"TALK TO ME:" A MIXED METHODS STUDY ON SERIOUSLY ILL PATIENTS' VIEWS ON PHYSICIAN BEHAVIOURS DURING ADVANCE CARE PLANNING AND END-OF-LIFE COMMUNICATION

Amane Abdul-Razzak, MD CCFP

A Thesis Submitted to the School of Graduate Studies in Partial Fulfillment of the Requirements for the Degree Master of Science

McMaster University © Copyright by Amane Abdul-Razzak, May 2013

MASTER OF SCIENCE (2013) MCMASTER UNIVERSITY
(Health Research Methodology) Hamilton, Ontario

TITLE: “Talk to Me:” A Mixed Methods Study on Seriously Ill Patients’ Views on Physician Behaviours during Advance Care Planning and End-of-Life Communication

AUTHOR: Amane Abdul-Razzak MD (McMaster University)

SUPERVISOR: Dr. John You

Pages: vii, 172

ABSTRACT

Background: With an aging Canadian population, there is a pressing need to understand how physicians can effectively communicate with people about advance care planning (ACP) in a manner that preserves their dignity, autonomy, and is satisfactory from the patient perspective. Front-line physicians are faced with multiple demands on their time, so it is imperative to develop strategies that are effective yet compatible with the realities of daily clinical life. The objective of this mixed methods study is to understand, from the perspectives of seriously ill hospitalized patients, the effect of modifiable physician behaviours on the perceived quality of end-of-life and ACP communication.

Methods: In this study, a convergent parallel mixed methods design is used, in which qualitative and quantitative strands are conducted in parallel, separately analyzed and then merged during a mixed methods analysis phase. Participants were recruited from inpatient medical wards at two academic hospitals in Hamilton, Ontario. The inclusion criteria identify a population with a high risk of mortality at 6-12 months. In the quantitative strand, the Quality of Communication (QOC) questionnaire was administered to measure patients' self-rated satisfaction with their physician's ACP communication skills. The primary analysis strategy involved calculating the strength of correlation between individual QOC items and a global satisfaction score. The three items with the

highest correlation values, and which represented practical suggestions for improving ACP-related communication, made up a short-list of priority behaviours. Some QOC items had a large proportion of responses that were coded as zero ('didn't do'); these items were dichotomized and t-tests were calculated to determine if there was a difference in the mean global satisfaction score between the two groups. In the qualitative strand, interpretive description methods were used to explore seriously ill patients' perceptions of the quality of ACP communication with their physicians. The mixed methods analysis phase involved the creation of a merged analysis table in which the qualitative themes were arrayed with the quantitative items that represented high priority behaviours.

Results: From the quantitative analysis, the three priority behaviours pertained to eye contact, providing full attention, and listening. The three major qualitative themes related to nonverbal behaviours; situating a patient in the context of their background, family and social roles; and assisting patients to make the challenging end-of-life transition. The merged analysis allowed for a fuller, contextualized understanding of why the QOC items with the strongest correlation measures were important from a patient perspective.

Conclusions: This mixed methods study is well-positioned to understand, holistically and from the patient perspective, physician behaviours that influence quality of communication at

the end of life. Illustrative examples from the qualitative strand helped to explain the importance of certain QOC items, and showcased the context in which these can occur. Although the process of ACP communication between a physician and patient requires an ability to appreciate the variability in patient preferences, the results of this study provide practical suggestions that can be incorporated in clinical practice.

ACKNOWLEDGEMENTS

First of all, I would like to thank my mom and dad: you two have most certainly been the biggest role models in my life and your unconditional love and tireless support keep me going. I would also like to thank my siblings: Sura and Samy, I know I don't get to choose my siblings but I would choose you a million times over if I had the chance. I would also like to thank my dear husband Sarmad: you are my rock and I love you.

I would also like to acknowledge the amazing support and guidance provided by Dr. John You, Dr. Diana Sherifali and Dr. Kevin Brazil. I have been fortunate to have such wise, encouraging and kind mentors.

Table of Contents

ABSTRACT....iii
ACKNOWLEDGEMENTS....vi
TABLE OF CONTENTS....vii
LIST OF TABLES....ix
GLOSSARY OF ABBREVIATIONS....x
CHAPTER 1: INTRODUCTION....1
1.1 Rationale and Objective....1
1.2 Background on Advance Care Planning and Study Scope....2
1.3 The Importance of Studying Advance Care Planning and End-of-Life Communication....4
1.4 Prior Efforts to Improve the Quality of Advance Care Planning....6
1.5 Patient Perspectives on Advance Care Planning....8
1.6 Summary....10

CHAPTER 2: METHODS....11
2.1 Background on Mixed Methods....11
2.2 Rationale for Mixing Methods....12
2.3 Study Questions....15
2.3.1 Quantitative Question....15
2.3.2 Qualitative Question....15
2.3.3 Mixed Methods Question....15
2.4 Study Population....16
2.4.1 Participant Recruitment....16
2.4.2 Selection Criteria....16
2.4.3 Collection of Demographic Information....18
2.5 Quantitative Strand....19
2.5.1 The Quality of Communication Tool....19
2.5.2 Quantitative Data Analysis....22
2.5.3 Quantitative Sampling Strategy....27
2.6 Qualitative Strand....28
2.6.1 Qualitative Data Analysis....29
2.6.2 Qualitative Sampling Strategy....33
2.7 Mixed Methods Phase....35
2.7.1 Data Collection....35
2.7.2 Mixed Methods Data Analysis....36
2.8 Ethics....37

CHAPTER 3: QUANTITATIVE RESULTS....39
3.1 Quantitative Strand Participants....39
3.2 Descriptive Statistics for QOC Responses....40
3.3 Primary Analysis: Measuring Strength of Relationship of

Each QOC Item with respect to the Global Rating Item.....43
3.4 Measuring the Statistical Significance of Differences in Mean GRI Scores for Dichotomized Items.....45
3.5 Secondary Analysis: Multivariate Linear Regression Modeling.....47
3.6 Summary of Quantitative Results.....50

CHAPTER 4: QUALITATIVE FINDINGS.....52
4.1 Qualitative Strand Participants.....52
4.2 Presentation of Findings.....53
4.3 The Analytic Trail.....55
4.4 Qualitative Themes.....58
4.5 Summary of Qualitative Findings.....85

CHAPTER 5: MIXED METHODS FINDINGS.....87
5.1 The Combination of Items 4 (listening to what you have to say) and 6 (giving you his/her full attention).....88
5.2 Presentation of Findings.....91
5.3 Summary of Mixed Methods Findings.....99

CHAPTER 6: DISCUSSION.....102
6.1 Summary of Study Findings.....102
6.2 Relationship of Study Findings to the Existing Literature.....108
6.3 Study Limitations.....117
6.4 Clinical Implications and Future Directions.....123
6.5 Conclusion.....128

REFERENCES.....130
APPENDIX A. Case Report Form.....138
APPENDIX B. Initial Qualitative Interview Schedule.....143
APPENDIX C. Letter of Information/Consent.....144
APPENDIX D. Study Flow Diagram.....148
APPENDIX E. Recruitment Flow Chart.....149
APPENDIX F. Frequency Histograms for Responses to QOC.....150
APPENDIX G. Bivariate Correlation Matrix for Items 1-6 and the GRI on the Quality of Communication Questionnaire 164
APPENDIX H. Univariate Linear Regression Plots for Items 1-6.....165
APPENDIX I. Multivariate Regression Modelling.....170
APPENDIX J. Regression Statistics for Best Multivariate Linear Model and Plot of the residuals.....171

LIST OF TABLES

Table 1 Characteristics of participants in quantitative strand

Table 2 Quality of communication questionnaire responses

Table 3 Bivariate correlations (Pearson r) for items 1–6 and global rating item

Table 4 T-test for difference in mean GRI score in groups with responses coded as “0” versus “1” (Items 7–13)

Table 5 Coefficients for multivariable regression model including items 2 (eye contact),3 (answering questions), and 6 (full attention)

Table 6 Characteristics of the qualitative interview participants

Table 7 Mixed Methods Merged Analysis Table

GLOSSARY OF ABBREVIATIONS

ACP	Advance Care Planning
AD	Advance directive
BMI	Body mass index
CARENET	Canadian Researchers at End of Life Network
CHF	Congestive heart failure
COPD	Chronic obstructive pulmonary disease
DV	Dependent variable
EOL	End-of-life
ESRD	End-stage renal disease
FEV_1	Forced expiratory volume in one second
GRI	Global rating item
IPF	Idiopathic pulmonary fibrosis
IV	Independent variable
LVEF	Left ventricular ejection fraction
NYHA	New York Heart Association
$PaCO_2$	Partial pressure of carbon dioxide
QOC	Quality of communication questionnaire
QUAL	Qualitative
QUAN	Quantitative
r	Pearson correlation coefficient
RCT	Randomized controlled trial
SDM	Surrogate decision-maker
VIF	Variance inflation factor

CHAPTER 1: INTRODUCTION

1.1 Rationale and Objective

Improving the quality of end-of-life (EOL) communication, and in particular advance care planning (ACP) communication, is a high priority for seriously ill patients in Canadian acute care hospitals. With an aging Canadian population, there is a pressing need to understand more about how to effectively communicate with people about their future healthcare wishes in a manner that preserves their dignity, autonomy, and is satisfactory from the patient perspective. Prior interventions to improve the quality of EOL and ACP communication have yielded mixed results, and when successful, have often incorporated interventions that are challenging to apply in most clinical situations.[1-4] One reason why there has been a lack of effective interventions may be, in part, because there has been a failure to incorporate patients' preferences and perspectives. Thus, using patient-centered priorities in the development of future interventions may increase the likelihood of their success. Moreover, front-line physicians are faced with multiple demands on their time, so it is imperative to develop interventions that are effective yet compatible with the realities of daily clinical life.

The objective of this mixed methods study is to understand, from the perspectives of seriously ill hospitalized patients, the effect of modifiable physician behaviours on the perceived quality

of EOL and ACP communication. The study results provide pragmatic strategies that may be incorporated into existing clinical practice without major disruption of a physician's routines. Knowledge created from this study may be used to inform the design of subsequent complex interventions aimed at improving the quality of EOL communication (e.g., educational interventions to improve healthcare providers' EOL communication and ACP skills, and others). In addition, the results of this study may be used to develop a training curriculum in ACP communication for front-line physicians.

1.2 Background on Advance Care Planning and Study Scope

Broadly speaking, Western societies place a high value on individual rights and autonomy; the desire for self-determination in EOL choices is reflective of this value, and ACP can be viewed as one of its manifestations.[5] Advance care planning can be understood as a process of information sharing, deliberation and decision-making about a patient's treatment options in the context of their personal values, perspectives, expectations, and fears about their health as they approach the end of life. This process can involve communication with family caregivers and loved ones, healthcare providers, clergy, spiritual care and social workers, among others.

Advance care planning conversations can help delineate what patients and family members value in terms of their health and

quality of life, what they wish to occur at the end of life, what they wish to avoid, and may also involve the nomination of a surrogate decision maker that represents the individual when he cannot speak for himself. The ACP process may also involve documentation of desired future healthcare decisions in the form of advance directives (AD); however, experts have recently cited the limitations of ADs, including inability to address unforeseen health circumstances, inclusion of ambiguous or impractical instructions, and even the questionable validity of ADs in circumstances where patients have an inadequate understanding of medical care and the nature of treatment options.[6,7] By placing the focus on documentation, there is a distraction away from the more important tasks of ongoing information sharing, communication, and preparation for future challenging and uncertain health circumstances. The focus of this study is on the ACP and EOL *communication* process between patients and physicians rather than the completion of an advance directive.

In addition to the physician and other members of the multidisciplinary healthcare team, ACP conversations should involve a patient's family members and loved ones, and any other people that the patient wishes to include. The literature shows that most EOL decisions occur in the context of ongoing discussions with loved ones; this relational context is crucial to successful ACP and is more likely to be effective than that which occurs only between a patient and his physician.[8] However, the

scope of this project is restricted to *patient* perspectives on *physician* behaviours during ACP and EOL communication rather than patient and family perspectives. The specific question allows for a depth and richness of understanding that would be more difficult to achieve with a broader focus that includes family members of seriously ill patients or other members of the healthcare team.

1.3 The Importance of Studying Advance Care Planning and End-of-Life Communication

Advance care planning has been suggested to help reduce end-of-life (EOL) care costs while improving the quality of care in the final days of life,[9,10] and terminally ill patients have identified a physician's ability to communicate about topics such as death and dying as a major priority to good EOL care.[11] Previous studies of seriously ill inpatients conducted through the Canadian Researchers at the End of Life Network (CARENET) revealed that two of the greatest opportunities to improve EOL care relate to: a)patient-physician communication and, b)involving the patient in the decision-making process.[12,13] A grounded theory study found that patients felt that engaging in the ACP process gave them "peace of mind."[14] A French longitudinal study suggested that surrogate EOL decision-making is associated with a high risk of post-traumatic stress disorder in caregivers when insufficient information is provided by the health care team about a loved one's medical status, while skillful EOL communication can reduce the impact of a difficult loss.[15] In 2008, a prospective cohort

study of 332 patient-family dyads found that EOL discussions led to less aggressive interventions which resulted in better bereavement adjustment in caregivers and longer length of patient enrollment in hospice programs.[16] In short, there is little question that effective, high quality ACP is a key target for improving the quality of end-of-life care for the elderly and seriously ill populations.

Despite the widespread understanding of the importance of ACP, studies indicate that the extent and quality of ACP is low. A cross-sectional survey conducted in the Netherlands showed that patients with advanced CHF or COPD were able to state their preferences on many EOL decisions, but that most have never discussed these items with their physician.[17] Heyland et al have reported findings from the first phase of a longitudinal multi-centre audit of ACP practice at 12 Canadian hospitals with 278 seriously ill patients and 225 family members: participants reported low levels of engagement with physicians in communication about ACP, and high levels of discordance (70%) between patients' stated preferences for EOL care and the actual goals of care documented in the hospital chart (e.g., full CPR versus comfort care).[18] The value of high quality ACP communication and the apparent paucity of such conversations creates an impetus to further study and understand how this situation can be improved.

1.4 Prior Efforts to Improve the Quality of Advance Care Planning

Interventional studies, aimed at improving both the prevalence and quality of ACP-related activities, have yielded heterogeneous results. An RCT involving patients with advanced congestive heart failure (CHF) or end-stage renal disease (ESRD) and their selected surrogate decision-makers (SDM) randomized two groups to usual care or a structured, disease-specific and patient-centered interview on ACP with a rigorously trained facilitator.[19,20] The primary study outcome was surrogate understanding of patient goals for care in four disease specific scenarios, such as whether the patient would want to undergo treatment if the expected outcome was a decline in functional status. The intervention group showed significantly higher agreement in comparison to the control group, with a kappa statistic 0.61-0.78 for intervention group versus 0.07-0.28 for the control group. This trial did not specifically investigate the impact of such an interview on patient-physician ACP communication. In 2010, a randomized controlled trial (RCT) that recruited 309 elderly (>80 years old) inpatients on internal medicine, cardiology and respiratory wards in a tertiary hospital revealed that, compared to usual care, expert-facilitated ACP improved physician knowledge of patient EOL wishes and improved patient and family satisfaction with the hospital stay.[21] The facilitators in this study were trained through an ACP curriculum that teaches the Respecting Choices model, which was developed in

1991 and has been used in the US, Australia and western Canada.[22] Given that many healthcare institutions may not be willing, or have the resources, to train staff members in this model, the generalizability of the study may be limited. A UK-based study used the themes generated from qualitative interviews of caregivers and health care providers of people with severe dementia to inform the development of a complex intervention aimed at improving health care providers' EOL communication skills.[23] The intervention consisted of an EOL needs assessment and ACP discussion by an experienced nurse, and was piloted in a subsequent RCT, but recruitment rates were low and attrition rates were high, thus precluding assessment of outcomes and raising questions about the burdensome nature of the intervention. Recently, an RCT evaluated whether the provision of patient-specific feedback forms to physicians could improve patient-rated quality of EOL communication in COPD outpatients.[24] Patient-rated quality of communication was statistically significantly higher in the intervention groups, but with a modest Cohen's effect size of 0.21. Patients' hesitation to provide direct feedback to their physician may be a practical limitation to the widespread use of such an intervention. A landmark RCT of a complex intervention to improve EOL communication and decision-making in seriously ill hospitalized patients, the SUPPORT trial, did not improve the rate or timing of completed 'do not resuscitate orders,' and did not reduce the number of days spent in ICU or pain levels as reported

by patients or surrogates.[25] While a large amount of literature has been dedicated to understanding why this trial was unsuccessful, one explanation may be that the design of the interventions was not directly informed by patient preferences about EOL communication, but rather was based on the ideas of physician leaders and study investigators. There is a need to learn, directly from the patient population, the elements of ACP communication that are effective. Furthermore, the interventions in many of these studies are resource and time-intensive; a need exists to understand how a physician may incorporate successful, time-efficient ACP communication strategies into their busy schedule that do not necessitate intensive training protocols.

1.5 Patient Perspectives on Advance Care Planning

Some studies have focused on the factors that contribute to high or low quality ACP from the patient perspective. In a mixed methods study that explored general medical outpatients' self-identified barriers to ACP communication, a major finding was that patients' information needs were not addressed by their physicians.[26] In a cross-sectional survey, patients with COPD frequently indicated that having trust in one's physician, and feeling that the physician cares about the 'whole person' were important facilitators, while a feeling that one's physician is uncomfortable discussing EOL issues, holds judgement about the

cause of one's illness (i.e. smoking) or has little time were highly endorsed barriers.[27] In two qualitative studies, including a large Canadian grounded theory study, patients with HIV and end-stage renal disease indicated that the beneficial aspects of ACP came more from the *social interaction* and discussion with loved ones about EOL care rather than the creation of a written advance directive, which seems to be a major focus in ACP literature.[28,29] In contrast, other studies that surveyed patients, family caregivers and healthcare providers suggested that most people agreed that written documentation of treatment preferences was of high importance.[30–32] Study results also suggest that patients and family members agree on the importance of naming a surrogate and knowing what to expect with regards to future health deterioration.[30,31] However, the literature reveals a great deal of heterogeneity when it comes to patient preferences for certain aspects of EOL communication, such as discussion of spirituality with physicians and wanting to know the timing of death.[30] The importance, from the patient perspective, of involving family caregivers in EOL discussions is consistently emphasized in the evidence base.[30–33] Although there have been many studies on patient perspectives of good EOL communication in general, there is little knowledge about patient perspectives on what *modifiable physician behaviours* contribute to high or low quality ACP communication. The study presented here directly addresses this knowledge gap.

1.6 Summary

ACP has many potential benefits but the current level and quality of ACP in Canada is low. To develop successful healthcare provider training and other strategies to improve ACP, it is imperative that we understand, from the perspective of patients, what physician behaviours they perceive to contribute to high quality ACP. The information provided by this study is novel in that it explores aspects of EOL communication that are important from the *patient perspective* rather than those from a physician or expert perspective. This study has a unique focus on providing suggestions on improving ACP communication that are practical and compatible with the typical clinician's work environment. In 2000, the UK-based Medical Research Council provided a framework for the design of RCTs of complex interventions. The framework recommends a 'pre-clinical' phase to establish an evidence base that suggests the intervention will have the effects that are intended.[34] This study can be seen to be contributory to the pre-clinical knowledge base. Furthermore, the knowledge gained by this study will be considered for inclusion in a curriculum designed to improve healthcare provider skills in EOL communication.

CHAPTER 2: METHODS

2.1 Background on Mixed Methods

Historically, there has been some controversy surrounding the legitimacy of mixed methods research. The paradigm debate related to the *incommensurability* of mixed methods because of the challenges of combining two methods with different ontological assumptions; the positivist paradigm underpinning quantitative methods relates to the idea of a singular and universally accepted truth, while the constructivist paradigm foundational to qualitative research acknowledges that truth is subjective, and peoples' perceptions and experiences result in multiple realities.[35–37] Furthermore, the ontological foundations of these methods lead to different approaches to acquiring knowledge about a subject matter: qualitative (QUAL) research embraces a subjectivist epistemology in which the subject and researcher work closely to generate theories inductively from the data, while quantitative (QUAN) research typically uses deductive methods that begin with a hypothesis that is accepted or rejected based on study data and analyses.[36] These different views on reality/truth and how knowledge is accrued challenged the wisdom of mixing methods.

Eventually the debate dwindled with the recognition that mixed methods research does not fit into either constructivist or positivist paradigms but in fact that *pragmatism*, which focuses on

the use of the research question to guide decision-making about the optimal research methods, is the best suited approach.[35,36,38] In the pragmatist approach, the use of both subjective and objective knowledge (i.e. allowing the mixing of qualitative and quantitative methods) is justifiable *if required by the research question that is posed*.[36] There are different typologies of mixed methods research designs, but the common ones are based on the relative importance, timing, and degree of interaction of the QUAL and QUAN components or 'strands'[39-41] In this study, a **convergent parallel mixed methods design**[39] is used, in which QUAL and QUAN strands are conducted in parallel, separately analyzed and then merged during a mixed methods analysis phase.

2.2 Rationale for Mixing Methods

End-of-life communication is a complex, multifaceted phenomenon that involves multiple contextual, psychological, social and spiritual factors. As Thorne states in a 2010 interpretive description study:

> *There are few absolute rules within human communication amenable to distillation into universal principles that apply across all conditions. Therefore, it is important to build an understanding not simply of what we think will be helpful, but why it is helpful and in what contexts.*[42]

Encounters between health care providers and patients often occur in a time-constrained environment, and therefore the QUAN strand is helpful to identify *which* behaviours are important to

patients. The goal is to create a short-list of priority behaviours and activities, and this is achieved primarily by measuring the strength of correlation between individual item scores on a quantitative instrument and a global rating item (GRI) and then selecting the items with the three highest correlation values (see section 2.5.2). In addition, the QUAL data is needed in order to answer the *why* questions: why are these behaviours important? The QUAL data is also helpful to elicit important physician behaviours that are not detected or measured in the QUAN strand. Finally, a merging of these two data sets will provide a fuller understanding than that which can be achieved by either method alone. In brief, a mixed methods study is needed for the purposes of complementarity: that is, to seek elaboration and illustration of the quantitative results through use of the qualitative findings.[38,39]

It is important to recognize that although physician behaviours during ACP is under study in both strands, in fact each strand examines the phenomena from different ontological paradigms. Therefore, the data from each strand will not be used for triangulation, in which different methods of data collection and analysis are employed in order to consider a topic from multiple angles and thus bolster the credibility of the findings.[38] Instead, the QUAL data will provide some context, illustration and explanation as to *why* certain items heavily influence patients' rating of the global quality of ACP communication.

A convergent parallel approach was selected because it had advantages over other mixed methods designs. Two other common design approaches are: the sequential explanatory design, and the sequential exploratory design.[39] In the former, qual questions are developed from the results of an initial QUAN phase in order to explain the quantitative results. In the latter, quan methods are used after an initial QUAL phase in attempt to assess the generalizability of the qualitative findings. However, the convergent parallel approach is best suited to the objective of this study: to obtain different but complementary information on patient preferences for EOL communication with their physician. The QUAN data relates to which behaviours are important from the patient perspective, and the QUAL data provides information about why these behaviours are important. Secondly, from a pragmatic perspective, the convergent parallel design is more time-efficient, which makes it a more feasible choice in the presence of time constraints. An explanatory sequential design was considered, but this would have required making an assumption that the QUAN tool used in the study has been demonstrated to have good construct validity and is a good basis from which to design the QUAL phase. As will be discussed later, this is a difficult assumption to make.

2.3 Study Questions

2.3.1 Quantitative Question:

Among seriously ill medical inpatients at two tertiary hospitals, which physician behaviours, as identified by a patient-reported questionnaire, are most predictive of a global rating of quality of advance care planning and end-of-life communication?

2.3.2 Qualitative Question:

What are seriously ill inpatients' perspectives on physician behaviours during advance care planning and end-of-life communication?

2.3.3 Mixed Methods Question:

To what extent do the qualitative interview data elaborate and elucidate the quantitative results?

2.4 Study Population

2.4.1 Participant Recruitment

Participants were recruited from inpatient medical wards at the Hamilton General Hospital and the Juravinski Hospital in Hamilton, Ontario. The participant must have been in hospital for at least 48 hours to allow time for an ACP conversation to have occurred. Medical charts were reviewed to assess eligibility, and the attending physician (or another member of the healthcare team) was contacted, who approached the patient to assess interest in study participation. The participant was directly approached by a research nurse only after discussion with a member of the healthcare team. During this initial contact, the participant completed a 14-item questionnaire (see section 2.5.1) with the assistance of the research nurse and was asked if they would be interested in taking part in a one-on-one interview with the study investigator at a later time (within 1-2 days).

2.4.2 Selection Criteria

This study focused on seriously ill medical inpatients who were at high risk of dying. The inclusion criteria are very similar to those used in previous CARENET studies, and identify a population with an estimated 6-month mortality risk of

50%.[12,13] Patients were recruited to the study if they met at least one of the following **inclusion criteria**:

a. Hospital admission for congestive heart failure (CHF) with New York Heart Association (NYHA) Class IV symptoms or left ventricular ejection fraction (LVEF) ≤25%.

b. Hospital admission for severe chronic obstructive pulmonary disease (COPD) with one or more of the following: body mass index (BMI) <21; an exacerbation requiring hospitalization over the past year; shortness of breath causing the patient to stop walking after 100m or after a few minutes on level ground; forced expiratory volume in 1 second (FEV_1)≤ 30% predicted; or partial pressure of carbon dioxide ($PaCO_2$)≥45torr.

c. Hospital admission for liver cirrhosis with at least one of the following: history of hepatic coma; Child's class C liver disease or Child's class B liver disease with gastrointestinal bleeding.

d. Hospital admission for issue related to active metastatic cancer.

e. ANY medical inpatient ≥ 80 years of age.

f. Any medical inpatient for whom a physician answers "no" to the following question: "Would you be surprised if this patient died within the next year?"

The last item on this list, known as the 'surprise question' in the literature, has been evaluated in prospective studies involving cancer, dialysis and primary care patients, and shown to be effective in identifying patients with an increased risk of mortality in one year.[43]

The exclusion criteria were as follows:

a. Unable to read and speak the English language.

b. Cognitive impairment, including mild cognitive impairment, dementia of any type, or delirium. This was determined by review of the medical charts or clinical assessment by the research nurse or physician.

c. Patient has not had ANY discussions with a physician related to advance care planning and/or their wishes for care at the end of life

d. Hospitalization time of less than 48 hours.

e. Unable to participate for other reasons:
   i)Participant fatigued or too sick
   ii)Participant/family refusal to participate for other reasons
   iii)Healthcare team member feels that patient is not appropriate for enrolment

2.4.3 Collection of Demographic Information

In order to compare the demographic data of those who volunteered to participate versus those who declined, data was collected for all patients who met study eligibility. The following data were collected through chart review: age, gender, primary diagnosis (criterion by which the participant fulfilled eligibility for the study) and co-morbidities. Patients were asked about their education background and ethnic background (Caucasian versus non-Caucasian). If patients were eligible but declined to participate, they were asked to provide a reason for not participating, although it was made clear that they were not

obliged to provide a reason if they did not wish (as per research ethics standards).

2.5 Quantitative Strand

In the quantitative strand, the Quality of Communication (QOC)[44] questionnaire was administered to measure patients' self-rated satisfaction with their physician's ACP communication skills. In addition, a global rating item (GRI) was included at the end of the questionnaire to measure overall patient satisfaction with their physician's ACP and end-of-life communication skills. These items were completed with the assistance of a research nurse, who provided further explanation of the items if needed. This type of assistance is recommended by the tool developers, who suggest that, at this stage of the tool's development, there is no consensus on optimal wording and thus further elaboration is likely helpful in promoting understanding of the content (R. Engelberg PhD, email communication, April 17, 2013).

2.5.1 The Quality of Communication Tool

The Quality of Communication questionnaire (QOC) is a patient-reported 13-item instrument that addresses aspects of communication about EOL and ACP issues with their clinician. This instrument has been validated for a sample of palliative

care patients in the US (both inpatients and outpatients) as well as for a sample of patients with oxygen-dependent COPD.

The development of the QOC was informed by a series of qualitative focus group studies on patients with advanced COPD, AIDS and cancer as well as health care providers (physicians, nurses and social workers) and family members of a person who was recently deceased.[11,45-49] These qualitative studies resulted in a large collection of qualitative data that were subsequently analyzed and used to inform the development of the QOC. This body of work provides some assurance of the content validity of the QOC tool.[50] A paper describing the psychometric characteristics of the QOC in 2006[44] found that an initial 17-item scale suffered from many missing values (30%-87%) on four items in particular. These items tended to deal with family interaction with the physician, but often the family was either unavailable or did not yet have a chance to meet with the physician. Other excluded items required the participant to infer their physician's intentions based on their actions (e.g., "respecting the things in your life that are important to you"); many participants did not feel that they could confidently make such an assessment. The remaining 13 items underwent factor analysis to show that the items were best divided into two sub-scales, one dealing with general communication issues and the other dealing specifically with

end-of-life communication. Importantly, the authors mention that this was consistent with conceptual frameworks of physician communication that were developed from qualitative analysis of family conferences in the intensive care unit setting. Each item showed good loading onto its assigned sub-scale, and good discriminant loading (loading of the two factors differed by ≥0.25).[44,51-53] Cronbach alpha was 0.91 for the first sub-scale and 0.79 for the second, suggesting reasonable internal consistency within each sub-scale.[44,51] The authors also reported good convergent and discriminant construct validity, with higher scores in each sub-scale being significantly associated with relevant global validation items, whereas there was appropriately weaker associations with global items that were hypothesized to have less relevance to a scale. Test-retest reliability and responsiveness characteristics of the QOC have not been published. Although there was demonstration of good internal consistency within sub-scales, Cronbach alpha for the full set of items was 0.50, raising some suspicion about the utility of the QOC in its totality to measure quality of communication.[50] However, this may be reflective of the two separate dimensions being measured in the tool (general communication and EOL communication). In this study, the analysis that was conducted does not focus on the use of the total QOC score, but rather the association between each item

and a global rating item (GRI) that measures global satisfaction with end-of-life communication. As such, the internal consistency of either the entire QOC or the subscales is not relevant to the study at hand. The case report form, containing the selection criteria, the QOC tool and the GRI, is included in Appendix A.

The QOC is currently in the early stages of development and requires further validation work, including work on face validity and ongoing efforts to improve content validity. However, it is the only tool, to the author's knowledge, that focuses specifically on patient-physician EOL communication. Furthermore, it is a brief instrument that is less likely to cause fatigue or add to the burden faced by the seriously ill study population.

2.5.2 Quantitative Data Analysis

The strength of relationship between each item on the QOC questionnaire and the GRI was determined by calculating the Pearson correlation coefficients (r), and a correlation matrix was constructed.[54,55] The items with the three largest r values were selected and formed the short-list of priority behaviours that physicians could focus on in order to improve EOL and ACP communication skills.

In the case of items on the EOL communication subscale (items 7-13), a large number of participants responded

'didn't do.' These items pertained to discussion of specific EOL topics, such as "talking to you about how long you might have to live" and "talking to you about the details concerning the possibility you might get sicker." Given that the population of interest in this study is seriously ill inpatients, such discussions are important, and the absence of such discussions can be interpreted as being a missed opportunity. Therefore, it was felt appropriate to code a 'didn't do' response as zero. This coding strategy was used in a previously published paper in which the primary outcome was patient satisfaction as measured by the QOC tool.[56] Because of the large number of zero values, a decision was made to transform items 7-13 into binary variables which could potentially be used as 'dummy-coded' variables in the regression model: scores of 0-6 were assigned a value of zero, and scores of 7-10 were assigned a value of one. This cut-off point was chosen based on practical reasoning and consensus amongst research team members: a value of 6 on the QOC scale corresponds to one point above the mid-way mark (as a reminder, the scale ranges from 0, which corresponds to "the very worst I could imagine," to 10, "the very best I could imagine"). The goal was to determine if each of these items, when done satisfactorily from the patient's perspective, resulted in a higher GRI score than when done poorly or not at all. If a lower cut-off point was chosen,

such as 5 or 6 out of 10, it was assumed that this would include cases where the item received a neutral rating or was performed only marginally well as per the participant. Another alternative would be to select a cut-off point based on the presence of a bi-modal distribution, but given that the first peak occurs at zero for all of items 7-13, this would lead to combining all non-zero responses together, thereby confusing the effect of poorly performed items (i.e those with a score of 1-4) with those with higher ratings. For these dichotomized items, a Student's t-test[57] was conducted to detect any statistically significant differences in the mean GRI scores between two groups: those who had a response coded as zero versus one. This provided the opportunity to assess whether a good rating, versus a poor rating or absence, of the behaviours presented in items 7-13 had an impact on the GRI score. A correlation measure was not calculated for items 7-13 because of the dubious utility of such a calculation given that these items were frequently not performed.

In the secondary, exploratory analysis, a multiple linear regression model was developed using simultaneous regression modeling (in which all items selected for inclusion were put into the model at the same time). The GRI was treated as the dependent variable (DV) and the individual QOC items as the independent variables (IVs). The goal was

to construct a model that incorporated three QOC items that, *when combined together*, explained the most variance in the GRI score. In a clinical encounter, more than one of the behaviours described in the QOC is likely to be displayed by the physician. The bivariate correlation coefficients measured in the primary analysis describe the correlation of each item with the GRI, but do not factor in the effect of other behaviours occurring during the same encounter. A multivariate model, however, is able to take into account the effect of other behaviours and provide a measure of the unique contribution of each of the behaviours on the GRI score.

A set of items were selected for possible inclusion in the final model based on practical reasoning as to what items might provide concrete and specific advice on helpful behaviours. In addition, items that had a lot of zero responses (i.e. items 7–13) were not considered for inclusion in the model because there is low utility in measuring associations of items that frequently did not occur. These three items were intended to serve as a suggested combination of behaviours that, *when performed together*, may potentially improve the global rating of patient satisfaction with physician EOL and ACP communication *more so than any other tested combination of three items*. It should be emphasized that because there were several candidate variables for

inclusion, a large number of multivariate linear regression models were developed and tested, and the model with the highest adjusted R^2 was selected (this is discussed further in section 3.5). Due to multiple testing, there exists a high chance of finding a spurious result (i.e. a result may be due to chance alone). Therefore, the secondary analysis results presented herein are of an exploratory nature.

One of the assumptions of multivariate linear regression modeling is that the DV is continuous, or at least that "the arithmetic mean is an appropriate descriptor."[58] The GRI score is an ordinal variable but is being treated as continuous, which assumes that there is equal spacing between points. This is a common assumption that has a precedent; an example of its use in the EOL literature involves a study on patient-rated satisfaction with EOL care.[12] Another assumption of multiple linear regression modeling is the presence of a linear relationship between each IV and DV.[59] As will be discussed in section 3.4, an approximate linear relationship between each IV in the final model and the DV is suggested by the appearance of bivariate scatterplots. A third assumption is the presence of *homoscedascticity*, or equal variance along all points of the regression line.[59] The presence of homoscedasticity is supported by means of a plot of the residuals (see section 3.4).

Multicollinearity was evaluated by calculating the Variance Inflation Factor (VIF) associated with each independent variable, with the intention of dropping any independent variable with a high VIF (i.e. >10).[59]

IBM SPSS Statistics version 20 software was utilized for all statistical analysis.[60]

2.5.3 Quantitative Sampling Strategy

Norman and Streiner recommend a sample size for a multivariable linear regression model analysis of at minimum 5 or 10 times the number of independent variables in order to give assurance of the stability of the estimates,[59] whereas Bausell recommends at least 25 participants per IV.[58] Initially, the *a priori* goal was to recruit enough participants such that there was adequate goodness-of-fit for a multiple linear regression model that included all 13 items in the QOC, with the GRI being treated as the DV. Depending on the source, the minimum required sample size ranges from 65 (Norman and Streiner) to 325 (Bausell). However, the regression approach was later revised to focus on the identification of three items that together explained the greatest proportion of variance in the GRI. Given this revised approach, 15 to 75 participants would be required to support goodness-of-fit. This study recruited 92 participants, thereby exceeding minimum sample requirements.

2.6 Qualitative Strand

In the qualitative strand, interpretive description methods[61-63] were used to explore seriously ill patients' perceptions of the quality of ACP communication with their physicians. Borne out of the nursing discipline, this qualitative method is quite flexible in that it utilizes methods that originate in social sciences, but allows for some variation in data collection and analysis methods in order to provide answers that are relevant to health care disciplines. This method has been chosen because, unlike many of the more traditional methods (e.g., grounded theory, phenomenology) of the social sciences, the focus of interpretive description is on understanding real-life clinical problems rather than the advancement of a theory.[62] Furthermore, some of the philosophical underpinnings of interpretive description, including the recognition of a subjective reality based on one's experience, and the acceptance of seemingly contradictory realities of different participants, align well with the patient-centered focus of this study. It is the patients' views that are crucial to the results of this study.

During the semi-structured interviews, patients were asked questions that paralleled data being collected in the quantitative strand; specifically, their perspectives of physicians behaviours and skills during ACP and EOL communication. The initial interview guide included an initial open-ended question to

establish a common base, as well as optional trigger questions to stimulate data collection (see Appendix B for initial interview schedule). In addition, elaboration on responses to QOC items was also elicited, in another attempt to ensure parallel questioning. The initial question was: "Can you tell me about your experience discussing advance care planning with your doctor?" The interview schedule was reviewed and approved by thesis committee members prior to submission for approval at the institutional Research Ethics Board. With the input of the debriefer (see section 2.6.1) the interview schedule underwent two cycles of modification throughout the data collection process, as emerging themes led to the addition of new question probes. Only one interviewer (Dr. Amane Abdul-Razzak) conducted the interviews in order to ensure consistency in style and approach. The interviewer is a family physician who has studied interview techniques through graduate-level course work and internship experience. Prior to proceeding with the interviews, the rationale and purpose of the interview was explained to each participant in a language that was appropriate and understandable. Participants were encouraged to pose any questions and ask for clarification from the interviewer. All interviews were audio recorded and later transcribed.

2.6.1 Qualitative Data Analysis

In contrast to other qualitative methods, interpretive description does not stress reflexivity—the act of considering

how one's personal experiences, values, perspectives and other personal ideas shape the research enterprise and affect data interpretation—as an important exercise. In fact, the lens of the clinician-researcher is considered useful as it facilitates the generation of results that are of clinical relevance—similar to the pearls of wisdom a learner might receive from an expert clinician.[64] Therefore, the data collection and analysis was conducted through the lens of a physician-researcher, with a focus on what information would be pertinent to other front-line physicians.

As is common to many types of qualitative research, interpretive description methods encourage a concurrent and iterative process of data collection and analysis.[65,66] At each stage of data analysis, some concepts arose that were not sufficiently probed by the initial interview schedule, so additional questions were continually added as the study progressed. Each interview was transcribed and the researcher immersed herself in the data by reading through the transcripts multiple times while making interpretive memos about interesting ideas that were mentioned by the interviewee. Field notes were made after each interview in order to document initial interpretive 'hunches' and to describe items that may not have been captured in the transcription, including the physical environment, participant descriptors, emotional tone and other non-verbal behaviours.[67]

This enhanced the ability to later contextualize a transcript, thereby promoting a fuller and richer understanding of the participant's account. A constant comparative analysis was conducted, in which new data was compared to emerging themes to assess if it supported and further developed the themes, or seemed to be contradictory.[68,69] This allowed for the detection of patterns and commonalities in the data, and encouraged the researcher to challenge and test thematic generation with new data derived from participants with different demographic characteristics than those who provided the earlier data (i.e. people of a different age group, gender or with different health problems).[62] Initially, very broad, loosely-based categories were constructed with no commitment to the labelling of each category; in essence these functioned as 'data bins.'[64] With repeated immersion in the data, analysis, and comparison of the developing themes with new data, these categories were further sorted and organized into interpretive themes. As Thorne states, themes do not emerge from the data of their own accord, "as if data analysis fairies magically appeared in the night, so that by morning, the data were properly coded, sorted, and sequenced without the benefit of human intervention."[70] Thematic generation demanded an active interpretive effort: reflection on the underlying meanings and messages behind textual excerpts.[71] The final result of this interpretive analytic process is a

typology of themes related to patient perspectives of physician behaviours during ACP communication.[64] Qualitative analysis was conducted with the aid of NVivo 10 software.[72]

The rigour, or trustworthiness, of the study was bolstered by the use of several strategies that are recommended in the interpretive description and qualitative research literature. During debriefing sessions, transcripts and emerging themes were reviewed by a more experienced qualitative researcher with doctoral-level training in health research. These sessions took place during three different time points; each one after a set of four interviews had been completed and analyzed by the primary author. The goal of these sessions was to provide alternate viewpoints, pose challenging questions, and to interrogate the analytic process by asking the researcher how they arrived at certain meanings and interpretations.[73] At each of these debriefing sessions, consensus was reached with the primary author about emerging themes and the addition of new probing questions in the interview schedule.

In addition to being a researcher with PhD training, the second reviewer (Dr. Diana Sherifali), or 'debriefer,' has a clinical nursing background, and as such was able to provide a complementary disciplinary lens through which to view the data. Through this complementary perspective, insights were gained that may have been missed by the primary author.

Through the use of the *thoughtful clinician test*, evolving interpretations were shared with an internal medicine physician (Dr. John You) who has experience in ACP, both clinically and as a researcher, in order to receive feedback about the congruence of the findings with his experiences and to assess for the possibility of missing perspectives.[62,74] As an alternative to member checking, a *credibility check* was conducted whereby the researcher discussed themes and summarized interpretations from previous interviews with participants in order to assess whether this aligned with their personal views, or if the participant could provide an alternative perspective (S. Thorne PhD, RN, email communication, October 2012). As an over-arching strategy, this study attempts to make a coherent presentation of findings, and then support these by examples directly from the data. This strategy should increase confidence in the trustworthiness of the qualitative analysis by making the trail of logic easily accessible to the reader.[75,76]

2.6.2 Qualitative Sampling Strategy

An attempt was made to select a subset of the participants in the quantitative strand based on maximum variation sampling techniques.[71] This technique was employed as much as possible, given time constraints and participant availability, to recruit people with different combinations of

the following demographic variables: race (Caucasian versus non-Caucasian), gender, and diagnosis (cancer versus non-cancer). This is supported by the literature, which shows that Caucasians and females are more likely to participate in ACP.[77,78] In addition there is evidence to suggest that the uncertain prognoses associated with non-cancer illnesses, as compared to cancer illnesses, pose a barrier to ACP communication.[79] By selecting patients from a variety of demographic groups, it is more likely that a fuller picture of the patient experience is achieved; furthermore, any commonalities that arise will be more valuable because they occur despite the heterogeneity of the sample.[71] A subgroup of the quantitative sample, rather than a separate sample, was utilized in order to facilitate cross-comparison of the quantitative and qualitative data.

The sample size for the qualitative strand was set at 12 participants. The goal was to collect data from 12 in-depth and data rich interviews rather than a larger number because time constraints may have compromised the depth of the results if a large number of interviews were pursued. Determination of the sample size in an interpretive description study can be somewhat challenging; however, the aim was to capture some of the variation in cases while understanding "that patients theoretically represent infinite variation in relation to their experiences."[80] Given this assumption, data saturation

was not the goal, as a health researcher cannot be fully confident that they have "tapped all relevant human variation."[80] Instead, the goal was to obtain a deeper understanding of the patient perspective while still recognizing that there may be outliers.

2.7 Mixed Methods Phase

The QUAN and QUAL strands were given equal priority in this concurrent mixed methods study:[39,81] data from both strands were equally important in answering the mixed methods research question. The QUAL data was merged with the QUAN data for the purposes of elaboration, context and illustration. This can be thought of as putting the "meat on the bones of dry quantitative findings."[39] Furthermore, the MM design can be described as having an independent level of interaction, signifying the separate QUAN and QUAL implementation of research questions, data collection and analyses.[39,81] In addition to the separate QUAN and QUAL analyses, the point of interface occurs at the data analysis stage, where the QUAN and QUAL results were merged together.[39,81]

2.7.1 Data Collection

The QUAL and QUAN data collected in the first phase of the study were used to conduct the mixed methods analysis. Parallel questions were addressed in the quantitative and qualitative

strands of this study, allowing for the collection of data that is conducive to merging in the mixed methods analysis phase.[82] For example, during the qualitative interviews, some QOC tool items were presented as 'probing' questions.

2.7.2 Mixed Methods Data Analysis

From the QUAN data, three 'priority' behaviours were derived from the QOC items. Priority items were selected from the set of QOC items that could provide concrete and pragmatic suggestions on how to improve EOL and ACP communication. This was further narrowed down to a selection of three items with the highest Pearson correlation coefficients with relation to the GRI. Then, the QUAL data was interrogated once again by reading through transcripts to identify data that could elaborate and complement the understanding gained by the QUAN items. Specifically, when the transcripts were re-read during the MM analysis phase, the researcher asked 'why' questions: why might these QOC items be of particular importance to improving quality of communication from the patient perspective? As a result, the mixed methods analysis provides an understanding that is greater than the sum of its parts. In addition, a concerted effort was made to seek out potentially contradictory or divergent data, such as QUAL data that challenged the purported importance of the three QOC items included in the regression model. A 3x3 merged data analysis

table was created (see table 7), in which the QUAL themes were arrayed with the QUAN items.[82,83] This table serves as a display of representative examples of the mixed methods analytic findings.

2.8 Ethics

Research ethics board approval was obtained prior to the initiation of the study. A written consent form (Appendix C) included all of the risks, benefits and alternatives to participating in the study. A thorough informed consent procedure was conducted for each participant, which involved verbal discussion, time to consider options and ask questions prior to providing written consent. All identifying information captured on digital audio recordings was removed from the transcripts and the audio recordings were deleted as soon as the interviews were transcribed. Interview data was labeled with a unique study ID number. Electronic copies of interview transcripts were kept on a password protected computer in a secure, locked office. Hardcopies of case report forms and questionnaires did not include any identifying information and was locked in a secure cabinet within a locked, secure office.

The patients involved in this study were seriously ill, and thus could be perceived as being more vulnerable than other study populations. However, within the palliative research community it

is recognized that seriously ill patients in fact do not present an unusual or exceptional case: by following the usual ethical principles of proper capacity assessment, patient autonomy, and informed consent, one can ensure that they are protecting the interests of the study population.[84] Furthermore, it has been noted that although research participants may not directly benefit from the results of the research, the process of participating can provide therapeutic benefits by providing an opportunity to have one's voice heard, and giving a sense of purpose and "being involved in a social enterprise."[85]

CHAPTER 3: QUANTITATIVE RESULTS

3.1 Quantitative Strand Participants

Study recruitment occurred from October 2012 to February 2013. Due to limited staffing resources, a consecutive sample could not be recruited and an intermittent (i.e. depending on research nurse availability) convenience sampling strategy was employed instead. In total, 93 people met study eligibility and only one refused to participate; an 86 year old Caucasian male who met the criteria 'medical inpatient age 80 years or older' refused because family reported that he felt too unwell (see study recruitment flowchart in appendix E). Table 1 displays demographic data for participants in the quantitative strand. The average age of participants at the time of recruitment was 82.5 years, with a range of 42-98 years. The majority of participants were female, Caucasian, and were eligible for participation because they met the study criteria 'medical inpatient age 80 years or older' (see table 1). Study participants had a mean and median of 2.5 and 3 hospitalizations respectively over the past year, with a range of 1-7 hospitalizations.

Table 1. Characteristics of participants in quantitative strand

Characteristic	No. of participants(%)
Age	
40–49	1 (1.1)
50–59	0 (0.0)
60–69	8 (8.7)
70–79	11 (12.0)
80–89	55 (59.8)
>89	17 (18.5)
Gender	
Female	65 (70.7)
Male	27 (29.3)
Education Level	
Elementary school	44 (47.8)
High school diploma	33 (35.9)
Postsecondary degree or diploma	12 (13.0)
Missing	3 (3.3)
Ethnicity	
Caucasian	90 (97.8)
Non-Caucasian	2 (2.2)
Reason for Inclusion	
Congestive heart failure	17 (18.5)
Chronic obstructive pulmonary disease	17 (18.5)
Liver cirrhosis	1 (1.1)
Active metastatic cancer	10 (10.9)
Medical inpatient age 80 years or older	47 (51.1)
MD answered ‘no’ to surprise question	0 (0.0)
No. Hospitalizations over past year	
1	23 (25.0)
2	33 (35.9)
3	22 (23.9)
4	8 (8.7)
≥5	4 (8.7)
Missing	2 (2.2)

3.2 Descriptive Statistics for QOC Responses

There were very few missing values (i.e ‘I don’t know’ responses), likely because of the assistance each participant received from the research nurse. For items 1–6, which comprised the general communication subscale, the mean scores ranged from

6.2 to 7.4. For items 7–13, which comprised the EOL-specific communication subscale, there were a large number of 'didn't do' responses. These were coded as zero values, as explained in section 2.5.2. The mean values for items 7–13 presented in table 2 below are those of non-dichotomized values. Frequency histograms are presented in Appendix F.

Table 2. Quality of communication questionnaire responses

QOC Item Number	No. missing values (%)	Mean	SD	Range
1. **Using words that you can Understand**	1 (1.1)	7.4	2.0	(1.0-10.0)
2. **Looking you in the eye**	8 (8.7)	7.0	2.5	(0.0-10.0)
3. **Answering all your questions about your illness and treatment**	0 (0)	6.2	2.9	(0.0-10.0)
4. **Listening to what you have to say**	0 (0)	7.3	2.1	(0.0-10.0)
5. **Caring about you as a person**	1 (1.1)	6.3	2.4	(0.0-10.0)
6. **Giving you his/her full attention**	0 (0)	7.2	2.2	(0.0-10.0)
7. **Talking with you about your feelings concerning the possibility that you might get sicker**	4 (4.3)	2.3	3.4	(0.0-10.0)
8. **Talking to you about the details concerning the possibility that you might get sicker**	0 (0)	2.8	3.5	(0.0-10.0)
9. **Talking to you about how long you might have to live**	0 (0)	0.5	1.5	(0.0-8.0)
10. **Talking to you about what dying might be like**	0 (0)	0.3	1.5	(0.0-10.0)
11. **Involving you in the decisions about treatments that you want if you get too sick to speak for yourself**	2 (2.2)	5.1	3.4	(0.0-10.0)
12. **Asking about things in life that are important to you**	1 (1.1)	1.1	2.8	(0.0-10.0)
13. **Asking about your spiritual or religious beliefs**	0 (0)	0.3	1.5	(0.0-9.0)
Global rating item: Overall, how would you rate this doctor's communication with you about the types of care that you would want if you became sicker or too sick to speak for yourself?	0 (0)	6.9	2.1	(0.0-10.0)

3.3 Primary Analysis: Measuring Strength of Relationship of Each QOC Item with respect to the Global Rating Item

As an initial step, the Pearson correlation coefficient (r) was calculated for each of items 1-6 and the GRI score. This was conducted in order to get a sense of the strength of correlation between each IV and the GRI (the DV). The results are presented in table 3 below. Item 5, asking "how good is your doctor at caring about you as a person?" had the highest Pearson r (0.642), indicating this to be the highest *single* predictor item of the GRI score. Item 3, asking "how good is your doctor at answering all your questions about your illness and treatment," had the lowest Pearson r (0.557), which can be interpreted to mean that this item is the weakest single predictor of all 6 items. Since the square of the correlation coefficient represents the proportion of the GRI score explained by an item, it is easier to compare the r^2 values of each item rather than the Pearson r values directly.[54] These are provided in table 3 below, showing that item 5 explained most of the variance compared to all other single items (41.2%) while item 3 explained the least (31.0%). It should be noted that there is only a 10.2% difference in the proportion of explained variance between the strongest and weakest predictor items. In addition, item 5 (caring about you as a person), had a lower mean score (6.2; see table 2) than most of the other items included in table 3. This low score, combined with a fairly strong correlation coefficient, presents an opportunity for improvement in quality of EOL communication. However, it is not clear how one

can teach physicians to 'care,' and so item 5 does not provide a specific or practical example on how to improve EOL communication.

Table 3. Bivariate correlations (Pearson r) for items 1–6 and global rating item

	N	**Pearson r (correlated with GRI)**	**P value**	**r^2 (proportion of variance)**
Item 1: Using words that you can understand	91	.577	<.001	0.333 (33.3%)
Item 2: Looking you in the eye	84	.609	<.001	0.371 (37.1%)
Item 3: Answering all your questions about your illness and treatment	92	.557	<.001	0.310 (31.0%)
Item 4: Listening to what you have to say	92	.602	<.001	0.362 (36.2%)
Item 5: Caring about you as a person	91	.642	<.001	0.412 (41.2%)
Item 6: Giving you his/her full attention	92	.579	<.001	0.335 (33.5%)

Of Items 1–6 presented in table 3 above, the three that provide practical examples of how to improve EOL care *and* have the highest r values are: item 2 (looking you in the eye), item 4 (listening) and item 6 (giving you full attention). Therefore, items 2, 4, and 6 comprise the short-list of priority behaviours that hold the most promise for improving physician EOL and ACP communication skills from the patient perspective.

3.4 **Measuring the Statistical Significance of Differences in Mean GRI Scores for Dichotomized Items**

As discussed in section 2.5.2, Items 7–10 were dichotomized to two values: scores of 0–6 were assigned a zero value and scores of 7–10 were assigned a value of one. A t-test was conducted for each of these items in order to look for a statistically significant difference in mean GRI scores between the two groups (i.e. those whose response were coded as zero versus one). In the case of items 7, 8, 10, 11 and 12 the t-test statistic suggests a statistically significant difference in the mean GRI scores between the two groups, with the group coded as zero having a lower mean than the group coded as one. For example, for item 7 'talking about your feelings concerning the possibility you might get sicker,' the group that was coded as zero had an average GRI score that was 1.39 points lower than the group that was coded as 1 (see first row, table 4). However, a major limitation in this analysis was the large number of zero values for items 7–10 and 12–13, for which 81–99% of responses were coded as zero. As a result, for these items the SDs of each of the comparator groups are substantially different, especially in the case of items with >90% zero values. Norman and Streiner caution that, if the two SDs are very different "one might rightly pause to question the whole basis of the analysis"[57] since the t-test is founded on the assumption that the two samples are drawn from the same population and thus have the same mean and SD. As a result, the t-test statistic for items 9, 10, 12 and 13 are difficult to interpret.

From a more practical perspective, the utility of measuring differences between two groups is questionable when there are very few participants in one of the groups.

Table 4. T-test for difference in mean GRI score in groups with responses coded as 0 versus 1 (Items 7–13)

Item	No. 0 response (%)	No. 1 response (%)	t-test	P value	Mean diff.	95% CI of difference	
						Lower	Upper
7. **Talking about feelings concerning possibility you might get sicker**	72 (81)	17 (19)	−2.56	.017	−1.39	−2.50	−0.27
8. **Talking about details concerning possibility that you might get sicker**	74 (81)	17 (19)	−5.31	<.001	−2.29	−3.17	−1.41
9. **Talking about how long you might have to live**	91 (99)	1 (1)	−1.52	.133	−3.19	−7.37	0.99
10. **Talking about what dying might be like**	90 (98)	2 (2)	−14.7	<.001	−3.22	−3.66	−2.79
11. **Involving you in decisions about**	55 (61)	35 (39)	−3.02	.003	−1.26	−2.10	−0.43

treatments that you want if you get too sick to speak for yourself							
12. **Asking about things in life that are important to you**	82 (90)	9 (10)	−4.82	<0.001	−2.39	−3.46	−1.32
13. **Asking about your spiritual or religious beliefs**	90 (98)	2 (2)	−0.59	0.661	−1.18	−25.3	22.98

3.5 Secondary Analysis: Multivariate Linear Regression Modelling

Since it is difficult, and of questionable utility, to accurately measure a correlation between EOL-specific communication items and the GRI if these items were reported as not occurring in most cases, binary-coded items that had a large number of zero values (>80%) were excluded from the multivariate model (i.e. items 7–10 and 12–13). Item 11 (involving you in decisions about treatments if you too sick to speak for yourself) had the highest number of non-zero responses in this group, with 61% of the responses coded as zero and 39% coded as one, and therefore was considered for inclusion in the regression model.

Item 5 (how good is your doctor at caring about you as a person) was excluded despite having the highest Pearson correlation coefficient out of items 1-6 because it does not provide a practical and specific suggestion on how to improve communication, which was a main criteria for inclusion (see section 2.5.2). As a result, 6 items were considered for inclusion in the multivariate model: items 1, 2, 3, 4, 6 and 11. Scatterplots of each of Items 1-6 versus the GRI score are presented in Appendix H. These plots reveal a roughly linear relationship between each of the items and the GRI (the DV), thereby meeting one of the assumptions of multiple linear regression.

As described in section 2.5.2, the intent was to construct a model with the three QOC items that accounted for the largest amount of variance in the GRI score. With 6 items, there are 20 unique combinations of 3 items as per the following formula:

$$C_r^{\,n} = \frac{n!}{r!(n-r)!} = \frac{6!}{3!3!} = \frac{720}{36} = 20$$

Where n = number of items
r = number of items taken at a time

For each combination of three items, a multivariate linear regression model was constructed, and the model with the largest adjusted R^2 was selected. A table displaying the adjusted R^2 for

all 20 models is included in Appendix I. As mentioned in section 2.5.2, this secondary analysis strategy involved multiple testing and thus there is a high chance of spurious results. As such, the results of this analysis are of an exploratory nature only.

The model that included items 2(looking you in the eye), 3(answering all your questions about your illness and treatment) and 6(giving you his/her full attention) had the highest adjusted R^2, with a value of 0.604. The model with the second highest adjusted R^2 explained almost as much variance in the DV, with a value of 0.582 (i.e. 58.2% of variance explained with this model versus 60.4% in model with the highest R^2) and included items 2, 3 and 4(listening to what you have to say). Table 5 below presents the correlation coefficients for the final model along with the 95% confidence intervals. The F-test was found to be highly significant ($p < 0.001$); this can be found along with the other regression statistics in appendix J.

Table 5. Coefficients for multivariable regression model including items 2 (eye contact),3 (answering questions), and 6 (full attention)

Item	**Unstandardized Coefficient (B)**	**P value**	**95% CI for B**	
			Upper	Lower
2 **(looking you in the eye)**	0.234	0.001	0.100	0.369
3 **(answering all your questions about your illness and treatment)**	0.243	<0.001	0.134	0.352
6 **(giving you his/her full**	0.331	<0.001	0.169	0.493

attention)				
Constant	1.375	0.009	0.357	2.393

The multiple linear regression equation can be written as:

$$\hat{G} = 1.375 + 0.234(Item2) + 0.243(Item3) + 0.331(item6)$$

where $\hat{G}$ = estimated GRI score

The model suggests that for every single-point change in item 2, the GRI score would change by 0.234. Similarly, a one-point change in items 3 and 6 would result in a change in the GRI score of 0.243 and 0.331 respectively.

A plot of the residuals is provided in appendix J. The random appearance of the points suggests equal variance along the regression line, or homoscedasticity.

3.6 Summary of Quantitative Results

The primary analysis involved the calculation of Pearson correlation coefficients for items 1-6. Although item 5(caring about you as a person) had the highest r value, it was excluded from the final list of priority behaviours as it did not provide a specific example of how to improve communication. Items 2 (looking you in the eye), 4(listening) and 6 (giving full attention) had the next highest three r values and thus comprised

the short-list of priority behaviours: behaviours that were suggested by the analysis to be most likely associated with a higher GRI score, thereby indicating patient satisfaction with the communication encounter. These items are used in the merged analysis during the mixed methods phase of the study (Chapter 5).

In the secondary analysis, multiple linear regression modelling suggests that the following three behaviours, when taken together, explain the most variance (approximately 60%) in the global rating of satisfaction in comparison to any other tested combination of three items: item 2(eye contact); item 3(answering all questions about illness and treatment); and item 6(giving patients full attention). The model involving items 2, 3 and 4 (listening to what you have to say) differed by only 2% in the proportion of variance explained. This analysis involved testing a total of 20 combinations, and so the results should be treated as being of an exploratory nature.

CHAPTER 4: QUALITATIVE FINDINGS

4.1 Qualitative Strand Participants

A total of twelve medical inpatients participated in the qualitative interviews. The average age of interviewees was 78 years old. Two participants had a primary cancer diagnosis, including one with metastatic breast cancer and one with metastatic colorectal cancer. Ten participants had a non-malignant primary diagnosis, including chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), idiopathic pulmonary fibrosis (IPF) and diagnoses that fit into the eligibility criteria labelled 'medical inpatient age 80 years or older.' The majority of participants were females, and all were Caucasian. Table 6 presents a summary of the characteristics of interview participants. Of the two non-Caucasian people who participated in the QUAN strand of the study, both refused to take part in the QUAL strand without providing an explanation. The interview times ranged from approximately 22 minutes to 78 minutes with an average length of 42

minutes. Most interviews were terminated by the interviewer when it was felt that a satisfactory amount of data had been collected; however, in two cases the interview was terminated by the patient due to fatigue.

Table 6. Characteristics of the qualitative interview participants

Characteristic	No. of participants (%)
Gender	
Male	3 (25)
Female	9 (75)
Age (years)	
40–49	1 (8)
50–59	0 (0)
60–69	3 (25)
70–79	1 (8)
80–89	4 (33)
>89	3 (25)
Ethnicity	
Caucasian	12 (100)
Non-Caucasian	0 (0)
Education Level	
Elementary school	2 (17)
High School Diploma	6 (50)
Post-secondary school (university or college)	3 (25)
Missing	1 (8)
Primary Diagnosis	
Cancer (site)	
Breast	1 (8)
Colorectal	1 (8)
Non-cancer	
Chronic obstructive pulmonary disease	3 (25)
Idiopathic pulmonary fibrosis	1 (8)
Congestive heart failure	1 (8)
Medical inpatient >80 years old	5 (42)

4.2 Presentation of Findings

Although participants were eligible for the study only if they had endorsed having some form of ACP discussion with a physician in the past, many informants reported that discussions were of a superficial nature and related primarily

to preferences for resuscitation. In these cases, the researcher encouraged interviewees to discuss what they perceived they would want if a more detailed ACP conversation occurred in the future. Many participants spontaneously shifted to accounts of EOL and ACP experiences with family members for whom they were the informal caregiver, and while this proxy account was not the primary purpose of the study, it often served as a vehicle for expression and elucidation of their personal preferences.

In a few instances, participants had an inconsistent account of the occurrence and depth of ACP communication; at some points in the interview it would appear that very little patient-physician exchange occurred while at others it was revealed that items such as hospice care, the limited benefit of aggressive measures in their current health state, and future deterioration had been addressed. As will be subsequently discussed, the inconsistency of accounts was, in and of itself, an important finding.

Three major themes were generated from data description and interpretation, and these pertained to: nonverbal cues that conveyed attentiveness to the whole person and compassionate care; acknowledgment of the importance of family ties and respect for a person's life story; and guidance through the challenging transition to end of life. Within

these major themes are sub-themes as discussed in the following text. Some excerpts are grammatically modified for the purposes of clarity, but care was taken to avoid altering any meanings. In cases where the excerpts were disjointed or awkward, paraphrasing was used instead of the verbatim quote. In some excerpts, the use of 'I' refers to the interviewer's voice and 'P' to the participant's voice. All names provided in the data excerpts have been changed to protect participant confidentiality.

4.3 The Analytic Trail

Initially, text excerpts from the first four interviews were grouped together based on their conceptual similarity. These groupings were assigned a label, but the focus was on recognizing patterns and similarities rather than committing to inferential understandings or the naming of themes. After the completion of the first four interviews, transcripts were read multiple times, analytic memos were documented, and data were subsequently sorted into categories. These included categories such as 'truth-telling,' 'perception that doctor cares about the patient' and 'baseline relationship.' At this point, the first four transcripts and initial categorizations were reviewed by the debriefer in order to evaluate the appropriateness of the initial categorizations, and this was discussed during the initial debriefing session (see section

2.6.1). During this session, the debriefer challenged the accuracy of applying the label 'truth-telling' to excerpts related to being candid about a difficult prognosis or diagnosis, since it made a surprising inference that physicians who did not discuss these items were intentionally deceiving their patients. A new question was added to the interview schedule in order to further explore how patients perceived the act, or lack thereof, of communication about difficult medical conditions. Furthermore, one category entitled 'patient giving back to the physician' was subsequently abandoned as it was found to be incongruent with the study's focus on *physician* behaviours. Two other probes were added to the interview schedule after this session: one inquiring about the importance of family involvement during ACP communication and how a physician might accommodate this; and one asking patients to consider if there were any disadvantages to candid communication from a physician about a difficult diagnosis or prognosis.

Two more cycles of data collection, analysis and debriefing occurred, each time after the completion of four more interviews. At each debriefing session, new data were compared and contrasted to pre-existing data and the developing themes. After the second debriefing session, it was found that participants consistently used terms suggesting honesty when talking about a physician's full disclosure of

difficult news, and terms that signified deceptive behaviour in cases where this was avoided. As such, an important theme, 'candor,' was developed. The categories 'baseline relationship' and 'perception that doctor cares' developed into the themes 'respecting one's background' and 'nonverbal behaviours,' respectively, to sharpen the focus on physician behaviours and attitudes. Additional probing questions about mental readiness to absorb information related to EOL and ACP options were generated because of data that seemed to highlight the challenges of ACP communication when a patient was unable to fully accept the gravity of their health condition. These were pursued during the last four interviews, resulting in the generation of the theme entitled 'friction between candour and readiness.'

Once all data were collected and a final analytic cycle occurred, the primary researcher contemplated the generation of a meta-theme 'caring for the whole person,' under which all other themes would fit. Participants often reflected that many diverse activities, including giving a candid prognosis, maintaining eye contact, and involving family, provided evidence of the physician's caring attitude; thus, an over-arching theme about 'caring' seemed to be appropriate. However, after further reflection and analysis, a decision was made to abandon the meta-theme as this was thought to shift the focus away from interpreting and illustrating each

individual theme, which was the main goal of the analysis, to defending the claim that 'caring' is the unifying concept.[76]

In total, 238 pages of single-spaced transcripts were reviewed by both the primary author and the debriefer during the analytic process. The following discussion presents the major themes and subthemes that resulted from this process.

4.4 Qualitative Themes

NONVERBAL BEHAVIOURS

A recurring theme in many interviews was that certain nonverbal behaviours had a profoundly positive effect on the communication encounter. Most of these actions did not require planning, the allotment of extra time, or specialized tools. However, they increased a person's confidence that the physician was putting forth an effort to understand them, and thus would be better able to tailor a plan to meet their individual needs, as expressed by this 84 year old woman:

> *I mean you're asking about an illness or condition and he knows so he should give you his full attention as well as looking at you physically, your mind and your face and what you're talking about because that all helps him understand. You can't just look at something and write down answers without looking at the person, you know. You're not getting anything of the person in there, are you? I think he needs to know you as a person.*

Respondents sometimes had some difficulty providing concrete examples of nonverbal cues that were helpful or harmful, instead saying things such as:

He's just a type of person that you can't help but like. When you walk into his office for an appointment, you immediately feel confident that he's going to help you right away.

However, with further probing it was revealed that data pertaining to nonverbal cues could be separated into two separate subthemes: emotional expression, and being present.

Expressing Emotion

A sympathetic facial expression or even an overt expression of sorrow was, at times, reassuring evidence that the physician truly cared for a person's well-being. This was especially the case when it came from a family physician with whom there was a long-term relationship. In one case, a participant differentiates between a seemingly distant oncologist, who seemed emotionally untouched while conveying difficult news, and an expressive family physician:

P: *The difference between my [family] doctor...is he is the type of doctor that would be very sad over the fact...*
I: *So is it always a good thing for the doctor to express emotion in your opinion?*
P: *Yeah, I think so. I think so.*

In another case, a middle-aged woman with idiopathic pulmonary fibrosis (IPF) reported that her physician shed tears while conveying that her prognosis would be poor if she did not receive a lung transplant. She contrasted this encounter with others:

*Now, the other doctors just came out and told me. They d*idn't care.

The physician who visibly conveyed emotion provided confirmation that their patient's well-being was important to them. Moreover, they showed that they were cognizant of the deep impact this would have on their life. During times of serious illness and frailty, people are often forced to navigate a confusing and often impersonal health care system, so a sense of personal connection with their physician may be desirable. It may also provide an opportunity for catharsis: by sharing their deep sorrow with their physician, patients may be able to derive some strength to continue their arduous journey.

Interestingly, even though she associated emotional expression with caring, the participant with IPF endorsed that while emotional expression from her family physician was positively regarded, the same behaviour from her specialist physician would be disturbing:

P: *Now with the specialist, uh, maybe I'd want him to hold back with his feelings.*
I: *Why?*
P: *Uh, because...he's the one who is looking after me about the lungs...then I'd worry.*
I: *Why would you worry if your specialist was emotional?*
P: *Because I'd want him to answer right away if there was something wrong. I wouldn't want anything to get in our way...*
I: *What do you think emotions would do to him?*
P: *It would tend to make me die quicker.*

I: *How is that? How do you think the emotions would affect a specialist?*
P: *Clearly it would make me die quicker.*

In this case it appears that the specialist physician was sought out solely for his medical expertise; the participant feared that emotional attachment would cloud his objectivity and thus preferred a more aloof approach. Another participant, a woman with advanced COPD, rejected the notion that there was any role for emotional exchange between a physician and a patient. When asked how she would feel about a physician who tried to elicit her feelings about her health circumstances, she responded as follows:

I wouldn't discuss my feelings with anybody, you know. I want the facts. Feelings are private things.

Here again, the physician's role was well-delineated as a medical expert and to this participant it seemed inappropriate to express emotions. It is important to note that these two cases represent a deviation from the data rather than a predominant theme; in all other interviews the participants endorsed that emotional expression would be desirable from their physician, regardless of their field of specialty.

Being Present

When probed for specifics on the behaviours of physicians who were perceived to be good communicators,

simple items seemed to have the largest impact. Eye contact was associated with the sense that the physician was: a) paying attention, and b) giving people the respect they deserved. A typical response was similar to the one articulated by this 82 year old woman:

I: *How good is the doctor at looking you in the eye...and what does that mean to you?*
P: *That he's paying attention and once again it goes back to respect. He's asked you a question. He's listening to your answer.*

Another typical response is as follows:

I: *How important is it to you that a doctor makes eye contact?*
P: *Very important because then they're actually listening to you, not dreaming up what they're having for supper, you know, or what their wife is doing, or [thinking] how much longer do I have to be here?*

Many respondents felt that it was highly important that a physician gave them their full attention during an encounter because it was a determinant of a successful medical consultation. A few people shared a belief that while physicians may have the medical knowledge, they could not solve a clinical problem without being fully aware of a patient's circumstances and personal story. Eye contact provided assurance that the physician was 'tuned in,' and a few participants conveyed that this would give them more confidence in the physician's assessment and advice.

The absence of eye contact was consistently described in very negative terms. A physician who would not maintain eye contact could easily lose the respect and confidence of her patients, as illustrated by the sentiments of one female participant with COPD:

I: What does that convey to you if they [doctors] don't look you in the eye?
P: Sneaky. Sneaky. Untrustworthy, you know. Totally dishonest.

One notable exception was a case in which a patient had a very high regard for his family physician and chose to justify his lack of eye contact:

He's the kind of doctor who very rarely looks too long in your eyes, not that he's trying to avoid anything but he's that shy kind of doctor. But he's very, very good, and when he diagnosis something he's usually spot on, you know.

In this case, the patient had a fond familiarity with his physician, and had built a trusting relationship over several years. As a result, he felt that he understood his physician well enough to be convinced that his lack of eye contact was inconsequential. This example suggests that, in some cases, a patient's global feeling of satisfaction with a physician may cause him to make allowances for some seemingly suboptimal behaviours. This was an atypical finding; all other participants felt that eye contact was a high priority behaviour.

A physician's body language could effectively convey openness to information exchange. A physician who positioned her body in a way that invited two-way communication and, on a more pragmatic level, accommodated the needs of the patient, garnered respect and appreciation from the patient. Subtle behaviours, such as putting down a pen during a discussion, were highlighted as important gestures that signified a physician's mindfulness of the person in front of them.

Just as participants expressed that eye contact shaped their perception of a physician's trustworthiness, so too did certain types of body language. One particularly illustrative case involved a decision-making process about an aggressive intervention:

An elderly female patient had previously indicated that she preferred mainly comfort measures, but a potentially life-threatening episode caused her to have second thoughts and she was reconsidering the possibility of cardiac surgery. She wished to address her options with the physician. When asked to describe her positive experience with the physician, she states:
"he got down on his knees there and he took my hand, you know, and he talks directly in your face. And you know, he was very, very self-assured. I felt as though I've got confidence in him."

Notably, the patient made no mention of the words he spoke. Rather, it was his body language and demeanor that 'spoke volumes,' put her at ease and increased her confidence in his

abilities. On the other hand, certain nonverbal behaviours could convey an insensitive attitude, which could add to the patient's distress:

A female patient describes a conversation with her specialist physician about cardiopulmonary resuscitation (CPR). After asserting his opinion on the futility of CPR, he abruptly left the room to see another patient. The participant speculated that perhaps it was the physician's emotional discomfort that caused him to leave the room, but regardless of his reason, she felt that the physician did not empathize with her.

SITUATING

In this second major theme, the term 'situating' is used to refer to the process of acknowledging a person in the context of his social milieu, including family and loved ones, as well as his background or life history. The two sub-themes within this category are: acknowledging family roles, and respecting one's background. Physicians who had built intimate relationships with patients and their loved ones over time were more likely to be regarded as good communicators in general, and more successful EOL and ACP communicators in particular. An important concept related to the ability of a physician to acknowledge a person's multiple familial and social roles and relationships, and to use that knowledge as a lens through which to discuss EOL issues such as diagnosis, prognosis, and surrogate decision-making. Similarly, physicians who were respectful of the rich life

history of the people they were caring for were more likely to have the doors of communication opened for them, to preserve the patient's dignity during the encounter, and to understand the patient's values and priorities.

Acknowledging Family Roles

In some cases, people indicated that their family physician took care of multiple family members and was witness to the development and growth of both themselves and their loved ones. This alone was enough to garner a sense of trust and allow the patient to feel comfortable in communicating with the physician. In other cases, a more specific consequence of knowledge of family roles was that the physician engaged and consulted with key family members during EOL and ACP conversations. In fact, the failure to involve family members during such conversations was perceived as a suboptimal behaviour, and the interviews revealed two distinct patterns of how this would be of negative impact. First, it was frequently expressed that family provided an important emotional support network, and their presence during such conversations allowed them to form a type of psychological and emotional refuge for the patient. Participants felt that a physician who discouraged or avoided family involvement ran the risk of worsening the traumatic impact of receiving such information:

> ***P:*** *When my mom was really sick we all went there [the hospital] and the doctor kind of sat and looked around the table and said, 'There's too many people here.' They wanted to take her into a room and tell her she had cancer.*
> ***I:*** *By herself?*
> ***P:*** *By herself. And I said, 'You know what? We're all coming. You're just going to have to deal with it, because you're going to tell her, you're going to get up and you're going to leave the room and we're going to be left with the aftermath.'*

Secondly, the family network was viewed as one in which there existed a profound interdependence; not only did family members take care of the patient, but the patient continued to take care of loved ones even in the midst of deteriorating health and functional decline. One of the ways that participants were able to show that they were continuing to look after loved ones was by including them in EOL and ACP conversations. By explicitly expressing their wishes for their future health care to family members, and sharing their plans for post-mortem events such as the funeral arrangements, participants felt that they could alleviate some of the psychological and financial caregiver burden they might later face. In one example, a woman with advanced COPD explains why discussing her desires to avoid intubation with her son is important to her. With a shaky voice, and tears in her eyes, she asserts that it would alleviate some of the uncertainty he would feel while taking care of her at the end of life:

I've already spoken to Jim about decisions, and, you know, resuscitation. He has to understand where I'm coming from and I want him to be involved in it...but I don't want him being lost, you know, with not knowing, not having had that conversation. So we had it and he's okay with it.

A case involving a mother of two young children represents an important variation on this theme. In this case, the woman explains that her major goal in planning for EOL was to make sure that her children were cared for, and never saw her suffering. She was intent on making plans that allowed her children to see her only when she was in reasonable health; when her health deteriorated she wanted her children to be with other family members in order to avoid any trauma they may experience by witnessing her declining health. She was also preoccupied about their welfare and future prospects if she were to die:

I: What are you trying to achieve by talking to your family about it [ACP]?
P: First of all for my kids, to know where my kids are going to be because me and my husband, we're going to be ex-husband and ex-wife soon. It's hard. That's harder to put up with than death if I die.
I: You mean for your kids it's hard?
P: Yeah, much harder. I know they need me to stay alive. One is [age] and one is [age]. The [younger one] needs me more than the [older one]. It's better that he sees that I'm fine than being real sick.
I: You mean you don't want him to see you suffering and getting worse?
P: Right. That's right.
I: You'd rather be around as healthy as you can.
P: Or not be around at all.

Her role as a mother surpassed all other priorities, and failure to recognize this may lead to fruitless conversations. On the other hand, by understanding and respecting the importance of her familial roles, a physician could increase the likelihood of engaging in ACP discussions that aligned with her values and priorities.

As a testament to the inextricable connection between family members, some participants explained that they would consider their family members' opinions with as much weight as their own, or even consider changing their ACP decisions at the request of a family member in order to protect them against emotional suffering:

One woman with a serious heart condition, who previously asked for comfort measures, changed her mind after speaking with her sons and decided to undergo an angiography with possible placement of a stent. She clearly explained that she did this to ease the minds of her children: while she wanted to forego invasive testing, her sons wanted her to undergo the procedure both for therapeutic reasons and in order to obtain more information about the condition of her heart.

Another participant describes how she would arrive at ACP decisions only through consensus with her children:

P: *When I was a child there wasn't very much talk about whether or not to keep someone alive, you know. Sometimes they did and people led dreadful lives I think...I don't know if the family had a choice or if it was the doctor's choice that they kept them going. But for my family I value their opinion and we know each other very well now so that we...I think if one of them opposed it, it would upset me a lot.*
I: *Opposed your decisions?*

P: *Yes. If they said, 'No, I don't like that' but they haven't, any of them. They've all agreed.*
I: *How would it affect your final decision if one of your children opposed your point of view?*
P: *Well I just wouldn't die yet [laughs]. I'd keep going until I'd sorted it out. Well we'd talk about it. That's what we do if it's something that's really bothering any of us. We'd talk about it and see if it could be sorted, you know.*

In effect, 'the patient' can be thought of as not only the individual with the illness, but also the close network of loved ones who consult with the individual, are affected by their healthcare decisions, and often influence their decisions. Failure to include them in the conversation may in fact be futile, just as any decision-making process can be futile when key stakeholders are not invited to the conversation.

Another important concept that emerged from the data relates to patient beliefs that ACP discussions should occur primarily within the family rather than with a healthcare provider. Participants asserted that a physician could never know their background, preferences and values to the same extent as family, and for this reason family members were better candidates for the conversation. In situations of incapacity, family could then convey ACP decisions to the physician. When asked with whom they would prefer to discuss ACP, a typical response is illustrated by the following excerpt:

I suppose it comes down to the fact that there's much more personal connection to the family. The doctor is just often, um, technological stuff, right?

The desired direction of information was from family members and the patient to the physician, and participants tended to reject the notion that the physician should initiate and guide a person through the ACP process:

Because I want my kids to know first, and I don't want them to hear 'Well your mother told me this is what she wants' kind of thing, you know? I think your family should be first to know and then they can even tell the doctor if something happened to me: 'This is what my mom wants.'

In general, participants did not believe that physicians should have a central role in ACP conversations. While some people felt there was some benefit in speaking to their physician during the ACP decision-making process, this was mainly to obtain information from the medical expert, at which point they would use this knowledge to inform future conversations with family.

In a slight variation of this theme, physicians were sometimes perceived as potential facilitators when communication between family members was exceptionally difficult. In this case, participants who had a long-standing positive relationship with a physician saw them as someone

who could reach out to family members to provide corroborative information in a sensitive and personal manner.

The doctor should talk to the immediate family, whoever is the most responsible member of the family and have that person try to put it across to whoever it is...because very often older people, even when they're getting sick like that they don't realize they are that sick. And you know, often people go senile when they're getting older and a lot of them are not with it. And I think they refuse to accept. Even if you as an expert were to turn around to a person like that and say 'I know you're going to die next week so what do you want to do? I think that person would turn around and say to you 'I don't believe you.' But a close member of the family...could say 'Well dad, you know we love you but we have to know what you would like us to do because we want to make sure that you leave this world as happy as you can be under the circumstances and knowing that your wishes were fulfilled.'

It is made evident in this case that even when a very strong relationship exists between a patient, their family and the physician, participants still perceived that the physician had a supportive role, while family took the lead in ACP conversations. By leveraging the support of family members, a physician could make use of their deep connection to facilitate information-sharing. As this participant suggests, the physician is a medical expert, but perhaps more importantly, the family members are the experts on the patient as a complex and multi-faceted individual. A physician who can combine her own medical expertise with family members' rich personal knowledge of the individual is more likely to have satisfactory outcomes during communication endeavours.

Respecting One's Background

In this seriously ill study population, people expressed a need to preserve their self-identity, which was sometimes felt to be under threat as they became exposed to often impersonal health care institutions. When giving examples of a highly regarded physician, respondents often pointed to a family doctor who took an active interest in their personal life. Over the years, such physicians accumulated knowledge of the milestones, trials, and triumphs that their patients experienced, and as a result the physician was regarded as a friend. This intimacy helped to facilitate ACP conversations. In comparing a long-term relationship with a retired family physician to the one with a newer physician who has taken his place, a participant explains how knowledge of one's personal history can impact ACP conversations:

P: *I don't know about this [new] doctor but Dr. Frank, he knew the whole family. He knew everything about us...he knew we had a cottage up north and knew we went up there and we all enjoyed it and everything else. And he knew...I'd been a patient for so long that he practically knew everything about me, you know. So I think the longer you go to a doctor I think the more relationship there is between the two of you.*
I: *So that rapport, how do you think that rapport would affect your talking about these advance care planning issues?*
P: *I'd be more open and I think he would be too because he'd be more comfortable, you know.*

Specialist physicians and physicians in an acute care setting are disadvantaged in this regard, as they are usually unable

to form long-term relationships with their patients. In such circumstances, the mere acknowledgement of this limitation, and recognition of the 'whole person,' may help people feel that they are valued and being appropriately cared for.

A 98 year old male patient with congestive heart failure recalled his dissatisfaction with a specialist physician who, over twenty years ago, had diagnosed him with cognitive dysfunction. The physician shared information about the patient's expected health deterioration and expressed incredulity that he was still working. The participant was angry at what he perceived to be a presumptuous attitude; he felt that the physician displayed disregard for his background as a high-performing professional. He explained that medical knowledge is only one important aspect of EOL and ACP discussions, and that knowledge of the person's background is also important though challenging to obtain given the limited number of encounters between a patient and a physician. When asked how the physician should have approached the situation, he offers:

"Well, you know, if I were a doctor talking to a man that was a hundred years old I'd be slightly humble about it."

Although the physician is privileged with medical knowledge, the patient is the expert in their own life. Physicians who can recognize that each patient has had a life journey as rich as their own may be more likely to communicate in a manner that conveys respect, humility and a commitment to an individualized approach to ACP communication.

The majority of interview participants were asked about their views on discussing spirituality with a physician. Most participants related the term 'spirituality' to a religious institution or their independent and individual

relationship to God. Although brought up by the interviewer in some cases, none of the participants related spirituality to existentialism or related ideas. For many people, spirituality forms an important aspect of their personal identity. Thus it might be anticipated that a physician's inquiry into one's spiritual beliefs would be desirable, as it seems to align with the endorsed need for a personal connection with the physician. However, when participants were asked to provide their views on discussions about spirituality with a physician, responses ranged from indifference to disinclination. One participant explains:

I don't think that's really important. I mean as long as your family knows about it. Like, I'm an Anglican, Protestant. I think if things are settled between my minister and myself I don't think the doctor...he has enough to do to look after me without worrying about my spirituality.

Some participants expressed that they would strongly dislike any physician's attempts to discuss spirituality. For example, the female participant with rapidly progressive IPF indicated that this would cause her to doubt a physician's aptitude, as she felt that clinical medicine and spirituality are incompatible:

When asked about how she would feel if a physician asked her about her spiritual beliefs, one participant responded without hesitation: "If they ever did ask me I'd wonder what was wrong with them." When asked to elaborate, she shared her belief that most physicians do not, and should not, involve spirituality and God in their clinical practice. To her, a physician should be confident in the skills and

knowledge they obtained in their training; reliance on spirituality signalled a lack of competence. Speaking specifically about the lung transplant she hoped to receive in the future, she stated, "If they involve God then I'd worry about them doing the surgery. I would worry about them doing the surgery and I'd want somebody else to do it, bottom line."

In most other cases, participants expressed a preference to avoid communication about spirituality because they felt it was inappropriate or even potentially offensive to discuss such matters with the physician:

Um, maybe it's a subject they don't want to hit on because you know what, politics and religion can be not good subjects to get in on, right?

Although participants expressed a desire for a certain degree of closeness from their physician, there appeared to be a need for clear relationship boundaries. Discussion of spirituality, for most people, would represent an overstepping of these boundaries, and could even be perceived as being socially inappropriate.

MAKING THE TRANSITION

'Making the transition' represents the third and final major qualitative theme. One aspect of the transition from a 'pre-morbid' lifestyle to one that is coloured by serious illness is the difficult task of acknowledging and planning for EOL and death. The data suggests that this transition usually does not happen easily or overnight, but often

involves an iterative process. The guidance of a sensitive and insightful physician who provides candid information and yet respects the difficulties that people often face when being confronted with difficult news can, however, help to ease the way.

Candour

One of the most dominant themes pertained to the firm conviction of the value of candid conversation with the physician. Specifically, candour was requested when discussing diagnosis, prognosis and future health deterioration. Participants expressed that a frank discussion would increase their trust and confidence in the physician and lead them to believe that the physician truly cared about their welfare:

I: How would you feel about your doctor talking to you about how long you might have to live? Is that something that's crossed your mind?
P: No. He's just not the type, you know. Some are, some aren't. Some are there just for the buck.
I: How would you feel if a doctor did that?
P: It wouldn't bother me.
I: It wouldn't bother you? How would it make you feel?
P: I would feel like he cared.

When participants explained why candid communication was preferable, it related to preservation of autonomy. Receiving such information often cued people to plan for the future by engaging in activities such as completing a personal

directive, discussing future wishes for health care, or assigning a surrogate decision-maker:

I:*What would you want to know?*
P: *How serious my illness is. Where would I go? Would I have to go to a hospice or something like that, you know? And just what would be my next step from there. And as I say, I'm someone who wants to know the truth. I don't want to be beating around the bush. I want somebody to tell me the way it is and react from there.*

The absence of physician-initiated discussions about prognosis and future health deterioration was interpreted as assurance of stable health. Moreover, if EOL topics were not addressed by the physician, then people were unlikely to initiate such conversations themselves because they tended to perceive a good health outlook:

Because if he's not coming out and saying anything to me, then I'm saying to myself 'I must still be okay.' That's what I'm getting from all of this. I'm still okay. He's not giving me the impression that I'm getting worse.

Participants specifically stated that it was undesirable for a physician to try to emotionally protect a patient by providing an unrealistically optimistic prognosis. Such behaviour was perceived to be harmful because it could paradoxically cause more emotional distress in the future. In these cases, the 'hard reality' was preferred because, as one participant eloquently states, the alternative is even worse:

I mean hope is good but false hope is not good because it'll shock you. If you get false hope, if somebody gives you false hope you tend to bank on that and then when it doesn't materialize that way, in other words it falls short, then you're liable to be a little bit annoyed and disappointed that you've been misled in some way, you know.

Some people felt that receiving open and candid communication about their health status would help them gauge when it was necessary to engage in certain social and personal activities. In some cases, this involved experiencing new things such as travelling or simply making new memories with family and friends. In others, it involved seeking psychological closure by expressing their love to family members, saying their final good-byes, or even, as evident in one case, protecting themselves from people who may cause them distress during the final days and weeks.

*Even if the doctor says 'You've got six weeks,' and you think 'Maybe there are ends I haven't wrapped up yet.' Nobody wants to leave th*ings unfinished and have things turn out badly. You would think that most normal people would want to say good-bye to certain people. In my case it's keeping certain people away...

Friction between Candour and Readiness

While several participants ardently expressed a desire for frank conversations about diagnosis and prognosis, with further probing it became evident that for some there existed an underlying tension between candour and the readiness to

accept information that would result in an unwelcome confrontation with their own mortality. Further complicating this conceptual 'tug of war' was the acceptance that in some cases, despite lack of emotional readiness, a time-limited prognosis or rapidly changing health status urgently necessitated a candid conversation with the physician. It was recognized that there was often no ideal solution, no way to ease the friction between candour and readiness. Some participants suggested that physicians were warranted in pressing ahead with open and candid ACP conversations when a rapid deterioration in health was anticipated in order provide people with the information that was necessary to allow them to plan their EOL journey:

I: *Before doctors get to the nitty-gritty of all this heavy talk...about end of life and everything, would you like them to check in with you to make sure you're ready to go there mentally?*
P: *Right. I'm sure they should unless it's, you know, you have another week to live and we've got do to this stuff, right?*

Unfortunately, it sometimes proved to be much more challenging to engage in effective ACP conversation when a person had not yet arrived at a state of acceptance. In such situations, despite a physician's strident efforts to discuss EOL matters, the patient may fail to recognize that such a conversation has occurred, as though trying to suppress, consciously or subconsciously, the memories of the ACP

conversation. This was made evident during an interview with a participant with advanced COPD:

Despite having been recently extubated and discharged from the ICU, a female participant with COPD asserted that there was no need to speak of ACP because she did not feel her illness was very advanced. With further discussion it became evident that her physician had in fact communicated that, should she suffer from another episode of respiratory failure, intubation may be futile. When mentioning the conversation with the physician about the futility of intubation, she did so as though it was an afterthought, of little significance to her ACP plans. In fact, she reasoned that if intubation worked once, it probably will work again. She speculated that her recent hospitalization was simply a bad flare up due to a virus, and that if she were careful to avoid future viral infections, she would be fine.

This woman seemed to be emotionally protecting herself from a reality she could not fully accept. Clearly, frank communication about her deteriorating health and the potential futility of intubation had no impact on her ACP decisions because of her lack of readiness to accept this information. In another example, a participant describes what seems to be a fluctuating readiness to engage in ACP communication:

I: *What do you think helps to make you mentally ready to talk about these things [ACP]?*
P: *Uh, when I'm really having bad days...*
I: *On the flip side, what if you're having a good week?*
P: *I don't want to think about it. I don't think about it. I just say, 'You know what? You just keep going.'*

Ironically, some people seem least interested in discussing EOL issues when their health is relatively stable, which is

usually when they are most able to make competent ACP decisions. This unfortunate finding may lead to 'reactionary' ACP, where discussions happen only during a crisis situation.

During one interview, a participant exhibited visual signs of discomfort, which she attributed to some ongoing pain issues; however, it was apparent that her restlessness increased when she was specifically asked about discussions of prognosis and future healthcare planning with her physician. Her accounts of the occurrence of ACP fluctuated; at times she denied any relevant conversations and at others she almost inadvertently mentioned such specifics as being placed on a hospice waitlist. She made it clear throughout the interview that while she recognized the need to discuss her wishes for her future health care, she was not ready to fully accept and discuss ACP:

It's very hard to adjust to. Very hard to adjust to I find because I try not to think over the next day but hey, you do, right?

The above cases depict an alternating state of avoidance and tentative acceptance: while people could acknowledge their health deterioration and had glimpses of insight into why ACP was important, they often chose to suppress such thoughts and focus on the present moment. This

seemed to be a coping mechanism, and attempts to bypass this by asserting the importance of making EOL decisions could potentially be not only ineffective, but harmful to the patient because of the lack of readiness to accept and absorb such information. As one participant stated:

I think a patient should be allowed to decide when they are ready.

The Iterative Process

The data suggests that ACP communication is most effective, from the patient perspective, when it is conceived not as a singular event that occurs at one point in time, but a process that is cyclical and occurs throughout a person's illness journey, sometimes changing focus in response to deterioration in health or the availability of new information and treatment options. In some cases, health deterioration triggers people to think about and discuss ACP, as in the case of one woman who was hoping for a lung transplant while dealing with the progression of her lung disease:

I: What do you think makes you prepared to talk about these things [ACP]?
P: Seeing how things are getting worse; the worse they get the more you talk about it, you plan ahead. Like right now I'm hoping that they'll come through with this set of lungs but if they don't, uh, and I still get worse and I come in the hospital again with pneumonia and what not, then I've got to think even harder.

In others, however, the advanced illness state that once seemed so distant and irrelevant suddenly becomes a stark reality, and people can react by opting for measures, such as cardiopulmonary resuscitation, that they previously expressed as being discordant with their wishes. The following example illustrates such a situation:

A woman hospitalized with a COPD exacerbation explained how her living will document, written several years prior, suggested that she would not want aggressive measures. However, the threat of impending respiratory failure caused her to change her opinion on what constituted 'aggressive measures,' and she subsequently agreed to undergo intubation. As a result of the progression of her illness and the need for more advanced treatment to overcome her increasingly severe exacerbations, she shifted her perspective on the appropriateness of pulmonary resuscitation.

Failure to revisit ACP in the context of new information or a changing overall health outlook may result in a mismatch between a physician's perceptions of a person's healthcare goals and the patient's actual priorities at a given point in time. In contrast, engagement in an iterative process of ACP, wherein each medical 'fork in the road' triggers another conversation, re-evaluation and clarification about ACP, is more likely to lead to EOL care that is congruent with patient wishes. The potential for ACP decisions to change with time is illustrated by one elderly female participant who recounts her recent battles with her health:

A woman with suspected coronary artery disease had, in the past, made it clear to her children that she was more inclined towards comfort care measures rather than curative treatment. However, as the physician discussed the limitations of using only lab tests and electrocardiograms for diagnosis, she decided, with the prompting of her children, to undergo angiography. She laughed as she recalled another scenario where she had a change of heart: when diagnosed with breast cancer a year ago, she underwent a mastectomy. Her children were surprised at her decision, as she had previously stated that she would never want to undergo surgery again because of bad experiences in the past.

It is important to be aware of the potential for changing preferences. Reliance on one-time communication encounters or previously documented wishes in the form of advance directives is a detriment to informed decision-making because each new scenario presents options that may not have been previously anticipated. An iterative process more effectively acknowledges the complexity and uncertainty of the EOL journey and serves to protect patient autonomy.

4.5 Summary of Qualitative Findings

Three major themes were interpreted from the data and these relate to: nonverbal behaviours that convey a personal connection, attentiveness and trustworthiness; showing respect for one's background and acknowledging family roles; and providing support during the difficult transition to EOL via candid conversation, attentiveness to a patient's readiness to receive difficult information, and engaging in

an iterative ACP process. These themes are used in the mixed methods analysis phase (see chapter 5).

CHAPTER 5: MIXED METHODS FINDINGS

A comparison of the three main QUAL themes with the three QOC items that comprised the short-list of helpful behaviours (i.e. those that provided practical examples of helpful behaviours and had the highest r values with respect to the GRI; see section 3.3) occurred during the merged analysis phase. The primary purpose of this mixed methods analysis strategy was *complementarity*, or elaboration of the QUAN results with the QUAL findings. What follows is a discussion of the convergence between the QUAN and QUAL findings, and consideration of how the QUAL findings help to enhance understanding of why the items in QOC with the highest r values, as identified in Chapter 3, are important predictors of the GRI score. During QUAN-QUAL data comparison, a search was made for any divergent findings between the QUAL findings and the QUAN results; such findings would require further analysis in order to explore why the discrepancy occurred. Although an attempt was made to ask parallel questions such that the data collected in the QUAN and QUAL strands were complementary to one another and could provide a fuller understanding of the topic of interest, in one case there was little intersection between the QUAN and QUAL data (see uppermost right cell in table 7). This will be discussed further at the end of the chapter.

5.1 The Combination of Items 4 (listening to what you have to say) and 6 (giving you his/her full attention)

Although item 4 (listening to what you have to say) had the second highest Pearson correlation coefficient and thus was included in the short-list of priority behaviours, a relative paucity of QUAL data that could provide elaboration on the importance of item 4 was noted during the MM analysis. Although a few participants mentioned the importance of listening, it was often in the context of a combination of behaviours that suggested that a physician was being fully attentive. In addition, there was a predominant focus, in the QUAL data, on issues related to item 6 on the QOC (giving you his/her full attention). This latter observation was rendered more credible by the fact that 'being present,' a very similar concept, emerged as a subtheme in the QUAL findings. Intuitively, listening and providing full attention are related concepts that are amenable to being combined, and it was postulated that listening was a concept subsumed under the larger construct of giving full attention. This speculation needed to be substantiated by the data. Therefore, the QUAL data was re-interrogated, this time to assess if it could support the combination of items 4 and 6 in the QOC. The first relevant finding was that when participants were asked to explain why listening or full attention was important to them, they provided the same explanation for both activities: it showed that a physician cared. For example, one

participant describes the significance of getting a physician's full attention as follows:

That somebody is concerned about you. You know, they want to know what your feelings are.

Similarly, another participant explained that her physician's poor listening skills conveyed a lack of concern for her welfare:

I think a doctor should listen more to the patient and kind of get their drift of what they think more so than 'that'll be 50 bucks or whatever for the visit'...they wanna see us because of the billings.

A second QUAL finding that supported the combination of items 4 and 6 was that participants seemed to perceive listening as an active process that required attentiveness, and implied that listening involved a commitment to interpreting what a person meant more so than taking one's words at face value (see cell G in table 7). As such, the lines often blurred between the activities of listening and giving full attention. In fact, participants sometimes mentioned listening and attentiveness in the same breath (see cell D in table 7).

Next, an exploration of QUAN data was pursued to provide further support for the combination of items 4 and 6. On the correlation matrix (see appendix G), the r value for items 4 and 6 was 0.733, suggesting a high correlation between

these two items. In fact, this correlation value was higher than between any other two items, including the correlation between any QOC item and the GRI. This result provided further justification for the combination of items 4 and 6 in the merged MM analysis table.

Given the reasoning derived from both the QUAL and QUAN data, items 4 and 6 are treated as one QUAN item in the MM analysis phase. In addition, item 1 (using words you understand) was added as the third QUAN item in the merged analysis table, as this item had the next highest r value (0.577).

5.2 Presentation of Findings

Table 7. Mixed Methods Merged Analysis Table

		Quantitative (Quality of Communication tool) Items		
		Item 2 Looking you in the eye **(r = 0.609)**	**Item 4** Listening to what you have to say **(r = 0.602)** **AND** **Item 6** "Giving you his/her full attention" **(r = 0.579)**	**Item 1** Using words that you understand **(r = 0.577)**
Qualitative Themes	**Nonverbal Behaviours**	**A.** *"Well anybody that looks one person in the eye you can trust."* **(96 y.o. female admitted with pleural effusions)** A patient explaining what the absence of eye contact conveys: *"Sneaky. Sneaky. Untrustworthy, you know. Totally dishonest."* **(67 y.o. female with COPD)**	**D. (old G)** *"He [doctor] was on his knees here, took my hand even, you know, to make sure that I heard and made the right decision."* **(82 y.o. female admitted with pleural effusions)** *"I mean you're asking about an illness or a condition and he [doctor] knows so he should give you his full attention as well as looking at you physically, your face and what you're talking about because that all helps him understand. You can't just write down answers without looking at the person..."* **(85 y.o. female**	N/A

			patient admitted with myocarditis)	
	Situating	**B.** *When asked "how important was it that the physician made eye contact with you" during ACP conversations, one participant replied: "Well, very much. And my son or daughter, I can't remember which one was there. He would look at me and then he'd look at her too, you know, so he could talk to both of us."* **(92 y.o. female admitted for hyponatremia)**	**E. (old H)** *"I think my family doctor would be the man I would trust most I think because specialist doctors they may be specialists but they're not on a one-to-one basis with people, you know. People are numbers to them, you know, whereas your family doctor you're not a number, you're a person, you're a living being and I think that's very important."* **(80 y.o. male with COPD)**	**G.** *"Sometimes it's so easy to have your questions misinterpreted because you're not in the field and the way you're presenting your question can be totally misunderstood. But they already seem to understand that patients really aren't that informed about the nitty-gritty and they probably mean this instead of that..." "...didn't speak down to me at all or didn't try to use words that they would know would not be understood."* **(67 y.o. female with COPD)**
	Making the Transition	**C.** *"They look you in the eyes. They tell you the truth." "How can you make decisions about what you want if you don't have all of the information you need?...And so I want every single tiny detail, you know, I want him to look me in the eye and tell me 100*	**F. (old I)** *"I try to deal with now, you know, and a little bit of the future."* **(67 y.o. female with metastatic breast cancer)**	**H.** *A patient with mild global aphasia after a recent stroke explains the importance of using understandable words: "It's important right now because I would need the better language, the more easier language..."* **(42 y.o. female with idiopathic pulmonary fibrosis and embolic**

		percent...” **(67 y.o. female with COPD)**		**stroke)** *“...because I had put down there ‘no heroic procedures’ and he said ‘this is a heroic procedure,’ and I said ‘oh well I want that one.’”* **(67 y.o. female with COPD)**

A. ‘Non-verbal behaviours’ theme and QOC item 2: ‘Looking you in the eye’

Item 2 of the QOC, which pertains to physician eye contact during EOL and ACP communication, had the highest r value, suggesting it to be a strong individual predictor of the GRI score and thus was included in the short-list of priority behaviours for improving EOL and ACP communication. This aligns nicely with the QUAL findings; during the qualitative interviews, participants consistently expressed the importance of eye contact. The QUAL data attests to patients’ perceptions that physicians who are able to maintain eye contact care for the patient as a person, are focused and attentive to the patient’s needs, and are trustworthy. In contrast, a physician who avoided eye contact seemed disinterested and even dishonest. Table 7 provides quotes, taken from data coded to the ‘non-verbal behaviours’ theme, that give further illustration of the importance of eye contact during EOL conversations.

B. 'Situating' theme and item 2 on QOC: 'Looking you in the eye'

The importance of acknowledging that each patient is embedded in a network of family and social relationships was discussed in the theme entitled 'situating' (see section 4.3). Participants clearly expressed their preference for family member involvement during the information-sharing and decision-making processes. A physician who made eye contact with family members provided a nonverbal cue that they acknowledged the importance of these relationships and were willing to include family in the ACP process.

C. 'Making the transition' theme and item 2 on the QOC: 'Looking you in the eye'

As discussed in section 4.3, the transition to end of life is a turbulent one that is often characterized by fluctuating readiness, a need for repeated conversations and reconsideration of treatment options. Participants also expressed a strong desire for candid conversation about what lies ahead from a trustworthy physician. In addition, from the QUAL themes it is suggested that eye contact from a physician helps to bolster the perceived trustworthiness of a physician. The integrated analysis provides a perspective that neither the QUAL nor QUAN strands could independently provide: a physician's eye contact is a simple behaviour that can serve to garner the much-needed trust of patients as they are guided through their end of life journey. During this uncertain

transition period, a physician who makes eye contact can instill confidence that the information provided is credible, and that the physician could be a reliable medical guide in the EOL journey.

D. 'Nonverbal behaviours' theme and QOC items 4: 'listening to what you have to say' and 6: 'giving you his/her full attention'

In the majority of cases, when participants gave examples of how a physician provided them with their full attention (or failed to do so), it involved nonverbal behaviours. Some simple but profound examples of nonverbal behaviours, derived from the QUAL data, that convey attentiveness include: eye contact, kneeling down or sitting down to be at eye level with the patient, or even putting down a pen while discussing important ACP options (see first quote in cell D, table 7).

As previously mentioned, participants perceived listening to be an active process, wherein the physician pays close attention the patient's words in order to avoid misinterpretation. Participants would commonly discuss the concepts of giving full attention and listening in the same breath, as though the two were intricately connected and attentiveness could not occur in the absence of skillful active listening (see second quote in cell D, table 7).

E. 'Situating' theme and QOC items 4: 'listening to what you have to say' and 6: 'giving you his/her full attention'

The intersection of these QUAN items and the QUAL theme relates to a physician's ability to recognize that people's EOL priorities are partly shaped by their life history and what they view as their most important roles and relationships. A physician who is attentive to a patient's life history and social circumstances, effectively addressing the 'whole person' rather than a medical case, is more likely to be able to facilitate helpful and effective ACP that aligns well with priorities of the individual. In some cases, a long-standing relationship with a patient allows for a deeper knowledge of his life history, but in the acute care situation where this is often not possible, a physician's commitment to being mindful of deficits when it comes to *knowing the person* is sometimes enough to create the conditions for a more personalized ACP approach.

F. 'Making the transition' theme and QOC items 4: 'listening to what you have to say' and 6: 'giving you his/her full attention'

A physician that is attentive to a patient's information needs, as well as their mental and emotional readiness to engage in ACP, is more likely to have a successful conversation. On the other hand, a physician who is inattentive and attempts to engage in conversations before a patient is fully ready may be met with resistance. In fact,

the conversation may turn out to be less than fruitful, or swept aside in the patient's mind in an attempt to suppress difficult emotions. In two cases in particular, a female participant with advanced COPD and another with metastatic breast cancer (see table 7), it was evident, based on their responses to specific questions, that a physician had spoken with them about important ACP issues, but the participants claimed that they were not yet sick enough to warrant further speculation or additional EOL conversations. By being fully attentive, a physician is more likely to be insightful to a patient's level of readiness to receive candid EOL information, and respond appropriately.

G. 'Situating' theme and item 1 on the QOC: 'using words that you understand'

The demographic characteristics of the study population reveal that 47.8% have not completed a high school diploma (table 1). Physicians have received several years of postsecondary training, and are also accustomed to using a language that is foreign to people outside of the medical field. It is important to remain cognizant of a patient's educational and professional background when providing sensitive information. The first quote provided in cell G of table 7 provides a corroborative example of the importance of appropriate language use during EOL and ACP conversation. However, as the second quote suggests, a balance must be

struck between providing information that can be easily understood and avoiding condescension.

H. 'Making the transition' theme and item 1 on the QOC: 'using words that you understand'

In an illustrative, and amusing, account of the foreign nature of medical terminology, one participant shares:

He (physician) says 'you put down you were in a vegetable state.' I said 'I did?' and I said 'oh you must be thinking this poor woman thinks she's a piece of broccoli!'" (laughs)

This same participant later described her confusion about the meaning of the phrase 'heroic measures' as it pertained to her ACP preferences (see second quote in cell H, table 7). Fortunately, this woman later discussed her resuscitation preferences with a physician who was able to break down her options to include individual and easily understandable items such as 'using a breathing tube.' As a person transitions into a life of progressive frailty and worsening functional capacity, the ACP decision-making process increasingly becomes a priority, but this is often complicated by many factors including emotional difficulty, prognostic uncertainty and the need to learn about complex medical treatments and options. Physicians can help to ease this process by using clear and accessible language.

In some cases, as a disease progresses or one's health and functional status declines, language needs may change. This may be seen, for example, in people with progressive dementia

or intermittent delirium related to underlying disease or medication side effects. In one poignant example, a young female participant suffers from an embolic stroke, resulting in mild global aphasia. She explains that, in her new state, she needs the physician to use simpler language than she had previously required (see first quote in cell H, table 7). As patients make the transition to end of life, physicians should be aware that, just as their physical abilities may change, so too may their cognitive and language abilities.

5.3 Summary of Mixed Methods Findings

The merged analysis strategy used in this chapter has allowed for a fuller understanding of why specific physician behaviours are important from a patient perspective by complementing the QUAN results with the QUAL findings. The nature of this merged analysis strategy requires that each QUAN item is merged with each QUAL theme. While this strategy demands a more thorough approach to the MM analysis—resulting in a more comprehensive account of how the two strands provide a fuller understanding of the topic at hand—it is not always possible as some of the data collected in the QUAN strand may be unrelated to some of the themes in the QUAL strand, and vice versa. This is the case in the cell that intersects ‘non-verbal behaviours’ (QUAL theme) with item 1 on the QOC (using words you understand); it would be

challenging to identify how these concepts might intersect. Because the two concepts were found to lack congruence, the decision was made to leave the cell empty rather than trying to force superficial or inappropriate data integration. It should be noted that this is not an issue of insufficient data collection as more data would not change the incongruent nature of the concepts, nor is it an example of data divergence. The latter suggests that the QUAN item and the QUAL theme are conceptually related, but that the actual content does not converge. For example, the data from the QUAN strand might suggest that a behaviour is of high importance (i.e. large positive r value), but informants in the QUAL strand endorse the behaviour to be of little significance or even harmful.

The r value of 0.602 for item 2 suggests that eye contact is a good predictor of global satisfaction with EOL communication; this is partly explained by the QUAL data, as informants reported that eye contact signifies a physician's concern for the individual. Furthermore, by engaging in eye contact with the patient's family and loved ones, the physician signals her willingness to include family in ACP, and this is complementary to the findings of participant-reported importance of family relationships. Findings from the QUAL theme 'making the transition' suggest that eye contact also promotes trust in the physician and causes

people to perceive the physician to be a reliable medical guide in the EOL journey.

Some of the communication behaviours that were identified as being important did not require words; eye contact, kneeling down or sitting at eye level with the patient are some examples of how a physician's body language shows a commitment to being fully present for the patient. This aligns nicely with the QUAN finding of the importance of items 4 (listening) and 6 (full attention). Furthermore, the QUAL data suggests that a fully attentive physician (i.e. item 6) is more likely to be attuned to the friction between candour and readiness that can arise during the EOL transition, and is also more likely to recognize the critical importance of family and loved ones in the ACP process.

Lastly, the mixed methods analysis provides a deeper understanding of the importance of item 1 on the QOC (using words you understand). Specifically: medical terminology is foreign to most patients, so the use of appropriate language is crucial to ensure sensitive and important information is adequately conveyed; and physicians should be aware that, as a person transitions to end of life, cognitive changes and language needs may result. By being mindful of these points, a physician can help create the optimal conditions for informed ACP decision-making.

CHAPTER 6: DISCUSSION

The following discussion provides a synthesis of study results, with a focus on the mixed methods findings, and places them in the context of the existing body of literature on patient preferences for ACP. Communication is a complex process, and as such it not possible to make broad generalizations or to claim to represent the topic through a fixed set of rules that can be applied to all EOL communication contexts. If anything can be interpreted with certainty, it is that the results of the QUAL strand suggest variation in patient preferences for physician behaviours during ACP conversation. However, the patterns and themes that emerge in the midst of this heterogeneity are more likely to be credible and pertinent.[71] Furthermore, the variability of patient preferences is a finding unto itself, as it suggests that EOL communication should be tailored to meet an individual's needs rather than attempting to use a 'one-size fits all' approach.

6.1 Summary of Study Findings

In the QUAN strand, the QOC tool was administered to 92 participants. For the primary analysis, the Pearson correlation coefficient was measured between each of items 1-6 and the GRI. The items that represented specific and practical examples of behaviours that might improve physicians' EOL communication skills from the patient

perspective *and* had the three largest r values were selected for the short-list of priority behaviours. These items were: item 2 (looking you in the eye, item 4 (listening to what you have to say) and item 6 (full attention), with r values of 0.609, 0.602 and 0.579 respectively. Of note, item 5 (caring about you as a person) had the highest r value but was not included in the short-list because it did not represent a specific example on how to improve EOL communication.

Items in the EOL-specific communication subscale (items 7-13) suffered from a large number of 'didn't do' responses, which were coded as zero. Because they were reported to occur infrequently, it was difficult to accurately measure the r value between each of these items and the GRI. For these items, responses were dichotomized, with ratings in the range of 0-6 coded as 'zero' and ratings from 7-10 coded as 'one.' Next, a t-test was conducted for each of items 7-13 to determine if there was a difference in mean GRI scores between groups. Although there was a statistically significant t-test result for items 7 (talking about feeling concerning possibility you might get sicker), 8 (talking about details concerning possibility you might get sicker), 10 (talking about what dying might be like), and 12 (asking about things in life that are important to you), the practical significance is uncertain considering that 81-98% of the responses were coded as zero (i.e. they were mostly reported as 'didn't do').

One exception is item 11 (involving you in decisions about treatment that you want if you get too sick to speak for yourself), in which 39% of responses were coded as 1, making the clinical significance of the result more plausible in comparison to the other items. In this case, the group coded as one had a statistically significant t-test with a mean GRI score that was 1.24 points (out of 10) higher than the group coded as zero. This suggests that physicians who received high scores (7 to 10 out of 10) on their ability to involve patients in advance treatment decisions would have a GRI score that was slightly higher than those who did not perform this activity or scored poorly (0 to 6) on this activity. However, it should be noted that item 11 is one of the lengthier items on the tool and involves complex wording; thus, it is possible that participants did not always accurately interpret the item. For example, some people may have interpreted it to be asking about involvement in *current* treatment decisions rather than *advance* treatment decisions.

In the secondary analysis, multivariate linear regression modelling was conducted, with the goal of determining the *combination* of three items that could explain the most variance in the GRI score. As with the primary analysis, although item 5 on the QOC tool (caring about you as a person) had the largest Pearson r value (0.642), it did not represent a specific and practical suggestion for improving

communication and therefore was not considered for entry in the multivariate model. 81–98% of the responses to items 7–10 and 12–13 on the QOC were coded as zero; these items were also excluded from the model since it is not possible to accurately estimate the effect of behaviours that are not commonly performed. As a result, 6 items were considered for inclusion: items 1 (using words that you can understand), 2 (looking you in the eye), 3 (answering all your questions about your illness and treatment), 4 (listening to what you have to say),6 (giving you his/her full attention) and 11 (involving you in the decisions about the treatments that you want if you get too sick to speak for yourself). The three items that, when combined together, explained the most variance in comparison to all other combinations of three are: items 2, 3 and 6. The model that included these three items had an R^2 of 0.604, which suggests that approximately 60% of the variance in the GRI score is explained by the combination of items 2, 3 and 6. These three items may be used as a suggestion for a combination of behaviours that hold promise for improving physician EOL and ACP communication skills, although the exploratory nature of this analytic strategy must be emphasized. It is notable that item 3 had the lowest Pearson r correlation with the GRI (when compared to items 1–2 and 4–6) in the bivariate correlation matrix (see appendix G). In addition, item 4 had the second highest r value but was not

included in the final model. This can be interpreted to mean that, while item 4 was a strong single predictor of the DV, and item 3 seemingly weaker, when all of the intercorrelations between variables were taken into consideration, it was the combination of items 2, 3 and 6 that explained the most variance in the GRI score.[58]

In the QUAL strand, interpretive description methods were used to inform data collection and analysis. Twelve interviews were conducted with seriously ill hospitalized patients and three themes emerged, which pertain to: nonverbal behaviours, situating a patient in the context of their life history and relationships, and helping people make the transition to end of life.

During the mixed methods phase, a 3x3 merged data analysis table was constructed, which arrayed the three QOC items on the short-list (from the primary analysis in the QUAN strand) with the three QUAL themes. The QUAL data was interrogated again, this time with the goal of further understanding the significance of these three QOC items, and the contexts in which they occurred. There was found to be a paucity of QUAL data related to item 4 (listening to what you have to say), but the QUAL and QUAN data both supported the combination of items 4 and 6 (giving you his/her full attention). Thus, items 4 and 6 were treated as a single item in the mixed

methods analysis table. In addition, item 1 (using words you understand), which had the next highest r value, was included in the third column of the merged analysis table.

The merged analysis helped to enhance understanding of the importance of eye contact (item 2 on the QOC), suggesting that a physician's ability to maintain eye contact conveyed their trustworthiness; a physician who made eye contact with family members was acknowledging the importance of family roles; and lastly that a physician's eye contact provided reassurance of the accuracy of the EOL information they were sharing, which was essential in helping to ease the ACP decision-making process and the transition to end of life. Similarly, a fuller understanding of the significance of item 1 (using words you understand) was achieved, suggesting: that physicians can help to reduce some of the challenges of ACP decision-making by using simple language to help people understand the resuscitation and treatment options that are often foreign to them; that as people transition to EOL, cognitive changes may occur that require a shift in language style; and that a physician who knows the educational and professional background of a patient is more likely to use language that is understood by the patient, although this must be tempered with a commitment to avoid being patronizing. The QUAL data also improved the understanding of item 4 (listening to what you have to say) and 6 (giving you his/her full

attention), indicating that nonverbal behaviours such as making eye contact or taking a person's hand conveyed attentiveness; that part of being fully attentive was maintaining mindfulness of the importance of a patient's life history and relationships; and that attention was required to gauge a patient's readiness to make the end of life transition.

6.2 Relationship of Study Findings to the Existing Literature

According to participant responses, there was a general paucity of EOL-specific communication with physicians both prior to and during hospitalization; this was evident in the qualitative interviews and also by the large number of 'didn't do' responses in the EOL communication subscale of the QOC questionnaire. This is a remarkable finding considering that all participants were seriously and chronically ill, with a high risk of mortalitiy at 6-12 months' time.[25,101] Furthermore, the study population experienced an average of 2.5 hospitalizations over the past year, representing multiple critical incidents that could have created an impetus to discuss EOL issues. This is not a unique result: a previous study that used the QOC also noted a large number of 'didn't do' responses on the EOL subscale.[56] Moreover, many other studies have similarly reported a low incidence of ACP conversations between patients and physicians.[56, 86-89]

Previous models of shared decision-making have emphasized the importance of patient-physician communication and patient autonomy.[90] However, an apparent message has emerged from the analysis of the data in this study: seriously ill patients prefer to share the decision-making process with family, and in some cases family members' opinions can have a strong influence on their ACP decisions. Other studies provide supportive evidence of these findings, including the results of the first phase of the Advance Care Planning Evaluation in Elderly Patients (ACCEPT) study, a multicenter prospective study that recruited a similar population as those included in this study. The results of ACCEPT showed that, of the 88.7% of participants who endorsed having discussed future care wishes with someone else, 92% had discussed it with a family member while only 30% had discussed this with their family doctor and 17% with a specialist physician.[18] A study on metastatic breast cancer patients showed that participants were three times more likely to have ACP conversations with family members than their physician.[91] This is echoed in studies on preferences of elderly patients and those with end-stage renal disease.[33,92] In addition, a 2004 study involving structured interviews with 51 CHF patients also supports the prioritization of family communication: the majority of participants indicated that they usually or sometimes take the advice of family members when it comes to medical decision-

making.[93] This highlights the need to reconsider the emphasis on autonomy in the EOL decision-making context; indeed, the re-conceptualization of decision-making as a social process that requires a relational approach has been discussed by the authors of this study. Therefore, it may be inferred that it is more helpful to view the 'patient' as a group of people: the individual with the illness and the loved ones who form their support network. This concept is embraced in Palliative Medicine, where the focus is on improving the lives of both the patient and family members.[94] Further support of the need to include family members is provided by the Inter-professional Shared Decision Making (IP-SDM) model[102]: the IP-SDM, which was developed in the primary care context and found to also be appropriate in the Intensive Care Unit setting, recognizes family members as key stakeholders in the decision-making process. The qualitative findings of this study add to the body of literature by highlighting the interdependence of a seriously ill individual and their family members: not only do family members provide the patient with much-needed support during the decision-making process, but by involving family in the ACP process, the patient is caring for them by reducing their future decision-making burden. An ethnographic study on nephrology outpatients resulted in similar findings, with most participants indicating that a major goal of ACP included reducing EOL decision-making burden on loved ones.[95] The

results of both the qualitative and mixed methods analysis add to the existing body of literature by providing an understanding of why certain physician behaviours convey a commitment to family inclusion, and by providing concrete examples of how a physician might encourage and incorporate a relational approach to the ACP communication process. Specifically, behaviours such as inviting questions from family members and making eye contact with them, signals the physician's interest in including loved ones in the ACP process. In addition, a willingness to make repeated visits to accommodate family members' schedules also conveys an understanding of the importance of the patient-family unit.

The QUAN results suggest that spirituality is rarely addressed by physicians: 93% of participants responded 'didn't do' on item 13 on the QOC, which pertains to the importance of a physician's inquiry into spirituality or religion. The QUAL data enabled exploration into patient perspectives of the importance of a physician's inquiry into one's spiritual welfare. The results were unambiguous: most participants indicated that it is unnecessary and even potentially harmful for a physician to inquire about spiritual matters, as it may negatively alter a person's perception of their physician or be perceived as an intrusion into private matters. This finding is at odds with the results of a cross-sectional survey on 100 patients with gynecologic malignancy, in which

52% of participants answered 'yes' to a question asking if physicians should ask their patients whether they would like to get help in discussing spiritual questions.[104] In this study, spirituality was defined both as religiosity and with respect to existentialist topics (e.g., 'what is the meaning of my life?'), which is similar to how spirituality was discussed during the qualitative interviews in this study. However, the cross-sectional study population was significantly different than the population in this study: all participants were female, all had an active malignancy, and the average age was younger (58 years old). These factors may partly explain the difference in results. A Canadian multicenter cross-sectional survey involving 440 patients found that 21% of participants rated spiritual or religious needs as 'extremely important,' while 30% rated it as being 'not at all' or 'not very' important.[105,106] Many other items were rated as being of higher priority than spiritual needs, including: continuity of care, symptom relief, having trust in the physician, having adequate information, and participating in the decision-making process. Although approximately one-fifth of the population did endorse spiritual needs as being a priority, there was no specification of the role of the physician in meeting these needs. A more recent Canadian cross-sectional survey conducted by the same authors found that 'feeling at peace' was a high priority item in their

seriously ill study population.[107] The item in the questionnaire that pertained to spirituality asked "how satisfied are you that you were at peace in the last six months?" The specific meaning of being 'at peace' was not defined, and it may be argued that peacefulness may or may not be related to spirituality; in Kabat-Zinn's Mindfulness Based Stress Reduction (MBSR) framework,[108] for example, mental peacefulness is achieved not by means of spirituality, but focuses instead on relaxation, calmness and inner balance. In addition, the published survey did not ask about physician involvement in promoting their feelings of peacefulness. Thus, although the findings of other studies seem to be discordant at the surface level, the specific content of the questions, the demographics of the study populations, and the lack of inquiry into the desired involvement of the physician are all factors that preclude direct comparison of results.

A clear and resounding preference for candour while discussing a diagnosis, prognosis or treatment option came through in this study. Candid information was felt to be important because it allowed people to plan for the future and to say goodbye to loved ones. In addition, in some cases receiving information about topics such as a limited prognosis served as a cue for the right time to engage in ACP decision-making. The EOL journey is full of uncertainty, and the study results suggest that provision of candid information equips

people with knowledge that serves to mitigate some of this uncertainty. Many other studies provide supportive evidence of patient preferences for candid EOL communication[95-97] including a discrete choice experiment on chronic kidney disease patients which found that most wanted early and detailed provision of prognostic information and ACP.[98] The mixed methods analysis allows for a deeper understanding of the importance of certain behaviours as it relates to candour and the challenging EOL transition; for example, eye contact signifies a physician's commitment to providing candid and trustworthy information, thereby making them a reliable ally in the EOL transition. Furthermore, the mixed methods analysis suggests that a physician who can provide much-needed EOL information, by answering all of a patient's questions, is effectively arming them with the knowledge that can help to reduce the uncertainty and confusion that often plagues people during the EOL transition.

The qualitative data elaborate on the significance of nonverbal behaviours such as expressions of emotionality, indicating that it shows that the physician feels a personal connection with the patient. For the most part, study participants have expressed a desire for a more personal connection with their physician, and this has also been observed in an interpretive description study by Thorne et al on a cancer population.[96] In their study, Thorne et al also

note that some people theorized that physicians maintained emotional aloofness in order to avoid adding complexity to the patient-physician relationship; this sentiment is echoed by two female participants in this study.

The mixed methods analysis suggests that attentiveness is required to gauge readiness to accept difficult information, and to avoid overwhelming with too much information or demanding immediate ACP decisions. Although participants expressed a desire for candid information, there seemed to be variation in the readiness to accept this information, or at least a variation in the rate at which they received information. In the same study cited above, Thorne et al put forth the idea that physicians should learn how to appropriately "titrate information."[96] Some participants seemed to prefer to focus on living in the present moment and dismissed the need to think of future healthcare needs. A 2005 study reported similar results: this cross-sectional study of 115 COPD patients found that patients sometimes prefer to focus on staying alive.[27] In some cases there was evidence of dual, fluctuating states of readiness and dismissal: the mixed methods analysis suggests that only an attentive physician can identify this fluctuation and determine the best time(s) to engage in ACP. Effective communication in this scenario would likely involve an ongoing and iterative process. The

literature supports the notion of ACP as a process rather than a one-time event.[100]

Another interpretation of the importance of giving a patient full attention, which was similar to the qualitative theme 'being present,' surfaced in the mixed methods analysis, this time relating to acknowledgement of the patient as a 'whole person.' Patients' reports indicate that it is important that a physician remains mindful of the significance of a person's life history and the important social roles they play(ed). This seems to help preserve one's self identity while dealing with the often impersonal healthcare environment, and aids in promoting a dignified EOL journey. This concept became more clear when patients expressed their preference to discuss sensitive EOL issues with their family physician: the long-term relationships that family physicians typically have with their patient population sometimes seems to put them at an advantage in comparison to acute care physicians or specialists. Chochinov's work on "dignity therapy,"[99] which involves the documentation of one's life history, important roles and achievements, and provides an opportunity to record advice to be posthumously shared with family members, is also based on the assertion of the importance of acknowledging the whole person in EOL care.

6.3 Study Strengths and Limitations

In the Good Reporting of a Mixed Methods Study (GRAMMS) framework, O'Cathain, Murphy and Nicoll[110] suggest criteria by which a mixed methods study can be appraised. The design, conduct and reporting of this study satisfies the GRAMMS criteria in several ways. Firstly, a description of the justification for using a mixed methods approach was given: this complex and multidimensional topic incorporated a quantitative strand to evaluate what physician behaviours were a priority in the ACP communication process and to quantify the importance of each behaviour, while the qualitative data served to provide a depth and richness of information that was complementary to the quantitative results. Furthermore, the type mixed methods design, including the sequence of methods, the equal priority of the qualitative and quantitative strands, the point of interface of the two strands and the way in which data was integrated has been clearly outlined. Description and justification of the sampling strategies were also provided. Lastly, the author has highlighted the insights gained by means of mixing methods.

There was a general paucity of in-depth ACP communication in this study population. Although this is a remarkable finding in and of itself, as discussed in section 6.2, it prohibited meaningful assessment of the correlation of the

EOL-specific items in the QOC (items 7-13) with the global rating of satisfaction. In addition, the qualitative findings presented herein often pertained to what patients *perceived* they would want from their physicians during EOL communication, and it is not clear how these hypothetical preferences align with what they would actually want. However, this is very similar to the issues encountered in 'discrete choice' experiments, in which participants are asked to make hypothetical 'trade-off' type healthcare decisions based on their values; and yet discrete choice experiments are considered to be useful for patient centered evaluations of health technologies.[98,109] Furthermore, the low incidence of ACP conversations is a pervasive problem in the EOL literature, which likely reflects the current clinical state of affairs. Thus, despite the limitations, this study contributes to the growing body of ACP literature, and provides more evidence of the need to address the problem of the lack of ACP in the older population.

Although the qualitative sampling strategy attempted to include non-Caucasians, only Caucasians agreed to take part in the interviews. Similarly, only two participants (2%) in the quantitative strand were non-Caucasians. As suggested by the literature, ethnic minorities may have different perspectives and thus the results of this study may not adequately represent the preferences of these populations. The average

age in the quantitative strand was 82.5 years old, and so may not be representative of the wishes of a younger population; however, this age group represents a high priority population for the study of EOL communication. Furthermore, the qualitative population represented a wider age range, and this variability was conducive to eliciting a fuller and more complex picture of EOL communication preferences. It should be noted however, that only one patient below the age of 50 was recruited, and some of the data generated in this case was unique, especially as it pertained to family roles and the need to consider the welfare of children. Since there was only one participant with this particular social circumstance, the concepts generated could not be further pursued in this study. Future studies could investigate patient preferences for physician behaviours during ACP conversations in younger populations and ethnic minorities.

The trustworthiness of the qualitative strand has been supported by means of several strategies, as discussed in section 2.6.1, and this is a major strength of the study. The confirmability of the qualitative findings is supported by the debriefing sessions and the documentation of a detailed audit trail. Study credibility is bolstered by use of the thoughtful clinician test and by means of a modified member checking strategy in which interpretations were presented to informants for feedback. The dependability of the qualitative

strand is facilitated by the detailed descriptions of the methods, and the fact that only one interviewer was used for the purpose of consistency.

This study focused on communication encounters between seriously ill patients and their physicians; thus, the results cannot be generalized to other members of the multidisciplinary healthcare team. However, by narrowing the focus to patient-physician communication, the depth and richness of information that resulted was likely greater than what may have occurred if the focus widened to encounters with other healthcare providers. This study took place at two academic hospitals in Hamilton, Ontario and therefore may not be generalizable to the community hospital or outpatient setting. However, the descriptions of the context and demographics of the study populations in both the qualitative and quantitative strands allow the reader to judge the transferability and generalizability, respectively, of the findings to another population of interest.

Some limitations arose from the use of the QOC tool itself. Item 3(answering your questions about your *illness* and *treatment*) asks about two related but distinct activities, and thus it is not clear if patient ratings pertain to answering questions about the illness, the treatment, or both. Due to the ambiguity this causes, Streiner and Norman caution

against the use of such "double-barrelled"[103] questions. One of the qualitative interviews revealed that a participant who endorsed having a high regard for his family physician rated his ability to maintain eye contact highly, despite the fact that this activity did not occur. This finding, which is a testament to the advantage of the mixed methods design, raises suspicion of a possible 'halo effect,' in which participants who have a good relationship with their physician might rate all items highly without differentiating between each individual item. Future validation work could focus on the prevalence of this type of bias and how it may be minimized; in fact, this type of bias may be present in many types of survey studies. Items 5(caring about you as a person) and 6(giving you his/her full attention) could be perceived as complex, multidimensional constructs and thus conceptualized as an *outcome* rather than a specific behaviour. It proved to be somewhat challenging to consider, on a practical and clinical level, the specific information that could be given to physicians on how to improve communication based on these items. For example, it is difficult to conceptualize how one may instruct a physician to 'care' about a patient during a communication encounter. Future studies could use items 5 and 6 as dependent variables and other, more specific behaviour items on the QOC (e.g., those related to eye contact or prognosticating) as independent variables in order to

understand how specific behaviours correlate with patient-rated scores on 'caring' and 'giving full attention.' Item 11(involving you in the decisions about the treatment that you want if you get too sick to speak for yourself) is somewhat lengthy and may be challenging for participants to fully comprehend; re-wording of this item may improve its face validity. Although the use of the QOC tool presented some challenges, at the current time it is the only tool that is relevant to the specific topic of focus in this study: patient-physician EOL communication. The use of a tool that has had some validation work done is more preferable than constructing a new tool, as time and resource limitations prohibited the design and psychometric evaluation of a new quantitative tool. Furthermore, although this tool requires further validation work, the content validity is supported by the focus group studies that were conducted during the early development phase (see section 2.5.1). From a pragmatic and ethical perspective, the brevity of the tool helped to minimize participant burden and fatigue.

A limitation in most mixed methods studies relates to sample size and the difficulty of balancing the very different size requirements of the quantitative and qualitative strands of the project. The constraints imposed by the complexity and time-consuming nature of mixed methods study designs challenges the researcher to reach a reasonable compromise.

While representativeness, accuracy and stability of results is best achieved in quantitative studies by recruiting large sample sizes, the use of the same sample size in the qualitative strand would be prohibitive in terms of time requirements and workload. Furthermore, the focus in qualitative research is on achieving rich, deep and *contextual* information rather than results that can be generalized to other scenarios. An attempt was made to achieve this by recruiting enough participants in the quantitative strand to ensure stability of the multivariate linear regression model, while thoughtfully selecting a smaller subgroup of the quantitative sample to provide answers to the qualitative research question at hand.

6.4 Clinical Implications and Future Directions

This study is novel and adds to the current body of ACP literature: it is the first study, to the author's knowledge, to focus on patient perspectives of what modifiable physician behaviours contribute to high or low ratings of EOL and ACP communication skills. Furthermore, it is the first mixed methods study on EOL and ACP-related communication between patients and physicians. The mixed methods analysis, which employed a merged analysis table, presents a novel, high level QUAL-QUAN data integration. The QUAN and QUAL results were complementary in that they were able to identify *which*

behaviours were perceived as being important during EOL and ACP communication from the patient perspective, and also *why* these behaviours were important and in which contexts.

The study findings can be used, along with evidence from other literature and expert opinion, to aid in the development of ACP training curricula for front-line physicians and resident physicians. In fact, the results of this study will be used in EOL communication training projects within some regional health authorities in Canada, including physician skills training seminars in ACP in Alberta (Jessica Simon MD, oral communication, October 2012) and projects focused on improving the ability of frontline staff to engage in ACP in British Columbia (Doris Barwich MD, oral communication, October 2012). Furthermore, the findings are complementary to the results of other studies on ACP communication and could be used to inform the development of a complex intervention that could be tested in future studies.

Both the QUAL findings and the QUAN results supported the combination of items 4 (listening to what you have to say) and 6 (giving you his/her full attention), and these items were treated as a single item during the mixed methods analysis phase. Future QOC validation studies could look at removing item 6 from the instrument and replacing it with items that relate to more specific behaviours (e.g., sitting

versus standing, facial expression) that correlate highly with the complex construct of 'full attention.' In other words, 'full attention' may be considered as a separate subscale.

A notable clinical implication of this study relates to the findings that suggest physicians have a less important role in the ACP process in comparison to family members. The QUAL data revealed that patients often prefer to involve family members rather than their physician in the ACP process, and as mentioned in 6.2, this finding is corroborated by other studies. Although further studies are needed to delineate the preferred role that physicians should play in the ACP process from the patient perspective, the findings of this study suggest that physicians are expected to provide technical and medical information while leaving the actual decision-making process to patients and their family members. In some challenging circumstances, a physician who has a long-term relationship with the patient may facilitate the communication process between a patient and their family; however, even in this circumstance the qualitative data suggests that the physician's role is mainly limited to leveraging the support of family members and other loved ones. This finding represents a deviation from traditional conceptions of the ACP process, in which the physician takes a central role in the shared decision-making process.[29]

Another important qualitative finding relates to the need for an iterative ACP process. As time passes, health deteriorates and new, unforeseen healthcare choices and decisions may arise. In these circumstances, a person's ACP decisions may change and it would be wise for a physician to periodically re-assess these decisions. Although this cyclical process may seem arduous, past discussions may be used as a basis for future discussions, and with time, patient familiarity, knowledge and capacity to make informed decisions may grow.

As discussed in section 6.2, there is some ambiguity in the literature with respect to patient preferences for physician involvement in spiritual care matters. Although some studies have shown that spirituality and feelings of peacefulness are priorities, others have indicated that they are less of a priority in comparison to other aspects of care. In addition, the concepts addressed in other studies, such as 'feeling at peace' are arguably different than religiosity and spirituality; and it is not clear what role physicians are expected to take with regards to addressing spiritual care needs. Additional studies are needed in order to further explore patients' preferences for physician involvement in spiritual issues, as well as the perceived understanding of what spirituality specifically entails.

Future projects could focus on preferences of seriously ill patients of ethnic minorities, as well as younger patients to determine if there is any major variation in terms of desires or concerns in these populations. In this study, participants were asked to speak about EOL communication encounters with any physician; future projects could compare patient preferences for communication from family physicians, specialist physicians and acute care physicians. Future studies could also focus on EOL and ACP communication between a patient and other members of the healthcare team, such as nurses and social workers. A study that recruited patient-physician dyads to measure concordance in the occurrence of ACP conversations would be informative, as this would indicate whether patients who state that ACP conversations did not occur do so because they do not recall them or do not identify them as ACP conversations, versus the actual lack of occurrence. This would help to sharpen the focus on future research questions: if people are not recognizing a physician's attempt to engage them in ACP, investigation should be conducted as to why this is occurring. Lastly, studies that focus on approaches to EOL communication in the context of a patient's fluctuating state of readiness or 'death denial' would provide much needed information on this challenging clinical dilemma.

6.5 Conclusion

This mixed methods study is well-positioned to understand, in a holistic manner and from the patient perspective, the physician behaviours that influence quality of communication at the end of life. The rationale for using a mixed methods design was clearly stated: the complex study topic begs for an understanding of not only *what* predicts patient satisfaction with physician EOL and ACP communication, but also *why* these factors are predictive and in which contexts. One objective was to provide practical suggestions on behaviours that can improve the communication process, and to some extent this was achieved: simple behaviours such as eye contact, answering patient questions and providing full attention appear to have a profound effect on the quality of EOL communication. By means of the mixed methods analysis, explanation was provided as to why the above three behaviours are helpful, and illustrative examples from the qualitative strand helped to showcase the context in which these can occur. For example, the high-priority behaviour of answering questions is even more preferable when it occurs in the presence of family.

Advance care planning is a priority given the aging healthcare population, but there is little knowledge about patients' preferences for EOL and ACP communication with their physician. Just as many life decisions are complex, so too are end of life decisions. Although this study provides some

practical suggestions, the challenging process of ACP communication between a physician and patient requires an ability to appreciate the variability in patient preferences, and a willingness to ask the right questions to assess individual needs.

References

1. Jones L, Harrington J, Barlow CA, et al. Advance care planning in advanced cancer: can it be achieved? An exploratory randomized patient preference trial of a care planning discussion. *Pall Support Care* 2011;9:3-13.
2. Volandes AE, Paasche-Orlow M, Barry MJ, et al. Video decision support tool for advance care planning in dementia: a randomized controlled trial. *BMJ* 2009;338:b1964.
3. El-Jawahri A, Podgurski LM, Eichler AF, et al. Use of video to facilitate end-of-life discussions with patients with cancer: a randomized controlled trial. *J Clin Oncol* 2009;28:305-310.
4. Clayton JM, Butow PN, Tattersall MHN, et al. Randomized controlled trial of a prompt list to help advanced care patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol* 2007;5:715-723.
5. Thomas K. Overview and introduction to advance care planning. In: Thomas K, Lobo B, ed. *Advance Care Planning in End of Life Care.* Oxford, UK: Oxford University Press; 2011: 3.
6. Perkins HS. Controlling death the false promise of advance directives. *Ann Intern Med* 2007; 147:51-57 and
7. Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Center Report* 2004;34:30-42.
8. Prendergast TJ. Advance Care Planning: pitfalls progress promise. *Critical Care Medicine* 2001;29:34-39.
9. Zhang B, Wright AA, Huskamp HA et al. Health care costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med* 2009; 169: 480-88.
10. Nicholas LH, Langa KM, Iwashyma TJ, Weir DR. Regional variation in the association between advance directives and end-of-life medicare expenditures. *JAMA* 2011;306(13):1447-53.
11. Curtis J, Wenrich MD, Carline JD et al. Understanding physicians' skills at providing end-of-life care: perspectives of patients, families and health care workers. *J Gen Intern Med* 2001; 16: 41-49.
12. Heyland DK, Groll D, Rocker G, Dodek P, Gafmi A et al. End-of life care in acute care hospitals in Canada: a quality finish? *J Palliat Care* 2005;21:142-50.
13. Heyland DK, Cook DJ, Rocker GM, et al. The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: the Canadian Health Care Evaluation Project (CANHELP) questionnaire. *Palliat Med* 2010; 24: 682-695.

14. Simon J, Murray A, Raffin S. Facilitated advance care planning: what is the patient experience? *J Palliat Care* 2008; 24: 256-64.

15. Azoulay E, Pochard F, Kentish-Barnes N, Chevret S, Aboab J, Adrie C, et al. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *Am J Respir Crit Care Med* 2005; 171:987-94.

16. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA* 2008;300: 16665-73.

17. Janssen DJA, Spruit MA, Schols JMGA, Wouters EFM. A call for high-quality advance care planning in outpatients with severe COPD or chronic heart failure. CHEST 2011; 139:1081-88.

18. Heyland D, Barwich D, Pichora D et al. Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med* 2013; 173(9): 778-787.

19. Kirchhoff KT, Hammes BJ, Kehl KA, Briggs LA, Brown RL. Effect of a disease-specific planning intervention on surrogate understanding of patient goals for future medical treatment. *J Am Geriatr Soc* 2010; 58:1233-40.

20. Briggs LA, Kirchhoff KT, Hammes BJ, et al. Patient-centered advance care planning in special patient populations: a pilot study. Journal of Professional Nursing 2004; 20(1): 47-58.

21. Detering KM, Hancock AD, Reade MC et al. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ 2010; 340:c1345. doi:10.113/bmj.c1345.

22. Respecting choices: and advanced care planning system that works; Respecting Choices Web site; http://respectingchoices.org. Accessed February 15, 2013.

23. Sampson EL, Thune-Boyle I, Kukkastenvehmas R et al. Palliative care in advanced dementia; a mixed methods approach for the development of a complex intervention. *BMC Palliative Care* 2008; 7:8 doi: 10.1186/1472-684X-7-8.

24. Au DH, Edmunds MU, Engelberg RA, Diehr PH, Bryson CL et al. A randomized trial to improve communication about end-of-life care among patients with COPD. *Chest* 2012; 141:726-735.

25. Connors AF, Dawson NV, Desbiens NA, et al. A controlled trial to improve care for seriously ill hospitalized patients: the study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA* 1995; 274: 1591-1598.

26. Schickedanz AD, Schillinger D, Landefeld CS et al. A clinicial framework for improving the advance care planning process: start with patients' self-identified barriers. *JAGS* 2009, 57:31-39.

27. Knauft E, Nielsen EL, Engelberg RA, Patrick DL, Curtis JR. Barriers and facilitators to end-of-life care communication for patients with COPD. *Chest* 2005; 127: 2188-96.

28. Martin DK, Thiel EC, Singer PA. A new model of advance care planning. *Arch Intern Med* 1999; 159:86-92.
29. Singer PA, Martin DK, Lavery JV et al. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med* 1998;158:879-884.
30. Steinhauser KE, Christakis NA, Clipp EC et al. Factors considered important at the end of life by patients, family, physicians and other care providers. *JAMA* 2000;284:2476-2482.
31. Steinhauser KE, Christakis NA, Clipp EC et al. Preparing for the end of life: preferences of patients, families, physicians and other care providers. *J Pain Symptom Manage* 2001;22:727-737.
32. Cherlin E, Fried T, Prigerson HG et al. Communication between physicians and family caregivers about care at the end of life: when do discussions occur and what is said? J Pall Med 2205;8: 1176-1185.
33. Hines SC, Glover JJ, Holley JL et al. Dialysis patients' preferences for family-based advance care planning. *Ann Intern Med* 1999; 130: 825-828.
34. Medical Research Council. A framework for development and evaluation of RCTs for complex interventions to improve health. Medical Research Council Website. http://www.mrc.ac.uk/Utilities/Documentrecord/index.htm?d=MRC0033. Accessed June 20, 2012.
35. Morgan DL. Paradigms lost and pragmatism regained. *JMMR* 2007;1:48-76.
36. Creswell JW, Plano Clark VL. The foundations of mixed methods research. In: *Designing and Conducting Mixed Methods Research.* Thousand Oaks, California: Sage; 2011: 19.
37. Johnson RB, Onwuegbuzie, Turner LA. Toward a definition of Mixed Methods Research. *JMMR* 2007;1:112-133.
38. Sale JEM, Lohfeld LH, Brazil K. Revisiting the quantitative-qualitative debate: implications for mixed-methods research. *Quality & Quantity* 2002;36:43-53.
39. Creswell JW, Plano Clark VL. Choosing a mixed methods design. In: *Designing and Conducting Mixed Methods Research.* Thousand Oaks, California: Sage; 2011:53.
40. Morse J, Niehaus L. Preface. In: *Mixed Method Design: Principles and Procedures*. Walnut Creek, CA: Left Coast Press;2009:9.
41. Leech NL, Onwuegbuzie AJ. A typology of mixed methods research designs. *Qual Quant* 2009; 43: 265-275.
42. Thorne S, Oliffe J, Kim-Sing C et al. Helpful communications during the diagnostic period: an interpretive description of patient preferences. *European Journal of Cancer Care* 2010; 19: 746-754.

43. Moss AH, Lunney JR, Culp S et al. Prognostic significance of the surprise question in cancer patients. *J Pall Med* 2010;7:837-840.

44. Engelberg R, Downey L, Curtis JR. Psychometric characteristics of a quality of communication questionnaire assessing communication about end-of-life care. *J Pall Med* 2006;9:1086-1099.

45. Curtis JR, Patrick DL. Barriers to communication about EOL care in AIDS patients. *J Gen Intern Med* 1997;12:736-741.

46. Curtis JR, Patrick D, Caldwell E, Greenlee H, Collier AC. The quality of patient-clinician communication about EOL care: a study of patients with AIDS and their primary care clinicians. *AIDS* 1999;13:1123-1131.

47. Wenrich MD, Curtis JR, Shannon SE et al. Communicating with dying patients within the spectrum of medical care from terminal diagnosis to death *Arch Intern Med* 2001;161:868-874.

48. Curtis JR, Wenrich MD, Carline JD et al. Patients' perspectives on physicians' skills at EOL care: differences between patients with COPD, cancer and AIDS. *Chest* 2002;122:356-362.

49. Wenrich MD, Curtis JR, Ambrozy DM, Carline JD, Shannon SE. Dying patients' needs for emotional support and personalized care from physicians: perspectives of patients with terminal illness, families and health care providers. *J Pain Symptom Manage* 2003;25:236-246.

50. Streiner DL, Norman GR. Validity. In: Streiner DL, Norman GR. *Health Measurement Scales: a Practical Guide to their Development and Use*. 4th ed. Oxford: Oxford University Press;2007:247.

51. Streiner DL, Norman GR. Selecting the Items. In: Streiner DL, Norman GR. *Health Measurement Scales: a Practical Guide to their Development and Use.* 4th ed. Oxford: Oxford University Press; 2007: 77.

52. Norman GR, Streiner DL. Principal components and factor analysis. In: Norman DR, Streiner DL. *Biostatistics the Bare Essentials.* 3rd ed. Shelton, CT: People's Medical Publishing House; 2008*:*194.

53. Norman GR, Streiner DL. Exploratory factor analysis. In: Norman GR, Streiner DL. PDQ *Statistics*. 3rd ed. Shelton, CT: People's Medical Publishing House;2003:144.

54. Norman GR, Streiner DL. Simple regression and correlation. In: Norman GR, Streiner DL. *Biostatistics the Bare Essentials.* 3rd ed. Shelton, CT: People's Medical Publishing House; 2008*:*132.

55. Norman GR, Streiner DL. Relationship between interval and ratio variables: linear and multiple regression. In: Norman GR, Streiner DL. PDQ *Statistics*. 3rd ed. Shelton, CT: People's Medical Publishing House;2003:144.

56. Janssen DJA, Curtis JR, Spruit MA et al. Patient-clinician communication about end-of-life care for Dutch and US patients with COPD. *Eur Respir J* 2011;38:268-276.

57. Norman GR, Streiner DL. Comparing two groups. In: Norman GR, Streiner DL. *Biostatistics the Bare Essentials.* 3rd ed. Shelton, CT: People's Medical Publishing House; 2008:70.

58. Bausell RB. Multiple Regression. In: Bausell RB. *A practical guide to conducting empirical research.* New York,NY: Harper & Row;1986:278.

59. Norman GR, Streiner DL. Mulitple regression. In: Norman GR, Streiner DL. *Biostatistics the Bare Essentials.* 3rd ed. Shelton, CT: People's Medical Publishing House; 2008:143.

60. *IBM SPSS Statistics* [computer program]. Version 21.0. Ireland: IBM Corportation; Nov 2012.

61. Neergaard MA, Olesen F, Andersen RS, Sondergaard J. Qualitative description—the poor cousin of health research? *BMC Medical Research Methodology* 2009;9:52 doi:10.1186/1471-2288-9-52.

62. Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. *Res Nurs Health* 1997;20:169-177.

63. Sandelowski M. Whatever happened to qualitative description? *Res Nurs Health* 2000;23:334-340.

64. Thorne S. Conceptualizing findings. In: Thorne S. *Interpretive Description.* Walnut Creek, CA: Left Coast Press;2008:163.

65. Thorne S. Data analysis in qualitative research. *Evid Based Nurs* 2000;3:68-70.

66. Thorne S. Making sense of data. In: Thorne S. *Interpretive Description.* Walnut Creek, CA: Left Coast Press;2008:141.

67. Bogdewic SP. Participant observation. In: Crabtree BF, Miller WL eds. *Doing Qualitative Research.* 2nd ed. Thousand Oaks, CA: Sage Publications;1999:47.

68. Creswell JW. Five qualitative approaches to inquiry. In: Creswell JW. *Qualitative Inquiry and Research Design.* 2nd ed. Thousand Oaks, CA: Sage Publications; 2007:53.

69. Thorne S, Kirkham SR, O'Flynn-Magee K. The analytic challenges in interpretive description. *International Journal of Qualitative Methods* 2004:3(1).

70. Thorne S, Darbyshire P. Landmines in the field: a modest proposal for improving the craft of qualitative health research. *Qualitative Health Research* 2005;15:1105-1113.

71. Patton M. *Qualitative evaluation and research methods*. Sage: Beverly Hills, CA: Sage Publications; 1990.

72. NVivo qualitative data analysis software; QSR International Pty Ltd. Version 10,2012.

73. Creswell JW. Standards of validation and evaluation. In: Creswell JW. *Qualitative Inquiry and Research Design.* 2nd ed. Thousand Oaks, CA: Sage Publications; 2007:201.

74. Thorne S. Framing a study design. In: Thorne S. *Interpretive Description.* Walnut Creek, CA: Left Coast Press;2008:73.

75. Sandelowski M. The problem of rigor in qualitative research, *Advances in Nursing Science* 1986;8: 27-37.

76. Thorne S. Writing findings. In: Thorne S. *Interpretive Description.* Walnut Creek, CA: Left Coast Press;2008:177.

77. Alano GJ, Pekmezaris R, Tai JY, Hussain MJ, Jeune J, Louis B et al. Factors influencing older adults to complete advance directives. *Palliat Support Care* 2010;8:267-75.

78. Smith AK, McCarthy EP, Paulk E, Balboni TA, Maciejewski PK et al. Racial and ethnic differences in advance care planning among patients with cancer: impact of terminal illness acknowledgement, religiousness, and treatment preferences.*J Clin Oncol* 2008;26:4131-7.

79. Lunney JR, Lynn J, Hogan C.Profiles of older medicare decedents. *J Am Geriatr Soc* 2008;50:1108-1112.

80. Thorne S. Strategizing a credible study. In: Thorne S. *Interpretive Description.* Walnut Creek, CA: Left Coast Press;2008:87.

81. Leech NL, Onwuegbuzie AJ. A typology of mixed methods research designs. *Quality and Quantity* 2009;43:265-275.

82. Creswell JW, Analyzing and interpreting data in mixed methods reseaerch. In: *Designing and Conducting Mixed Methods Research.* Thousand Oaks, California: Sage; 2011:203.

83. Garrett A.L, Leslie-Pelecky D.L. Applying three strategies for integrating quantitative and qualitative databases in a mixed methods study of a non-traditional graduate education program. *Field Methods* 2010;22:154-174.

84. Addington-Hall JM, Bruera E, Higginson IJ, Payne S. *Research Methods in Palliative Care.* Oxford: Oxford University Press; 2007.

85. Fine PG. Maximizing benefits and minimizing risks in palliative care research that involves patients near the end of life. *J Pain Symptom Manage* 2003; 25: S53-62.

86. Heffner JE. Advance Care Planning in Chronic Obstructive Pulmonary Disease: barriers and opportunities. *Current Opinion in Pulmonary Medicine* 2001;17: 103-109.

87. Kirkpatrick JN, Guger CG, Arnsdorf MR, Fedson SE. Advance directives in the cardiac care unit. *American Heart Journal* 2007;154(3).

88. Sampson EL, Jones L, Thuné-Boyle ICV, Kukkastenvchmas R, King M, Leurent B, Tookman A, Blanchard MR. Palliative assessment and advance care planning in severe dementia: an exploratory randomized controlled trial of a complex intervention. *Palliative Medicine* 2010;25:197-209.

89. Curtis JR, Engelberg RA, Nielsen EL, Au DH, Patrick DL. Patient-physician communication about end-of-life care for patients with severe COPD. *Eur Respir J* 2004;24: 200-205.

90. Elwyn G, Edwards A, Kinnersley P. Shared decision-making in primary care: the neglected second half of the consultation. *Br. J Gen Pract*. 1999 June; 49(443):477-482.

91. Ozanne EM, Partridge A, Moy B, Ellis KJ, Sepucha KR. Doctor-patient communication about advance directives in metastatic breast cancer. *J Pall Med* 2009; 12(6).

92. Evans N, Pasman HRW, Payne SA, Seymour J, Pleschberger S, Deschepper R, Bregie OD. Older patients' attitudes towards and experiences of patient-physician end-of-life communication: a secondary analysis of interviews from British, Dutch and Belgian patients. *BMC Palliat Care* 2012; 11(24).

93. Clarke G, Hall RT, Rosencrance G. Physician-patient relations: no more models. *The American Journal of Bioethics* 2004; 4: W16-W19.

94. WHO Definition of Palliative Care. World Health Organization Web site.http://www.who.int/cancer/palliative/definition/en/ Accessed March 10,2013.

95. Davison SN. Facilitating advance care planning for patients with end-stage renal disease: the patient perspective. *Clin J Am Soc Nephrol* 2006;1:1023-1028.

96. Thorne S, Armstrong E, Harris SR, Hislop TG, Kim-Sing C, Oglov V, Oliffe JL, Stajduhar KI. Patient Real-Time and 12-month retrospective perceptions of difficult communications in the cancer diagnostic period. *Qualitative Health Research* 2009;19: 1381-1394.

97. Davidson PM. Difficult conversations and chronic heart failure: do you talk the talk or walk the walk? *Curr Opin Support Palliat Care* 2007;1:274-278.

98. Davison SN, Seija KK, Currie GR. Patient and health professional preferences for organ allocation and procurement, end-of-life care and organization of care for patients with chronic kidney disease using a discrete choice experiment. *Nephrol Dial Transplant* 2010; 25:2334-2341.

99. Chochinov HM. *Dignity Therapy: Final Words for Final Days*. Oxford: Oxford University Press; 2012.

100. Singer PA, Martin DK, Lavery JV, Thiel EC, Kelner Merrijoy, Mendelssohn DC. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med* 1998;158: 879-884.

101. Pattison M, Romer AL. Improving care through the end of life: launching a primary care clinic-based program. *J Pall Med*. 2001; 4(2):249-254.

102. Kryworuchko J, Stacey D, Peterson WE, Heyland DK, Graham ID. *Am J Hosp Pall Med.* 2012;29(1):36-46.

103. Streiner DL, Norman GR. Interpretability. In: Streiner DL, Norman GR. *Health Measurement Scales: a Practical Guide to their Development and Use*. 3rd ed. Oxford: Oxford University Press;2003: 61.

104. Miller BE, Pittman B, Strong C et al. Gynecologic cancer patients' psychosocial needs and their views on the physician's role in meeting those needs. *Int J Gynecol Cancer*. 2003;13:111-119.

105. Heyland DK, Groll D, Rocker G et al. End-of-life care in acute care hospitals in Canada: a quality finish? *J Palliat Care.* 2005;21:142-150.

106. Heyland DK, Dodek P, Rocker G et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ.* 2006;174(5). Doi:10.1503/cmaj.050626. Acessed online March 2012.

107. Heyland DK, Cook DJ, Rocker GM et al. Defining priorities for end-of-life care in Canada. *CMAJ.* 2010;182(16). Doi:10.1503/cmaj.100131. Accessed online April 2013.

108. Mindfulness. Calgary Mindfulness-Based Stress Reduction Interest Group website. http://www.mindfulnesscalgary.ca/ Accessed April 18, 2013.

109. Ryan M. Discrete choice experiments in health care: NICE should consider using them for patient centered evaluations of health technologies. *BMJ*. 2004;328:360-261.

110. Cameron, R 2011, 'Quality frameworks and procedural checklists for mixed methods research' paper presented to the 14th Annual AVETRA Conference 2011: Research in VET: Janus- Reflecting Back, Projecting Forward, Melbourne, 27-29 April, http://avetra.org.au/wp-content/uploads/2011/05/6ppt.pdf

APPENDIX A. Case Report Form

CASE REPORT FORM

Study Title:

TALK TO ME: A Mixed Methods Study on Seriously Ill Inpatients' views on Physician Behaviours during Advance Care Planning
Locally Responsible Investigator: Dr. John You
Principal Investigator: Dr. Amane Abdul-Razzak

Clinical Trial Site (circle one): HGH JHCC

Study ID number: Date of Visit (dd/mm/yyyy):

I am confident that the information supplied in this case record form is complete and accurate data. I confirm that the study was conducted in accordance with the protocol and any protocol amendments and that written informed consent was obtained prior to the study.

Investigator's Signature:

Date of Signature (dd/mm/yyyy):

A. Inclusion Criteria

1. Hospital admission for CHF with NYHA Class IV disease or LVEF ≤25%. YES NO

2. Hospital admission for severe COPD with one or more of the following: BMI <21; an exacerbation requiring hospitalization over the past year; shortness of breath causing the patient to stop walking after 100 m or after a few minutes on level ground; $FEV_1 \leq$ 30% predicted; or $PaCO_2 \geq$ 45torr. YES NO

3. Hospital admission for liver cirrhosis with at least one of the following: history of hepatic coma; Child's class C liver disease or Child's class B liver disease with gastrointestinal bleeding. YES NO

4. Hospital admission for issue related to active metastatic cancer. YES NO

5. ANY medical inpatient ≥ 80 years of age. YES NO

6. Any medical inpatient for whom a health care provider (MD/RN) answers "no" to the following question: "Would you be surprised if this patient died within the next year?" YES NO

B. **Exclusion Criteria**

1. Unable to read and speak the English language. YES NO
2. Cognitive impairment, including documented mild cognitive impairment, dementia of any type, or delirium. YES NO
3. Patient has not had ANY discussions with a physician related to Advance Care Planning and/or their wishes for care at the end of life. YES NO
4. Hospitalization time of less than 48 hours. YES NO
5.
6. Unable to provide informed consent for other reasons:

   i) Participant fatigued or too sick YES NO
   ii) Participant/family refusal to participate for other reasons. YES NO
   iii) Healthcare team member feels that patient is not appropriate for enrolment. YES NO

C. Demographic Data:

1. Age (years):
2. Gender (check one): M F
3. Level of education (tick one):

_____ Elementary school

_____ High school diploma

_____ Postsecondary education (degree or diploma)

4. Diagnosis (the one(s) that allowed this participant to meet eligibility criteria):
5. **Number of hospitalizations over past year**
6. Ethnic background(circle one): **Caucasian** **non-Caucasian**

Demographic Data (con...):

Please circle if any of the following comorbid conditions are present (Charlson Comorbidity Index):

1. Acquired Immunodeficiency Syndrome (AIDS)

2. Cerebrovascular disease (e.g., stroke)

3. Chronic pulmonary disease

4. Congestive heart failure

5. Connective tissue disease

6. Dementia

7. Hemiplegia

8. Leukemia

9. Malignant lymphoma

10. Myocardial infarction

11. Peripheral vascular disease (e.g., ischemic limb)

12. Diabetes mellitus (without end organ damage)

13. Diabetes mellitus (with end organ damage)

14. Liver disease

15. Renal disease

16. Malignant solid tumor (non metastatic)

17. Malignant solid tumor (metastatic)

D. Quality of Communication Questionnaire

We would like to know, in as much detail as possible, how good the doctor taking care of your medical problems in the hospital is at talking with you about your illness and the types of care that you would want if you became sicker or too sick to speak for yourself. We know that many people think very highly of their doctors. To help us improve communication between doctors and their patients, please be critical.
Using the following scale, where "0" is the worst you could imagine, and "10" is the best you could imagine, please tell me the best number for each statement. Please circle "Didn't do" if your doctor has never done the activity in the statement, and circle "Don't know" if you are not sure or cannot remember.

When talking with Doctor x_____ about important issues like becoming very ill, how good is he/she at:

	The very worst I could imagine										The very best I could imagine		
1. Using words that you can understand.	0	1	2	3	4	5	6	7	8	9	10	Didn't do	Don't know
2. Looking you in the eye.	0	1	2	3	4	5	6	7	8	9	10	Didn't do	Don't know
3. Answering all your questions about your illness and treatment.	0	1	2	3	4	5	6	7	8	9	10	Didn't do	Don't know
4. Listening to what you have to say.	0	1	2	3	4	5	6	7	8	9	10	Didn't do	Don't know
5. Caring about you as a person.	0	1	2	3	4	5	6	7	8	9	10	Didn't do	Don't know

6.Giving you his/her full attention.	0 1 2 3 4 5 6 7 8 9 10	Didn't do	Don't know
7. Talking with you about your feelings concerning the possibility that you might get sicker.	0 1 2 3 4 5 6 7 8 9 10	Didn't do	Don't know
8. Talking to you about details concerning the possibility that you might get sicker.	0 1 2 3 4 5 6 7 8 9 10	Didn't do	Don't know
9. Talking to you about how long you might have to live.	0 1 2 3 4 5 6 7 8 9 10	Didn't do	Don't know
10. Talking to you about what dying might be like.	0 1 2 3 4 5 6 7 8 9 10	Didn't do	Don't know
11. Involving you in the decisions about the treatments that you want if you get too sick to speak for yourself.	0 1 2 3 4 5 6 7 8 9 10	Didn't do	Don't know
12. Asking about the things in life that are important to you.	0 1 2 3 4 5 6 7 8 9 10	Didn't do	Don't know
13. Asking about your spiritual or religious beliefs.	0 1 2 3 4 5 6 7 8 9 10	Didn't do	Don't know

14. Overall, how would you rate this doctor's communication with you about the types of care that you would want if you became sicker or too sick to speak for yourself?

0 = "the very worst I could imagine" and 10 = "the very best I could imagine"
(Circle one)

0 1 2 3 4 5 6 7 8 9 10

APPENDIX B. Initial Qualitative Interview Schedule

Preamble (suggested script for interviewer):

This research study will be looking at how doctors' behaviours can be helpful or not in discussing your future health care needs. We are especially interested in topics such as planning what kind of medical care you would want in the future if you cannot speak for yourself, what kind of treatment you would want in the future if you get sicker, whether or not you would like "heroics" like CPR, and whom you would like to speak on your behalf if you could not speak for yourself. Think of these topics, as well as other discussions that are related to these topics but may not be exactly the same. We will call all of these topics "advance care planning topics." Please think of any doctor who you have talked to the most about advance care planning topics when answering the questions.

Initial Question

Can you tell me about your experience with discussing advance care planning with your doctor?

Second Question

Can you think of things that ANY (hypothetical) doctor could do or say to make talking about advance care planning easier or more effective?

Can you think of things that ANY (hypothetical) doctor could do or say that would "turn you off" while talking about advance care planning?

Third Question

Did you document any decisions after speaking with your doctor?

Further Probes as Needed:

Were there things your doctor did or said that you appreciated when talking about advance care planning?

Can you think of things that your doctor did or said that "turned you off" when talking about advance care planning?

If patients indicate no conversation occurred ask: "Why do you think he/she didn't have the conversation with you?"

Why do you think you feel comfortable/uncomfortable (as the case may be) to talk to your doctor about advance care planning?

Why do you think your doctor feels comfortable/uncomfortable (as the case may be) to talk to your doctor about advance care planning?

APPENDIX C. Letter of Information/Consent

LETTER OF INFORMATION / CONSENT

QUALITY OF ADVANCE CARE PLANNING COMMUNICATION WITH PHYSICIANS: A MIXED METHODS STUDY IN SERIOUSLY ILL HOSPITALIZED PEOPLE

Investigators:

Local Principal Investigator:

Dr. John You
Department of Medicine
McMaster University
Hamilton, Ontario, Canada
(905) 525-9140 ext. 21858
E-mail: jyou@mcmaster.ca

Student Investigator:

Amane Abdul-Razzak
Department of Clinical Epidemiology & Biostatistics
McMaster University
Hamilton, Ontario, Canada
(289) 981-9069

Purpose of the Study

You are invited to take part in a study on the quality of doctors' communication in advance care planning. The term "advance care planning" refers to planning for the types of health care that you would want if you get sicker or too sick to speak for yourself. Advance care planning makes sure that you have a "voice" in the future if your health gets worse by sharing what medical treatments and procedures you would and would not want. This can involve only talking about these topics, but often involves recording your wishes on paper. Advance care planning can also include choosing a loved one to speak on your behalf in the future if you cannot communicate. A major goal of advance care planning is sharing your values and making sure that future doctors and nurses are aware of these values and respect them in the future.

We want to learn more about what you, as a patient, think doctors can do to improve the quality of these discussions. This study is being done for a thesis project. The knowledge that is gained by this study will help healthcare professionals understand what patients want their doctors to do or say during advance care planning discussions.

What will happen during the study?

Roughly 65 participants will be included in this study. You will be asked to complete a questionnaire about advance care planning. This should take about 15 to 20 minutes. This can occur in your hospital room or in a quieter meeting room. For example, one question asks "when talking with your doctor about important issues like becoming very ill, how good is he/she at looking you in the eye?" You will be asked to rate your doctor from a 0 to 10 where 0 means "the very worst I could imagine" and 10 means "the very best I could imagine." If you don't know or if your doctor didn't do this, you can circle "don't know" or "didn't do" on the questionnaire.

You might also be asked to participate in a one-on-one interview with one of the researchers to get more ideas about what you think affects the quality of the way your doctor talks to you about advance care planning. The researcher will ask you a few questions but you will be encouraged to speak whatever is on your mind about the topic. This should take between 15 minutes up to an hour, depending on how much you would like to say. This will occur in a quiet meeting room for privacy. With your permission, the interviewer will audio tape the interview and may take some written notes. This will help to keep track of the information you will provide. For example, the interviewer will ask "can you tell me about what happened when you spoke to your doctor in the hospital about advance care planning topics?"

We will ask you for background information like your age and your medical diagnosis.

Are there any risks to doing study?

It is not likely that there will be any harm or discomfort from this study. However, some people may feel uncomfortable talking about past talks with their doctor that did not go very well.

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable, and you can stop taking part at any time. Your privacy will be protected (this is explained below).

Are there any benefits to doing this study?

The research may not benefit you directly. We hope to learn more about what doctors can do or say to make talking about advance care planning more pleasant and helpful for their patients. This study could help current doctors and training doctors (residents) learn about how to improve the way they talk to patients about advance care planning.

If you participate in a one-on-one interview, you will receive a $10 gift card as a small token of appreciation for your time.

Confidentiality

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but the main researchers, Dr. Amane Abdul-Razzak, Dr. You and the research nurse will know whether you participated unless you choose to tell others. ***The way you rate your doctor and what you say during the interview will be strictly confidential and will not affect your medical care in any way.***

The information you provide will be kept in a locked cabinet where only Dr. Amane Abdul-Razzak will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, the data will be destroyed.

What if I change my mind about being in the study?

It is your choice to be part of the study. If you decide to be part of the study, you can decide to stop at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. You will have the option of removing your data from the study. If you do not want to answer some of the questions you do not have to, but you can still be in the study. ***Your decision whether or not to be part of the study will not affect your health care services in any way.***

How do I find out what was learned in this study?

This study should be completed by approximately July 2013. If you would like a brief summary of the results, please let us know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact:

arazzak@haltonhealthcare.on.ca

OR

Amahny81@hotmail.com

This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). The REB is responsible for ensuring that participants are informed of the risks

associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call The Office of the Chair, HHS/FHS REB at 905.521.2100 x 42013.

CONSENT

I have read the information presented in the information letter about a study being conducted by Dr. John You and Dr. Amane Abdul-Razzak, of McMaster University.

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

1. I agree that the interview can be audio/video recorded. Yes No

2. I would like to receive a summary of the study's results. Yes No

If yes, where would you like the results sent:

Email: _____

Mailing address: _____

_____

3. I agree to be contacted about future research and I understand that I can always decline the request. Yes No

Please contact me at: _____

Name of Participant (Printed): _____

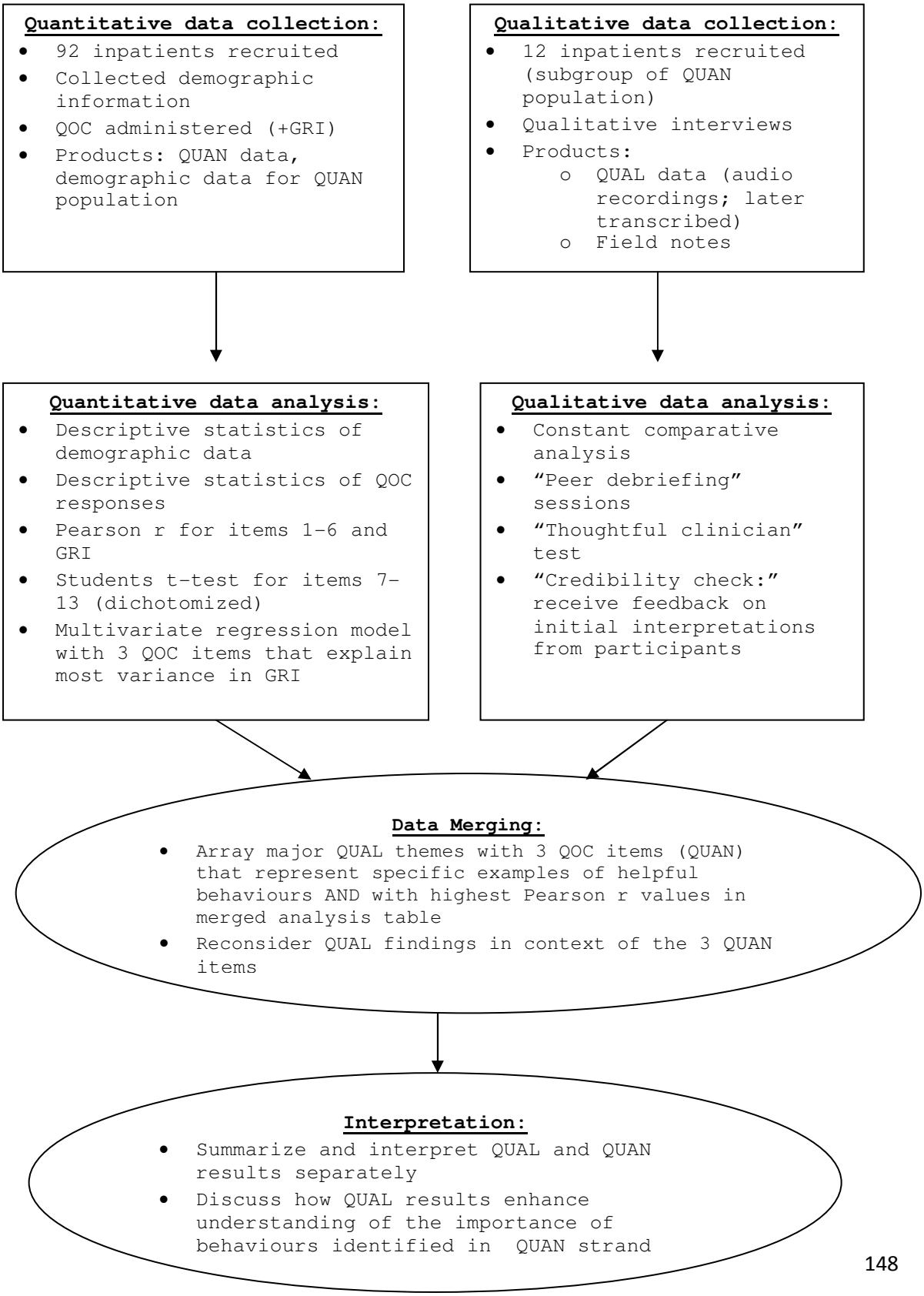
Signature: _____ Date: _____

Consent form explained in person by:

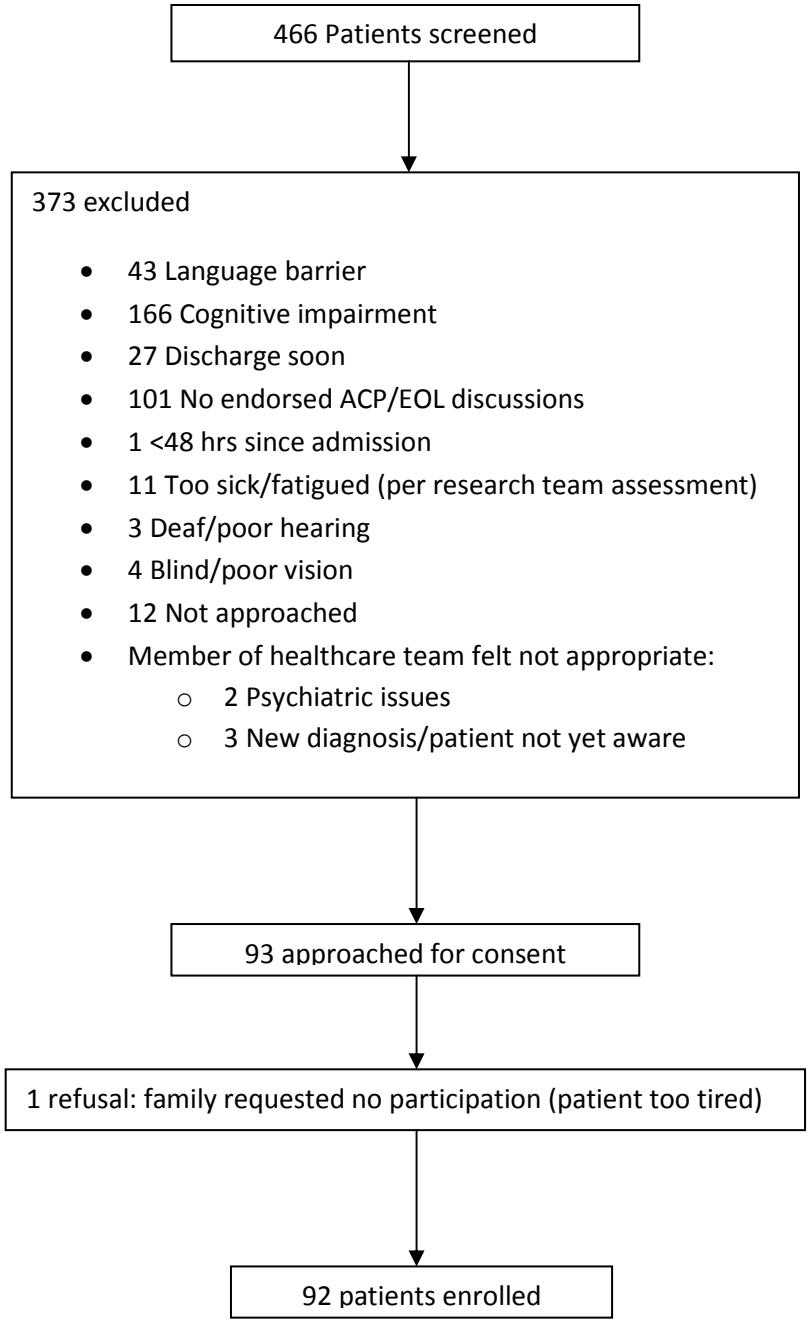
Name and Role (Printed): _____

Signature:_____ Date:_____

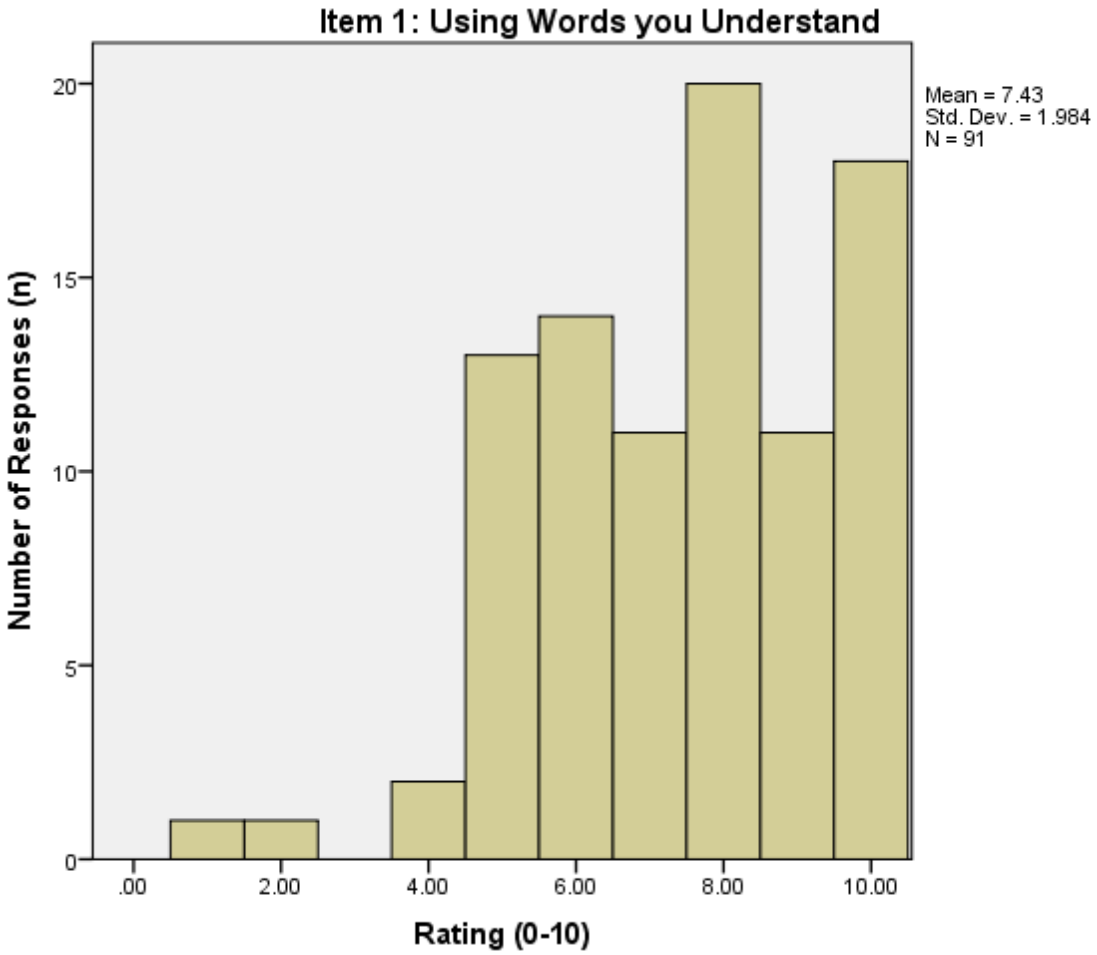
APPENDIX D. Study Flow Diagram

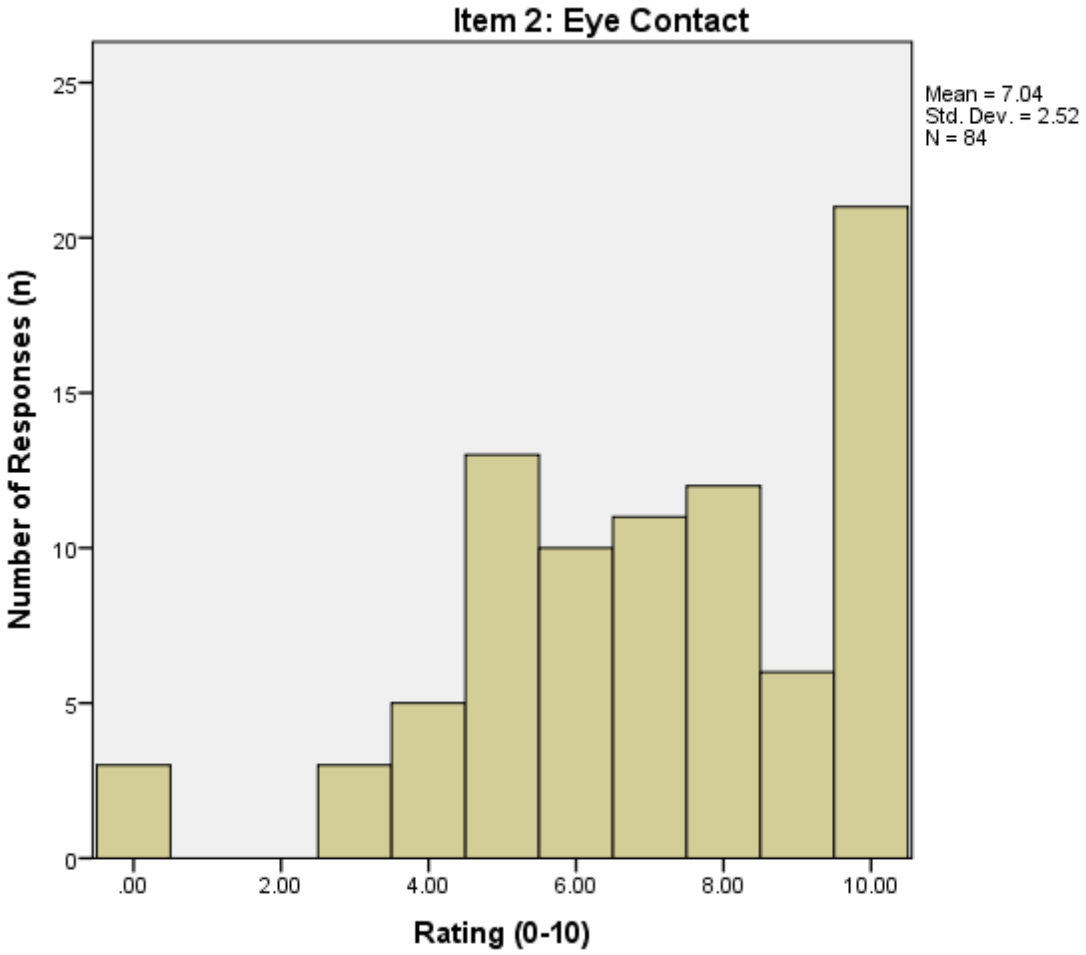


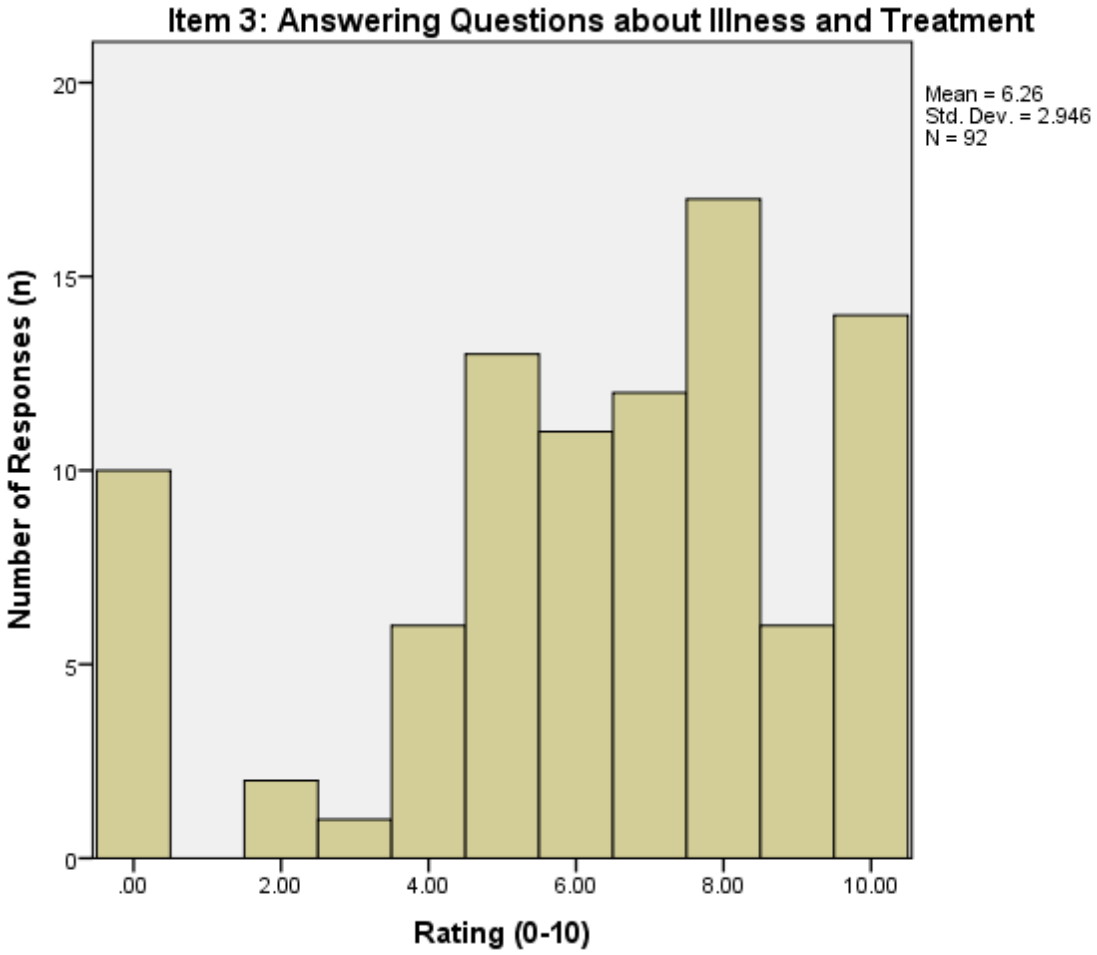
Appendix E. Recruitment Flow Chart

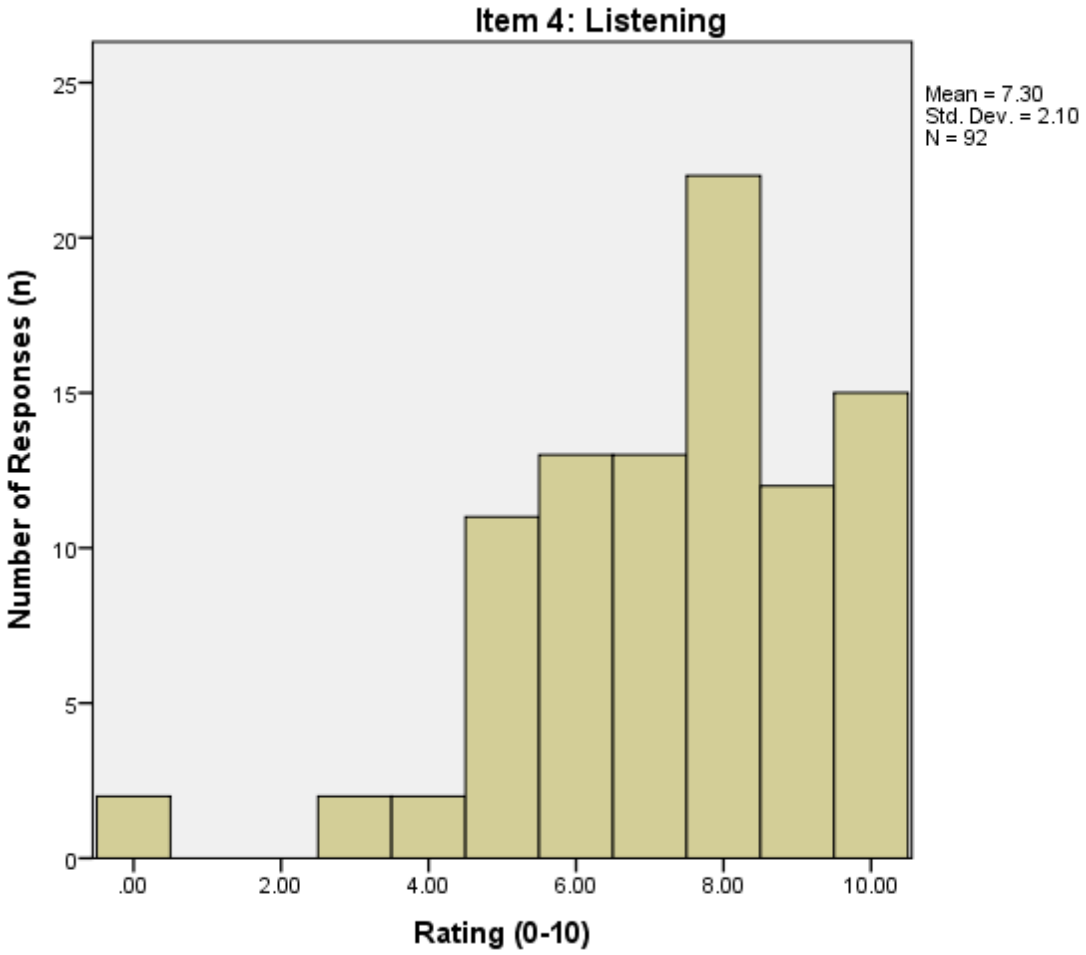


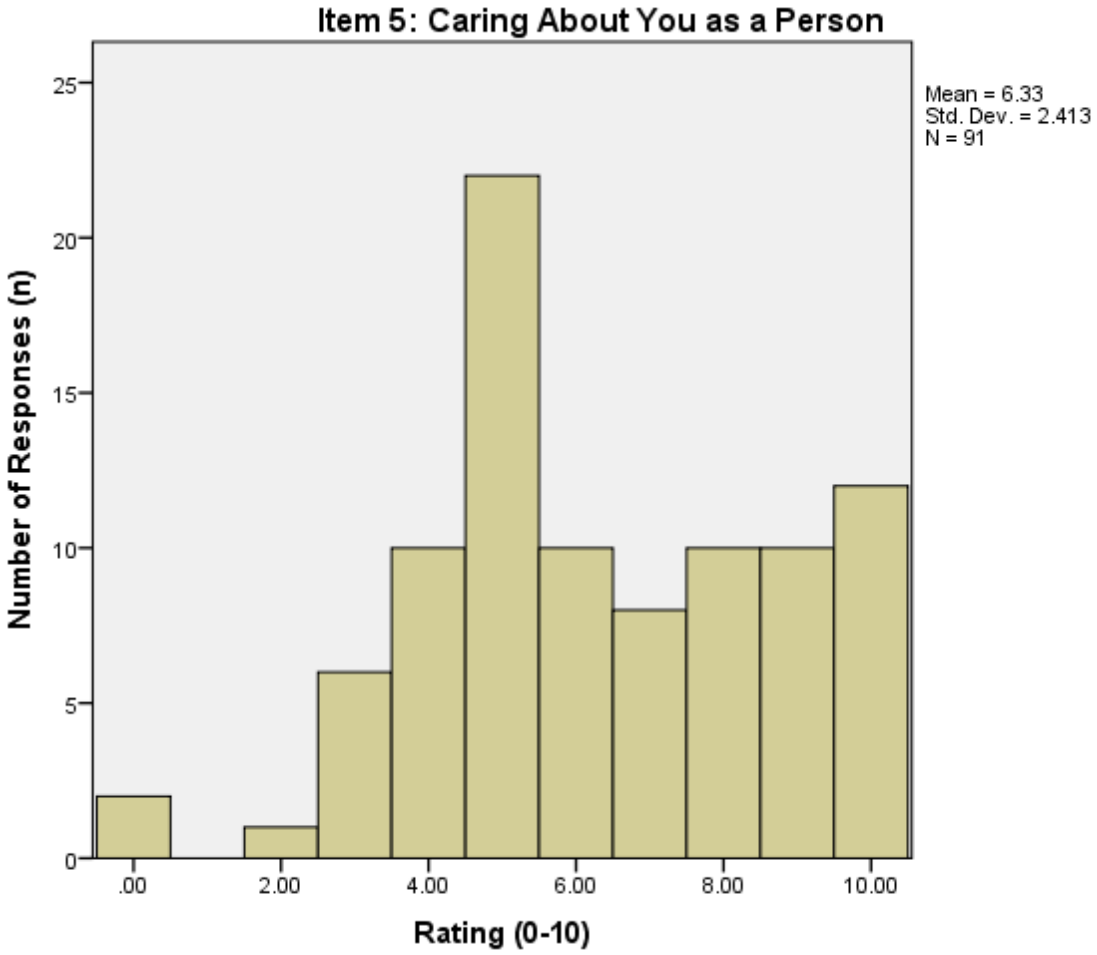
Appendix F. Frequency Histograms for Responses to QOC Items

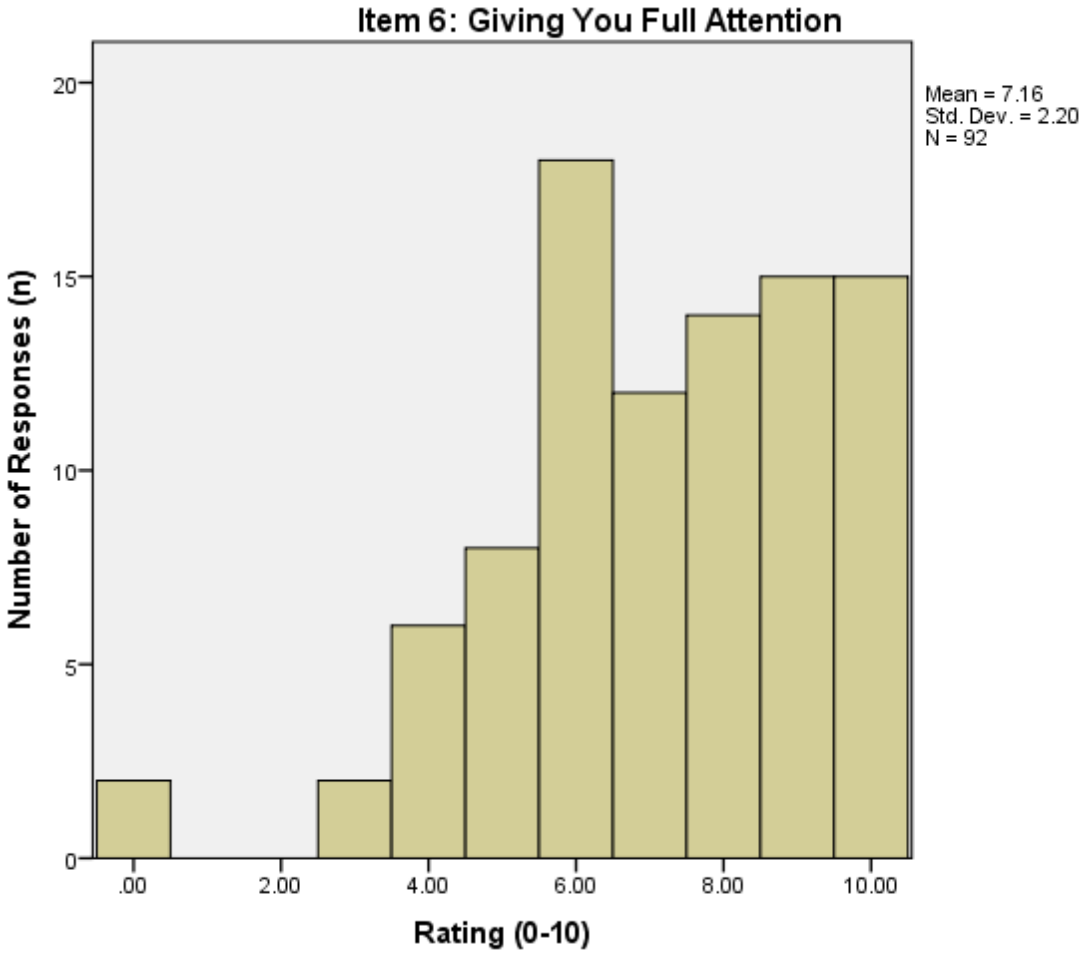


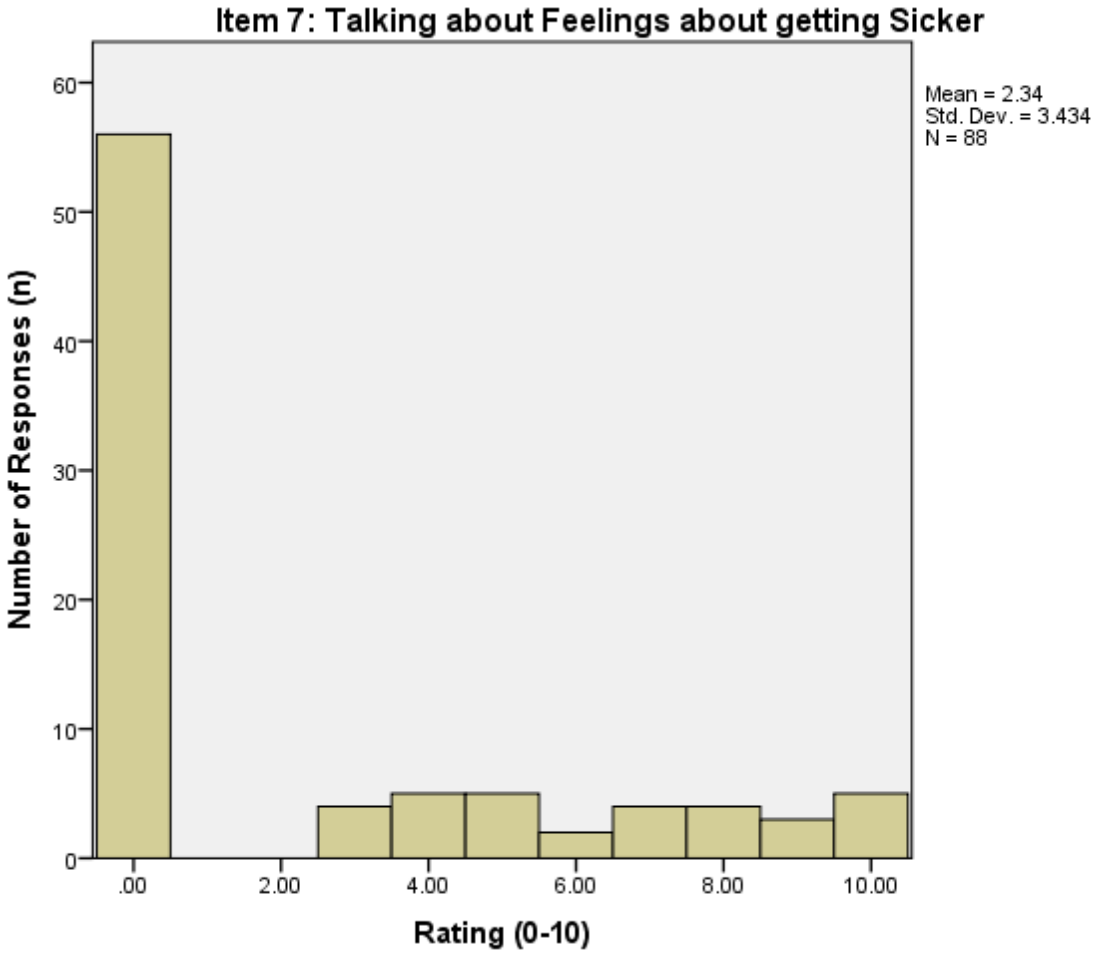

Item 2: Eye Contact
Mean = 7.04
Std. Dev. = 2.52
N = 84
Number of Responses (n)
0
5
10
15
20
25
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)

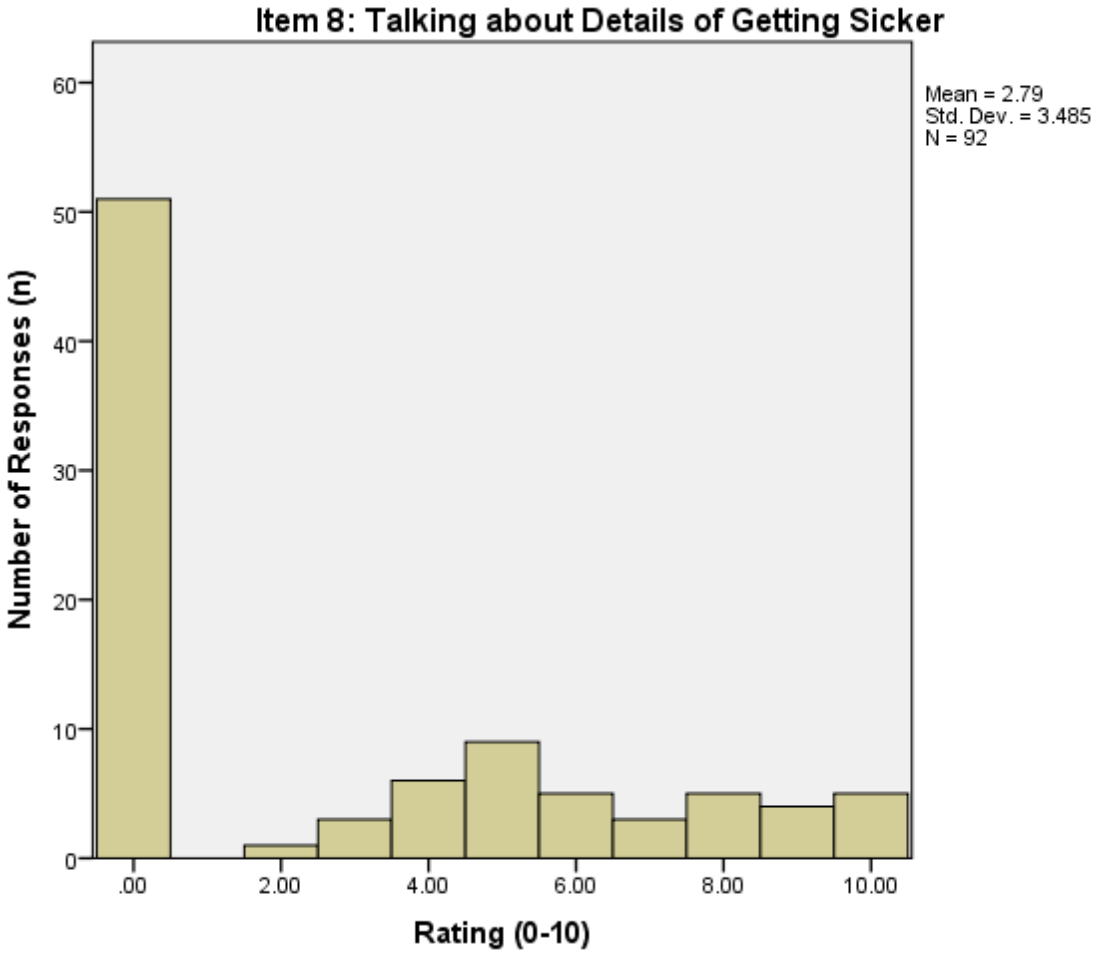

Item 3: Answering Questions about Illness and Treatment
Mean = 6.26
Std. Dev. = 2.946
N = 92
Number of Responses (n)
0
5
10
15
20
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)

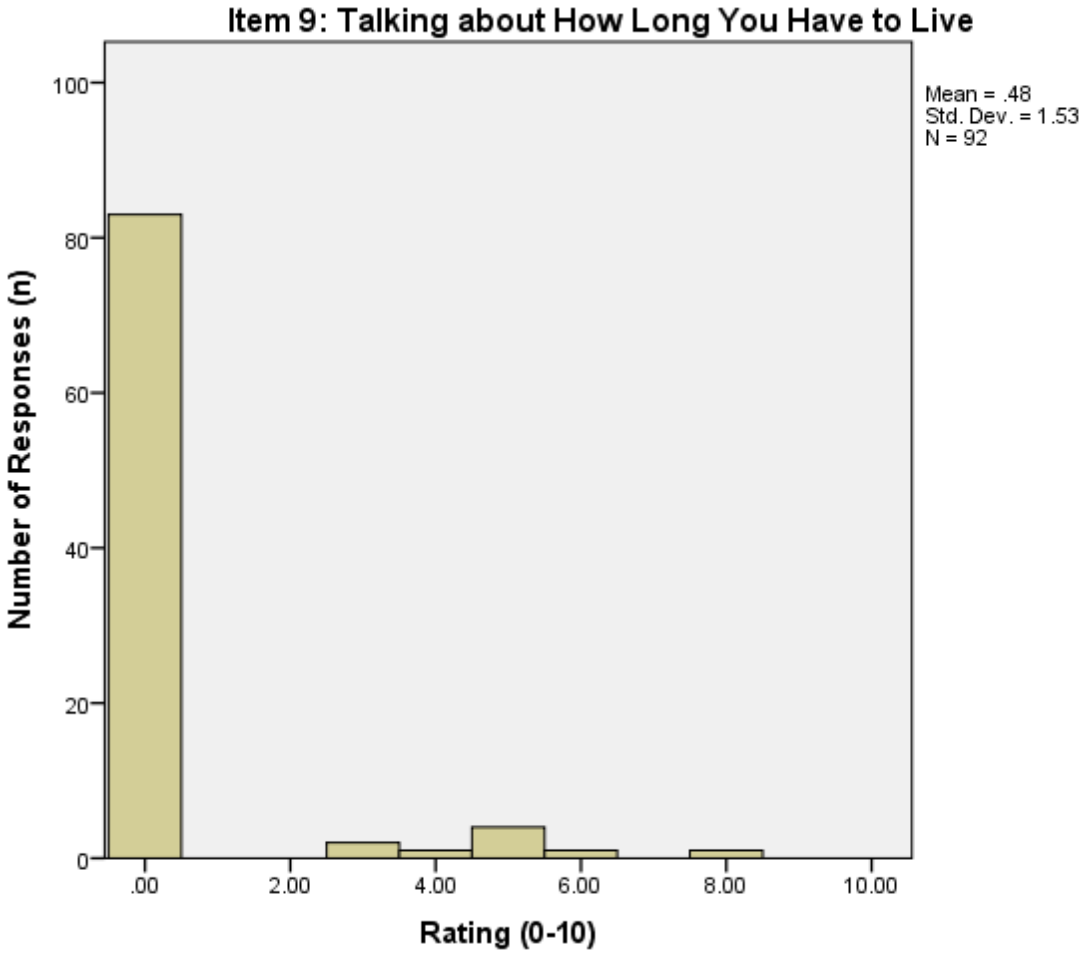

Item 4: Listening
Mean = 7.30
Std. Dev. = 2.10
N = 92
Number of Responses (n)
0
5
10
15
20
25
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)

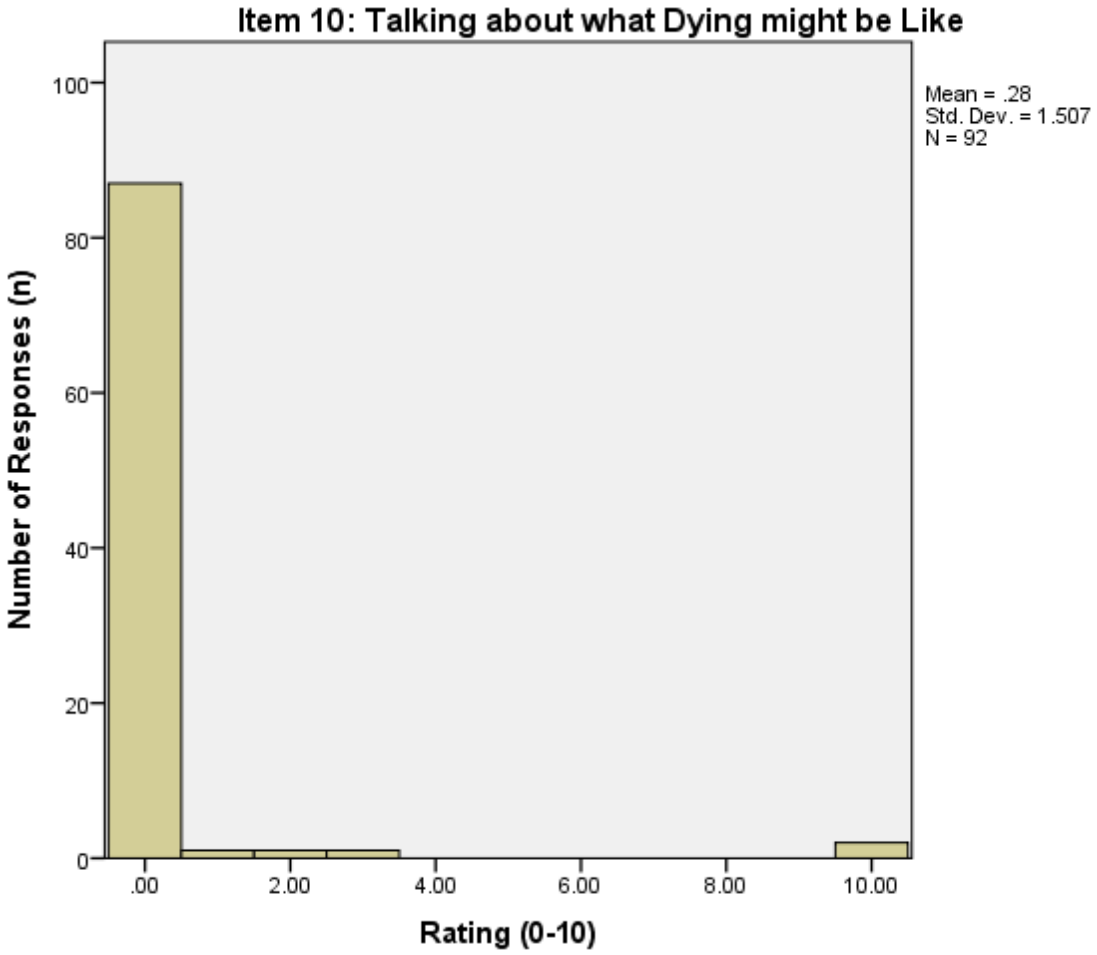

Item 5: Caring About You as a Person
Mean = 6.33
Std. Dev. = 2.413
N = 91
Number of Responses (n)
25
20
15
10
5
0
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)

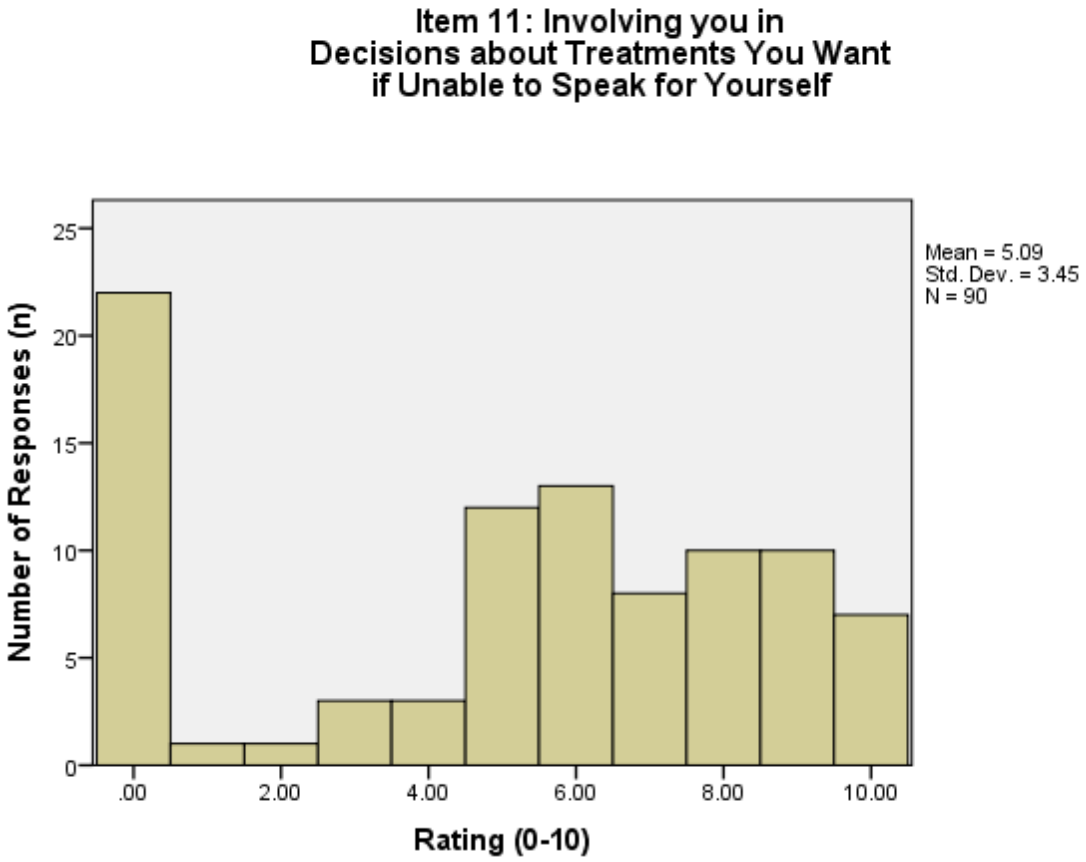

Item 6: Giving You Full Attention
Mean = 7.16
Std. Dev. = 2.20
N = 92
Number of Responses (n)
0
5
10
15
20
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)

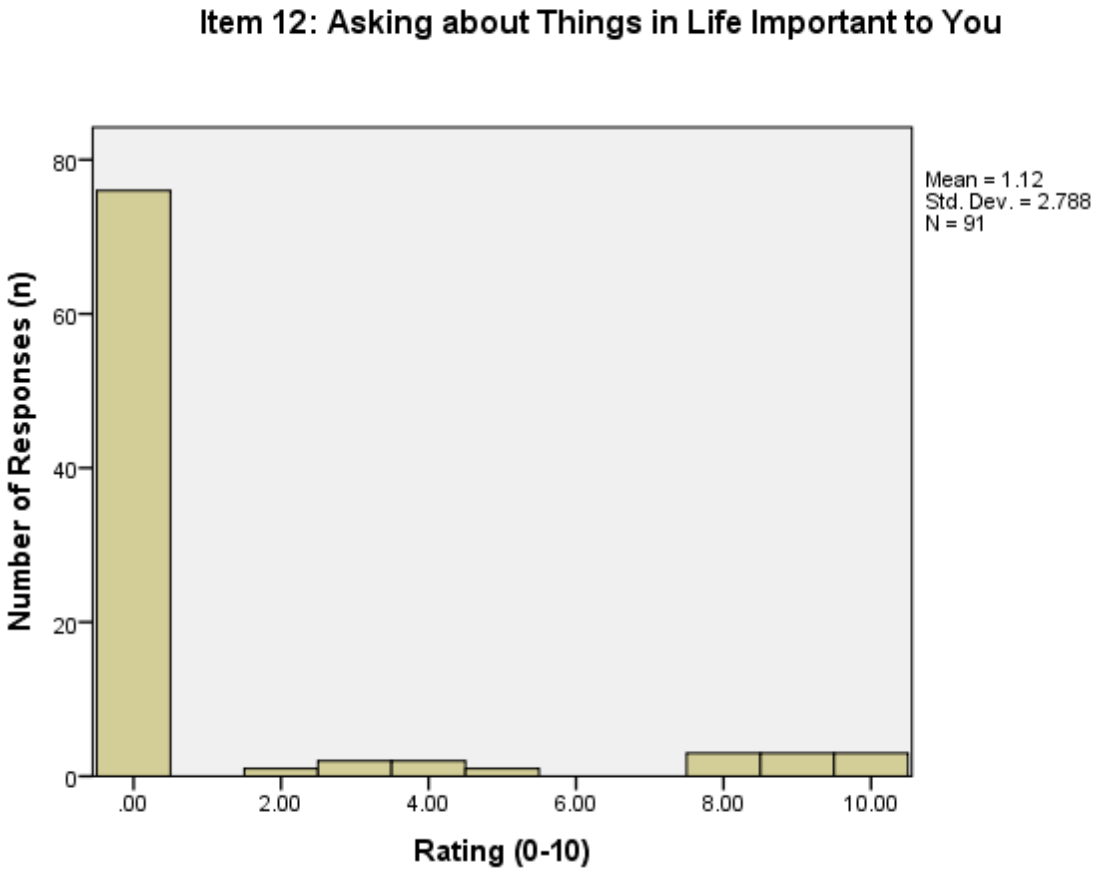

Item 7: Talking about Feelings about getting Sicker
Mean = 2.34
Std. Dev. = 3.434
N = 88
Number of Responses (n)
0
10
20
30
40
50
60
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)

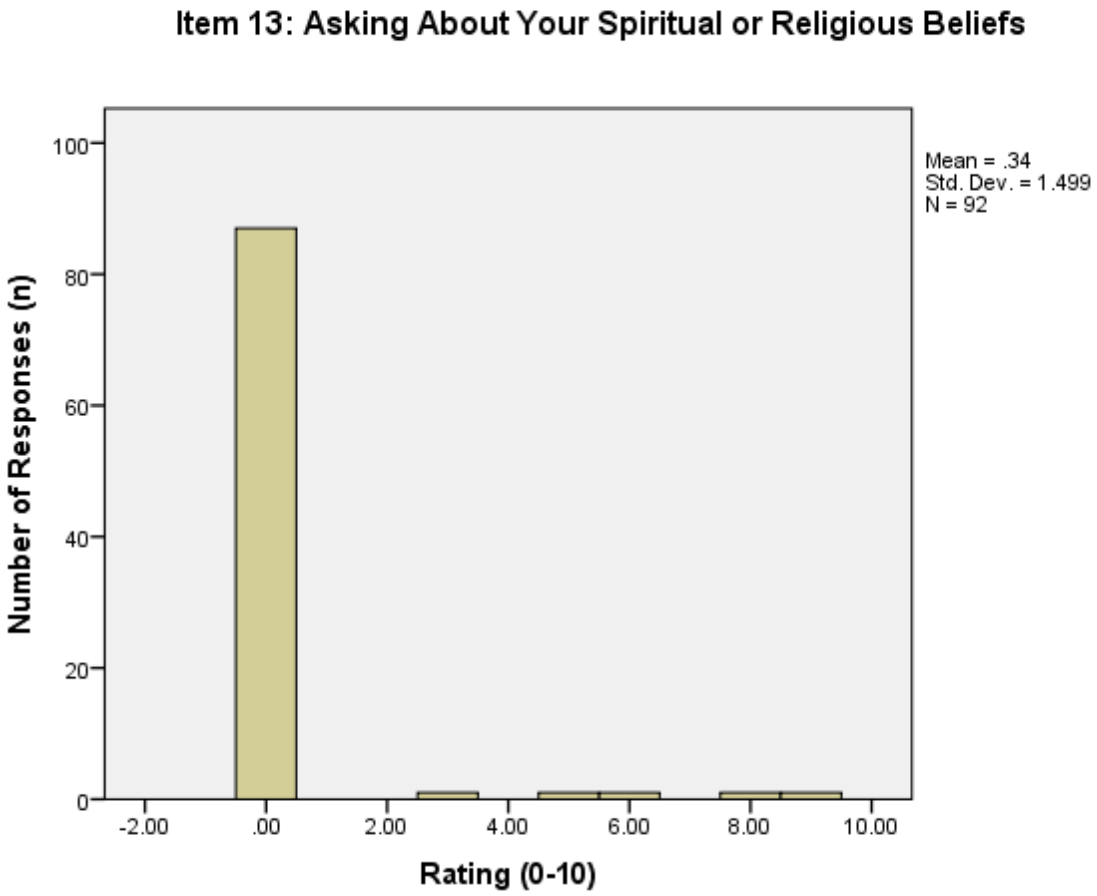

Item 8: Talking about Details of Getting Sicker
Mean = 2.79
Std. Dev. = 3.485
N = 92
Number of Responses (n)
0
10
20
30
40
50
60
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)

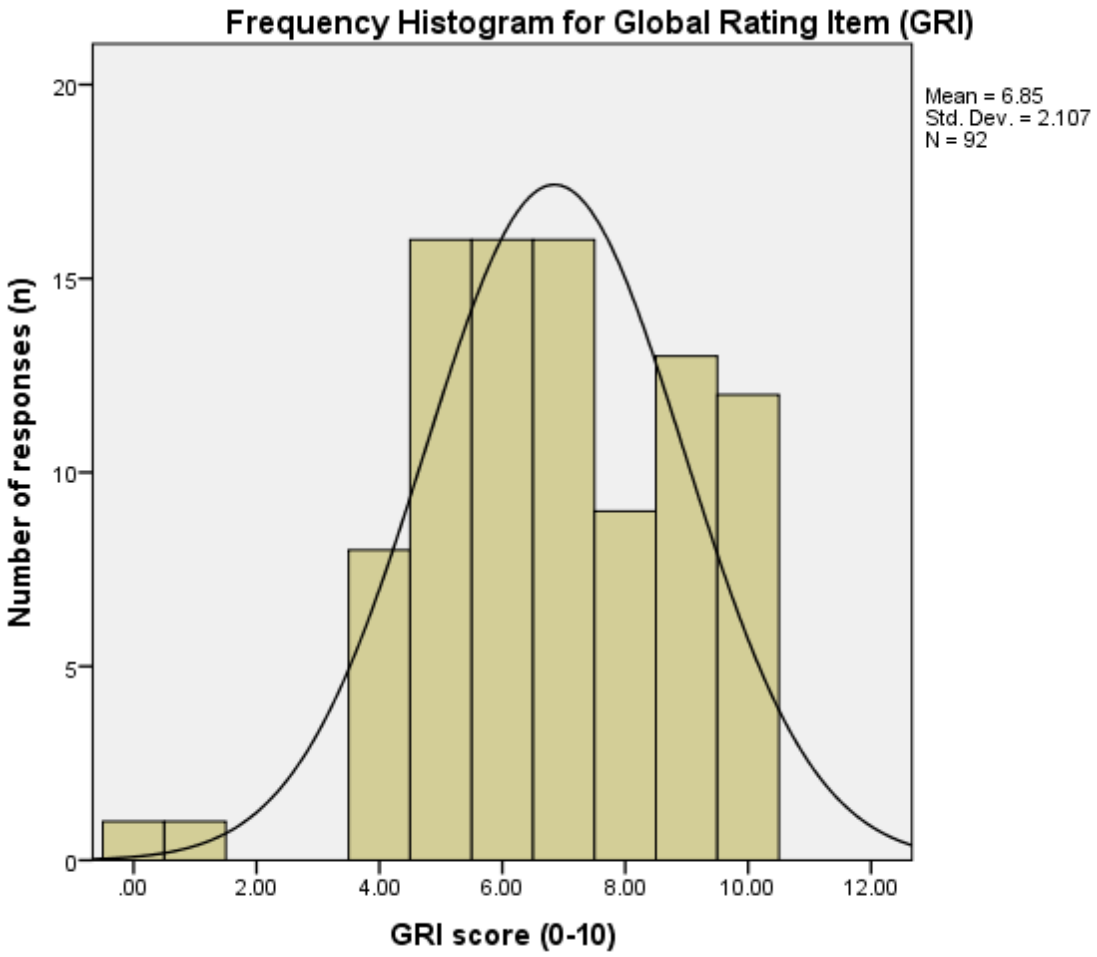

Item 9: Talking about How Long You Have to Live
Mean = .48
Std. Dev. = 1.53
N = 92
Number of Responses (n)
100
80
60
40
20
0
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)


Item 10: Talking about what Dying might be Like
Mean = .28
Std. Dev. = 1.507
N = 92
Number of Responses (n)
100
80
60
40
20
0
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)


Item 11: Involving you in
Decisions about Treatments You Want
if Unable to Speak for Yourself
Mean = 5.09
Std. Dev. = 3.45
N = 90
Number of Responses (n)
25
20
15
10
5
0
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)


Item 12: Asking about Things in Life Important to You
Mean = 1.12
Std. Dev. = 2.788
N = 91
Number of Responses (n)
0
20
40
60
80
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)


Item 13: Asking About Your Spiritual or Religious Beliefs
Mean = .34
Std. Dev. = 1.499
N = 92
Number of Responses (n)
100
80
60
40
20
0
-2.00
.00
2.00
4.00
6.00
8.00
10.00
Rating (0-10)


Frequency Histogram for Global Rating Item (GRI)
Mean = 6.85
Std. Dev. = 2.107
N = 92
Number of responses (n)
0
5
10
15
20
.00
2.00
4.00
6.00
8.00
10.00
12.00
GRI score (0-10)

Appendix G. Bivariate Correlation Matrix for Items 1–6 and the GRI on the Quality of Communication Questionnaire

Correlations

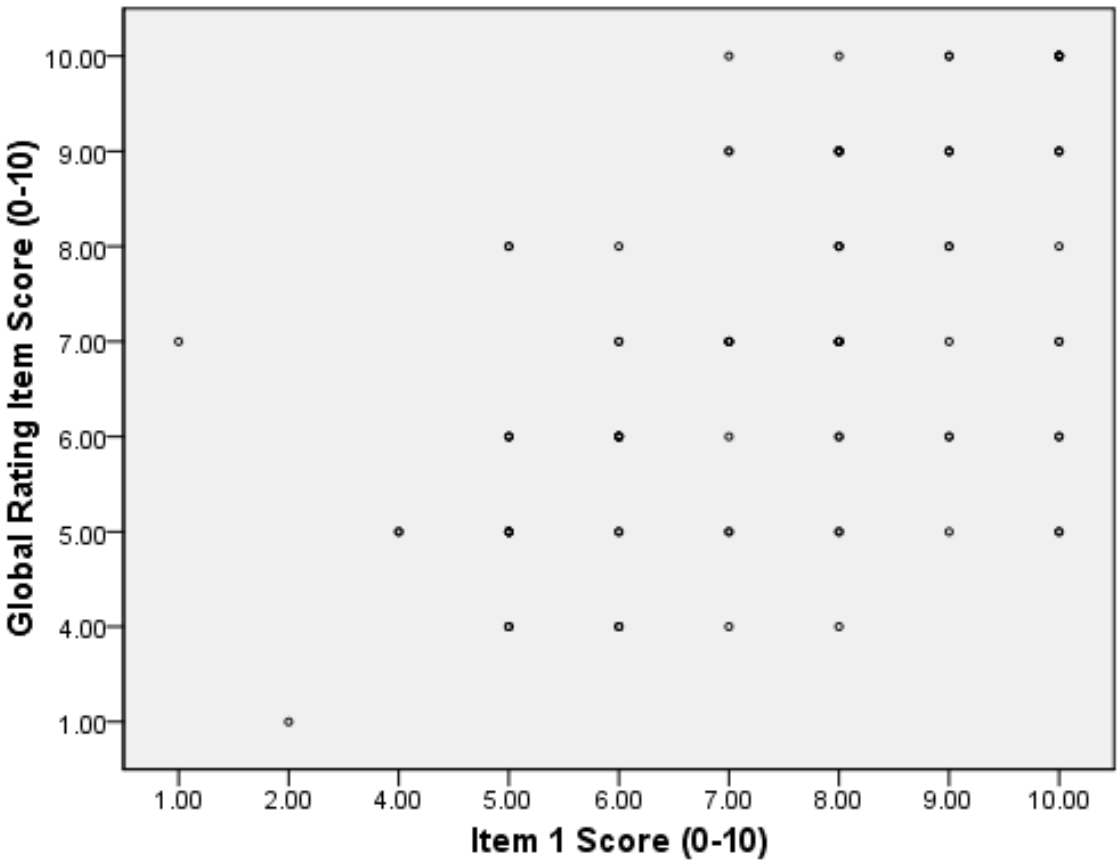
		Item 1	Item 2	Item 3	Item 4	Item 5	Item 6	GRI
Item 1: Using words that you can understand	Pearson Correlation	1	.524**	.202	.556**	.437**	.422**	.577**
	Sig. (2-tailed)		.000	.055	.000	.000	.000	.000
	N	91	83	91	91	90	91	91
Item 2: Looking you in the eye	Pearson Correlation	.524**	1	.312**	.595**	.587**	.579**	.609**
	Sig. (2-tailed)	.000		.004	.000	.000	.000	.000
	N	83	84	84	84	83	84	84
Item 3: Answering all your questions about your illness and treatment	Pearson Correlation	.202	.312**	1	.436**	.496**	.354**	.557**
	Sig. (2-tailed)	.055	.004		.000	.000	.001	.000
	N	91	84	92	92	91	92	92
Item 4: Listening to what you have to say	Pearson Correlation	.556**	.595**	.436**	1	.719**	.733**	.602**
	Sig. (2-tailed)	.000	.000	.000		.000	.000	.000
	N	91	84	92	92	91	92	92
Item 5: Caring about you as a person	Pearson Correlation	.437**	.587**	.496**	.719**	1	.678**	.642**
	Sig. (2-tailed)	.000	.000	.000	.000		.000	.000
	N	90	83	91	91	91	91	91
Item 6: Giving you his/her full attention	Pearson Correlation	.422**	.579**	.354**	.733**	.678**	1	.579**
	Sig. (2-tailed)	.000	.000	.001	.000	.000		.000
	N	91	84	92	92	91	92	92
Global Rating Item (GRI)	Pearson Correlation	.577**	.609**	.557**	.602**	.642**	.579**	1
	Sig. (2-tailed)	.000	.000	.000	.000	.000	.000	
	N	91	84	92	92	91	92	92

**. Correlation is significant at the 0.01 level (2-tailed).

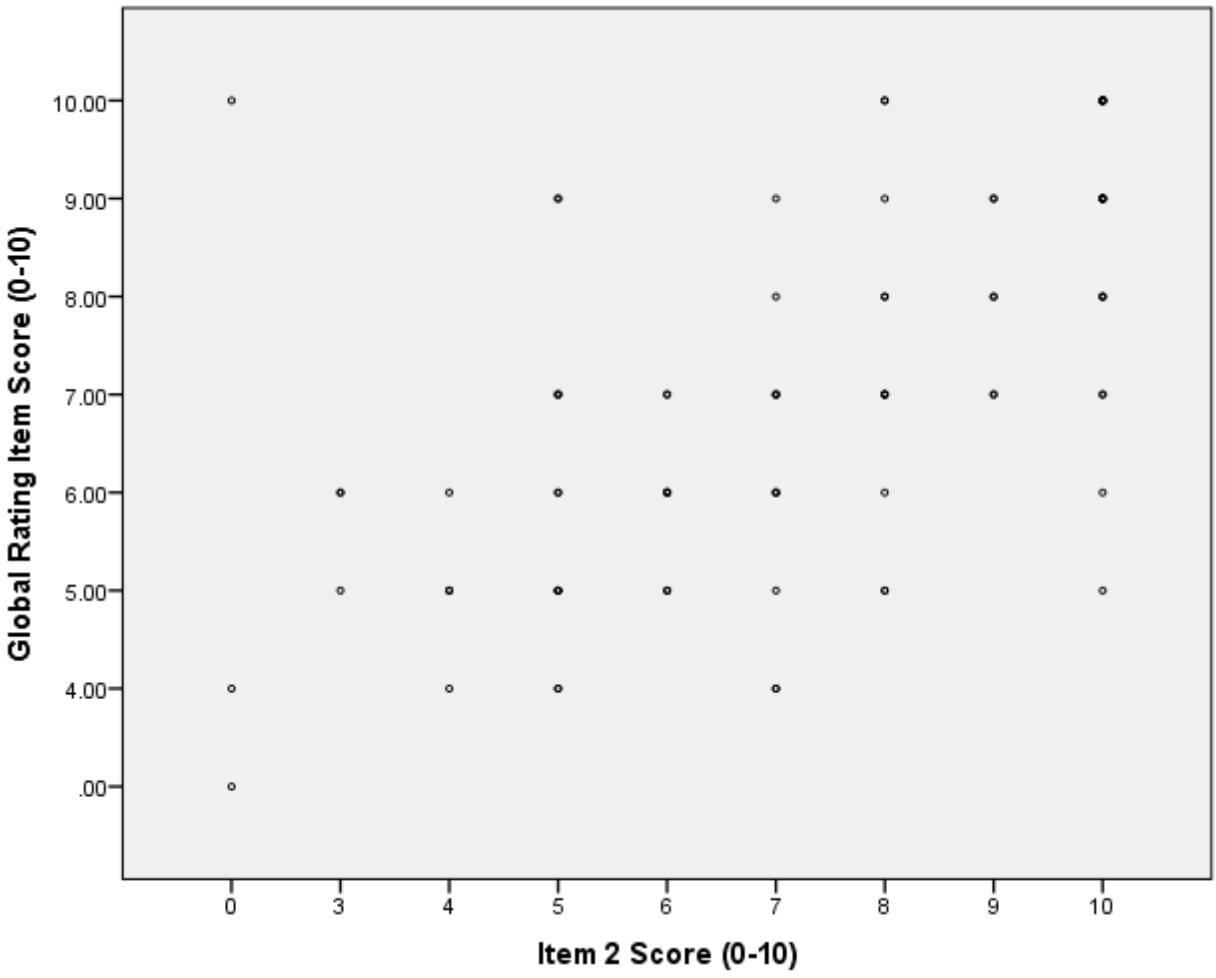
Appendix H. Univariate Linear Regression Plots for Items 1–6

Univariate Linear Regression Plot for Item 1 (Using Words You Understand) vs. GRI

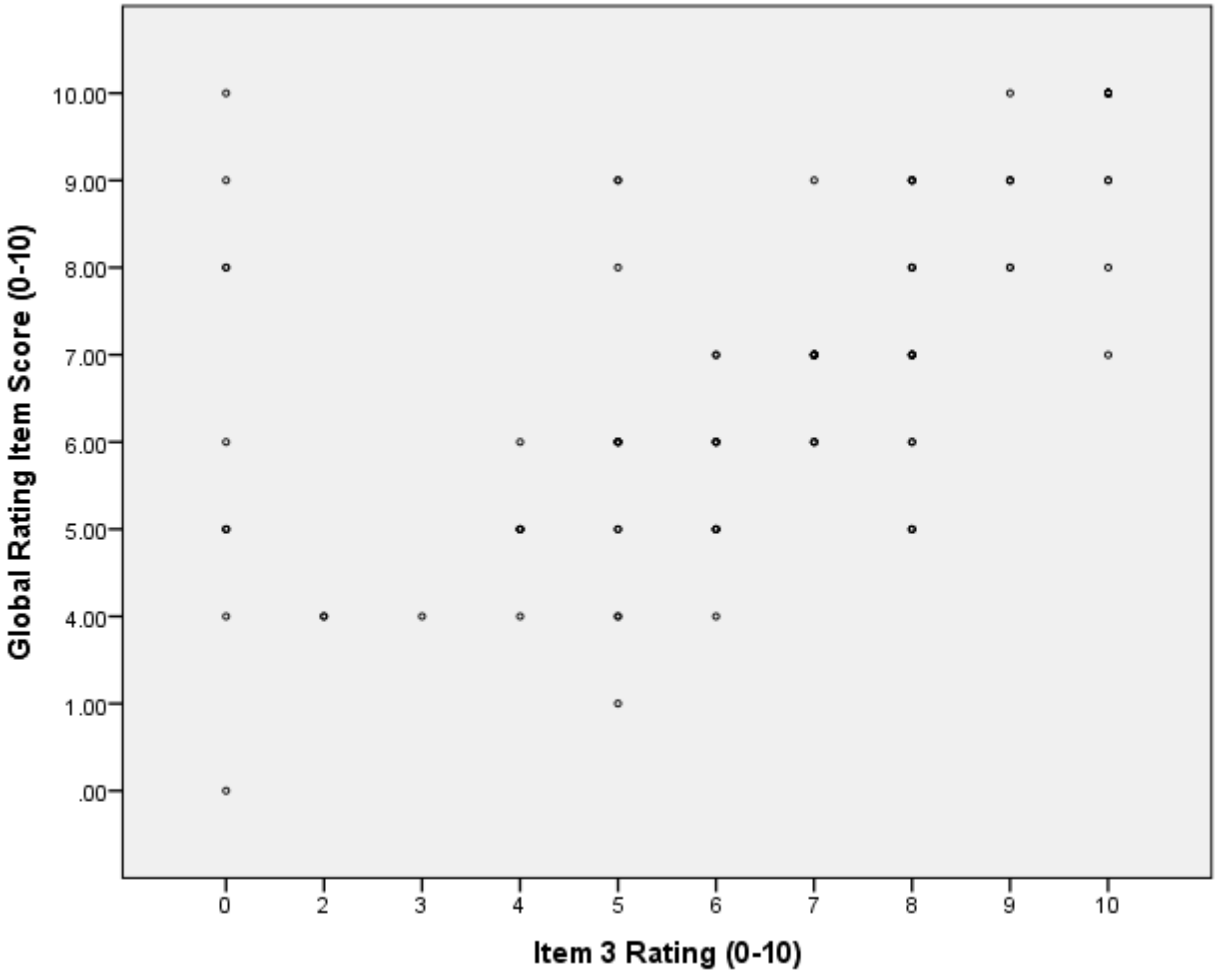
(Pearson r = 0.58)



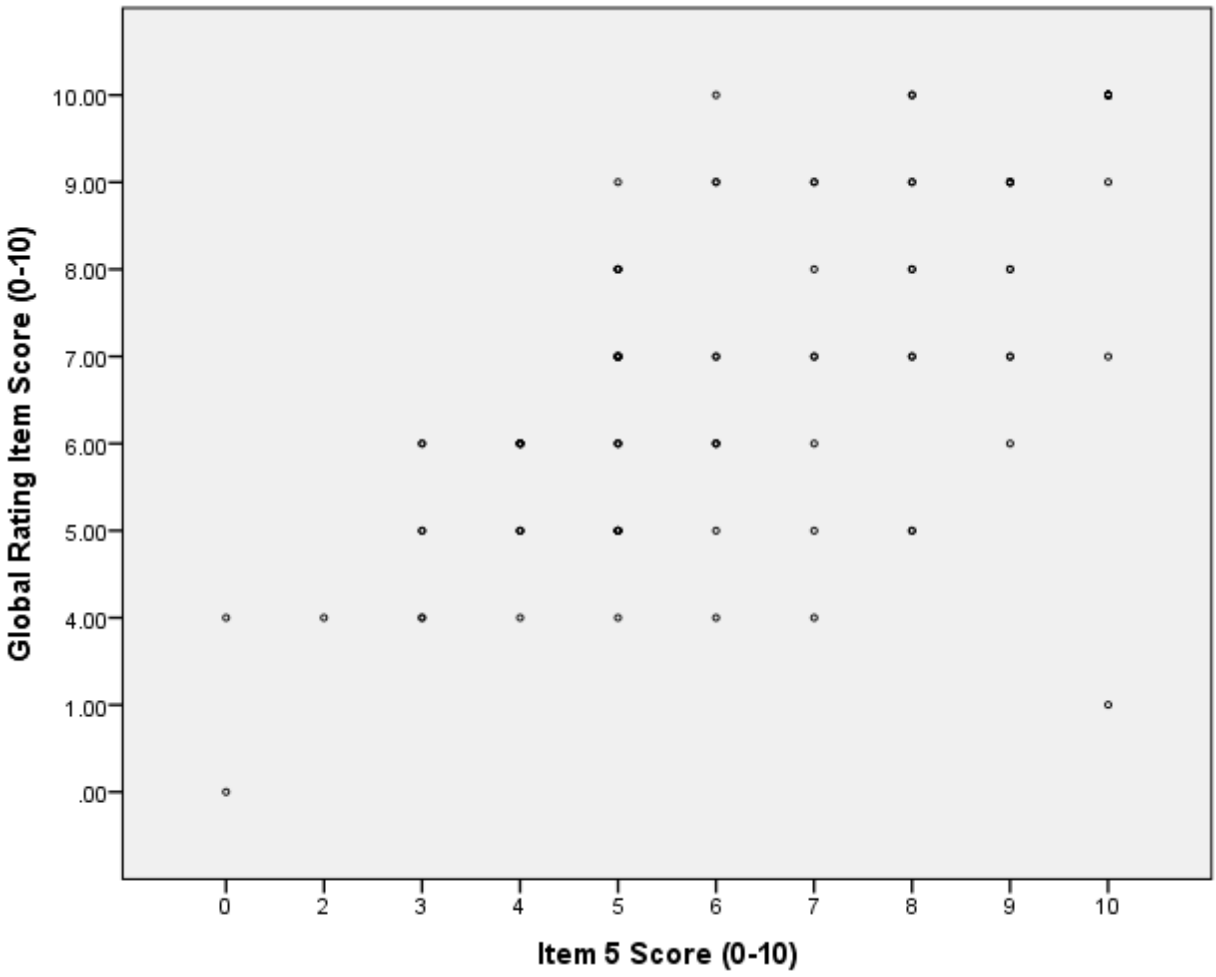
Univariate Regression Plot for Item 2(Eye Contact) vs. GRI (Pearson r = 0.61)



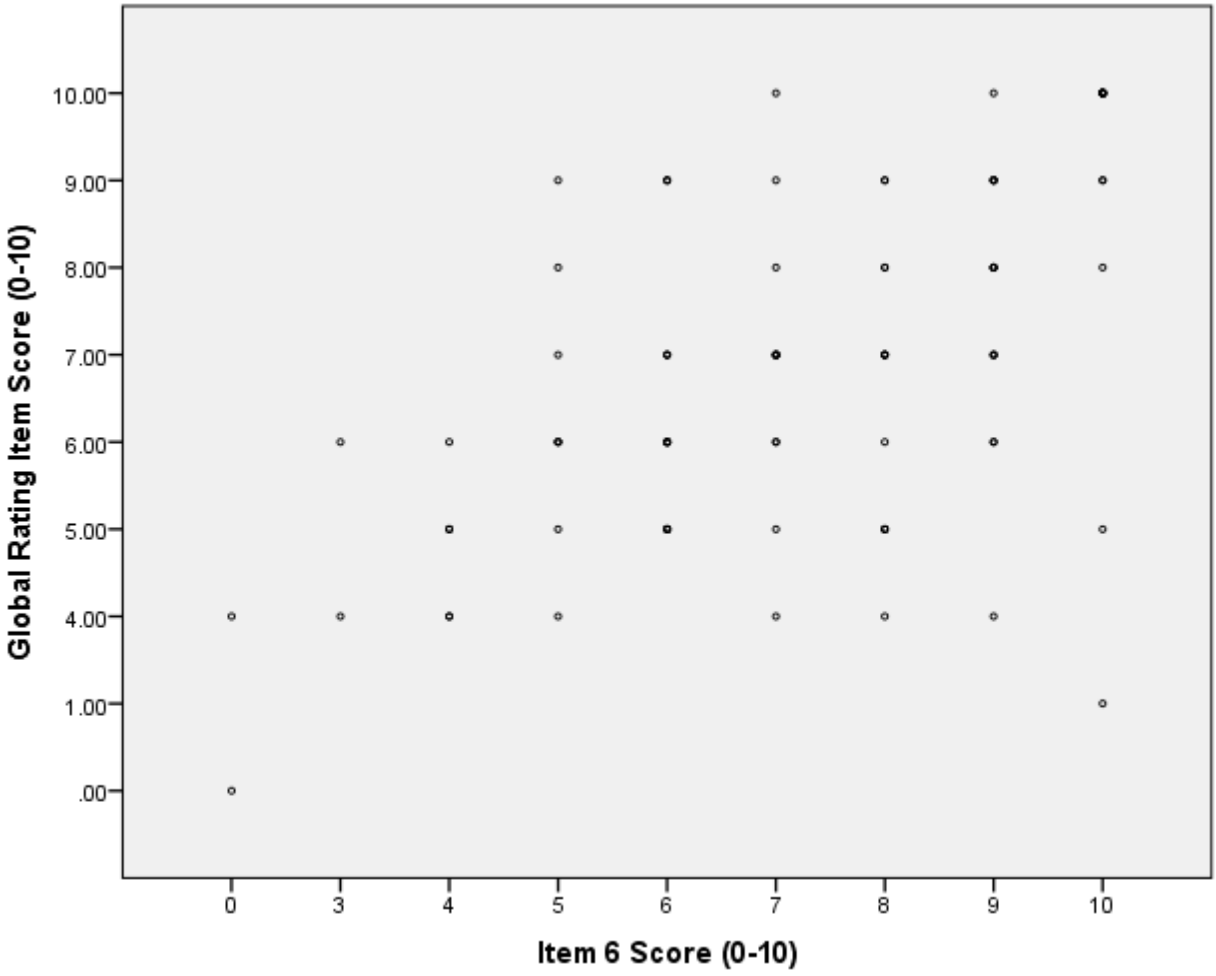
Univariate Regression Plot for Item 3(Answering Questions about Illness and Treatment) vs. GRI (Pearson r = 0.56)



Univariate Regression Plot for Item 4(Listening) vs. GRI (Pearson r = 0.60Univariate Regression Plot for Item 5(Caring about You as a Person) vs. GRI (Pearson r = 0.642)



Univariate Regression Plot for Item 6(Giving You Full Attention) vs. GRI
(Pearson r = 0.58)



Appendix I. Multivariate Regression Modelling for all 20 Combinations of 3 QOC Items

Items in Model	R	R^2	Adjusted R^2
2,3,6	**0.787**	**0.619**	**0.604**
2,3,4	0.773	0.597	0.582
2,3,11	0.751	0.564	0.547
2,6,11	0.748	0.559	0.542
2,4,6	0.747	0.557	0.541
1,3,4	0.749	0.561	0.540
1,3,6	0.743	0.552	0.536
2,4,11	0.740	0.547	0.530
1,3,11	0.734	0.539	0.522
1,2,3	0.733	0.537	0.520
3,6,11	0.721	0.520	0.504
3,4,11	0.713	0.509	0.492
3,4,6	0.709	0.503	0.486
1,2,6	0.705	0.496	0.477
1,6,11	0.691	0.477	0.459
1,2,4	0.682	0.465	0.445
1,4,11	0.671	0.450	0.431
4,6,11	0.663	0.439	0.420

1,4,6	0.662	0.438	0.419
1,2,11	0.645	0.416	0.394

Appendix J. Regression Statistics for Best Multivariate Linear Model (Items 2,3,6)

Model Summary[b]

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.787[a]	.619	.604	1.25917

a. Predictors: (Constant), Item_6_Full_attention, Item_3_answering_questions_about_illness_and_treatment, Item_2_eye_contact

b. Dependent Variable: Global_Item

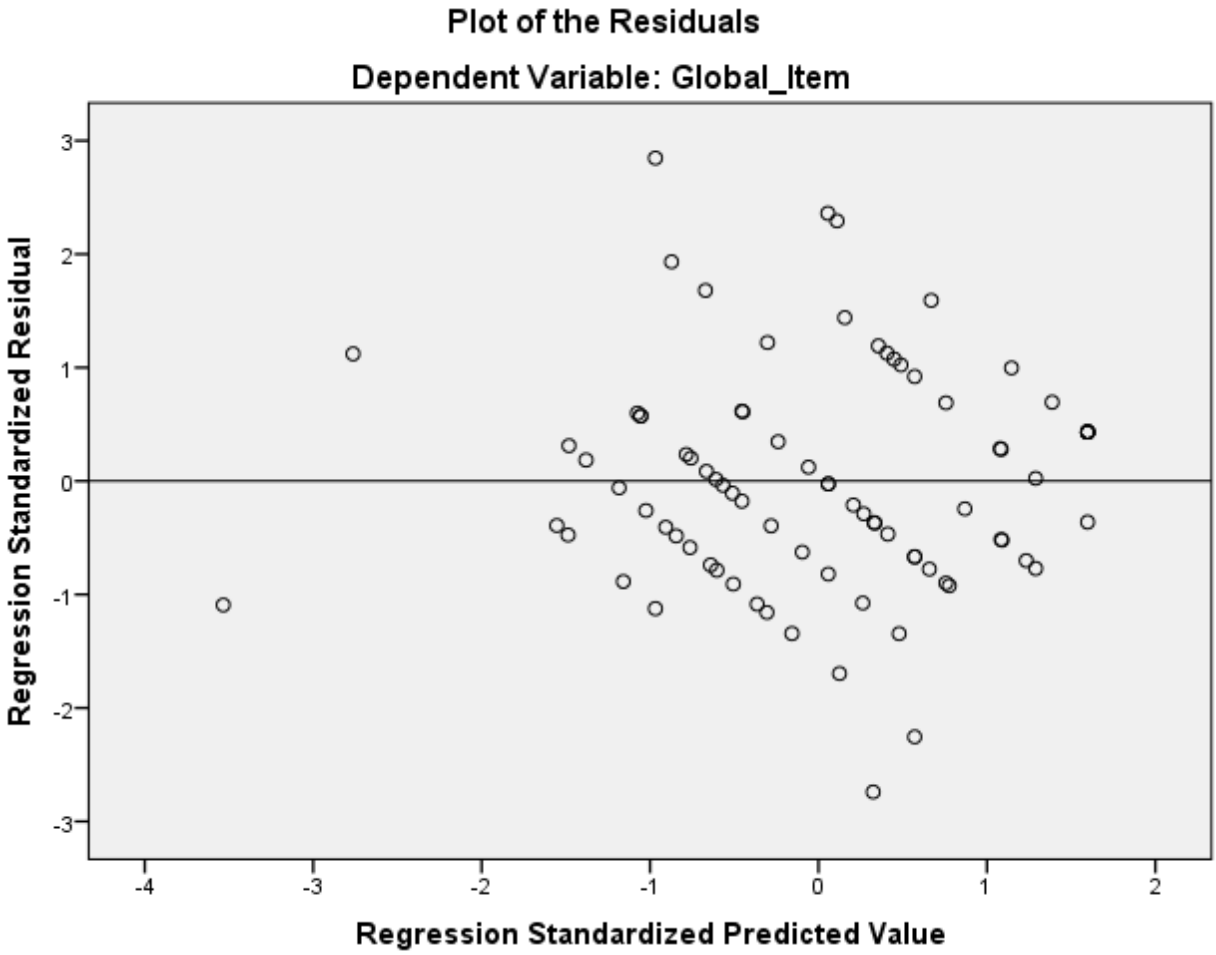
ANOVA[a]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	205.863	3	68.621	43.280	.000[b]
	Residual	126.840	80	1.585		
	Total	332.702	83			

a. Dependent Variable: Global_Item

b. Predictors: (Constant), Item_6_Full_attention, Item_3_answering_questions_about_illness_and_treatment, Item_2_eye_contact

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Collinearity Statistics	
		B	Std. Error	Beta			Tolerance	VIF
1	(Constant)	1.375	.511		2.688	.009		
	Item_2_eye_contact	.234	.068	.295	3.466	.001	.658	1.519
	Item_3_answering_questions	.243	.055	.337	4.423	.000	.818	1.222
	Item_6_Full_attention	.331	.081	.361	4.063	.000	.602	1.660

a. Dependent Variable: Global_Item