Psychosocial Assessment in Oncologic Nursing:
Cognitive Strategies and Documentation Practices

By

Kathy Ann Johnson

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
(Nursing)

at the
UNIVERSITY OF WISCONSIN-MADISON
2015

Date of final oral examination: 8/3/2015

The dissertation is approved by the following members of the Final Oral Committee:

Kristine Kwekkeboom, Professor, Nursing (chair)
Earlise Ward, Associate Professor, Nursing
Cecilia Ford, Professor, English
Linsey Steege, Assistant Professor, Nursing
Elizabeth Rice, Associate Professor, Nursing

DEDICATION

This work is dedicated to all patients, as we all will be one day.

ACKNOWLEDGEMENTS

Kathy would like to thank the following people:

- Dr. Kristine Kwekkeboom and her dissertation committee for catching me and guiding me to the finish line.
- My family, especially Megen, who gives me unfailing love and support.
- My friends, especially Margaret, who listens to and wonders with me.
- Dr. Patricia Flatley Brennan
- Dr. Eileen Porter
- Dr. Kwekkeboom's Research Group
- Dr. Brennan's HealthSystems Lab
- The University of Wisconsin – School of Nursing faculty, staff, and funding support

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ABSTRACT

According to the Institute of Medicine (2008), the psychosocial concerns of patients with cancer are often unaddressed. Psychosocial care is the topic of this dissertation. The first paper reports the pilot testing of an intervention designed to help patients in the outpatient oncology setting "be known". Patient home audio recordings were made into word clouds for efficient representation to nurses. Audio content covered four areas: identity expression, response to cancer, currently facing, and personal stories. Most patients expressed a desire to communicate specific things saying, "*I do want to say*". Not all nurses embraced the opportunity to further connect with patients. This prompted investigation into the process of psychosocial assessment and documentation. The second paper reports the analysis of interviews with nurses from in- and outpatient oncology and home hospice settings about psychosocial assessments. Nurses reported five types of cues and two principles used when recognizing cues ('There is no universal cue'; 'Be alert for differences'). Nurses used questions that were broad, specific, or referred to a previous encounter. Principles used when seeking information were reported: 'Psychosocial assessment requires purposeful effort'; 'Establish trust'; 'Find the (nursing) problem'; 'You can always ask later-respect/connect'. Differences in the nurses' reports of cues and information seeking across settings indicated that the practice setting has a role in how psychosocial assessments are accomplished. Barriers to psychosocial assessment were reported: the patient, within the nurse, available tools, the environment, and the organization. The third paper explores the documentation of psychosocial assessments—why nurses choose to document (or not), location of documentation, and differences by practice setting. Nurses reported three reasons to document (to communicate patient condition; organizational requirement, prompt from record), and five reasons for not documenting ('just conversational'; difficult to reduce patient words; communicate verbally instead; 'no good place in record'; and 'it's someone else's job'). Findings suggest a significant amount of cognitive work in deciding if and how to document. Inconsistencies in the approach to documentation emerged, both within and across settings. Findings have implications for record design and for training in ways that are compatible with practice setting.

CHAPTER 1: Introduction

Problem and significance

The overall prevalence of psychosocial distress in patients with cancer is estimated to be between 24.5% and 59.3%, with variability across the cancer trajectory (Delgado-Guay, Parsons, Li, Palmer, & Bruera, 2009; Dunn et al., 2013; Gao, Bennett, Stark, Murray, & Higginson, 2010; Kendall, Glaze, Oakland, Hansen, & Parry, 2011). There is evidence that psychosocial distress may amplify pain expression (Mori, Elsayem, Reddy, Bruera, & Fadul, 2012), and that the presence of distress is associated with other somatic symptoms, e.g., fatigue, sleep disturbance, dyspnea, nausea, appetite loss (Clark, Rochon, Brethwaite, & Edmiston, 2011; Lewis, Salins, Kadam, & Rao, 2013; Yamagishi, Morita, Miyashita, & Kimura, 2009). Psychosocial distress has a detrimental effect on emotional functioning, social functioning, mental health, and overall quality of life (Montazeri et al., 2008). Psychosocial distress can be so severe that a dissociative response is triggered, creating an emotional numbness that affects the aggressiveness of care and end-of-life discussions (Maciejewski & Prigerson, 2013).

Nurses have a unique and defined role in health care, and are responsible for the assessment and treatment of psychosocial distress. According to the American Nurses Association's (ANA) Social Policy Statement (2010),

> Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, and alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations (p.10).

This dissertation investigates the real-world application of the phrase "the diagnosis … of human response" as it is applied to the psychosocial care of patients with cancer, first looking at the patient response in illness, and then at the nursing interpretation and documentation of that response.

Narrative as the patient response in illness

A narrative is a representation of a world via language or visual medium, whose primary function is to communicate the human experience (Fludernik, 2009). Narratives provide rich and detailed information about how illnesses are experienced (Frank, 1995; Charmaz, 1993). There is evidence that the elicitation of narrative data, including stories, has positive health benefits (Merz, Fox, & Malcarne, 2014); however, interventions that elicit and acknowledge patient narrative data remain separate from the usual care process (Cepeda, et al., 2008; Olsson et al., 2011).

It is asserted here that the regular or ongoing capture of patient narrative is a logical next step in the diagnosis of the patient response to illness. This capture may provide insight into patients' goals, values, and preferences-- aspects of patient-centered communication. Today’s technology affords multiple devices with features that allow quick and nearly effortless capture (if not transcription) of a person’s narrative. All narrative data have purpose-- from putting a life circumstance into words to seeking information. Emotional disclosure is not the aim of narrative capture, as patients with cancer don't always want to talk about emotional or difficult feelings (Kvale, 2007). This strategy may yield information about what topics patients consider important and wish to have acknowledged, and could give insight into the patient's response to illness. Chapter two explores the remote capture and content of patient narrative, a partial representation of the patient's response to illnesss.

Assessment

Psychosocial assessment refers to the assessment of social history, level of stress, coping patterns, "neurovegetative" changes (physical symptoms that signal a change in neurophysiological functioning: sleep patterns, appetite, energy level, etc.), the patient's understanding of illness, mental status (seeking evidence of dysfunction), personality style, and major issues of illness (Barry, 1989, p. 9-11). Little is known about the cognitive work of assessing the cancer patient's response to illness—the psychosocial assessment. According to a survey of oncology nurses, 84% of the responding nurses said that the process of psychosocial assessment occurs through nurse-patient interview and discussion (Gosselin et al., 2011). A grounded theory study of the (mental health) assessment practices of home hospice nurses had similar findings (Hackett & Gaitan, 2007).

The care of oncology patients is largely deficient in addressing patients' psychosocial concerns (IOM, 2008; Puts, Papoutsis, Springall, & Tourangeau, 2012). National Comprehensive Cancer Network (NCCN) clinical practice guidelines for distress management suggest periodic screening for patients with cancer at times when patients are expected to experience more distress (at their initial visit, at appropriate intervals, and as clinically indicated by changes in disease status) (NCCN, version 2.2014). However, these guidelines also state that a clinical assessment of the patient is required, regardless of the score on a distress-screening tool. As members of the primary oncology team who have extended time with patients over multiple settings throughout the trajectory of cancer, nurses are expected to perform psychosocial assessments. How this is accomplished is unknown. Chapter three explores this question. Supplemental data and analysis regarding barriers to making a psychosocial assessment are found in Appendix 1.

Documentation

The role of documentation in care planning may have increasing significance as the trajectory of cancer can now extend several years, with patients requiring care across multiple settings, multiple times. As a communication tool, a legal and administrative document, and a data repository, the electronic health record (EHR) and the documentation held within it contribute significantly to the quality and continuity of patient care (Keenan, Yakel, Tschannen, & Mandeville, 2008). Although a historically neglected piece of documentation, when completed, psychosocial assessment and care planning have been documented in a narrative note, often using a mnemonic to structure the note (e.g., SOAP - Subjective, Objective, Assessment, Plan). SOAP notes give a clearly documented path of evidence of the nurse's thought process from subjective and objective data collection to assessment, diagnosis and care planning. There is evidence, however, that EHRs have changed both the structure of the record and the work practices of health care professionals (Kerr, 2012; Park, Lee, & Chen, 2012; Petrakaki, Barber, & Waring, 2012). The EHR still contains a place to record narrative notes, but they are less visible. This change in location may symbolically indicate that narrative notes have a (forced) lower priority than other required nursing documentation.

There is evidence that EHR systems have particularly changed *nurses'* workflow, assessment and documentation practices (Ackerman et al., 2012; Kossman &

Scheidenhelm, 2008; Lehoux, Sicotte, & Denis, 1999; Rogers, Sockolow, Bowles, Hand, & George, 2013). It is logical to assume that these changes extend to oncology nurses' psychosocial assessments and documentation of psychosocial distress. The available documentation options, perhaps composed of nursing standardized languages, may be too restrictive, discouraging the use of more accurate and/or descriptive words necessary in a psychosocial assessment. Chapter four explores how nurses document a psychosocial assessment.

Purpose of this research

Despite the high prevalence of psychological distress, most patients do not get the professional help they need. Nurses are charged with the responsibility of "the diagnosis … of human response" in psychosocial care of patients with cancer but it is unknown how this is accomplished. Broadly speaking, the purpose of this research is to explore patient-nurse communication about non-physical concerns, first through the feasibility testing of an intervention designed to efficiently bring patient narrative data into the care process as a way to understand the patient response to illness, and second, by documenting nurse reports of psychosocial assessments, barriers to making psychosocial assessments, and documentation practices of psychosocial assessments in the electronic health record. The specific aims are:

1. To document nurses' reports of recognition and determination of relevance of patient cues in psychosocial assessment (Chapter 3)
2. To document nurses' reports of information seeking in initial and ongoing psychosocial assessment (Chapter 3)

3. To determine if and how nurses report the use of the theoretical construct of "knowledge structures" in psychosocial assessment (Chapter 3)
4. To document nurses' report of barriers to making psychosocial assessments (Appendix 1 and Chapter 5)
5. To describe nurses' reports of their documentation of psychosocial assessment in the EHR (Chapter 4)
6. To explore whether nurses' reported psychosocial assessments and documentation differ across care settings. (integrated in Chapters 3 & 4)

Understanding how nurses make and document a psychosocial assessment can inform guidelines, documentation systems design, and training programs to ensure that psychosocial assessment findings are systematically incorporated into care planning, and that interventions are delivered to address patients’ psychosocial needs.

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CHAPTER 2: Pilot Study

Title

MyWords: helping patients be known in the outpatient oncology setting

Potential Authors
Kathy A. Johnson[a]
Anne Chevalier McKechnie[b]

[a]School of Nursing
University of Wisconsin-Madison
701 Highland Ave.
Madison, WI 53705

[b]School of Nursing
University of Minnesota-Twin Cities
308 Harvard St. SE
Minneapolis, MN 55455

Corresponding Author
Kathy A. Johnson
School of Nursing
University of Wisconsin-Madison
701 Highland Ave.
Madison, WI 53705
kajohnson25@wisc.edu
Phone: 414-531-5776
Fax: not available

Acknowledgements:
This study was supported by a Wisconsin Distinguished Graduate Fellowship and by the Eckburg Fund at the University of Wisconsin-Madison School of Nursing. The first author gratefully acknowledges the guidance and helpful comments of Dr. Kristine Kwekkeboom in the production of this manuscript. The authors gratefully acknowledge the expertise of Elizabeth Rice, RN, PhD for her contributions to the analysis. Importantly, the authors express sincere gratitude to the patients of the participating clinic and its staff and nurses.

Keywords: communication, patient narrative, being known, outpatient oncology, stories
Running head: MyWords

Abstract

Communication is of particular importance in the care of patients with cancer, where effective patient-provider communication is necessary to meet the psychosocial as well as the physical needs of the patient (Institute of Medicine, 2008). Incorporating interventions that support patients' feeling of "being known" could improve the patient-centeredness of patient-provider communication. A technology-enhanced intervention was designed to capture and efficiently represent remotely captured patient narrative data, and to facilitate a patient's feeling of being known in the outpatient setting. Ten outpatient chemotherapy patients were invited to make three home audio-recordings in a one-week period. Recordings were transcribed and then processed into a printed word cloud image that was designed to be a stimulus for conversation between patient and chemotherapy nurse. This pilot field study had two aims: (1) to determine the feasibility of the intervention, and (2) to determine the characteristics and content of the home audio recordings. Recruitment, retention and completion data, field notes and semi-structured interviews with participants were used to determine feasibility and to describe audio-recording content. Eighty-three percent of eligible patients consented to participate, 80% of those completed audio recordings, 70% developed a word cloud and 60% shared it with their nurse. Audio recording length ranged from 2:03 to 23:33 minutes. Four (not mutually exclusive) categories of audio content were identified including (1) identity expression (33%), (2) my response to cancer (26%), (3) what I'm currently facing (25%), and (4) other personal stories (16%). Seventy five percent of the patients expressed a desire to communicate specific things saying, "*I <u>do</u> want to say*", with a strong emphasis

on "do", or else by repeating themselves. Participants were more likely to share concerns about what they were currently facing in later recordings. The intervention was deemed feasible, and the content that participants shared can inform future interventions to support patient-centered communication.

Introduction

Patient-provider communication is a critical aspect of health care, affecting proximal (understanding, satisfaction, feeling known, rapport), intermediate (adherence, self-care skills) and distal (survival, pain, suffering) health outcomes (Street, Makoul, Arora & Epstein, 2009). This is of particular importance in the care of patients with cancer, where effective patient-provider communication is necessary to meet the psychosocial as well as the physical needs of the patient (Institute of Medicine, 2008). According to the Institute of Medicine, patient-provider communication in cancer care needs to be patient-centered and aligned with the patient's goals, values, and preferences (Institute of Medicine, 2013). Patient-centered communication is defined in terms of processes and outcomes of the patient-provider interaction: (1) eliciting, understanding, and validating the patient's perspective; (2) understanding the patient within his or her own psychological and social context; (3) reaching a shared understanding of the patient's problem and its treatment; and (4) helping a patient share power by offering him or her meaningful involvement in choices relating to his or her health (Epstein, et al., 2005). Attention to these processes and outcomes can support patient-centered communication and improve health outcomes.

The Psycho-Oncology Consultation Model (POCM) (Deshields and Nanna, 2010) suggests specific interventions for clinicians to use with cancer patients that are consistent with IOM recommendations. One of these interventions is to "hear the patient's story". By listening to the patient's story, the provider becomes aware of the patient's interpretation of his/her situation, and what he/she finds relevant and/or distressing, thus validating the importance of the client's experience of their cancer (Deshields and Nanna, 2010).

Despite an emphasis on patient-centered communication and the provision of holistic care (Epstein & Street, 2007), we found no reports of interventions that facilitated patients being known by their providers, or that aimed to understand the patient within their own context. Further, no found framework or model indicated how different health care professionals might operationalize and accomplish patient-centered communication within their specific discipline roles and settings. As consistent providers of ongoing care, (oncology) nurses have a key role in the provision of patient-centered communication. Therefore, we designed an intervention to facilitate patients' being known by eliciting their personal story, and then representing that story in the form of an image, a word cloud (an image of words), with the intent to stimulate conversation between patient and nurse.

The intervention pilot tested here, "MyWords" is based on the intervention suggested by the POCM: "hear the patient's story". It is grounded in three areas of existing research: 1) "being known" in the oncology setting, 2) patient narrative, and 3) visual representation. Figure 1 depicts the intervention and its relationship to the POCM model. The intervention is the process of bringing patient's home thoughts and concerns into the clinical setting, to facilitate their being known. This is accomplished by using a created word cloud of patient words as a talking point.

Review of Literature

"Being known" in the oncology setting

From the patient’s perspective, “being known” by his/her provider is a highly valued aspect of patient-provider communication, and considered by patients as patient-centered communication (Clayton, 2009). Thorne and colleagues (2005) describe “being known” as “making a human connection distinct from the diseased organ or mechanical body” (p.890-891); it reflects an acknowledgement of one’s personhood within the context of cancer. In a qualitative longitudinal study of 200 patients with cancer and their providers, patients emphasized that provider communication must convey an understanding of patient uniqueness within the complex experience of having cancer. Though there were individual patient variations as to what it meant to be known, two core dimensions were identified: 1) the acknowledgment of individual preferences, knowledge, emotional needs, beliefs, and values, and 2) the acknowledgement of the personal challenges associated with having cancer (Thorne, 2005). Clarke's (2010) study of patients with esophageal cancer support Thorne, et al.'s findings:

> "The desire to be viewed and known as an individual and not just a tumour … was manifest for our participants particularly at the early stages of their illness experience. For our participants, ‘being known’ was represented on a very basic physiological level, but also on a more personal level… (p. 5).

"Knowing the patient" is a "process of understanding and treating the person as a unique individual", and includes "having knowledge of specific patient perceptions, including appraisals and interpretations" (Radwin, 1996, p. 1143). The provider is required to "pull out" patient perceptions, appraisals and interpretations—a difficult task in the time-limited clinic setting. The intervention tested here instead elicited narratives from patients in their homes, and used them to facilitate being known by “pushing” their personal story to their providers. Since Thorne et al (2005) report that there were individual variations of "being known", the choice of topics was left to the patient. We do not know what information patients want their nurse to know about them.

Patient Narrative

A narrative is a representation of a world via language or visual medium, whose primary function is to communicate the human experience (Fludernik, 2009). Narratives emphasize the active, self-shaping quality of human thought (Hinchman & Hinchman, 1997), and can provide rich and detailed information about how illnesses are experienced (Frank, 1995; Charmaz, 1993). There is evidence that the elicitation of narrative data, including stories, has positive health benefits. In a meta-analysis of 146 studies of written and verbal emotional disclosure on physical and psychological outcomes, Frattaroli (2006) reported a significant positive average effect size of r=.075. In a systematic review of 13 expressive writing intervention studies, in which patients are asked to write about their deepest emotions and thoughts, Merz, Fox, & Malcarne (2014) report that "Although the majority of the intervention effects were null, there were main effects for expressive writing on sleep, pain, and general physical and psychological symptoms" (p. 339). Despite these findings, interventions that elicit and acknowledge patient narrative data remain separate from the usual care process (Cepeda, et al., 2008; Olsson et al., 2011).

Care must be taken to balance the benefits of narrative capture with the burden that it can place on the patient. Indeed, the act of writing has been reported as challenging for patients with advanced cancer. In a study of 24 palliative care patients, Bruera et al., (2008) had a very rapid accrual rate, but only two persons completed the requested four writing sessions. Participants were critical of their assignment as a "writing task", wanting to choose their own topic, and to complete the writing on their own time. Some asked for audio-recorders instead.

The regular or ongoing capture of patient narrative would be a logical step in the acknowledgement of the patient experience in the provision of patient-centered communication, as it could provide insight into patients' goals, values, and preferences. Today's technology affords multiple devices that have features that could allow quick and nearly effortless capture (and soon, transcription) of a person's narrative. It is asserted that all narrative data have purpose-- from putting a life circumstance into words to using words to seek information. This data is not always in the form of a story, nor does it have the aim of emotional disclosure, as patients with cancer don't always want to talk about emotional or difficult feelings (Kvale, 2007). In designing the MyWords intervention, the use of audio recorders was chosen because of its ease of use; an unstructured and undirected approach was selected to give the patient the choice of topic. This strategy may yield information about what topics patients consider important and wish to have acknowledged. It is conceivable that these topics—core aspects of being known--- could give insight into patients' goals, values and preferences.

Visual representation

A word cloud is an image of words created from a text corpus. The use of a word cloud as part of the MyWords intervention was motivated by the use of "imagery as data" for learning and reflection (Frost & Smith, 2003). The sharing of photo journals between fellow patients and their providers has been used to facilitate conversations about health issues, connecting medical facts with personal experience (Frost and Smith, 2003; Rich, 2000). Patients became more vocal about asking questions and sharing personal anecdotes when there was an image to discuss; the image became a stimulus for a more focused conversation. Thus we chose to use a free software program, Wordle^{TM}, to create a word cloud from the transcripts of patients' audio recordings (http://www.wordle.net/). (Figure 2). The created word cloud is the image used to stimulate conversation between the patient and the provider. The Wordle software linearly increases the font size based on word frequency, showing the most frequent words in the largest font and the least used in the smallest font. The result is an image that gives a quick way into the data.

The purpose of this study was to pilot the MyWords intervention with persons receiving treatment for cancer. The study had two aims: 1) to determine the feasibility of the intervention in the outpatient oncology clinic setting, and 2) to determine the characteristics and content in these home audio recordings, and to evaluate changes over time.

Method

Study design

A descriptive study design was used. Participants were asked to make three home audio recordings, create a Wordle, share it with their research nurse, and complete an interview to determine their perceptions of the intervention. Institutional Review Board approval was obtained prior to initiating study procedures.

Sample and Setting

A convenience sample of ten English-speaking adults was recruited from the outpatient chemotherapy clinic of a suburban Midwestern health care agency. The chemotherapy clinic has an average 1:15 nurse to patient ratio. Participants were 18 years or older, English speaking and reading, and were currently receiving chemotherapy for cancer (any site, any stage). No additional demographic information was collected.

Instruments

The researcher kept field notes to capture recruitment, retention rate, completion of study procedures and reasons for attrition. A semi-structured interview guide was used to capture the participants' reaction to the intervention (Figure 3).

Procedure

Recruited participants gave consent, provided brief clinical information (age, gender, month of diagnosis, type of cancer), and were then taught by the researcher how to use the audio-recorder. Participants were instructed to make at least 3 recordings over the next week, or more if desired. The following questions were provided as prompts to help participants think of something to say if needed.

- What is a favorite story that you like to tell about yourself?
- What would you like your nurse to know about you as a person?
- Talk about a story that is relevant for you at this moment.
- How would people describe you, and do you agree with them?

The researcher emphasized that participants did not have to use the prompts if they knew what they wanted to talk about. After making their recordings, patients mailed the recorders in a prepaid box directly to the researcher, who transcribed the recordings.

The researcher met with participants at the next subsequent visit, either after their blood work was drawn or during the chemotherapy treatment. At that appointment, the participant and researcher reviewed the transcribed text, and processed it using the Wordle software. Wordles were created and printed with each participant, one for each of their recordings. Participants were asked to share their Wordle with their treatment nurse during that clinic visit. The researcher was not present when the Wordle was shared with the treatment nurse. The researcher met with participants after they shared their Wordle and conducted a final audio-recorded semi-structured interview. Participants received $20 cash following the interview.

Staff oncology nurses received an email and an oral introduction to the study at a staff meeting, including a Wordle sample. Nurses were asked to make comments or inquiries about words that stood out when the Wordle was presented by a patient. Nurses' responses to the Wordle were not measured in this study, thus, nurses were not consented and the nurse-patient interactions were not observed or recorded.

Analysis

Descriptive statistics (frequencies, percentages, medians) were computed to summarize sample characteristics and recruitment/retention rates. Content analysis was used to identify and summarize participants' perceptions of the intervention (feasibility) and to analyze characteristics and content of home audio recordings. The first author transcribed the audio-recordings of the semi-structured interviews.

The background of the qualitative researcher is reflected in the lens through which the data is analyzed. The first author (KAJ) has training in qualitative methods, including narrative analysis---how, why, and when people tell stories. The second author's (ACM) research concerns families and their response to stressful events. The authors first independently read through the transcripts. First cycle coding was applied to text segments by the primary author. These codes were inductively derived, and kept at a descriptive, "summative, essence-capturing" level (Miles, Huberman, & Saldana, 2014). Assigned codes were not mutually exclusive; i.e., more than one code could be applied to a segment of text. For example, the following quote was coded as both “identity expression-who I am (job)” and “what I want nurse to know about me”. Because of the strength of the voice in the recording and the repetition, it was also coded as “I DO want to say”.

> *I would like to the nurses to know that I am a veterinarian and I work every day, even on my chemo weeks. And the nurses don’t seem to recognize that I have a life outside of my chemotherapy. And I would like them to know that I am working and that I’m going to continue working as much as I can, despite the chemotherapy. I enjoy my work and it takes my mind off of my troubles when I am working.*

The second author then independently reviewed the code labels and assigned codes to text segments. The independently coded transcripts were discussed and discrepancies reviewed, with final coding decisions made through discussion with input from a third experienced qualitative researcher. The assigned codes were grouped together and the resulting categories were assigned a label through a discussion of their common attributes. MaxQDA software was used for data management.

Results

Sample Characteristics

Participants included four males (ages 60-77) and 6 females (ages 47-64), ranging from two to seven months since diagnosis. All participants were observed to be Caucasian, reflecting the demographics of the geographic area of recruitment. Cancer diagnoses included three breast, two lymphoma, two lung, two leukemia, and one colon cancer.

Feasibility

Recruitment.

Twelve patients were invited to participate over two days and ten patients agreed and enrolled (recruitment rate 83%). Reasons for declining participation were not collected.

Retention/attrition.

The retention rate, determined as participants who made audio recordings, was 80%. "I'm too sick" was the reason reported by one participant who did not make a recording; the other participant was lost to follow up. Of the eight who made audio recordings, six participants made three recordings, one made two recordings and one made four recordings.

Study completion.

The study completion rate, determined as the number of participants who made a Wordle, was 70%. One participant did not make a Wordle because she had completed her treatment and did not return to the clinic. Of the seven who made Wordles, six participants shared their Wordle with the treatment nurse. The one participant who did not share his Wordle did not receive chemotherapy consequent to myelosuppression.

Perceptions of the intervention.

No one reported that using the recorder was distressing. However, there were varied levels of perceived difficulty in expressing thoughts orally. Participant comments regarding using the recorder included: *"It was no big deal."* and *"Thank goodness you're not asking me to write. I can't seem to write these days."; (no discomfort);"I was nervous at first…I think that after I kinda had that melt down I thought I'd better put this down." (moderate discomfort),* and *"I would have preferred writing*" and *"I don't like talking to a machine."(*high discomfort). Two patients prepared to make their recording by writing notes.

Participants had no concerns about sharing their recordings, saying, *"It's personal but it's also a privilege to be able to share it. It's just an honor, to have people actually take the time to listen to it", "Ah, fine",* and *"No one knows me, so it didn't bother me."*

Participants gave a range of comments about their thoughts about the Wordle: "*Well, I remember that I laughed—it just brought joy to my heart*", *"It was really moving when you look at it",* and *"It wasn't so much the substance of the words, but the pattern that I saw"* to *"I just don't know what to think*" and "*I don't know what it's supposed to look like."* Women changed the colors and layout of their Wordles on the laptop screen prior to printing them; the men did not.

Patients reported a range of nurse responses to Wordles: *"She (the nurse) loved hearing what were behind these words"* and "*She actually set aside time, you know, to sit here and we were face to face and (could) actually go a little deeper into what I have* *been going through"* to *“She never took the time to discuss it with me”*. *"It served as a trigger to expand on something."*

Participants seemed to appreciate the opportunity to talk and indicated that this intervention could generate topics that would not have come up in normal conversation: "*I was asked certain questions [by the nurse] and then had to think about (it) for awhile and then [the nurse] to make me talk about it… which was good*." Participants said that they wouldn't mind sharing the Wordle with others in the clinic "*if they're interested"*. All said they would share with their family. Participants said they would keep their Wordle, some in a binder *"with my sickness stuff"* or for framing, choosing their Wordle colors for a specific place in their home. One participant said, *"I’ll probably just maybe put them in the back of my journal. I actually I have a box of stuff that I’m saving. It’s a burning box. That’s my thing, when it’s done it’s getting torched."*

Audio recording characteristics and content

Characteristics.

The audio-recordings ranged in length, from 2:03 to 23:33 minutes. (Figure 4). The median length across participants was 5:21 minutes (women Md. = 10:11 min., men Md. = 2:29). The shortest recording (2:03 min.) was made by a woman, and the participant farthest from diagnosis date. The longest recording (23:33) was also made by a woman, but the participant was closest to diagnosis date. The question prompts were either directly or indirectly stated in four different participants' recordings (50%). The two prompts used most often were "What would you like your nurse to know about you as a person?" (n=4) and "How would people describe you and do you agree?" (n=4)

Content.

Narrative content was identified in four major categories: (1) expressions of identity (38 coded text segments), (2) response to cancer (30 coded text segments), (3) currently facing (29 coded text segments), and (4) stories (19 coded text segments) (Figure 5).

Expressions of identity.

The category 'expressions of identity' describes text segments in which the participant describes him or her self in a way that's unrelated to cancer. Seven of eight (87.5%) of participants recorded content in this category. Four groups of codes make up this category: (1) who I am (latent or manifest), and included references to patient's job; (2) descriptions of my family, (3) how people describe me, and (4) what I want my nurse to know (the last two are prompt questions). Although all of the recorded material could be considered content that the patient wishes the nurse to know, this code was applied when these specific prompt words were spoken ("I want the nurse to know…"). Examples for this category of identity expression include the following:

> "*I am a wife and mom of three wonderful children. My husband is xxx. My daughter xxx is 23, my son xxx is 22, and xxx is 18 and a senior at (xxx) high school. I've been married for 26 years and I live in (city)."* (coded: who I am, descriptions of my family)
>
> *"I believe people would describe me as a family man."* (coded: how people describe me)
>
> *"And one thing I often wish they might know, too, is what I've been through in my life—teaching for 30 years and home-schooling 4 kids. And while the cancer came rather suddenly, I had stepped down from teaching full time in the classroom, thinking this was a good time to start teaching part time.* (coded: what I want nurse to know, who I am/job)

Response to cancer.

The category "response to cancer" encompassed text segments that referred to how cancer had changed the patient's perspective or how the patient has adapted or adjusted to having cancer. In these text segments, cancer is referenced in some way. Six of eight (75%) of participants recorded content in this category. This category included five codes.

The code "a global response to the cancer journey" was applied to text segments that had a reflective tone. For example, the participant who was the farthest from her diagnosis date, and had the shortest recording said this three times: "*I just want to say now that it is over, all my treatments are over and everything, I did have a positive experience. It was really scary at first. It ended up being a positive thing.*"

Three women participants made text segments that referred to faith as a response to cancer. It was clear that, for these women, their faith was central to their coping with cancer.

> "*I thank God every day for giving me strength as well. I am very religious and I know things happen for a reason and I know everything is going to be ok. We just have to trust in God, and do our very best to believe that everything is going to be ok. And He, God knows what He's doing. So I just trust in Him and all the providers that are helping me. And I know I'm going to make it through this."*

Three different women expressed the reframing a life situation while having cancer. One participant noted, "*I thank God everyday that I, luckily, if you're going to get cancer, this is a pretty good cancer to get.*"

This study was conducted in the season of fall, a time of family traditions and customs. Facing cancer at this time of year, especially with a recent diagnosis, may be particularly difficult. Participants related 'Doing usual activity while having cancer'.

> *"I'm even grateful that today I got to make pumpkin pies for thanksgiving because my family obviously has been impacted by the cancer. Everyone was like, just go buy pumpkin pie, and I was like, no, I need to make the pumpkin pies cause that's just what I have always done for thanksgiving. And it was very special to me that I felt well enough and I've had a good week end and so the strength was there and the joy of sneaking on some Christmas music."*

The final code in this category of response to cancer includes patients expressing their gratitude to health care providers.

> "*And I think of all the sweet nurses on Wednesday because like my swimming instructor every step along the way they're there saying that went really well, or you're doing really well-- you're handling the Benadryl well today. Or they'll sit when it's not going well and they'll hold my hand and talk and listen to me and those things are so crucial for not feeling alone and scared.*"

Currently facing.

The third category of codes, "currently facing", refers to immediate issues with cancer, and includes four codes: what it's like to have cancer (including experienced symptoms), comparisons made to others, descriptions of received support (good and bad, not from health care provider), and current relevant concern (a prompt question). Six of eight (75%) of participants recorded content in this category. Examples from this category include:

> "*Being in remission is a very surreal thing. I asked over and over and over, are you sure. Are you positive I'm in remission, because being in remission doesn't mean you feel any better. While you're still going through chemotherapy, you still feel like crap. You still look like crap. You still don't feel any better. And I*

> *don't think people –don't understand that. I was very apprehensive to tell people that I'm in remission and, basically, I think that all your friends and family just think that you feel all better. And you should be back to your normal self and that is not the case*." (what it's like to have cancer; description of received support/bad)

> "*I do want to say that this week I kind of had a bad day on Tuesday. I kind of had a meltdown, and I have not done that since (date) when I found the news out. I think it attributes to my cousin who I saw last Sunday. She has esophageal cancer and about a month ago they gave her a month. So it was three weeks and she's not doing so good. And the reality of what cancer does and how it affects everyone kind of came to light to me. I'm certainly not in the position she is but I think that in seeing her and the reality, it just kind of made me really really think hard.*" (comparison to others; I DO want to say)

> *"One story that is really not a story that's relevant to me at this moment is my concern with the winter and the chemotherapy."* (current relevant concern)

Stories.

The final category covers text that explicitly used the word "story", or else related a series of connected events. Six of eight (75%) of participants recorded content in this category. There were three codes included in this category: the story of their diagnosis, their favorite story (a prompt question), and other stories. Though it was not elicited, five of the eight patients spontaneously gave their diagnosis story. Samples of coded text from this category include:

> *"When I was diagnosed I was very scared. Your mind spins to 'where is it?' 'how big is it'. Just get it out."* (diagnosis story)

> *"One story that we like to tell, my wife will tell it and I will tell it also, is that when our son (name) was born, I was working in my office and took her up to the hospital because she was going into labor…"* (favorite story)

> *"Also, shortly after I was diagnosed with cancer it was really hard. My son got sick with kidney stones and he needed to have surgery. That was a lot to deal with. And my Mom had to come and stay with us, and that was really hard to have somebody take care of us. And I didn't like that much. But we got through it and he's better".* (other story)

Emphasized content.

Six of the eight patients expressed a desire to tell specific things, saying "*I do want to say*", with strong emphasis on "do", or else repeating themselves. (Table 1). Again, codes were not mutually exclusive, with many text segments having more than one code assigned.

Changes over time.

Differences in category occurrence (Figure 6) over time showed that participants were more likely to share concerns about what they were currently facing on in later recordings, with one participant making a fourth recording to share a current relevant concern.

Discussion

This pilot study was deemed to be feasible in the outpatient chemotherapy setting based on an 83% recruitment rate over two days, and a 70% completion rate. Participant responses were generally favorable, with participants appreciating the opportunity to talk, especially about issues that would not come up in normal clinic conversation. Since there was a range in nurse responses to the Wordles, it is possible that there was some confusion or lack of clarity as to how to incorporate the Wordle into the clinic visit. Indeed, one of the nurses was a float nurse.

Participants made from two to four recordings over the course of a week, with a greater than ten fold difference in the length of the recordings (approximately two minutes, to approximately twenty minutes in length). Narrative content was distributed in four major categories: expressions of identity, response to cancer, currently facing, and stories. Some of this content was particularly emphasized.

Though the sample size was small, this pilot study gives some key insights. First, the range of ages (47-77 years), time since diagnoses (2-7 months), and balance in gender during recruitment indicate that this kind of intervention is of interest to a range of patients. However, "being too sick" remains a barrier to (continued) participation. Patients have definite preferences in terms of mode of communication-- some preferring to write, and others preferring to audio record. It is unknown if this would vary based on place in the cancer trajectory. Based on the recording content that was particularly emphasized through repetition or tone of voice, we can speculate that there is some content that participants felt important to communicate.

The category 'Currently facing', which included the code 'current relevant concerns' was more frequent in the third recordings than in the first two recordings, and even prompted a fourth recording. This oblique approach to conveying concerns-- taking a long time to broach the topic of current symptoms--was also found in an analysis of clinician-patient encounters during COPD office visits (Chatwin, et. al., 2014).

The inductively derived codes in the category of response to cancer' reflect and support findings present in the literature. For instance, in the study of gratitude in women with metastatic breast cancer, Algoe & Stanton (2012) suggest that an expression of gratitude indicates a willingness to "advance the relationship". According to the authors, the receipt of this willingness (on the part of the health care provider) has implications for understanding a patient's needs and preferences. The expression of gratitude could be interpreted as willingness, even a reaching out, to be known.

In a study of social comparisons made by women with advanced ovarian cancer, Morrell et al (2012) reported that participants favored seeing oneself as better off than others with the same diagnosis and avoided contact with similar patients. Though the participants of the MyWords study were not diagnosed with advanced cancers, the inductively generated code of 'comparisons made to others' supports the findings of Morrell and colleagues (2012) in that the spontaneously spoken comparisons made used the preferred downward contrasts ("*I'm certainly not in the position she is…").*

The distinct concepts of spirituality and faith and their role in coping and psychological wellbeing have been topics of research with cancer patients and survivors (Gonzalez, et al., 2014; Leeson, et al., 2014; White & Verhoef, 2006). However, faith was the concept spoken here. This may be because it is easier to express faith and/or religiosity than a more diffuse concept of spirituality, especially in this extemporaneous talk.

The frequency of talk related to identity confirms earlier work regarding cancer and identity (Clarke, 2010; Jones, Parker-Raley, & Barczyk, 2011). It must be acknowledged that some of these identity expressions were used as a way for patients to introduce themselves on the recording. This may not occur if a nurse who is familiar with the patient gives the intervention. Indeed, four of the participants used a salutation and/or a closure of sorts ("Hi Kathy", "Thank you"). This was unexpected, and gives insight into how the technology (here, audio-recorders) embody the requester of the information. In other words, despite this being an asynchronous interaction, the participants talked to someone; the intended listener is imagined.

It was surprising that audio recording content related to 'stories' -- a popular phrase in healthcare and marketing vernacular-- was not more prevalent. Although the definition of story is not universal, an emphasis on "hearing the patient's story" may be incomplete or insufficient as a goal of psychosocial care. The creation of a (formal) story requires ordering, meaning making and coherence, aspects that a patient currently undergoing chemotherapy, especially someone who is newly diagnosed, is still doing.

Limitations

Besides having a very small sample size, this study is further limited by its lack of cultural diversity in the sample. Future work will investigate the feasibility and acceptability of this intervention with other cultural groups.

Conclusion

We now have some indications of what patients might want their nurses to know about themselves, what is relevant and concerning, and what was particularly important to tell. An intervention that encourages simple identity expression and verbalization of an individual's response to cancer, along with the capture of current concerns, is feasible and may be a viable adjunct in the provision of patient-centered communication, and to facilitate a feeling of being known. Patient preferences for mode of communication should be honored. This type of intervention requires nurses who see value in both the elicitation and acknowledgement of this kind of data. With advances in communication technologies (patient portals, improved voice recognition technologies, and automated and/or natural language processing), followed by acknowledgement, an intervention like this addresses two of Epstein and Street's (2007) proposed core functions of patient-centered communication: validating the patient's perspective and understanding the patient within his or her own psychological and social context. Ongoing interventions that encourage identity expression may be helpful as patients negotiate and practice the new identity that comes with a new cancer diagnosis. Future research may explore the nurse reception of this type of enhanced communication, and the effect it has on patient-centered communication in terms of proximal and distal health outcomes.

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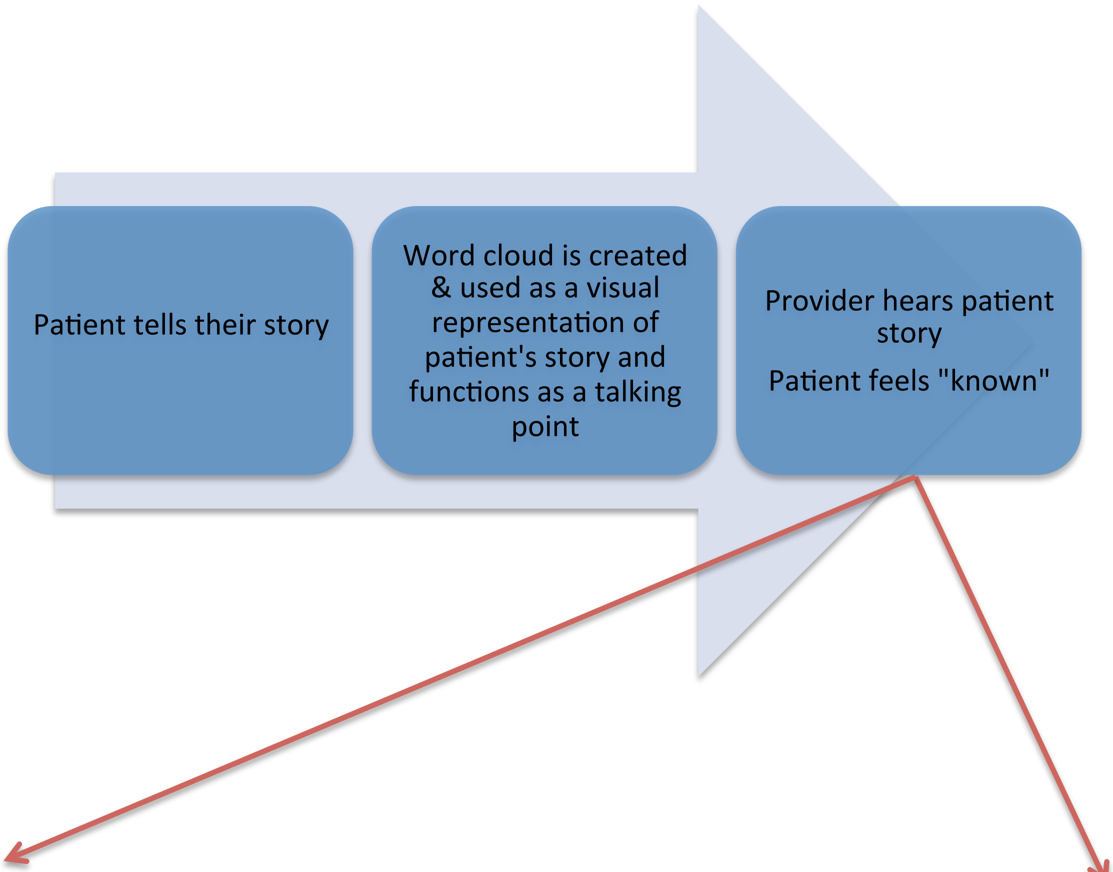
Figures

Figure 1. Conceptual Framework of MyWords Intervention



Interventions	**Goals of Care**				
	Minimizing distress and symptoms	**Building on patient's strengths**	**Enhancing self-efficacy**	**Expanding repertoire of coping strategies**	**Addressing informational needs**
"Hear" the patient's story	√		√		√

"Hear" the patient's story: one intervention of the Psycho-Oncology Consultation Model (POCM)

Figure 2. Sample Wordle

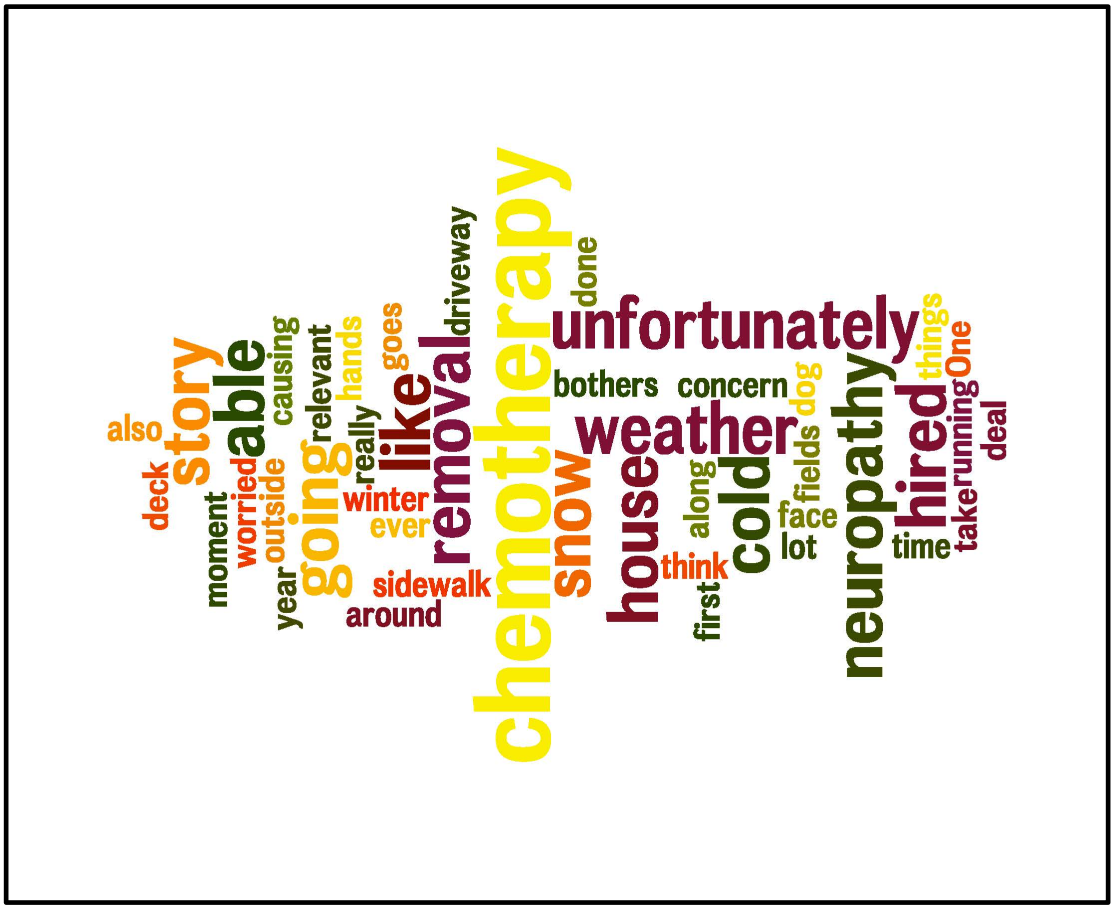


Figure 3. Interview Guide for MyWords participants

1. Please describe when you made your recordings. Was it the same time each day? Were there events that made you think that you should record something?

2. How do you feel about sharing these recordings?

3. Please describe your thoughts when you first saw your word picture. What was your reaction? Did you change anything on it? Did you want to change something?

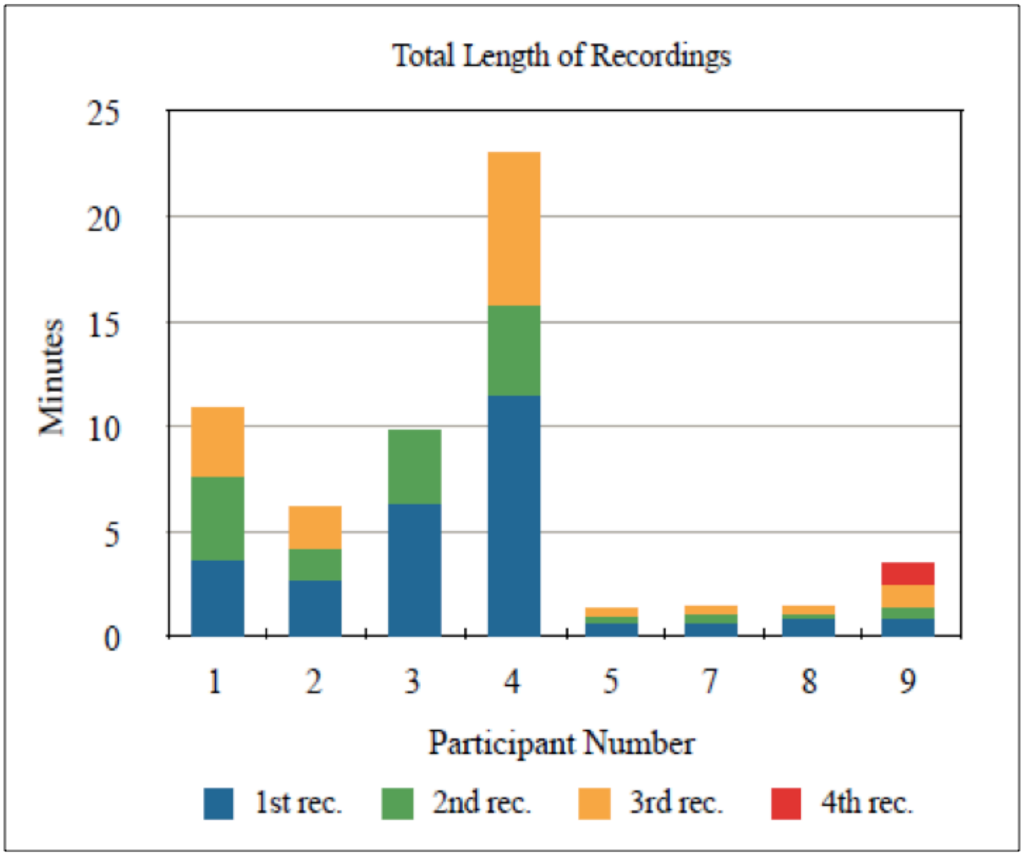
4. Please describe what happened when you showed this to your nurse.

5. Do you think that the word picture showed things that you haven’t or might not have talked about before?

6. Would you like to share your word picture with anyone else here in the clinic? Anyone else?

7. What will you do with your word picture?

Figure 4. Recording Length



Female Participants #1 - 5
Male Participants #7 - 9

Figure 5. Percentage of Codes by Category

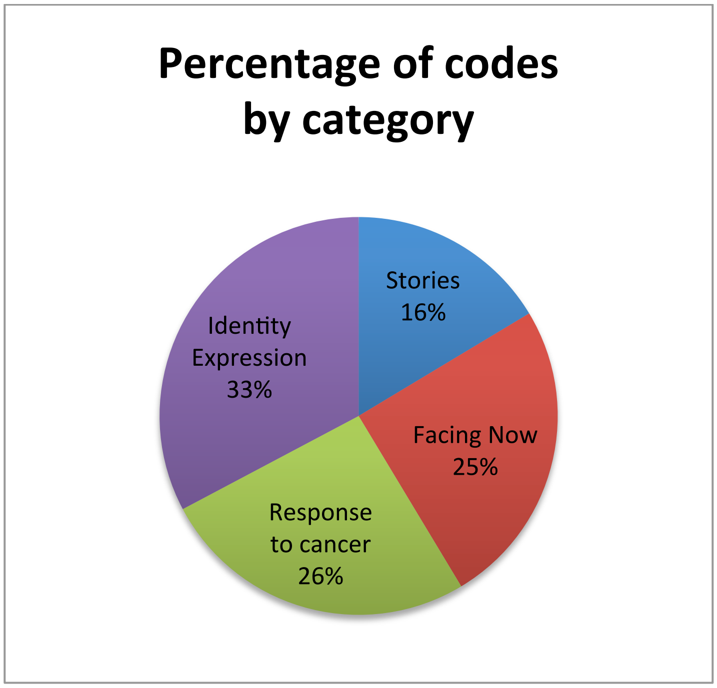
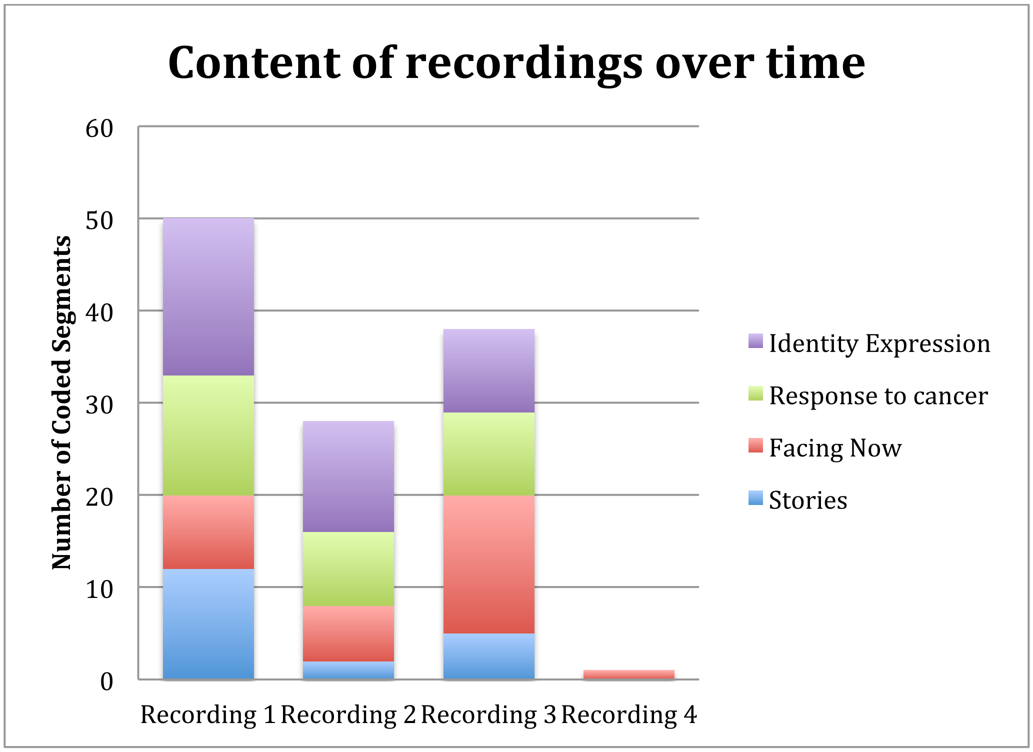


Figure 6. Content of Recordings Over Time



Table

Table 1. "I DO want to say…"

Quotes coded as "I DO want to say". These are also coded under the associated category.	**Category**
I often wish they might know too what I've been through in my life—teaching for 30 years and home-schooling 4 kids. And while the cancer came rather suddenly, I had stepped down from teaching full time in the classroom, thinking this was a good time to start teaching part time . I had worked for 6 months with a resume and interviews and that, and had just gotten what seemed like a ready made job for me, teaching part time, writing to junior highers. And I was excited about that. But I had to step down, and that's ok.	Identity Expression
I would like to the nurses to know that I am a veterinarian and I work every day, even on my chemo weeks, ….and that I'm going to continue working as much as I can, despite the chemotherapy.	Identity Expression
And one thing I wanted to mention was that one of my therapists said to me that she had never been with a patient who had such a matriarchal lineage.	Identity Expression
I do want to say that this week I kind of had a bad day on Tuesday. I kind of had a meltdown, and I have not done that since (date) when I found the news out.	Currently Facing
What's relevant to me at this moment is my concern with the winter and the chemotherapy.	Currently Facing
I do want to say that she (her cousin with cancer) has been through, she has been through a ton.	Currently Facing
I do want to say that the total staff and nurses here are very caring, extremely caring.	Response to Cancer
I hope they realize that I appreciate them nurses so much.	Response to Cancer
Just want to say now that it is over all my treatments are over and everything I did have a positive experience.	Response to Cancer

CHAPTER 3: Cues, Information Seeking, and Knowledge Structures - Concepts of Psychosocial Assessment in Oncologic Nursing

Title: Cues, Information Seeking, and Knowledge Structures: Concepts of Psychosocial Assessment in Oncologic Nursing

Potential Authors
Kathy A. Johnson[a]
Anne Chevalier McKechnie[b]

[a]School of Nursing
University of Wisconsin-Madison
701 Highland Ave.
Madison, WI 53705

[b]School of Nursing
University of Minnesota-Twin Cities
308 Harvard St. SE
Minneapolis, MN 55455

Corresponding Author
Kathy A. Johnson
School of Nursing
University of Wisconsin-Madison
701 Highland Ave.
Madison, WI 53705
kajohnson25@wisc.edu
Phone: 414-531-5776
Fax: not available

Acknowledgements:
This study was supported by a Wisconsin Distinguished Graduate Fellowship Award and by the Eckburg Fund at the University of Wisconsin-Madison School of Nursing. The authors gratefully acknowledge the guidance and encouragement of Dr. Kristine Kwekkeboom in the production of this manuscript. Thanks also to the expertise of Catherine Cherwin, RN, PhD, Xiaochen Chen, RN, PhD(c), and Yingzi Zhang RN, PhD(c) for their contributions to the analysis. The authors express sincere gratitude to the participating institutions and nurses for their contributions.

Keywords: assessment, psychosocial assessment, cues, nursing, information seeking
Running head: Psychosocial Assessment

Abstract

Clinical practice guidelines for psychosocial distress management recommend periodic distress screening for patients with cancer. While screening is the first step in the evaluation and treatment of psychosocial distress, a clinical assessment by the nurse is still required--regardless of the score on the distress tool. The purpose of this research was to explore how oncology nurses make psychosocial assessments across inpatient oncology, outpatient oncology, and home hospice care settings. Nurses (n=33) from these practice areas participated in a semi-structured interview and responded to two stimulus audio recordings. Using Crow, Chase, & Lamond's (1995) framework of the cognitive process of nursing assessment as a guide, thematic analysis was used to code data into categories of cue recognition, information seeking and knowledge structures. Nurses reported five different types of cues to psychosocial distress (verbal, physical/body language, behavioral, environmental, and physiological signs) and two guiding principles used when detecting those cues ('There is no universal cue' and 'Be alert for differences'). Nurses used three different kinds of questions to seek information in a psychosocial assessment (broad, specific, and referring to a previous encounter) and four guiding principles to seeking information ('Assessment requires honest effort and purpose'; 'Nurses should work to establish trust'; 'Find the problem that nursing can help with'; and 'You can always ask later – respecting/connecting'). Three broad domain knowledge structures emerged: knowledge relating to disease or treatment, family and/or support structures, and personal coping/response to illness. Patient-specific knowledge structures, the application of domain knowledge structures to a patient and his or her

immediate situation, were identified in the principles that nurses reported using when recognizing cues. Differences were demonstrated in the nurses' reports of cues and information seeking across the three settings, indicating that the practice setting itself has a role in how psychosocial assessments are accomplished. This research gives an indication of the complexity of the cognitive processes involved in making a psychosocial assessment. Clinically, these findings point to the role and potential value of psychosocial assessments as adjuncts to distress thermometer screenings. These findings may also inform nurse educators as they teach nursing students how to make a psychosocial assessment. Future research should explore and work toward developing a model or standard of "expertness" in psychosocial assessment—one that weighs or at least considers the role of setting in that development.

Introduction

The Institute of Medicine (2013) lists psychosocial support as one of the five components of high-quality cancer care that should span the cancer care continuum, and calls for an adequately-staffed, trained, and coordinated workforce that provides competent cancer care aligned with patients' needs, values, and preferences. Unattended, the psychosocial distress associated with cancer affects somatic symptoms such as fatigue, sleep disturbance, dyspnea, nausea, appetite loss (Clark, Rochon, Brethwaite, & Edmiston, 2011; Lewis, Salins, Kadam, & Rao, 2013; Yamagishi, Morita, Miyashita, & Kimura, 2009), and may amplify the perception of pain (Mori, Elsayem, Reddy, Bruera, & Fadul, 2012). Psychosocial distress has a detrimental effect on emotional functioning, social functioning, mental health, and overall quality of life (Montazeri et al., 2008). Further, psychosocial distress mediated immune dysregulation may be a contributing factor to cancer recurrence (Mathews, et. al., 2010) and survival (Satin, Linden, & Phillips, 2009). With an overall prevalence of psychosocial distress estimated to be between 24.5% and 59.3% across the cancer trajectory (Gao, Bennett, Stark, Murray, & Higginson, 2010), it is imperative that the psychosocial needs of cancer patients are both assessed and addressed.

Clinical practice guidelines for distress management (National Comprehensive Cancer Network guidelines, version 2.2014) suggest periodic screening for patients with cancer at times when patients are expected to experience more distress (initial visit, at appropriate intervals, and as clinically indicated by changes in disease status). Screening is the first step in the evaluation and treatment of distress and involves the use of a screening tool and an associated problem list. This rapid method of identifying patients with psychosocial distress is typically conducted by non–mental-health professionals using brief self-report questionnaires to determine whether an individual needs referral for more extensive assessment and treatment (cancer.gov). However, according to current National Comprehensive Cancer Network guidelines (version 2.2014), a clinical assessment of the patient is required--regardless of the score on the distress tool. As members of the primary oncology team who have extended time with patients, nurses are in an optimal position to perform these clinical assessments.

Assessment is the systematic gathering of relevant and important patient data, and nursing assessment focuses on the patient's physical and psychosocial response to illness (Wilkinson, 2011). According to the American Nurses Association Standards of Practice, the competencies of assessment include but are not limited to: the elicitation of patient values, preferences, expressed needs and their knowledge of the healthcare situation, the assessment of family dynamics and the impact on patient health and wellness, the identification of barriers to effective communication, the synthesis and documentation of available data, information and knowledge relevant to the situation to identify patterns and variances (Wilkinson, 2011). The evaluative findings of assessment determine the logical cascade of diagnosis and intervention. While there is a growing body of literature about how nurses make clinical judgments and perform clinical decision-making in situations regarding (acute) *physical conditions* (Gazarian, 2013), little is known about the process of how nurses make routine psychosocial assessments.

Review of Literature

The process of nursing psychosocial assessment has received limited study. Only one ethnographic study of the process of psychosocial assessment was found. In the practice area of maternal-child health, Rollans, Schmied, Kemp, & Mead (2013) report that, for maternal mental health assessments in the postnatal period conducted in homes and clinics, the Edinburgh Depression scale was administered at all nurse-patient interactions. However, a psychosocial assessment was conducted in only 50% of the interactions. The authors' qualitative analysis of nurse participant discussion groups revealed four themes that described the approach nurses took to make a psychosocial assessment: 'Engagement: getting that first bit right', "Doing some paperwork'; 'Creating comfort" and 'Psychosocial assessment: doing it another way". Nurses reported using observation of the mothers with their baby, noting nonverbal communication, and using intuition to make their psychosocial assessment (Rollans, Schmied, Kemp, & Mead, 2013). No other research related to the process of psychosocial assessment in other nursing practice areas was found.

In their fundamental training, nurses learn that psychosocial assessment requires "the perception of subjective and objective cues" with attention to the following eight factors: social history, level of stress during the year before the clinical encounter, normal coping pattern, "neurovegetative" changes (physical symptoms that signal a change in neurophysiological functioning: sleep patterns, appetite, energy level, etc.), the patient's understanding of illness, mental status (seeking evidence of dysfunction), personality style, and major issues of illness (Barry, 1989, p. 9-11). However, the cognitive work of the perception, interpretation, and/or evaluation of subjective and objective cues was not described.

No research was found that investigated how oncology nurses perceive, interpret and/or evaluate the "subjective and objective cues" of psychosocial assessment. Although Gosselin (2007) and Hackett & Gaitan (2007) report that the psychosocial assessment of patients with cancer is accomplished through patient interview, the observations, patient cues, and questions used in the nurse-patient interview have not been detailed. The purpose of psychosocial assessment is to look for and evaluate the psychological and social condition of patients and their families so that interventions may be used to address those conditions. It is imperative that nurses provide space for the patient's potential meaning and suffering to emerge, and be sensitive to the existence of potential cues. Understanding the cognitive strategies used may also give insight into setting (space and time) requirements for psychosocial assessment and inform nurse educators as to the skills required.

The conceptual framework guiding this research is based on the work of Crow, Chase, & Lamond (1995). These authors offer the only article found that attempted an analysis of the cognitive process of (general) nursing assessment. The authors assert that information seeking and the determination of cue relevance are part of the cognitive work of assessment. Crow and colleagues (1995) also assert that, in the process of assessment, nurses refer to nursing domain specific knowledge structures and patient-specific knowledge structures. Figure 1 is derived from the work of these authors. These three concepts (cue recognition and relevance, information seeking, and knowledge structures) will be reviewed.

Cue recognition and relevance.

A "cue" is defined as "a verbal or non verbal hint that suggests an underlying unpleasant emotion and would need a clarification from the health provider" (Del Piccolo, Finset, & Zimmermann, 2008, p. 3). This definition is becoming a standard for the coding of patient-provider interactions (e.g., Heyn, Finset, & Ruland, 2013; Mjaaland, Finset, Jensen, & Gulbrandsen, 2011; Wright, Humphris, Wanyonyi & Freeman, 2012). Crow and colleagues (1995) asserted "the determination of cue relevance" as a cognitive strategy of assessment. However, cue recognition is necessary before its relevance can be determined. Cue recognition is asserted here as the identification of, the noticing of, a cue; cue relevance is asserted as an evaluation of the salience of the cue. A patient saying, "I'm overwhelmed" is an example of a cue. Crying is an example of a cue. However, the work of Eriksen and Rydahl-Hansen (2009) suggests a volume dimension to patient cues. The authors describe more subtle patient verbal cues in the palliative care setting, e.g., short sentences that only hinted at signs of suffering.

As a concept found in conceptual models of clinical decision-making (Gillespie 2010; Hoffman, 2009; Narayan & Corcoran-Perry, 1997), clinical judgment (Tanner 2006; Thompson, Foster, Cole, & Dowding, 2005), and clinical reasoning (Simmons, Lanuza, Fonteyn, Hicks, & Holm, 2003), cues play a major role in psychosocial assessment. While there may be nurse experts in psychosocial assessment, these nurses have not been identified, nor has the recognition or use of cues in psychosocial assessment studied. In observational studies of non-simulated nurse-patient consultations, nurses responded to approximately 25% of patients' emotional cues (DeLeeuw, 2014; Uitterhoeve, 2009), but in these studies a "cue" was defined by the researcher, not by the nurse.

Information Seeking.

Information seeking is the gathering and organization of information needed to make an assessment (Crow, Chase, & Lamond, 1995). The research literature on nurse information seeking has been limited to identifying the sources nurses use in decision-making, where a problem has already been named (handoff reports, monitoring equipment, knowledge of the patient's history and baseline presentation) (Gazarian, 2013). Research by O'Leary & Mhaolrúnaig (2012) and similar work by Roberts, While, & Fitzpatrick (1995) suggests that this type of information seeking behavior by nurses is performed in response to uncertainty. In this perspective, information seeking is solving an identified problem, instead of a way to gather data about the patient's current state, which is the purpose of assessment.

McLeod and colleagues (2010) give insight as to how knowing the family of the oncology patient is accomplished through nurse assessment in the oncology clinic, inpatient and home (palliative) care settings. Their descriptions indicate the cognitive strategy of information seeking: listening for clues, learning their non-verbal and prosodic (tone of voice) cues, paying attention to eye contact, and evaluating for a “look of concern or ease". Nurses' questioning practices were used as a way to understand patient and family relationships.

Knowledge Structures.

The conceptual work of Crow and colleagues (1995) suggested (nursing) domain-specific knowledge structures and patient-specific knowledge structures as concepts used in general assessment. Domain-specific knowledge structures shape the way problems are met in everyday nursing practice, and what nursing actions are taken (Crow et al., 1995; MacNeela, Scott, Treacy, & Hyde, 2010). The concept of domain knowledge structure is conceptualized in clinical decision-making and reasoning models as: "knowing the profession" (Gillespie & Patterson, 2010); "reflection on clinical learning" (Tanner 2006); and "working knowledge" (O'Neill, Dluhy, & Chin, 2005). For example, expecting patients to experience symptoms of distress at the time of screening for cancer recurrence is an example of oncology nursing domain-specific knowledge. This knowledge, which involves the structures of (1) disease and/or treatment processes, and (2) potential patient and/or family responses, is used in assessment and planning for intervention.

Patient-specific knowledge refers to knowledge that is specific to individual patients. A patient-specific knowledge structure is a representation of “knowing the patient" (Zolnierek, 2014), a concept also found in conceptual models for clinical reasoning, decision-making or critical thinking (Gillespie & Patterson, 2010; Tanner 2006). Patient habits, idiosyncrasies, and "normals" –all part of knowing the patient—are viewed as a collection of concepts making up a patient-specific knowledge structure. Continuing with the example above, knowing that this particular patient has a disrupted support system at the time of screening for cancer recurrence may suggest the need for a nursing intervention that wasn't needed when that support system was intact. Patient-specific knowledge structures refer to the application of domain knowledge structures to an individual and his/her immediate situation.

Psychosocial assessment across care settings.

Psychosocial distress is found throughout the cancer trajectory. In the inpatient oncology settings, Clark, Rochon, Brethwaite, & Edmiston (2011) reported that 63.5% of their sample scored within the range of psychological distress for their gender. For patients with breast and gynecological cancers, the prevalence rates of psychological distress are 45% and 32%, in inpatient and outpatient care, respectively (Reuter, Raugust, Marschner, & Harter (2007). Gao and colleagues (2010) cite the prevalence of psychological distress as 24.5% in outpatient care and 59.3% in palliative care. These percentages only report one facet of a psychosocial assessment—the outcome of an administered screening or instrument. No research was found that investigated the process of how nurses' psychosocial assessments are accomplished and if or how these assessments might vary as the focus of care changes. Nurses have more opportunities than other health care providers for multiple or extended (time) interactions with patients. Understanding how nurses accomplish a psychsocial assessment is important for nursing training programs and staffing needs.

The purpose of this research was to explore how oncology nurses make psychosocial assessments across care settings (inpatient oncology, outpatient oncology, and home hospice). The specific aims were: (1) to document nurses' reports of recognition and determination of relevance of patient cues in psychosocial assessment;

(2) to document nurses' reports of information seeking in initial and ongoing psychosocial assessment; (3) to determine if and how nurses' report the use of the theoretical construct of "knowledge structures" in psychosocial assessment; and (4) to explore differences in the nurses' reports of these aspects of psychosocial assessment across the three settings.

Method

Study design.

A qualitative descriptive study was conducted. Semi-structured interviews with oncology nurses were chosen as the method to achieve the stated aims. Participant's responses to two audio-recordings based on actual patient-recorded data from a prior study were used as a complementary data source.

This study was reviewed and determined to be exempt by the Institutional Review Board.

Sample and settings.

Nurses were recruited from the inpatient oncology units, outpatient oncology clinics (chemotherapy and radiation therapy), and home hospice services of seven health care agencies in the Midwestern United States. Designed to maximize recruitment, the only inclusion criterion was that participants were nurses who identified themselves as interacting with and making psychosocial assessments of their patients with cancer.

Instruments.

Interview Guide.

The interview guide was informed by the concepts of assessment found in the literature (cue recognition/relevance, information seeking, and knowledge structures) (Figure 2). Neither "cues" nor "information seeking" were defined in the interview questions to allow the participant to interpret the concepts in their own way. General open-ended questions were asked to understand how psychosocial assessments were made. Nurses were also asked to recall a time when interacting with a distressed patient and to describe what they observed.

Participant Stimulus Response Notes.

Participants were asked to respond to two audio recordings. The first recording was that of a male chemotherapy patient with a clear concern about neuropathy and it's impact on his daily life. The second recording was that of a female chemotherapy patient talking about her feelings and experience of the week after biopsy and before diagnosis. Participants were asked to "Write down anything you might document in the (electronic) health record as part of a psychosocial assessment. Making no documentation is perfectly acceptable." Participant answers were discussed with the researcher.

Participant Questionnaire.

The participant questionnaire was used to collect basic demographic information, including gender, age, highest level of education completed, and practice setting. No other demographic information was collected.

Procedure

Recruited participants met with the researcher for a private semi-structured interview. After obtaining consent, the researcher asked the participants to describe their job responsibilities in their practice setting. The stimulus recordings were played and participants wrote their responses to the two stimulus recordings. Their answers and thoughts about the recordings were discussed. The Distress Thermometer was brought up by a participant and discussed in an early interview, and a question about use of this instrument was added to subsequent interviews. Participants were reimbursed $50 for their time and effort.

Analysis

Transcripts of the interviews and stimulus responses were analyzed using the thematic analysis procedure described by Braun and Clarke (2006) and Boyatzis (1998). The first author reviewed the transcripts for accuracy and to become immersed in the data.

A team of researchers conducted the data analysis. The first author (KJ) and the second author (ACM) have training in qualitative methods and experience with the analysis of interview data. A panel of three doctoral students with expertise in oncology nursing also independently coded data, contributing to the trustworthiness of this research.

First, the interviews were read carefully and repeatedly to identify segments of text relevant to the stated aims. The first author made the initial data reduction by extracting text segments that represented "cues described by nurses", "reports of (verbal) information seeking by nurses", and "knowledge structures". Text segments representing "Cues described by nurses" were identified and extracted when the nurse reported how a cue was recognized, or when a cue was described. Text segments representing "Reports of (verbal) information seeking" were identified and extracted using Crow and colleagues' (1995) definition: the gathering and organization of information needed to make an assessment", with the additional stipulation of this being done verbally. Finally, text segments representing "Knowledge structures" were identified and extracted when there was a reference to a concept that is within the purview of nursing, e.g., family dynamics, personal coping, or disease process. The second author similarly and independently extracted these types of text segments from 20 of the 33 interviews, ensuring that the relevant information was captured from all of the interviews.

The first author then inductively generated codes based on recurring patterns found in the extracted data. The reliability of the application of these codes was checked by a panel of three doctoral students with expertise in oncology nursing. Each panel member independently coded excerpts of interview and stimulus data from two inpatient, outpatient, or home hospice nurses using the inductively generated codes. The percentage of coding agreement between the first author and the three panel members was calculated for the six (of 33) nurses' text segments. The percentage of agreement ranged from 80 – 100%. Categories were refined through the use of constant comparison, resulting in a more parsimonious final coding scheme. Changes from original coding scheme to the final coding scheme are found in the supplementary material. Following analysis, the generated data were determined to be of sufficient breadth and depth to address the stated aims (O'Reilly & Parker, 2012).

Differences in the nurse reports of psychosocial assessment processes were observed across settings. A composite summary was created for each nurse by noting all of the cues, information seeking strategies, and domain knowledge structures used by that individual nurse. The relative prevalence of each concept was then summarized by practice setting. (See Appendix 2 for procedure).

Results

Sample Characteristics

A stratified convenience sample of 33 nurses was recruited from seven Midwestern institutions: 11 nurses from inpatient units at two institutions, 13 nurses from outpatient settings at two institutions, and 9 nurses from three home hospice institutions. The participants were self-selected, observed to be Caucasian, and ranged in age from 23 – 60 years (M=39.48, SD=12.14). Most participants were female (n=28, 85%), with most having a BSN degree or higher (n=28, 85). Information about the number of years in practice was not collected.

Aim 1. Nurses' reports of cue recognition

Participants reported five types of behaviors or observations as cues: verbal cues, physical (body language) cues, behavioral cues, environmental cues, and physiologic cues (signs). A description of the type of cue and a participant quote is provided below.

Types of cues.

Nurses' reports of verbal cues were similar to the previously noted definition used for coding patient-provider interactions—a hint requiring follow up by a health care professional. Both semantic content and tone of voice were recognized as cues, particularly when there was a change from the patient's normal manner of speaking.

> *"...his voice is starting to get louder and louder, talking more rapidly, you know getting red in the face"* (inpatient).

Nurses also considered how much (more or less) the patient talked with the nurse as a cue.

> *"So it's like you go over and over these things. So she was saying that she was blaming herself for her diagnosis, for her cancer diagnosis. And so she was going through thing after thing. 'Well I must have stepped in a mud pie, I must have been exposed to bacteria that caused this cancer'. I mean she went, it went on and on and on."* (outpatient)

> *"Yeah, you know, I'd say how well they're willing to interact with me is something that I also do, you know, because if someone is willing to sit down and talk with me for an hour, if they want I could sit down and talk to them forever. But some patients you can go and I can just tell they want me like in and out, take care of my stuff, and then just go,* (home hospice).

Physical (body language) cues included observations made of a non-moving patient --body position, facial expression, eye contact, and hygiene. This category did not include any patient movement or talk.

> *"Well, obviously if you've got your hands to your chest or crossed or you're not even looking at me, you know, or when I come into the room and they're just still, you know, looking out the window, obviously they're not in the mood to kind of talk about things."* (inpatient).

> *"She wasn't as put together as she usually was. She usually wears a really pretty head scarf and she didn't have that on, just she looked sick then. When she came in she looked sick, but she had hope, and then she looked sick.* (inpatient)

Behavioral cues of distress were described as observations of body movements (pacing, hitting, or "not moving very much") and interactions -- with others or with the nurse.

> *"...This was something where the guy was obviously I mean he was pacing up in the room and up until that point I had what I thought were normal interactions with him*

and all of a sudden he became very agitated and upset and I walked in "hey buddy what's going on" and he goes bam right in the nose. I had a bloody nose. And that was totally unexpected and obviously I had no idea that that was his anxiety, his agitation, he was up to the level he was lashing out at someone. (inpatient).

Nurses also reported patients' cancellation of treatments as a cue of distress.

" (The patient) *cancelled social worker, cancelled OT, cancelled home health aid….* (home hospice).

Environmental cues of distress were reported as being found in the condition of the patient's immediate surroundings.

"You know, it always makes me sad when someone says we'll do phone checks because we have plenty of people like "did you take your medicine today?", "yep". Okay. "Do you have swelling in your legs?"…."nope, not a problem". And the next time the nurse goes in, the med box hasn't even been touched, there's not any garbage to be taken out because they haven't had time to make a meal or no energy to make a meal" (home hospice).

Physiologic cues (increasing shortness of breath or respiratory rate) were also reported as cues of distress.

"*A young woman in her 50's who had extensive interstitial lung disease... And we were using narcotics to help with her respiratory status and her pain because she had a lot of pain associated with it. And she immediately became short of breath when we started talking about changing her extended release morphine. So she just sort of was sitting there and we were conversing and I said you know we think it might be appropriate for us to increase your extended release morphine because your breathing status is becoming worse and then that just immediately set her off and I think it was partially because she knew that meant she was dying or much closer to dying, partially because she had been so uncomfortable. And I think that I sensed later in the assessment that she'd wished someone had talked to her about that earlier."* (home hospice)

Nurses' reports of cue relevance.

Crow, Chase, and Lamond (1995) included the determination of cue relevance as part of their model of general assessment. The determination of cue relevance was succinctly phrased by one participant: "All cues are important. That's what makes them a cue." For the nurses in these settings, all cues were, by definition, important; recognition of a cue signaled cue relevance.

Principles used in recognizing and interpreting cues.

Two guiding principles for using cues emerged from analysis of the interviews. One principle reported by nurses was, 'There is no universal cue'. Nurses noted that there are individual differences in what distress looks like. The usual behavior (normal) of each patient must be considered, i.e., you must have patient-specific knowledge to recognize distress in a particular patient.

> *"There's no real clear 'this is what overwhelmed looks like', you know. I would say one person they're overwhelmed, you know they're sleeping all day and they just don't want to deal with it anymore. Another person's overwhelmed can be you know that they're anxious and they can't sit and they're you know up and down and cleaning the house, doing their med box, you know I've seen kind of that and everything in between. So there's no real… I wouldn't say real consistency of when somebody's overwhelmed looks like. One person's normal is another person's distress".* (home hospice)

A second guiding principle that emerged was the principle of 'Being alert for differences'. This principle has three aspects: different from previous interaction, different between nurse observation and patient report, and different from expected.

Nurses indicated that it was important to compare the current received cues in light of previous interaction. For example, an inpatient nurse stated, *"I guess one of the cues is the fact that they are not acting in a way that is consistent with their previous interactions with you".* Nurses also compared what he/she (nurse) was seeing and what the patient was saying.

> *You'll look at this (*the completed Distress Thermometer) *and you're like, according to the sheet you're struggling. But you'll go talk to them and they're laughing and joking. So you're trying to like, is this a true presentation you know? So that's kind*

of hard. But then you'll have the person who will score like an 8 and thinks the world is crumbling and you say "hi I'm [name] I'll be your infusion nurse" and they're in tears and you're like what did I say?" (outpatient).

The third aspect of 'being alert for differences' principle was the description of cues that were different from an expected behavior or observation at this point of their disease process or treatment course. An inpatient nurse reported a cue to psychosocial distress as, *"Their emotions are a lot more exaggerated than the situation would warrant"*. Similarly, an outpatient nurse described how she considered where the patient was in their treatment in recognizing a cue:

> "*I think about what the treatment is going to be, where they're at in it, so you coordinate cues with what stage of the treatment are they in, when did they last see their doctor…*" (outpatient).

Aim 2. Reports of Information Seeking

Two categories of codes emerged from the data related to 'information seeking': (1) types of questions asked as part of a psychosocial assessment and (2) principles used when asking those questions. Participants reported asking three types of questions: (1) Broad, general, conversational questions; (2) Specific direct questions, perhaps to confirm or disconfirm observations; and (3) Questions that refer to a previous encounter. Four guiding principles used when seeking information were described or inferred: (1) Assessment needs to be done with honest effort and purpose; (2) Work to establish trust and rapport; (3) Find the problem that nursing can help with; and (4) You can always ask later – respecting/connecting.

Types of questions.

The first type of question used for information seeking in making a psychosocial assessment was a question that was general and broad. Nurses considered these questions conversational, serving to help patients feel comfortable or to give patients the opportunity to direct the conversation.

> *"Sometimes it's just a matter of just talking about not the illness at all. What do you do for a living, you know, tell me about your family, or oh my gosh you look so pretty in green. Something that doesn't… they're sure you're going to come in, take everything away, and make their life miserable to die"* (home hospice).

> *"Sometimes you can ask them about or even just it's good, like to ask them about where they live or when their family comes to visit and they kind of open up."* (inpatient).

The second type of question asked when seeking information was a specific or direct question. The following participant quote shows how a direct question has a different purpose, in this case to get to the 'why' the patient is not taking pain medications.

> *"I think it's okay to say I'm* (the nurse) *really worried about the way that your wife or your sister is really resistant to you* (the patient) *taking these pain medications, or I'm really worried about what I see… trying to be as concrete as possible."* (inpatient)

The third and final type of question used in information seeking was a question that referred to a previous encounter. Some of the inpatient nurses anecdotally reported their support of the primary nursing care model in their work setting, noting that the multiple interactions afforded them the opportunity to build relationships by bringing up past conversations.

(nurse's response to stimulus)*"… when that patient comes back into clinic, you can say is your neuropathy worse, has it changed other aspects of your life, that now you can't go down the stairs and get your dog food or now you can't you know, how is this affecting your life or have you found that now you don't have to take care of the snow,*

> *you can go and walk down the street and take your dog so that he can run in the fields you know. I think it's also that important follow up component that we don't have the ability to document right now because if you ask about that one thing that they mentioned two weeks ago is going, they are more than likely to say hey by the way, this this this and this. And now that I've thought about it, you know what I mean? Like it opens that conversation"* (inpatient).

Guiding principles for information seeking.

Nurses also described guiding principles that should be used when seeking information. The first principle is that psychosocial assessment needs to be made with honest effort and purpose. For example, an inpatient nurse stated, *"looking and saying "how are you feeling" instead of being like 'how you are you feeling' when I'm doing five other things"*. Being willing to sit down and talk was necessary to make a psychosocial assessment.

> *"If I notice somebody is in emotional distress I just honestly sit with them at their bed, eye level like we're doing now. I don't stand above them and I just hold their hand and ask them what's going on and usually, unless they're more of a closed off personality, usually they'll end up talking. Just to have somebody who is willing to sit down and take the time"* (inpatient).

Second, the nurse should work to establish trust. Nurses indicated that a trusting relationship was necessary to identify the real problems.

> *"I mean it all depends on what kind of rapport I have with them. If it's someone, maybe, that just had, you know, maybe towards the end of my shift… instead of being overbearing right off the bat, because I mean that person isn't… you're not going to all of a sudden connect with them. But throughout the shift, if you can kind of meet their needs, and, you know, be attentive, so you can kind of establish that trust"* (inpatient).

The third guiding principle that nurses alluded to was to 'Find the problem that nurses can help with'. Note that a specific question is used here to get to the reason for the patient's not eating.

"'*How have you been eating' is a terrible question, you know. 'What'd you eat for breakfast' is completely different. 'So if you ate oatmeal for breakfast why do I not see an oatmeal bowl? Did you really have enough energy to wash the dishes and put them away? Do you mind if I look in your cupboard… it doesn't look like you have any food. What are you going to eat for lunch?' So those specific things are much easier done when you're right there in the room with them. And then usually they're like, okay I didn't eat, and this is why and it brings out all of that emotion -- what do we need to do then to just make this better? Or, you know, I don't want to take any food anymore, and my daughter keeps bringing all this stuff and they keep bringing meals and I don't want them to. Okay so let's talk about that. Because we can help that. And we can help that communication if that's what you're choosing to do and nobody's going to think bad of you because you do that, that's what your choice is right now in this illness. So it's a lot of psychosocial*" (home hospice).

The final guiding principle for information seeking was 'You can always ask later – respecting/connecting'. Nurses respected that the patient does not always want to talk *now*. Nurses recognized that patients need time to reflect and process disease or treatment related information on their own, but convey that they (the nurses) are here to listen.

"If I sensed something was wrong I wouldn't just like unleash and ask them a bunch of questions about it. With primary nursing you can kind pick and choose your time and see maybe today is just a rough day, we don't need to talk about this right now, but tomorrow if you're feeling a little better that would be a better time to talk about this and just sensing based on how the patient is feeling at the time if it's a better time to talk about their concerns so with primary nursing it makes it a little bit easier" (inpatient).

In addition to documenting nurses' reports of information seeking, the second aim of this study also included a comparison between information seeking in initial and ongoing psychosocial assessment. Initial psychosocial assessment was prompted in the inpatient setting by the admission assessment page on the electronic health record. As one inpatient nurse commented, "We only ask the 'juicy' questions at time of admission." The "juicy" questions referred to the psychosocial aspect of coping.

> *Yeah. I think again it's harder on that day basis to assess that…I mean, I keep going back to that admission questions because it's where we really ask some of the juicy questions you know, I will ask how are you coping with all this news, how are you coping with coming back in for your third cycle. "Oh these things are going alright" or you know "I'm feeling good today" and then moving on. Daily, I mean when you're in there and you're kind of assessing their pain or other symptoms, it kind of makes you piece together they're having a pretty good day when really you know they may not so I think a lot of it is assumptions and not how they're actually feeling.* (inpatient)

This participant quote shows how the psychosocial assessment section of the admissions page in the EHR acts as a (work - structured) prompt to make a psychosocial assessment at the time of admission, and that (daily) psychosocial assessment is a piecing together of pain and other symptoms. This nurse seems to be admitting that daily psychosocial assessment may be based on nurse assumptions.

Aim 3. Reports of domain- and patient-specific knowledge structures

Domain-specific knowledge structures.

No nurse directly referred to knowledge structures, either domain- or patient-specific. However, by analyzing the topics referred to in the cues data and the topics of questions in the information seeking data, three broad categories of domain knowledge structures emerged. The first domain knowledge structure was related to either the disease process or treatment. The following quote provides an example of drawing on general nursing knowledge regarding symptom management.

> *A lot of times medications or pain management can be, like you'll get a cue when you start talking about their pain meds. And if they're not working then they'll want to speak up about that.* (home hospice).

The remaining two domain knowledge structure were related to (1) the family and/or support structure, and (2) personal coping or response to illness. The following quote was coded for both of these domain knowledge structures, as well as verbal and behavioral cues.

> *It's not necessarily what you ask but you can get a lot from how the patient is acting every day, who comes and visits, are they on the phone, do they have people they can call, do they reach out to me, you know. I think just watching them and observing them says a lot about how they are coping.* (outpatient).

Patient-specific knowledge structures.

Again, nurses did not report "patient-specific knowledge structures". However, the guiding principles from the cues data ('There is no universal cue' and 'Be alert for differences' from patient norm, etc.) clearly indicate that there is a reflection on patient individuality, both in the recognition and interpretation of cues, and in the manner in which information is sought.

Aim 4. Differences across settings.

The relative prevalence of the types of cues reported (Figure 3), the reports of guiding principles used for information seeking (Figure 4), and the reports of domain knowledge structures (Figure 5) were observed by setting. Verbal cues were reported by all nurses in all three settings. Physical (body language), behavioral, and environmental cues were also reported in all settings, in decreasing order. Physiological cues were not reported by nurses in the outpatient setting. A greater proportion of home hospice nurses reported using behavioral, environmental, and physiological cues than in- or outpatient nurses.

In regards to reports of guiding principles used in information seeking in each setting, only inpatient nurses reported the need to be purposeful when seeking information. A greater proportion of inpatient nurses also reported 'You can always ask later--respector/connector' behavior as a guiding principle compared to outpatient and home hospice nurses. Fewer nurses in the outpatient setting spoke about the development of trust or finding the problem than the nurses from the inpatient or home hospice setting.

A greater proportion of hospice nurses used the domain knowledge structures of "disease and treatment" and "family/support" in cues and information seeking than in- or outpatient nurses. A greater proportion of inpatient nurses reported focusing on cues related to personal coping, whereas a greater proportion of home hospice nurses reported seeking information in the personal coping domain. A greater proportion of home hospice nurses sought more kinds of information than nurses from the other two settings, and from all three knowledge domains.

Discussion

The stated aims of this research were to document nurses' reports of cues, information seeking, and knowledge structures, (Figure 6) and to make a comparison across three care settings. Nurses' reports of what is recognized as a cue expand our understanding of the scope of cues recognized beyond "verbal" and "nonverbal". Del Piccolo, Finset, and Zimmermann's (2008) definition of a cue as "a verbal or nonverbal hint suggesting an underlying unpleasant emotion needing clarification" (p. 3) was developed based on the study of doctor-patient consultations. It is likely that the behavioral and environmental cues reported by these nurses as cues in a psychosocial assessment would not be present in a doctor-patient consultation. It appears that nurses have the opportunity to recognize a wider range of cues in making psychosocial assessments. Nurse reports from each setting indicated different opportunities to make psychosocial assessments. For instance, in the home, the nurses see the whole patient in situ—eating, elimination, interaction with family, hygiene, etc. In the clinic, the interaction is time limited. In an inpatient setting, particularly in those where a primary nursing care model is in use, nurses have extended time and days for multiple observations and interactions.

Nurses' reports of verbal information seeking revealed three types of questions used to get information to make a psychosocial assessment. The topics of the questions varied, and the sample quotes indicate topics from very specific to very general. Topics were captured by the broad domain knowledge structure categories. The four guiding principles that emerged from the information seeking data (Assessment needs to be made with honest effort and purpose; Work to establish trust; Find the problem(s) that nursing can help with, and respector/connector behavior) reflect the subtle and consistent thread of the relationship aspect of nursing.

The two principles reported as being used in cue recognition ('There is no universal cue', and 'Be alert for differences') clearly reflect Crow and colleagues' (1995) described patient-specific domain structures. As discussed earlier, it seems that there must be a general conception of what distress looks like to make a psychosocial assessment, but the individual personality, usual behavior, appearance, etc. and situation of each patient must be considered. This is consistent with the concept of 'patient-centered' care, and reflects Epstein and Street's (2007) proposed core functions of validating the patient's perspective and understanding the patient within his or her own psychological and social context.

The comparison of cues, information seeking, and domain knowledge structures across the three settings indicate how nursing is practiced in that setting and what the priorities are. For instance, in terms of both types of cues and guiding principles, inpatient and home hospice nurses' reports were largely similar. In these settings, nurses have a more extended time with their patients—time to observe more behavioral cues, environmental cues, and physiological signs. The need to maintain the flow of patients through the (outpatient) clinic was anecdotally reported:

> *To be honest, we only have so much time with the patients, and then you're expected to take more and more and more. So, to be honest, you almost hope something doesn't come up. You know. I know that sounds cold.*
>
> *I think that if someone decided that psychosocial was important enough we would have time for it. Would I have time for it? I would have time for it if the person was just perfectly fine. And had no problems. Then there are some patients that would get into a story and the physician would be knocking on the door needing to get in because it was taking up too much time. So it's a catch 22.*

In terms of guiding principles, the fact that "being purposeful" when information seeking was only reported by inpatient nurses could indicate that it is only in this setting where it requires a special effort in daily practice. Perhaps in home hospice it is understood. Inpatient nurses have eight hours during which they can respect and/or connect, particularly where the primary nursing model is used. The 'development of trust' and 'seeking to find the problem that nurses could help' with was reported by a greater proportion of inpatient and home hospice nurses. These tasks require time and are perhaps more easily done in these settings. However, the patient must have an interest in developing trust/relationship, and that is not always the case, as one outpatient nurse speculated:

> *It's a time thing for people. Sometimes they* (patients) *don't want to build that relationship because then it connects them to the diagnosis. And if they stay away from the people that are treating them, it's* (the diagnosis*) not true. And I've noticed that a lot too.*

The domain knowledge structures referred to in the cues reported by hospice nurses reflect a nursing priority of managing symptoms and including the family in the scope of the assessment. Cues related to personal coping are still present, but, at least in this sample of home hospice nurses, were not reported as often. There are two possible reasons for this. First, nurses in this setting could understand their role as attending to the physical condition, so that the patient can attend to personal coping. These nurses reported the most physiologic signs as cues. Second, many of these patients may not be in a condition to present cues related to personal coping (e.g., comatose, altered mental status). These nurses then rely more on behavioral (including family interactions), environmental, and physiological cues.

Compared to inpatient nurses, more outpatient nurses sought cues relating to disease/treatment and family support. This could be because family support is particularly important in this population for getting patients in for treatment and caring for patients at home. A greater proportion of outpatient nurses sought cues relating to disease/treatment, perhaps because these cues have implications for treatment choice.

Limitations

One limitation of this research is that the participants were self-selected. Participants could have elected to participate because they were particularly interested in the topic, because they felt particularly skilled at making psychosocial assessments, or simply to receive the remuneration. Therefore, it is possible that the participants were not representative of their setting. Another limitation is that no attempt was made to recruit participants of diverse racial or ethnic background. As a result, this research does not reflect cultural nuances that nurses with a more diverse background might report. Another limitation is that the concept of "knowledge structures" was not asked about directly. Finally, it is a limitation that these were *reports of* cues and information seeking used in making psychosocial assessments, not observations of psychosocial assessments. The findings are grounded in words based on both the researcher/interviewer and the participant skill and articulation in the moment.

Conclusions

This study expands our understanding of cues beyond being verbal or nonverbal, and presents the types of questions asked and the guiding principles used by nurses when they are seeking information. While Barry (1989) noted the topics of psychosocial assessment, the findings of this study offer detailed data about how a psychosocial assessment is accomplished in the inpatient oncology, outpatient oncology, and home hospice settings. It is important to note that this interview data was examined using the practice setting as the variable of interest. Future work should consider other collected demographic variables: age, gender, level of education. Clinically, these findings point to the role and potential value of these nursing assessments as adjuncts to distress thermometer screenings. These findings may also inform nurse educators as they teach nursing students about what it means to assess for psychosocial distress. Future research should explore and work toward developing a model or standard of "expertness" in psychosocial assessment—one that weighs or at least considers the role of setting in that development.

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Figures

Figure 1. Conceptual Framework based on the work of Crow, Chase, & Lamond (1995).

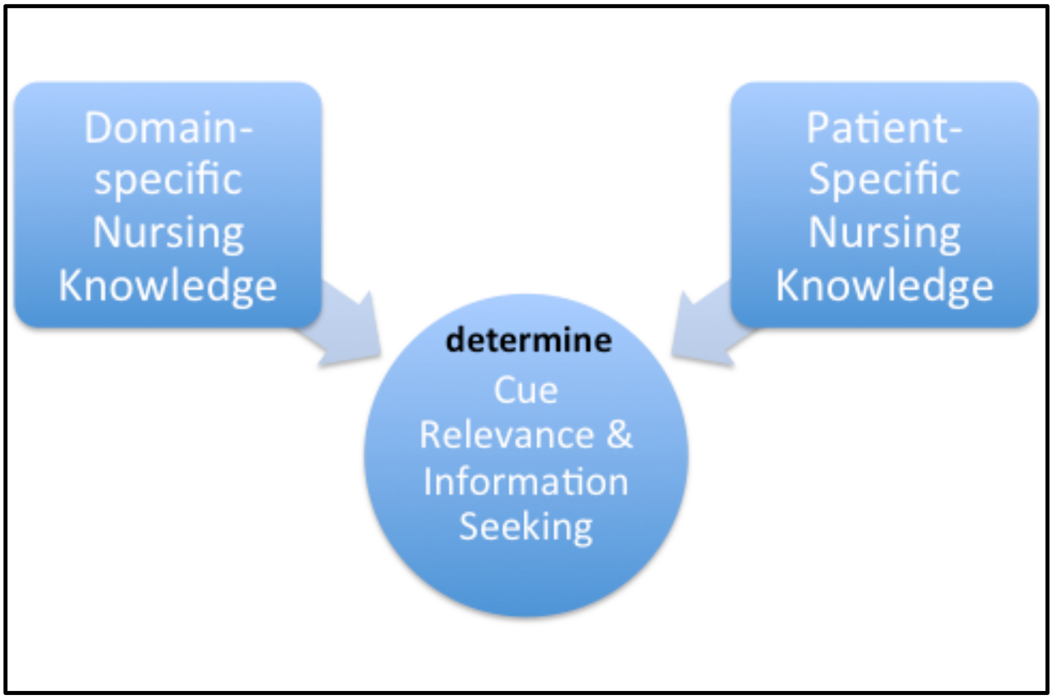


Figure 2. Interview guide questions regarding assessment (Revised – added question regarding use of Distress Thermometer).

Role/Description of your job in this setting

Use Distress Thermometer in your setting? How?

Assessment –general questions
- What does the term "psychosocial assessment" mean to you?
- How do you make your psychosocial assessments?
- Are there things that helped you make that assessment?
- What kinds of things hindered you in making that assessment? (Barriers)

Some nurses say that they watch for "cues".
- What does a cue look or feel like?
- How can you tell it's a cue?
- How can you tell if it's important?

Infoseeking
- What things do you look for, look at, observe, ask when making a psychosocial assessment?
- What are your sources?
- Think back to a time when you were interacting with a distressed patient. What did that patient look like/ act like? How did you know they were distressed?
- What did you do next? Why?

Some nurses also talk about "knowing the patient".
- What role does knowing a patient play in how you make your psychosocial assessment?

Final comments on making psychosocial assessments?

Figure 3. Percentage of nurses reporting different types of cues

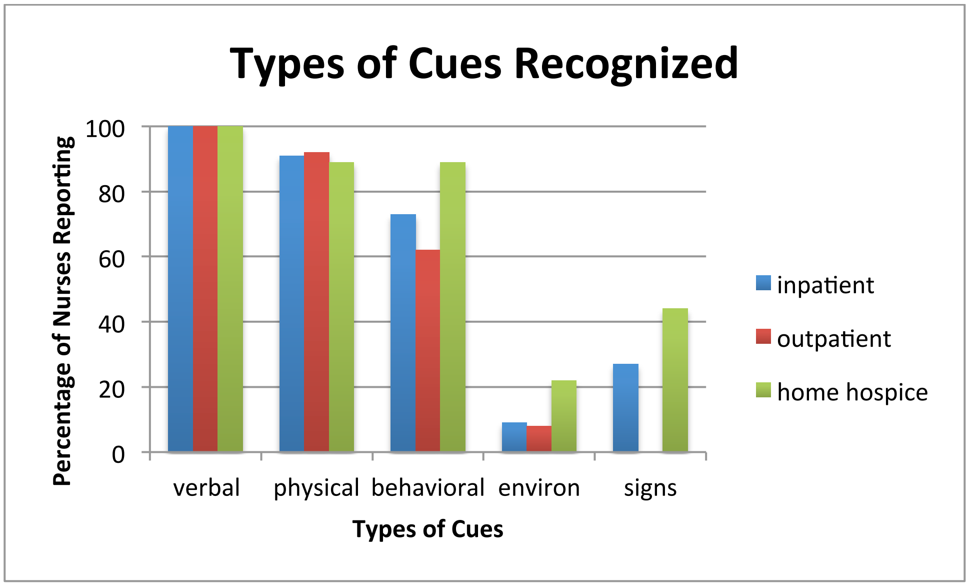


Figure 4.

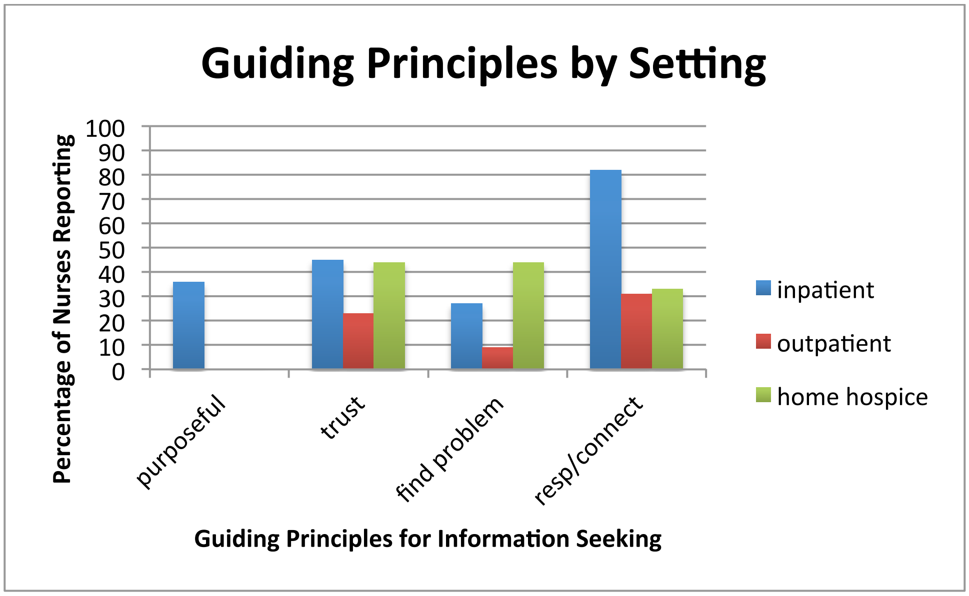
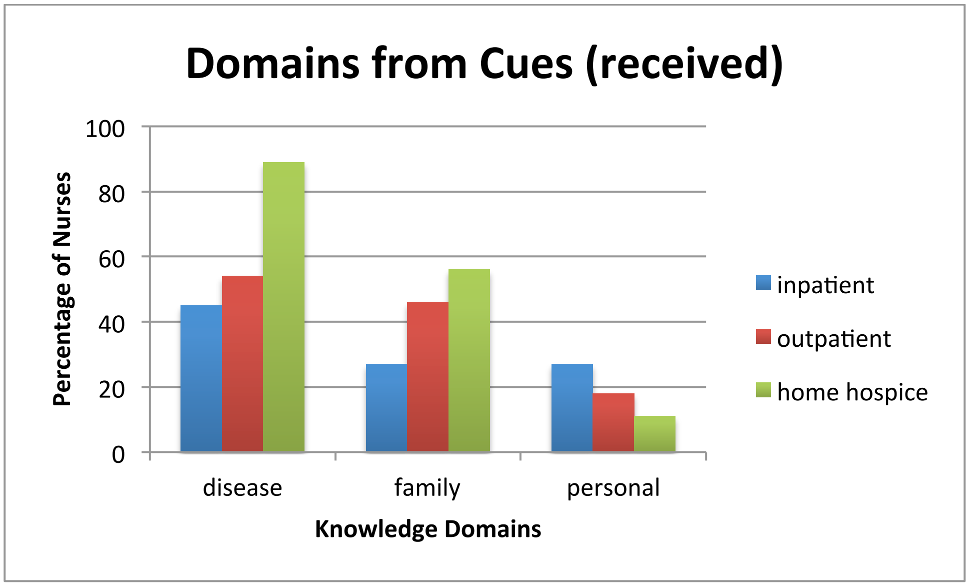

Guiding Principles by Setting
Percentage of Nurses Reporting
100
90
80
70
60
50
40
30
20
10
0
purposeful
trust
find problem
resp/connect
Guiding Principles for Information Seeking
inpatient
outpatient
home hospice

Figure 5.


Domains from Cues (received)
Percentage of Nurses
100
80
60
40
20
0
disease
family
personal
Knowledge Domains
inpatient
outpatient
home hospice

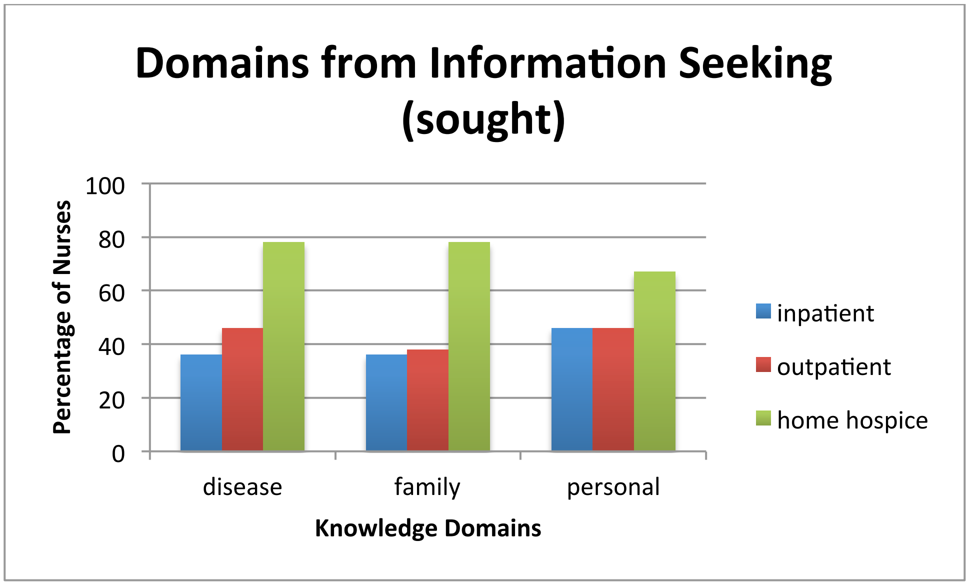
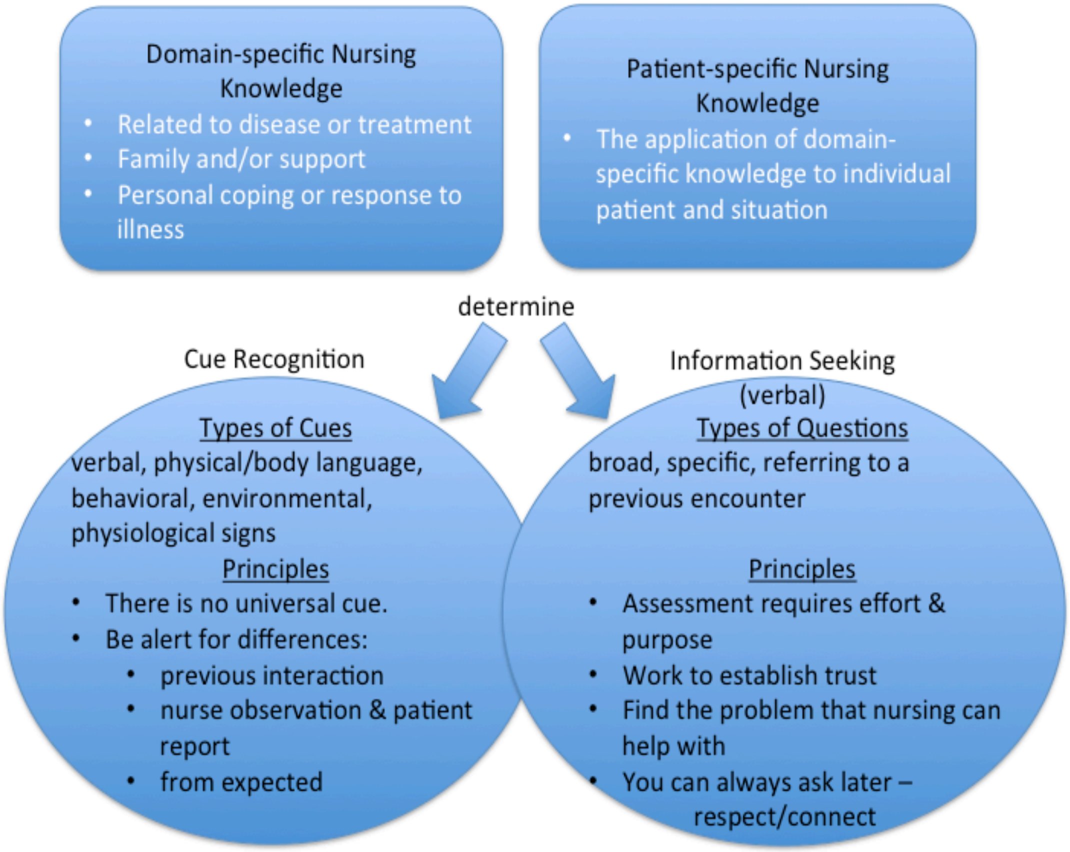

Domains from Information Seeking (sought)
Percentage of Nurses
100
80
60
40
20
0
disease
family
personal
Knowledge Domains
inpatient
outpatient
home hospice

Figure 6. Study findings. Further description found in Appendix 3.



CHAPTER 4: Nurse Documentation of Psychosocial Assessment in Oncology Settings

Title: Nurse Documentation of Psychosocial Assessment in Oncology

Potential Authors
Kathy A. Johnson[a]
Anne Chevalier McKechnie[b]

[a]School of Nursing
University of Wisconsin-Madison
701 Highland Ave.
Madison, WI 53705

[b]School of Nursing
University of Minnesota-Twin Cities
308 Harvard St. SE
Minneapolis, MN 55455

Corresponding Author
Kathy A. Johnson
School of Nursing
University of Wisconsin-Madison
701 Highland Ave.
Madison, WI 53705
kajohnson25@wisc.edu
Phone: 414-531-5776
Fax: not available

Acknowledgements:
This study was supported by a Wisconsin Distinguished Graduate Fellowship and by the Eckburg Fund at the University of Wisconsin-Madison School of Nursing. The authors gratefully acknowledge guidance and comments of Dr. Kristine Kwekkeboom in the production of this manuscript. The expertise of Jane B. Peace, PhD, RN and Jane M. Carrington, PhD, RN is acknowledged for their contributions to the analysis. The authors express sincere gratitude to the participating institutions and nurses for their contributions.

Keywords: documentation, electronic health record, cognitive work, nursing, nursing informatics
Running head: Documentation

Abstract

Documentation is an important part of the communication of assessment, care planning and intervention in psycho-oncologic care. Documentation may have increasing significance as the trajectory of cancer can now extend several years, with patients requiring care across multiple settings, multiple times. The purpose of this research was threefold: (1) to report the reasons nurses choose to document or not to document their psychosocial assessment; (2) to describe the location of the documentation; and (3) and to describe any differences in documentation by setting (in- and outpatient oncology, and home hospice). A thematic analysis of semi-structured interviews with 33 nurses was conducted. Nurses chose to document because (1) there is a need to communicate a patient condition; (2) there is an organizational requirement, and (3) the EHR prompts documentation. Nurses reported five reasons for not documenting: (1) the interaction with the patient was "just conversational"; (2) "it's hard to decide what to document"; (3) nurses chose to communicate the assessment verbally instead of documenting in the EHR; (4) the EHR is perceived as "not having a good place" to document psychosocial assessments; and (5) documenting a psychosocial assessment was perceived to be someone else's job. Nearly all nurses from all settings cited the need to communicate a patient condition as the most common reason to document the psychosocial assessment, and would make that documentation as some kind of free text. Participants across settings reported “no place to document” as the most common reason not to document followed by “communicate verbally rather than document in the EHR” among inpatient nurses, “hard to decide what to document” among hospice nurses, and “just conversational”

among outpatient nurses. Besides suggesting a significant amount of cognitive work in deciding if and how to document a psychosocial assessment, the conflicting responses (do/don't document, free text/tick box, formal/informal documentation) illustrate inconsistencies in the approach to documentation, both within and across settings. Findings have implications for EHR design and for training in ways that are consistent with the purview of nursing and compatible with the place of practice.

Introduction

According to the Institute of Medicine, the psychosocial concerns of patients with cancer are often unaddressed (Institute of Medicine, 2008). Psychosocial concerns cover a range of areas for assessment: social history, level of stress, coping patterns, physical symptoms, the patient's understanding of illness, mental status, and major issues of illness (Barry, 1989, p. 9-11). If these concerns are left unattended, patients with cancer may experience psychosocial distress, affecting physical, emotional, and social functioning, mental health and overall quality of life (Clark, Rochon, Brethwaite, & Edmiston, 2011; Lewis, Salins, Kadam, & Rao, 2013; Montazeri et al., 2008; Yamagishi, Morita, Miyashita, & Kimura, 2009).

In addition to periodic screening and ongoing patient assessment recommended by clinical practice guidelines (National Comprehensive Cancer Network, version 2.2014), the achievement of good psychosocial care requires the documentation of that assessment in the electronic health record (EHR). As a communication tool, a legal and administrative document, and a data repository, the EHR and the documentation held within it contribute significantly to the quality and continuity of patient care (Sullivan, 2012). The role of documentation in care planning may have increasing significance as the trajectory of cancer can now extend several years, with patients requiring care across multiple settings, multiple times. With a unique holistic view of the person in their response to illness, nurses are present and responsible for the documentation of psychosocial care across a span of time and settings. Nurses' role in the documentation of psychosocial care is critical.

Review of Literature

Documentation of psychosocial assessment before electronic health records.

The documentation of the psychosocial assessment of patients has historically held a low priority for nurses. In a qualitative descriptive study of medical/surgical nurse-reported inhibitors and facilitors to the documentation of nursing practice, time was reported as the major inhibitor to documentation, and that "time for documentation (was created) by … omitting the psychosocial nursing assessments and interventions" (Tapp, 1990, p. 234). Similarly, in an audit of (written) nursing assessment documentation on medical and gerontological units, the documentation of the assessment of the psychological and social aspects of daily living was rated as "poor", without "enough detail to reflect the individuality of the patient" or "recording what is normal for the patient" (Davis, Billings, & Ryland, 1994). The authors reported that the documentation emphasized the biological and medical aspects of the patient, and speculated that this finding reflected the biopathological model of training and a lack of emphasis on psychosocial aspects used by many schools of nursing.

Advent of the electronic health record.

The Health Information Technology for Economic and Clinical Health (HITECH) Act, a portion of the American Recovery and Reinvestment Act of 2009, established programs to "improve health care quality, safety, and efficiency through the promotion of health information technology, including electronic health records and private and secure electronic health information exchange" (http://healthit.gov/policy-researchers-implementers/health-it-legislation accessed June 7, 2015). The requirement for electronic health records has changed the way health care professionals work, including documentation practices (Park, Lee, & Chen, 2012; Petrakaki, Barber, & Waring, 2012).

Documentation of psychosocial assessment since the implementation of EHRs.

Thus far, there is evidence that the EHR has been inadequate to support the information needs of nursing in regards to the communication and coordination of care (Carrington & Effken, 2010; Keenan, Yakel, Lopez, Tschannen, & Ford, 2013; Kossman & Scheidenhelm, 2008). Nursing standardized languages focus on nursing diagnosis, intervention, and nursing outcomes. Assessment, the part of the nursing process that initiates the cascade to diagnosis, intervention, and outcomes, is not covered in these standardized languages. In their review of nursing care plans for neurological and surgical patients, Hayrinen and colleagues (2010), report finding little documentation relating to assessment. Of the documentation that was present, the assessments most commonly described the need for care, not the condition of the patient.

Specific to psychosocial assessment, Kim, Dykes, Thomas, Winfield, & Rocha (2011) report that psychosocial nursing diagnoses (e.g., hopelessness, ineffective coping, death anxiety) are not used as often as health behavioral or physiological diagnoses in the EHR. MacNeela, Scott, Treacy, & Hyde (2006), reporting their conceptual analysis of the Nursing Minimum Data Set (NMDS), echo the findings of David, Billings, & Ryland (1994) regarding written documentation from twelve years earlier:

> Ironically, by focusing on physical status and care, NMDS may perpetuate the relative invisibility of domains of nursing such as psychosocial and co-ordination work. The conceptualization and empirical validation of ‘core’ elements of nursing has not received as much attention as instrument development and data quality. The potential role of field research to suggest, rather than confirm, data elements, has not been realized (p. 49).

While the EHR still contains a place to record narrative SOAP (Subjective, Objective, Assessment, Plan structured nursing) free-text notes, they may be less visible in some systems. These changes may symbolically indicate that narrative notes have a (forced) lower priority than other required nursing documentation. Already a historically challenged object of documentation, these changes may further contribute to inadequate psychosocial care in oncology.

The quality and continuity of patient care depends on the documentation practices found in health information systems (Keenan, 2008), particularly for patients with cancer. Because the focus of care changes throughout the disease and treatment trajectory, it is logical to assume that there may be differences in nurse documentation across care settings. For example, it is not known if or how the shift from curative care to palliative or hospice care affects documentation. Looking exclusively at documentation at end of life, Hegarty and colleagues (2005) report that documentation in "acute" wards in Australia (it's not clear if this means the intensive care unit or an inpatient unit) does not reflect the non-physical dimensions of care, either assessment or intervention. No research was found that compared psychosocial documentation across settings.

The purpose of this research was to investigate nurses' documentation practices regarding psychosocial assessment. The specific aims are (1) to document the reasons nurses in home hospice, inpatient, and outpatient oncology settings choose to document or not to document their psychosocial assessments, (2) to describe where that documentation is made in the EHR; and (3) to describe any differences in documentation by practice setting.

Method

Study design.

A qualitative descriptive study was conducted. Semi-structured interviews with oncology nurses from different settings were chosen as the appropriate method to understand the nursing point of view and to achieve the stated aims. Participants' responses to two audio recordings of patient narrative content from a prior study were used as a complementary data source to general questions about documentation to contribute to the depth and breath of data generated (Bowen, 2008). This study was reviewed and determined to be exempt by an Institutional Review Board.

Sample and settings.

Nurses were recruited from the inpatient oncology units, outpatient oncology clinics (chemotherapy and radiation therapy), and home hospice services of seven health care agencies in the Midwestern United States. Designed to maximize recruitment, the only inclusion criterion was that participants were nurses who identified themselves as interacting with and making psychosocial assessments of their patients.

Instruments.

Stimulus and Interview Guide.

After describing their role and job description, participants were asked to respond to two audio recordings. The first recording was that of a male chemotherapy patient.

> Recording #1: *One story that is really not a story that's relevant to me at this moment is my concern with the winter and the chemotherapy. I am very worried about that because of the neuropathy that goes along with the chemotherapy and the cold weather. I have a dog that I like to take running in the fields and I also unfortunately have to deal with snow removal at the house and I'm not going to be able to do that I don't think and so unfortunately we've hired the snow removal*

> *the drive way, the sidewalk around the house and our deck. We've hired that done this year for the first time ever and it bothers me a lot that I'm not going to be able to do that but I cannot be outside in the cold weather, cold weather because of the chemotherapy, and the neuropathy that it's causing in my hands and face and things like that.*

The second recording was that of a female chemotherapy patient talking about her feelings and experience of the week after biopsy and before diagnosis.

> Recording #2: *You have no idea what's going to happen during that week. You have no idea if you're going to live, if you're going to die, it would be better if they just told you nothing and told you that they would have to take a biopsy and let you know in a week what was going to happen. So basically you go through sheer terror for a week, unknowing what's going to happen with the balance of your life and everybody rallies around you telling you don't worry, it's going to be okay, but it's not. It's not their life hanging in the balance.*

Participants were asked to "Write down anything you might document in the (electronic) health record as part of a psychosocial assessment. Making no documentation is perfectly acceptable." Participant answers were discussed with the researcher.
This was followed by general open-ended questions about documentation using an interview guide (Figure 1).

Participant Questionnaire.

The participant questionnaire was used to collect basic demographic information: gender, age, highest level of education completed, and practice setting. No other demographic information was collected.

Procedure

Recruited participants met with the researcher for a private one-hour semi-structured interview. After obtaining consent, the researcher asked the participants to describe their job responsibilities in their practice setting. The stimulus recordings were played and participants wrote their responses to the two stimulus recordings. Their answers and thoughts about the recordings were discussed before continuing with more general questions. Participants were reimbursed $50 for their time and effort.

Analysis

Interviews and stimulus responses were analyzed using the thematic analysis procedure described by Braun and Clarke (2006) and Boyatzis (1998). The first author reviewed the transcribed interviews for accuracy and completed multiple readings to become immersed in the data.

Data analysis was conducted by a team of researchers. The first author (KJ) and the second author (ACM) have training in qualitative methods and experience with the analysis of interview data. Two nursing faculty with expertise in nursing informatics also independently coded data, contributing to the trustworthiness of this research.

First, the interviews were read carefully and repeatedly to identify segments of text relevant to the stated aims. Patterns emerged regarding "why/why not document" and "where document". The first author made the initial data reduction by extracting text segments that represented these two concepts. The second author independently repeated this process for 20 of the 33 interviews, ensuring that the relevant information was extracted from the interviews.

The first author then inductively generated and applied codes based on recurring patterns within the extracted data. Two nursing informatics faculty who have qualitative research experience checked the reliability of the application of these codes. Each faculty member independently coded randomly selected excerpts of stimulus data and general interview data from three inpatient, outpatient, and home hospice nurses. The percentage of coding agreement between the first author and the two faculty members ranged from 77% - 100% for six (of 33) nurses' text segments. Categories of codes were refined through the use of constant comparison, resulting in a more parsimonious final coding scheme (Table 1). Changes made from the original coding scheme to the final coding scheme are found in the supplementary material (Appendix 4). Following analysis, the generated data were determined to be of sufficient breadth and depth to describe the phenomenon of documentation of psychosocial assessment by oncology nurses (O'Reilly & Parker, 2013).

Results

Sample Characteristics

A stratified convenience sample of 33 nurses were recruited from seven Midwestern institutions: 11 nurses from inpatient units at two institutions, 13 nurses from outpatient settings at two institutions, and 9 nurses from three home hospice institutions. All nurses were using an electronic health record. Participants were self-selected, observed to be Caucasian, and ranged in age from 23 – 60 years (M=39.48, SD=12.14). Most participants were female (n=28, 85%), with most having a BSN degree or higher (n=28, 85%).

Aim 1. Reasons nurses chose to document or not document psychosocial assessment.

Participants reported three reasons why they chose to document, and five reasons why they choose not to document their psychosocial assessments. The sample quotes used to illustrate the themes are taken from both the stimulus response data and the response to the general questions.

Why document?

First, nurses reported documenting a psychosocial assessment when *there was a need to communicate the patient's condition to other health care providers*. Either the patient condition had changed or there was new information to be communicated or an action to be taken (e.g., making a referral).

> *"There is a place for that fear of unknown, there is a checkmark, a box for that fear. People telling you it's going to be okay and it's not. That would have to go into the narrative and I think feeling like her life was out of balance, I think that makes her a high risk that the social worker and everybody needs to help her find that balance. And that might have to go into a narrative."* Response to Stimulus – Hospice

Second, nurses reported making a documentation regarding psychosocial assessment because there was an *organization requirement* to do so.

> *"Their mood and their kind of social interaction with family members, if they are calm, cooperative, like irritable or they won't maybe talk to their visitors, that's kind of like their choices. But that's the only thing like more psychosocial that we have to document."* General questions – Inpatient

> *"I mean there certainly is space to do it and we do have mandatory, you have to put something here on every patient for at least your comprehensive assessment you have to fill out something psychosocial related."* General questions – Hospice

The third reason reported for making documentation was that the structure of the *electronic record prompted* them to do so. Having a clear place to put something – a hole to fill—acted as prompt to fill it.

> *"Well, there are cues when you're going down through that particular line in the documentation, obviously they're not going to cue you that they are regarding fear and anxiety, but, you know, when you're asking what is their mood, that kind*

> *of thing, then that would be an appropriate place to chart that. And they do have that option in there as far as a drop down."* General questions - Inpatient

Why not document?

Nurses reported five reasons for choosing not to document. First, nurses reported that there was no need to document when the interaction was perceived as "just conversational."

> *"So much of what I do is very conversational and it's just spending time with people and learning about them and hopefully that will help us provide them with either better care or care that's more in tune with what they need as far as balancing coming here and seeing us and the impact that makes on their life."* General questions - Outpatient

A second reason reported for not documenting was that it was hard to decide what to document. Nurses reported difficulty making the reduction of many patient words or emotions to a single or few words. Some nurses viewed their assessment as a "personal opinion", and possibly inaccurate. For this reason, many nurses described using patient quotes in their free text notes.

> *"But my idea of they are upset, like I could see them as being angry about it but they may not feel like they're angry about it, they just might be like a general upset like they are not angry because you know some people with the tone of voice like I think their tone of voice can change how you document something, I think that's a big thing"*. General questions – Inpatient

> *"I mean I just find it hard to document that mood because I feel like sometimes they have so much different emotions that it's so hard to just say, well either good, sad, you know? It's hard to kind of judge that because sometimes they're sad, sometimes they're angry, sometimes they're okay. And it kind of depends on what nurse comes in or what nursing aid, maybe they don't like that nurse and maybe they're in a mood with them but then be fine with me*. General questions – Inpatient

Patient access to the health record also tempered some nurses' documentation.

> "*I think the only thing with the electronic health record is that sometimes you have to maybe be a little more vague in how you verbalize things knowing that patients have access to their charts. And so if somebody is already angry saying, and they're charting you know she seems angry might be something that you wouldn't necessarily want her to read.*" General questions – Inpatient

Third, nurses chose to communicate with other health care providers verbally instead of documenting in the electronic health record. In her response to Recording #1, an outpatient nurse stated:

> *"I'm not sure that I would document that, I mean because it's more of a concern about his quality of life, which is, of course, like a concern for his chemotherapy dosing. I guess I would make sure my provider was aware that was his concern, but I don't know that I would document it".* Stimulus response – Outpatient

Fourth, nurses reported difficulty in finding a place for it in the electronic health record.

> *"I don't think so because it doesn't have a psychosocial assessment section. It's got a social history, it's got a family history, it's got a medical history and a surgical history-- those are all separate."* General questions – Outpatient

> *"I don't think I really documented because there really was nowhere appropriate to document. Yes, I probably should have put it in the shift summary, but it was more of a verbal thing and there was no place to free text other than a little quick progress note -- but we have the option of flat affect..."* General questions - Inpatient

Finally, some nurses reported that it was "not my job".

> *"We have this psychosocial area which is usually filled in by the social worker, not the nurse. We don't fill in there. And we are in orientation encouraged that is really more the social worker's aspect of her job."* General questions – Hospice

Aim 2. Location of documentation of psychosocial assessment

Participants brought up three possible locations for documentation, with free text documentation in a progress or collaborative note used most frequently. Use of the tick boxes associated with "mental" status, or "mood/affect" on documentation flow sheets was also noted, using the free text space available there-- even if it was limited and required an extra click to get to. Finally, documentation was made on informal notes used by nurses at the time of shift handoffs, or "sticky notes" (electronic and paper) left for other health care service providers—items that are not part of the permanent record. Participants also mentioned using email, and this was an adjunct to documentation in the record.

Aim 3. Differences in documentation practices by setting.

Figure 2 depicts the differences in documentation practice by setting. Across settings, the most frequent reason for documenting the psychosocial assessment was the need to communicate the information to other health care providers. Documenting in response to EHR structural prompts was reported across settings, though more in the hospice and inpatient settings than in outpatient (Figure 2A). Organizational requirements to document were noted by hospice and inpatient nurses, but not by outpatient nurses.

All five reasons for not documenting were reported by nurses across the three settings, though in varying degrees (Figure 2B). 'Just conversation' was reported by outpatient and inpatient nurses more frequently than hospice nurses as a reason for not documenting. 'Hard to decide what to document' was reported by hospice and inpatient nurses more frequently than outpatient nurses. 'Verbal instead' and 'No place in the EHR' was cited most frequently by inpatient nurses, and to a lesser degree by hospice and outpatient nurses. It's 'Not my job' was reported most frequently by hospice nurses.

Free text (in a narrative, collaborative, or progress note) was the most frequently reported location of documentation of a psychosocial assessment (Figure 2C). Tick boxes were used across the three settings, with inpatient and hospice nurses reporting use of them more frequently than outpatient nurses. Informal means of documentation (email, sticky notes, not part of the permanent record) were reported most frequently by inpatient nurses, but were also used by hospice nurses. Outpatient nurses did not report using informal documenting locations for psychosocial assessments.

Discussion

The purpose of this study was to investigate nurses' documentation practices regarding psychosocial assessment, and to describe differences in documentation by setting. We have reported the reasons that nurses in home hospice, inpatient, and outpatient oncology settings choose to document or not to document their psychosocial assessments, and have described where documentation was made. The conflicting responses (do/don't document, free text/tick box, formal/informal documentation) illustrate variety in the approach to documentation of psychosocial assessment both within and across settings.

Why nurses choose to/not to document

The findings of this study suggest that nurses document a psychosocial assessment because they perceive a need to communicate a patient condition to other health care providers. This is congruent with and supports the primary purpose for documentation according to the AHRQ publication *Patient safety and quality: An evidence-based handbook for nurses* (2008): "The primary purpose for documentation and recordkeeping systems is to facilitate information flow that supports the continuity, quality, and safety of care" (p.3-175). However, nurses' reports of the additional use of informal and/or verbal means to communicate a psychosocial assessment suggest two influencing factors in the decision to document. (1) Either it's simply easier to communicate with other providers who are in close proximity than to make a documentation of the assessment in the EHR, or (2) there is limited trust in the efficacy of the EHR as a tool for communication with other health care providers. Verbal communication assures that the message is received, unlike EHR documentation. Choosing verbal methods of communication over written documentation, particularly regarding the non-physical aspects of care, have been reported previously (Howse & Bailey, 1992).

The findings of this study suggest a significant amount of cognitive work involved in the documentation of a psychosocial assessment. A series of decision points could be inferred. First, the data suggest a decision as to what part of the interaction is "just conversation" and what is part of a psychosocial assessment. Conversation doesn't have to be documented, but a psychosocial assessment does. This is followed by the decision about the content of that documentation. Documenting gives a public permanence to the assessment-- an assessment that nurses acknowledge may or may not be accurate or is true only for the moment. This is followed by a decision about which words will best and most concisely represent those emotions, statements, or evaluation. Using patient words in quotes simplifies that decision. Having to reduce to a single word, e.g., "angry", may be more efficient, but, as one nurse stated, "some things you just can't drop down" (in a word menu). This finding regarding the cognitive work involved in documenting a psychosocial assessment also supports earlier work by Howse and Bailey

(1992). In interviews with four hospital nurses, participants reported "difficulty condensing information and committing opinions to writing" (p.376).

Noteably, the EHR was cited as both a reason to document and a reason not to document. A prompt of some type (e.g., a provided space) was a good cue to document, but the options for documentation were not always viewed as adequate – "there's no place". Karkkainen and colleagues (2005) opine that electronic documentation is based on hierarchical classifications of *nursing* needs and interventions, and suggest that these prestructured pathways may challenge the documentation of patient-specific concerns. However, given the nurse-reported frequency of the "free text" choice for documenting a psychosocial assessment in this study, it's not clear that the EHR is posing a barrier.

Some nurses spoke about their training, either learning SOAP (subjective, objective, assessment, plan) structured documentation, or documenting by exception. This training may be transferred to the way documentation is approached in the EHR. For instance, the reported preference for using patients' words in direct quotes echoes the "subjective" aspect of SOAP charting. Remnants of "documentation by exception" training were found as well: "I only document things that are perceived to be abnormal". If distress is an expected (and appropriate) emotion, then it may not be documented.

Where psychosocial documentation is located

The most common location for the documentation of a psychosocial assessment was in a free text note, although other areas were also used. Having multiple places to document is inefficient and makes information retrieval challenging. Further research is needed to determine what type of design and/or format would not only encourage documentation of psychosocial assessments, but would capture the information in a manner that is easily accessible by other health care providers.

Practice setting differences

Similar to Karkkainen, Bondas, and Eriksson's (2005) metasynthesis of studies of nursing documentation, the findings of the current study recognize the effect of the organization on documentation. The differences in documentation practices reported by practice setting reflected the contextual features of that setting. For instance, the proximity of other health care providers in the inpatient setting makes it easy for nurses to verbally address physicians, social workers, or others with requests for a referral and to share information at shift handoff. Team collaboration is a priority in the hospice setting, where perhaps roles and responsibilities are more clearly defined.

Limitations

One limitation of this research is that the participants were self-selected. Participants could have elected to participate because they were particularly interested in the topic, because they felt particularly skilled at making and documenting psychosocial assessments, or simply to receive the remuneration. Therefore, it is possible that the participants were not representative of all nurses practicing in their setting. Similarly, demographic characteristics of nurses that may influence assessment and documentation choices (e.g., age, gender, race, years in practice, specialty training) were not considered in this analysis. Another limitation is that no attempt was made to recruit participants of diverse racial or ethnic background. As a result, this research does not reflect cultural nuances that nurses with a more diverse background might report. Finally, it is a limitation that these were *reports of* documentation. The use of audio-recordings as stimuli as a contributing source of data does not guarantee that this is how documentation is practiced in a real world setting. The findings are grounded in words based on both the researcher/interviewer and the participant skill and articulation in the moment.

Conclusion

Documentation of psychosocial assessment requires a significant amount of cognitive work, and is reported by nurses as being shaped by organizational requirements, role responsibilities, the EHR, and prior training. Variation in the approach to documentation within and across settings may impact care quality and patient outcomes. These findings highlight the challenges in committing a psychosocial assessment to documentation, and point to the need for education and training. Future research might explore the "tipping point" for documentation—how do nurses gauge the "need to communicate" as strong enough to merit documentation, and might identify ideal locations for documentation based on evidence of message receipt and action to treat psychosocial distress.

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Tables

Table 1. Coding Definitions

Final Coding Scheme for Documentation	
Three reasons why document	
Code label	**Definition**
Need to communicate	Patient condition required communication to other health care providers
Organizational requirement	Documentation occurs because there is an expectation from the organization -- "have to"
EHR prompts me	The electronic record prompts the user to document
Five reasons why don't document	
"Just conversational"	The interaction is perceived as just conversational. Documentation is not necessary.
Hard to decide what to document	It's hard to reduce patient's words succinctly and accurately. Challenging to mentally create a representation of patient condition/feelings, the preface to documenting
Verbal instead	Nurses chose to communicate information to other health care providers verbally
No place in EHR	"There's not a good place" to document, or there's a mismatch between the word choices available in the EHR and the words the nurse wants to use
Not my job	Psychosocial assessment (and documentation) is seen as someone else's job

Figures

Figure 1. Interview guide with stimulus response questions

Role/Description of your job in this setting

We're going to listen to two audio-recordings that are based on real outpatient chemotherapy patient words recorded at home. The paper is divided into two sections, one for each of the recordings that we'll listen to. As you listen to each, I'd like you to **write down anything you would document** in a real situation in the electronic health record **as part of a psychosocial assessment for this person.** It may be nothing! That's fine. You can arrange things how you'd like to. It's blank so that you can take as many notes as you like, and put them where you want to. (play first recording). Take as much time as you need.

Did you make any documentation?

Yes—what did you write, what was your thinking, where would this go in your record?

No--- why not, what was your thinking?

Is there anything about the EMR that helps you document this kind of assessment?

What about the EMR hinders documenting your assessment?

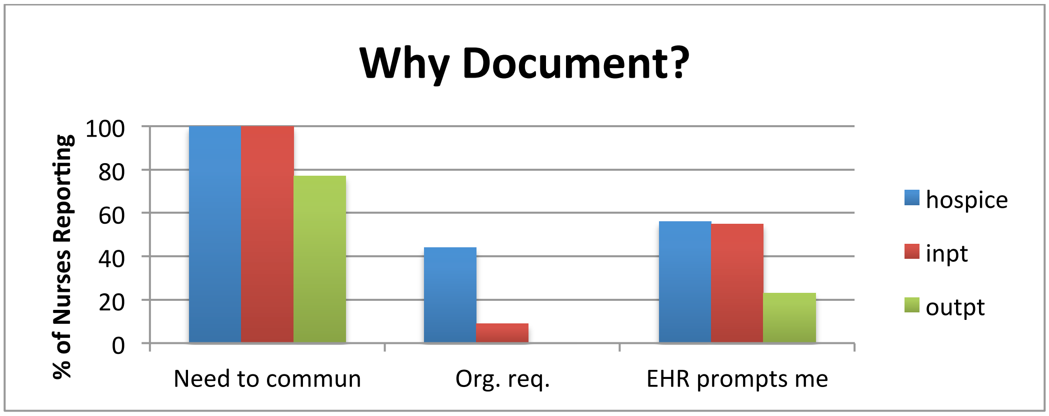
If you could design a section of the electronic health record to assist you in either assessing or documenting, what would it look like?

Recall a time when you were interacting with a distressed patient. Did you make any documentation – why or why not?

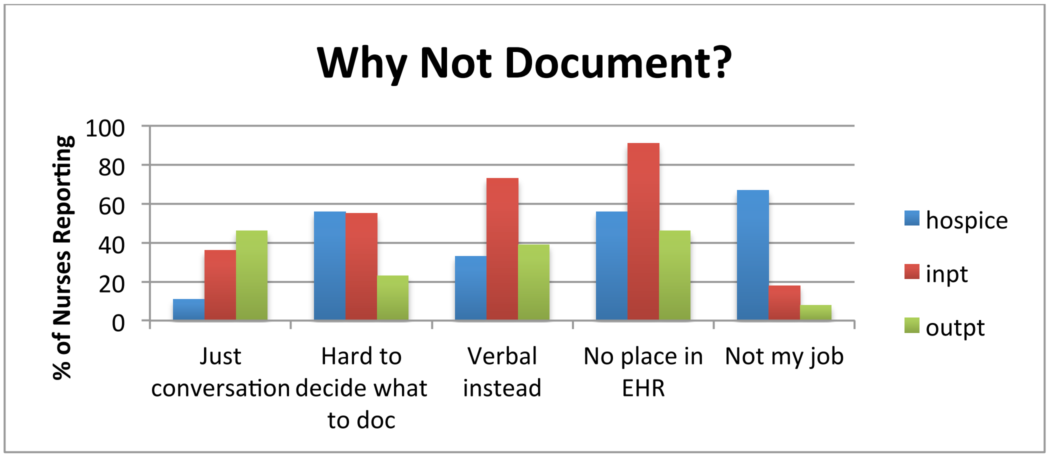
Use Distress Thermometer in your setting? How?

Figure 2. Nurses' Documentation Responses by Practice Setting

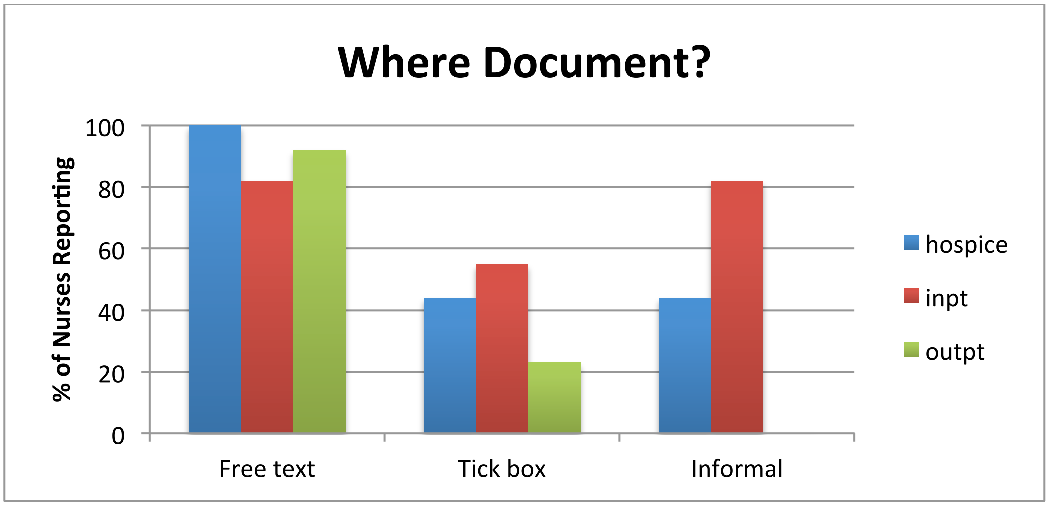
2A.



2B.



2C.



CHAPTER 5: Summary

This dissertation adds to nursing knowledge in the areas of patient narrative, psychosocial assessment, and the documentation of psychosocial assessment. Results are reviewed in light of existing literature. Areas of future research areas are considered.

The role and potential of narrative – pilot study

Despite evidence of positive psychological outcomes (health-related quality of life, lower depression and anxiety scores), interventions that elicit and acknowledge patient narrative data remain separate from the usual care process (Benish-Weisman, et al., 2014; Cepeda, et al., 2008; Crogan, Evans, & Bendel, 2008). The piloted intervention, MyWords, was the first known attempt to bring patient narrative data directly to nurses in the clinical setting. The intervention was deemed feasible and demonstrated potential in facilitating patients being known by their provider. 'Expressions of identity', 'response to cancer', and 'current concerns' accounted for 84% of the narrative space. Seventy five percent of the patients expressed a desire to communicate specific things saying, "*I do want to say*". However, marked differences were noted in patient comfort level in speaking orally; some would have preferred typing. Given these findings, the following areas of research are proposed (Figure 1).

Future work should include a bigger and more diverse sample. It is not known if this type of intervention would be acceptable to persons of different racial and ethnic background. Perhaps the patient should choose with whom they would like to share their narrative. The remote collection of patient narrative would seem to address issues with not being ready to talk and being (momentarily) overwhelmed, as the intervention puts the patient in control of the timing of narrative creation. Different modes of communication (text, video) could be offered. If text is used, perhaps natural language processing tools can assist in analysis and interpretation. Video capture (as a visual narrative) has been used to understand children's experience of living with asthma (Rich, 2000; Rich, 2005), but this has not been tried within the oncology population. Also, in the MyWords pilot study, patients' were more likely to share concerns about what they were currently facing in later recordings. It is not known if the content of patient narrative would change over multiple exchanges, and how. Could we use lexical processing to detect changes in content that signaled distress and a need for intervention?

A second area of research is the nurse receipt of the patient narrative; this was not investigated in the pilot study. Future work could investigate the cognitive work involved in the interpretation of remotely collected patient narrative data. The act of interpretation of narrative data could be considered a rapid qualitative analysis. We don't know exactly what skills are required, if those skills might be taught, and how. How do these skills relate to active listening? Further, which health care service (nursing, social work, spiritual care) is most appropriate to receive and interpret the narrative data?

There is little doubt that a cancer diagnosis is an existential threat. The narrative content requested of patients in the MyWords study was relatively undirected. An ongoing intervention may be helpful as patients negotiate and practice the new identity that comes with a new cancer diagnosis. However, the content of the intervention could also be more directed, for example, to assist patients in determining end of life goals, preferences, and values. Research by Young & Rodrigez (2006) demonstrated this in their interviews with veterans regarding preferences for end of life care. During interviews, the authors asked participants to explain their understanding of four terms: life-sustaining treatment, terminal condition, decision-making capacity, and state of permanent unconsciousness. Responses came in narrative form and revealed participants' values and goals. It's not known if this could be automated. However, just having the intervention available provides the opportunity for a patient to think through some difficult topics when they are ready to do so. If it became a standard of care, the ongoing patient experience of illness could be monitored and interpreted. More established advance care planning tools like "MyWishes" (Lyon, et al., 2010; Weiner, et al, 2012) may be incorporated.

The MyWords intervention was based on "hearing the patient's story", an intervention in Deshield & Nanna's Psycho-Oncology Consultation Model (2008). However, at this point there is no outcome measure. The development of a measurement of "being known" may be helpful as an outcome measure in determining intervention efficacy. Recent qualitative work adds to the growing recognition of "being known" as a valued aspect of patient care (Abdul-Razzak, et al., 2014; Jacobsen, et al., 2015). Such a measure may be also useful at end of life. One of the fears expressed by patients is the fear of abandonment (Back, et. al., 2009; Cohen, 2009; Curtis, et al., 2005); it is not known if "being known" (to what degree and how) could preclude a feeling of abandonment at end of life.

Psychosocial assessment

Cues, information seeking, knowledge structures, and setting.

Existing literature regarding psychosocial assessment has focused on two broad areas: (1) the development and use of screening instruments to assess distress (e.g., Andreu, et al., 2013; Fischbeck, et al., 2013; Huberty & Buckley, 2014;), and (2) the study of patient cues and provider cue responses (de Leeuw, et al., 2014; Hsu, et al., 2012; Sheldon, et al., 2014). This dissertation study adds knowledge about the process nurses use to make a psychosocial assessment and what nurses recognize as cues. Differences in psychosocial assessment based on care setting were revealed.

A cue has been defined as "a verbal or non-verbal hint that suggests an underlying unpleasant emotion and would need a clarification from the health provider" (Del Piccolo, Finset, & Zimmermann, 2008, p. 3). This definition is based on a patient-provider meeting (not a nurse), and usually in a situation with a goal or intention (a consultation). When nurses see patients, the duration is longer and the interaction is not completely goal focused. The types of cues reported by nurses in this study expand our understanding of cues, beyond verbal or non-verbal (body language) hints to include environmental, behavioral, and physiologic cues. The question of relevance was succinctly described as part of the definition of a cue. Perhaps more significant was the emergence of the guiding principles for looking at cues and seeking information, giving insight as to *how to look* rather than what to look for. A possible advantage of identifying the guiding principles is that they can be tested in multiple settings.

Verbal information seeking included three types of questions: broad, specific, and referring to a previous interaction. Four principles of information seeking were discerned: requires effort and purpose, establish trust, find the problem nursing can help with, and respect/connect. The types of questions and the discerned principles reflect concepts found in nursing theorist Hildegard Peplau's theory on the interactive relationship between the nurse and patient (1989). According to Peplau, the relationship between nurse and patient is itself a part of the therapeutic process, helping patients to make sense of and learn from their responses to experiences related to illness (Peplau, 1997).

Nurse reports of the respect/connect principle illustrate nurses' recognition that patients are not an open shelf of emotions and concerns that are waiting for inventory by the nurse. Nurses participate (knowingly or unknowingly) in the moment-to-moment construction of the interaction of which psychosocial assessment is a part. Further, since patients (humans) are in progress, and the relational aspect of nursing respects that developing narrative by building on successive encounters. These observations stand in stark contrast with a task-based nursing agenda and the prescription of work shaped by the EHR.

Nurses did not explicitly report the concept of "knowledge structure", but nurses were not asked this directly. Three broad categories of domain knowledge structures were inferred from nurses reports of cues and information seeking: (1) related to disease or treatment; (2) the family and/or support structure; and (3) personal coping or response to illness. These categories demonstrate a basic yet comprehensive bio-psychosocial model.

Though intended for physicians, Borrell-Carrio, Suchman, and Epstein (2004) propose a biopsychosocial-oriented clinical practice, with the inclusion of principles such as "the active cultivation of trust" and "(use) an emotional style characterized by empathic curiosity" (p. 576). These same principles that emerged in the information seeking data generated here. Patient-specific knowledge structures were reported as the application of the domain-specific knowledge structures. The guiding principles from the cues data (There is no universal cue, and Be alert for differences from patient normal, etc.) indicate a reflection on the individual patient, both in the recognition and interpretation of cues, and the manner in which information is sought.

The reason for the use of a stratified sample based on setting was to determine if psychosocial assessments differed when the focus of care changes. The same cues, principles and reasons were reported across the settings, but with different relative frequencies. These differences perhaps indicate more about the context of care than the focus of care. In terms of guiding principles, shift work gives nurses the opportunity to use the respect/connect principle, because he or she can return to the patient within several hours. Home hospice and outpatient nurses do not have this option. Inpatient and home hospice nurses, particularly in settings that use a primary care model, have more extended time for conversations to build trust, to observe physiologic signs, and to observe patient behavior in an environment. Outpatient nurses are pressured to keep the clinic flowing. No literature was found that reported the comparison of different practice contexts.

Future research (Figure 2) might include ethnographic study to more fully explore the organizational culture or other contextual features that affect the process of psychosocial assessment. This type of study may also give insights into the effect of team and collaborative work on the nursing work of psychosocial assessment in specific practice settings. Future research should examine this dataset in terms of the age, educational level, or training/experiences of nurses. Work toward developing a model or standard of "expertness" in psychosocial assessment—one that weighs or at least considers the role of setting in that development-- is indicated.

Barriers to making psychosocial assessments (Appendix 1).

The SEIPS (Systems Engineering Initiative for Patient Safety) is a framework used to understand the structures, processes, and outcomes of work systems (Carayon, et. al., 2006). This framework has been used to understand other areas of nursing work, e.g., in medication administration (Frith, 2013) and the study of technology-enhanced home care nursing (Johnson, et. al., 2008). The SEIPS framework concepts have been used here as a priori codes to understand the nursing work of psychosocial assessment.

Nurses reported multiple barriers to making a psychosocial assessment. Organization-related barriers, and time in particular, were the barriers noted the most often. In this category of barriers, 'They are not here to see me', 'Not a priority in my work', and 'we only ask juicy questions at admission' illustrate the clear role of the practice setting, and the manifest or latent care priorities held there.

Task-related barriers stemmed from the observation of patients being closed off (cue) because of being not ready to talk (to a particular nurse) or being overwhelmed. An outpatient nurse shared a speculation as to why some patients are closed off:

> *"Sometimes they (patients) don't want to build that relationship because then it connects them to the diagnosis. And if they stay away from the people that are treating them, it's not true."*

Nurse reporting of this patient cue as a barrier suggests that nurses understand a psychosocial assessment as an extended conversation, and more than observation or perception.

Nurse-related barriers included perceptions of personal ability or desire to make a psychosocial assessment, and personal and professional boundaries. When described, training for psychosocial assessment occurred in a "psych rotation" during nursing school, or during nurse resident training. "It took time and practice" for nurses to feel comfortable talking with patients. Although nurses' ages and education levels were collected, the data were not examined in light of these variables in this analysis. This is a topic of future research.

The tool/technology-related barriers indicate the strong role of the electronic record in determining how nursing *is practiced*, in addition to how nursing practice is documented. References made to "available tools" may indicate a (developing?) dependence exclusively on structured tools for assessment. Exploration of the unintended consequences of structured assessments and checklists on work skills is another possible focus of research.

The environmental-related barrier of having others present supports Oguchi and colleagues' findings (2010) that patients express fewer cues when family members are present. It is logical that nurses would see family presence as a barrier to psychosocial assessment. The environmental barrier, "I'm a guest in their home", has been reported earlier in studies of community (home) nursing (Carr, 2001; McGarry, 2009; McIntosh, 1996). McIntosh (1996) explored the development of nurses' experiential knowledge in community nursing. In McIntosh's study, "being a guest" had to be negotiated with the nurse's agenda while in the home, and this was learned through experience. Inexperienced nurses found that patient care could be compromised if families dictated the agenda. In the current analysis, reports of "being a guest" as a barrier could indicate evidence of this negotiation.

There are multiple barriers to making a psychosocial assessment, some more easily addressed than others. Interventions designed to assess (e.g, screening with a distress thermometer) and address (e.g., assigning the task to one health service) psychosocial concerns face significant challenges.

Documentation of Psychosocial Assessment

The findings of this study suggest a significant amount of cognitive work is involved in nurses' documentation (or not) of a psychosocial assessment, giving insights into this complex aspect of nursing care. This finding regarding the cognitive work involved in documenting a psychosocial assessment supports earlier work (pre – EHR) by Howse & Bailey (1992).

Nurses reported three reasons to document and five reasons not to document. The EHR was cited in both cases. A prompt of some type (e.g., a provided space) was a good cue to document, but the options for documentation were not always viewed as adequate – "there's no place". Karkkainen and colleagues (2005) assert that electronic documentation is based on hierarchical classifications of *nursing* needs and interventions, and suggest that these prestructured pathways may challenge the documentation of patient-specific concerns. However, given the frequency of the "free text" choice for documenting a psychosocial assessment in this study, the EHR is not posing a barrier.

Future research with this dataset might include examination of the documented responses to the two stimulus audio-recordings in light of collected nurse variables (age, educational level, training) (Figure 3). What is the content of that documentation? Is it a report (data near, e.g., patient quotes) or an evaluation? These findings could inform nurse education and training. Chart review and ethnographic study would help to understand who uses the documentation and what kind of content is required to support that provider's work.

Attending to oncology patients' psychosocial needs is a goal of the Institute of Medicine (2013) and is part of the oncology nurse's standard of practice (Brant, 2004). Some of the barriers to psychosocial assessment are amenable; some are not. There is room for improvement in the use of the EHR in the documentation of psychosocial assessment, and potential for use of patient narrative data to facilitate psychosocial care.

Figures

Figure 1. Future Directions: Patient Narrative

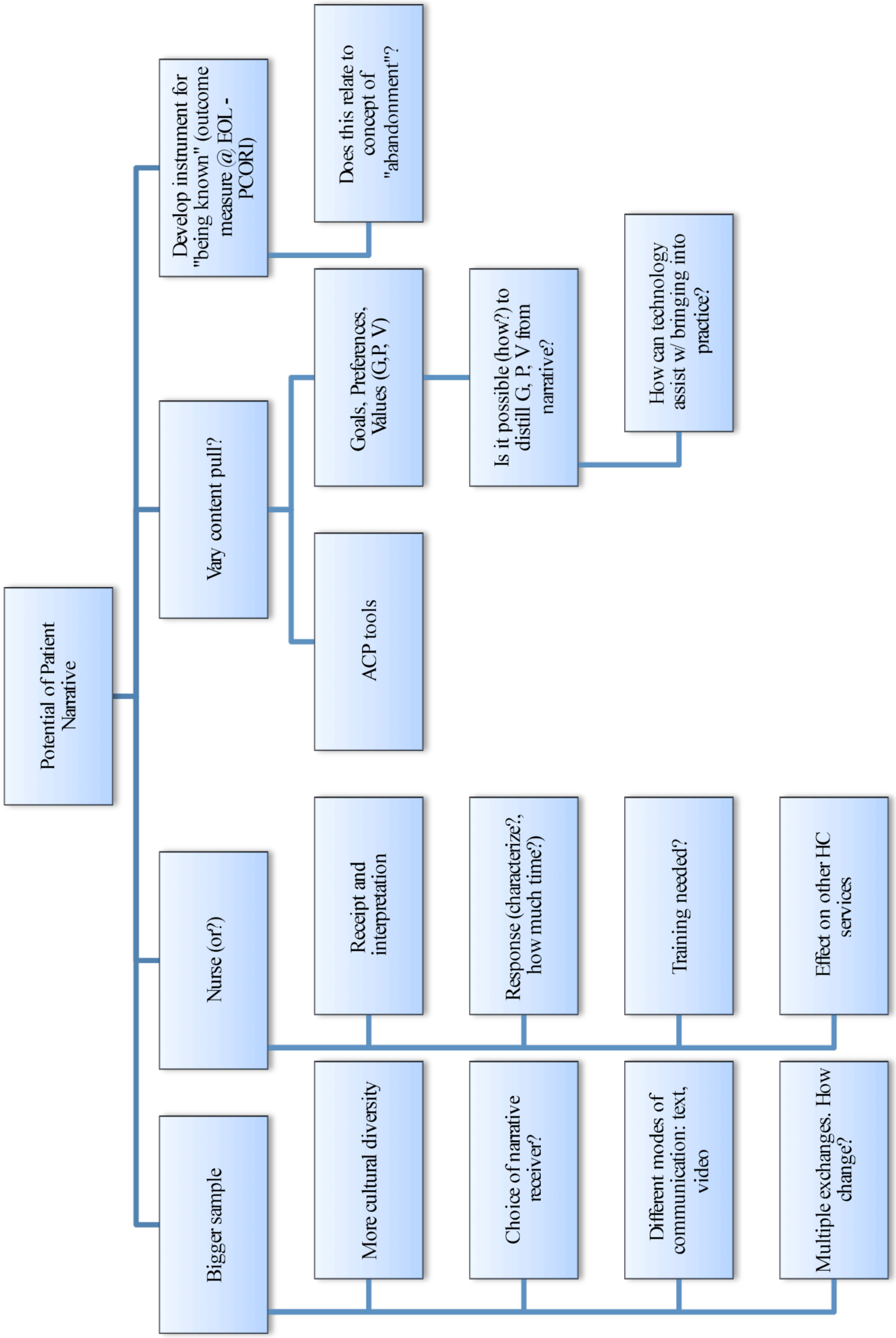


Figure 2. Future study of psychosocial assessment

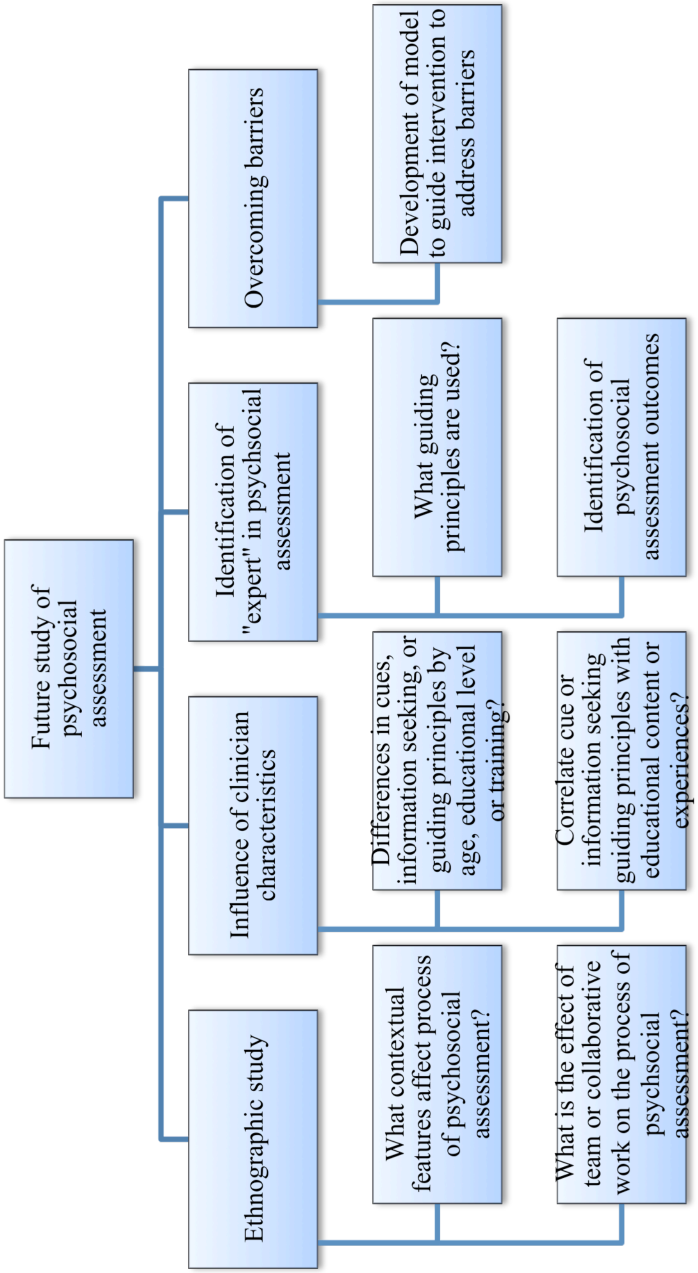
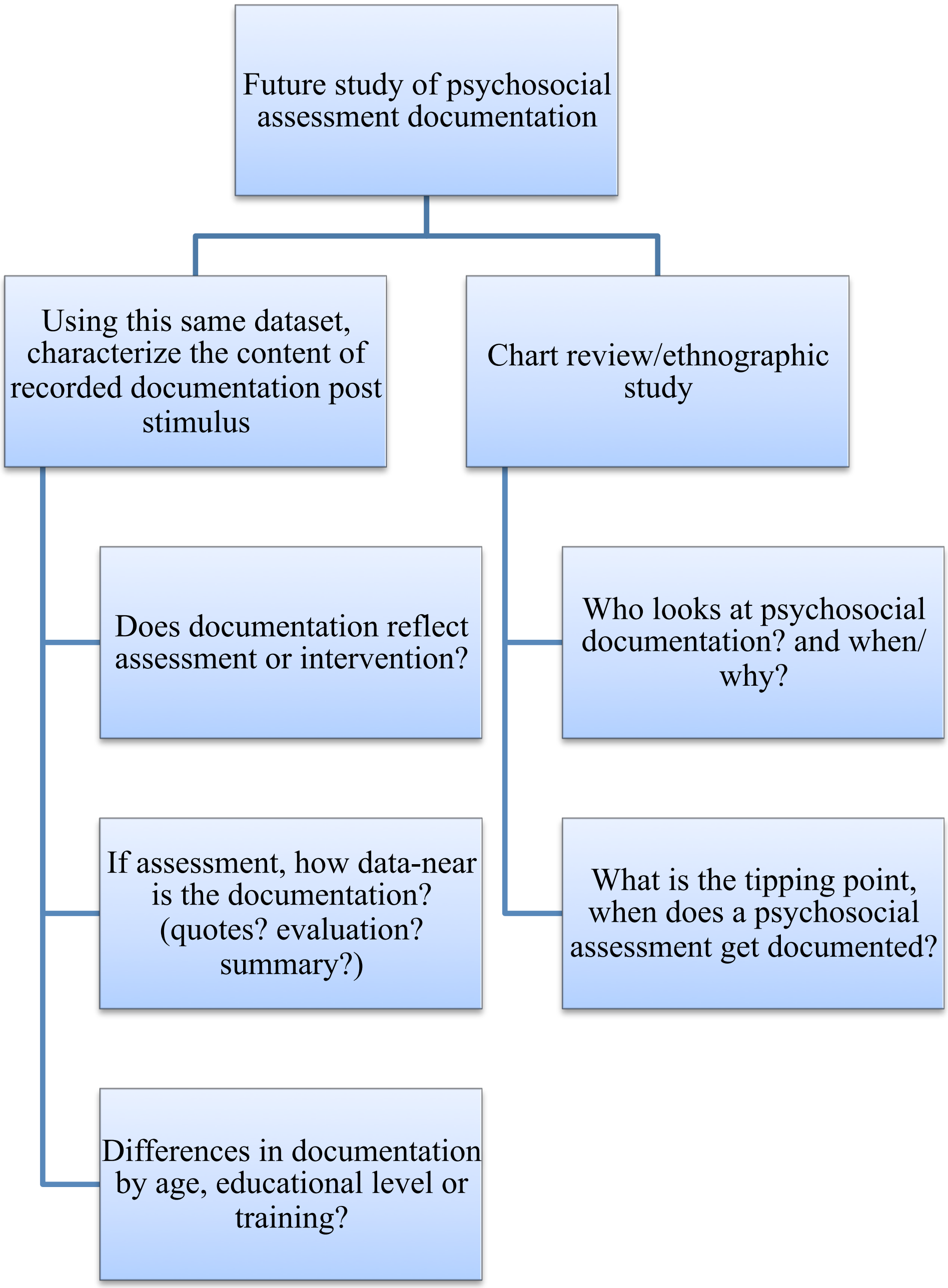


Figure 3. Future study of psychosocial assessment documentation



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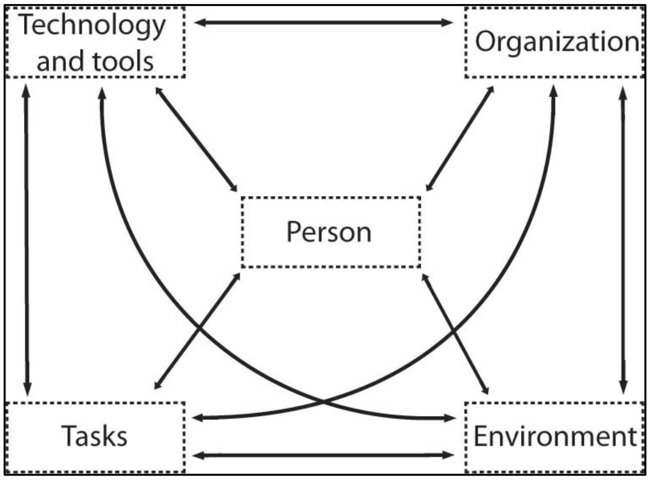
APPENDICES

Appendix 1. Barriers to making a psychosocial assessment

Introduction: The purpose of this secondary analysis was to document the barriers to making a psychosocial assessment as reported by 33 nurses from the inpatient, outpatient and home hospice settings using the lens of the SEIPS (Systems Engineering Initiative for Patient Safety) work system model, pictured right. This model is a framework for understanding the structures, processes, and outcomes and the inter-relationships of these concepts in work systems (Carayon, et al., 2006).



Method: Interviews were analyzed using the template approach of thematic analysis (Crabtree & Miller, 1999; King, 2004). This approach employs the use of an initial (a priori) template into which the data is coded; the concepts of the SEIPS model are used here (Table 1). Data is then further analyzed within the a priori codes, resulting in findings arranged in a hierarchical format.

The first author made the initial data reduction by extracting text segments that represented "barriers to psychosocial assessment". Another member of the research team independently repeated this process for 20 of the 33 interviews, ensuring that the relevant information was extracted from the interviews. The first author then developed and applied the a priori codes based on the SEIPS framework. Two nursing informatics faculty who have experience with qualitative research checked the reliability of the application of these a priori codes, with a percentage of coding agreement between the first author and the two faculty members ranging from 77% - 100%.

Table 1. Template of SEIPS model concepts applied in the context of nurse identified "barriers to a making a psychosocial assessment (PSA)"

Original SEIPS model	**AppliedTemplate Concept**	**Coding Definition**
Task – the job content, challenges, demands	**Task** = specifically the retrieval of cues and/or information from patient in order to make a psychosocial assessment.	A barrier to making a PSA is related to the patient. Ex: patient closed off, patient physical condition, patient inability to articulate. Patient may also be "too sick", and making a PSA has lower priority.
Person – the individual at the center of the work system performing patient care-related tasks. Includes education, skills, knowledge, motivation, needs, physical & psychological char.	**Interviewed Nurse**	A barrier to making a PSA is within the nurse, personal comfort or perceived lack of skill in talking with patients, retrieving cues or information
Tools/technology - various information technologies (EHR, decision support tools)	**Tools/technology**	A barrier to making a PSA relates to some aspect of the EHR--the structure or lack of it. Includes Distress thermometer.
Environment – layout, noise lighting, work station design	**Environment**	A barrier to making a PSA is the physical layout of area of care. Includes presence/absence of family members.
Organization – coordination, collaboration, organizational culture, work schedule, social rlnshps, mgmt. style	**Organization**	A barrier to making a PSA is found how the work is divided (formally or informally declared) among health care team. Includes time given to complete task.

Results: All a priori SEIPS concepts were represented in the "barriers to making a psychosocial assessment" interview data. The resulting hierarchy is noted in the text box below. Because the SEIPS model is a framework for understanding the entire work system, interview data could be relevant for more than one category, exemplifying the inter-relationships of concepts. Discussion and conclusions found in Chapter 5.

1. Task-related barriers – Patient closed off because
    A. Not comfortable with particular nurse: *"I'm not their regular nurse*"
    B. Not ready to share: *"They gotta think—what do they really want to divulge?"*
    C. Overwhelmed: *"Patients are just 'done' after spending time in clinic".*
2. Nurse-related barriers
    A. Lack of training, experience, or practice
    B. Personal boundary, knowing impairs thinking/judgment: *"I am careful not to know them too deeply...because it can get really emotional…and it hampers my decision making careful not to ask"*
    C. Not part of my job
        1. *"We're used to just looking at the patient and their diagnosis and everything medical that we just don't see the actual psychosocial part."*
        2. *"Social workers are more specialized in the psych/social stuff*".
3. Tool/technology-related barriers
    A. *"There's no place to put it"* in EHR.
    B. "*There are no hints* (from EHR) *to do it".*
    C. "*The tools and resources we have are very limited."*
4. Environment-related barriers
    A. Lack of space - *"We need the exam room."*
    B. Lack of privacy
        1. Others present in the room
        2. Only curtains between treatment chairs
    C. *"I am a guest in their home."*
5. Organization-related barriers
    A. Time
    B. They are not here to see me.
    C. Not a priority (in my work) – *"You just gotta make sure your heart's beating."*
    D. We only ask "juicy questions" at time of admission

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Appendix 2. Supplementary Material for Chapter 2.

Consent form for MyWords Study (5 pages)

PROTOCOL TITLE: MyWords: helping patients be known as a person in the outpatient oncology setting
Revised: May 25, 2015
Consent Form

Title of research study: MyWords: helping patients be known as a person in the outpatient oncology setting

Investigators: Mike Thompson, MD, PhD, ProHealth Regional Cancer Center, Kathy Johnson, MS,RN from University of Wisconsin Madison School of Nursing

We invite you to take part in a research study because you interact with nurses in the outpatient setting, and because you are receiving chemotherapy treatment. We would like to know if the process tested here enriches communication between you and your nurse.

What you should know about a research study

- Someone will explain this research study to you.
- You volunteer to be in a research study.
- Whether or not you take part is up to you.
- You can choose not to take part in the research study.
- You can agree to take part now and later change your mind.
- Whatever you decide it will not be held against you.
- Feel free to ask all the questions you want before you decide.

Who can I talk to?

If you have questions, concerns, or complaints, or think the research has hurt you talk to the research team. Mike Thompson, MD, PhD, 262-928-2570, Kathy Johnson 414-531-5776. Ms. Johnson’s advisor at UW School of Nursing: Dr. Patricia Brennan, (608) 263- 5251 or pbrennan@ie.engr.wisc.edu.

This research has been reviewed and approved by an Institutional Review Board. You may talk to them at (262) 928-8677 or Research.Institute@phci.org for any of the following:

- Your questions, concerns, or complaints are not being answered by the research team.
- You cannot reach the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide input about this research.

Why are you doing this research?

The purpose of this research is to see if a word picture can be used to help you be known as a person in the outpatient oncology clinic. Research studies have shown that patients value being known by their care providers. Other research has shown that patients have many concerns that are not talked about in their treatment visits. By asking you to make voice recordings at home, we are hoping that more of those needs can be communicated and met, and that you feel known as a person.

We are using audio-recordings because writing can be difficult for patients receiving chemotherapy.

How long will the research last?

We expect that you will be in this research study for about 3 – 4 weeks.

How many people will be studied?

We expect about 10 people to be in this research study. This study is only being conducted at the ProHealth Regional Cancer Center Clinics.

What happens if I say yes, I want to be in this research?

The first meeting will occur during a scheduled clinic visit. If you choose to take part in the study, you will receive a small audio-recorder to take home and instructions how to use it at a scheduled clinic visit.

Over the next week you are asked to speak into the recorder at least three times, more if you want to. There will be some questions to prompt you, or you may talk about whatever you'd like your nurse to know about you. Please, only use the recorder yourself.

After you've made at least 3 recordings, you are asked to mail the audio-recorder back to the researcher.

At your next scheduled clinic visit, the researcher will meet you about 15 minutes earlier than your scheduled appointment to make your "word picture" with you. This interaction with the researcher will be audio-recorded.

Your word picture will be created and printed from the words you recorded. Words that you say more often will show up larger than other words. You will have the final say about what words are included. It might look something like this:

You are asked to share your word picture with your treatment nurse. The word picture is supposed to act as a point of discussion; it is not meant to replace any interaction or communication.

You may keep your word picture if you want to, but the researcher will also have an electronic copy.

After you've shared your word picture with your nurse, the researcher would like to do a brief audio-recorded interview with you.

PROTOCOL TITLE: MyWords: helping patients be known as a person in the outpatient oncology setting
Revised: May 25, 2015

Overview of Study Steps:

1. Meet with researcher during regular clinic visit time. Get recorder and instructions.
2. Make at least 3 audio-recordings at home over 1 week.
3. Mail audio-recorder to researcher.
4. Meet researcher 15 minutes before clinic visit to make word picture (this is audio-recorded).
5. Share word picture with treatment nurse.
6. Short interview with researcher about experience (this is audio-recorded).

What happens if I say no, I do not want to be in this research?

You may decide not to take part in the research and it will not be held against you.

What happens if I say yes, but I change my mind later?

If you agree to take part in the research now and want to stop at any time, it will not be held against you.

If you decide to leave the research, contact the investigator so the recording device can be collected.

Is there any way being in this study could be bad for me?

There is a small risk that you become uncomfortable speaking about certain things, especially knowing that they are being recorded and will be listened to by someone else, or as you are recording. If you are uncomfortable you are free to stop recording at any time.

You may decide later that you don't want to share words that you have recorded at home. These may be deleted later.

Will being in this study help me any way?

We cannot promise any benefits to you or others from your taking part in this research.

What happens to the information you collect?

Efforts will be made to limit your personal information, including research study and medical records, to people who have a need to review this information. We cannot promise complete secrecy. Organizations that may inspect and copy your information include the IRB and other representatives of this organization.

The audio-recordings that you make at home, and the ones made with the researcher, will not be identified with your name. These recordings will be tagged with a code number. The code number will only be connected with your name on a single document that is kept on an electronic document on a double password protected server at the University of Wisconsin School of Nursing. The same is true of the word picture that you create.

The exact words and phrases that you use on the recordings, or the word pictures, may be used for publication in research journals or at conferences. Your name will not be included.

Can I be removed from the research without my OK?

The person in charge of the research study or the sponsor can remove you from the research study without your approval. Possible reasons for removal include failure to follow instructions of the researcher, or if the research staff decides that the study is no longer in your best interest. The sponsor can also end the research study early.

We will tell you about any new information that may affect your health, welfare, or choice to stay in the research.

What else do I need to know?

There is no payment for your time and effort in this research study. There is no direct benefit to you for taking part in this study.

Also, we will ask you to read a portion of this consent form as a way to help familiarize yourself with the recording device.

Signature Block for Capable Adult: Long Form

Your signature below indicates your permission to take part in this research and to the use and disclosure of your protected health information:

DO NOT SIGN THIS FORM AFTER THIS DATE →

Signature of participant	Date
Printed name of participant	
Signature of person obtaining consent	Date
Printed name of person obtaining consent	Form Date

[Add the following block if you will obtain a witness to the signature (required for all Veterans Administration (VA) research)]

Signature of witness to signature	Date
Printed name of person witnessing signature	

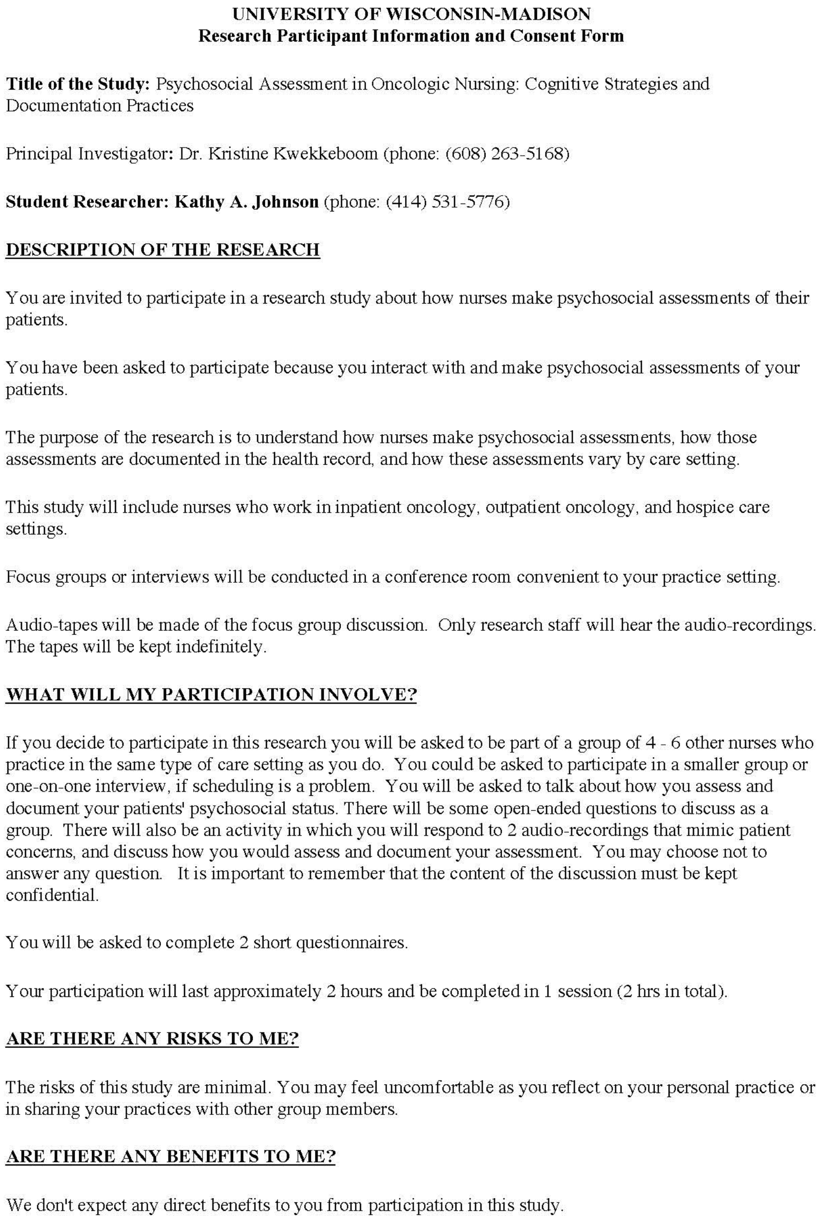
[Add the following block if a witness will observe the consent process (required for the short form of consent documentation)]

My signature indicates that the information in the consent document and any other written information was accurately explained to, and apparently understood by, the participant, and that consent was freely given by the participant.

Signature of witness to consent process	Date
Printed name of person witnessing consent process	

Appendix 3. Supplementary Material for Chapter 3.

Consent form for Psychosocial Assessment in Oncologic Nursing Study (2 pages).



UNIVERSITY OF WISCONSIN-MADISON
Research Participant Information and Consent Form

Title of the Study: Psychosocial Assessment in Oncologic Nursing: Cognitive Strategies and Documentation Practices

Principal Investigator**:** Dr. Kristine Kwekkeboom (phone: (608) 263-5168)

Student Researcher: Kathy A. Johnson (phone: (414) 531-5776)

DESCRIPTION OF THE RESEARCH

You are invited to participate in a research study about how nurses make psychosocial assessments of their patients.

You have been asked to participate because you interact with and make psychosocial assessments of your patients.

The purpose of the research is to understand how nurses make psychosocial assessments, how those assessments are documented in the health record, and how these assessments vary by care setting.

This study will include nurses who work in inpatient oncology, outpatient oncology, and hospice care settings.

Focus groups or interviews will be conducted in a conference room convenient to your practice setting.

Audio-tapes will be made of the focus group discussion. Only research staff will hear the audio-recordings. The tapes will be kept indefinitely.

WHAT WILL MY PARTICIPATION INVOLVE?

If you decide to participate in this research you will be asked to be part of a group of 4 - 6 other nurses who practice in the same type of care setting as you do. You could be asked to participate in a smaller group or one-on-one interview, if scheduling is a problem. You will be asked to talk about how you assess and document your patients' psychosocial status. There will be some open-ended questions to discuss as a group. There will also be an activity in which you will respond to 2 audio-recordings that mimic patient concerns, and discuss how you would assess and document your assessment. You may choose not to answer any question. It is important to remember that the content of the discussion must be kept confidential.

You will be asked to complete 2 short questionnaires.

Your participation will last approximately 2 hours and be completed in 1 session (2 hrs in total).

ARE THERE ANY RISKS TO ME?

The risks of this study are minimal. You may feel uncomfortable as you reflect on your personal practice or in sharing your practices with other group members.

ARE THERE ANY BENEFITS TO ME?

We don't expect any direct benefits to you from participation in this study.

WILL I BE COMPENSATED FOR MY PARTICIPATION?

You will receive $50 for participating in this study.

If you do withdraw prior to the end of the study, you will receive no money.

There is no reimbursement for parking or childcare expenses.

HOW WILL MY CONFIDENTIALITY BE PROTECTED?

Confidentiality cannot be guaranteed with a focus group, as other subjects will be present. Focus group subjects are instructed to keep what is discussed at the focus group as confidential.

While there will probably be publications as a result of this study, your name will not be used. Only group characteristics will be published.

If you participate in this study, we would like to be able to quote you directly without using your name. If you agree to allow us to quote you in publications, please initial the statement at the bottom of this form.

WHOM SHOULD I CONTACT IF I HAVE QUESTIONS?

You may ask any questions about the research at any time. If you have questions about the research after you leave today you should contact the Principal Investigator Dr. Kristine Kwekkeboom at (608) 263-5168. You may also call the student researcher, Kathy A. Johnson at (414) 531-5776.

If you are not satisfied with response of research team, have more questions, or want to talk with someone about your rights as a research participant, contact the UWHC Patient Relations Representative at 608-263-8009 or University of Wisconsin Medical Foundation Patient Relations Representative at 800-552-4255 or 608-821-4819.

Your participation is completely voluntary. If you decide not to participate or to withdraw from the study it will have no effect on any services or treatment you are currently receiving.

Your signature indicates that you have read this consent form, had an opportunity to ask any questions about your participation in this research and voluntarily consent to participate. You will receive a copy of this form for your records.

Name of Participant (please print):______________________________

____ ______________

Signature Date

__________ I give my permission to be quoted directly in publications without using my name.

Coding Instructions for Coding Panel for Psychosocial Assessment in Oncologic Nursing Study.

Please find an attached excel file (workbook) with your name on it. There are two sheets within your workbook: one labeled "cues" and one labeled "information seeking". You will be coding on both sheets.

Each sheet contains text segments from two different nurses. Each of you has been randomly assigned the data from two nurses.

You will be coding for three general categories (bolded) for both cues and information seeking. Before you begin coding, familiarize yourself with the coding scheme in the tables below. It will make it easier for you to "hear" them in the data.

Code by reading the text segment slowly-- maybe even out loud. Remember this is people talking; rarely are there complete sentences or thoughts. If there are contradictions, code both of them. Mark an "x" in the cells of the all of the codes you feel could be applied to this segment. You should be able to say to yourself, "I hear this code right here in this phrase". **Do not expect to have a code applied in each of the big three categories!** Sometimes I had only one "x" for the whole text segment. I am looking for presence of the codes, not "loudness". Code definitions/examples are in the following tables.

Supplementary Material – Original Coding Scheme

CUES IN PSYCHOSOCIAL ASSESSMENT

Types of Cues reported as being used in psychosocial assmt

Excel Column	Working Code label	Definitions/Examples
C	Body language cues	Body appearance, position, demeanor, facial expressions, eye contact, crying, hygiene, mood, deer in the headlights
D	Verbal cues	What is said (words), how said (tone) (anger)
E	Behavioral cues	Body movements, actions, what patients do, interactions with others with them, hitting
F	Environmental cues	Condition of surroundings
G	Physiologic cues (signs)	Observable physiologic changes (heart rate, resp rate). Signs, not symptoms

Process/ Principles used regarding cues used in psychosocial assmt

	Working Code label	Definition/examples
I	Everyone is different	Being mindful of people having different personalities. This can make it hard to recognize distress.
J	Being alert for differences	Different from base line or normal or normal for most pts, different from last visit, from what you're saying (on Distress Thermometer) and what I'm seeing
K	Including the family in the scope of assmt	Assmt of pt includes assmt of interactions w family
L	How much do they talk to/engage with me?	Is pt. open for conversation? A lot or not?
M	Is pt. compliant/asserting himself/planning	There is a "good" patient – does what he's told, what's expected. Asserting self/opinion can be either good or bad. "Good" because it represents engagement, taking control when there often isn't a lot to control, and "Bad" because it can be loud, frustrating, demanding

Knowledge Structures from Cues (Domain): inferred from analysis of identified cues, processes, and principles that emerged from data

EXCEL COLUMN	Working Code labels	Definition/examples
O	Concepts related to disease process or treatment	Includes meds, pain, tx choices, lack of options
P	Family dynamics/support	Pt's support system/social system
Q	Personal Coping	Includes awareness, acceptance, personal response to illness

Supplementary Material – Original Coding Scheme continued

Information Seeking

(VERBAL) Ways of Infoseeking used in making psychosocial assmt

EXCEL COLUMN	Working Code labels	Definition/examples
C	Asking general/broad/conversational questions	Includes "how are you feeling?". Usually used for developing rapport/rlnshp, opening the door
D	Asking specific questions – goals, what did you have for breakfast, do you have pain	
E	Confirming/disconfirming observations/cues/distress thermometer	You seem sad today. Your DT score says this, but I'm not seeing it… I (nurse) am seeing this, what do you see?
F	What do you (pt) know? Why do you think I'm here	Used to figure out patient's knowledge about their situation. Begins conversation or opens door to conversation about stage of illness and personal response to it
G	Questions that refer to a previous visit/encounter. Bringing something from past forward.	Is your daughter still seeing that guy? Last time you were here you were worried about X—are you still?
H	Following up or pursuing a pt comment OR and observation made of environment	(seeing pics on the wall) Are these your grandchildren?

Processes/Principles used in information seeking when making a PSA

EXCEL COLUMN	Working Code labels	Definition/examples
J	Establishing rapport/trust/making a connection	They won't talk to you/you won't get to the real problems unless they trust you. You have to make a connection
K	Respect or connect?	Nurse can see pt not interested in talking now, approaches later.
L	Relating physical to psychosocial and vice versa	Your face is calm but your HR is high. Incr. resp. rate/SOB w/topic change
M	Assmt needs to be made with purpose, an honest effort	Acknowledgment that it takes effort, presence on nurse's part to get a PSA
N	Sometimes they just need to vent/talk	Infoseeking/my being interested can open a flood of emotions, and just talking helps them.
O	Finding the problem(s) that nursing can help with	Asking/searching for ways to define the problem or to separate solvable problems from unsolvable problems.

Supplementary Material – Original Coding Scheme continued

Knowledge Structures from Infoseeking: inferred from analysis of identified ways of infoseeking, processes, and principles that emerged from data

EXCEL COLUMN	Working Code labels	Definition/examples
Q	Concepts related to disease process or treatment	Includes meds, pain, tx choices, lack of options
R	Family dynamics/support	Pt's support system/social system
S	Personal Coping	Includes awareness, acceptance, personal response to illness

Changes to Coding Scheme

After coding using the original coding scheme was completed, it became clear that some coding labels could be combined with others, resulting in a more refined and parsimonious final coding scheme. See changes from original coding scheme to final scheme below. No (previously applied) text segment code was changed in this process.

Original Coding Scheme	Location in Final Coding Scheme
"Everyone is different"	Changed to "There is no universal cue"
"Including the family in the scope of assessment" and "Is patient compliant/asserting himself/planning"	Included with "Behavioral cues"
"How much do they talk to me?"	Included with "Verbal cues"
"Ways of Information Seeking"	Changed to "Types of Questions"
"Confirming/disconfirming observations/distress thermometer", "What do you (patient) know? Why do you think I'm (nurse) here?", "Following up or pursing a patient comment or observation of environment"	Included in "Specific questions"
"Relating physical to psychosocial and vice versa"	Included in "Specific questions"
"Sometimes they just need to vent"	Removed – doesn't fit with stated aims
"Respect or connect"	Renamed to "You can always ask later – respect/connect"

Final Coding Scheme

Final Coding Scheme for Cues	
Five Types of Cues	
Code label	**Definitions/Examples**
Verbal cues	What is said (words), how said (tone) (anger).
Physical/body language cues	Body appearance, position, demeanor, facial expressions, eye contact, crying, hygiene, mood
Behavioral cues	Body movements, actions, interactions with others (family) with them, hitting. Is patient compliant/asserting himself/planning ?
Environmental cues	Condition of surroundings
Physiologic cues (signs)	Observable physiologic changes (heart rate, respiratory rate).
Two Principles used regarding Cues	
Everyone is different	Being mindful of people having different personalities. This can make it hard to recognize distress.
Being alert for differences	Different from baseline, or what is expected for most patients, different from last visit, difference between what you're saying (including on Distress Thermometer) and what I'm seeing

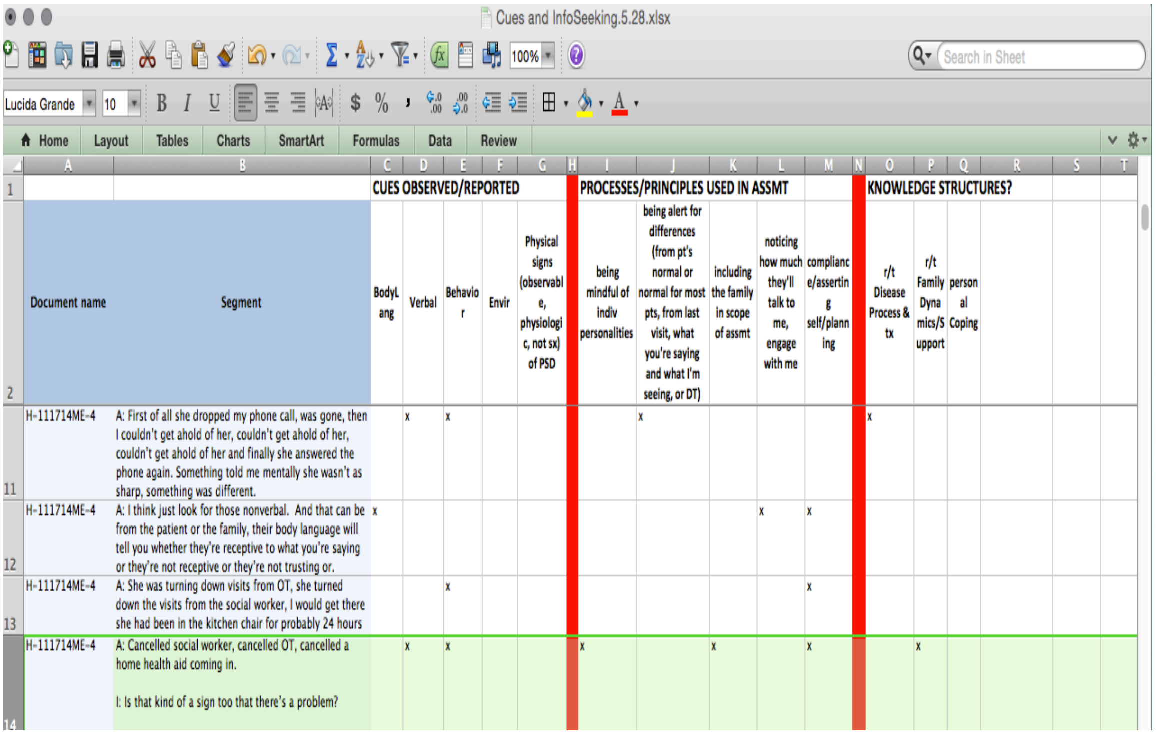
Final Coding Scheme for (verbal) Information Seeking	
Three Kinds of Questions	
Code labels	**Definition/examples**
Asking general, broad, conversational questions	Includes "how are you feeling?". Usually used for developing rapport/relationnship, opening the door
Asking specific questions	~What are your goals today, what did you have for breakfast, do you have pain. ~What do you (pt) know? Why do you think I'm here (Used to figure out patient's knowledge about their situation. Begins conversation or opens door to conversation about stage of illness and personal response) ~Following up or pursuing a pt comment OR and observation made of environment -(seeing pics on the wall) Are these your grandchildren? ~Relating physical to psychosocial and vice versa- Your face is calm but your heart rate is high. Increased respiratory rate/shortness of breath with topic change
Questions that refer to a previous visit/encounter. Bringing something from past forward.	Is your daughter still seeing that guy? Last time you were here you were worried about X—are you still worried about that?

Four Principles used regarding information seeking	
Code labels	**Definition/examples**
Assessment requires effort and purpose	Acknowledgment that it takes effort, presence on nurse's part to get a PSA
Work to establish trust, a connection	They won't talk to you/you won't get to the real problems unless they trust you. You have to make a connection
Finding the problem(s) that nursing can help with	Asking/searching for ways to define the problem or to separate solvable problems from unsolvable problems.
You can always ask later (Respect or connect)	Nurse can see pt not interested in talking now, approaches later.

Three Domain-Specific Knowledge Structures	
Concepts related to disease process or treatment	Includes meds, pain, tx choices, lack of options
Family dynamics/support	Patient's support system/social system
Personal coping or response to illness	Includes awareness, acceptance, personal response to illness

Process for making a nurse composite summary:

This is how the text segments were reduced to make a nurse composite summary for nurse H-111714ME-4. (This was an early coding scheme.) The line with the most x's was chosen (green highlight), and then the x's from nurse's other lines were marked into that line. Line 14 was kept, and x's were added to line 14 in the following columns: "body language", "being alert for differences", "noticing", and "related to disease process" because they were concepts covered by different text segments. Then the text segment (on line 14) was removed; it was no longer the single focus of analysis. This reduction process ensured that all of a nurse's text segments about a concept could be acknowledged, while comparisons could be made about relative presence of the concept within each setting.



	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q
1			CUES OBSERVED/REPORTED						PROCESSES/PRINCIPLES USED IN ASSMT						KNOWLEDGE STRUCTURES?		
2	Document name	Segment	BodyLang	Verbal	Behavior	Envir	Physical signs (observable, physiologic, not sx) of PSD		being mindful of indiv personalities	being alert for differences (from pt's normal or normal for most pts, from last visit, what you're saying and what I'm seeing, or DT)	including the family in scope of assmt	noticing how much they'll talk to me, engage with me	compliance/asserting self/planning		r/t Disease Process & tx	r/t Family Dynamics/Support	personal Coping
11	H-111714ME-4	A: First of all she dropped my phone call, was gone, then I couldn't get ahold of her, couldn't get ahold of her, couldn't get ahold of her and finally she answered the phone again. Something told me mentally she wasn't as sharp, something was different.		x	x					x					x		
12	H-111714ME-4	A: I think just look for those nonverbal. And that can be from the patient or the family, their body language will tell you whether they're receptive to what you're saying or they're not receptive or they're not trusting or.	x									x	x				
13	H-111714ME-4	A: She was turning down visits from OT, she turned down the visits from the social worker, I would get there she had been in the kitchen chair for probably 24 hours			x								x				
14	H-111714ME-4	A: Cancelled social worker, cancelled OT, cancelled a home health aid coming in. I: Is that kind of a sign too that there's a problem?		x	x				x		x		x			x	

Appendix 4. Supplementary Material for Chapter 4.

Coding Instructions for Psychosocial Assessment in Oncologic Nursing - Documentation

Please find an attached excel file (workbook) with your name on it. You will be coding for two general topics on the three sheets in your workbook: barriers to making a psychosocial assessment (PSA) (1 sheet), and documentation of PSA (2 sheets). One of these two sheets re: documentation is data gathered in response to two stimulus audio-recordings that the nurses listened to. The other sheet re: documentation is data gathered that was not related to the stimulus.

Before you begin coding, please familiarize yourself with the coding scheme in the two tables below. It will make it easier for you to "hear" them in the data. Use Table 1 for "Barriers to PSA" and Table 2 for the two documentation sheets.

Please code by reading the text segment slowly-- maybe even out loud. These data are transcripts of interviews; rarely are there complete sentences or thoughts. If there are contradictions, code both of them. Mark an "x" in the cells of the all of the codes you feel could be applied to this segment. You should be able to say to yourself, "I hear this code right here in this phrase". I am looking for presence of the codes, not "loudness". Code definitions and some examples are in the following two tables.

Feel free to write comments on any of the sheets!

Original Coding scheme for sheets"Doc re-Stimulus" & "Doc re-NonStimulus"

Excel Column	**Do/Don't Document**	**Determinants**	**Coding definition**
H	DO	Volume or presence of cues	Nurses document PSA when: • the patient emotion is "blatant" • there is a change from patient's normal • there are accompanying physical cues • there are words of suicidal ideation • the nurse feels there is a risk to patient safety
I	DO	Communication required to other HCP	Nurses document PSA when • change in the plan of care • there is a need/desire to communicate to others. Ex: Patient agreed to talk with social worker • information is relevant for the next shift or future patient interaction
J	DO	Org. requirement	Nurses document PSA because it is expected or required by their organization
K	DO	EHR prompts me	Structure of EHR prompts user to document
M	Don't	"Just Conversational" with patient	Nurses don't document PSA when the interaction is perceived as "just conversational", no need to document, patient "just venting"
N	Don't	Communicate verbally instead w/other HCP	Nurses don't document because they prefer/choose to pass on the relevant information verbally (to physician, other team members)
O	Don't	Limited by EHR . Lost and no one will read	Nurses don't document because "there's no good place" -- it's lost in the EHR and no one will read it.
P	Don't	It's hard to reduce	Nurses don't document because there are a lot of patient words to reduce succinctly.
Q	Don't	Mismatch	Nurses don't document because there is a mismatch between the assessment to available word choices.
R	Don't	It's not my job	Don't document because it's someone else's job
T	Free text		Location is for free text documenting, e.g., collaboration note, progress note. Includes "psycohosocial" tab
U	System tick boxes		Mood/affect, neuro status, teaching, etc. May have a text box available here too, but have to mentioned tick box (or equivalent)
V	Informal note		Email, sticky note, shift to shift note. Not part of permanent record

Changes to Documentation Coding Scheme

After coding using the original coding scheme was completed, it became clear that some coding labels could be combined with others, resulting in a more refined and parsimonious final coding scheme. See changes from original coding scheme to final scheme below. No (previously applied) text segment code was changed in this process.

Original Coding Scheme	Location in Final Coding Scheme
Why document?	
"Volume of cues" was combined with "Communication required"	"Need to communicate"
Why not document?	
Combined "Limited by EHR" and "Mismatch"	"EHR hinders"
"It's hard to reduce" renamed	"What to document?"

Final Coding Scheme for Documentation

Three reasons why document	
Code label	**Definition**
Condition required communication to others	There is a need to communicate the patient's condition to other health care providers
Organizational requirement	Documentation occurs because there is an expectation from the organization
EHR prompts	The structure of the electronic record prompts the user to document
Five reasons why don't document	
"Just conversational"	The interaction is perceived as just conversational. Documentation is not necessary.
"What to document?"	It's hard to reduce patient's words succinctly and accurately. (making the representation of patient condition/feelings, the preface to documenting)
Communicate verbally instead	Nurses prefer to communicate information verbally
EHR hinders	"There's not a good place" because there's a mismatch between the word choices available in the EHR, and the words the nurse wants to use
It's not my job.	Psychosocial assessment (and documentation) is seen as someone else's job