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Conceptualizing prognostic awareness in advanced cancer: A systematic review

Allison J Applebaum¹, Elissa A Kolva², Julia R Kulikowski¹, Jordana D Jacobs¹, Antonio DeRosa¹, Wendy G Lichtenthal¹, Megan E Olden³, Barry Rosenfeld², and William Breitbart¹

¹Memorial Sloan-Kettering Cancer Center, USA

²Fordham University, USA

³Weill Cornell Medical College, USA

Abstract

This systematic review synthesizes the complex literature on prognostic awareness in cancer. A total of 37 studies examining cancer patients' understanding of their prognosis were included. Prognostic awareness definitions and assessment methods were inconsistent across studies. A surprisingly high percentage of patients (up to 75%) were unaware of their poor prognosis, and in several studies, even their cancer diagnosis (up to 96%), particularly in studies conducted outside of North America. This review highlights surprisingly low rates of prognostic awareness in patients with advanced cancer as well as discrepancies in prognostic awareness assessment, suggesting the need for empirically validated measures of prognostic awareness.

Keywords

advanced cancer; awareness of diagnosis; peaceful awareness; prognosis; prognostic awareness

Prognostic awareness (PA), particularly as it relates to the awareness of a terminal prognosis or shortened life expectancy in patients with advanced cancer, has become a topic of research and clinical interest in healthcare communication, palliative care, and psycho-oncology. Studies have found a significant relationship between accurate PA and reduced psychological distress in patients with advanced cancer (Chochinov et al., 2000; Dunn et al., 1993; Innes and Payne, 2009; Lichtenthal et al., 2009; Thompson et al., 2009; Wright et al., 2008). Furthermore, accurate PA has been found to facilitate end-of-life planning, including discussions about life-prolonging treatment preferences and the establishment of do-not-resuscitate orders (Bradley et al., 2001; Mack et al., 2008), and appears to have a significant, positive impact on the quality of life of patients with advanced cancer and their caregivers, including improved bereavement outcomes (Hebert et al., 2009; Ray et al., 2006).

Patients may report limited or inaccurate PA due to a lack of information provided by physicians, an incomplete understanding of the information provided, or an intentional or

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Corresponding author: Allison J Applebaum, Memorial Sloan-Kettering Cancer Center, 641 Lexington Avenue, 7th Floor, New York, NY 10022, USA. applebaa@mskcc.org.

unintentional refusal to accept their terminal prognosis (Hagerty et al., 2005; Hancock et al., 2007). Reviews of the literature on physician communication of PA have shown that over the past 50 years, physicians reported an increasing level of comfort discussing diagnostic information with advanced cancer patients but are often less forthcoming with information concerning prognosis despite patient preference to the contrary (Butow et al., 1996, 2002; Charlton, 1992; Chochinov et al., 2000; Hagerty et al., 2005; Hancock et al., 2007). Additionally, it is not uncommon for patients to manifest denial, refusing to acknowledge a terminal prognosis and maintain hope for cure or long-term survival in the face of contradictory evidence (Chochinov et al., 2000; McClement and Chochinov, 2008).

Preference for and disclosure of prognostic information also varies across cultures, as there is evidence that cultural norms and values provide the foundation for physician disclosure of information to patients and their families (Holland et al., 1987; Mitchell, 1998; Mobeireek et al., 2008; Tan et al., 2012). For example, in collectivist cultures such as India and Japan, where the interdependence of family members and respect for elders are particularly emphasized, the communication of accurate prognostic information to patients is often more limited, as disclosure of bad news may be deemed disrespectful. Moreover, the role that the family unit plays in a patient's diagnostic and prognostic awareness (PA) and medical decision-making is often more central in non-Western cultural groups, such as Saudi Arabia and The Republic of Singapore (Mobeireek et al., 2008; Tan et al., 2012). In such groups, there may be more reliance on family members to receive and control disclosure of prognostic information to the patient. Therefore, the Western medical paradigm of truth telling does not appear to hold cross-culturally and instead is often seen as highly undesirable (Mitchell, 1998).

Study purpose

It is important for clinicians to understand their patients' level of PA so that medical and psychosocial care may be optimized. Our clinical experience providing psychosocial services to advanced cancer patients suggests a need to assess PA prior to the initiation of psychosocial interventions to reduce psychological distress and facilitate coping and treatment planning. To date, however, the literature has yet to reach a consensus on how PA is best defined and evaluated. The purpose of this systematic review was to synthesize the literature on PA, with an emphasis on how PA is defined and measured among patients with advanced cancer.

Method

Systematic literature searches were conducted in five databases for English-only references, excluding case reports and letters, within the date range of 1 January 1990 to 12 December 2012: MEDLINE, Embase, The Cochrane Library, CINAHL, and PsycINFO. For all databases, both controlled vocabulary and text word searches were performed. All search results were combined in a bibliographic management tool (EndNote), and duplicates were eliminated both electronically using the capabilities in EndNote and manually to identify any duplicates missed by the software.

This search strategy had three components, and all components were linked together with the AND operator: (1) cancer, cancer staging; (2) awareness, health knowledge, attitudes; and (3) prognosis, diagnosis. After combining the three components, the results were either limited to exclude case reports and letters by using a filter option (Embase, PsycINFO) or excluded by attaching the specific publication type tags to the search string using the NOT operator (Embase). The results of the databases that did not have a filter or operator option (Cochrane, CINAHL) of eliminating the desired publication types were triaged during the investigator assessment process of the review.

Results were also filtered to include only references pertaining to adult age groups (>19). This was possible in both PubMed and CINAHL, while Embase uses an >18 designation to limit to adults. Cochrane and PsycINFO both do not have an age limit option in their filters. Articles focusing on younger samples were excluded from this review. Also, non-English language publications retrieved from PsycINFO and Cochrane were excluded by the reviewers. For a complete list of Medical Subject Headings (MeSH) and keyword terms used, please refer to the PubMed search strategy in Appendix 1.

Of the 14,985 articles retrieved, 37 met inclusion criteria for this systematic review (see Table 1). The articles were divided according to the method of measurement of PA. Measurement approaches included the following: (1) structured methods (participants were asked to respond to identical questions about PA), (2) semi-structured methods (assessors used an interview guide that contained a list of questions or topics to be covered in a particular order, allowing participants' responses to shape the course of the interview), or (3) unstructured methods (utilizing open-ended interviewing techniques to derive information (Bernard, 2005; Patton, 2002) (Figure 1).

Results

Structured measurement of PA

Of the 37 studies reviewed, 25 (68%) employed a structured method for assessing PA. Of these, 6 (Lichtenthal et al., 2009; Phelps et al., 2009; Prigerson, 1992; Ray et al., 2006; Smith et al., 2008; Wright et al., 2008) used a measure of PA (referred to by the author as *terminal illness acknowledgement* (TIA)) developed by Prigerson (1992), which asks "How would you describe your current health status?" and offers the following response options: "relatively healthy," "seriously but not terminally ill," and "seriously and terminally ill." Here, PA is defined as awareness that one's illness is serious and terminal. For example, Lichtenthal et al. (2009) examined the relationship between psychiatric disorders and cognitive and emotional acceptance of terminal health status among patients at various stages of disease progression. PA was found to increase with closeness to death. Ray et al. (2006) examined the relationship between PA and psychological distress and advanced care planning among 280 advanced cancer patients. Using the TIA, the authors divided participants into two groups: 26.7 percent of their sample was categorized as having *TIA*, while the remaining 73.3 percent of the sample was categorized as having *no TIA*.

Six studies evaluated patients' understanding of the aim (palliative or curative) of treatment as a proxy for PA (Chow et al., 2001; Derman and Serbest, 1993; Leighl et al., 2011;

Numico et al., 2009; Pronzato et al., 1994; Tang et al., 2008). For example, in their study of awareness of diagnosis and prognosis in recently diagnosed patients in Italy, Numico et al. (2009) had clinicians respond “yes” or “no” to a series of statements, including “The patient demonstrates awareness/comprehension of his/her prognosis.” and “Is the patient correctly informed about the meaning (curative or palliative) of future treatments?” The results indicated that of the 649 patients evaluated (41% of whom had advanced disease), 55 percent were considered to have full PA.

PA was defined similarly by the Italian Group for the Evaluation of Outcomes in Oncology (1999) using two visual analog scales representing curability and disease severity to assess PA. The scales were anchored with “very easy to cure” and “very difficult to cure” for curability and “not severe disease” to “quite severe disease” for disease severity. Of the 2,088 patients evaluated, 26 percent of patients with metastatic disease believed the illness to be “difficult to cure” and 47 percent believed their disease was “severe.” Robinson et al. (2008) also conceptualized PA as the likelihood of curability.

Four studies that employed structured measurement approaches relied on questions that equated PA with patients’ estimates of their proximity to death (Fried et al., 2006; Haidet et al., 1998; Helft et al., 2003; Weeks et al., 1998). For example, in their evaluation of patients with metastatic colorectal disease, Haidet et al. (1998) asked patients to predict the probability that they would be alive 2 and 6 months after the interview by choosing one of the following responses: greater than 90 percent, about 75 percent, about 50/50, about 25 percent, and less than 10 percent. 75 percent of patients reported a 90 percent chance of survival at 6 months (in comparison to the 5% reported by these patients’ physicians).

Chan (2011) used clinical data mining to collect data regarding the PA of deceased hospice patients in China. Patients and their caregivers completed the Support Team Assessment Schedule (STAS), a clinical assessment tool commonly used in palliative care (Higginson and McCarthy, 1993). Responses were used to categorize participants into five categories of awareness: (0) full awareness of prognosis, (1) prognosis under- or overestimated by 200 percent, (2) uncertain about becoming well or long-term prognosis, (3) unrealistic (e.g. expecting to return to normal activity or work for a year, when the prognosis is only 3 months), and (4) expecting to become completely well. Of the 935 patients included in the study, about half (49.5%) were deemed fully aware of their prognosis, while 25.5 percent fell into category 1, 10.7 percent into category 2, 1.4 percent into category 3, and 0.1 percent (1 patient) had no awareness of their prognosis.

Price et al. (2012) administered an established measure of illness representations (the Brief Illness Perception Questionnaire (IPQ; Broadbent et al., 2006)) to patients with advanced cancer. The measure assesses perceptions that people form in response to a health threat, including beliefs about the timeline or expected course of the illness. Although this measure was successful in identifying the relationships between illness perceptions and depression in advanced cancer, the authors concluded that the timeline question was not appropriate for use in a population with a limited prognosis.

Semi-structured measurement of PA

Of the 37 studies reviewed, 8 (22%) employed semi-structured approaches to measure PA. Andruccioli et al. (2007), Burns et al. (2007), Chochinov et al. (2000), and Johnston and Abraham (2000) evaluated PA in patients with advanced disease, while the other four studies (Brokalaki et al., 2005; Caruso et al., 2000; Gattellari et al., 1999; Morasso et al., 1997) enrolled patients at various stages of their disease (i.e. some with advanced disease but others with early-stage disease).

In their evaluation of PA in 100 Italian hospice patients, Andruccioli et al. (2007) asked patients, “What are your plans when you will go back home?” “What are your wishes for the future?” and “What are you expecting from Hospice?” The assessor rated patients as “aware” if they indicated that their disease was terminal, if they had realistic plans given their life expectancy, and if they knew that their hospice treatment was palliative as opposed to curative. In this study, PA was defined as an awareness of the terminal nature of one’s disease, the purpose of treatment, and as an awareness of a shortened life expectancy. The results showed that 62 percent of patients were aware of their prognosis. Notably, 27 percent of patients evaluated were unaware of their cancer diagnosis.

Brokalaki et al. (2005) examined both prognostic and diagnostic awareness in patients at a cancer center in Greece by asking questions about their knowledge of diagnosis, treatment, and prognosis (specific questions not provided). The results indicated a surprisingly low level of diagnostic awareness of this sample, as 59 percent of patients were unaware of their cancer diagnosis.

Burns et al. (2007) evaluated PA in 117 patients with advanced cancer and their caregivers regarding whether the goals of treatment were to monitor illness, to improve quality of life, to control illness, or to cure the disease. Paired responses were then used to evaluate the level of congruence between patients and their caregivers and were classified into three PA categories: (1) full awareness (both respondents understand that the treatment was not intended to cure), (2) partial awareness (one member of the pair correctly understood that the treatment was not curative), and (3) nonawareness (either misperception when both members of a pair believed that the treatment would cure the disease or confused if both members indicated that they did not know whether treatment aimed to cure or not or one member of the pair indicated that they did not know, while the other said that they believed treatment would cure). One-third of dyads (33.3%) were aware that the treatment goal was not curative, while 29 percent were partially aware and 37.6 percent were categorized as nonaware.

Chochinov et al. (2000) developed an assessment method that asks patients “What do you understand of your illness?” and three follow-up questions (“How serious do you believe things are?”; “What have you been told?”; and “Do you have a sense of how much time might be left to you?”). Based on patients’ responses, the interviewer rated patients’ PA as “No Acknowledged Awareness” (i.e. the illness is curable with no terminal prognosis), “Limited Awareness” (i.e. the illness is terminal but has unrealistic survival expectations), and “Full Awareness” (i.e. full understanding of the illness and the imminence of death). Using this method, accurate PA among advanced cancer patients is defined as an awareness

that their disease cannot be cured and their life span is shortened. Of the 200 patients evaluated, the majority (73.5%) were rated as having Full Awareness, 17 percent had Limited Awareness, and 9.5 percent had No Acknowledged Awareness (Chochinov et al., 2000).

Caruso et al. (2000) also used a semi-structured interview to assess PA, but did not specify the questions asked. They reported that 43 percent of patients had accurate PA as a result of stating one of the following during the interview: “I know my cancer is advancing/my cancer is advancing,” or “I know I have metastases/I have metastases.” According to this method, PA is defined as awareness that one’s disease is not localized.

In their examination of the role of denial in the accuracy of PA in cancer patients at various stages of disease, Gattellari et al. (1999) assessed 244 patients via a semi-structured interview (using seven unspecified questions) that assessed the extent of their disease, the goal and type of treatment, and the probability that treatment would result in a cure, prolongation of life, and, if relevant, palliation. The results indicated that while 60 percent of participants understood the goals of the treatment they were receiving, only 18, 13, and 18 percent correctly estimated the likelihood of their treatment achieving a cure, prolonging life, and palliation, respectively. As in previous studies (Andrucioli et al., 2007; Chochinov et al., 2000), these authors conceptualized PA as a multidimensional construct that included elements of disease curability, purpose of treatment, and life span estimates.

Finally, Morasso et al. (1997) described the development of a semi-structured measure of PA. First, 36 patients were interviewed regarding their knowledge of their diagnosis and perception of treatment goals and outcomes, information that was used to inform 13 domains of cognitive and emotional correlates of PA. These domains were then incorporated into a semi-structured interview that was used to classify patients into seven awareness levels as follows: (1) completely aware patient; (2) aware rationalizing patient; (3) aware denying patient; (4) aware introvert patient; (5) aware patient with inconsistencies; (6) not aware, informed patient; and (7) completely unaware patient. The interview was used to classify 54 patients with various cancer diagnoses and stages of disease. Of these patients, 37 percent were completely aware (category 1), 35.2 percent were partially aware (levels 2–5), and 27.8 percent were not aware of their diagnosis (level 6 or 7).

Unstructured measurement of PA

Of the 37 studies, 4 (Barnett, 2006; Chandra et al., 1998; DeWalden-Gałoszko, 1996; Papadopoulos et al., 2011) employed unstructured approaches to assessing PA. Barnett (2006) evaluated PA among 106 advanced cancer patients in the United Kingdom using an open-ended interview that included questions (unspecified) about patients’ understanding of prognosis. The majority (78%) of the sample had an accurate understanding of their diagnosis, close to half (49%) had a realistic timeline and PA, and 22 percent were realistic about their prognosis, in general, but not the timeline. However, the limited description of the assessment makes it difficult to determine how these authors defined PA other than as awareness of a limited life span.

Chandra et al. (1998) assessed PA by asking open-ended questions to newly admitted cancer patients at an oncology center in South India. Close to half of their sample (46%) was unaware of their diagnosis, and of those who were aware of having cancer, only 28 percent were aware of the intent of treatment (curative vs palliative). In this study, awareness of the purpose of treatment was equated with PA.

Degree of PA

This review indicated a wide range of PA, from 0 to 75 percent, but with no clear relationship to study methodology. For example, of the studies that used a structured interview, the range of “full awareness” or an accurate understanding of prognosis reported was 9 (Justo Roll et al., 2009) to 73.5 percent (Chochinov et al., 2000). In some cases, this was linked to the absence of awareness of the cancer diagnosis altogether (Pronzato et al., 1994).

The definitions of PA included multiple components, such as awareness that one’s disease is metastatic, awareness of the terminal nature of one’s illness, awareness of the purpose of treatment, and/or awareness of a shortened life expectancy. Several studies assessed only one of these components (Chow et al., 2001; Fried et al., 2006; Sapir et al., 2000), while others evaluated many or even all of these components (Chochinov et al., 2000; Gattellari et al., 1999; The Italian Group for the Evaluation of Outcomes in Oncology, 1999). This variation in the way PA was defined precludes our ability to make comparisons between studies about the percentage of participants who had accurate PA.

Prognosis is arguably a moving target that fluctuates over the course of the cancer trajectory (Vickers and Brewster, 2012). In order to determine the accuracy of patients’ prognosis, objective medical data and/or physician ratings stemming from such data are needed. Only one study (Haidet et al., 1998) included patient and physician ratings of prognosis. Several studies compared patients’ PA with physicians and/or caregivers’ ratings of patients’ PA and described accuracy in terms of the concordance between these ratings (Andruccioli et al., 2007; Caruso et al., 2000; Chochinov et al., 2000; DeWalden-Gałoszko, 1996). However, physicians, too, are often poor prognosticians (Christakis, 1999); therefore, while concordance may be useful in facilitating treatment planning, it is also subject to error.

Correlates of PA

Although the majority of the 37 studies did not specifically examine correlates of PA, several common themes emerged. The most consistent correlates of PA were education (Brokalaki et al., 2005; Pronzato et al., 1994; The Italian Group for the Evaluation of Outcomes in Oncology, 1999) and younger age (Brokalaki et al., 2005; Caruso et al., 2000; Numico et al., 2009). In several studies, education was positively correlated with PA, while age was negatively correlated with PA, such that younger patients and those with higher levels of education were more likely to report higher PA than patients with less education and those who were older. Additional demographic variables positively associated with PA included female gender (Chochinov et al., 2000; Pronzato et al., 1994) and White race (Smith et al., 2008).

Psychiatric correlates of PA have also emerged (Caruso et al., 2000; Chochinov et al., 2000; Helft et al., 2003; Lichtenthal et al., 2009; Smith et al., 2008). Chochinov et al. (2000) found that the presence of depression was associated with denial or inaccurate PA, while Justo Roll et al. (2009) found that anxious patients were less likely to ask physicians for diagnostic and prognostic information. Additional factors that appeared to correspond to more accurate PA include increased proximity to death (Lichtenthal et al., 2009), the accuracy of caregivers' PA, open discussion of prognosis within the patient and/or family (Chandra et al., 1998; Johnston and Abraham, 2000), and the patients' full participation in end-of-life discussions (Wright et al., 2008). Importantly, correlates of PA did not appear to differ across the various study methodologies employed.

Discussion

The goal of this review was to synthesize the literature on PA, with an emphasis on how PA is defined and measured. Some studies defined PA as the awareness of metastatic or advanced disease (Chochinov et al., 2000; Numico et al., 2009; Ray et al., 2006; Wright et al., 2008), whereas others required the estimation of likelihood of survival for specified periods of time (Fried et al., 2006; Haidet et al., 1998; Weeks et al., 1998). Furthermore, studies varied in their conceptualization of PA as a uni- or multidimensional construct, which may explain the wide range of accurate PA reported. Even in instances in which rates appeared similar, such as those reported by Andruccioli et al. (2007) and Caruso et al. (2000), closer examination of the questions employed revealed considerable discrepancies in the manner in which PA was assessed. Andruccioli et al. (2007) used psychologist ratings to evaluate patients' levels of PA, which may not have directly tapped into patients' understanding of their prognosis and was contingent on the personal judgment of the psychologist. Evaluations of patients' PA by physicians in the study by Caruso et al. (2000), however, were based on patients' expressing, "My cancer is advancing" or "I have metastases," during an unstructured interview. While the report of such phrases would appear to be a valid indicator of PA, it is also possible that this approach discouraged responses that addressed other elements of PA (i.e. that included plans for a distant point in the future) from emerging. These studies suggest the need for tailored questions that directly assess the construct of PA and its various facets.

Overall, there was very little consistency in the method of measuring PA. The majority ($N = 25$) of the 37 studies reviewed here employed structured assessment techniques. The most commonly used structured assessment technique was the TIA (Prigerson, 1992), which was used in five additional studies (Lichtenthal et al., 2009; Phelps et al., 2009; Ray et al., 2006; Smith et al., 2008; Wright et al., 2008). There was great variation among the other 14 structured assessment approaches (as well as the semi- and unstructured assessments), in terms of the method of assessing PA (e.g. verbal vs visual analogue), the reporter (patient vs interviewer), and the manner in which PA was described (in terms of illness severity vs estimates of time until death).

Several of the studies reviewed did not explicitly state how PA was defined (Barnett, 2006; Brokalaki et al., 2005; Derman and Serbest, 1993; DeWalden-Gałoszko, 1996; Gattellari et al., 1999). Such omission of information regarding methodology is a significant barrier to

drawing conclusions about the optimal means of assessment. Additionally, very few of the studies (Barnett, 2006; Haidet et al., 1998; Justo Roll et al., 2009) reported the psychometric properties of the measures employed. Although use of the structured and semi-structured assessments appears to offer more face validity than the use of unstructured measures, the absence of descriptions of psychometrics of the methods employed precludes our ability to draw conclusions about their relative reliability and validity.

An area that deserves further investigation is variations in patient- versus clinician-rated PA. Clinician estimates of PA hinge on the interviewer's knowledge about the patient's diagnosis, overall morbidity and mortality rates, and available treatments, as well as the clinician's ability to effectively elicit the patient's thoughts about his or her prognosis. This can be strengthened or hindered by the type of assessment method employed, as it appears that some yield more accurate information. Similarly, the accuracy of self-reported PA is difficult to fully determine. Patients' PA can be influenced by the information received from or withheld by physicians, discussions with family, an inability to understand information provided, or a voluntary or involuntary refusal to believe information. Additional studies are needed that assess the accuracy of *both* clinician- and patient-reported PA.

Our results indicated a wide range of PA among advanced cancer patients. Across studies, accurate PA ranged from 0 to 75 percent. Additionally, several of the studies reviewed also examined rates of diagnostic awareness among advanced cancer patients, which was extremely varied, ranging from 23 to 96 percent (Baek et al., 2012; Derman and Serbest, 1993).

This review also identified correlates of PA, including the significant negative correlation between depression and accurate PA (Caruso et al., 2000; Chochinov et al., 2000; Helft et al., 2003; Lichtenthal et al., 2009; Smith et al., 2008). Patients who are depressed may be less motivated to derive an accurate understanding of their prognosis so that they may plan for future treatments. Accuracy of PA was also correlated with the accuracy of caregivers' PA, open discussion of prognosis within the family, and the patient's participation in end-of-life discussions. Indeed, a growing body of literature documents the significant impact of caregivers' willingness to communicate honestly with the patient about such information on patients' PA (Hagerty et al., 2005; Hinton, 1999; Johnston and Abraham, 2000).

Several studies have shown that in non-Western countries (e.g. Korea; Yun et al., 2011), it is common for prognostic information to be communicated first to the family or caregivers, who are then responsible for conveying (and hence, potentially withholding) this information to the patient. Under these circumstances, the patient's PA is contingent on the caregiver and his or her willingness and ability to accept and communicate the information. Not surprisingly, patients who are active participants in end-of-life conversations with their physicians and family members are more likely to have an accurate understanding of their prognosis (Johnston and Abraham, 2000; Thompson et al., 2009; Wright et al., 2008). Although a more comprehensive and systematic evaluation of cross-cultural differences is outside of the scope of this review, this topic is more thoroughly addressed by Barnett (2006) and Hagerty et al. (2005).

Limitations

Our understanding of how PA was assessed is limited by studies that provided incomplete information about their assessment method. Because only a handful of studies utilized similar approaches to assessing PA, and these studies typically addressed different issues, meta-analytic procedures could not be reliably utilized as a means of evaluating the impact of study methodology on results obtained. Additionally, while our intention was to include studies that evaluated PA among patients with advanced cancer, several studies enrolled participants who were heterogeneous with respect to cancer stage and therefore included prognostic information for patients at earlier stages of their disease. Finally, our exclusion of studies published in languages other than English may have biased the results.

Conclusion and future directions

A large body of literature has examined the communication of prognosis to patients with advanced cancer, although relatively little of this literature has utilized any empirical approach to quantifying PA. Those studies that have assessed PA among patients with potentially terminal medical illnesses reveal substantial variation in how PA was assessed across studies. Because little research has focused on examining the relative utility of these various approaches to defining and measuring PA, no consensus exists regarding which approach may be most useful for clinical or research purposes. Such research is necessary before any recommendations can be offered regarding the existing assessment techniques or to begin the development of a “gold standard” approach. Although it is premature to offer any recommendations on the basis of this review, it is likely that a comprehensive definition of PA will be multifaceted, in order to account for the various aspects of PA (i.e. aim of treatment, temporal proximity to death) highlighted in this review. Such a definition should also account for the impact of patients’ culture on PA, as valid assessment measures that are culturally sensitive and attend to the unique ways in which PA is addressed globally are needed. Until a “gold standard” approach to measuring PA is developed, we would urge researchers and clinicians to make their assessment approaches explicit and to describe the psychometric properties of these approaches. Such data are critical to begin evaluating alternative measurement techniques and comparing data across different research studies. Because levels of awareness of a patient’s prognosis may significantly impact the treatment decision-making process, assessment of PA has significant implications for patient care and end-of-life planning.

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Appendix 1

PubMed search strategy

- #1 (“Neoplasms”[mesh] OR “Neoplasm Staging”[mesh] OR cancer OR malignan* OR “Stage I” OR “Stage II” OR “Stage III” OR “Stage IV” OR “Stage 1” OR “Stage 2” OR “Stage 3” OR “Stage 4” OR “Stage One” OR “Stage Two” OR “Stage Three” OR “Stage Four”)
- #2 (“Awareness”[mesh] OR “Health Knowledge, Attitudes, Practice”[mesh] OR “Patient Acceptance of Health Care”[mesh] OR awareness)
- #3 (“Prognosis”[mesh] OR “Diagnosis”[mesh] OR prognosis OR diagnosis)
- #4 (Case Reports[ptyp] OR Letter[ptyp])
- #5 (#1 AND #2 AND #3) NOT #4
- #6 (#1 AND #2 AND #3) NOT #4 Filters: Publication date from 1990/01/01 to 2012/12/03
- #7 (#1 AND #2 AND #3) NOT #4 Filters: Publication date from 1990/01/01 to 2012/12/03; English
- #8 (#1 AND #2 AND #3) NOT #4 Filters: Publication date from 1990/01/01 to 2012/12/03; English; Adult: 19+ years; Adult: 19–44 years; Aged: 65+ years; Middle Aged + Aged: 45+ years; Middle Aged: 45–64 years; 80 and over: 80+ years

Figure 1.
PRISMA flow diagram.

Source: Reproduced with permission from the study by Moher et al. (2009).

Table 1

Assessments of PA.

Study	PA measurement	Cancer dx/stage/N/country	PA outcome
<i>Structured interview</i>			
Baek et al. (2012)	Decisional Conflict Scale (DCS) that includes 16 items informing 5 subscales: "uncertainty regarding treatment decision, being uninformed regarding their condition, lacking value clarity, lacking support, and lacking satisfaction with treatment decision."	Het/Adv/N = 98/Korea	96% aware of dx; 51% aware of prognosis
Chan (2011)	Pts' responses to the Support Team Assessment Scale (STAS) were used to classify pts into five categories of PA: 0 = full awareness of prognosis; 1 = prognosis under- or overestimated by 200%; 2 = uncertain about becoming well or long-term prognosis; 3 = unrealistic; 4 = expecting full recovery.	Het/Adv/N = 935/China	49.5% full awareness of prognosis (category 0); 25.5% prognosis under- or overestimated by 200% (category 1); 10.7% uncertain about becoming well or long-term prognosis (category 2); 1.4% unrealistic (category 3); 0.1% no awareness (category 4)
Chan and Woodruff (1997)	Do you have complete/some/none understanding of the outlook of your illness?	Het/Adv/N = 130/Australia	10% unaware of dx; 33% aware of prognosis
Chow et al. (2001)	My cancer is curable/not curable/don't know	Het/Adv/N = 60/Canada	35% curable; 48% not curable
Derman and Serbest (1993)	45-item questionnaire assessed DA/PA; Pts categorized as "know prognosis," "optimistic about prognosis"	Unspecified/unspecified/N = 45/Turkey	23% aware of dx/prognosis
Fried et al. (2006)	"If you had to take a guess, how long do you think you might live?" (<1 mo, 1–6 mos, 7–12 mos, >12 mos)	Het (cancer/COPD heart failure)/Adv/N = 214/USA	17% reported accurate PA
Haidet et al. (1998)	Pts predicted probability of being alive at 2 and 6 mos after interview: >90%, ~75%, ~50/50, ~25%, and <10%	Colorectal/Adv/N = 520/USA	75% reported 90% 6-month survival
Helft et al. (2003)	Pts estimated death from cancer: w/in no specified time frame, 5 yrs, and 1 yr; Responses included (1) "It is certain that it (death) will occur," (2) "it is probable that it will occur," (3) "it is not probable that it will occur," and (4) "it is not possible that it will occur"	Het/Adv/N = 179/USA	16% death probable within 1 yr
The Italian Group for the Evaluation of Outcomes in Oncology (1999)	Two visual analog scales, PA indicated via mark on line from 0 (very easy to cure/not severe disease) to 100 (very difficult to cure/severe disease)	Het/Het/N = 6098/Italy	26% with metastases believed "difficult to cure"
Justo Roll et al. (2009)	Pts asked, "What do you know about your condition?" Physician binary coding of PA	81.3% solid tumor/Adv/N = 91/Cuba	41% aware of dx; 9% aware of prognosis
Leighl et al. (2011)	A treatment decision aid was used to assess pt understanding of the definition of metastatic cancer and	Het/Adv/N = 100/Australia/Canada	89% understood the meaning of metastatic

Study	PA measurement	Cancer dx/stage/N/country	PA outcome
	the palliative intent of the chemotherapy they were being offered		cancer; 57% understood the palliative intent of the chemotherapy they were being offered
Lichtenthal et al. (2009)	TIA (Prigerson, 1992): "How would you describe your current health status?" Response options: 1 = relatively healthy, 2 = seriously but not terminally ill, and 3 = seriously and terminally ill	Lung, colon, breast, pancreatic/Adv/N = 289/USA	TIA was 65% among pts w/in 1 mo of dying
Numico et al. (2009)	Physician answered yes/no: (1) The pt demonstrates awareness/comprehension of diagnosis of malignant tumor? (2) The pt demonstrates awareness/comprehension of his/her prognosis? (3) Is the pt correctly informed about the meaning (curative or palliative) of future treatments? (4) If he/she has undergone diagnostic examinations, is he/she aware of the results? (5) If he/she has undergone treatments (e.g. surgery), is he/she aware of the results? (6) Does he/she know about the possibility of further treatments (such as adjuvant or palliative chemotherapy)?	Unspecified/Het/N = 649/Italy	55% full PA; 79.3% full DA
Phelps et al. (2009)	TIA (Prigerson, 1992)	Het/Adv/N = 345/USA	PA estimate not provided; TIA associated with high religious coping
Price et al. (2012)	Brief IPQ	Het/Adv/N = 300/United Kingdom	Authors state that Brief IPQ was not appropriate for accurately measuring PA
Prigerson (1992)	TIA	Geriatric/Adv/N = 76 triads ^a /USA	42% unaware of prognosis
Pronzato et al. (1994)	17-item questionnaire evaluates DA/PA, treatment aims, and information provided	Het/Adv/N = 100/Italy	62% unaware of dx
Ray et al. (2006)	TIA (Prigerson, 1992)	Het/Adv/N = 280/USA	26% aware of prognosis; 17.5% peaceful/aware
Robinson et al. (2008)	Pts predicted possibility of cure using 11 response options: 0%, 1–10%, 11–20%, etc.	Het/het/N = 147/USA	Pessimistic physician statements during appointments led to more accurate PA
Sapir et al. (2000)	Assessment of understanding of stable/progressive disease	Het/Adv/N = 103/Israel	30% full awareness of prognosis
Smith et al. (2008)	TIA (Prigerson, 1992)	Het/Adv/N = 449/USA	TIA was 52%
Tang et al. (2008)	Pts asked if they knew diagnosis and prognosis; those who knew either/both indicated the name of the disease and whether it was curable/incurable	Het/Adv/N = 1108 dyads ^b /Taiwan	50.1% aware of prognosis

Study	PA measurement	Cancer dx/stage/N/country	PA outcome
Weeks et al. (1998)	Pts asked, "What is the chance you will live for 2 mos or more if current plan of care remains the same? How about 6 mos or more?" Response options: 90% or better, about 75%, ~50/50, ~25%, <10%, do not know	Colon and lung/Adv/N = 917/ USA	Pts overestimated 6-month survival
Wright et al. (2008)	TIA (Prigerson, 1992)	Het/Adv/N = 332 dyads+/USA	37.7% aware of dx
Yun et al. (2011)	PA assessed by asking, "Do you know your/ your relative's disease?" Answer: 1 do not know/early/ advanced/terminal/ other	Het/Adv/N = 481 Korea	58.4% aware of prognosis
<i>Semi-structured</i>			
Andruccioli et al. (2007)	DA assessed by the following: (1) What type of illness do you have? (2) Why are you recovered in this ward? (3) What are your present and previous treatments? PA assessed by the following: (1) What are your plans when you will go back home? (2) What are your wishes for the future? (3) What are you expecting from the Hospice?	Het/Adv/N = 100/Italy	70% aware of dx, 38% aware of prognosis
Brokalaki et al. (2005)	Questions not specified, but pts were asked about their knowledge of dx, treatment, and prognosis	Unspecified/Unspecified/N = 203/Greece	59% not aware of dx, PA information not provided
Burns et al. (2007)	Pts and caregivers were asked whether treatment aim was "to cure," and responses were used to classify dyads as having (1) full awareness, (2) partial awareness, or (3) nonawareness	Het/Adv/N = 117 pt/ caregiver dyads/Australia	33.3% dyads full PA, 29% partial awareness, 37.6% no awareness
Caruso et al. (2000)	Pts classified by physicians as aware of prognosis according to use of "my cancer is advancing" or "I have metastases" in response to questions (not specified)	Het/Het/N = 403/Italy	43% aware of disease
Chochinov (2000)	Patients asked: "What do you understand of your illness?" If necessary, additional follow-up questions were asked to assess patient level of awareness. Interviewer rated patient as (1) = No Acknowledged Awareness, (2) = Limited Awareness, or (3) = Full Awareness	Unspecified/Adv/N = 200/ Canada	73.5% complete awareness, 17% partial awareness, 9.5% no awareness
Gattellari et al. (1999)	Pts reported diagnosis, disease extent, treatment goal, and probability that treatment would result in a cure/ prolongation of life/palliation	Het/Het/N = 244/ Australia	71% had DA; 49% correctly estimated goals of treatment achieving cure, life prolongation, or palliation
Johnston and Abraham (2000)	Questions were not specified, six topics were explored: communication/awareness, psychosocial needs, spiritual needs, quality of life, satisfaction with care setting, preferences for death	Unspecified/Adv/N = 16/ United Kingdom	PA estimation not provided
Morasso et al. (1997)	13 areas of cognitive and emotional correlates of PA	Het/Unspecified/N = 54/Italy	37% completely aware of prognosis; 35.2%

Study	PA measurement	Cancer dx/stage/N/country	PA outcome
	identified were used to inform creation of semi-structured interview that classified pts according to seven patterns of PA, from “completely aware pt” to “completely unaware pt”		partially aware of prognosis; 27.8% not aware of dx
<i>Unstructured</i>			
Barnett (2006)	Pts were asked open-ended questions about level of understanding of DA/PA	Het/Adv/N = 109	78% aware of dx, 49% aware of prognosis
Chandra et al. (1998)	DA assessed by pts’ use of terms “cancer” or “malignancy” in response to open-ended questions; pts asked whether treatment was curative/palliative	Het/Het/N = 294/India	54% aware of dx; 72% aware of dx were unaware of treatment intent
DeWalden-Gatuszko (1996)	Clinician assessed awareness of diagnosis and stage with pt/family	Unspecified/Adv/N=410/Poland	DA/PA rates were not reported
Papadopoulos et al. (2011)	Caregiver acknowledgement of awareness of prognosis, and pt use of terms “cancer” or “tumor”	Het/Het/N = 212/Greece	60% of patients were aware of their disease

PA: prognostic awareness; DA: diagnostic awareness; Het: heterogeneous; Adv: advanced; Dx: diagnosis; Mo: month; Pt: patients; Yr: year; TIA: terminal illness acknowledgement; W/: with; IPQ: Illness Perception Questionnaire; COPD: chronic obstructive pulmonary disease.

^aTriads of physicians, terminally ill patients, and their primary caregivers.

^bDyads of primary caregivers/terminally ill patients.