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Measuring double awareness in patients with advanced cancer: A preliminary scale development study

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Abstract

Background. Individuals with advanced cancer face the challenge of living meaningfully while also preparing for end of life. The ability to sustain this duality, called “double awareness,” may reflect optimal psychological adaptation, but no psychometric scale exists to measure this construct.

Objectives. The purpose of this study was to develop a novel scale to measure double awareness in patients living with advanced cancer.

Methods. Guided by best practices for scale development, this study addresses the first three of nine steps in instrument development, including domain clarification and item generation, establishment of content validity of the items, and pre-testing of the items with patients.

Results. Instrument development resulted in a 41-item measure with two dimensions titled “life engagement” and “death contemplation.” Items retained in the measure displayed face validity and were found to be both acceptable by patients and relevant to their lived experience.

Significance of results. The results of this scale development study will allow for full validation of the measure and future use in clinical and research settings. This novel measure of double awareness will have clinical utility and relevance in a variety of settings where patients with advanced cancer are treated.

Introduction

Advanced or metastatic cancer is most often incurable, but advances in treatment allow some patients to live with this condition for years after their diagnosis – albeit with immense uncertainty about their future. These individuals face the unique challenge of engaging meaningfully in their lives, while also living with awareness of and preparation for their death. The ability to sustain this duality has been termed “double awareness,” a term coined by Rodin and Zimmermann in 2008. This concept has been explored theoretically and is considered to represent the optimal psychological adaptation to advanced disease. Sustaining double awareness has been demonstrated to be relevant for psychotherapeutic interventions for patients living with advanced cancer (Colosimo et al. 2018; Nissim et al. 2012b) and is central to the Managing Cancer and Living Meaningfully (CALM) intervention (Rodin and Hales 2021). However, there is currently no psychometric scale to measure double awareness.

Current measures of psychological adaptation to advanced disease tend to assess psychopathology or distress in response to dying but fail to capture the dual processes of living and coping with death simultaneously. However, living with the awareness of eventual death is a central human problem that becomes foreground in the context of serious illness. Individuals in this circumstance face the challenge of continuing to work, raise children, maintain relationships, and respond to other demands in one's life, while also managing their disease and preparing for the end of life. This duality involves what we have called “life engagement” and “death contemplation.” Life engagement is the ability and willingness to participate in life in a way that is aligned with one's values, meaning, and goals. Death contemplation refers to the ability and willingness to face the end of life, including thinking, feeling, discussing, and planning for it. Double awareness is proposed to represent an adaptive response to the existential paradox of living while dying (Colosimo et al. 2018; Lo et al. 2014; Rodin and Zimmermann 2008; Rodin et al. 2018). However, in the absence of a scale to quantify the construct, the relationship between double awareness and other psychological outcomes remains only theoretical.

Several existing constructs and scales have been used to assess psychological adaptation in patients with advanced cancer. These include measures of death acceptance (Klug and Sinha 1988), which assesses attitudes of openness or neutrality towards death, and measures of death

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anxiety (Krause et al., 2015; Shapiro et al. 2021). The latter assesses distress about dying and death, including about the shortness of time and about the dying process itself. Psychological adaption has also been assessed by measures of depression (Kroenke et al. 2001, Hinz et al. 2016) and quality of life (Hench et al. 2010). The latter such measures tend to assess the level of pain, distress, physical strength and functioning, and symptom burden. Life satisfaction typically measures global attitudes about one's life (Diener et al. 1985) and meaning-making refers to a psychological approach to dealing with difficult circumstances, often measured by scales that assess attitudes and spiritual beliefs (Breitbart et al. 2010).

Double awareness, as we have conceptualized it, shares features with each of the constructs that have been used to assess psychological adaption to advanced disease, but is unique in several respects. Each of the other scales include items related to only one domain, while double awareness addresses both life-related and death-related phenomena. Further, other measures tend to be based on single constructs, such as (a) distress (e.g., death anxiety, depression), (b) functioning (e.g., quality of life), or (c) attitudes and beliefs (e.g., life satisfaction, death acceptance, meaning-making). Double awareness allows for a more comprehensive understanding by assessing emotions, cognitions, and behaviors related to confronting death, engaging in life, as well as the oscillation between these two processes.

The present study aimed to fulfill the need for a measure of double awareness by developing such a scale for individuals with advanced cancer. Following the guidelines for best practices in scale development set forth by DeVellis (2017) and detailed in Boateng et al. (2018), we developed a new instrument. We identified the construct of interest, generated items, assessed content validity through an expert review of the items, and pre-tested questions through cognitive interviews with a sample of patients from the population of interest.

Methodology

According to DeVellis (2017) and Boateng et al. (2018), the development and validation of a new scale should consist of three phases: item development, scale development, and scale evaluation. Within these phases there are nine crucial steps, the first three of which are detailed in this paper: (1) identification of the domain and item generation, (2) content validity, and (3) pre-testing questions. The remaining six steps of this process are necessary for full development and evaluation of this scale and will be the focus of a future study.

Phase 1: Identification of domain and item generation

Step 1a: Identification of the domain

The development of the Double Awareness Scale was informed by the available literature on double awareness and the broader literature on the experience of living with advanced cancer. This literature included theoretical accounts of the concept of double awareness as well as themes derived from qualitative interviews with advanced cancer patients about their experiences of living while dying. This literature provided the theoretical and empirical basis for the Double Awareness Scale. The construct of interest was defined as: the ability to engage meaningfully in one's life while also attending to (thinking about) and planning for one's death. We have termed these two distinct processes: (1) life engagement and (2) death contemplation. We sought to measure each of these

dimensions on separate subscales, with each score calculated independently. High scores on both scales would indicate high double awareness and optimal coping, while discrepant scores would indicate that the respondent may be stuck in one process (e.g., focusing on death) and neglecting another (e.g., engaging in life). This two-dimensional structure, with the assessment of two distinct processes, makes this scale unique and distinct from other measures frequently used in this population.

Step 1b: Item generation

The relevant empirical and theoretical literature described above was reviewed and used to generate an initial pool of items that are grounded in theory. Generated items are consistent with Dillman et al.'s (2014) guidelines for writing survey questions. These include choosing the appropriate question format, creating items that pertain to all respondents, asking one question at a time, and ensuring that questions use simple, familiar language, as few words as possible, and simple sentence structure.

The Double Awareness Scale has a 4-category frequency scale measurement format. We chose to use a frequency scale rather than an agreement scale, as frequency scales have been shown to better assess affect and behaviors that are likely to change over time while agreement scales are more appropriate for measurement of trait variables, such as personality or beliefs (Khadka et al., 2012; Tong et al. 2020). The question format is one that asks participants to indicate how often a statement is "true for me." The four response categories are (1) Rarely, (2) Sometimes, (3) Often, and (4) Nearly Always.

Items were phrased to be sensitive to the dying experience and not to promote defensiveness or distress. Several items were included to assess the same idea with different words, with the ultimate intention to remove whichever item did not perform as well statistically. Several items were designed to be reverse coded, reflecting the inverse of the construct (e.g. "I avoid thinking about dying" is a reverse coded Death Contemplation item).

Step 2: Content validity

Following the development of the initial item pool, the items were reviewed by expert judges including Dr Gary Rodin, the co-developer of the construct of double awareness, three palliative care physicians and one nurse practitioner working in a palliative care clinic. These judges reviewed the items for content validity, assuring that the questions address the construct of double awareness, and provided feedback on clarity of the items, as well as the scales format. The judges either accepted, rejected, or suggested modifications to the items. After the initial review, modified items were again reviewed by the team of judges and the same process was repeated until there was consensus on all items.

Phase 2: Scale development

Step 1: Pre-testing questions

In this phase, we recruited patients living with advanced cancer to participate in cognitive interviews and provide feedback about the meaningfulness, relevance, and acceptability of items in the scale. All procedures were reviewed and approved by the Institutional Review Board at the University of Arizona and the University of Arizona Cancer Center Scientific Review Committee.

Participants. Five participants were recruited from the University of Arizona Cancer Center in Tucson, AZ, to participate in a 2-hour qualitative interview, during which they provided feedback on the

preliminary Double Awareness Scale. Participants were recruited via referrals from palliative care physicians, social workers, and psychiatrists. All participants spoke fluent English, were over the age of 18, and had a diagnosis of stage IV, advanced or metastatic cancer. Interviews took place at the University of Arizona Cancer Center, and participants were compensated for their time.

Procedure. After providing informed consent, participants were presented with the list of items and asked to participate in a cognitive interview. This evidence-based practice involves asking participants to verbally share their interpretation of and response to the items as they read through them, including emotional reactions, thoughts, and comments about the phrasing of items (Padilla and Leighton 2017). All interviews were audio recorded to capture the participants' response. At the end of the interview, participants were also asked to comment on their overall thoughts about the measure and whether they would recommend the questionnaire be given to another person living with advanced cancer.

Documenting feedback. Following the qualitative interviews, audio recordings of the interviews were reviewed. Comments regarding strong emotional reactions to items, suggestions for items to be rephrased or omitted, and suggestions for additional items were documented. Comments about the overall acceptability of the measure and its format were also documented.

Results

Phase I Results: Identification of domain and item generation

Step 1a: Identification of the domain

Review of the literature yielded 10 articles that reference double awareness, either directly or indirectly, by documenting themes and important aspects of the experience of living with advanced cancer and preparing for death (see Table 1). The articles reviewed included four conceptual analyses and six qualitative studies representing data from 392 patients. From this review, categorical themes emerged that informed our item generation process. The following categories emerged within the construct of life engagement: (1) connection with others, (2) enjoying the present, and (3) meaning and purpose. The following categories emerged within relevance to death contemplation: (4) distress and emotions about death and dying, (5) planning for the end of life, (6) thoughts of death, and (7) legacy after death.

Step 1b: Item generation

Initial item generation based on the literature and categories above resulted in a pool of 52 items.

Step 2: Content validity

Expert judges reviewed the 52 generated items and provided feedback on content validity. The judges either accepted, rejected, or suggested modifications to the items and provided explanations for their responses. Based on feedback and consensus from the judges, the following modifications were made to the scale:

(1) Three items were rejected on the basis of content validity because they seemed to assess global attitudes about death that are likely to be stable over time (e.g. "I accept that I will someday die"). These items therefore do not accurately assess a patient's current state with regard to acceptance of their circumstances/death.

- (2) Five items were rejected on the basis of content validity because they seemed to assess values and preferences about one's life and death that most people would endorse (e.g. "It is important to me to stay hopeful"). Judges agreed that double awareness is better evaluated through cognitions, emotional reactions, and behaviors than through stated values or preferences.
- (3) One item was rejected on the basis of content validity because it referred to thoughts of the afterlife. Judges agreed that while thoughts of the afterlife are common in patients facing end of life, they are not an indicator of double awareness.
- (4) Four items were rejected on the basis of structure and clarity, because judges believed they would be confusing to patients or interpreted in different ways. Instead of modifying these items, new items were generated to better assess the respective item.
- (5) Two items were added to assess connection with loved ones as life engagement items.
- (6) One item was added to address imagining the wellbeing of their surviving loved ones after their death.
- (7) One item was added to assess behavioral preparations for death (e.g. "I have talked to my loved ones about the care I would like to receive in the last part of my life").

The process of review by expert judges resulted in 44 items in total, with 21 items on each subscale and two exploratory items to assess the "oscillation" between life engagement and death contemplation.

To assess the readability of the scale items, a Flesch Reading Ease score was calculated. This score is an assessment of the readability of a piece of text on a scale from 0 to 100 (Flesch 1948). The modified list of 44 items achieved a Flesch Reading Ease score of 80.0, considered "easy to read," and Flesch-Kincaid Grade Level of 4.5.

Phase II results

Participants

Five individuals with advanced cancer were recruited for participation in cognitive interviews (see Table 2 for sample characteristics). Boateng *et al.* (2018) recommends to conduct cognitive interviews with 5–15 participants, or until saturation is achieved. Upon completing five interviews, we found that no new insights or feedback emerged and therefore concluded that saturation had been achieved.

Modifications to the items

Participant feedback was used to determine which items to change, add, or remove from the scale. The accepted revisions involved (a) rephrasing items with qualifiers such as "most days," in order to avoid overlap with the frequency response scale, (b) rephrasing items regarding connection with others to refer to "loved ones" or "close others" rather than "family," in order to apply to all respondents, (c) removing items that suggest an amount of "time" left to live, and (d) adding an item that asked explicitly about creating a legacy. Importantly, while more than one participant suggested adding questions about the afterlife, we chose not to include any items about the afterlife because spiritual and religious beliefs are separate and distinct from the domain of interest. These revisions ultimately led to modifications to seven items, the removal of four items, and the addition of one new item, resulting in a new scale of 41 items.

Table 1. Literature reviewed

First author	Type of source	Sample population	<i>n</i>	Key finding	Categorical themes emerged ^a
Arantzamendi et al. (2020)	Secondary analysis of qualitative data	Patients with advanced cancer	22	Identified five phases of awareness of dying: struggling, accepting, living with advanced cancer, sharing the illness experience, and reconstructing life	1 <input checked="" type="checkbox"/> 2 <input checked="" type="checkbox"/> 3 <input type="checkbox"/> 4 <input checked="" type="checkbox"/> 5 <input type="checkbox"/> 6 <input checked="" type="checkbox"/> 7 <input type="checkbox"/>
Colosimo et al. (2018)	Concept & task analysis	N/A	N/A	Double awareness involves existential tension, confronting death, life narrative, avoiding death, interpersonal connections, and integrating life and death.	1 <input checked="" type="checkbox"/> 2 <input type="checkbox"/> 3 <input checked="" type="checkbox"/> 4 <input checked="" type="checkbox"/> 5 <input checked="" type="checkbox"/> 6 <input checked="" type="checkbox"/> 7 <input type="checkbox"/>
Vehling et al. (2018)	Qualitative study	Patients with advanced cancer	17	Assessed daily dynamics of loss orientation, life engagement, end of life preparation, distraction, and hope.	1 <input type="checkbox"/> 2 <input checked="" type="checkbox"/> 3 <input checked="" type="checkbox"/> 4 <input checked="" type="checkbox"/> 5 <input checked="" type="checkbox"/> 6 <input type="checkbox"/> 7 <input checked="" type="checkbox"/>
Willig and Wirth (2018)	Qualitative, meta-synthesis	Patients with metastatic cancer	318	The meta-synthesis generated 19 theme clusters that informed the construction of four master themes: trauma, liminality, holding on to life, and life as a cancer patient	1 <input checked="" type="checkbox"/> 2 <input checked="" type="checkbox"/> 3 <input checked="" type="checkbox"/> 4 <input checked="" type="checkbox"/> 5 <input checked="" type="checkbox"/> 6 <input checked="" type="checkbox"/> 7 <input type="checkbox"/>
Rodin (2017)	Discussion	N/A	N/A	Interventions attended to legacy creation, management of the disease and relationships, self-concept and attachment security, sense of meaning and purpose, and mortality and future-oriented concerns	1 <input checked="" type="checkbox"/> 2 <input checked="" type="checkbox"/> 3 <input checked="" type="checkbox"/> 4 <input type="checkbox"/> 5 <input checked="" type="checkbox"/> 6 <input type="checkbox"/> 7 <input checked="" type="checkbox"/>
McLeod-Sordjan (2014)	Concept analysis	N/A	N/A	Death preparedness involves a transition of facilitated communication with a healthcare provider that leads to awareness and/or acceptance of end of life, as evidenced by an implementation of a plan	1 <input checked="" type="checkbox"/> 2 <input type="checkbox"/> 3 <input checked="" type="checkbox"/> 4 <input type="checkbox"/> 5 <input checked="" type="checkbox"/> 6 <input checked="" type="checkbox"/> 7 <input checked="" type="checkbox"/>
Nissim et al. (2012b)	Qualitative, longitudinal study	Patients with advanced lung and GI cancer	27	Three goals of living while dying include: controlling the dying process, valuing life in the present, and creating a living legacy	1 <input type="checkbox"/> 2 <input checked="" type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input checked="" type="checkbox"/> 6 <input checked="" type="checkbox"/> 7 <input type="checkbox"/>
Rodin and Zimmermann (2008)	Discussion	N/A	N/A	Psychoanalytic concepts relevant to the context of advanced and terminal cancer include death anxiety, denial, and acceptance; feelings about death and dying, living meaningfully, and relational concerns	1 <input checked="" type="checkbox"/> 2 <input type="checkbox"/> 3 <input checked="" type="checkbox"/> 4 <input checked="" type="checkbox"/> 5 <input type="checkbox"/> 6 <input checked="" type="checkbox"/> 7 <input type="checkbox"/>
Coyle (2006)	Qualitative study	Patients with advanced cancer	7	Three subthemes encompassed the “hard work” of living in the fact of: orienting to disease and maintaining control, searching for and creating a system of support and safety, and struggling to find meaning and create a legacy	1 <input checked="" type="checkbox"/> 2 <input type="checkbox"/> 3 <input checked="" type="checkbox"/> 4 <input type="checkbox"/> 5 <input checked="" type="checkbox"/> 6 <input checked="" type="checkbox"/> 7 <input checked="" type="checkbox"/>
Block (2001)	Qualitative study	Patient with advanced pancreatic cancer	1	Goals identified as central to a “good” death: optimizing physical comfort, maintaining continuity of self, maintaining and enhancing relationships, making meaning of one’s life and death, achieving a sense of control, confronting, and preparing for death	1 <input checked="" type="checkbox"/> 2 <input type="checkbox"/> 3 <input checked="" type="checkbox"/> 4 <input checked="" type="checkbox"/> 5 <input checked="" type="checkbox"/> 6 <input checked="" type="checkbox"/> 7 <input type="checkbox"/>

^a(1) Connection with others, (2) enjoying the present (3) meaning and purpose, (4) distress and emotions about death and dying, (5) planning for end of life, (6) thoughts of death, and (7) legacy after death.

Acceptability

At the conclusion of the qualitative interview, we asked participants to share their overall thoughts on the measure. Open-ended questions of this kind are common practice and valuable in assessing the acceptability of behavioral interventions for a target

population (Ayala and Elder 2011). We also asked patients to respond “Yes/No/I’m not sure” to the questions (1) “Do you think this measure is acceptable to give to people living with cancer?” and (2) “Would you recommend this measure to another patient with cancer?” All five participants responded “Yes” to these questions. Three participants emphasized that they believed these questions

Table 2. Qualitative study sample demographic information

	M/n	SD/%
Female	4	80%
Age	67.2	6.8
Ethnicity (White)	5	100%
Employment (retired)	4	80%
Education (college)	5	100%
Relationship (married)	4	80%
Time since diagnosis (years)	3.36	3.9

to be important for people with cancer to think about and that they are not commonly discussed in medical settings. The psychometric validity of these questions will be an avenue for further research.

Discussion

In response to the need for a psychometric scale to measure double awareness, our research group sought to develop a novel self-report measure of this construct. This paper represents the first step in that process, which will be followed by a second study to more fully evaluate and validate the developed scale. At this juncture, we have: (1) demonstrated that double awareness can be measured via self-report, (2) developed a preliminary 41-item measure for further analysis, and (3) established acceptability of the generated items for individuals living with metastatic cancer.

This third point about the acceptability of the measure is particularly important to establish because of the common belief that talking to terminally ill individuals about their death will inevitably lead to intolerable distress. Indeed, our participants were comfortable with the questions and, in some cases, participants described feeling relieved to have a place to discuss their thoughts and feelings about death. However, it is also important to consider the potential bias of self-selection in the present study. Individuals who are more comfortable contemplating their death and discussing their experience with advanced cancer might have been more likely to participate in this type of research study. Nevertheless, participant responses showed that there are individuals willing to and capable of engaging with these questions without suffering adverse effects. Further research will be crucial in evaluating the psychometric properties of the scale and the generalizability beyond this small group.

Limitations

The limitations of this study include the homogeneity of the sample of participants in Phase II. The five participants who completed cognitive interviews were majority female (80%), white (100%), retired (80%), and college educated (100%). Due to self-selection factors and time constraints, we were unable to recruit a demographically representative sample for this phase of the process. Therefore, it is crucial that further evaluation of the scale involve demographically diverse samples in order to optimize the generalizability of this measure.

The Double Awareness Scale was developed for use with individuals living with advanced cancer. However, the construct and the scale are applicable more broadly, especially to those living with advanced or life-limiting illnesses. Future studies should address the validity and applicability of this scale in other populations.

Future directions

This paper outlines the first three steps in the development of a new measure of double awareness. Completion of the remaining six steps of Boateng *et al.*'s (2018) process is essential for this measure to be validated and useful in clinical and research settings. Immediate next directions include the administration of the developed survey to a large demographically diverse sample of at least 200 participants, with the data collected to be examined with factor analysis, item-level analysis, and tests of reliability and validity.

Upon full evaluation and validation of the Double Awareness Scale, there are several ways in which this measure could have clinical and research utility. It could be used to identify patients who may benefit from psychological care and/or symptom control measures and as an outcome measure to assess the impact of therapeutic interventions (Kozlov *et al.* 2018; Von Blanckenburg and Leppin 2018). The Double Awareness Scale may also be used to facilitate end-of-life conversations that include consideration of prognosis, contemplation of death, and meaningful engagement in life. This scale can offer information to the provider about the patient's willingness to reflect on the end of life and to make practical preparation for it, as well as their engagement in meaningful activities, connections to others, and ability to participate in life. This instrument could also be used as a quantitative measure of change, allowing providers to assess the effectiveness of conversations and interventions over time. Future research should assess the impact of the Double Awareness Scale in clinical settings and explore the impact of psychological and palliative interventions and communication of health care providers on double awareness in patients with advanced disease.

The Double Awareness Scale also has potential utility in research settings. This instrument is relevant and could be integral to the evaluation of interventions designed for patients with advanced cancer, including the Managing Cancer and Living Meaningfully (CALM) intervention. CALM was developed by Gary Rodin and colleagues at Princess Margaret Cancer Center in Toronto, Ontario, CA, and was designed specifically to enhance double awareness in patients with advanced cancer (Nissim *et al.* 2012a). At present, CALM has demonstrated effectiveness in two randomized controlled trials (Lo *et al.* 2014; Rodin *et al.* 2018). The Double Awareness Scale has the potential to enhance the validity of future trials of CALM, as it is the first instrument designed to specifically measure a key target of this intervention.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951523001669>.

Competing interests. None declared.

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