2012

ASSESSING NUMERACY IN ONCOLOGY: THE ROLE OF PATIENT PERCEPTION AND PREFERENCES

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DISSERTATION

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A dissertation submitted in partial fulfillment of the
requirements for the degree of Doctor of Philosophy in the
College of Arts and Sciences
at the University of Kentucky

By
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Lexington, Kentucky

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Lexington, KY

2012

ABSTRACT OF DISSERTATION

ASSESSING NUMERACY IN ONCOLOGY:
THE ROLE OF PATIENT PERCEPTION AND PREFERENCES

Treatment decision making (TDM) in oncology is complex. Understanding treatment information is essential for shared TDM. Research suggests many patients have low numeracy. This mixed methods study explored numeracy and experience with numbers in a sample of individuals diagnosed with follicular lymphoma. Participants completed questionnaires (N = 32) and interviews (N = 20) assessing numeracy, decisional conflict and regret, and number preference. Results suggest that mean objective numeracy was relatively high, and most reported high confidence in numerical ability. Most participants preferred to receive numbers during the TDM process. There was no relationship between numeracy and decision outcomes. Future research should investigate the use of numeracy measures in practice and the impact of patient preferences and beliefs on shared TDM.

KEYWORDS: Treatment Decision Making, Oncology, Follicular Lymphoma,
                    Numeracy, Patient Preferences

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3/30/2012
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ASSESSING NUMERACY IN ONCOLOGY:
THE ROLE OF PATIENT PERCEPTION AND PREFERENCES

By

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March 23, 2012

I dedicate this dissertation to every first generation college student.
"Success is to be measured not so much by the position that one has reached in life...as by the obstacles which he has overcome while trying to succeed."
– Booker T. Washington

ACKNOWLEDGMENTS

There are many individuals that have helped this work become possible. First, my Dissertation Chair, Dr. Jamie L. Studts, provided a space for me to create ideas, think, and grow. His mentorship has placed an enormous role in my development as a "thinker" and a professional. Next, the entire Clinical Psychology department at UK provided unmatched support throughout my graduate career. I will always be grateful for the department for taking a chance on me and allowing me to continue to grow as a person and as a professional.

The support of my friends and family has been just as important. I am grateful for the continued encouragement of my family. I will also always be grateful for the support and love of my cohort, the most beautiful, intelligent, and inspiring group of women that I have ever met.

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Background and Significance

Assessing Numeracy in Oncology: The Role of Patient Perception and Preferences

Historically, medical TDM has primarily followed a paternalistic model (Charles, Gafni, & Whelan, 1999; Edwards & Elwyn, 2009). This model is becoming increasingly less common as more and more patients become active participants in the TDM process (Arora, 2003; Sheridan, Harris, & Woolf, 2004; Stiggelbout et al., 2006). This increase in patient participation in decision making has led to the development of a more collaborative, shared, or patient-centered approach to treatment communication (Apter et al., 2008; Edwards & Elwyn, 2009; Epstein, Alper, & Quill, 2004; Eggly et al., 2009; Sheridan, Harris, & Woolf, 2004). This process involves the participation of both patient and physician in sharing information, assessing patient preferences and needs, and using this information to collaboratively decide on a course for treatment (Sheridan, Harris, & Woolf, 2004).

Patient involvement in this process has been found to have a number of positive psychological outcomes, including increased satisfaction, less anxiety and improved coping (Epstein & Street, 2007), and less regret about treatment decisions (Clark, Wray, & Ashton, 2001; Davison, So, & Goldenberg, 2007). Patients may also experience more trust in their physician and more confidence in their ability to participate in TDM when involved in the process. Additionally, patient participation in health care has also been shown to lead to improvements in health outcomes, such as medication compliance (Adams, Appleton, Wilson, & Ruffin, 2005).

Despite these positive outcomes, research in this field has uncovered significant challenges regarding patient involvement in TDM. Specifically, there is strong evidence

to suggest that the majority of patients have limited understanding of the treatment information they are presented (Gigerenzer, Gaissmaier, Kurz-Mileke, Schwartz, & Woloshin, 2008; Moxey, O'Connell, McGettigan, & Henry, 2003; Nelson, Reyna, Fagerlin, Lipkus, & Peters, 2008). This lack of understanding limits the ability for patients to participate in a shared or collaborative TDM process, make an autonomous decision about their care, and to truly provide informed consent for treatment (O'Connor, Stacey, & Jacobsen, 2011; Sheridan, Harris, & Woolf, 2004; Sullivan, 2003). Effective health communication is necessary to ensure that patients make an informed choice based on adequate understanding. Ineffective communication can have serious consequences for patients, including reduced treatment adherence, decreased use of preventative services, (Vahabi, 2007) and inadequate understanding of the seriousness of their disease and the risk and benefits of treatment (Sheridan, Harris, & Woolf, 2004).

This is of particular concern in the oncology setting. TDM in this setting is often more complex due to the nature and gravity of the illness. Cancer TDM commonly involves weighing multiple treatment options with ranging benefits and risks. Patients making these decisions have the added burden of knowing that the choice will likely result in trade offs between survival and quality of life. Research has also highlighted the unique emotional environment in which cancer treatment decisions are made. There is evidence to suggest that a diagnosis of cancer causes significant emotional distress, symptoms of posttraumatic stress, anxiety, and depression, and a reduction in psychological well-being (Cordova et al., 1995; Costanzo, Ryff, & Singer, 2009; McBride, Clipp, Peterson, Lipkus, & Demark-Wahnefried, 2000). The emotional distress that patients experience following a cancer diagnosis may significantly increase the

difficulty with which they are able to weigh different treatment options (Diefenbach et al., 2008; Fischoff, 1999). Cancer patients are required to organize and consider complex treatment information in light of their own preferences for treatment at a time when their capacity for decision making is likely impaired because of these strong emotions (Consedine & Moskowitz, 2009; Rini et al., 2009). In addition, there are some cancers, such as follicular lymphoma, in which research has not produced definitive evidence that any of the available treatment options increase survival, adding to the complexity and uncertainty regarding which treatment to choose.

Effective treatment communication is complex. One necessary, but often challenging component is to provide patients with numerical treatment information, such as probabilities of side effects or treatment response, in order for them to make a treatment choice based on accurate information (Apter et al., 2009; Fischoff, 1999; Reyna, Nelson, Han, & Dieckmann, 2009). However, this process is complicated by the lack of numeracy in the general population (Nelson et al., 2008; Reyna, Nelson, Han, & Dieckmann, 2009) and the emotional nature of a cancer diagnosis as noted above. It is therefore essential to identify cost-effective methods to reduce the burden experienced by cancer patients who wish to be actively involved in the treatment process. Examining numeracy and how it impacts understanding of treatment information and subsequent treatment decisions is one potential means of simplifying this process for patients. Using a mixed methods approach, this study proposes to examine the utility of subjective and objective numeracy measures and the relationship between numeracy and TDM in a sample of individuals previously diagnosed with follicular lymphoma. This study will incorporate a qualitative approach to describe patient's experiences with numeracy and

preferences for communication about quantitative treatment information during oncology treatment consultation.

<center>Numeracy and TDM</center>

Numeracy and Informed Consent

Recent research on numeracy, an individual's ability to comprehend and utilize numerical information, demonstrates that a large proportion of individuals struggle with basic numerical operations (Fagerlin et al., 2007; Galesic & Garcia Retamero, 2010; Lipkus, 2007; Reyna & Brainerd, 2007; Reyna, Nelson, Han, & Dieckmann, 2009; Peters, Hibbard, Slovic, & Dieckmann, 2007). This difficulty with comprehension of quantitative information has also been found in the TDM setting. A study by Weinfurt et al. (2005) demonstrated that a substantial proportion of patients making decisions about clinical trial participation misunderstood the statement "For every 100 patients like me, the treatment will work for 40 patients." Twenty-eight percent of participants understood this statement to mean that their doctor had 40% confidence that the treatment would control their cancer or that the treatment would reduce their disease by 40%. This lack of understanding of basic percentages and probabilities may significantly impact the ability of patients to weigh the benefits and risks of various treatments and choose one that fits with their personal preferences.

Patients are not only hindered by their level of understanding of numerical concepts and operations, but may also change their treatment decisions based on the format in which treatment information is presented (Garcia-Retamero & Galesic, 2010; Moxey et al., 2003; Nelson et al., 2008; Peters, Hart, & Fraenkel, 2011). There have been a number of studies using cancer treatment information that have demonstrated a

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significant effect of the frame used to present information on the type of treatment chosen. Framing is defined as the presentation of logically equivalent information in different ways that may bias how an individual interprets the information (Wilson, Purdon, & Wallston, 1988). For example, presenting a risk of mortality as a 20% risk of death (negative frame) may be interpreted differently than presenting it as an 80% chance of survival (positive frame) despite the fact that these are logically equivalent ways of describing the same risk. Studies examining positive and negative framing have demonstrated that the use of frames bias individuals toward either a risk-approach or risk-avoidance treatment choice (McNeil, Pauker, Sox, & Tversky, 1982; McNeil, Pauker, & Tversky, 1988; O'Connor et al., 1985; O'Connor, 1989).

Patients that have low health literacy and numeracy are often more susceptible to framing effects and overestimate risk more than those with higher literacy and numeracy (Reyna, Nelson, Han, & Dieckmann, 2009). Health literacy includes having an accurate understanding of general health information, as well as of disease, the health care process, and health terms (Epstein & Street, 2007). Health numeracy is somewhat dependent upon health literacy, and involves the ability to understand and manipulate numbers used in a health context and then act on that health information to promote good health (Lipkus & Peters, 2009, Nelson et al., 2007). Studies have shown that those with lower health numeracy and literacy also face negative health consequences. A study of patients using warfarin for therapy found that those with lower health numeracy and literacy had poor anticoagulation control and were unable to correctly titrate their medication to remain in a therapeutic range (Estrada, Martin-Hryniewicz, Peek, Collins, & Byrd, 2004). Another study examining diabetes-related numeracy in diabetic patients

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found that lower numeracy was associated with lower perceived self-efficacy and fewer self-management behaviors (Cavanaugh, Huizinga, Wallston, Gabretsadik, Shintani, Davis, et al. 2008) This research raises significant concerns about presenting treatment information to patients in numerical terms.

Based on the evidence that many individuals have difficulty understanding numerical information, other studies have examined the effectiveness of communicating treatment information in a qualitative form (Cheung et al., 2010; Wallsten, Budescu, Zwick, & Kemp, 1993; Windschitl & Wells, 1996). This involves using qualitative descriptors such as "unlikely," "rare" or "sometimes" to present treatment information. Research on the use of qualitative descriptors in cancer TDM has not demonstrated that this type of communication is preferential to providing quantitative treatment information (Gurmankin et al., 2004; Knapp, Gardner, Carrigan, Raynor, & Woolf, 2009; Knapp, Gardner, Raynor, Woolf, & McMillan, 2010; Young & Oppenheimer, 2009). These studies have found that patients tend to overestimate risk and misinterpret treatment information regardless of whether the information is provided in a qualitative or quantitative form.

Accurate understanding of treatment information is essential in order for patients to be able to participate in a collaborative TDM process and provide informed consent for treatment. Problems with basic understanding of numerical information and the influence of communication format on understanding significantly hinder the ability of patients to make informed treatment decisions (Reyna, Nelson, Han, & Dieckmann, 2009). In the oncology setting, patients make challenging treatment decisions that often have significant consequences for survival and quality of life. Therefore, it is essential that

patients accurately understand the risk and benefits of treatment. To ensure that patients are making an optimal treatment decision based on accurate understanding, it is necessary to continue investigating methods to improve this process for patients. Learning more about patient's familiarity with and facility for numbers may aid in the design of treatment communication that patients can comprehend and apply in their decision making processes.

Assessment of Numeracy

Numeracy has been demonstrated to play a significant role in patient's medical decisions, and low numeracy has been associated with less understanding and use of health information (Fagerlin et al., 2007; Peters, Hibbard, Slovic, & Dieckmann, 2007). One possible means of improving the TDM process would be to tailor numerical information to a patient's desire for and ability to comprehend it. However, to do this, it is necessary to systematically assess each patient's level of numeracy. This would provide the patient's health care team with essential information that can aid in the development of more effective treatment communication efforts. Once information is received about a patient's level of numeracy, interventions can then be implemented to tailor the information they receive to match their skills and preferences. Ideally, this would maximize the likelihood that the patient will leave the treatment consultation with an accurate understanding of their treatment options.

Most research has focused on objective measures of numeracy that test patients' ability to calculate percentages, frequencies, and probabilities. Objective numeracy assessments provide information regarding patients' skills in basic numerical operations. Since numeracy is not accurately determined either by observable traits or self-report

(Nelson, Reyna, Fagerlin, Lipkus, & Peters, 2008), brief objective numeracy measures can help physicians identify those who may have difficulty understanding quantitative information. Schwartz, Woloshin, Black, and Welch (1997) developed a brief measure of numeracy that has been used to assess the relationship between numeracy and ability to use risk reduction information. Their questionnaire assesses numeracy using three questions measuring familiarity with probability, percentages, and proportions. The authors found that those with higher numeracy were more accurate at applying mammography risk reduction information. These results highlight the difficulty that low numeracy patients are likely to have with quantitative treatment information.

Lipkus, Samsa, and Rimer (2001) expanded Schwartz and colleague's (1997) three-item scale. This newer instrument added eight items that were framed in the context of health risks. This instrument is now widely used to assess objective numeracy in a health setting (Nelson et al., 2008). Despite the benefits of assessing objective numeracy, there are some inherent complications with using these measures in practice. The time necessary to complete the task and the difficulty patients may have in completing it may result in frustration, missing data, or refusal to complete the measures (Fagerlin, Ubel, Smith, & Zikmund-Fisher, 2007; Nelson, Reyna, Fagerlin, Lipkus, & Peters, 2008).

An alternative method to objective measures of numeracy is the measurement of subjective numeracy, or a patient's self-rated mathematical aptitude. Measures of subjective numeracy have recently been developed to address concerns regarding the aversion some patients have to completing objective numeracy measures as well as the difficulties completing these measures by phone or mail. The Subjective Numeracy Scale (Fagerlin et al., 2007) is a leading example of a recently-validated measure of subjective

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numeracy. It contains two subscales; one measuring patient's self-reported mathematical aptitude, and one measuring preference for receiving mathematical versus descriptive information. The authors reported a correlation of .68 between the subjective numeracy measure and the Lipkus, Samsa, and Rimer (2001) 11-item numeracy scale. This measure of subjective numeracy provides valuable information regarding the patient's perceived ability to work with numbers as well as their preference for working with numbers. However, this scale was validated on general medical patients and the general public. It is yet unknown if subjective and objective numeracy correlate as highly in a group of cancer patients that have experience with making treatment decisions. Before utilizing subjective numeracy as a proxy for objective numeracy in a cancer population, it is necessary to examine the construct validity of subjective numeracy in an oncology setting due to the unique nature of a cancer diagnosis and subsequent TDM process.

Numeracy and Decision Outcomes

An understudied aspect of numeracy is the impact that one's level of numeracy has on decision outcomes. While there is evidence to indicate that one's numeracy impacts treatment choice (Garcia-Retamero & Galesic, 2010; Nelson et al., 2008), there have been no studies examining the impact of numeracy on relevant decision-related outcomes, including how patients feel about their treatment choice. A low level of numeracy may increase the conflict that patients experience about their treatment decision due to confusion or uncertainty about the best treatment choice for them. Using the Ottawa Decision Support Framework, decisional conflict and regret were chosen as the decision-related outcomes to examine. This conceptual framework presents decisional conflict, or uncertainty, about a decision as a central decision need that must be addressed

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in order to make an informed, quality decision (O'Connor, Stacey, & Jacobsen, 2011).

Decision regret was also included as a decision-related outcome based on prior evidence

suggesting that patients who experience greater conflict surrounding their treatment

decision later experience more regret about their decision (Brehaut et al., 2003). This may

have important implications for future treatment decisions, particularly in populations of

patients that are required to make multiple treatment decisions.

<div align="center">Patient Preferences</div>

Preference for Communication Format

Patient preferences for communication format are another important aspect of the

TDM process. Findings from studies examining the use of tailored health information

have found that this can have significant positive outcomes: tailored health messages are

more likely to be read and remembered, are rated as more attention catching, and are

perceived as being more personally relevant (Hawkins, Kreuter, Resnicow, Fishbein, &

Dijkstra, 2008; Kreuter & Wray, 2003). Petty and Cacioppo's Elaboration Likelihood

Model posits that people are more likely to be active and thoughtful when processing

information when they are motivated and able to do so. The model further suggests that

one of the essential components of motivation is perceived personal relevance of the

message (Petty & Cacioppo, 1981).

This model provides a structure for understanding how personal preference for

treatment communication format may influence subsequent retention and understanding.

Patients who receive treatment information that is not in a format they prefer, such as

receiving numerical information when they prefer verbal information, may not be

motivated to attend actively to and process the information given to them. This could

potentially increase the difficulty they would have comprehending and applying the treatment information they receive to make a treatment decision.

Patient preferences for treatment communication format have rarely been studied in the oncology setting. A recent review (Poe, 2010) identified only four studies that have assessed patient preferences for communication format in a cancer setting. The results from these studies demonstrated that most patients had a preferred mode of receiving information, but that this preference varied widely, emphasizing the importance of assessing preferences in all patients (Knapp et al., 2010; Lobb et al., 1999; Mazur, Hickam, & Mazur, 1999; Studts et al., 2005). Two of the studies (Lobb et al., 1999; Studts et al., 2005) provided qualitative data on why patients had preferences for particular communication formats. For example, some patients reported that different forms of communication seem confusing or negative; while others may perceive the same form of communication more positively (Lobb et al., 1999; Studts et al., 2005). It is likely that patients have preferences for receiving treatment information that is based on their level of understanding or comfort with a particular format. Patient's preferences for qualitative information may reflect a discomfort with numbers, or a preference for information in a positive frame may demonstrate a misunderstanding of equivalent numerical estimates. It may be important to assess both level of numeracy and patient preferences in all patients before they receive information about their treatment options.

TDM in Follicular Lymphoma

Reducing the burden of the TDM process is particularly important in cancers where patients are required to make multiple treatment decisions, such as follicular lymphoma. Follicular lymphoma is a non-Hodgkin lymphoma, and it is considered an

indolent, or slow-growing, cancer that is located in the lymph nodes (Advani, Rosenberg, & Horning, 2004; Conconi et al., 2010; van Besien & Shouten, 2007). Patients with follicular lymphoma survive a median of nine to ten years, and generally die as the result of treatment-resistant disease, the transformation to a more aggressive pathology, or from complications of therapy (Conconi et al., 2010; Rohatiner & Lister, 2005). Advanced stage disseminated indolent lymphomas are generally considered incurable and are characterized by a repeated, initial response to treatment that is transient, and subsequent repeated relapse (Advani, Rosenberg, & Horning, 2004; Rohatiner & Lister, 2005; Salles et al., 2011). This recurrent relapse requires follicular lymphoma patients to make multiple treatment decisions over their disease trajectory.

Although numerous treatment approaches have been used in this patient population, none have resulted in long-term survival without cancer in a large percentage of patients (Ardeshna et al., 2003; Conconi et al., 2010; Horning, 2000; Linch, 2001). Because patients will experience multiple relapses with little hope for a definitive cure of their disease, treatment often focuses on controlling the disease rather than curing it (Wake et al., 2002). Additionally, a recent study with follicular lymphoma patients (Poe, Hayslip, & Studts, in press) revealed that a majority of patients reported significant anxiety and cancer-specific distress. These unique characteristics make the TDM process for patients with follicular lymphoma particularly complex. However, there has been little research investigating the decision making process among individuals diagnosed with follicular lymphoma.

Aims and Hypotheses

The increase in patient participation in decision making has led to a shift from a paternalistic, physician-driven decision making process to a more collaborative, patient-centered process (Eggly et al., 2009; Epstein, Alper, & Quill, 2004; Sheridan, Harris, & Woolf, 2004). This shift has had positive outcomes for patients (Adams, Appleton, Wilson, & Ruffin, 2005; Clark, Wray, & Ashton, 2001; Davison, So, & Goldenberg, 2007; Epstein & Street, 2007). However, research highlighting deficits in patient understanding of treatment information raises interest in improving the process of communicating treatment information. Clearly communicating treatment information to patients is an essential factor in the development of collaborative patient-physician relationships and the provision of quality health care (Arraras et al., 2007; Sheridan, Harris, & Woolf, 2004; Vahabi, 2007). The assessment of patient numeracy and preferences for communication format is one potential method of improving this process. This information can aid in the development of time and cost-effective interventions that address the barriers to understanding treatment information and facilitate informed TDM. In addition, although it is known that lack of numeracy and communication format can influence treatment decisions, it is yet unknown what impact this has on important decision outcomes that may affect future treatment decisions.

To address these gaps in the literature, this study employed a mixed methods approach (Creswell, 2003; Creswell & Plano Clark, 2007; O'Cathain, Murphy, & Nicholl, 2010) to investigate these issues in a sample of individuals previously diagnosed with follicular lymphoma. Mixed methods research involves the collection, analysis, and integration of both quantitative and qualitative data to answer research questions

(Creswell & Plano Clark, 2007; O'Cathain, Murphy, & Nicholl, 2010). The use of a mixed method approach has several advantages. Mixed methods research integrates both quantitative and qualitative data on a topic, providing a way for researchers to study similar data from different perspectives (Creswell, 2004; Tashakkori & Creswell, 2007). The use of quantitative data alone on understudied topics may result in the design of measures that do not fully incorporate all important aspects of a phenomenon (Creswell, 2003). The inclusion of qualitative data adds the perspective of the population being studied, which may further refine current quantitative measures or lead to the development of future quantitative measures (Cagle & Wells, 2008). The use of a qualitative approach also provides information on themes that may be present, and thus can further inform later quantitative research (Creswell & Plano Clark, 2007). One potential disadvantage of the mixed methods approach is difficulty with successful integration of the data from both methods (Bryman, 2007; Creswell, 2003; O'Cathain, Murphy, & Nicholl, 2010). The current study employed a concurrent mixed methods approach (Creswell & Zhang, 2009). In this approach, quantitative and qualitative data are collected at the same time point. The data are then analyzed separately, and the results are merged in the interpretation. Trends in the quantitative and qualitative data are examined to determine how the results from the two methods corroborate, support, or contradict each other (Creswell & Zhang, 2009).

In this study, the qualitative interview data was used to enhance the quantitative data on objective and subjective numeracy. The inclusion of the qualitative data supported the quantitative data by describing the patient's experience and comfort with numbers in the TDM process. In addition, the qualitative data extended this further by

describing patient's experiences that are not captured by the quantitative measures. The research questions in this study will be most effectively answered through the integration of these two methods of data collection, making a mixed methods approach the most appropriate research methodology.

The overall goal of this project was to explore numeracy and patient experience with numbers in a sample of follicular lymphoma patients. The first aim of this study was to examine the psychometric properties of the Subjective Numeracy Scale and to explore the construct validity of subjective numeracy in an oncology setting. It was hypothesized that subjective numeracy will be significantly and positively correlated with objective numeracy. The second aim of this study was to examine the relationship between subjective and objective numeracy and measures of TDM. It was hypothesized that 1) subjective and objective numeracy would be significantly and negatively correlated with decision regret and 2) subjective and objective numeracy would be significantly and negatively correlated with decisional conflict. Finally, the third aim of this study was to utilize qualitative interview data to provide additional information about numeracy by exploring and describing: 1) patient reports of the use of numbers in the clinical consultation and perceived ability to work with numbers, and 2) patient perception of and preference for the use of numbers in TDM. Data for this study was taken from a previously conducted study of the TDM processes in individuals diagnosed with follicular lymphoma.

Chapter Two: Method

Accrual Procedure

Eligible study participants were identified from clinic records at the University of Kentucky's Markey Cancer Center. Prior to contacting eligible candidates, permission to contact specific patients was sought from their treating oncologist. After receiving oncologist permission, individuals were approached at the clinic or contacted by letter and invited to participate in a study that would involve completing a questionnaire packet. Participants were compensated $25 for completing and returning the packet. Participants were also asked to participate in an in-person or telephone semi-structured interview. A trained interviewer completed these interviews using a semi-structured interview guide. Individuals who completed the interview received an additional $50.

Participants

Adults with a diagnosis of follicular lymphoma were recruited from the University of Kentucky's Markey Cancer Center in Lexington, Kentucky. All study procedures were reviewed and approved by the Institutional Review Board at the University of Kentucky. Participants were invited regardless of current treatment status. Participants were eligible if they were: (a) age 18 or older; (b) had a cancer diagnosis of follicular lymphoma with no other cancer history (other than non-melanotic skin cancer); (c) diagnosed in the last 10 years; (d) and able to read and write English.

A total of 69 eligible participants were identified and sent a letter of invitation to participate in the study. Of the 69 eligible participants, 4% (n= 3) were deceased, 4% (n = 3) declined participation, and 36% (n = 25) did not respond to the invitation letter. A total of 59% (n = 39) indicated interest in study participation. Of these, 36 individuals

provided informed consent. Ultimately, 32 completed questionnaire packets were received for a final completion rate of 48% (32/66). Of those that completed the questionnaires, 20 individuals also completed the interview. The average interview time was 27.7 minutes (SD = 14.7; range = 11.2-66.3).

<p align="center">*Measurement: Quantitative*</p>

Participants (N = 32) completed a questionnaire that included five sets of instruments: (1) a background/medical information questionnaire, and measures assessing (2) role preferences in TDM, (3) numeracy, (4) treatment decision outcomes, (5) psychological distress. The measures relevant to this study will be described below.

Subjective Numeracy

Participants were administered the Subjective Numeracy Scale (SNS; Fagerlin et al., 2007). The scale was developed to address concerns regarding the measurement of objective numeracy, such as distance administration and negative reactions from individuals completing objective numeracy scales. The scale includes eight items and comprises two subscales. Participants were asked four questions regarding their perceived ability to calculate percentages and fractions and four questions regarding preferences for receiving numerical or verbal information. Participants responded by circling a number from 1 (not at all) to 6 (extremely). One subscale measures patient's self-reported mathematical aptitude, and one measures preference for receiving mathematical versus descriptive information. Possible scores range from 8 to 48 on the full scale and 4 to 24 on the subscales. Higher scores indicate a higher aptitude and preference for numerical information. The final scale demonstrated good reliability in the validation sample (.82) and the authors reported a correlation of .68 with Lipkus, Samsa,

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and Rimer's numeracy scale (2001). The internal consistency was not reported for either subscale in the validation study. The SNS has not been previously used in an oncology setting.

In this sample, reliability analyses revealed a Cronbach's alpha of .90 for the full scale of the SNS, demonstrating good reliability. The mean of the full scale was 34.6 (*SD* = 9.9). The mean score of the aptitude subscale was 16.9 (*SD* = 5.8), and the mean of the preference subscale was 17.8 (*SD* = 4.8).

Objective Numeracy

To measure objective numeracy, participants were administered the 11-item Numeracy Scale (Lipkus, Samsa, & Rimer, 2001). This is a widely used scale comprised of questions measuring familiarity with probability, ability to covert a percentage to a proportion, and the ability to convert a proportion to a percentage. The score is calculated by counting the number of correct responses. It has been found to have adequate internal consistency (.70 to .75). In validation samples, between 29% to 34% of participants correctly answered all questions (Lipkus, Samsa, & Rimer, 2001). The 11-item Numeracy scale demonstrated good internal consistency in the current study sample (.84). The mean score on the 11-item Numeracy Scale in the study sample was 8.06 (*SD* = 2.5).

Decision Regret

To measure regret pertaining to the participants' most recent treatment decision, the Decision Regret Scale (DRS) was used (Brehaut, et al., 2003). This five-item measure was developed to assess regret as a function of a health care decision. Participants were asked to reflect on their most recent treatment decision and indicate the extent to which

they agreed with the items by circling a number from 1 (strongly agree) to 5 (strongly disagree). Two of the items were negatively phrased to avoid yea-saying bias. Scoring consisted of reversing the scores of the two negatively phrased items and then taking the mean of all five items. The means are then converted to a score ranging from 0 to 100 by subtracting 1 and multiplying by 25. Higher scores indicate greater regret. In the validation samples, reported regret was fairly low, with the mean item scores falling well below the middle of the scale across validation groups. Convergent validity analyses demonstrated medium to large correlations with measures of decision satisfaction, decision conflict, and quality of life. This measure was validated on a sample of newly diagnosed breast cancer and prostate cancer patients, and reliability estimates in the validation sample ranged from .81 to .86, depending on the sample. The reliability of the DRS in this sample was consistent with the validation sample (.87). The mean score on the total DRS was 14.2 (SD = 15.5).

Decisional Conflict

To assess conflict patients experienced when making a treatment decision, participants were administered the Decisional Conflict Scale (O'Connor, 1995). The Decisional Conflict Scale (DCS) includes 16 items and was developed to elicit: 1) health-care consumers' uncertainty in making a health-related decision; 2) factors contributing to the uncertainty; and 3) health-care consumers' perceived effective decision making. The uncertainty subscale contains 3 items, the factors contributing to uncertainty subscale contains 9 items, and the effective decision making subscale contains 4 items. Respondents are asked to consider treatment decisions they have just made or are about to make and to respond using a five-point Likert scale. Responses are scored from 1

(strongly agree) to 5 (strongly disagree). Negative statements are reversed scored, with high scores indicating higher decision conflict. Possible scores on the full scale DCS range from 16 to 80. Possible scores on the subscales of the DCS are as follows: Uncertainty subscale, 3 to 15; Factors contributing to uncertainty subscale, 9 to 45; Effective decision making subscale, 4 to 20. The DCS has previously been used in oncology settings to assess decisional conflict in cancer patients, and has been reported to have a reliability estimate between .75 and .97 (Dolan & Frisina, 2002; Koedoot et al., 2001; Mancini, Santin, Chabal, & Julian-Reynier, 2006). Construct validity was tested by comparing DCS scores with decisions to accept, reject, or delay a decision to participate in cancer screening, as well as knowledge about the risks of breast cancer. Those who had delayed or were unsure about screening had higher scores on the DCS. In addition, those with higher scores on the DCS also had less knowledge of breast cancer risks, adequately demonstrating that the DCS measures the construct of decisional conflict (O'Connor, 1995). In this sample, the full scale reliability of the DCS was good (.87). The mean score on the full scale of the DCS was 31.6 (*SD* = 8.1).

Measurement: Qualitative

The analysis of the interview data involved both quantitative content analysis (Hsieh & Shannon, 2005; Rourke & Anderson, 2004) and qualitative description (Sandelowski, 2000). The interview was comprised of questions on the use of numbers during treatment consultations. The responses to the following interview prompts will be reported in this study: "Sometimes doctors use numbers to describe benefits and risks of different treatment options. Do you remember if your oncologist or your doctor used numbers in your most recent treatment consultation that involved making a treatment

decision?"; "What do you think about using numbers to talk about treatment options?";
"Would you prefer your doctor to use numbers to talk about treatment options?"; "Do
you think you are able to understand numbers used to talk about treatment options?." The
interviews were digitally recorded and transcribed.

Data Analysis

Quantitative Data Analysis

Criterion & Power Calculation

The criterion to determine statistical significance for all statistical analyses was *p*
<.05 (two-tailed). Correlations were assessed using Cohen's criteria (Cohen, 1992). A
small effect for a correlation is indicated by .10, a medium effect by .30, and a large
effect by .50. A *post hoc* power analysis based on a sample of 32 participants estimated a
power of .14 to detect a small effect, .54 to detect a medium effect, and .94 to detect a
large effect. Alternatively stated, the study has power of .80 to detect statistically
significant correlations of .45 or greater.

Hypothesis tests

Hypothesis 1: Subjective numeracy will be significantly and positively correlated
with objective numeracy. To test this hypothesis, a Pearson product moment correlation
was conducted to determine the degree of relationship between scores on the Subjective
Numeracy Scale (and its two subscales) and scores on the 11-item Numeracy Scale. A
large effect is hypothesized, based on the previous findings by Fagerlin et al. (2007).

Hypothesis 2a: Subjective and objective numeracy will be significantly and
negatively correlated with decision regret. A Pearson correlation was conducted to

determine the degree of the relationship between scores on the Subjective Numeracy Scale, 11-item Numeracy Scale, and scores on the Decision Regret Scale.

Hypothesis 2b: Subjective and objective numeracy will be significantly and negatively correlated with decisional conflict. A Pearson correlation was conducted to determine the degree of the relationship between scores on the Subjective Numeracy Scale, 11-item Numeracy Scale, and scores on the Decisional Conflict Scale.

The quantitative questionnaire data was analyzed using the Statistical Package for the Social Sciences (SPSS) version 18.0 and compared to the qualitative data.

Qualitative Data Analysis

Quantitative Content Analysis

First, interview transcripts were reviewed using quantitative content analysis (Hsieh & Shannon, 2005; Rourke & Anderson, 2004). Questions were developed based on the original interview guide and then categorized by the response. Dichotomous questions asked during the interview were captured for quantitative content analysis. A second rater coded this data to ensure adequate inter-rater reliability, and kappa coefficients for each question were calculated. Kappa values were high, indicating substantial agree between raters. These questions included: "Did your oncologist used numbers during your treatment consultation?" (Kappa = .89, $p < .001$); "Would you prefer your doctor to use numbers to talk about treatment options?" (Kappa = .82, $p < .001$); "Do you think you are able to understand numbers used to talk about treatment options?" (Kappa = 1.0, $p < .001$). Responses indicating "yes" or "no" were tallied and reported along with the qualitative data. The in-depth content explaining why these responses were chosen was described using a qualitative descriptive approach, described

in the next section. These responses were also compared to responses on the quantitative questionnaires, and any consistencies or discrepancies between the two are discussed.

Qualitative Descriptive Analysis

After tallying responses to the dichotomous interview questions, the interview transcripts were analyzed using a qualitative descriptive approach (Sandelowski, 2000). This method is particularly useful for data that provides a straightforward answer to an investigator's question. This approach utilizes a low-inference method of reporting qualitative data. Qualitative data using this method provides a summary of the facts of the data in everyday language. The focus is on providing an accurate description of the experience of the participants, rather than interpreting the data according to a particular theory, framework, or system (Sandelowski, 2000). The codes used to interpret the data are derived from the data itself, rather than the application of a series of pre-determined codes developed by the researcher (Sandelowski, 2000). Thus, this data was not interpreted in light of a particular theory or framework.

The step-by-step analysis was guided by a general analysis approach described by Creswell (2007). The analysis began with multiple readings of the relevant portions of the interview transcriptions by one rater. While reading through the trancriptions, notes were made on the most commonly occurring themes. From these notes, a preliminary codebook was developed based on the codes extracted from the data. The rater then repeated this process by re-reading the transcripts, making notes, and identifying codes a second time. This allowed the rater to compare concordant and discordant codes from the first and second analysis. The second iteration of this process was then used to refine and clarify the first codebook into the development of a final codebook (2.0).

After the development of the final codebook, the data was again re-read and coded according to the themes. After final coding, themes were collapsed into broader categories. Following the development of the codebook, the Atlas.ti version 5.2 qualitative data software program was used to organize segments of texts by the identified themes.

Chapter Three: Results

Sample Description

A total of 32 individuals provided informed consent and completed the study questionnaire. Twenty individuals completed the interview portion of the study in addition to the questionnaire. Participants were predominately female (59%), Caucasian (94%), and married (81%) and were an average age of 57 (SD = 10.2; range = 36-78). Eighty-four percent of the sample identified themselves as having a Christian religious affiliation, and more than half (58%) of the sample reported attending religious services once or more per week. Two-thirds of the sample reported an annual household income of less than $70,000. Approximately half of the sample reported working at least part-time (48%), and twenty-percent of participants reported being permanently unemployed due to sickness. Participants were an average of four years since diagnosis (SD = 3.1; range = 1 to 10) and an average of 12 months since their most recent treatment decision (SD = 17.3; range = 1 to 72). See Table 1 for a complete demographic description of the sample.

Table 1

Demographic and Clinical Variables of the Sample

Variable	*M*	SD	% of Patients	Frequency
Age	57	10.5		
Gender				
Male			40.6%	19
Female			59.4%	13
Number of Children	2.2	1.2		
Had Children			93.7%	30
Marital Status				
Married			81.2%	26
Unmarried			18.8%	6
Race				
White, Non-Hispanic			93.7%	30
Black, Non-Hispanic			3.3%	1
Not Reported			3.3%	1
Religious Affiliation				
Christian			84.3%	27
No religious affiliation			6.2%	2
Other			6.2%	2
Not Reported			3.3%	1
Annual Income				
Less than $25,000			18.8%	6
$25,000 to $39,999			18.8%	6
$40,000 to $54,999			6.3%	2
$55,000 to $69,999			21.9%	7
$70,000 to $84,999			9.4%	3
$85,000 to $100,999			12.5%	4
More than $100,000			12.5%	4
Current employment status				
Full time			37.5%	12
Part time			9.4%	3
Housewife or homemaker			9.4%	3
Temporarily unemployed			3.2%	1
Retired			15.6%	5
Permanently unemployed due to sickness			18.8%	6
Permanently unemployed, with independent means			3.2%	1
Not Reported			3.2%	1
Insurance status				
Medicare			12.5%	4
Medicaid			6.3%	2
Private			25%	8
HMO/PPO			56.2%	18

Note: Percentages may not add to 100 due to rounding.

Quantitative Data Analysis

Properties of the Subjective Numeracy Scale

To address the first study aim, an examination of the psychometric properties of

the SNS, analyses were conducted to describe scale properties including internal

consistency reliability and construct validity. Reliability analysis revealed a Cronbach's

alpha of .90 for the full scale of the SNS, demonstrating good reliability. The subscales

also demonstrated adequate reliability (aptitude subscale = .92; preference subscale =

.78).

The mean of the full scale was 34.6 (range = 13-48; *SD* = 9.9). The mean score of

the aptitude subscale was 16.9 (range = 6-24; *SD* = 5.8), and individual item means

ranged from 3.66 to 4.84 on the response option set that ranged from 1-6. These scores

indicate a trend toward confidence in self-rated numerical aptitude. The mean of the

preference subscale was 17.8 (range = 4-24; *SD* = 4.8), with individual item means

ranging from 4.06 to 4.81 (response options ranged from 1 to 6), suggesting an overall

preference for numerical information over verbally descriptive information. A Pearson

product moment correlation was conducted to determine the degree of relationship

between the full scale and the subscales of the SNS. There was a significant and positive

correlation between the full scale of the SNS and the aptitude subscale (r = .94, p < .001)

as well as the preference subscale (r = .80, p < .001). There was also a significant

correlation between the aptitude subscale and the preference subscale of the SNS (r = .55,

p = .002).

To examine the construct validity of the SNS in an oncology setting, a Pearson

product moment correlation was conducted to determine the degree of relationship

between scores on the SNS (and its two subscales) and scores on the 11-item Numeracy Scale. Scores on the full scale of the SNS were significantly and positively correlated with the 11-item Numeracy Scale ($r = .40$, $p = .03$). Scores on the aptitude subscale of the SNS and the 11-item Numeracy Scale were also positively and significantly correlated ($r = .44$, $p = .01$); however, the preference subscale of the SNS was not significantly correlated with the objective numeracy scale ($r = .28$, $p = .13$).

Numeracy, Conflict, and Regret

To address the second study aim, the relationships between subjective and objective numeracy and measures of TDM (e.g., decision regret and decisional conflict) were also explored. The mean score on the DRS was 14.2 (range = 0-50; $SD = 15.5$), suggesting that the average participant in this study reported little regret. Descriptive statistics for the DCS showed a similar trend, with a mean of 31.6 (range = 16-52, $SD = 8.1$). This indicates that few participants were reporting decisional conflict.

A Pearson product moment correlation was used to test the hypothesis that scores on the SNS and 11-item Numeracy Scale would be significantly and negatively correlated with decision regret See Table 2. Results showed no significant relationship between the full scale SNS and the DRS ($r = -.06$, $p = .78$). Analysis of the subscales of the SNS also found no significant relationship between either the SNS aptitude subscale ($r = -.04$, $p = .81$) or the SNS preference subscale ($r = -.06$, $p = .74$) and the DRS. Finally, there was no significant relationship between the 11-item Numeracy Scale and the DRS ($r = .26$, $p = .15$).

Table 2

Correlations Between SNS, 11-item Numeracy Scale, and DRS

Measure	DRS
SNS Full Scale	-0.17
SNS Aptitude	-0.04
SNS Preference	-0.29
11-item Numeracy Scale	0.26

Note: * p < .05; ** p < .01

A Pearson product moment correlation was also used to test the hypothesis that scores on the SNS and 11-item Numeracy Scale would be significantly and negatively correlated with decisional conflict. See Table 3. There was no significant relationship between the full scale SNS and the full scale of the DCS ($r = -.13$, $p = .50$). Analysis of the subscales of the SNS also found no significant relationship between either the SNS aptitude subscale ($r = -.27$, $p = .49$) or the SNS preference subscale ($r = -.06$, $p = .77$) and the full scale DCS. Finally, there was no significant relationship between the 11-item Numeracy Scale and the full scale of the DCS ($r = -.03$, $p = .87$).

The relationship of the subscales on the DCS to scores on the SNS and 11-item numeracy scale were also explored with a Pearson correlation. See Table 3. None of the subscales on the DCS were significantly correlated with scores on the full scale SNS (uncertainty: $r = -.19$, $p = .31$; factors contributing to uncertainty: $r = -.09$, $p = .60$; effective decision making: $r = -.10$, $p = .92$). Similarly, none of the subscales on the DCS were significantly correlated with scores on the SNS aptitude subscale (uncertainty: $r = -.15$, $p = .42$; factors contributing to uncertainty: $r = -.13$, $p = .49$; effective decision making: $r = -.02$, $p = .93$) or the SNS preference subscale (uncertainty: $r = -.14$, $p = .46$; factors contributing to uncertainty: $r = -.02$, $p = .93$; effective decision making: $r = -.56$, $p = .77$). Additionally, none of the subscales on the DCS were significantly correlated with scores on the 11-item Numeracy Scale (uncertainty: $r = -.04$, $p = .82$; factors contributing to uncertainty: $r = -.02$, $p = .90$; effective decision making: $r = -.01$, $p = .96$).

Table 3

Correlations Between SNS, 11-item Numeracy Scale, and DCS

Measure	DCS	DCS Uncertainty	DCS Fact. Uncertainty	DCS Eff. DM
SNS Full Scale	-0.18	-0.20	-0.14	-0.10
SNS Aptitude	-0.13	-0.15	-0.13	-0.02
SNS Preference	-0.18	-0.18	-0.13	-0.16
11-item Numeracy Scale	-0.03	-0.04	-0.02	-0.01

Note: * p < .05; ** p < .01

Qualitative Data Analysis

     Numerical Experiences and Preferences

With regard to the third study aim, both questionnaire and interview data explored patient perceptions of their numerical aptitude and preference for receiving numbers in a treatment consultation. For ease of understanding, the results for the third aim will described according to the categories of themes identified in the interview data: Aptitude, Preferences, and Potential Barriers. Frequencies and percentages of the identified themes can be found in Table 3. When applicable, each category will be described by first presenting the results of the quantitative content analysis followed by the relevant themes and representative quotes. Consistencies and discrepancies between the interview data and the questionnaire data will be outlined in the discussion section.

     Numerical Aptitude

Results from the quantitative content analysis showed that the majority of participants interviewed (60%) indicated that numbers were used during their treatment consultation. In addition, interview data revealed that 75% of respondents reported that they understood numbers when used to describe treatment information, while 10% reported that they were not confident in their ability to understand numbers used during treatment consultations. See Table 4.

Table 4

Quantitative Content Analysis (N = 20)

	Frequency	%
Did your oncologist use numbers during your treatment consultation?		
Yes	60	12
No	40	8
Unsure	0	0
Unclear response	0	0
Would you prefer your doctor to use numbers to talk about treatment options?		
Yes	65	13
No	25	5
Unsure	5	1
Unclear response	5	1
Do you think you are able to understand numbers used to talk about treatment options?		
Yes	75	15
No	10	2
Unsure	0	0
Unclear response	15	3

There were a number of themes identified in the interview data when following the quantiative content analysis with a qualitative descriptive approach, listed in Table 5.The Aptitude category was represented by the theme Misunderstanding of Numerical Principles. This theme was defined as a statement demonstrating a misunderstanding of statistical or numerical principles; exemplified by the following comment made by a participant in response to the question: "So what do you think about using numbers like that to discuss treatment options?"

> *"I think it's good… if somebody tells you, well you're going to live 5 years or say 1 in 5 people survive 5 years after they were diagnosed with this type of cancer. You know that's giving you a life expectation of 5 more years."*

This statement indicated that the participant assumes that they are included in the "1 in 5" statistic, which seems to impact the individual's understanding of their own prognosis and disease course. Another participant's statement clearly represents the confusion that can occur when providing statistics in a clinical setting:

> *"…Cuz it seems to me like there was an 80% mentioned, but I'm like well what does that mean? 80% I'll die?... Cuz I mean I knew enough to know that if I was hearin that if it was 20% chance I'll live…or is it 80% that I'll die?"*

A misunderstanding of basic statistical probabilities regarding risks and benefits of treatment likely significantly influences how an individual makes decisions about their treatment. The statements made by multiple participants in the interview indicated that these misunderstandings might be relatively common.

Table 5

Identified Themes in Patient's Experiences of Numerical Treament Information (N = 20)

Theme	% mentioned	Frequency of theme	# of times mentioned
Aptitude			
Misunderstanding of Numerical Principles	10	2	3
A statement demonstrating a misunderstanding of numerical or statistical principles.			
Preferences			
Need for Numbers	45	9	13
A belief that percentages and odds about treatment reduce ambiguity and are necessary in order to make a treatment decision.			
Distrust of Statistics/Provider	15	3	5
An opinion that statistics can be manipulated to persuade, resulting in distrust of numerical treatment information.			
Numerical Anxiety	10	2	2
A statement by a participant indicating that they prefer not to receive numerical treatment information due to a tendency to dwell/worry about the numbers.			
Trust in Physician	10	2	4
Statement demonstrating trust that physicians will provide necessary information.			
Tailored Treatment Information	25	5	7
Indication that treatment information must be relatable and should be adjusted to patient preferences, education, or level of understanding.			
Potential Barriers			
Passive Avoidance of Numbers	20	4	7
A statement indicating that a participant ignored or did not pay attention to numerical treatment information.			
Religious Faith	10	2	4
A belief that God ultimately decides whether a person will be cured of cancer, making it unnecessary to receive numbers/ statistics about treatment information.			

Numerical Preference

When interviewed, 65% of participants indicated that they preferred the use of numbers in a treatment consultation, while 25% reported that they did not want numbers used to discuss their treatment options or decision. Of those that reported they preferred the use of numbers in a treatment consultation, 66% reported that their oncologist did use numbers to discuss treatment options.

Several themes identified in the qualitative interview data provide further insight into patient preferences for receiving numerical treatment information. The Preference category was represented by the following themes: Need for Numbers, Distrust of Statistics/Provider, Numerical Anxiety, Trust in Physician, and Tailored Treatment Information. See Table 3 for frequencies and percentages.

The preferences of those that wished to receive numerical treatment information were represented by the theme Need for Numbers. This was defined as a belief that percentages and odds about treatment reduce ambiguity and are necessary in order to make a treatment decision. Some participants stated that numbers were helpful in gaining an idea of what to expect. When asked if the use of numbers in the treatment consultation was helpful, one participant responded:

> *"It was very helpful for me. It helped me sure because it gives you more of an idea what lays ahead."*

Others discussed the necessity of numbers for weighing treatment options.

> *"I think it's a good thing. Basically it's, otherwise you probably could go into it just very blindly going, okay this is just going to fix everything. So I prefer the numbers to know that you know you if have a 50/50 which is better than you know 40/60 or whatever. You know and so yeah, I prefer the numbers to you know just*

blindly going along and going, okay you know we'll just see where it takes us you know."

"I think that's a good way, I think that's a good way to talk about it because you know to me you need to know what we're talking about; out of 100 people, how many people really survive the surgery, how many people really survived before they got to the treatment. So I think that's a good way of, for me to describe in numbers."

Participants with a preference for numbers also indicated that numbers can help reduce ambiguity.

"I mean to me it's much clearer to say you know you have a 80% survival chance as opposed to saying you know you have a very good survival chance because you know to me that might be 51%."

"…I don't think words can do it justice. There's a big difference between saying, there's a good chance of something happening and saying, there's only a 1% chance; but I'm comfortable with numbers. So I just, to me if you said, there's a good chance of this happening, it means nothing to me. If you say, there's a 1% chance or 1/2 % chance or a 5, then it means something to me."

The views of participants who stated that they did not wish to receive numerical treatment information were represented by two themes: Distrust of Statistics/Provider, and Numerical Anxiety. Distrust of Statistics/Provider was defined as an opinion that statistics can be manipulated in order to persuade, therefore, numerical treatment information provided by the physician cannot be fully trusted. A number of participants cited distrust of how numerical information can be manipulated as a reason to not receive numerical treatment information.

"Yeah, but that's just me because again, statistical information, it all depends on how you look at it you know…I don't think he was trying to you know like be dishonest with me or whatever but you can use statistics any old way you want to I mean you know…Well it's the source I question, the numbers I don't."

These individuals expressed a preference to receive qualitative treatment information based on a distrust of how numerical information could be manipulated in order to persuade them to accept a particular treatment.

This preference for receiving qualitative descriptions over numerical treatment information was also explained by anxiety over numbers. Several participants described feeling anxious when given treatment information in numerical terms. This was represented by the theme Numerical Anxiety, which was defined as a preference not to receive numerical treatment information due to a tendency to dwell or worry about the numbers. When asked if they would prefer receiving treatment information numerically, one participant responded:

> *"No, I would not, I would not prefer that because you'd always have those numbers in your mind and you would always dwell on that 10% or 20% that it could reoccur and I don't think it's good personally I don't, no."*

The previous themes represented specific preferences for receiving numerical treatment information. The remaining themes reflected an overall acknowledgment of the importance of adequate patient-physician communication and the need to communicate preferences for receiving treatment information to their physician. This acknowledgement was represented by two themes, Trust in Physician and Tailored Treatment Information. The theme Trust in Physician was represented by a statement that the physician was trusted to provide the necessary treatment information. As one participant explained,

> *"I would prefer to know, and I think that's something that involves once again trust because I could just let my doctor know you know, this is something that I would like to know. You see I think this is a back and forth between the doctor and a patient you know. Don't keep any secrets from me or there are things that I would rather not know you know. I think that should be a personal individual decision."*

Other participants recognized the need for physicians to tailor the information according to the patient's preferences and level of understanding, as reflected by the theme Tailored Treatment Information.

> *"This is going to sound elitist but I think a balanced use of percentages or numbers can be helpful but if you're dealing with a, if you're dealing with a person who is, whose economic or, and/or education background is significantly limited. Then I, then I think you may use those but don't assume that it's going to say much...*

> *Because there would certainly be plenty of people economically and academically challenged who have a whole lot of saviness and common sense but I think, yeah I think some of it really depends and I don't know how a doctor makes this decision. I think some of it depends on the doctor's initial assessment of the patient's world view."*

These last two themes in the Preferences category represent a more comprehensive view of the treatment communication process that goes beyond whether or not patients prefer receiving a particular type of information and highlights the importance of communication between patients and providers.

Potential Barriers to Patient Engagement

Two themes were identified in the interview data that were distinct from numerical aptitude and preference and were not represented in the quantitative data. These concepts may act as additional barriers in obtaining informed consent. These themes, Passive Avoidance of Numbers and Religious Faith, appear to represent intrinsic patient characteristics or beliefs that may limit patient engagement in the TDM process.

Passive Avoidance of Numbers was defined as a statement that the patient ignored or did not pay attention to numerical treatment information provided to them.

> *"...I guess that didn't matter at the time or it didn't, I don't know, it's just like...I don't, I remember something about the numbers but I don't remember a whole lot about it; it's just like it went over my head or wasn't that important. Have you ever done that where you, somebody says? I don't know if you've been in a*

situation like that but it's like you're, you just want to hear a certain part of what he's saying but you don't, you don't really care about the odds of it all."

When asked if they preferred to receive odds or percentages regarding their treatment, these patients also indicated that they did not want to be given this information:

"No, I don't think, I don't like to think about something happening."

"…he's used numbers to say a certain percentage of people do this treatment and your odds are 50/50 or 60/40 or you know; I don't pay attention to numbers, I really don't."

The final theme identified from the interview data was Religious Faith. This theme was defined as a belief that God ultimately decides whether a person will be cured of cancer, making it unnecessary to receive numbers/statistics about treatment information. This belief was endorsed by several participants that completed the interview.

"No, numbers don't mean a great deal to me. It's just, you know if it works, if it works; if it doesn't, it doesn't. There's, well how can I explain this? To me, there's no downside to this. There's an inconvenience factor…Either one or two things are going to happen; either the doctors are going to come up with a cure for it and I'll praise God for that because it'll be a testament to God's greatness or they're not going to come up with a cure for it and one of these days I'm going to go home.

And when I first got diagnosed, I came home and I went to my prayer spot and I started praying. And pretty soon I wasn't praying; I was just mad, and I was yelling at God, well just blamed Him for everything that ever went wrong with my life. And you take this for what it's worth but I heard a voice and called me by name and it said, you know, I can help you but you have to give it to me, you can't do it by yourself. And I got back down on my knees and I gave it to God that very day and I've been at peace with it ever since. So yeah, numbers, yeah they don't mean that much to me."

Exploratory Analysis

A number of exploratory analyses were conducted to examine questions that resulted from the initial investigation of the primary aims. These analyses are reported in the following section.

11-Item Numeracy Scale

The mean score on the 11-item Numeracy Scale was 8.06 (range = 0-11; SD = 2.5). Only 12.5% of participants correctly answered all items on this scale, a significant difference between this sample and the samples used to validate this instrument. In the validation study, (Lipkus, Samsa, & Rimer, 2001) 29 to 34% of the samples answered every item correctly. To determine which items were particularly difficult for participants, frequencies of correct and incorrect responses were calculated. Participants seemed to struggle most with questions regarding the calculation of a percentage chance that an arbitrary event would occur. For example, only 28% of the sample correctly answered a question that required a percentage calculation based on a 1 in 1,000 chance. Encouragingly, however, our sample performed best on questions that were specific to a medical context. Nearly all (94%) participants correctly identified the biggest risk of a disease in a 1 in *n* format, and a percentage format (97%). Most participants (88%) also correctly calculated person B's percent risk of a disease if it was doubled that of person A's, and 91% also successfully calculated the number of people that would get a disease based on a percentage.

Table 6

Percentage of correct responses on the 11-item Numeracy Scale (N = 32)

Question	%	Frequency
In the Big Bucks Lottery, the chance of winning a $10.00 prize is 1%. What is your best guess about how many people would win a $10.00 prize if 11,000 people each buy a single ticket to BIG BUCKS? *Answer: 10 persons out of 1,000*	62.5	20
In the Acme Publishing Sweepstakes, the chance of winning a car is 1 in 1,000. What percent of tickets to Acme Publishing Sweepstakes win a car? *Answer: 0.1%*	28.1	9
Which of the following numbers represents the biggest risk of getting a disease? (1 in 100, 1 in 1,000, 1 in 10?) *Answer: 1 in 10*	93.8	30
Which of the following numbers present the biggest risk of getting a disease? (1%, 10%, 5%?) *Answer: 10%*	96.9	31
If Person A's chance of getting a disease is 1% in ten years, and person B's risk is double that of A's, what is B's risk? *Answer: 2%*	87.5	28
If Person A's chance of getting a disease is 1 in 100 in ten years, and person B's risk is double that of A's, what is B's risk? *Answer: 2 of 100*	59.4	19
If the chance of getting a disease is 10%, how many people would be expected to get the disease out of 100? *Answer: 10*	90.6	29
If the chance of getting a disease is 10%, how many people would be expected to get the disease out of 1000? *Answer: 100*	90.6	29
Imagine that we rolled a fair, six-sided die 1,000 times. Out of 1,000 rolls, how many times do you think the die would come up even? (2, 4, or 6)? *Answer: 500 out of 1,000*	46.9	15
If the chance of getting a disease is 20 out 1,000, this would be the same as having a ___% chance of getting the disease. *Answer: 20*	78.1	25

The chance of getting a viral infection is .0005. Out of 10,000 people about how many of them are expected to get infected?   71.9   23

Answer: 5 people

_____

Chapter Four: Discussion

Recent literature examining health numeracy and literacy has highlighted the difficulty that many patients have with understanding complex numerical treatment information (Garcia-Retamero & Galesic, 2010; Nelson et al., 2008; Peters, Hibbard, Slovic, & Dieckmann, 2007; Reyna & Brainerd, 2007; Reyna, Nelson, Han, & Dieckmann, 2009). Simply providing information to patients does not necessarily translate to comprehension and ability to use the information provided (Peters, Hibbard, Slovic, & Dieckmann, 2007). In order for patients to make informed decisions about their oncological care, it is necessary to identify aspects of the TDM process that can be simplified and improved. This is of particular concern in populations of cancer patients that typically make multiple treatment decisions over the course of their disease (e.g., follicular lymphoma).

The purpose of this study was to explore numeracy and patient experience with numbers in a sample of follicular lymphoma patients using a mixed methods approach. The first aim of this study was to examine the psychometric properties of the Subjective Numeracy Scale and explore the construct validity of subjective numeracy in an oncology setting. The second aim of this study was to examine the relationship between subjective and objective numeracy and measures of TDM. Finally, the third aim of this study utilized qualitative interview data to provide additional information about numeracy by exploring and describing 1) patient reports of the use of numbers in the clinical consultation and perceived ability to work with numbers and 2) patient perception of and preference for the use of numbers in TDM.

Summary and Interpretation of Findings

   Properties of the Subjective Numeracy Scale

   The SNS was developed to use as a proxy for patient's objective level of numerical ability (Fagerlin et al., 2007) but prior to this study had not been validated on a sample of cancer patients. Reliability analyses demonstrated that the SNS has adequate internal consistency reliability in this sample. In addition, reliability analyses of the subscales suggested that the items on the aptitude subscale may be reduced without compromising reliability in order to reduce patient burden. The results of a Pearson product moment correlation in this sample indicated a medium to large correlation between patient scores on the full SNS and scores on the 11-item Numeracy Scale (Lipkus, Samsa, & Rimer, 2001). Analyses indicated a similar relationship between the aptitude subscale of the SNS and the 11-item Numeracy Scale. However, there was no statistically significant relationship between the preference subscale of the SNS and the 11-item Numeracy Scale.

   The magnitude of the correlation between subjective and objective numeracy in this sample is lower than the large effect found in the original validation sample of the SNS (Fagerlin et al., 2007). In addition, no significant correlation was found between the preference subscale of the SNS and the 11-item numeracy scale. The SNS was designed with two subscales that represent two distinct constructs, aptitude and preference. The results from this sample indicated that the preference subscale had no utility as an indicator of objective numerical ability. The authors of the SNS suggest that this measure replace traditional measures of objective numeracy (Fagerlin et al., 2007). Based on the examination of the psychometric properties of this scale in this study, it may be

premature to conclude that the full scale of the SNS should be used as a replacement for objective numeracy measures.

Further analyses of the SNS in conjunction with the interview data and the 11-item Numeracy Scale raised additional concerns about the use of self-rated numerical ability as a replacement for the measurement of objective numerical ability. Almost all participants interviewed reported that they were able to understand the numerical information used by their oncologist during a treatment consultation. In addition, the scores on the aptitude subscale of the SNS indicated that nearly half of participants feel they are good or extremely good at calculating simple mathematical problems such as percentages and fractions. However, when compared to the scores on the 11-item Numeracy Scale, very few participants correctly answered all the questions and almost one-quarter of the sample correctly answered six or fewer questions. Additionally, these measures were completed by mail. Although participants were not provided instructions on the use of a calculator, it may be assumed that several participants used a calculator to aid in responding, therefore these results may be an overestimate of numerical ability in this sample. Finally, the numerical information provided in an actual treatment consultation is likely more complex than that represented in the 11-item Numeracy Scale (Peters, Hibbard, Slovic, & Dieckmann, 2007). The results from this study may then be considered a "best case scenario" for patient understanding of basic numerical operations. This discrepancy between patient's perception of their numerical ability and their actual understanding of numerical information in a treatment consultation has significant implications for the utility of subjective numeracy ratings in clinical practice.

Results from this study suggest that further research is needed before the measurement of subjective numeracy is used as a proxy for objective numeracy in a cancer population. A recent study by Galesic and Garcia-Retamero (2010) found that the SNS successfully differentiated between participants who scored very low and very high on an objective numeracy measure. It was not possible to do a similar comparison in this study, for two reasons: Most participants in the current study rated themselves highly on the SNS, leaving little variation in scores; and few participants scored very high on the 11-item Numeracy measure. As this is the first study examining this relationship in a cancer population, conclusions on the use of the SNS in clinical practice cannot yet be drawn. There are a number of concerns about using a subjective numeracy measure in place of an objective numeracy measure in this population prematurely. The reduced capacity for adequate decision making (Consedine & Moskowitz, 2009; Diefenbach et al., 2008; Fischoff, 1999; Rini et al., 2009) and the potentially life threatening consequences of an uninformed treatment choice in the oncological setting likely outweigh the time saving benefit of omitting measures of objective numeracy in the TDM process. Patients with lower numeracy have more difficulty using numerical information to make a decision than those with higher numeracy (Peters, Hibbard, Slovic, & Dieckmann, 2007; Schwartz, Woloshin, Black, & Welch, 1997). Accurately assessing numeracy is a first step in providing interventions to patients who will have more difficulty understanding numerical treatment information. The results from this study indicated that patients in this sample significantly overestimate their actual numerical ability, suggesting that caution is needed when relying solely on a subjective numeracy

measure to assess a patient's ability to understand the risks and benefits of various treatment options.

Numeracy, Conflict, and Regret

The second aim of this study was to investigate the relationship between subjective and objective numeracy and measures of decision conflict and regret. There have been no previous studies that have examined the potential consequences of low numeracy on the TDM experience. There were no significant relationships between subjective and objective numeracy and patient reported conflict and regret. Few patients in this sample reported high levels of conflict and regret regarding their most recent treatment decision, limiting the ability to detect significant relationships between the constructs. Additionally, in this sample, patients had a tendency to overestimate their own numerical ability. It is possible that patients' perceptions of their understanding of the treatment information they are given is more significant for decision conflict and regret than objective understanding. For example, if patients expressed confidence in their ability to understand numerical treatment information, it is unlikely that they would report high levels of conflict or regret about their treatment decision due to confusion or misunderstanding of the information they were given. Patients that did report conflict and regret may have done so for reasons unrelated to their subjective or objective understanding of numerical treatment information.

Numerical Experiences and Preferences

The final aim of this study was to further explore patients' experiences with numbers in a treatment consultion, perceived numerical aptitude, and preferences for numbers during the TDM process using qualitative interviews. Overall, the interview data

supported the results found in the quantitative data and provided further insight into the role that patient preferences and beliefs may play in the treatment consultation. The qualitative data provided a more comprehensive view of patient experiences during the treatment consultation. This data supported concerns regarding patient understanding of numerical treatment information and also provided important information about the varied needs and preferences of patients when receiving treatment information. Finally, this data also identified potential barriers for TDM engagement and informed consent that may be separate from the ability for patients to comprehend the information provided to them.

Almost all patients reported that numbers were used during their treatment consultation. No recent studies were found regarding the prevalence of numerical information given in oncological treatment consultations. However, a 1998 study investigating the use of quantitative estimates of prognosis in adjuvant breast cancer treatment (Ravdin, Siminoff, & Harvey, 1998) found that only 39% of women reported the use of these estimates. There are a number of reasons why these reports of number use may vary, such as the increase in patient participation in TDM since 1998. Despite the lack of prevalence research in number use in oncology treatment consultations, these data suggest that a substantial number of cancer patients are receiving treatment information in a quantitative format. Communicating information about treatment often necessitates the use of numbers, such as the percentage of patients who survive for five years, the magnitude of effectiveness of different treatments, and probability that the patient will experience side effects (Lipkus & Peters, 2009; Peters, Hibbard, Slovic, & Dieckmann, 2007; Reyna, Nelson, Han, & Dieckmann, 2009; Smith, 2003). The high

proportion of patients in this study who encountered the use of numbers when describing treatments highlights the need for further investigation on the use of numbers in treatment consultations and its impact on how patients make decisions.

Similar to the results found on the aptitude subscale of the SNS, most patients reported that they were confident in their ability to understand numbers used when discussing treatment information. However, this perceived numerical aptitude was inconsistent with actual numerical performance as measured by the 11-item Numeracy Scale. Very few participants answered all questions on this scale correctly, and a substantial portion answered less than six questions correctly. These results are consistent with a recent study using an adapted version of the Lipkus, Samsa, and Rimer (2001) scale. A study by Galesic & Garcia-Retamero, 2010 found that a sample of German and United States citizens correctly answered two-thirds of the items on a 9-item version of this scale. As in this study, these questions required patients to perform basic mathematical opeations, such as calculating a percentage. As noted above, actual treatment information is often much more complex than that represented in objective numeracy measures. For example, in situations where it is uncertain what the best treatment is, patients may be requried to calculate differences between therapies and make inferences about the best choice based on that information (Peters, Hibbard, Slovic, & Dieckmann, 2007). The interview data also contained examples of misunderstandings of basic numerical principles when patients described the information given to them by their physician, such as the meaning of a "1 in n" statistic. This overstimation of numerical ability may have negative consequences for patients. Patients may assume they understand the information provided, and therefore not ask questions clarifying

comparisons between treatments. Physicians may also perceive that these patients comprehend the information and not ask follow-up questions that check for understanding. Ultimately, this confidence in numeracy may result in patients making treatment decision based on inaccurate or incomplete understanding of the risks and benefits involved.

Most interviewed participants reported that they had a preference for receiving numbers to describe treatment information. This was consistent with an overall trend toward a preference for numerical information on the preference subscale of the SNS. Other studies using cancer populations have found that a significant proportion of patients prefer the use of numbers to describe treatment information over the use of qualitative descriptors (Lobb et al., 1999; Mazur, Hickam, & Mazur, 1999). This is consistent with the findings of the current study. One item on the SNS preference subscale asked if participants had a preference for describing a chance of something happening in words or numbers. On this item, the mean response was 4.4 out of 6, with a response of 6 indicating a strong preference for the use of numbers. In addition, thirty-five percent of participants indicated that they would "always" prefer a chance description in numbers, while only 16% reported that they would "always" prefer this description in words.

The participants in this study that elaborated on their preference for the use of numbers described them as necessary for understanding treatment risks and benefits and reducing ambiguity. Other studies examining patient preferences in a cancer setting have not specifically queried patients about why they preferred the use of numbers. However, studies of individuals in the general population provide evidence that numbers are more

precise and accurate than qualitative descriptors or graphs (Gurmankin, Baron, &

Armstrong, 2004; Lipkus, 2007; Nakao & Axelrod, 1983; Sutherland, 1991), and some

studies have suggested that individuals trust quantitative information more (Wallsten,

Budescu, Zwick, & Kemp, 1993).

Alternatively, the smaller group of participants that did not wish to receive

treatment information in a numerical form reported two reasons for this preference. The

most commonly mentioned concern about numerical information included the possibility

of numbers and statistics being manipulated in order to persuade. Participants described

distrust of numerical treatment information based on the idea that it could be presented in

a way that led the patient to a particular treament choice (presumably, the physician's

preference for treatment). There is evidence that physicians may use information to

persuade toward their own preferred treatment choice (Lelie, 2000). Of particular concern

in the oncology setting, a study of radiation oncologists and urologists suggests that

physicians have a bias toward their specialty and may make recommendations or the

treatment they deliver despite lack of support from randomized clinical trials (Fowler,

Collins, Albertson, Zietman, Elliott, & Barry, 2000). However, individuals lower in

numeracy tend to view numerical information given by their physicians as less

trustworthy (Gurmankin, Baron, & Armstrong, 2004), making this concern an important

one to directly address when presenting treatment information to patients.

Patients also cited numerical anxiety as a reason they did not prefer the use of

numbers in treatment consultations. Patients described the use of numbers resulting in

enhanced rumination about particular percentages, such as the risk for recurrence. This

anxiety about numerical treatment information may be a result of difficulty understanding

the meaning of the numbers given, as less numerate people are more likely to be influenced by other sources of information, such as emotions, mood, and distrust of physicians (Peters, Hibbard, Slovic, & Dieckmann, 2007; Smith, 2003). There are a number of reasons why patients may not wish to receive numerical treatment information, which may reflect valid concerns about the quality and clarity of the information they are given. However, these reasons may also be masking low numeracy and discomfort for numbers, which further supports an argument for the assessment of numeracy prior to treatment consultations.

The remainder of the data regarding preferences was not specific to the use of numbers and generally reflected the need for adequate communication between patients and providers. Some patients mentioned trust that their physician would give them the information they needed to make a good decision, reflecting a more paternalistic view of TDM. This theme may encompass those patients who wish to have a less active role in the TDM process. Finally, a quarter of participants described the importance of treatment information being tailored to each patient based on ability level. This was the second most commonly occurring theme in the data, suggesting that patients wish the treatment consultation process to be individually fitted to them. This idea is consistent with research evidence that tailored messages are more likely to be read and remembered, may enhance personal relevance, and promote effortful processing (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008; Kreuter & Wray, 2003; Petty & Cacioppo, 1981).

Lastly, the interview data provided important information that may cause difficulties for shared decision making and obtaining informed consent. Several patients mentioned an avoidance of numbers by ignoring or "not paying attention" to the

numerical information given to them. These patients appeared to be describing a tendency to avoid numbers in order to keep from thinking about their disease or their odds of recovery. It is possible that similar to numerical anxiety, avoiding discussion of numbers in the treatment consultation may be indicative of low numeracy and difficulty comprehending numerical treatment information. However, this may simply be an indication that a more passive role in the decision making process is desired. Finally, two patients mentioned that their belief in God made receiving numerical treatment information unnecessary. They described a feeling that God will decide if they will live or die, therefore, it was not necessary for them to attend to the treatment information given to them. A study examining the attitudes of lung cancer patients and their physicians found that highly religious individuals rate their faith as very important in the TDM process, even more highly than whether the treatment would cure their disease (Silvestri, Knittig, Zoller, & Nietert, 2003). Research suggests that religious beliefs may have positive benefits for cancer patients, such as improved coping and well-being, although the methodological rigor of studies measuring this construct has been questioned (Howsepien & Merluzzi, 2009; Visser, Garssen, & Vingerhoets, 2009). However, there may be negative outcomes as well, including the idea of fatalism, or that one's fate is controlled by God, which has been linked to lower rates of screening and treatment (Powe & Finnie, 2003). This particular theme seems to be a reflection of this concept, and therefore raises some concerns regarding the impact of this belief on shared decision making and obtaining informed consent for treatment.

The interview data collected in this study provides a more in-depth understanding of how patients experience the TDM process regarding quantitative information.

Although patients may report confidence in their ability to understand the numerical treatment information given to them, this may not be reflected in their accuracy of understanding. Additionally, most patients appear to find numerical treatment information important, but many may lack the skills needed to condense this information and apply it to their own needs and preferences. While the majority of patients in this study preferred to receive numerical treatment information, there is also a significant proportion that did not. Reasons for this preference varied, but may be an indicator of low numeracy or a desire for a more passive role in the TDM process.

Limitations

Limitations of this study should be noted. First, the study sample was relatively small, potentially limiting the statistical power to detect statistically significant effects. It is also not possible to draw firm conclusions from a sample of this size. In addition, this study was homogenous. All but one participant was Caucasian, most participants resided in rural areas of Kentucky, and most participants identified as having a Christian religious affiliation. This limits the ability for these study results to be broadly applied to the general population. In addition, the educational level of the participants was not assessed. As a result, it was not possible to examine the relationship between educational level and numerical ability. Finally, participants were asked to discuss their most recent treatment decision. The length of time from this decision to study enrollment varied widely between participants. This may have impacted the accuracy with which patients were able to report on their experience.

Clinical Relevance

The sample size of the current study was small, limiting the ability to make strong recommendations based exclusively on these results. Despite the small sample of this study, results are consistent with recent literature reviews on numeracy and TDM, supporting the following conclusions and recommendations.

This study supports previous research identifying the difficulty that the general population has with understanding basic numerical calculations, (Fagerlin et al., 2007; Galesic & Garcia-Retamero, 2010; Lipkus, 2007; Reyna, Nelson, Han, & Dieckmann, 2009; Peters, Hibbard, Slovic, & Dieckmann, 2007; Weinfurt et al., 2005) and provides strong evidence of the tendency to overestimate numerical ability. Other researchers have pointed out that physicians tend to overestimate how much patients understand (Gattellari, Butow, Tattersall, Dunn, & MacLeod, 1999) and may not check for understanding (Epstein & Street, 2007; Lobb, Butow, Kenny, & Tattersall, 1999). Based on this tendency to overestimate ability by both patients and physicians, further research is needed on the exclusive use of subjective numeracy measures in research and clinical practice. Currently, use of objective numeracy measures may be the most accurate and direct way to identify low numerate patients.

This study also provides evidence that the TDM process is more complex than the ability to understand treatment information. Patient preferences and beliefs also provide important insight into the willingness and ability that patients have to attend to information provided to them in a treatment consultation. Most patients preferred the use of numerical information in treatment consultations, but the discrepancy between patient's subjective and objective numerical ability highlights the need for information to

be adapted to a level that they can understand. A significant number of patients interviewed in this study also expressed the desire for information to be tailored to each patient. Not only is this consistent with evidence that tailoring information leads to improved attention and processing, (Hawkins, Kreuter, Resnicow, Fishbein, & Dijkstra, 2008; Kreuter & Wray, 2003; Petty & Cacioppo, 1981) but in this study it also seems to be consistent with patient preferences. A number of excellent reviews have condensed research findings on easing this process for patients and can be referenced for concrete suggestions for clinical practice (Lipkus, 2007; Lipkus & Peters, 2009; Nelson et al., 2008; Peters, Hibbard, Slovic, & Dieckmann, 2007).

Finally, the qualitative data from this study provides unique insight into the reasons behind patient preferences for the type of treatment information they receive. There were varied perceptions of the need for treatment information in this study, indicating that it may be helpful to assess these preferences in practice to improve patient engagement. A number of these preferences, such as numerical anxiety and avoidance of numbers, may be associated with low numeracy. Assessing patient preferences may be an additional way for physicians to identify patients that are uncomfortable with the use of numbers or their role in the TDM process. This conclusion is supported by a recent study on individuals from the general population in the United States and Germany (Galesic & Garcia-Retamero, 2011). This study found that about one-third of low numerate patients preferred to take a more passive role in the TDM process than they typically do, while high numerate patients were more satisfied with their role.

Patients may disregard numerical treatment information because of confusion, lack of understanding, or they may wish to take a more passive role in the TDM process.

These distinctions must be made in order to ensure that patients are participating in the process at the level they desire and are provided information at a level consistent with their desired role. Additionally, patients may hold some beliefs, such as religious faith, that may limit their desire to engage in the TDM process. However, regardless of the level of participation patients wish to have in this process, it is still necessary to provide information to patients in a way that ensures that physicians are obtaining informed consent for treatment (Sheridan, Harris, & Woolf, 2004). Therefore, the results from this study, in conjuction with previous research findings, suggest that a thorough assessment that includes patient's preferred role for decision making, objective numeracy, and preferences for information format may aid in obtaining informed consent and encouraging shared decision making (Alper, & Quill, 2004; Eggly et al., 2009; Sheridan, Harris, & Woolf, 2004).

Future Research and Conclusions

This study provides insight into the measurement of patient numerical ability and patient preferences during the TDM process. One important area for future research includes further study of the measurement of subjective numeracy in practice. Overestimation of numerical ability in this study and others highlights the need to determine the quickest and most accurate way to identify patients who may have more difficulty understanding numerical treatment information.

In addition, this study also points out the potential benefit of continuing to assess patient's desired role in the TDM process, as well as patient preferences for the type of treatment information they receive. Future research should continue to investigate the implications of incorporating patient preferences into the TDM process. It is yet unknown

the potential ramifications of discrepancies between patient preferences for information format and the type of information they receive. This study also uncovered potential barriers toward engagement in shared decision making that are associated with but may be distinct from numerical ability. These barriers may be more difficult to identify during the TDM process and require further elucidation. It will be helpful for future studies to examine how personal beliefs, such as religious beliefs, may impact the level of engagement a patient has in a shared decision making model.

The results from this study provide further insight into how patients experience the TDM process. It is hoped that the information gathered from this study will lead to further refinement of communicating treatment information in a clear and understandable way. As shared decision making becomes the norm, it is essential to continue to balance the ethical duty of obtaining informed consent with patient abilities, preferences, and beliefs.

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PUBLICATIONS

Poe, J.K., Hayslip, J.W., & Studts, J.L. (in press). Decision making and distress among individuals diagnosed with follicular lymphoma. *Journal of Psychosocial Oncology.*

MANUSCRIPTS IN PREPARATION

Poe, J.K. A review of numerical and qualitative treatment communication in oncology. Manuscript in preparation.

NATIONAL CONFERENCE PRESENTATIONS

Poe, J.K., Hayslip, J.W., & Studts, J.L. (2012). Assessing Numeracy in Oncology: The Role of Patient Perception and Preferences. Paper presented at the Comparative Effectiveness Research Symposium: Shared Decision Making: Opportunities to Implement Comparative Effectiveness Research in Clinical Practice, St. Louis, Missouri.

Poe, J.K. (2010). Treatment decision making in follicular lymphoma: Patient preferences regarding involvement of physicians and significant others. Poster session presented at the Society of Behavioral Medicine's 31st annual meeting, Seattle, Washington. Paper presented at the Kentucky Psychological Association Academic Conference, Louisville, KY.

Steffens, R.F., **Poe, J.K.**, & Studts, J.L. (2010). Patient decision making regarding lung cancer screening cancer screening (LCS). Poster presented at the Society of Behavioral Medicine's 21st annual meeting, Seattle, Washington.

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