

ELEMENTS OF ONCOLOGY PATIENT-PROVIDER COMMUNICATION:
INCREASING PATIENT WELL-BEING IN THE
DELIVERY OF DISTRESSING NEWS.

by

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ABSTRACT

The elements of trust and communication in the patient-provider relationship have an influential role on the patient's perceived satisfaction, healing, and overall experience. The current study aimed to identify, from the patients' perspective, tactics physicians can use to increase patient well-being in the delivery of distressing news, especially among oncology patients. It was hypothesized that (a) people, regardless of demographic characteristics, would want more time with their physicians when being diagnosed with cancer; (b) an increase in information received would be desired from younger, more educated patients (as compared to older & less educated persons); and (c) empathetic statements would be preferred by all types of patients over encouraging statements from their physicians. Participants consisted of 50 oncology patients who were administered a questionnaire and oral interview. The results found that 86.1% of participants wanted 15-30 min for the initial discussion of distressing news, and 79% of patients indicated a desire for moderate involvement in their treatment process. Education had no correlation; however, there was a negative relationship between age and involvement, with older adults expressing a reduced desire for health information. Encouraging statements were preferred by all types of patients and overall, with higher education, less words were used by patients to describe their illnesses. The results of this study are useful for physicians to better disclose a cancer diagnosis to their patients and help to improve well-being.

INTRODUCTION

“He comes walking in at 8 o’clock at night, and I just kind of knew. My heart went, ‘O God why is he here?’ ... They didn’t have the right diagnosis. They asked if I wanted to see a priest. They asked if I wanted to be resuscitated if something happened at night and left. So I was in my room all night staring at the ceiling going, ‘oh my God what am I going to do?’ Am I going to have to sell the house? Move? Put the dog to sleep?”

These comments were taken from a female cancer survivor who participated in the current study. As they illustrate, oncology patients often experience anxiety as a result of the communication style between a patient and doctor during the initial diagnosis (Derogatis et al., 2001). In addition, it has been reported that 47% of patients with cancer experience periods of anxiety, fear, and lowered psychological well-being (Derogatis et al., 2001). The current study aims to identify, from the patients’ perspective, tactics physicians can use to alleviate fear in the delivery of distressing news. It was hypothesized that demographical factors, such as age and education, would influence the amount of information desired by the patient. Specifically, older and more educated persons are believed to want more time with their physicians compared to those who are younger and less educated. In addition, the amount of time a physician spends with a patient upon the delivery of distressing news was investigated. It was predicted that participants would prefer longer time periods as compared to shorter.

Patient-Doctor Communication in Health Settings

Communication is a context-driven event. The type as well as the amount of information shared between communicators is dependent on the setting and relationship they share.

Anthropological studies among general practitioners and psychiatrists have found that patient-

doctor communication in hospital settings often involves the doctor asking questions and getting answers (Woodhead et al., 2015). This leads the physician to be perceived in a position of power since the exchange is not equally led by both parties (Silverman, 2000). Power is an aspect of all social relationships, and inherently is neither good nor bad (Goodyear-Smith, 2001). However, knowledge of a patient's personal life and history serves to reinforce the patient's sense of a relationship with their physician and can lead to greater trust and information sharing. When doctors fail to utilize personal communication tactics, it is found that patients develop meaningful relationships with other professionals and doctors remain isolated, only relating to patients from a position of power (Woodhead et al., 2015). Therefore, it can be beneficial for both parties in patient-doctor communication to extend beyond the exchange of medically-related information in health settings.

Considering the patient specifically, communication is an important aspect to focus on in the patient-provider relationship because it has been found to influence the well-being of the patient (Bartley et al., 2014; Little, 2015). How the physician relates to the patient can influence the amount of information the patient is willing to share with the doctor (Goodyear-Smith, 2001; Silverman, 2000; Woodhead et al., 2015). The withholding of information is negatively correlated to patients' sense of social well-being (Bartley et al.). For instance, in a study conducted by Little and colleagues (2005), researchers found that general practitioners briefly trained in personal elements of communication had higher physician ratings of satisfaction, distress, and partnership by the patients. As these are characteristics associated with well-being (Butow et al., 1998; Derogatis et al., 2001; Egestad, 2013), it can be concluded that high-quality communication is associated with increases in patient well-being.

In establishing a patient-provider relationship that empowers the patient, communication creates positive affect that leads to well-being (Butow et al., 1998). Studies of patient-provider interactions found that patient anxiety was reduced when the provider took time to build a relationship and accepted responsibility for treatment and corresponding side effects (Egestad, 2013). This is because it creates a feeling of security for the patient as well as a level of understanding and transparency of the treatment. In knowing what is occurring, the patient can feel more involved and empowered. Furthermore, studies have demonstrated that doctor-patient communication has an association with patient quality of life and well-being, mainly dependent on the doctors' attitude (Cramm et al., 2015; Zhou et al., 2014). To learn what may influence doctors' attitudes, studies have identified factors that influence communication from doctors' perspectives. For example, a qualitative study found that doctors were likely to misjudge patients' need for information when disclosing distressing news to these individuals (Furber et al., 2013). This resulted in lost opportunities to explore what patients were thinking, how they felt about their experience, or what they understood might happen to them in the future. Doctors disclosed they often worry that providing information will overly concern patients and, as a consequence, they often make paternalistic decisions to protect the patient from potentially distressing information (Furber et al., 2013). This perception by physicians that information is less important than patients believe it to be leads to a discrepancy of needs being met and barrier to open, successful communication (Laine et al., 1996). Additionally, a study of primary care practice found that increased education was associated with decreased number of misunderstandings (Snyder et al., 1976). It can be extrapolated that misunderstandings are prevented by use of medical resources to gain information. Concurrent with this, studies with

prostate, breast, and colorectal cancer patients found a positive correlation between formal education and active involvement in decision making (Akinyemiju et al., 2016; Lepore et al., 2016; Zarcos-Pedrinaci et al., 2016).

It has been identified that patients' top preferences regarding the delivery of bad news are information, open dialogue, and shared decision making, but that doctors do not always prepare patients for what is happening to them in an active open awareness context (Barnett, 2006; Elkin et al., 2007; Furber et al., 2013; Mauri et al., 2009). For example, a study found only 41% concordance with patient preference due to lack of continual checking in with the patient (Mauri et al., 2009). Knowing that positive relationships alleviate the fear patients experience in the oncology setting, this identifies a problem with patient-provider communication. Yet, most published research has focused on physician's ideas of what the patient wants, not directly asking the patient to state his desires.

As the aforementioned research suggests, physicians' perceptions of patient-doctor communication are often inconsistent with patients' stated preferences (Elkin et al., 2007). However, there is less research that explicitly identifies what these patient preferences are. Therefore, the purpose of the current study was to explore the patients' perspective on communication and how that affects their well-being. By investigating the elements patients find to be most important, the discrepancy will be reduced and physicians will be better equipped to implement the identified elements in their communication. Since improved communication is correlated to increased patient well-being, the physicians can better achieve their goal of caring for their patients.

Need for Better Communication with Oncology Samples

Although research has been done examining factors that influence patient-doctor communication in general medicine settings, very little work has been conducted among individuals diagnosed with cancer. Cancer patients are a particularly important sample to study given the threat of experiencing intense physical pain, loss of control, and possibly death (Maynard, 2003). For example, a study examining patients undergoing diagnostic evaluations for cancer found a high prevalence of anxiety and lowered quality of life prior to knowledge of the illness (Moseholm et. al, 2016). After the diagnosis of cancer has been confirmed, it has been found that anxiety levels increase even throughout treatment (Moseholm et al.). Additionally, the incidence of anxiety and depressive illness in patients who underwent mastectomy was found to be 33%, and 38% for those who underwent a lumpectomy followed by radiotherapy (Fallowfield, Baum, Maguire, 1986). While patients undergoing chemotherapy had lower levels of anxiety than those who were not, oncology patient depressive symptoms assessed by the Beck Depression Inventory were indistinguishable from those individuals who had attempted suicide (Edwards & Clarke, 2004; Plumb & Holland, 1977). Based on these studies, it can be concluded that fear and anxiety in an oncology setting significantly decreases patients' psychological well-being. Not only is this problematic for the patient's mental health and overall contentment with life, but correlations have been found between psychological distress and disease progression in a variety of cancers (Bloom & Spiegel, 1984; Chida et al. 2008; Cohen & Pressman, 2006; Lerman, Kash, & Stefanek, 1993). Therefore, anxiety can result from receiving a cancer diagnosis, which circularly impacts a patient's well-being. It is necessary to combat this in order to improve resilience, longevity, and decrease the likelihood of remission.

Since a strong correlation has been found between high-quality patient-doctor communication and improved well-being, open communication could be employed to decrease the anxiety experienced by cancer patients. In support of this, many studies have found that an open awareness context is often used by people to help them live through a crisis in their lives (Timmermans, 1994; Copp, 1999; Mamo, 1999). This is not a simple solution in the field of oncology, however, as disclosing information to patients about cancer is often difficult. For instance, prior studies on communication within cancer populations has found that distressing news, such as a cancer diagnosis, is unwelcome and often has a devastating effect on the patient and their family (Beach et al., 2005; Edwards & Clarke, 2004). Yet the health benefiting effects of patient-provider communication are important and more research connecting communication in cancer populations is needed.

Many questions have arisen in the literature about patient preferences in the types of statements used in patient-provider communication. These types of statements include encouragement, empathy, or reassurance (Beach et al., 2005; Wasserman et al, 1984). Knowing this can be a useful guide for physicians in establishing a relationship with their patients. It has been indicated that a conversation lasting longer than 10 min to discuss distressing news is correlated to increased patient satisfaction and positive physician ratings by the patient (Figg et al., 2010). However, the specific amount of time preferred explicitly expressed by patients is still left to be discovered. This poses an issue for physicians in budgeting their time and schedules because 1 hour versus 11 min is a significant difference. Patient preferences for items such as types of statements and length of time to dedicate to the initial delivery of distressing news are

what this research aims to investigate. In improving communication in this way, improved relationships and patient empowerment will lead to more positive affect and healing

The purpose of this research was to examine if patients with cancer prefer longer conversations with their physicians and more information included compared to shorter ones with less information. The following hypotheses were made:

Hypothesis 1. It was predicted that people, regardless of demographic factors, would want more time with their physicians when being diagnosed with cancer.

Hypothesis 2. Further, it was expected that patients would want to be moderately involved in their treatment process. It was expected that information received would be desired from younger, more educated patients, and that the opposite would be found for older generations and less educated patients.

Hypothesis 3. It was hypothesized that empathetic statements, such as, “It is difficult to grasp, I know, and I’m very sorry” would be preferred by all types of patients over encouraging statements, such as, “It will be okay.”

Finally, this research was exploratory to examine age and educational differences in patient’s discussion of their illness.

METHOD

Participants

Participants were oncology patients who had been admitted into the oncology wings of the Scottsdale Healthcare Hospitals. The sample included 50 participants, 29 women and 21 men, who were age 18 years and older. All were able to cognitively understand and verbally answer the interview questions in English, and were mentally competent and medically stable, as

assessed by the unit manager. The patients were approached during hospitalization and were queried only if they expressed a willingness to complete a brief interview.

Excluded patients were those younger than 18 years of age, mentally incompetent, medically unstable, and those who declined the interview. All genders were included, as well as all racial, ethnic, and socioeconomic groups were intended. The age demographic was collected in the form of decades. There was much reluctance and discomfort demonstrated by the patients when directly asked for their age during the pilot studies, so it was decided to ask for the decade from which they were born. From the total number of participants, 28% were over 80 years old (born earlier than the 1930s), 23% were in their 60s (born in 1950s), 19% were in their 70s (born in 1940s), 19% were in their 50s (born in 1960s), and the remaining participants were distributed in the decades younger. Highest education achieved was asked, and the sample was found to have 30% 1-2 years of college, 30% Bachelor's degree, 21% with a post graduate degree, and 18% with a high school diploma or GED. A majority of the sample had breast cancer (26%), with lung, lymphoma, and pancreatic the second highest (9.3%), and colon in third (7.0%).

The subject population was obtained through contact with the unit manager and nurse practitioner for the oncology units of the hospital. Participants were personally asked if they were willing to participate in an interview for the improvement of the patient experience. Consent forms were given to the participants. No monetary compensation was offered to remove the potential for bias in the interviews.

Materials

There were two preliminary open ended focus group sessions conducted as a means of creating the original questionnaire. The purpose of this was to receive patient preferences from

the beginning of aspects in the delivery of distressing news that could be improved upon. The original questionnaire contained topics the focus group participants had expressed, including a free recall of receiving their diagnosis and three sections ranking physician actions.

There were 13 patients interviewed in first pilot study questionnaire, but after speaking to individuals it was realized that some of the information was redundant, so it was removed and the next version was created. Also, the original method of ranking the items appeared confusing to some participants. To simplify, the questionnaire was changed so patients assign a number 1-3 to each item, with 3 being the most important.

There were 11 interviews conducted with this second pilot study version, until it was realized that questions about physician time, community resources, and life expectancies were missing. This brought to fruition the completion of the final version of the questionnaire. This consisted of an initial demographics section, serving a dual purpose of aiding the participant in feeling comfortable to disclosing more personal information, as well as discovering possible correlations with preferences. The first part was the qualitative portion asking for a free recall of their diagnosis followed by a series of additional identifying questions (“I would like to begin with you recalling when you first received the news regarding your cancer diagnosis from a health care provider. Will you tell me about it? When did you first receive your diagnosis? From who? Did you have any idea? Do you feel there was sufficient time to take of the emotions that ensued? How much time do you feel is ideal? At the time of first hearing the news, would you have liked to hear prognosis information, such as life expectancy? What about now?”). The next two questions (“Please rank each of the following on a scale of 1-3, with 3 being the most helpful in making you feel less anxious and fearful when first receiving the distressing news;”

“Please rank each item on a scale of 1-3 [3 being most important] the ways you would like to be more involved”) responses on a 1 (*not at important to me*) to 3 (*very important to me*) scale.

Finally, the last section consisted of pairs of statements to evaluate preferences of hearing encouraging versus empathetic statements from their physician. These statements included items such as, “You will do great” vs. “I can only begin to imagine what you must be feeling.” These statements came from a previous validated list of empathetic and encouraging physician statements by Wasserman et al. (1984). The final version of the questionnaire had 33 interviews conducted with it.

Procedure

The questionnaire was handed to patients to complete. The oral interview of the questionnaire occurred one-on-one in the patient’s respective hospital room. The qualitative part was audio recorded, and then the quantitative section was completed. Confidentiality was maintained through the assignment of participant identification numbers. There were no identifying data kept on the patients, and the results were stored in a locked cabinet in the investigator’s locked office.

The qualitative portion (#1 on the questionnaire) involved the patient recalling when he/she received the initial cancer diagnosis and how the physician conducted the conversation. The participants were asked about tactics his/her physician employed (verbal or nonverbal) and whether or not he/she found them helpful in reducing the ensuing fear and anxiety. The interview also included information such as what type of physician gave the diagnosis and if the patient had known the physician prior. This prior relationship was determined by a minimum of a 5 min appointment on a previous day. In addition, this was the time where the patient disclosed if they

felt they received sufficient time with the physician to take care of their ensuing emotions, or what their ideal amount of time would have been. The qualitative portion of the questionnaire was analyzed using LIWC (Linguistic Inquiry and Word Count; Pennebaker, Booth, & Francis, 2007).

RESULTS

Hypothesis 1 findings. Descriptive statistics were performed on the data to see the amount of time patients preferred spending with their physicians when being diagnosed with cancer. The results showed that 86.1% of participants wanted 15-30 min for the initial discussion of distressing news, with 56% of persons preferring 15-20 min. Age nor education had any effect on these findings.

Hypothesis 2 findings. A reliability analysis was conducted on the 10 involvement items. The scale reliability was low (Crobach's $\alpha = 0.546$). However, when dropping Item 9 (i.e., "Keeping a calendar of your upcoming treatments and appointments") scale reliability improved ($\alpha = 0.601$). Because of this, the nine involvement items were averaged together to get a total score. Fourteen percent of patients indicated no interest in being involved in their treatment, 79% of patients indicated a desire for moderate involvement, and 7% indicated a desire for as much involvement as possible. Correlational analyses were then done to look at involvement scores and how they were related to age and education (see Table 1). Older adults were less interested in receiving information about their cancer diagnosis compared to younger individuals. There were no significant correlations found with involvement and education.

Table 1. The correlation between age/education and involvement questions. * $p < 0.05$ ** $p < 0.10$

Question	Age Correlation	Education Correlation
How involved do you want to be in your treatment process?	-0.291**	0.081 not statistically significant
To what degree do you want to know what to expect?	-0.314*	-0.072 not statistically significant
Being informed about valuable websites to explore.	-0.261**	0.001 not statistically significant
Being informed about support groups and other community resources.	-0.411*	-0.043 not statistically significant
Being informed about nursing and other medical resources.	-0.284**	-0.293**
Overall involvement	-0.440*	-0.039 not statistically significant

Hypothesis 3 Findings. A dependent t-test was significant, $t(31) = 3.333, p = 0.002, R^2 = 0.510$, with patients preferring encouragement ($M = 5.344, SD = 2.280$) more than empathy ($M = 2.656, SD = 2.280$). In order to see the relationship between education, age, and support, empathy and encouragement scores were converted to z-scores and a difference in values was computed. Higher scores indicated greater preference for encouragement. There was no significant relationship between support and age, $r = -0.095, p = 0.606, R^2 = 0.009$, or education, $r = -0.218, p = 0.230, R^2 = 0.048$.

Exploratory LIWC findings. The program LIWC codes for a variety of constructs in participants' writing (e.g., references to close relationships, mood, etc.; see Table 2 for the list of constructs). Overall, with respect to education, individuals with more schooling said less about their cancer diagnosis in the interview, were less focused on close relationships (i.e., friends & family), and used fewer words of anger when discussing their cancer. (Alternatively, less educated persons talked more, were more focused on friends and family, and were angrier about

their diagnosis.) For age, older adults were more likely to use positive words in describing their cancer diagnosis, along with expressing a heightened accessibility of death-related constructs. They were, however, less likely to discuss their family as part of their interview.

Table 2. Language analyses as a function of age and education. * $p < 0.05$ ** $p < 0.10$

Word Types	Age correlation	Education correlation
words per sentence	-0.046 not statistically significant	-0.596**
family words (e.g., daughter, husband, aunt, etc.)	-0.577**	-0.580**
friend words (e.g., buddy, friend, neighbor, etc.)	0.367 not statistically significant	-0.580**
positive words (e.g., love, nice, sweet, etc.)	0.694*	0.086 not statistically significant
anger words (e.g., hate, kill, annoyed, etc.)	0.367 not statistically significant	-0.580**
death words (e.g., bury, coffin, kill)	0.554**	-0.002 not statistically significant

DISCUSSION

The current research sought to investigate elements of patient-provider communication in the delivery of distressing news. The aim was to improve this exchange by identifying factors that would increase patient well-being. Since it is the patients who are primarily affected, the aim of the current work was to find relationships between demographic factors and patient preferences. Being difficult to generalize preferences across a large amount of people, it was hypothesized that age and education level would influence patient preferences due to background commonalities in those areas.

One aim of the current work was to test the hypothesis that individuals, regardless of demographic characteristics, would prefer spending more time with their doctors. In support, the

present study found that 86% of the participants sampled wanted to spend at least 15-30 min with their doctors to discuss their cancer diagnosis. Although yet to be examined in oncology patients, this finding is consistent with prior work among general medical patients. A survey of ALS patients and their caregivers revealed that greater time spent discussing the diagnosis was correlated with higher patient/caregiver satisfaction (McCluskey, 2004). This was also found to with the current study. In regards to specific the amount of time desired by patients with their physician when receiving distressing news, prior research has indicated that a conversation lasting longer than 10 min is correlated to increased patient satisfaction and positive physician rating by the patient (Figg et al., 2010). However, the specific amount of time preferred explicitly expressed by patients was still left to be discovered. The current research findings that 86.1% of patients desired 15-30 min with their physician suggests a more specific window of time to guide physicians when discussing distressing news with patients. This is important, acknowledging the busy and demanding schedules of doctors.

An additional goal of the current study was to explore how age and education influenced patients' desire for involvement in their treatments. It was hypothesized that an increase in information received would be desired from younger, more educated patients, and that the opposite would be found for older generations and less educated patients. Previous studies have found that older populations demonstrate decreased involvement in treatment decision making (Burack et al., 2000; Mold et al., 1994). However, it is not identified if patients prefer this inactive role. The current research identified this: 14% of patients indicated no interest in themselves being involved in their treatment, 79% of patients indicated a desire for moderate involvement, and 7% indicated a desire for as much involvement as possible. Older adults were

less interested in receiving information about their cancer diagnosis compared to younger individuals. There were no significant correlations found with involvement and education. Many of the prior studies conducted regarding this phenomenon are dated, and cultural norms may have shifted in the last 15-20 years. The current study supports these earlier findings, demonstrating that over time the positive correlation between age and involvement level has remained consistent. In addition, this study suggests it is the older patients' desire to remain less actively involved in the formation of a treatment plan.

A third goal of the current research was to test the hypothesis that empathetic statements, such as "It is difficult to grasp, I know, and I'm very sorry" would be preferred by all types of patients over encouraging statements, such as "It will be okay." This hypothesis was based on the prior research by Wasserman and colleagues (1984) demonstrating that mothers exposed to higher levels of empathy had higher satisfaction and greater reduction in concerns as compared to encouraging statements. However, it was found that the patients in the current study preferred encouraging support over empathetic statements. The discrepancy may be a result of the hope many oncology patients cling on to, which encouragement would provide. This suggests an area for additional research to investigate.

Finally, this research was exploratory to examine age and educational differences in patient's discussion of their illness. The exploratory portion of the study found that patients with higher education levels spoke less overall words when describing their illness, as well as older generations spoke more positive language and were more comfortable addressing death. Implications of the findings suggest potential relationships between education level, age, and affect towards patients' situations. Further research is needed to investigate why more educated

patients use less words to describe their illness, older adults using more positive language, or less educated and younger adults involve more familial and friend words. It is hypothesized that the less information and understanding patients have, the more they rely on support systems (family and friends) and talking about their illness (increased overall words). In addition, it is predicted that older adults have come to accept their illness more than younger adults, which is why they use more positive language and words related to death when describing their cancer.

Although there was support for the different hypotheses, there are some limitations that need to be addressed. Seeing that this study involved a small sample size of 50 patients, it is difficult to extrapolate the findings to any general populations as a whole. Adding to this, participants represented a diverse sample of cancer diagnoses (e.g., breast, lung, etc.) rather than examining one form of cancer. It is recommended that future studies collect a much larger sample of participants, preferably focusing on one type of population (i.e., breast) in greater detail. In addition, it is noted that each patient is an individual with many factors influencing his or her preferences. Although the result revealed that patients preferred more time with their doctors, with older and less educated adults expressing less time, there are other individual difference characteristics that should be taken into consideration. For example, the social support or an attachment style of a person may exaggerate any effects. Securely attached persons, in comparison to insecurely attached individuals, should be getting their support needs met by relationship partners to the extent that they don't need their physicians as much. Additionally, someone with a higher need for cognition may require more information to be provided, and will actively seek resources, to meet their information processing needs. Future studies should examine these and other moderating variables (e.g., gender – physician & patient, disease

progression, etc.). Additionally, the study started out as an exploratory venture, which is why the questionnaire used has not yet been validated by any other studies. This posed to be a limitation in examining the level of involvement preferences. A future study to validate the questionnaire items would be beneficial, as well as an experimental approach. This would prove useful in the ability to manipulate time spent with the physician upon the delivery of distressing news to see if increased time has an effect on patient satisfaction and overall well-being (i.e. physical and psychological well-being).

Despite these limitations, this study could be used by physicians to better disclose a cancer diagnosis or other bad news to their patients. The implications of this research to improve patient-doctor communication in the delivery of distressing news are still important. In finding patient preferences to increase their well-being in a very emotionally-charged context as a cancer diagnosis, physicians can be better informed with how they approach these conversations with different types of patients. This study opens up invitations to further investigations of how to improve this phase of a patient's treatment. With the increase of specific communication practices, patient empowerment will aid in the improvement of well-being.

QUESTIONNAIRE

PID:

Date:

Patient Interview

Hello, I hope the staff is taking great care of you! My name is _____ and we are conducting a research project looking at doctor-patient communication. This project was developed by a student who became interested in this during her mother's battle with breast cancer throughout her childhood. Her mother felt helpless and she wanted to know how to better take part in the medical decisions that affected her life. The doctor seemed only interested in her physical care, and seemed less attentive to the emotional aspect of the diagnosis and treatment and how their communication could impact the situation. We are hoping to learn about patients' preference on how health care providers can provide effective methods for communicating distressing news to reduce patients' fear and increase their involvement in their care. Interest in the emotional and mental well-being of cancer patients is a relatively new field and we are hoping to improve overall patient satisfaction. We will ask you a few questions and record your responses on an app developed for this research. Your participation is voluntary, you may choose not to answer a question, and you may stop at any time. Your identity will be kept confidential and in fact you may choose your own code name or alternative identity and write it on the consent form. Do you have any questions before we begin?

Demographic questions:

1. Do you have any children? Pets?
2. What are your hobbies?
3. What is your highest level of education?
4. What is your occupation?
5. In what decade were you born?

1. I would like to begin with you recalling when you first received the news regarding your cancer diagnosis from a health care provider. Will you tell me about it?

(If need prompting use: Where were you? What did the doctor do when they first walked in? What doctor told you? How did you feel?)

2. a. When did you first receive your diagnosis? From who? Did you have any idea?
- b. What type of cancer do you have? What stage is it now?
- c. Do you feel there was sufficient time to take of the emotions that ensued? How much time do you feel is ideal?
- d. At the time of first hearing the news, would you have liked to hear prognosis information, such as life expectancy? What about now?

3. Please rank each of the following on a scale of 1-3, with 3 being the most helpful in making you feel less anxious and fearful when first receiving the distressing news:

___ Asked if it was okay to discuss the worrisome findings, to ensure that it was an acceptable moment.

___ Told you the statistics regarding the rate of success or failure of the proposed treatment(s).

___ Physician showing an understanding, to a degree, what emotional turmoil you are experiencing.

___ Inclusion of your ideas and suggestions.

___ Asking questions regarding aspects of your life outside of your diagnosis to treat you as a whole person and not just a “cancer patient”.

___ Explaining what to expect.

___ Displaying sympathy for your feelings and validating your fears.

___ Being told the practical implications of the disease and treatment on your everyday life.

___ Recalling success stories of people who have had similar types of cancer and treatments.

___ Scheduling a follow up visit or phone call to address questions (what percent of your questions would you trust yourself to come up with during the initial delivery of the news?)

4. Do you want to be more involved, less, or the same amount with the decision making process in your treatment plan with your oncologist?

Please rank each item on a scale of 1-3 (3 being most important) the ways you would like to be more involved:

___ Being told at the beginning of possible pathways your disease and treatment could take.

___ Being informed about valuable websites to explore (i.e. NIH/NCI/WebMD).

___ Being informed about support groups and other community resources.

___ Being informed about nursing and other medical resources to personally answer your questions.

___ Establishing specific, achievable, short term goals with your physician.

___ Being encouraged to freely disclose concerns.

___ Keeping a calendar of your upcoming treatments and appointments.

___ Encouraging you to record your physical and emotional symptoms daily to better address concerns.

5. Which statements would you imagine would help alleviate your fear and anxiety?

a. “You will do great.” vs “I can only begin to imagine what you must be feeling.”

b. “It will be okay.” vs “It is difficult to grasp, I know, and I’m very sorry.”

c. “You will get through this, you are strong.” vs “This is overwhelming, I know.”

d. “You have great support, so this will be okay.” vs “I know how upsetting this has to be so I won’t go into too much detail now.”

e. “It will be fine, you should do well with the treatment.” vs “Anyone hearing news like this would feel as you do.”

- f. “The odds are in your favor, you should do great.” vs “You are not alone in your feelings.”
- g. “Most people do very well with the treatment.” vs “What you are feeling is completely normal.”
- h. “Your prognosis is very favorable, and you should do well.” vs “How can I help right now?”

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