark	Prospective observational study Low response rate
Weeks et al <sup>9</sup> (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 your cancer" Response options: "Very likely" "Somewhat likely" "A little likely" "Not at all likely" "Don't know"	Lung cancer ( $P < .001$ ) Identified as white ( $P < .001$ ) Integrated health network ( $P = .002$ ) Perceived negative communication with HCP ( $P = .002$ )	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

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Appendix • Data Extraction Table, Continued

Author Year Study Origin	Aim	Sample/Patient Characteristics	Conceptualization of ADS	Operationalization of ADS	Factors That Impact ADS	Results of Having ADS	Key Results	Strengths/ Limitations
Yun et al <sup>75</sup> (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 y old	No conceptual definition provided	Participants that stated "was not at all likely" to be curative were considered to have awareness (p1617) <b>Ability of patient to state stage of disease at diagnosis/contextual characteristics—consequences</b> Do you know your disease stage?" Answer choices: I don't know, early stage, advanced stage, terminal stage, other Also, other "end of life issues" were evaluated, but they are not clear as to what they are (p2475)	Communication with HCP (not statistically measured)	More likely to use palliative care (P = .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

Abbreviations: ADS, awareness of disease status; aOR, adjusted odds ratio; BCC, basal cell carcinoma; CHF, congestive heart failure; CI, confidence interval; COPD, chronic obstructive pulmonary disease; CPR, cardiopulmonary resuscitation; DNR, do not resuscitate; ECOG, Eastern Cooperative Oncology Group; EOL, end of life; GU, genitourinary; HCP, healthcare provider; HRQOL, health-related quality of life; ICU, intensive care unit; LE, life expectancy; MG, malignant glioma; MI, myocardial infarction; OR, odds ratio; PA, prognostic awareness; QOL, quality of life; QLQ-C30, European Organisation for Research and Treatment of Cancer Core Quality of Life questionnaire.