Arts & Sciences Electronic Theses and Dissertations

Arts & Sciences

Spring 5-15-2022

Effects of a Patient Question Prompt List on Outpatient Palliative Care Appointments

Meghan McDarby
Washington University in St. Louis

Follow this and additional works at: https://openscholarship.wustl.edu/art_sci_etds

Part of the Psychology Commons

WASHINGTON UNIVERSITY IN ST. LOUIS

Department of Psychological & Brain Sciences

Dissertation Examination Committee:
Brian Carpenter, Chair
Elyse Everett
Debra Parker Oliver
Thomas Rodebaugh
Denise Wilfley

Effects of a Patient Question Prompt List on Outpatient Palliative Care Appointments
by
Meghan McDarby

A dissertation presented to
The Graduate School
of Washington University in
partial fulfillment of the
requirements for the degree
of Doctor of Philosophy

August 2022
St. Louis, Missouri

Table of Contents

List of Figures

<u>List of Tables</u>

<u>Acknowledgements</u>

always find a way to keep up. Thank you, Olive, for keeping me from gaining the "dissertation 15" and for "helping Mama." And above all, to my life partner, my confidant, the Hillary to my Bill . . . and "'cause I know you'd read a thousand drafts" if I needed you to: thank you, Lara, for being. I am here because of you. As Tennyson once said, "I am a part of all that I have met."

<div align="right">Meghan McDarby</div>

Washington University in St. Louis
August 2022

To Kristin Manojlovic Gentilini, Marion Raymond, and Mary Ellen Rossiter, who taught me about living, dying, and walking.

ABSTRACT OF THE DISSERTATION

Effects of a Patient Question Prompt List on Outpatient Palliative Care Appointments

by

Meghan McDarby

Doctor of Philosophy in Psychological & Brain Sciences

Washington University in St. Louis, 2022

Professor Brian D. Carpenter, Chair

Question prompt lists (QPLs) promote patient and care partner participation during medical

appointments. The current study evaluated use of a 25-question QPL during initial outpatient

palliative care appointments. I applied tenets of Social Cognitive Theory to investigate the

relation between appointment participation, state anxiety, and perceived self-efficacy in the

context of a QPL intervention. Participants were patients and care partners attending the patient's

first outpatient palliative care appointment at an academic hospital. Participants were randomly

assigned to receive the QPL before the appointment ($n = 29$ appointments) or to receive usual

care ($n = 30$ appointments). Audio recordings of appointments were transcribed and coded for

total questions asked and assertions made. Participants also self-reported state anxiety, perceived

self-efficacy in question asking, and perceived self-efficacy in getting health care information at

pre- and post-appointment. On average, participants in QPL appointments did not ask

significantly more questions or make significantly more assertions compared to participants in

usual-care appointments. On average, participants reported a decrease in state anxiety from pre-

to post-appointment, but there was no interaction effect of time and condition. There was also a

main effect of time on self-efficacy in question asking, such that self-efficacy increased from

pre- to post-appointment, but there was no interaction effect of time and condition. Despite their

promise in previous studies, my results suggest QPLs may lack potency to shift certain types of participation, at least in palliative care appointments, and that other mechanisms of Social Cognitive Theory may better characterize the relation between question asking, state anxiety, and perceived self-efficacy.

Chapter 1: Introduction

Palliative care is a specialized medical service for individuals with serious, life-limiting illness. The primary goals of palliative care are to support symptom management and improve quality of life for patients and their care partners. In the hospital setting, palliative care is delivered by an interprofessional team, with members including physicians, nurse practitioners, social workers, chaplains, and psychologists (World Health Organization, 2002).

Quality communication is a pillar of palliative care around the world (Gamondi et al., 2013; National Consensus Project for Quality Palliative Care, 2018), and professional organizations, including the American Academy for Hospice and Palliative Medicine (AAHPM; 2009), the American Society of Clinical Oncology (Ferrell et al., 2017), and the Canadian Hospice and Palliative Care Association (CHPCA, 2013), emphasize the importance of communication skills that promote information exchange between patients, their care partners, and clinicians. Among the range of services offered by palliative care clinicians that depend on effective communication are clarification of treatment preferences, goals of care discussions, advance care planning, and bridging communication between the patient, their care partners, and other clinicians (Back et al., 2014; Jack et al., 2003, 2004; McDarby & Carpenter, 2019). These roles underscore the relevance of communication in the palliative care setting and highlight both the frequency and importance of interpersonal interactions between patients and palliative care clinicians. Furthermore, scoping evidence indicates that effective communication is associated with important downstream outcomes, including goal-concordant, person-centered care (Levinson et al., 2010), less aggressive medical care (Wright et al., 2008), and improved bereavement outcomes for care partners (Petursdottir et al., 2020).

A number of guidelines (e.g., Ferrell et al., 2018; Ngo-Metzger et al., 2008) have been developed by leaders in serious illness research and practice in order to underscore the essential role of communication between clinicians and patients. The tenets of these guidelines are reflected in several communication interventions and protocols, including the VitalTalk model (Arnold et al., 2017), the Serious Illness Care Program (SICP; Bernacki et al., 2015), and the SPIKES six-step protocol (Baile et al., 2000), all of which recommend two complementary approaches for promoting quality communication in the palliative care setting. One approach is training clinicians with strategies to communicate more effectively with patients. Intervention research suggests that clinicians whose training highlights communication skills report improvements in overall communication abilities (Goelz et al., 2011), high confidence and comfort in communication (Wittenberg-Lyles et al., 2014), increased communication self-efficacy (Erickson et al., 2015), and increased knowledge about how to deliver bad news (Rucker & Browning, 2015). Other research indicates that communication skills training for clinicians increases the likelihood of patient care planning (e.g., goals of care conversations) (Curtis et al., 2018), increases patient satisfaction with care (Haskard et al., 2008), and in some cases, is associated with reductions in patient-reported anxiety (Bernacki et al., 2019). Thus, there is compelling evidence that tools that target clinicians' communication skills are effective at promoting competency in communication and, therefore, at supporting high-quality, person-centered care.

The complementary approach for promoting quality communication between palliative care clinicians and their patients is to help patients develop their own communication skills. Although clinicians have been targeted with more facility—communication skills interventions can be delivered in large groups as part of preprofessional training and professional development

programs (see Back et al., 2007 and Bylund et al., 2010)—patients also can be "trained up" on skills and techniques that promote their success in palliative care communication. Indeed, several interventions targeting patients have been developed for this purpose, including Sharing Patient Illness Representations to Increase Trust (SPIRIT; Song & Ward, 2015), the Stanford Letter Writing Project (Periyakoil et al., 2017), and appointment coaching (Doorenbos et al., 2016; Sansoni et al., 2015). These interventions empower patients during medical conversations, encouraging increased participation and contributions to care conversations (Alders et al., 2017). Thus, although the onus falls on palliative care clinicians to communicate effectively with patients in ways that are understandable, empathic, and inclusive (Mroz et al., in press), evidence suggests that patients can benefit from interventions that target their own communication skills. However, in order to feel confident in communication-related tasks, patients must also feel equipped to participate actively in interactions with clinicians in the palliative care environment. One theory that has been used to explain how communication interventions shape clinician (Grudzen et al., 2016) and patient (Street et al., 2010) behavior in health care encounters, and that also elucidates important pathways by which patients might develop confidence in palliative care communication, is Social Cognitive Theory (SCT).

1.1 Perceived Self-Efficacy and Palliative Care Communication

Social Cognitive Theory (Bandura, 1986, 2001), originally known as Social Learning Theory, was developed by Albert Bandura to characterize learning as a social process that occurs within the social environment. In other words, learning is posited to be shaped by interactions between the individual, the individual's behavior, and both the function and value of that behavior in the social environment. Since it was proposed by Bandura, SCT has been used as a theoretical framework for research in a range of areas, including health behavior change (e.g.,

Schwarzer & Renner, 2000) and patient communication about cancer-related pain (Street at al., 2010).

According to SCT, *perceived self-efficacy*, or the belief that one can control aspects of one's behavior and environment, enables goal attainment. Perceived self-efficacy can be thought of as "the foundation of agency," as it provides individuals with direct insight into whether they feel confident to act on and follow through with plans to achieve goals (Bandura, 2000, p. 17). SCT suggests that four factors shape the development of perceived self-efficacy: verbal persuasion (i.e., encouragement from others), vicarious learning (i.e., modeling), performance accomplishments (i.e., mastery experiences), and physiological arousal (i.e., emotional states) (Bandura, 1986).

As a framework for conceptualizing mechanisms by which perceived self-efficacy increases, SCT outlines pathways that could support the development of patient self-efficacy in palliative care communication. Perceived self-efficacy is integral to patient communication in palliative care: without beliefs that they can successfully communicate with care clinicians, obtain health-related information, and participate actively, patients and their care partners will forego asking important questions, learning about and clarify treatment preferences, and engaging in goals of care discussions. Importantly, perceived self-efficacy in the palliative care setting could be supported by each of the four factors outlined by SCT, including effective verbal persuasion from clinicians (e.g., "That's a great question, lots of other patients with your condition ask that question too."), vicarious learning (e.g., patients observe videos of other patients engaged in model communication), performance accomplishments (e.g., patients successfully ask questions during an appointment), and physiological arousal (e.g., patients successfully manage anxiety during an appointment).

In accordance with care that is truly person centered, patients must be encouraged to participate actively in health care communication (Eggly et al., 2017; Institute of Medicine, 2001). As a result, interventions that aim to increase self-efficacy may leverage patient autonomy (see Figure 1). I propose that by promoting mastery experiences in communication (i.e., increased participation), as well as offering instrumental support that may assist with the management of physiological arousal (i.e., reduced anxiety), such interventions would promote patients' confidence in their perceived skills and abilities related to communicating in health care settings. Furthermore, improvements in self-efficacy would likely promote continued participation and greater reductions in physiological arousal, initiating, to some extent, a feedback loop, wherein active participation and the development (or maintenance) of self-efficacy support one another (Roter et al., 1988). This hypothesis is based on prior literature suggesting that training in communication skills promotes increased self-efficacy about communication in health care settings (Haywood et al., 2006; Kidd et al., 2004) and that patients believe perceived self-efficacy contributes to their participation in health care settings (Bailey et al., 2022). One tool that is designed to scaffold patient participation in communication and is hypothesized to promote self-efficacy via performance mastery and physiological arousal management is the Question Prompt List (QPL).

1.2 Question Prompt Lists

Question Prompt Lists are communication tools designed to support patients who are seeking information about their illness and treatment options from health care clinicians. QPLs are comprised of sets of questions and topics that can be referenced by patients during conversations with clinicians to spark discussion (Sansoni et al., 2015). As a whole, QPLs are not dissimilar to nationwide initiatives aimed to promote patient participation in health care (e.g.,

the Agency for Healthcare Research and Quality's "Questions to Ask Your Doctor" initiative) in that they highlight questions that could augment communication between patients and clinicians about illness concerns.

In terms of their use, commonly, patients receive a QPL in advance of a health care appointment and use the tool to guide conversations with their clinicians. The questions included in a QPL often cover a range of topics, and patients may use some or all of those questions during their appointment. Moreover, QPLs can be general or disease specific. For example, a QPL offered to older adults deciding whether to follow through with a high-risk surgery (Steffens et al., 2016) includes questions like, "In your opinion, will surgery make me feel better?" and "After I leave the hospital, what type of care do you think I will need?" Another QPL designed for patients with cancer includes questions that range from, "Exactly what kind of illness do I have?" to "How do I get my affairs in order and write a will?" (Yeh et al., 2014). Ultimately, the goals of QPLs are to empower patients to participate actively in health care conversations and encourage discussions between patients and clinicians about important care and treatment topics (Sansoni et al., 2015).

1.3   Previous Research on QPLs

Prior research has substantiated the effectiveness of QPLs for a variety of patient populations and indicates that QPLs support communication in a multitude of ways. QPLs have been developed for patients with various serious and life-limiting illnesses, including cancer (Clayton et al., 2007), heart conditions (Bolman et al., 2005), and chronic kidney disease (Lederer et al., 2016). Moreover, research suggests that QPLs have a positive impact on communication behaviors, such as increasing total patient question asking and question asking about specific topics, including prognosis (Sansoni et al., 2015). The following section (a)

reviews previous literature that has investigated the effects of a broad range of QPL interventions on patient participation and anxiety and (b) enumerates key limitations associated with previous studies that should be addressed in future research.

1.3.1 QPLs and Participation

To facilitate quality patient-clinician communication and collaborative practices like shared decision making, patients must participate actively in their care via *appointment participation*, or by making direct contributions to conversations with clinicians in the form of asking questions and making assertions (Eggly et al., 2017; Street et al., 2007). As outlined by SCT, participating actively in health care conversations not only depends on but is also likely to promote the development of self-efficacy beliefs; performance accomplishments and mastery (i.e., successful participation in health care communication) enhance self-efficacy, with higher self-efficacy presumably creating a positive feedback loop to increase new opportunities for mastery (see Figure 1).

Findings from three systematic reviews provide evidence that QPLs are successful at increasing overall participation. In the earliest of the three reviews, Kinnersley and colleagues (2008) conducted a meta-analysis to investigate the effectiveness of question-asking interventions. These interventions spanned multiple health care settings, including general practice, oncology, obstetrics, and cardiology. Their meta-analysis of the studies with data that could be extracted ($n = 14$ of 17) indicated a small but significant overall effect of question asking interventions on question asking ($d = 0.27$, range = 0.19-0.36). Averaged across studies, patients assigned to a control group asked 4.77 questions, while patients assigned to receive a question asking intervention asked 6.13 questions. Most individual studies included in this

review reported effect sizes in the small to medium range, and the effect size estimate confidence intervals for nine of the 14 studies included zero.

In a second systematic review that did not calculate intervention effect sizes, Brandes and colleagues (2015) qualitatively summarized the effectiveness of QPL interventions at increasing participation, focusing on question asking in the oncology setting. Six of the 16 studies included in their review reported total number of questions asked by patients, and four of those studies indicated that patients in the QPL intervention group asked significantly more questions than patients in the usual care group. Of note, three of the four studies that reported a significantly greater number of questions asked in the QPL group were not part of the original review conducted by Kinnersley and colleagues in 2008. As one example, Clayton and colleagues (2007) randomized advanced cancer patients and their care partners to receive a standard palliative care consultation ($n = 82$) or to receive a QPL prior to their palliative care consultation ($n = 92$). They evaluated the effectiveness of a 112-question QPL developed by their group (Clayton et al., 2003) for palliative care patients, covering eight subject areas, including "about the palliative care team," "treatment," and "end of life issues." Compared to the standard consultation group, patients in the QPL group asked 2.31 (95% CI, 1.68-3.18) times more questions overall, indicative of a small to medium effect (Chen et al., 2010). Patients who received the QPL also asked more prognostic-related questions and discussed more end-of-life (EOL) issues in health care appointments when using a QPL. As another example, Smets and colleagues (2012) examined the usefulness of a QPL for patients with esophageal cancer to obtain information about a curative esophagectomy procedure. Their findings indicate that patients assigned to receive the QPL asked more questions ($Mdn = 12$ questions) during their appointment compared to patients who received usual care ($Mdn = 8$ questions).

In a third review of QPLs conducted by Sansoni and colleagues (2015), the authors considered the effectiveness of QPLs designed for a variety of patient groups, including patients with cancer, primary care patients, cardiology patients, and individuals with depression. Their findings were organized to facilitate comparisons between standalone QPL interventions and QPL interventions supported by another supplementary intervention (e.g., coaching). Notably, of the three standalone QPL interventions that were not included in the review conducted by Brandes and colleagues (2015), none significantly increased number of questions asked.

Two major randomized controlled trials too recent to be included in the aforementioned reviews also evaluated the effectiveness of QPL interventions at increasing patient participation. Eggly and colleagues (2017) evaluated a 43-question QPL to be used by Black patients with cancer during their oncology appointments to discuss treatment. The QPL booklet included questions regarding diagnosis, treatment, chemotherapy, and help with coping, among other topics. A sample of 114 patients was randomly assigned to receive usual care ($n = 40$), use a QPL during their appointment ($n = 40$), or use a QPL and have a coach to help them formulate questions before their appointment ($n = 34$). Compared to usual care, participants in the QPL-only condition participated more actively than patients assigned to the usual care and QPL + coach arm (Eggly et al., 2017). The authors reported a medium effect of the intervention on promoting overall patient participation ($d = 0.55$). On the other hand, Schwarze and colleagues (2020) conducted a randomized controlled trial of a QPL for older adult patients considering major surgery. Patients assigned to the QPL group ($n = 223$) received a QPL by mail in advance of their upcoming surgical consult appointment, while the rest of the sample ($n = 223$) was assigned to usual care. Topics addressed by the QPL include, "Should I have surgery?" and "What can I expect if surgery goes well?" The authors found no effect of the intervention on

appointment participation and hypothesized their null finding was potentially due to "low penetration" of the QPL in the sample because the QPL was distributed by mail, and no follow-up was conducted to ensure that participants had received the QPL in advance of their appointment. Despite their variability, overall, the findings of these reviews and empirical studies suggest that QPLs have a small to medium effect on increasing question asking during medical appointments in a variety of populations, including among individuals with serious illness.

1.3.2 QPLs and State Anxiety

It is not uncommon for patients with serious illness to report nervousness and anxiety surrounding health care appointments and interactions, especially in advance of their appointments (e.g., fear of not knowing what to say, fear of how my doctor will react, fear of what results will emerge) (Clayton et al., 2017; Mehnert et al., 2009; Miller et al., 2013). As a result, in line with the tenets of SCT, management of physiological arousal, hereafter referred to as 'state anxiety,' may be one method by which to increase palliative care appointment participation and increase perceived self-efficacy. Previous models (see Street et al., 2009) and my own proposed mechanism based on SCT (see Figure 1) point to the direct path between communication skills training and reductions in state anxiety. In sum, communication skills training (i.e., access to a person-centered communication tool like the QPL) would result in more effective management of anxiety about a palliative care appointment, thereby leading to increased participation during the appointment and increased self-efficacy about participating in the appointment. Increased self-efficacy in appointment participation contributes to a feedback loop, scaffolding more efficient management of physiological arousal. Therefore, patients and care partners who receive a communication tool prior to a health care appointment (compared to

patients and care partners receiving no such tool) would experience lower pre-appointment anxiety as well as a greater decrease in anxiety from pre- to post-appointment. Existing literature also suggests that patient perceptions of better communication with clinicians is associated with lower post-appointment ratings of anxiety (Miller et al., 2013). As a whole, person-centered communication tools like the QPL are hypothesized to support the management of state anxiety, as knowing about appropriate questions to ask during a palliative care appointment presumably reduces uncertainty about how one ought to participate during an appointment, thereby increasing the likelihood of confidence in one's communication abilities.

Previous work has focused on the effectiveness of QPLs at reducing patient state anxiety across health care appointments (i.e., from pre- to post-appointment) and reports mixed results. For example, in their meta-analysis of QPL interventions, Kinnersley and colleagues (2008) calculated a nonsignificant effect of six QPL interventions that measured patients' self-reported state anxiety immediately after health care appointments only ($d = -0.08$). Most studies included in their review report that QPL use reduced anxiety from pre- to post-appointment, when both time points were measured, but by an amount that was not statistically significant. For example, Brown and colleagues (1999) examined the effectiveness of a 17-item QPL intervention among patients with cancer meeting with a medical oncologist for the first time. Participants were randomized to the control group ($n = 20$), QPL group ($n = 20$), or QPL + coaching group ($n = 20$). Immediately prior to the appointment and immediately following the appointment, patients reported state anxiety. There was no significant change in anxiety for participants in any group.

In their descriptive review, Brandes and colleagues (2015) evaluated nine studies that measured patient anxiety before and after a QPL intervention. Five reported no effect of the QPL intervention, two reported that anxiety was reduced only at a distal follow-up time point (i.e., 6-

week follow-up), and two other studies reported that participants in the QPL intervention condition reported increased anxiety after being presented with the intervention. Sansoni and colleagues (2015) reported on a set of additional studies that measured the effects of a QPL on patients' state anxiety. Among the three studies included in their review that were unique compared to those included in the previous review (i.e., Brandes et al., 2015), results suggested anxiety reducing effects of question-asking interventions. For example, Martinali and colleagues (2001) reported that coronary artery disease patients assigned to a frequently asked questions intervention ($n = 53$) —which involved reviewing a list of questions in advance of their outpatient appointment with a cardiologist—reported less state anxiety immediately after their visit with the cardiologist compared to participants in the control group ($n = 50$). Bolman and colleagues (2005) used the same set of frequently asked questions in a randomized controlled intervention with 105 patients who had coronary artery disease and reported that patients who participated in the intervention ($n = 46$) also reported significantly less anxiety immediately before their appointment compared to participants who did not partake in the intervention. Data from another study conducted by Thompson and colleagues (1990) suggested that obstetric and gynecologic patients assigned to develop three questions prior to an outpatient medical appointment ($n = 29$) reported that they had experienced less anxiety during their medical appointment, compared to participants in a control group ($n = 24$). This study did not specifically examine pre- and post-appointment levels of anxiety.

In more recent studies not included in previous reviews, results regarding the effectiveness of QPL interventions at decreasing anxiety from pre- to post-appointment are also mixed. For example, Schwarze and colleagues (2020) found that among older adults considering major surgery, anxiety increased among participants assigned to use the QPL ($n = 223$)

compared to participants receiving usual care ($n = 223$), but that the increase was not statistically significant. On the other hand, a preliminary investigation of a QPL designed specifically for patients with palliative care needs (Arthur et al., 2017) indicated that among a sample of patients who were instructed to use a QPL during their palliative care appointment ($n = 100$), anxiety significantly decreased from pre- to post-appointment. However, this study was a single-arm intervention and did not compare changes in anxiety in participants assigned to receive usual care. Overall, while several prominent studies in the QPL literature have cited reductions in anxiety as a primary beneficial outcome of QPL use, the literature is still mixed, and the hypothesized effect of these interventions on anxiety is very small.

1.3.3 Limitations of Previous QPL Research

Several limitations could explain differences in the overall significance and strength of QPL findings reported in previous research: study design variability, measurement inconsistency, and lack of a unifying theory to predict expected outcomes. First, study design is highly heterogeneous across studies. For example, methodology varies in terms of when participants receive a copy of the QPL to review (e.g., one week in advance of the appointment versus immediately before the appointment), whether participants are instructed about how to use the QPL during the appointment (Eggly et al., 2017), whether use of the QPL is encouraged by the health care team during the appointment (Clayton et al., 2007), and where patients are in the treatment trajectory when they receive the QPL (e.g., new patients versus established patients; Brown et al., 1999). As a result, previous findings are constrained by uncertainties regarding whether treatment fidelity was maintained (e.g., Did participants bring the QPL to the appointment, and if so, did they know how to use it?) and whether outcomes would be different if patients had been targeted at a different point in their care trajectory (Schwarze et al., 2020).

Findings to date suggest that QPLs may be more effective toward increasing question asking when they are endorsed by the health care team and provided immediately in advance of the health care appointment (Sansoni et al., 2015), yet a constellation of study design factors— including when, but also how, and to whom the QPL is offered—could shape the effectiveness of QPL interventions (McDarby et al., 2021).

Second, variability in the measurement of both appointment participation and state anxiety is a major flaw of previous research and could reasonably account for inconsistencies in findings. For example, appointment participation has been measured in a myriad of ways across studies, including total questions asked (Clayton et al., 2003), types of questions asked (Buffington & Schwarze, 2019; Cegala et al., 2000; Clayton et al., 2007), and assertions made, including expressions of concern, requests, and decisions made (e.g., Eggly et al., 2017). These and other authors employ independently generated codebooks which are not publicly available in full, leading to reduced opportunities for replication of results or to establish consistency across studies (but see Buffington & Schwarze, 2019 as an example of a codebook that is freely available online). Studies that employ comprehensive codebooks measuring multiple features of participation may be better equipped to explain the full range of effects of QPL use. Furthermore, state anxiety, while typically measured using the State-Trait Anxiety Inventory (Spielberger et al., 1983), is not always specifically assessed with regard to state anxiety *about the appointment*, which could reasonably differ from state anxiety at the time of the appointment. If patients misattribute their arousal at the time of the appointment to contemporaneous stressors (e.g., traffic on the way to the appointment), pre-appointment reports of state anxiety could be significantly inflated or deflated, resulting in post-appointment regression to the mean and findings that are not statistically or clinically significant. Studies that assess state anxiety at time

points proximal to the time of the appointment (i.e., immediately before and/or immediately after) and that ask about state anxiety in the context of the appointment itself may be more likely to produce accurate representations of the effects of QPL use on anxiety.

Finally, the QPL literature is significantly limited due to its lack of a unifying, falsifiable theory under which proposed mechanisms of QPL interventions can be tested. As a result, findings from previous research can be difficult to evaluate in the greater context of how QPLs ought to facilitate patient communication in the palliative care setting. Although tenets of patient-clinician communication are often referenced in QPL research (Clayton et al., 2007; Eggly et al., 2017), and communication training interventions for clinicians in other care settings (e.g., oncology) have relied on self-efficacy theory to guide hypotheses and study design (Grudzen et al., 2016; Street et al., 2010), no known QPL studies have established a design within the parameters of an existing theory or framework. As a result, previous findings do not necessarily elucidate the field's understanding of how QPLs work and whether the outcomes they seem to affect are due to predicted mechanisms outlined by a priori hypotheses based in theory. For example, most QPL intervention research examines total patient question asking and patient anxiety but fails to link those outcomes to changes in patient self-efficacy or health care outcomes of interest (e.g., future hospitalizations and medical interventions). As another example, many QPL studies investigate anxiety as an outcome measure but do not establish nor ground hypotheses regarding anxiety in a theory (e.g., Yeh et al., 2014). In summary, the enumerated limitations of previous research on QPL interventions raise questions regarding the magnitude and direction of findings reported in the QPL literature but also provide room to improve and enhance future research in this area.

1.4 QPLs in Outpatient Palliative Care

QPLs may be particularly useful in palliative care for two primary reasons. First, given the nature of palliative care—a service that is specifically designed to support individuals with physical, emotional, and spiritual distress ensuing from a *life-limiting* illness—patients and care partners are often burdened by a constellation of symptoms associated with serious illness (Choi & Seo, 2019; Teunissen et al., 2007) and report elevated levels of anxiety regarding their care and treatment (Spencer et al., 2010; Wilson et al., 2007). As a result, these patients and their care partners could benefit from QPLs as a mechanism to support communication about illness-related information and to help manage anxiety in the health care setting, especially early in the palliative care trajectory. Second, the lay population—including care partners of individuals with palliative care needs (Dionne-Odom et al., 2019)—frequently reports misconceptions about palliative care (Kozlov et al., 2018), thus a QPL could be useful to address those misconceptions and associated anxiety early in the palliative care trajectory, in advance of the patient's first appointment. Namely, palliative care is often conflated with hospice, by both laypersons (Shalev et al., 2018) and non-palliative care clinicians (McDarby & Carpenter, 2019). This confusion between care that is truly "end" of life focused and care that is intended to provide broad support for serious illness experiences is widespread and can interfere with conversations intended to support patients and care partners coping with serious illness (Slomka et al., 2016), as some patients and care partners assume that the purpose of their referral to palliative care is to be told that they "are going to die" (McDarby & Carpenter, 2019). Thus, because palliative-related topics are especially difficult to discuss and frequently conflated with EOL care (Cheng et al., 2019), there is a clear reason to target palliative care patients with QPL interventions.

Prior research has begun to establish the utility of QPL interventions in the palliative care setting. For example, Clayton and colleagues (2003) developed the first QPL intended for

palliative cancer care outpatients. More recently, Arthur and colleagues (2016) created a much shorter, 25-question QPL, also specifically for outpatient palliative care patients (see Appendix A). Topics covered by questions on the list include symptoms, treatment, and lifestyle; caregiver concerns; EOL issues; the palliative care service as a whole; and support options. In 2017, Arthur and colleagues conducted a preliminary, single-arm investigation of their tool, examining the feasibility and perceived helpfulness of the QPL from the perspectives of both patients and clinicians. The authors recruited 100 patients with cancer attending their first palliative care outpatient appointment at the University of Texas MD Anderson Supportive Care Center and evaluated patient perceptions of helpfulness of the QPL, physician perceptions of helpfulness of the QPL, frequency of questions from the QPL chosen by patients to discuss with clinicians, as well as pre- to post-appointment reductions in patient anxiety. Results indicated that 77% of patients believed that the QPL helped them communicate with their doctor, 74% reported that they would write questions down before seeing their doctor in the future, and 60% reported that the QPL helped them to think of questions/ concerns they had not considered before. Generally, patients were more interested in asking symptom-related questions and less interested in questions related to EOL topics. Furthermore, anxiety significantly decreased among participants from pre- to post-appointment.

However, since publishing their preliminary findings in 2017, to my knowledge neither Arthur and colleagues nor other groups have conducted additional investigations of the 25-item QPL in the palliative care setting, underscoring the need for additional work in this area. Furthermore, given that their work to date has focused on evaluations of feasibility and acceptability, there is a limited understanding of how a brief palliative care QPL affects other outcomes, namely patient participation and self-efficacy. Moreover, although they examined the

effects of the QPL on anxiety reduction, their single-arm study design could not establish whether use of a QPL reduces anxiety from pre- to post-appointment above and beyond reductions that might happen with usual care. In other words, no research has taken a comprehensive approach to evaluate the effectiveness of a brief QPL in facilitating patient participation in communication and management of anxiety in the outpatient palliative care setting.

1.5   The Current Study

The purpose of the current study was to evaluate the effectiveness of a 25-question QPL to increase participation among patients in outpatient palliative care attending their first appointment and their care partners. In the current study, I hypothesized that QPL use enhances performance accomplishments and supports the management of physiological arousal (i.e., anxiety reduction), consistent with SCT (Bandura, 1986), increasing perceived self-efficacy and, in turn, increasing patient and care partner appointment participation in the palliative care setting. The study has the following specific aims:

Aim 1 Determine whether a QPL increases participation compared to usual care.

> **H1a.** Patients and care partners who receive the QPL will ask more questions during the appointment compared to participants assigned to usual care.

> **H1b.** Patients and care partners who receive the QPL will ask a greater proportion of questions that come directly from the QPL compared to questions not on the QPL.

> **H1c.** Patients and care partners who receive the QPL will make more assertions during the appointment compared to participants assigned to usual care.

Aim 2 Determine whether a QPL decreases state anxiety about the appointment compared to usual care.

H2a. State anxiety will be lower among participants who receive the QPL at pre-appointment compared to participants assigned to usual care.

H2b. State anxiety will decrease more significantly from pre- to post-appointment for participants who receive the QPL compared to participants assigned to usual care.

Aim 3 Determine whether a QPL increases perceived self-efficacy in question asking (i.e., confidence in question asking) and perceived self-efficacy in getting health care information compared to usual care.

H3a. Self-efficacy in question asking will increase more significantly from pre- to post-appointment for participants who receive the QPL compared to usual care.

H3b. Self-efficacy in getting health care information will increase more significantly from pre- to post-appointment for participants who receive the QPL compared to usual care.

Aim 4 Determine whether appointment participation and post-appointment anxiety are associated with post-appointment ratings of perceived self-efficacy in question asking and perceived self-efficacy in getting health care information, across study conditions.

H4a. Total participation, in terms of total questions asked, will predict post-appointment self-efficacy in question asking.

H4b. Total participation, in terms of total questions asked, will predict post-appointment self-efficacy in getting health care information.

H4c. Post-appointment anxiety will be negatively associated with post-appointment self-efficacy in question asking.

H4d. Post-appointment anxiety will be negatively associated with post-appointment self-efficacy in getting health care information.

Chapter 2: Method

2.1   Participants

I recruited patients scheduled to attend their first outpatient palliative care appointment (all 60 min) over Zoom with a single palliative care team at a large academic hospital in the Midwest. I also recruited patients' care partners who planned to attend the appointment. Thus, participants in the current study were both first-time palliative care outpatients and their care partners. Patient eligibility included being at least 18 years old and attending an outpatient palliative care appointment for the first time. Care partner eligibility included being at least 18 years old. Patients with known cognitive impairment, evidenced by a primary diagnosis in the medical record associated with diminished capacity in advanced stages (e.g., Alzheimer disease and related dementias, amyotrophic lateral sclerosis) and corresponding information indicating diminished capacity (e.g., notation of an adult child as the primary decision maker) were eligible to participate in the study only if (a) their legally authorized representative provided verbal consent on their behalf, (b) their legally authorized representative planned to attend the appointment, and (c) the patient verbally assented to participation. In instances when a patient required a legally authorized representative to provide consent on their behalf, the legally authorized representative was contacted before the patient; then, after both the legally authorized representative and I had thoroughly described the study to the patient, and time was allotted for the study team to answer questions, the patient was asked to assent. Patients were immediately excluded from the study if they or any of their care partners who planned to attend the appointment declined willingness to participate in the study.

Between October 2020 and June 2021, I identified 143 eligible patients with initial outpatient palliative care appointments (see Figure 2). The administrative coordinator for the

21

outpatient palliative care clinic forwarded information to me about all new patient appointments as they were scheduled in the medical record. I contacted 142 of these patients (or their legally authorized representative, when cognitive impairment was indicated) by telephone to determine whether they were interested in participating in the study. I did not contact one patient because, according to their medical record, they were extremely sick, and it was unclear who should be contacted as a legally authorized representative. Of the 142 patients/legally authorized representatives who were contacted by phone, 38 reported that they were not interested in participating, 18 could not be reached by phone, two enrolled in hospice before the study team made contact, two were admitted to the hospital and seen by the palliative care team as inpatients before the study team made contact, and seven cancelled their palliative care appointment before the study team made contact. The remaining five patients were deemed ineligible either because they were patients with diminished capacity who I attempted to enroll prior to updating my IRB protocol to include care partners as participants in this study ($n = 3$; in October 2020, at the beginning of recruitment) or because they had a primary diagnosis of cancer ($n = 2$; in June 2021, at the end of recruitment), as Washington University requires special board approval to conduct research with samples consisting of >30% patients with cancer, and I did not acquire such approval prior to starting this project.

In total, 70 patients consented to participate in the study. Eight of the patients who consented did not complete study participation, either because they missed their appointment ($n = 6$) or because they asked to withdraw from the study ($n = 2$). After data collection, I excluded data from three patients who I learned had been seen by the palliative care team previously as inpatients, and from one appointment during which there were technical difficulties that interfered with audio recording. Thus, the final study sample consisted of 59 patients (i.e., 59

appointments) and 54 care partners (Figure 2). Eighteen patients (30%) attended their appointments alone, without a care partner. Eleven patients (19%) attended with a care partner but were able to provide consent independently to participate in the study, while 30 patients (51%) attended with a care partner and displayed potential evidence of diminished cognitive capacity prior to enrollment in the study, thus their care partners also provided consent for their participation as an added layer of confirmation. Patients—and their care partners, when applicable—were randomized to receive usual care ($n = 30$ patients and their corresponding care partners) or to receive the QPL ($n = 29$ patients and their corresponding care partners). All study procedures were approved by the Washington University Institutional Review Board.

Appointments in the current study were hosted by a single outpatient palliative care team. Study appointments were always attended by the palliative care physician. At least one social worker was present at 45 appointments (76%), and one of two palliative care fellows was present at 23 appointments (39%). Overall, 10 appointments (16%) were attended only by the palliative care physician; 29 appointments (49%) were attended by two clinicians (i.e., palliative care physician and social worker, or palliative care physician and palliative care fellow); 20 appointments (34%) were attended by the physician, fellow, and one social worker; and one appointment (1%) was attended by the physician, fellow, and two social workers. The palliative care physician led all appointments, sometimes co-leading the appointment with the palliative care fellow when one was present. All clinicians who participated in appointments provided verbal consent to participate in the study per procedures approved by the Institutional Review Board.

2.2 Procedure

The study team verified each recommended patient's study eligibility, examined the medical record for evidence of a diagnosis with cognitive impairment, and contacted either the patient or the patient's legally authorized representative to gauge interest in participation. Potential participants were provided with a summary of the study, including its overarching aim of identifying ways to better understand communication during initial palliative care appointments and to improve patient and care partner experiences during initial palliative care appointments. Interested participants (both patients and care partners, when applicable) provided verbal consent to participate over the telephone and were subsequently randomly assigned to one of two study conditions using block randomization. Care partners were automatically assigned to the same condition as their patient. Participants randomized to usual care did not receive any additional instructions or information about the appointment from the study team. Participants randomized to receive the QPL were informed over the telephone that they would receive an email with a list of questions that patients and care partners sometimes find useful to bring with them and ask during outpatient palliative care appointments. Participants, including both patients and care partners, were asked to provide their email address and were emailed a PDF copy of the QPL immediately after the recruitment phone call.

All study appointments were conducted by telephone ($n = 5$) or over Zoom ($n = 54$). Appointments occurred by phone when participants did not have a webcam or experienced difficulties connecting to Zoom. Participants were instructed to arrive to their appointment approximately 10 min early to complete pre-appointment questionnaires. When the appointment occurred over the telephone, the study team scheduled a time to call participants no more than 15 min before the appointment to complete the pre-appointment questions. Because my hypotheses

regarding self-efficacy were not constrained by timing, participants responded to questions about self-efficacy either at the time of consent or immediately before their appointment.

Participants assigned to the QPL group were asked to verify that they had received the email with the QPL (intention to treat, $n = 27$, see Figure 2). On average, participants in the QPL group who received the QPL self-reported that they had looked at the QPL for approximately 18 min before the appointment ($SD = 29$ min, range = 0-180 min). All participants were reminded that their appointment would be audio recorded. Participants were also reminded that they would be asked to complete a series of post-appointment questions. Participants attending over Zoom were asked to stay on the Zoom link immediately after the appointment, and the study staff completed study questions over Zoom. For participants attending their appointment over the telephone, the study team made a plan to contact participants by telephone immediately after their appointment ended in order to ask post-appointment questions. Participants who completed all study measures were offered compensation of $20.00.

2.3   Materials

2.3.1 Palliative Care QPL

Participants (i.e., patients and their corresponding care partners) assigned to the QPL group received a 25-item QPL for outpatient palliative care appointments (Arthur et al., 2016). The tool is applicable to patients with any advanced disease and their care partners and covers a range of topics, including questions about symptom management, psychological and spiritual care needs, communication, and needs of caregivers. See Appendix A for full QPL.

2.4   Measures

2.4.1 Demographics and Disease Context

Demographic and contextual information for each patient was collected from the electronic health record at baseline: sex, date of birth, race, ethnicity, marital status, education level, disease, and body system affected by disease. Demographic information for care partners, as well as any missing demographic information for patients, was collected directly from care partners and patients at the time of study recruitment. Care partners reported their relationship to the patient, age, sex, race, ethnicity, marital status, and education level.

2.4.2 Appointment Participation

I developed a comprehensive codebook to examine metrics of appointment participation (see Appendix B). The codebook was based on coding schemes used in previous research to measure patient participation during health care appointments (Buffington & Schwarze, 2019; Eggly et al., 2017) and seminal research about the dimensions of assertiveness (e.g., Arrindell et al., 1988; Lorr & More, 1980). The codebook was designed to be comprehensive and fairly circumscribed to the constructs of interest to facilitate opportunities for replication and ensure consistency in coding during this study. The codebook delineated specific instructions for how to identify *questions* and *assertions* made by patients and care partners during outpatient palliative care appointments.

2.4.2.1 Questions. I operationally defined questions as features of speech that (a) are made directly from a patient or care partner to a clinician and follow the typical phrasing and voice inflection[1] of a question; *and* are made either (b) to obtain information related to care from a clinician *or* to clarify something that was already stated by a clinician. This definition was developed based on the definition of questions used by Eggly and colleagues (2017) and was

---

[1] If coders could not discern whether a statement was a question by reading the appointment transcript, the codebook stated that they should listen back to the audio recording of the appointment. As a result, voice inflection was used as a metric of defining a question in the current study if a statement could not be coded using phrasing alone.

also informed by the coding structure employed Cegala and colleagues (2000) in their work on patient participation during medical interviews. The following types of statements did not adhere to the operational definition of questions, and, therefore, were not coded as questions in the current study: pleasantries (e.g., "How are you doing today?"); requests (e.g., "Can you put in that order?"; see *requests* below, and Appendix B); statements made to obtain information that is solely needed for the purpose of carrying the conversation forward (e.g., "Uh, I take the carbo, you know, the small one?") or to orient the clinician (e.g., "Do you know how I saw Dr. Smith back in June?"); statements about technical difficulties (e.g., "Can you see me now?"); figures of speech not intended to obtain care-related information, or that are personal (e.g., "Have you been to Nashville before?"); mention of a question (e.g., "I have a question about that medication."); statements that a patient or care partner proceeds to answer themselves; jokes, sarcasm, and rhetorical questions; and statements that were repeated by a patient or care partner because the clinician explicitly asked for them to be repeated. Please refer to Appendix B for detailed coding guidelines.

2.4.2.2 Assertions. Two types of assertions were coded. I operationally defined *requests* as statements that specifically involve a patient and/or care partner asking for something from the palliative care team. Consistent with previous QPL coding schemes (see Eggly et al., 2017), requests sometimes, but not always, follow the sentence structure and voice inflection[2] of questions (i.e., "Could you give me her phone number?" and "Please send us a copy of the purple form." are both requests), and in fact, are monikered "assertive questions" in other work referenced in the development of this study (Cegala et al., 2000). I did not code statements as

---

[2] If coders could not discern whether a statement was a request by reading the appointment transcript, the codebook stated that they should listen back to the audio recording of the appointment. As a result, voice inflection was used as a metric of defining a request in the current study if a statement could not be coded using phrasing alone.

requests if they involved a patient or care partner asking for something in passing (e.g., "Hold on a sec while I adjust the camera."). However, I did code statements as requests when they involved a patient or care partner going out of their way to request a behavior that would directly benefit their experience during the appointment (e.g., to physician: "Could you please speak up? We hear a lot of feedback.").

I operationally defined *decisions* as statements which indicate that a patient or care partner has made a choice. I only coded assertions as decisions if they explicitly reflected choices made in the context of the current palliative care appointment and had been clearly discussed by the patient or care partner and the team during the appointment. Statements that reflected choices made in the past, outside of the appointment, were not coded as decisions (e.g., "I already told them that I never want to be on a ventilator."). To be counted as a decision, a statement also had to be tied to a tangible action or outcome. For example, if after discussing do not resuscitate orders during the appointment, a patient said, "Yes, I would like to fill out a DNR," the statement would be coded as a decision, as it reflects a tangible action that the patient would take (i.e., completing the form) and an outcome that would happen as a result (i.e., the patient would not be resuscitated if their heart stopped). Please refer to Appendix B for detailed coding guidelines.

2.4.2.3 Appointment Participation Coding Process. All study appointments were audio recorded. Trained undergraduate research assistants transcribed audio recordings from appointments into text transcripts in Microsoft Word. Then, two coders (MM and HS) used transcripts to calculate metrics of appointment participation. The preliminary coding protocol was established prior to the start of the study and was refined during the early stages of coding. The protocol involved (1) coding questions in all transcripts, then (2) coding assertions in all

transcripts. Coders were not blind to participant condition, as participants in the QPL condition often referred to the QPL during their appointments.

The coders developed a codebook comprised of preliminary operational definitions of questions, decisions, and requests, based on previous coding schemes (e.g., Cegala et al., 2000; Eggly et al., 2017). The working operational definition for questions was initially refined using five randomly selected study transcripts as training transcripts, then continuously refined as needed throughout the coding process. The working operational definitions for decisions and requests were initially refined using four randomly selected study transcripts as training transcripts and were continuously refined as needed throughout the coding process. When major adjustments were made to the working operational definitions early in the process, coders revisited transcripts that had previously been coded to ensure that they were consistent with the updated coding scheme.

Before coding questions, both coders met to review the codebook and to discuss how it would be applied to the study transcripts. Then, five transcripts were chosen at random for both coders to independently code questions in those transcripts. Coders were instructed to (1) read through the codebook before starting to code, (2) read the entire transcript once, then (3) read the entire transcript a second time to apply codes. Coders met one week later to compare and discuss codes for the first five transcripts, achieving a good preliminary intraclass correlation coefficient (ICC) based on consistency between total number of questions coded by each coder, within each transcript (ICC = .86, p < .001). The coders repeated the same process for five additional transcripts and obtained a similarly good, but slightly lower, ICC (ICC = .75, p < .002). Although the coders achieved good preliminary ICCs, the coding process continued, with each coder independently coding transcripts each week (in increments of 5-8 transcripts), then

meeting each week for 1-2 hr to discuss coding discrepancies, review questions, and update the codebook. Both coders coded questions in all 59 study transcripts.

Similarly, before coding assertions, both coders met to review the codebook and to discuss how it would be applied to the study transcripts. Then, coders applied the preliminary version of the codebook to independently code assertions in four transcripts over a 1-week period. Coders were instructed to (1) read through the codebook before starting to code, (2) read the entire transcript once, then (3) read the entire transcript a second time to apply codes. Coders met one week later to compare and discuss codes, achieving a preliminary ICC indicative of poor reliability, based on consistency between total number of assertions coded by each coder, within each transcript (ICC = .45, $p < .05$). Coders retrained on coding guidelines by reviewing the coding manual together and discussing examples and non-examples between the coders. The coders repeated the same process for four additional transcripts and obtained an ICC indicative of good reliability for assertions (ICC = .84, $p < .02$). Afterward, the coding process continued with independent coding of each transcript by both coders, in increments of 8-12 transcripts, then meeting weekly to resolve discrepancies. Both coders coded assertions in all 59 study transcripts.

After coding was completed, frequency counts of questions and assertions were tallied for patients and care partners within each appointment transcript. Once the frequency counts were completed for each appointment transcript, two trained coders, unblinded to participant condition, examined the questions and assertions that had already been extracted by MM and HS to determine (a) how many questions were asked directly from the QPL among participants assigned to the QPL condition and (b) how many questions asked were unrelated to questions from the QPL.

2.4.3 State Anxiety

The Brief State Anxiety Measure (BSAM; Berg et al., 1998) is a 6-item measure of state anxiety. It is based on the original 20-item State Trait Anxiety Inventory (STAI; Spielberger et al., 1983). The items (e.g., *worried, comfortable)* measure present moment anxiety and are rated on a 4-point ordinal scale from 1 (*not at all*) to 4 (*very much so*). In the current study, participants were instructed to rate items based on their present moment anxiety about the palliative care appointment. Reports from the original development of the measure indicate that it has good internal consistency (Cronbach's $\alpha = .83$) and that it is highly correlated with the STAI ($r = .93$) (Berg et al., 1998). In the current study, reliability for the BSAM was good at baseline (see Table 3).

2.4.4 Perceived Self-Efficacy

2.4.4.1 Self-Efficacy in Question Asking During Medical Appointments. Consistent with Bandura's conceptualization of the concept of self-efficacy, participants responded to a single item about confidence in question asking during palliative care appointments (i.e., "I feel confident in my ability to ask questions during a palliative care appointment."). Participants were asked to respond with a single number between 0 (*I don't feel confident in my ability at all*) to 100 (*I feel completely confident in my ability*). Previous research indicates using a single-item measure of self-efficacy is a valid method by which to measure the construct (Williams & Smith, 2016), given that it is moderately correlated with a 10-item measure of general self-efficacy (Schwarzer & Jerusalem, 1995). In the current study, Spearman's rank correlation indicated that the single-item assessment of self-efficacy in question asking was positively correlated with the AURA measure of self-efficacy in obtaining health care information at baseline ($r_s = .28$, $p = .00$).

2.4.4.2 Self-Efficacy in Obtaining Health Care Information. The Ask, Understand,

Remember Assessment (AURA; Clayman et al., 2010) is a 4-item measure of self-efficacy

regarding one's ability to obtain health care information. More specifically, it is a way to

measure an individual's confidence in performing necessary health care communication tasks.

The items from this measure are adapted versions of questions from the Communication and

Attitudinal Self-Efficacy (CASE) Cancer Measure (Wolf et al., 2005) about patient-clinician

relationships. Items include "It is easy for me to ask for help if I don't understand something,"

and "It is easy for me to understand my doctor's instructions." Participants first rate whether they

agree or *disagree* with each statement, then they rate whether they disagree or agree *a little* or *a*

lot. Thus, each item is rated on a 4-point ordinal scale, from 1 (*disagree a lot*) to 4 (*agree a lot*).

Results from the original development and validation of this measure with a sample of 330

hypertension patients indicate that it has acceptable reliability (Cronbach's $\alpha = .75$) and good

validity, as indicated by a significant correlation with the Chronic Disease Self-Efficacy Scales (r

$= 0.31$; Clayman et al., 2010). In the current study, reliability for the AURA was acceptable

(Table 3).

2.5   Data Analysis

I used SPSS Version 27 and R (version 4.1.2) to conduct all analyses. Data were

reviewed to determine whether assumptions for planned analyses were met (i.e., normal

distribution of data, outliers, normal distribution of residuals, homogeneity of variance, and

homoscedasticity). Because nearly all outcomes of interest were not normally distributed

according to the Shapiro-Wilk test of normality, I first conducted all statistical analyses with

transformed versions of variables. Specifically, I used exponential transformation for variables

with a negatively skewed distribution, including pre- and post-appointment ratings of self-

efficacy in question asking, pre- and post-appointment ratings of self-efficacy in obtaining health information, and pre- and post-appointment ratings of state anxiety. I used square root transformation for variables with a positively skewed distribution, including total questions and total assertions. However, analyses conducted with transformed versions of variables produced the same null results as analyses conducted with the original variable values. As a result, for ease of interpretation of outcome variables and their meaning in the context of the present study, all analyses reported herein were conducted with variables that were not transformed.

Missing data from patients and care partners occurred in measurements of state anxiety, self-efficacy in question asking, and self-efficacy in getting health care information (see Table 2). In some instances, data were missing because a patient was unable to answer a question due to cognitive impairment or confusion, and therefore did not complete any pre- or post-appointment questions (15 participants total: six patients assigned to usual care; nine patients assigned to receive QPL). In other instances, data from patients and care partners were missing due to insufficient time to interview the participant immediately before or after the appointment. Patients who could not complete study measures (and therefore were never asked to complete pre- and post-appointment measures) were completely excluded from analyses. However, because it was unknown whether responses from other participants were missing at random, missing not at random, or missing completely at random, I conducted a multiple imputation ($m =$ 100) using the mice package in R to simulate values for missing responses from these participants on measures of state anxiety, self-efficacy in question asking, and self-efficacy in getting health care information. Data generated via multiple imputation were used to conduct analyses for Aims 2, 3, and 4.

First, descriptive statistics were calculated to characterize the sample. The effect of the QPL intervention on patient and care partner appointment participation (**Aim 1**) was examined using two, one-way ANOVA models. The first model used total questions asked by both patients and care partners combined during the appointment as the dependent variable and condition (usual care or QPL) as the independent variable. The second model used total assertions made by patients and care partners combined during the appointment as the dependent variable and condition as the independent variable. Appointment participation by patients and care partners was strategically combined (Brandes et al., 2014) because all appointments were scheduled to be 60 min, and as a result, total appointment participation was constrained by a standardized appointment length. Between-group and within-group differences in change in anxiety (**Aim 2**) were examined with linear mixed effects model analysis using the lme4 package in R. I included state anxiety as the dependent variable and added fixed effects of time and condition, as well as the interaction between time and condition. I included participant as a random effect. Between-group and within-group differences in change in self-efficacy in question asking and in obtaining health care information (**Aim 3**) were examined with 2 separate linear mixed effects model analysis using the lme4 package in R. I included each type of self-efficacy as the dependent variable in one model and added fixed effects of time and condition, as well as the interaction between time and condition. I included participant as a random effect. Relations between appointment participation and post-appointment perceived self-efficacy in question asking, as well as between post-appointment anxiety and post-appointment perceived self-efficacy in question asking (**Aim 4**), were examined by calculating Spearman rho correlation coefficients. Patient and care partner reports of self-efficacy in question asking, self-efficacy in obtaining health care information, and state anxiety were combined for analyses in Aims 2 through 4 (a)

because preliminary analyses conducted with patients and care partners separately did not yield different results and (b) to generate larger cell sizes for each analysis.

2.5.1 Power Analysis

The primary outcome of interest was the difference in total appointment participation, defined as the sum of questions asked and assertions made during the appointment, between participants in the usual care and QPL groups. A previous meta-analysis of heterogeneous QPL interventions indicated that there is a small effect of QPLs on question asking during health care appointments ($d = 0.27$, range = 0.19-0.36; Kinnersley et al., 2008). However, more recent randomized controlled trials of QPLs applied to patient populations like the patients in the current sample (Clayton et al., 2007; Eggly et al., 2017) indicate that the effect size associated with QPL interventions may be more in the small to medium (Clayton et al., 2007; OR = 2.33, 95% CI, 1.68-3.18) or medium range (Eggly et al., 2017; $d = 0.55$). An a priori power analysis using G*Power suggested that a total sample of 90 patient appointments (45 per condition) would be sufficient to detect an effect in the medium range ($f = 0.30$) with 80% power at $\alpha = 0.05$. Because the final sample was much smaller due to unexpected COVID-19 pandemic-related factors, the current study was underpowered to detect an effect of the QPL intervention on question asking.

Chapter 3: Results

3.1 Demographics

Demographic characteristics of the final sample are available in Table 1. The mean age of patients was 68.5 (SD = 12.4, range = 30-89), and a slight majority was female (59%). Most were White (88%), and none self-reported Hispanic or Latino ethnicity. In terms of marital status, most patients were married (71%), and 40% reported having earned a bachelor's degree or higher. The majority of patients had a primary diagnosis affecting neurological function (e.g., amyotrophic lateral sclerosis, Parkinson's disease) or cancer, with fewer patients having a primary diagnosis affecting the lungs, heart, or another body system.

Care partners were present at 78% of appointments (n = 46 appointments). The mean age of care partners was 60.2 (SD = 12.7, range = 31-83), and most care partners were female (68%). Most care partners were White (91%), and more than half of care partners were spouses or significant others. Most care partners had a bachelor's degree or higher (65%). Among appointments attended by a care partner, most were attended by one care partner (n = 37, 81%), with fewer attended by two care partners (n = 8, 17%) and only one appointment attended by four care partners (2%).

3.2 Effects of the Intervention on Appointment Participation (Aim 1)

3.2.1 Questions Asked

I hypothesized (**H1a**) that patients and care partners who received the QPL would ask more questions compared to participants assigned to usual care (see Table 3 for descriptive statistics). A one-way ANOVA revealed no significant effect of the intervention on question

asking, $F(1,57) = 0.17$, $p = .49$, partial $\eta^2 = .009$. I also hypothesized (**H1b**) that patients and

care partners who received the QPL would ask a greater proportion of questions from the QPL

compared to questions not directly from the QPL. On average, only 5% of total questions asked

by patients and care partners assigned to receive the QPL came directly from the QPL, while

95% of questions asked were not from the QPL (see Table 3). Questions directly from the QPL

were only asked in 8 appointments (27%). Because of the small number of questions asked from

the QPL during QPL appointments, statistical comparisons were not pursued.

3.2.2 Assertions Made

I hypothesized (**H1c**) that patients and care partners who received the QPL would make

more assertions (i.e., requests and decisions) during the appointment compared to participants

assigned to usual care (see Table 3). A one-way ANOVA revealed no significant effect of the

intervention on making assertions, $F(1,56) = 3.00$, $p = .09$, partial $\eta^2 = .05$.

3.3 Effects of the Intervention on State Anxiety (Aim 2)

I hypothesized (**H2a**) that patients and care partners assigned to the QPL condition would

report lower pre-appointment levels of state anxiety (see Table 3). There was a significant

difference between pre-appointment ratings of state anxiety between participants assigned to

usual care or the QPL condition, such that participants assigned to the QPL condition reported

lower ratings of state anxiety at pre-appointment, $t(9798) = -6.87$, $p < .001$. I also hypothesized

(**H2b**) that there would be an interaction effect between time and condition, such that

participants in the QPL condition would report a greater reduction in anxiety from pre- to post-

appointment. This hypothesis was not supported, (beta = -0.02, $t = -0.29$, $p = .77$, 95% CI_{beta}[-

0.15, 0.11]). There was no effect of condition, (beta = 0.08, $t = 0.57$, $p = .57$, 95% CI_{beta}[-0.20,

0.36]). There was, however, an effect of time across conditions, such that there was an average

reduction in state anxiety from pre- to post-appointment, (beta = 0.16, t = 3.21, p = .001, 95% CI$_{beta}$[0.06, 0.25]).

3.4 Effects of the Intervention on Perceived Self-Efficacy (Aim 3)

3.4.1 Self-Efficacy in Question Asking

There was a significant difference between pre-appointment ratings of self-efficacy in question asking between conditions, such that participants assigned to the QPL condition reported lower levels of self-efficacy in question asking before the appointment, $t(9798)$ = 11.67, $p < .001$ (see Table 3). I hypothesized (**H3a**) an interaction effect between time and condition, such that participants randomized to the QPL condition would report a significantly greater increase in confidence in question asking from pre- to post-appointment compared to participants assigned to usual care. The linear mixed effects model was not significant, (beta = 0.75, t = 0.38, p = .71, 95% CI$_{beta}$[-3.16, 4.65]). There was no effect of study condition, (beta = -3.89, t = -1.37, p = .17, 95% CI$_{beta}$[-9.48,1.68]). There was, however, an effect of time, such that there was an average increase in self-efficacy in question asking from pre- to post-appointment across conditions, (beta = 3.31, t = 2.31, p = .02, 95% CI$_{beta}$[0.51, 6.11]).

3.4.2 Self-Efficacy in Getting Health Care Information

There was a significant difference between pre-appointment ratings of self-efficacy in getting health care information between participants in the usual care condition and the QPL condition, $t(9798)$ = -7.20, $p < .001$ (see Table 3). I hypothesized (**H3b**) that there would be an interaction effect between time and condition on participants' self-efficacy in getting health care information, such that participants randomized to the QPL condition would report a significantly greater increase in self-efficacy in getting health care information from pre- to post-appointment compared to participants in the usual care condition. A two-way, repeated measures ANOVA

was not significant (beta = 0.005, t = 0.13, p = .90, 95% CI$_{beta}$[-0.07, 0.08]). There was no main effect of study condition (beta = 0.08, t = 0.78, p = .43, 95% CI$_{beta}$[-0.12, 0.28]) or time (beta = 0.04, t = 1.59, p = .11, 95% CI$_{beta}$[-0.01, 0.09])

3.5 Relations Between Appointment Participation, State Anxiety, and Perceived Self-Efficacy (Aim 4)

Based on the proposed mechanism of self-efficacy development and growth (Figure 1) and SCT (Bandura, 2000), I hypothesized that total questions asked would be significantly positively associated with patients' and care partners' post appointment levels of self-efficacy in question asking. Total questions asked was significantly associated with post-appointment ratings of self-efficacy in question asking (**H4a**) (r_s = .18, p = .00) and post-appointment ratings of self-efficacy in getting information (**H4b**) (r_s = .13, p = .00). I also hypothesized that post-appointment anxiety would be significantly negatively associated with participants' post-appointment perceived self-efficacy in question asking (**H4c**) and perceived self-efficacy in getting information (**H4d**). These ratings were significantly associated, such that lower ratings of post-appointment anxiety were associated with both higher ratings of post-appointment perceived self-efficacy in question asking (r_s = .26, p = .00) and getting information (r_s = .26, p = .00).

Chapter 4: Discussion

This study tested the effects of a QPL (Arthur et al., 2016) on participation during initial outpatient palliative care appointments using SCT (Bandura, 2000) as a framework (see Figure 1). Patients and care partners who received a QPL specific to palliative care before attending their appointment did not ask more questions or make more assertions (i.e., decisions, requests) than participants assigned to usual care. Furthermore, there was no effect of the QPL on reducing anxiety or increasing self-efficacy across the appointment compared to usual care. There was, however, a main effect of time: on average, participants in both study conditions reported decreased anxiety and increased self-efficacy in question asking after their appointments. Across participants, there was a significant association between total questions asked and post-appointment ratings of self-efficacy. Furthermore, post-appointment perceived self-efficacy in question asking was significantly associated with state anxiety, such that lower anxiety was associated with higher ratings of perceived self-efficacy. Findings from the current study suggest that a QPL may not be effective in increasing patient and care partner appointment participation during initial outpatient palliative care appointments, but that participation may be associated with ratings of self-efficacy and state anxiety. Importantly, this work was limited by an underpowered sample. Findings underscore the need for future research with larger samples that examines other mechanisms by which QPLs may support self-efficacy in patients and care partners in outpatient palliative care settings.

4.1   QPLs and Appointment Participation

In the current study, patients and care partners who received a QPL before the patient's palliative care appointment did not ask more questions or state more assertions compared to participants assigned to usual care. Thus, these findings add to the existing, mixed literature

about the effects of QPL use on appointment participation during outpatient medical

appointments (e.g., Sansoni et al., 2015). Although much of the landmark work in this field—

which has focused on question-asking as a primary form of participation—suggests that patients

and care partners participate more when they have access to a person-centered communication

resource like the QPL (Clayton et al., 2007; Eggly et al., 2017), my findings did not mirror those

results. To the contrary, findings from the current study parallel more recent work calling into

question the effectiveness of QPLs and indicating that, in certain circumstances, patients and

care partners ask very few questions from QPLs during medical appointments, even when they

report plans to ask questions from the list before their appointment (Jenkins et al., in press).

Previous critiques have posited multiple explanations for null effects of QPL

interventions, including limited "penetration" of the intervention in the study population

(Schwarze et al., 2020). I was aware before conducting this study that other QPL research groups

had expressed concern about QPL use based on method of delivery (e.g., USPS mail); thus, I had

intended to distribute the QPL to participants in-person, in advance of their appointments, and

provide them time to review the QPL immediately beforehand, a method shown to be more

effective (Sansoni et al., 2015). However, this part of the study design was established before the

COVID-19 pandemic necessitated that all appointments be virtual (Lally et al., 2021), and email

may not have been an effective modality of distribution. Because I emailed the QPL to

participants and could not precisely measure how (and for how long) they reviewed the QPL, I

could not verify the extent to which it "penetrated" the study sample, aside from the significant

infrequency with which questions were asked directly from the QPL (potentially suggesting low

penetration). I did, however, ask participants at the beginning of the appointment whether they

had received the QPL; I also asked how long they had taken to review the QPL, with most

participants reporting that they had reviewed it for at least 5 min. However, I was not always confident about the comprehensiveness of their review of the QPL, and I suspected in some cases that participants were prone to social desirability when reporting about their use of the QPL as part of the study or, anecdotally, when they mentioned it to the palliative care team during appointments. Future work should continue to investigate how elements of QPL delivery potentially elevate their effectiveness and perceived usefulness among patients and care partners. Likewise, researchers might also consider asking participants for qualitative feedback about the timing of their receipt of the QPL (e.g., Did you have enough time to review the QPL? Would it have been [better/worse/the same] if you had received the QPL on [the same day as the appointment/when you scheduled the appointment], and why? Would you have been more likely to ask more questions if you received a reminder to use the QPL, and why?).

More recent research has suggested that other QPL delivery factors, including the amount of information that participants receive about the intervention when it is given to them, predict intervention effects. In the current study, it is possible that receiving the QPL electronically *and* without a detailed overview may not have been sufficient to secure participant buy-in, therefore resulting in null effects. Preliminary work has begun to explore the effectiveness of QPL interventions that include more robust "coaching," or scaffolding about how to use the QPL, from a trained medical professional (e.g., nurse) or study staff member (Rodenbach et al., 2017). This type of approach has the potential to increase user buy-in and reduce uncertainty about how the QPL could be deployed during an appointment. However, existing QPL research that has compared the effects of a QPL-only condition to parallel coaching or training interventions (Brown et al., 1999; Eggly et al., 2017) is complex to interpret, as the coaching interventions seem to target other mechanisms of changing patient participation, especially within the

framework of SCT (i.e., verbal encouragement). Therefore, I believe that future work should continue to investigate the usefulness of QPL interventions augmented by coaching or educational support, but that all future work should simultaneously be guided by the parameters of a falsifiable theory like SCT to outline the mechanisms by which such interventions operate.

It is also possible that the QPL was made obsolete by the deftness of the palliative care team in the current study: patients and care partners simply did not need to ask questions during their appointments because topics suggested on the QPL were preemptively raised by this highly-skilled team. For example, nearly all appointments began with the entire team introducing themselves and the palliative care physician asking the patient/care partner what their referring clinician had told them about palliative care and the palliative care team. After patients and care partners offered their perspectives on palliative care, the palliative care physician provided an explanation of the goals of palliative care, as well as details about their background and training as a palliative care clinician. Similarly, toward the end of most appointments, the physician asked the patient and care partner whether they had completed an advance directive and whether they had discussed goals of care. As a result, patients and care partners may not have found it necessary to ask certain questions on the QPL (e.g., Who are the members of the palliative care team?). In the current study, observational data suggest that content associated with as many as one-third of the questions on the QPL could have been addressed by the team in certain appointments before patients would have had a chance to ask explicitly. This hypothesis—that patients and care partners asked fewer questions because the palliative care team covered important content without them having to ask in the first place—is worthy of further investigation, specifically in the context of person-centered care (Eklund et al., 2019).

If QPLs are intended to facilitate participation initiated by patients and care partners to make palliative care appointments more collaborative, alternate approaches to QPL use that maximize patient and care partner participation may be worthy of further investigation. Future research in this domain could evaluate the effectiveness of QPLs with questions meant either to augment standard topics covered during initial outpatient palliative care appointments or that can be customized to address unique patient and care partner needs. Other research might examine QPL use in follow-up appointments when content delivered by the palliative care team is less standardized or comprehensive. Finally, future work might build upon strategies used in previous work (e.g., clinician endorsement of the QPL; Walczak et al., 2014) and related strategies (e.g., distribution of the QPL by the palliative care team v. the study team) that implicitly facilitate opportunities for more collaborative care.

Relatedly, as has been suggested by other authors (e.g., Kinnersley et al., 2008), it is also possible that person-centered QPL interventions may not be robust enough to encourage clinicians to change their style of interacting with patients during appointments, especially if those appointments have some degree of natural flow and standardization, including a predetermined length. In other words, it is possible that there is simply not enough time for patients to ask a range of questions from a QPL during an initial outpatient palliative care appointment, and that it may be difficult for physicians to customize initial appointments based on patient and care partner needs when a plan is in place to cover set topics across appointments. For example, Barton and colleagues' (2020) secondary analysis of the effects of a QPL on patient question asking during oncology appointments suggested that patients and care partners in the QPL condition prompted oncologists for more information compared to patients and care partners in the usual care condition, but that across study appointments, oncologists did not

always provide customized information based on patients and care partners' unique questions. Future research to address these complexities could involve semi-structured interviews with palliative care clinicians to understand their general expectations about patient and care partner question asking during initial appointments. This work should specifically solicit clinicians' suggestions for ways to make these appointments more collaborative and individualized to patient and care partner needs while also addressing core content that is standardized across patients during initial appointments. Future work might also turn back to clinicians as intervention targets (i.e., clinician coaching), as structured coaching interventions for clinicians have demonstrated great promise in research thus far (Shamaskin-Garroway et al., 2021).

To my knowledge, only one study to date (Eggly et al., 2017) has examined the effects of a QPL intervention on assertions made during medical appointments, with positive results, but relatively broad definitions of assertions and lack of a unifying theory. In the current study, clear and specific definitions for assertion types were operationalized in advance, yet the intervention effect was null. It is possible that the null effect can be explained by the fact that there were simply limited opportunities for patients and care partners to state requests and make decisions during these appointments. For example, in the case of requests, it was not uncommon for a clinician to offer to do something without the patient or care partner needing to ask in the first place (e.g., "I'll send your prescription over to the pharmacy"), equally across study conditions. In terms of decisions, it is possible that their infrequency was related to the nature of topics being discussed during these *initial* outpatient palliative care appointments, which tend to focus on symptoms, advance care planning, and identifying support needs (Schroedl et al., 2014). Although most appointments included discussions about goals of care and treatment options, it was uncommon for final decisions about these topics to be made specifically within the

constraints of the hour-long appointment (Eliott & Olver, 2011). Regarding assertions as a whole, it is also possible that because a QPL is designed to "prompt questions" it does not effectively increase other types of appointment participation via performance accomplishments (Figure 1). As a result, future work examining the effects of QPL use on multiple types of appointment participation should base hypotheses on expectations for what types of assertions (Arrindell et al., 1988) are most likely to be increased by the scaffolding offered by QPLs. Furthermore, future research endeavors might consider whether QPLs—including QPLs with different types of questions—shape appointments across the palliative care trajectory uniquely depending on the types of conversations happening during those appointments (e.g., introduction to palliative care versus decisions about goals of care).

4.2   QPLs and Social Cognitive Theory

4.2.1 State Anxiety

This study was the first to investigate the effectiveness of a person-centered QPL intervention within the parameters of SCT (Bandura, 2000), a comprehensive and well-established theoretical framework that posits that self-efficacy develops via mechanisms of verbal persuasion, vicarious learning, performance accomplishments, and management of physiological arousal. I hypothesized that participants assigned to the QPL condition would report a more significant decrease in anxiety after their appointment, based on the tenets of SCT and some research evidence that providing participants with a tool to support participation reduces their anxiety about the appointment. That hypothesis was not supported. Instead, results indicate reduced anxiety across all participants, regardless of whether they received the QPL prior to their appointment.

Previous studies that have explored the link between QPL use and state anxiety report mixed findings (Brandes et al., 2014) and small effect sizes (Sansoni et al., 2015), perhaps because of methodological variability across studies. My findings corroborate previous mixed outcomes despite my attempt to reduce measurement variance by asking participants to rate their state anxiety *immediately* before and after their appointment. It is not clear that my results indicate a true null effect of the QPL on anxiety, or that a QPL is not, on its own, a meaningful way to reduce anxiety related to palliative care appointments, given my underpowered sample. However, observations from the current study suggest that it is complicated to measure state anxiety about palliative care appointments among individuals who, at baseline, experience a great deal of anxiety and worry related to many other things, at any given time (Wilson et al., 2007). In fact, several participants in the current study mentioned during the administration of the BSAM that they were worried "because of everything going on," including things that were unrelated to the appointment (e.g., being stuck in traffic), and could not disentangle that present moment anxiety from their anxiety related to the appointment, despite being oriented to answer the question specifically about the appointment. As a result, these observations point to the imprecision associated with measurements of anxiety at pre- and post-appointment and underscore the importance of precise, consistent measurements of anxiety in future QPL research aiming to determine their effectiveness at decreasing physiological arousal. Future work should also consider using more direct measures of physiological arousal (e.g., heart rate) (Kantor et al., 2001; Tichon et al., 2014).

That participants in both study conditions reported decreased anxiety from pre- to post-appointment raises questions regarding what else about attending an outpatient palliative care appointment—including what happens during those appointments—could assuage patient and

care partner anxiety. For example, previous research in psycho-oncology has examined how the type of clinical information that a patient receives during an initial oncology appointment (e.g., recommendations for future treatment) shapes post-appointment ratings of anxiety (Bronner et al., 2017) and suggests that recommendations for certain treatment options foster greater anxiety than others. In the current study, it is possible that patients and care partners could have reported lower post-appointment ratings of anxiety if they felt satisfied or relieved about recommendations made by the palliative care team, especially if they were anticipating less than satisfactory recommendations or no recommendations at all. In fact, because palliative care teams have the expertise to make specific recommendations about pain and symptom management strategies that are sometimes not considered by the patient's primary treating team (Kozlov et al., 2015), it is possible that patients and care partners could leave a palliative care appointment with greater understanding of ways to manage difficult symptoms and, potentially, less anxiety about managing those symptoms. Relatedly, it is possible that patients and care partners reported less anxiety after the appointment because they were relieved to know they would have a supportive, invested team involved in the patient's care throughout the course of their disease. On the other hand, it is also possible that participants' lower ratings of anxiety at post-appointment reflect feelings of relief that the appointment was over, or even more simply, reflect regression to the mean. Research aiming to build upon the current study might consider qualitative questions that examine participants' anxiety, including to what they attribute increases and decreases in their anxiety before, during, and after the appointment. This adjunctive approach could also improve upon the limitations of survey measures used to capture anxiety.

4.2.2 Perceived Self-Efficacy

To my knowledge, this study is the first to examine self-efficacy outcomes in the context of a QPL intervention study. As predicted by SCT, I hypothesized that participants assigned to the QPL condition would report an increase in self-efficacy in the context of their appointment as they asked more questions and made more assertions. This hypothesis was not supported. Like anxiety, results indicate that ratings of self-efficacy in question asking increased from pre- to post-appointment across all participants, regardless of whether they received the QPL intervention before their appointment. We did not find any significant effects with regard to self-efficacy in getting health care information. The primary explanation for this null finding is that this study did not effectively leverage performance accomplishments (in the form of asking questions and making assertions) as a mechanism of self-efficacy development. That is, patients and care partners who had the QPL did not ask more questions, and therefore did not have more opportunities for performance accomplishments, despite having a tool to facilitate such opportunities. As a result, it is still possible that, if more effective, a QPL or similar person-centered communication intervention could increase self-efficacy via performance accomplishments. Furthermore, it is also possible that total participation during an appointment in the form of question asking and assertion making is not a precise way to promote performance accomplishments. For example, future research might consider approaches such as asking patients and care partners to reflect on details about their performance in participating (e.g., Did you ask the questions you wanted to ask? Did you get all your questions answered?) or simply asking participants to reflect broadly on the quality of their participation, as these strategies could represent a more valid way to examine this construct.

On the other hand, it is also possible that other mechanisms of self-efficacy development (e.g., verbal persuasion, vicarious learning) would prove more powerful than—or would have a

compounding effect upon—performance accomplishments, in terms of increasing patient and care partner self-efficacy. Indeed, some previous research has inadvertently explored the link between verbal persuasion in QPL interventions and appointment participation by examining the effects of those interventions when their use is encouraged by the care team (Brown et al., 2012; Walczak et al., 2014). Results suggest that this adjunctive design feature is associated with increased appointment participation, but research to date has not specifically examined its utility with regard to self-efficacy development. In the current study, based on my qualitative observations of appointment dialogue, I believe other mechanisms of self-efficacy development, namely, verbal persuasion, did shape self-efficacy. As one example, it was common for the palliative care physician to normalize patient and care partner experiences by saying things like, "That symptom you just mentioned is something that most of my patients have experienced," or, "Most patients with your disease also decide not to be placed on a ventilator." Across appointments, the physician also made encouraging, validating comments like, "Wow, you're ahead of the curve, it's great that you already completed your advance directive." In the context of a palliative care appointment, verbal persuasion could take these and many other forms that would ultimately lead to self-efficacy growth and development, including praise for participation (Back et al., 2010), but also empathy for concerns expressed during the appointment (Mroz et al., in press; Pollak et al., 2020) and general support for the patient's self-efficacy (Bergeron et al., 2021). Importantly, verbal persuasion could very well shape self-efficacy development in palliative care settings irrespective of concurrent person-centered communication tools offered to patients and care partners. Future work should continue to investigate the effectiveness of QPLs within the parameters of self-efficacy and SCT (Bandura, 2000), emphasizing unique mechanisms by which self-efficacy is more or less likely to grow. Researchers pursuing this

work should pay particular attention to measuring the unique effects of each mechanism of self-efficacy development, considering stepped-wedge designs (Hemming et al., 2015) to maximize opportunities to understand unique effects of each interventional component.

Based on SCT and my proposed model of the links between appointment participation, self-efficacy, and anxiety, I also hypothesized that total appointment participation would be significantly positively associated with post-appointment ratings of self-efficacy in asking questions and in obtaining health care information. My data offer preliminary support for these hypotheses, which further underscores the need for additional research to unpack the mechanisms by which self-efficacy develops in patients and care partners. Importantly, previous research suggests that ratings of self-efficacy increase when patients perceive that they have succeeded in solving a problem that they saw as a problem in the first place (e.g., patients thought they were bad at question asking, then successfully asked questions, and got answers) (Bodenheimer et al., 2002; Ilioudi et al., 2010). As a result, future work should ask patients and care partners to reflect upon what factors contributed to their pre- and post-appointment ratings of self-efficacy, and more specifically, whether they believe that their actual participation was principal in shaping their perceived ability to participate during the appointment.

4.3 Limitations

The current study and its findings should be interpreted considering several limitations. The first set of limitations relates primarily to the characteristics of my sample. First, and perhaps most importantly, this study was originally powered as a randomized trial, yet complications due to the COVID-19 pandemic necessitated an abridged sample, which limited power as a result. Notably, recruitment was stalled at my original recruitment site for 8 months, which necessitated that I obtain IRB approval to conduct the study at a second site (i.e., the site

from which all participants were recruited in the current study). By the time I obtained approval to conduct the study at the original recruitment site, I discovered that patient flow was significantly reduced in the context of the pandemic (often only one new patient appointment per month), thus I did not collect any data from the original study site. All additional research related to QPL use in palliative care settings should prioritize sample sizes that are sufficiently powered to detect meaningful differences in all outcomes of interest. Importantly, future work conducted with larger sample sizes would also create opportunities to conduct subgroup analyses (e.g., age, sex, race, patient/caregiver role).

In addition, I cannot ensure the generalizability of these findings to other palliative care teams, to other patients with palliative care needs, or to other care partners in palliative care settings. This study was conducted in a sample of patients attending their first outpatient palliative care appointment at a large, academic medical center, and all appointments were conducted by the same palliative care team. If there is variability across institutions and across palliative care teams in terms of how initial outpatient palliative care appointments are conducted (e.g., standardized content, appointment length), and importantly, which/how many clinicians are present during initial appointments, concomitant variability in terms of opportunities for patients and care partners to participate may follow. Future research employing similar designs should consider the role of unique palliative care teams in shaping the structure, content, and flow of initial appointments, including patient question asking. For example, I hypothesize that initial appointments with more flexibility in terms of length and content covered, may create more opportunities for patient and care partner participation in the form of question asking, specifically.

Also related to generalizability is the fact that this sample consisted mostly of White, highly educated participants, who self-reported high levels of perceived self-efficacy in asking questions during palliative care appointments at baseline. Level of self-efficacy reported by participants at baseline was not significantly level of education. The original recruitment site was selected specifically due to the racial, ethnic, and socioeconomic diversity of its patient population, yet for reasons previously described, recruitment at that site was not feasible. In fact, multiple participants in the current study mentioned during their appointments having an adult child who was employed in health care, including one patient who stated that her adult son—a physician—had encouraged her to make the appointment. Another patient was, himself, a retired physician. If the current study had been conducted in a sample with lower self-efficacy in participating in palliative care appointments, the QPL may have been more effective at facilitating appointment participation and increasing participants' self-reports of self-efficacy thereafter. For example, at least two participants in my study stated their gratitude about being contacted to participate: they reported limited knowledge about palliative care, including a limited understanding of why their appointment had been scheduled in the first place. These comments suggest that participants with little confidence in their understanding of palliative care might have felt more confident if provided with a "cheat sheet" of relevant questions to ask. As a result, I recommend that future research investigating the utility of QPLs in promoting self-efficacy examine their effectiveness in groups with lower levels of baseline self-efficacy in participating during health care appointments and lower levels of baseline knowledge of palliative care.

The second set of factors which limited the current study relate to its overall design and implementation. Despite my careful attention to designing this trial in a way that would improve

upon flaws in previous research, some of my attempts to "right the wrongs" of other work were unsuccessful. For example, I elected to administer the state anxiety measure as close to immediately before each appointment and immediately after each appointment to limit opportunities for participants to respond about their anxiety regarding issues unrelated to the upcoming appointment. However, questions and anecdotal responses from participants throughout the study suggest that it is nearly impossible for patients and care partners to separate feelings of anxiety and stress about their overall wellbeing from feelings of anxiety and stress about their upcoming appointment. Future work should investigate use of even more simplified, straightforward measures of state anxiety, including single-item measures of state anxiety or visual analog scale measures of state anxiety (Davey et al., 2007) that repeatedly orient participants to respond only about their anxiety regarding the appointment itself (e.g., I am going to ask you about your level of anxiety at this moment, right now, about your upcoming appointment. This question is only about the anxiety you have surrounding your appointment, not about anxiety you may have about other things at this time, such as your illness or treatment.). Future work should also consider integrating physiological measures of state anxiety (e.g., heart rate, skin conductance) for even more precise measurements (Constantinou et al., 2021).

As another example, despite my attempt to standardize the distribution of the QPL via email to ensure uptake by participants, the passivity of this design may have inadvertently thwarted QPL use. At least one participant had trouble accessing the QPL during the appointment because he planned to look at the questions on his phone but also had to login to the virtual appointment on his phone, so he could not view both simultaneously. Other participants reported looking at the list for "5-10 minutes when they got the email," while one participant

reported that they were "on a [20 min] phone call about it, discussing what we wanted to talk about." If the study had proceeded as originally planned, in person, participants would have had a standardized amount of time to review the QPL in advance of their appointment, right before entering their appointment, which could have reduced a significant amount of variability. Future researchers should prioritize procedures that standardize the timing of QPL delivery and the opportunity for uptake by participants. Future work should also examine the equity of QPL and other related communication interventions for participants with different needs (e.g., level of literacy) and opportunities for access (e.g., printer for hard copy, smart phone to view QPL in an app).

Lastly, although this work attempted to leverage SCT as a framework to examine the relation between appointment participation and perceived self-efficacy, it seems that qualitative information about participants' perceptions of their self-efficacy—and what contributed to their self-efficacy during their appointments—would have augmented my understanding of self-efficacy development in the context of palliative care appointments. While the single-item measure of self-efficacy that was used in the current study is perhaps the most valid way to measure self-efficacy as conceived by Bandura (1986), it lacks the richness of qualitative approaches. For example, in some appointments, very few questions were asked, yet it is possible that participants could have felt more confident in their ability to participate because the single question that they did ask represented a significant deviation from behavior in other medical appointments (i.e., asking no questions), or that they received such a rich response to that single question that it increased their confidence in their ability to ask questions during palliative care appointments. These and related research questions indicate a need for additional qualitative work that explores patients' and care partners' explanations for primary factors that

contribute to the development of perceived self-efficacy during palliative care appointments; importantly, they would support understanding of which other pathways outlined by SCT—or other, unknown pathways—scaffold self-efficacy development in the context of palliative care. Similar work would use related qualitative methods to ask palliative care clinicians about their perceptions of patients' and care partners' participation during appointments and what tactics they believe to be most supportive of developing their self-efficacy in the context of those appointments. If, indeed, perceived self-efficacy grows in ways as simple as receiving one useful response to a single question during a palliative care appointment, this knowledge would inform intervention development to enhance person-centered care at both the patient and clinician level.

4.4 Implications for QPL Use in Palliative Care

The current study revealed that a QPL intervention does not effectively increase question asking during initial outpatient palliative care appointments. However, observational data seem to suggest that not only patients and care partners, but also clinicians, may still benefit from access to a QPL in the context of palliative care appointments.

First, even if they do not increase total question asking, and even if they do not increase the likelihood that specific, pre-defined questions are asked, QPLs may still "prompt" patients and care partners to ask certain types of questions they may not have considered before. Though questions directly from the QPL were only asked in 27% of appointments in the QPL group, it is possible that patients and care partners would not have thought to ask those questions at all had they not been referenced on the QPL: in other words, if a benign intervention like the QPL, which technically requires limited resources to disseminate to patients, is helpful for 27% of patients and their care partners, might it still hold some clinical utility? In fact, findings from the original feasibility study about the QPL used in the current study suggested that patients and care

partners reported the QPL helped them think of questions they had not thought of before (Arthur et al., 2016). As a result, perhaps there is some remaining clinical merit to QPL use in outpatient palliative care, even if there is no evidence of statistically significant improvement in total appointment participation.

Second, it is also possible that QPLs have the capacity to support and encourage question asking in specific domains that may otherwise be challenging for patients and care partners to approach. For example, in the QPL designed by Arthur and colleagues (2016), 28% of questions focus specifically on EOL issues, a topic that is notoriously difficult for patients, care partners, and clinicians to discuss in the context of serious illness care (Brighton & Bristowe, 2016; Fakhri et al., 2016). Of particular note is that in the current study, three appointment transcripts from the QPL condition (10%) included a very specific question from the QPL focused on EOL (e.g., "What can I expect in my last few days of life?"). As a result, offering QPLs that highlight questions related to EOL and other challenging topics (e.g., decision making about life sustaining treatments) may facilitate question asking that could otherwise be difficult for patients and care partners. Even in the case that QPLs only facilitate these types of questions in a minority of patient appointments, one could argue that supporting even a single patient in asking a question about EOL care would be clinically meaningful.

Lastly, QPL use by patients may support person-centered care by directing palliative care clinicians to focus on specific topics with greater relevance to patients. In fact, approximately halfway through the current study, the physician on the palliative care team asked me to share the QPL with the palliative care team so that they could offer it to other patients in the future, it appeared to be so useful in terms of "adding to the conversation." Importantly, because the scope of practice of palliative care includes a range of topics, from symptom management to EOL care

discussions (Aslakson et al., 2014; McDarby & Carpenter, 2019; Rabow et al., 2013), questions raised by patients may guide clinicians to focus on specific palliative care topics that are likely to offer the greatest benefit to the patient and care partners. Furthermore, because consultation requests from specialty care clinicians to the palliative care team can lack specificity about the primary reason for the consult (Bischoff et al., 2018), offering patients and care partners the opportunity to ask questions with greater relevance to their own care may facilitate clinician understanding of topics that will be most useful moving forward in care.

4.5 Conclusion

Question prompt lists are a person-centered communication intervention hypothesized to increase patient and care partner participation during medical appointments. Findings from the current study, though underpowered, indicate that simply providing a QPL to patients and care partners via email in advance of the patient's initial outpatient palliative care appointment is not effective at increasing total appointment participation during these appointments. Results also suggest that patients and care partners who have access to a QPL during their first palliative care appointment do not experience a significant reduction in anxiety or increase in self-efficacy about participating in palliative care appointments compared to usual care. These findings add to the inconsistent literature about the effectiveness of QPLs in palliative care settings, though sample and design limitations argue for caution in their interpretation.

References

Alders, I., Smits, C., Brand, P., & van Dulmen, S. (2017). Does patient coaching make a difference in patient-physician communication during specialist consultations? A systematic review. *Patient Education and Counseling*, *100*(5), 882-896. https://doi.org/10.1016/j.pec.2016.12.029

American Association of Hospice and Palliative Medicine (AAHPM). (2009). Hospice and palliative medicine core competencies, version 2.3. http://aahpm.org/uploads/education/competencies/Competencies%20v.%202.3.pdf

Arnold, R.M., Back, A.L., Baile, W.F., Edwards, K.A., & Tulsky, J.A. (2017). The oncotalk/vitaltalk model. In D.W. Kissane, B.D. Bultz, P.N. Butow, C.L. Bylund, S. Noble, & S. Wilkinson (2nd ed.), *Oxford textbook of communication in oncology and palliative care*, (pp. 363-368). Oxford University Press. https://doi.org/10.1093/med/9780198736134.003.0056

Arrindell, W. A., Sanderman, R., Van der Molen, H., Van der Ende, J., & Mersch, P. P. (1988). The structure of assertiveness: A confirmatory approach. *Behaviour Research and Therap*y, *26*(4), 337-339. https://doi.org/10.1016/0005-7967(88)90087-3

Arthur, J., Yennu, S., Williams, J., Tanco, K., Liu, D., Stephen, S., & Bruera, E. (2016). Development of a question prompt sheet for cancer patients receiving outpatient palliative care. *Journal of Palliative Medicine*, *19*(8), 883-887. https://doi.org/10.1089/jpm.2015.0545

Arthur, J., Yennu, S., Zapata, K. P., Cantu, H., Wu, J., Liu, D., & Bruera, E. (2017). Perception of helpfulness of a question prompt sheet among cancer patients attending outpatient

palliative care. *Journal of Pain and Symptom Management, 53*(1)*,* 124-130.

    https://doi.org/10.1016/j.jpainsymman.2016.08.017

Aslakson, R. A., Curtis, J. R., & Nelson, J. E. (2014). The changing role of palliative care in the

    ICU. *Critical Care Medicine*, *42*(11), 2418-2428. https://doi.org/10.1097/

    CCM.0000000000000573

Back, A. L., Arnold, R. M., Baile, W. F., Fryer-Edwards, K. A., Alexander, S. C., Barley, G. E.,

    ... & Tulsky, J. A. (2007). Efficacy of communication skills training for giving bad news

    and discussing transitions to palliative care. *Archives of Internal Medicine*, *167*(5), 453-

    460. doi:10.1001/archinte.167.5.453

Back, A. L., Arnold, R. M., Baile, W. F., Edwards, K. A., & Tulsky, J. A. (2010). When praise is

    worth considering in a difficult conversation. *The Lancet*, *376*(9744), 866-867.

    https://doi.org/10.1016/S0140-6736(10)61401-8

Back, A. L., Park, E. R., Greer, J. A., Jackson, V. A., Jacobsen, J. C., Gallagher, E. R., & Temel,

    J. S. (2014). Clinician roles in early integrated palliative care for patients with advanced

    cancer: A qualitative study. *Journal of Palliative Medicine*, *17*(11), 1244-1248.

    https://doi.org/10.1089/jpm.2014.0146

Baile, W.F., Buckman, R., Lenzi, R., Glober, G., Beale, E.A., & Kudelka, A.P. (2000).

    SPIKES—A six-step protocol for delivering bad news: Application to the patient with

    cancer. *The Oncologist*, *5*(4), 302-311. https://doi.org/10.1634/theoncologist.5-4-302

Bailey, A., Mallow, J., & Theeke, L. (2022). Perceived self-efficacy, confidence, and skill

    among factors of adult patient participation in transitional care: A systematic review of

    quantitative studies. *SAGE Open Nursing*, *8*, 23779608221074658. https://doi.org/

    10.1177/23779608221074658

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Prentice-Hall.

Bandura, A. (2000). Self-efficacy: The foundation of agency. In W.J. Perrig & A. Grob (Eds.), *Control of human behavior, mental processes, and consciousness: Essays in honor of the 60th birthday of August Flammer* (pp. 17-33). Lawrence Erlbaum Associates Publishers.

Barton, E., Moore, T. F., Hamel, L., Penner, L., Albrecht, T., & Eggly, S. (2020). The influence of a question prompt list on patient-oncologist information exchange in an African-American population. *Patient Education and Counseling*, *103*(3), 505-513. https://doi.org/10.1016/j.pec.2019.09.020

Berg, C. Z., Shapiro, N., Chambless, D. L., & Ahrens, A. H. (1998). Are emotions frightening? II: An analogue study of fear of emotion, interpersonal conflict, and panic onset. *Behaviour Research and Therapy*, *36*(1), 3-15. https://doi.org/10.1016/S0005-7967(97)10027-4

Bergeron, C., Czajkowska, Z., Coroiu, A., Sewitch, M., Hall, N. C., & Körner, A. (2021). The impact of physician support on skin self-examination among melanoma patients: A serial mediation model with self-efficacy and intentions to perform skin exams. *Patient Education and Counseling*, *104*(9), 2364-2370. https://doi.org/10.1016/j.pec.2021.02.028

Bernacki, R., Hutchings, M., Vick, J., Smith, G., Paladino, J., Lipsitz, S., Gawande, A. A., & Block, S.D. (2015). Development of the serious illness care program: A randomised controlled trial of a palliative care communication intervention. *BMJ Open*, *5*(10), e009032. http://dx.doi.org/10.1136/bmjopen-2015-009032

Bernacki, R., Paladino, J., Neville, B. A., Hutchings, M., Kavanagh, J., Geerse, O. P., ... &

    Block, S. D. (2019). Effect of the serious illness care program in outpatient oncology: a

    cluster randomized clinical trial. *JAMA Internal Medicine*, *179*(6), 751-759.

Bischoff, K., O'Riordan, D. L., Marks, A. K., Sudore, R., & Pantilat, S. Z. (2018). Care planning

    for inpatients referred for palliative care consultation. *JAMA Internal Medicine*, *178*(1),

    48-54. https://doi.org/10.1001/jamainternmed.2017.6313

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of

    chronic disease in primary care. *JAMA*, *288*(19), 2469-2475. https://doi.org/10.1001/

    jama.288.19.2469

Bolman, C., Brug, J., Bär, F., Martinali, J., & van den Borne, B. (2005). Long-term efficacy of a

    checklist to improve patient education in cardiology. *Patient Education and*

    Counseling, *56*(2), 240-248. https://doi.org/10.1016/j.pec.2004.02.018

Brandes, K., Butow, P. N., Tattersall, M. H., Clayton, J. M., Davidson, P. M., Young, J., ... &

    Walczak, A. (2014). Advanced cancer patients' and caregivers' use of a Question Prompt

    List. *Patient Education and Counseling*, *97*(1), 30-37.

Brandes, K., Linn, A. J., Butow, P. N., & van Weert, J. C. (2015). The characteristics and

    effectiveness of question prompt list interventions in oncology: A systematic review of

    the literature. *Psycho-Oncology*, *24*(3), 245-252. https://doi.org/10.1002/pon.3637

Brighton, L. J., & Bristowe, K. (2016). Communication in palliative care: Talking about the end

    of life, before the end of life. *Postgraduate Medical Journal*, *92*(1090), 466-470. https://

    doi.org/10.1136/postgradmedj-2015-133368

Bronner, M. B., Nguyen, M. H., Smets, E. M., van de Ven, A. W., & van Weert, J. C. (2018). Anxiety during cancer diagnosis: Examining the influence of monitoring coping style and treatment plan. *Psycho-Oncology*, *27*(2), 661-667. https://doi.org/10.1002/pon.4560

Brown, R., Butow, P. N., Boyer, M. J., & Tattersall, M. H. N. (1999). Promoting patient participation in the cancer consultation: Evaluation of a prompt sheet and coaching in question-asking. *British Journal of Cancer*, *80*(1), 242-248. https://doi.org/10.1038/sj.bjc.6690346

Brown, R. F., Bylund, C. L., Li, Y., Edgerson, S., & Butow, P. (2012). Testing the utility of a cancer clinical trial specific Question Prompt List (QPL-CT) during oncology consultations. *Patient Education and Counseling*, *88*(2), 311-317. https://doi.org/10.1016/j.pec.2012.02.009

Buffington, A. S., & Schwarze, M. L. (2019). Patient preferences project, Wisconsin Surgical Outcomes Research Program, University of Wisconsin School of Medicine and Public Health. Madison, WI. http://www.hipxchange.org/questioncoding

Bylund, C. L., Brown, R., Gueguen, J. A., Diamond, C., Bianculli, J., & Kissane, D.W. (2010). The implementation and assessment of a comprehensive communication skills training curriculum for oncologists. *Psycho-Oncology*, *19*(6), 583-593. https://doi.org/10.1002/pon.1585

Canadian Hospice Palliative Care Association. (2013). *A model to guide hospice palliative care*. Canadian Hospice Palliative Care Association. https://www.chpca.ca/wp-content/uploads/2019/12/norms-of-practice-eng-web.pdf

Cegala, D. J., McClure, L., Marinelli, T. M., & Post, D. M. (2000). The effects of communication skills training on patients' participation during medical

interviews. *Patient Education and Counseling*, *41*(2), 209-222. https://doi.org/10.1016/s0738-3991(00)00093-8

Chen, H., Cohen, P., & Chen, S. (2010). How big is a big odds ratio? Interpreting the magnitudes of odds ratios in epidemiological studies. *Communications in Statistics—Simulation and Computation*, *39*(4), 860-864. https://doi.org/10.1080/03610911003650383

Cheng, B.T., Wangmo, T., & Hauser, J.M. (2019). Patterns of palliative care beliefs among adults in the US: Analysis of a national cancer database. *Journal of Pain and Symptom Management*, *58*(6), 1056-1067. https://doi.org/10.1016/j.jpainsymman.2019.07.030

Choi, S., & Seo, J. (2019). Analysis of caregiver burden in palliative care: An integrated review. *Nursing Forum*, *54*(2), 280-290. https://doi.org/10.1111/nuf.12328

Clayman, M. L., Pandit, A. U., Bergeron, A. R., Cameron, K. A., Ross, E., & Wolf, M. S. (2010). Ask, understand, remember: a brief measure of patient communication self-efficacy within clinical encounters. *Journal of Health Communication*, *15*(S2), 72-79. https://doi.org/10.1080/10810730.2010.500349

Clayton, J., Butow, P., Tattersall, M., Chye, R., Noel, M., Davis, J. M., & Glare, P. (2003). Asking questions can help: Development and preliminary evaluation of a question prompt list for palliative care patients. *British Journal of Cancer*, *89*(11), 2069-2077. https://doi.org/10.1038/sj.bjc.6601380

Clayton, J. M., Butow, P. N., Tattersall, M. H. N., Devine, R. J., Simpson, J. M., Aggarwal, G., Clark, K. J., Currow, D. C., Elliott, L. M., Lacey, J., Lee, P. G., & Noel, M. A. (2007). Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *Journal of Clinical Oncology*, *25*(6), 715-723. https://doi.org/10.1200/JCO.2006.06.7827

Clayton, M. F., Dingley, C., & Donaldson, G. (2017). The integration of emotional,

immunological and communication responses to medical oncology surveillance

appointments during breast cancer survivorship. *Cancer Nursing*, *40*(2), 124-134.

https://doi.org/10.1097/ncc.0000000000000375

Constantinou, E., Georgiou, D., Karekla, M., & Panayiotou, G. (2021). Subjective distress and

physiological reactivity during anxiety-evoking imagery in social anxiety. *Personality*

and Individual Differences, *182*, 111095.

Curtis, J. R., Downey, L., Back, A. L., Nielsen, E. L., Paul, S., Lahdya, A. Z., ... & Engelberg, R.

A. (2018). Effect of a patient and clinician communication-priming intervention on

patient-reported goals-of-care discussions between patients with serious illness and

clinicians: a randomized clinical trial. *JAMA Internal Medicine*, *178*(7), 930-940.

Davey, H. M., Barratt, A. L., Butow, P. N., & Deeks, J. J. (2007). A one-item question with a

Likert or Visual Analog Scale adequately measured current anxiety. *Journal of Clinical*

Epidemiology, *60*(4), 356-360. https://doi.org/10.1016/j.jclinepi.2006.07.015

Dionne-Odom, J. N., Ornstein, K. A., & Kent, E. E. (2019). What do family caregivers know

about palliative care? Results from a national survey. *Palliative & Supportive*

Care, *17*(6), 643-649. https://doi.org/10.1017/S1478951519000154

Doorenbos, A. Z., Levy, W. C., Curtis, J. R., & Dougherty, C. M. (2016). An intervention to

enhance goals-of-care communication between heart failure patients and heart failure

providers. *Journal of Pain and Symptom Management*, *52*(3), 353-360. https://doi.org/

10.1016/j.jpainsymman.2016.03.018

Eggly, S., Hamel, L. M., Foster, T. S., Albrecht, T. L., Chapman, R., Harper, F. W., Thompson,

H., Griggs, J. J., Gonzalez, R., Berry-Bobovski, L., Tkatch, R., Simon, M., Shields, A.,

Gadgeel, S., Loutfi, R., Ali, H., Wollner, I., & Penner, L. A. (2017). Randomized trial of

a question prompt list to increase patient active participation during interactions with

black patients and their oncologists. *Patient Education and Counseling*, *100*(5), 818-826.

https://doi.org/10.1016/j.pec.2016.12.026

Eklund, J. H., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Höglander, J.,

Sundler, A. J., Condén, E., & Meranius, M. S. (2019). "Same same or different?" A

review of reviews of person-centered and patient-centered care. *Patient Education and*

Counseling, *102*(1), 3-11. https://doi.org/10.1016/j.pec.2018.08.029

Eliott, J. A., & Olver, I. (2011). Dying cancer patients talk about physician and patient roles in

DNR decision making. *Health Expectations*, *14*(2), 147-158. https://doi.org/10.1111/

j.1369-7625.2010.00630.x

Erickson, J. M., Blackhall, L., Brashers, V., & Varhegyi, N. (2015). An interprofessional

workshop for students to improve communication and collaboration skills in end-of-life

care. *American Journal of Hospice and Palliative Medicine*, *32*(8), 876-880.

https://doi.org/10.1177/1049909114549954

Fakhri, S., Engelberg, R. A., Downey, L., Nielsen, E. L., Paul, S., Lahdya, A. Z., Treece, P. D.,

& Curtis, J. R. (2016). Factors affecting patients' preferences for and actual discussions

about end-of-life care. *Journal of Pain and Symptom Management*, *52*(3), 386-394.

https://doi.org/10.1016/j.jpainsymman.2016.03.012

Ferrell, B. R., Temel, J. S., Temin, S., & Smith, T. J. (2017). Integration of palliative care into

standard oncology care: ASCO clinical practice guideline update summary. *Journal of*

Clinical Oncology Practice, *13*(2), 119-121. https://doi.org/10.1200/JOP.2016.017897

Ferrell, B. R., Twaddle, M. L., Melnick, A., & Meier, D. E. (2018). National consensus project

      clinical practice guidelines for quality palliative care guidelines. *Journal of Palliative*

      Medicine, *21*(12), 1684-1689. https://doi.org/10.1089/jpm.2018.0431

Gamondi, C., Larkin, P., & Payne, S.A. (2013). Core competencies in palliative care: An EAPC

      white paper on palliative care education. *European Journal of Palliative Care, 20*(2), 86-

      91.

Goelz, T., Wuensch, A., Stubenrauch, S., Ihorst, G., de Figueiredo, M., Bertz, H., Wirsching, M.,

      & Fritzsche, K. (2011). Specific training program improves oncologists' palliative care

      communication skills in a randomized controlled trial. *Journal of Clinical Oncology,*

      29(25), 3402-3407. https://doi.org/10.1200/JCO.2010.31.6372

Grudzen, C. R., Emlet, L. L., Kuntz, J., Shreves, A., Zimny, E., Gang, M., ... & Arnold, R.

      (2016). EM Talk: Communication skills training for emergency medicine patients with

      serious illness. *BMJ Supportive & Palliative Care*, *6*(2), 219-224.

Haskard, K. B., Williams, S. L., DiMatteo, M. R., Rosenthal, R., White, M. K., & Goldstein, M.

      G. (2008). Physician and patient communication training in primary care: Effects on

      participation and satisfaction. *Health Psychology*, *27*(5), 513-522.

Haywood, K., Marshall, S., & Fitzpatrick, R. (2006). Patient participation in the consultation

      process: A structured review of intervention strategies. *Patient Education and*

      Counseling, *63*(1-2), 12-23. https://doi.org/10.1016/j.pec.2005.10.005

Hemming, K., Haines, T. P., Chilton, P. J., Girling, A. J., & Lilford, R. J. (2015). The stepped

      wedge cluster randomised trial: Rationale, design, analysis, and reporting. *BMJ*, *350,*

      h391. https://doi.org/10.1136/bmj.h391

Ilioudi, S., Lazakidou, A., & Tsironi, M. (2010). Information and communication technologies

    for better patient self-management and self-efficacy. *International Journal of Electronic*

    Healthcare, *5*(4), 327-339. https://doi.org/10.1504/IJEH.2010.036205

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st*

    century. The National Academies Press. https://doi.org/10.17226/10027

Jack, B., Hillier, V., Williams, A., & Oldham, J. (2003). Hospital based palliative care teams

    improve the symptoms of cancer patients. *Palliative Medicine*, *17*(6), 498-502.

    https://doi.org/10.1191/0269216303pm794oa

Jack, B., Hillier, V., Williams, A., & Oldham, J. (2004). Hospital based palliative care teams

    improve the insight of cancer patients into their disease. *Palliative Medicine*, *18*(1), 46-

    52. https://doi.org/10.1191/0268216304pm846oa

Jenkins, H., Rupert, D. J., Etta, V., Peinado, S., Wolff, J. L., Lewis, M. A., Chang, P., & Cené,

    C. (in press). Examining information needs of heart failure patients and family

    companions using a pre-visit question prompt list and audiotaped data: Findings from a

    pilot study. *Journal of Cardiac Failure*. https://doi.org/10.1016/j.cardfail.2021.11.012

Kantor, L., Endler, N. S., Heslegrave, R. J., & Kocovski, N. L. (2001). Validating self-report

    measures of state and trait anxiety against a physiological measure. *Current*

    Psychology, *20*(3), 207-215.

Kidd, J., Marteau, T. M., Robinson, S., Ukoumunne, O. C., & Tydeman, C. (2004). Promoting

    patient participation in consultations: A randomised controlled trial to evaluate the

    effectiveness of three patient-focused interventions. *Patient Education and*

    Counseling, *52*(1), 107-112. https://doi.org/10.1016/s0738-3991(03)00018-1

Kinnersley, P., Edwards, A., Hood, K., Ryan, R., Prout, H., Cadbury, N., MacBeth, F., Butow,

    P., & Butler, C. (2008). Interventions before consultations to help patients address their

    information needs by encouraging question asking: A systematic review. *BMJ*, *337*, a485.

    https://doi.org/10.1136/bmj.a485

Kozlov, E., Carpenter, B. D., Thorsten, M., Heiland, M., & Agarwal, A. (2015). Timing of

    palliative care consultations and recommendations: Understanding the

    variability. *American Journal of Hospice and Palliative Medicine*, *32*(7), 772-775.

    https://doi.org/10.1177/1049909114543322

Kozlov, E., McDarby, M., Reid, M. C., & Carpenter, B. D. (2018). Knowledge of palliative care

    among community-dwelling adults. *American Journal of Hospice and Palliative*

    Medicine, *35*(4), 647-651.

Lally, K., Kematick, B. S., Gorman, D., & Tulsky, J. (2021). Rapid conversion of a palliative

    care outpatient clinic to telehealth. *JCO Oncology Practice*, *17*(1), e62-e67. https://doi.

    org/10.1200/OP.20. 00557

Lederer, S., Fischer, M. J., Gordon, H. S., Wadhwa, A., Popli, S., & Gordon, E. J. (2016). A

    question prompt sheet for adult patients with chronic kidney disease. *BMC*

    Nephrology, *17*(1), 155. https://doi.org/10.1186/s12882-016-0362-z

Levinson, W., Lesser, C. S., & Epstein, R. M. (2010). Developing physician communication

    skills for patient-centered care. *Health Affairs*, *29*(7), 1310-1318. https://doi.org/

    10.1377/hlthaff.2009.0450

Lorr, M., & More, W. W. (1980). Four dimensions of assertiveness. *Multivariate Behavioral*

    Research, *15*(2), 127-138. https://doi.org/10.1207/s15327906mbr1502_1

Martinali, J., Bolman, C., Brug, J., van den Borne, B., & Bar, F. (2001). A checklist to improve

    patient education in a cardiology outpatient setting. *Patient Education and Counseling,*

    42, 231-238. https://doi.org/10.1016/S0738-3991(00)00126-9

McDarby, M., & Carpenter, B. D. (2019). Barriers and facilitators to effective inpatient palliative

    care consultations: A qualitative analysis of interviews with palliative care and

    nonpalliative care providers. *American Journal of Hospice and Palliative*

    Medicine, *36*(3), 191-199. https://doi.org/10.1177/1049909118793635

McDarby, M., Mroz, E., Carpenter, B. D., Dionne-Odom, J. N., & Kamal, A. (2021). A Research

    Agenda for the Question Prompt List in Outpatient Palliative Care. *Journal of Palliative*

    Medicine, *24*(11), 1596-1597.

Mehnert, A., Berg, P., Henrich, G., & Herschbach, P. (2009). Fear of cancer progression and

    cancer-related intrusive cognitions in breast cancer survivors. *Psycho-Oncology*, *18*(12),

    1273-1280. https://doi.org/10.1002/pon.1481

Miller, L. S., Shelby, R. A., Balmadrid, M. H., Yoon, S., Baker, J. A., Wildermann, L., & Soo,

    M. S. (2013). Patient anxiety before and immediately after imaging-guided breast biopsy

    procedures: Impact of radiologist-patient communication. *Journal of the American*

    College of Radiology, *10*(6), 423-431. https://doi.org/10.1016/j.jacr.2012.11.005

Mroz. E.L., McDarby, M., Arnold, R.M., Bylund, C.L., Kutner, J.S., & Pollak, K.I. (in press).

    Empathic communication in specialty palliative care encounters: An analysis of

    opportunities and responses. *Journal of Palliative Medicine.*

National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for*

    quality palliative care, 4th edition. National Coalition for Hospice and Palliative Care.

    https://www.nationalcoalitionhpc.org/ncp.

Ngo-Metzger, Q., August, K.J., Srinivasan, M., Liao, S., & Meyskens, F.L. Jr. (2008). End-of-life care: Guidelines for patient-centered communication. *American Family Physician*, *77*(2), 167-174.

Periyakoil, V. S., Neri, E., & Kraemer, H. (2017). A randomized controlled trial comparing the letter project advance directive to traditional advance directive. *Journal of Palliative Medicine*, *20*(9), 954-965. https://doi.org/10.1089/jpm.2017.0066

Petursdottir, A. B., Sigurdardottir, V., Rayens, M. K., & Svavarsdottir, E. K. (2020). The impact of receiving a family-oriented therapeutic conversation intervention before and during bereavement among family cancer caregivers: A nonrandomized trial. *Journal of Hospice & Palliative Nursing*, *22*(5), 383-391. https://doi.org/10.1097/NJH.0000000000000679

Pollak, K. I., Gao, X., Arnold, R. M., Arnett, K., Felton, S., Fairclough, D. L., & Kutner, J. S. (2020). Feasibility of using communication coaching to teach palliative care clinicians motivational interviewing. *Journal of Pain and Symptom Management*, *59*(4), 787-793.

Rabow, M., Kvale, E., Barbour, L., Cassel, J. B., Cohen, S., Jackson, V., Luhrs, C., Nguyen, V., Rinaldi, S., Stevens, D., Spragens, L., & Weissman, D. (2013). Moving upstream: A review of the evidence of the impact of outpatient palliative care. *Journal of Palliative Medicine*, *16*(12), 1540-1549. https://doi.org/10.1089/jpm.2013.0153

Rodenbach, R. A., Brandes, K., Fiscella, K., Kravitz, R. L., Butow, P. N., Walczak, A., Duberstein, P. R., Sullivan, P., Hoh, B., Xing, G., Plumb, S., & Epstein, R. M. (2017). Promoting end-of-life discussions in advanced cancer: Effects of patient coaching and question prompt lists. *Journal of Clinical Oncology, 35*(8), 842–851. https://doi.org/10.1200/JCO.2016.68.5651

Roter, D. L., Hall, J. A., & Katz, N. R. (1988). Patient-physician communication: A descriptive

    summary of the literature. *Patient Education and Counseling, 12*(2)*,* 99-119. https://

    doi.org/10.1016/0738-3991(88)90057-2

Rucker, B., & Browning, D. M. (2015). Practicing end-of-life conversations: Physician

    communication training program in palliative care. *Journal of Social Work in End-of-Life*

    & Palliative Care, 11(2)*,* 132-146. https://doi.org/10.1080/15524256.2015.1074140

Sansoni, J. E., Grootemaat, P., & Duncan, C. (2015). Question prompt lists in health

    consultations: A review. *Patient Education and Counseling*, *98*(12), 1454-1464. https://

    doi.org/10.1016/j.pec.2015.05.015

Schroedl, C., Yount, S., Szmuilowicz, E., Rosenberg, S. R., & Kalhan, R. (2014). Outpatient

    palliative care for chronic obstructive pulmonary disease: A case series. *Journal of*

    Palliative Medicine, *17*(11), 1256-1261. https://doi.org/10.1089/jpm.2013.0669

Schwarze, M. L., Buffington, A., Tucholka, J. L., Hanlon, B., Rathouz, P. J., Marka, N., Taylor,

    L. J., Zimmermann, C. J., Kata, A., Baggett, N. D., Fox, D. A., Schmick, A. E., Berlin,

    A., Glass, N. E., Mosenthal, A. C., Finlayson, E., Cooper, Z., & Brasel, K. J. (2020).

    Effectiveness of a question prompt list intervention for older patients considering major

    surgery: A multisite randomized clinical trial. *JAMA Surgery*, *155*(1), 6-13. https://

    doi.org/10.1001/jamasurg.2019.3778

Schwarzer, R., & Jerusalem, M. (1995). Generalized self-efficacy scale. In J. Weinman, S.

    Wright, & M. Johnston (Eds.), *Measures in health psychology: A user's portfolio. Causal*

    and control beliefs (pp. 35-37). NFER-NELSON.

Schwarzer, R., & Renner, B. (2000). Social-cognitive predictors of health behavior: Action self-

efficacy and coping self-efficacy. *Health Psychology*, *19*(5), 487-495. https://doi.org/

10.1037/0278-6133.19.5.487

Shalev, A., Phongtankuel, V., Kozlov, E., Shen, M. J., Adelman, R.D., & Reid, M. C. (2018).

Awareness and misperceptions of hospice and palliative care: A population-based survey

study. *American Journal of Hospice and Palliative Medicine*, *35*(3), 431-439. https://

doi.org/10.1177/1049909117715215

Shamaskin-Garroway, A., DeCaporale-Ryan, L., Bell, K., & McDaniel, S. (2021). Physician

communication coaching: How psychologists can elevate skills and support resident

education, professionalism, and well-being. *Journal of Clinical Psychology in Medical

Settings*. https://doi.org/10.1007/s10880-021-09808-x

Slomka, J., Prince-Paul, M., Webel, A., & Daly, B. J. (2016). Palliative care, hospice, and

advance care planning: Views of people living with HIV and other chronic

conditions. *Journal of the Association of Nurses in AIDS Care*, *27*(4), 476-484.

https://doi.org/10.1016/j.jana.2016.02.003

Smets, E. M. A., Van Heijl, M., Van Wijngaarden, A. K. S., Henselmans, I., & van Berge

Henegouwen, M. I. (2012). Addressing patients' information needs: a first evaluation of a

question prompt sheet in the pretreatment consultation for patients with esophageal

cancer. *Diseases of the Esophagus*, *25*(6), 512-519.

Song, M., & Ward, S. E. (2015). Making visible a theory-guided advance care planning

intervention. *Journal of Nursing Scholarship, 47*(5)*, 389-396. https://doi.org/10.1111/

jnu.12156

Spencer, R., Nilsson, M., Wright, A., Piri, W., & Prigerson, H. (2010). Anxiety disorders in

advanced cancer patients: Correlates and predictors of end of life outcomes. *Cancer,*

116(7), 1810-1819. https://doi.org/10.1002/cncr.24954

Spielberger, C., Gorsuch, R., Lushene, R. E., Vagg, P. R., & Jacobs, G. A. (1983). *Manual for*

the State-Trait Anxiety Inventory (rev ed.). Consulting Psychologists Press.

Steffens, N. M., Tucholka, J. L., Nabozny, M. J., Schmick, A. E., Brasel, K. J., & Schwarze, M.

L. (2016). Engaging patients, health care professionals, and community members to

improve preoperative decision making for older adults facing high-risk surgery. *JAMA*

Surgery, 151(10), 938-945. https://doi.org/10.1001/jamasurg.2016.1308

Street, R. L., Jr., Gordon, H., & Haidet, P. (2007). Physicians' communication and perceptions of

patients: Is it how they look, how they talk, or just the doctor? *Social Science &*

Medicine, 65(3), 586-598. https://doi.org/10.1016/j.socscimed.2007.03.036

Street, R. L., Jr., Makoul, G., Arora, N. K., & Epstein, R. M. (2009). How does communication

heal? Pathways linking clinician–patient communication to health outcomes. *Patient*

Education and Counseling, *74*(3), 295-301. https://doi.org/10.1016/j.pec.2008.11.015

Street, R. L. Jr., Slee, C., Kalauokalani, D. K., Dean, D. E., Tancredi, D. J., & Kravitz, R. L.

(2010). Improving physician–patient communication about cancer pain with a tailored

education-coaching intervention. *Patient Education and Counseling*, *80*(1), 42-47.

https://doi.org/10.1016/j.pec.2009.10.009

Teunissen, S. C. C. M., Wesker, W., Kruitwagen, C., de Haes, H. C., Voest, E. E., & de Graeff,

A. (2007). Symptom prevalence in patients with incurable cancer: A systematic review.

Journal of Pain and Symptom Management, 34(1), 94-104. https://doi.org/10.1016/

j.jpainsymman.2006.10.015

Tichon, J. G., Wallis, G., Riek, S., & Mavin, T. (2014). Physiological measurement of anxiety to evaluate performance in simulation training. *Cognition, Technology & Work*, *16*(2), 203-210.

Thompson, S. C., Nanni, C., & Schwankovsky, L. (1990). Patient-oriented interventions to improve communication in a medical office visit. *Health Psychology*, *9*(4), 390-404.

Walczak, A., Butow, P. N., Clayton, J. M., Tattersall, M. H., Davidson, P. M., Young, J., & Epstein, R. M. (2014). Discussing prognosis and end-of-life care in the final year of life: A randomised controlled trial of a nurse-led communication support programme for patients and caregivers. *BMJ Open*, *4*(6), e005745. https://doi.org/10.1136/bmjopen-2014-005745

Williams, G., & Smith, A. P. (2016). Using single-item measures to examine the relationships between work, personality, and well-being in the workplace. *Psychology*, *7*(6), 753-767. http://dx.doi.org/10.4236/psych.2016.76078

Wilson, K. G., Chochinov, H. M., Skirko, M. G., Allard, P., Chary, S., Gagnon, P. R., Macmillan, K., De Luca, M., O'Shea, F., Kuhl, D., Fainsinger, R. L., & Clinch, J. J. (2007). Depression and anxiety disorders in palliative cancer care. *Journal of Pain and Symptom Management, 33*(2), 118-129. https://doi.org/10.1016/j.jpainsymman.2006.07.016

Wittenberg-Lyles, E., Goldsmith, J., Ferrell, B., & Burchett, M. (2014). Assessment of an interprofessional online curriculum for palliative care communication training. *Journal of Palliative Medicine, 17*(4)*, 400-406. https://doi.org/10.1089/jpm.2013.0270

Wolf, M. S., Chang, C. H., Davis, T., & Makoul, G. (2005). Development and validation of the

    Communication and Attitudinal Self-Efficacy scale for cancer (CASE-cancer). *Patient*

    Education and Counseling, 57(3), 333-341.

World Health Organization. (2002). *WHO definition of palliative care*. https://www.who.int/

    health-topics/palliative-care

Wright, A. A., Zhang, B., Ray, A., Mack, J. W., Trice, E., Balboni, T., Mitchell, S. L., Jackson,

    V. A., Block, S. D., Maciejewski, P. K., & Prigerson, H. G. (2008). Associations between

    end-of-life discussions, patient mental health, medical care near death, and caregiver

    bereavement adjustment. *JAMA, 300*(14), 1665-1673. https://doi.org/10.1001/

    jama.300.14.1665

Yeh, J. C., Cheng, M. J., Chung, C. H., & Smith, T. J. (2014). Using a question prompt list as a

    communication aid in advanced cancer care. *Journal of Oncology Practice*, *10*(3), e137-

    e141. https://doi.org/10.1200/JOP.2013.001295

Table 1

Sample Characteristics

	Usual Care Appointments (n = 30)				Question Prompt List (QPL) Appointments (n = 29)			
	Patients (n = 30)		Care Partners (n = 25)		Patients (n = 29)		Care Partners (n = 29)	
	N/M	*%/SD*	*N/M*	*%/SD*	*N/M*	*%/SD*	*N/M*	*%/SD*
Age	66.3	12.6	60.5	15.3	70.9	12.0	60.0	10.5
Gender								
Female	18	60	16	64	17	59	21	72
Male	12	40	9	36	12	41	8	28
Race								
Asian	1	3	1	2	0	0	0	0
Black	4	14	1	4	3	10	3	10
White	25	83	23	92	26	90	26	90
Hispanic	0	0	0	0	0	0	0	0
Marital Status								
Single/ never married	5	17	3	12	3	10	1	4
Married	22	73	21	84	20	70	27	92
Divorced	1	3	1	4	1	3	1	4
Widowed	2	7	0	0	2	7	0	0
Missing	0	0	0	0	3	10	0	0
Diagnosis								
Neurodegenerative disease	20	66			18	62		
Cancer	5	17			10	34		
Disease affecting lungs (e.g., chronic Obstructive pulmonary disease)	2	7			1	4		
Disease affecting heart (e.g., congestive heart failure)	2	7			0	0		
Disease affecting other body system	1	3			0	0		

Table 2

Participant Completion of Pre-Appointment and Post-Appointment Quantitative Study Measures

	Usual Care Appointments (n = 30)				Question Prompt List (QPL) Appointments (n = 29)			
	Patients (n = 24ᵃ)		Care Partners (n = 25)		Patients (n = 20ᵃ)		Care Partners (n = 29)	
	N	*%*	*N*	*%*	*N*	*%*	*N*	*%*
Pre-Appointment Measures								
Self-Efficacy in Question Asking	24	100	20	80	20	100	27	93
Self-Efficacy in Getting Health Care Information	24	100	21	84	19	95	27	93
State Anxiety	20	83	18	72	16	90	23	79
Post-Appointment Measures								
Self-Efficacy in Question Asking	22	92	20	80	16	80	27	93
Self-Efficacy in Getting Health Care Information	22	92	20	80	16	80	27	93
State Anxiety	20	83	18	72	15	75	22	76

ᵃReflects total number of patients eligible to complete study measures based on level of cognitive function

Table 3

Primary Outcome Variables in the Usual Care or Question Prompt List (QPL) Conditions

|	Cronbach's α	Usual Care					Question Prompt List (QPL)				
		N	M	SD	Range	Skew	N	M	SD	Range	Skew
Appointment Participation											
Total Questions Asked			9.37	10.3	0-49	2.52		11.2	10.1	0-49	2.01
From QPL								0.66	1.72	0-8	3.35
Not from QPL			9.37	10.3	0-49	2.52		10.6	8.95	0-41	1.67
Total Assertions Made			2.23	2.08	0-7	0.60		1.38	1.68	0-6	1.44
Pre-Appointment Measures											
State Anxiety	.83	38	2.53	0.60	1.67-4	0.42	43	2.70	0.83	1-4	-0.43
Self-Efficacy in Question Asking		45	88.5	18.5	20-100	-2.34	49	83.2	22.0	10-100	-1.61
Self-Efficacy in Getting Health Care Information	.65	46	3.53	0.56	1-4	-2.37	49	3.61	0.49	1.25-4	-2.56
Post-Appointment Measures											
State Anxiety	.85	38	2.99	0.63	1.83-4	-0.10	37	3.02	0.82	1.17-4	-0.52
Self-Efficacy in Question Asking		42	96.0	9.2	60-100	-2.59	43	92.7	12.5	50-100	-1.98
Self-Efficacy in Getting Health Care Information	.77	42	3.63	0.56	1-4	-2.94	43	3.71	0.50	1.50-4	-2.59

Figure 1

Proposed Mechanism of Perceived Self-Efficacy Development in a Communication Intervention
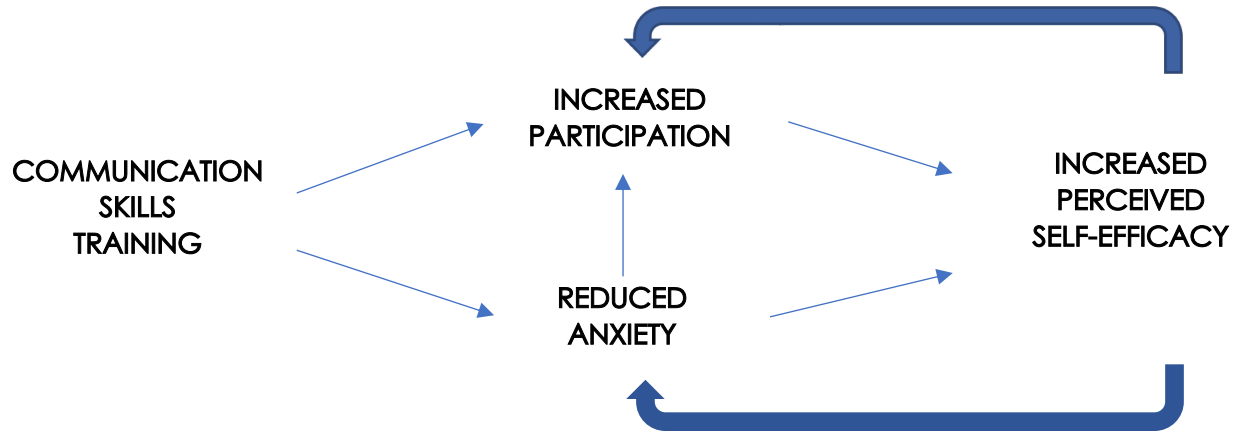
Note: The proposed mechanism is adapted from Social Cognitive Theory (Bandura, 1986).

Figure 2

CONSORT Diagram to Describe Study Recruitment Flow
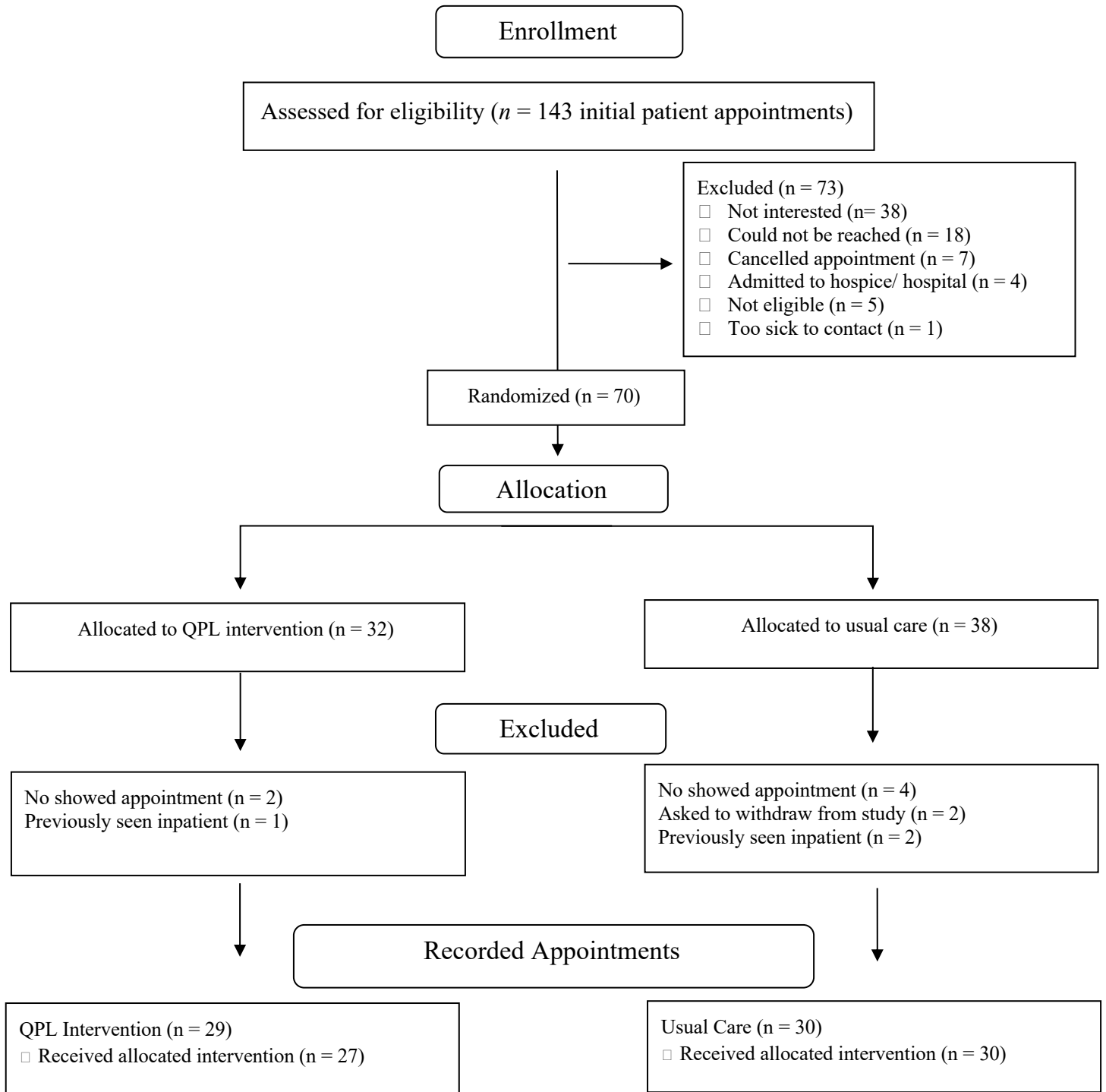
Appendix A

PALLIATIVE CARE QUESTION PROMPT SHEET
The following are common questions that people with life-threatening illnesses sometimes ask their doctors. Please place a check mark in the box next to the ones that you may like to ask today, and the doctors will do their best to answer them.

THE PALLIATIVE CARE TEAM AND SERVICES

☐ 1. Who are the members of the palliative care team, and what do they do?
☐ 2. How do I access the services offered by the palliative care team?
☐ 3. How and when can I contact the palliative care team?
☐ 4. What is the role of my primary physician now that I have been referred to the palliative care team?
☐ 5. Can someone help me to communicate with other members of my family about what is happening to me?
☐ 6. Is there someone I can talk to about my fears, concerns, spiritual or religious needs?
☐ 7. What support is available for other people in the family, such as my caregiver or my children?

SYMPTOMS, TREATMENT, AND LIFESTYLE

☐ 8. If I have symptoms, what can be done to improve them? (e.g., pain or discomfort, constipation, shortness of breath, nausea or feeling sick, lack of appetite, tiredness, dry mouth)?
☐ 9. What are the common side effects of my medications?
☐ 10. Are there any medications that I should stop taking because of their interactions with the newly prescribed medication?
☐ 11. Can I stop taking the pain medication if my pain goes away?
☐ 12. What can I do if I am not coping?
☐ 13. Who can I talk to about the medical care that I want in the future when I am no longer able to speak for myself?
☐ 14. What symptoms may occur in the future and what should I do if they arise?
☐ 15. How can I cope with the changes in my body as a result of this illness?

END-OF-LIFE ISSUES (*these questions may or may not be useful for you*)

☐ 16. How do I get my affairs in order and write a will?
☐ 17. How do I get information about advance directives?
☐ 18. How do I get information about hospice?
☐ 19. Is it feasible for me to die at home rather than in the hospital?
☐ 20. What can I expect in my last few days of life?

FOR CAREGIVERS (*these questions may or may not be useful for them*)

☐ 21. How do I get help if I am no longer able to take care of my loved one?
☐ 22. What skills will I need as a caregiver?
☐ 23. How can I best support the person that I am caring for?
☐ 24. What should I say when the person that I am caring for asks, "am I dying?"
☐ 25. Will you be able to tell me when it is getting close to the time that he/she will die?

Question Prompt List in PC Codebook

Meghan McDarby & Hannah Silverstein

2022

TABLE OF CONTENTS

Introduction

As part of this project, we will be coding for two types of communication by patients and family members: questions and assertions. We will code each type of communication one at a time (code questions first, then assertions).

General Information

Here are some general guidelines to review before you get started:

1. We are only coding for questions asked and assertions made by <u>patients and care partners</u>. Please do not code any questions asked or assertions made by members of the palliative care team.

2. We are only coding for questions asked <u>to the palliative care team</u> and assertions made with the intention of being addressed by the health care team.

Administrative Tasks

1. Open the respective family folder on Box.

2. Make a copy of the original transcript. Label it as Family X—[YOUR NAME] CODES.

3. To mark a code in the actual word document, use the "Review" function in Word. Create a comment bubble at any place where you are coding. In that comment bubble, you should include two pieces of information: the speaker's identity, and the type of communication (i.e., question or assertion).

4. Once you are finished coding an entire transcript (first for questions, then for assertions), you will use the excel document to record information about the codes, including the Family ID, page number, line number, speaker, type of communication (i.e., question or assertion), and actual text of the question or assertion.

5. Please save everything to Box.

Coding Guidelines

Here is how you should code for each statement type:

1. Read through the entire transcript once to understand its content.

2. Read through the entire transcript a second and third time, specifically looking for (1) questions, then (2) assertions.

3. When you find questions that adhere to the coding criteria, mark them (as outlined above) using the comment feature in MS Word, designating speaker and statement type.

4. Transfer codes into the Excel spreadsheet with corresponding information.

5. If at any time you are uncertain whether something counts as a question or assertion, **download the audio file and listen back to the segment of audio to make a final determination.** It is possible that we will also do this together during coding meetings if we are attempting to resolve a discrepancy issue.

FEATURES OF COMMUNICATION

Questions

We are interested in the total number of questions asked by patients and care partners as part of this study.

What **counts** as a question?

- Questions are actively asking for information or to clarify something that was said by the clinician. See examples that follow.

- The patient/CP asks for <u>information</u>

  "How can I get in touch with your nurse?"

  "Should I take duloxetine every day?"

  "Will chemotherapy make me sleepy?"

- The patient/CP asks the health care clinician to <u>clarify</u> something that they said.

  "Does that mean I need to stop taking aspirin?"

  "So are you recommending that I start hospice now?"

  "So try sleeping on my back?"

- The patient/CP asks a <u>logistical question</u> (could be clarifying or for information)

  "So you'll send that form over in the mail to us later today?"

  "So I should call and set up an appointment for the next treatment?"

What **does not** count as a question?

- Making a request

  When a patient/CP asks for something directly ("Can you write me a prescription for my pain?" "Can you send me the DNR form in the mail?"), this should be coded as an assertion, NOT a question.

- Passively stating something (that sounds like a question, and that might be RESPONDED TO by the clinician like a question) but is not actually a question.

  "I don't know if I should call the doctor for his heart pain."

"I don't know if we should change his medication."

- General check-in

"How are you doing today?"

"How are you enjoying the nice weather?"

- Asking a question that is only for the sake of getting the clinician to say the name of a drug/medication/procedure so that they can have a conversation about it, not because the patient is asking for information that they want to retain for future use.

"Oh, I take the . . . for my arthritis . . . what is the name of that blue pill?"

"How do you pronounce that...carbidopalevi?"

- Patient/CP asks a question but then answers their own question so quickly that the physician doesn't even have time to/attempt to respond.

- Patient/CP makes a joke, uses sarcasm, or asks a rhetorical question.

"I've got a beautiful wife, right?"

"I mean, does she really not know by now that I'm tired?"

"Haven't you seen me dancing and singing on TV before?"

- Patient/CP asks a "memory question" in order to cue a response from clinician to continue conversation.

"It's the medication that's blue...?"

- Patient/CP repeats the same question that they already asked (or nearly the same question, maybe worded slightly differently) because the clinician couldn't hear them the first time and essentially asked them to repeat it. The first time they ask, question counts. The second time they ask would not count.

Patient: "How do I request information about advance care planning?"

Clinician: "I couldn't hear that."

Patient: "How do I get the information about care planning?"

- Patient/CP asks about something Zoom-related.

  "Can you see me now?"

  "Is the lighting better here?"

  "Did we lose audio for a second?"

- Patient/CP asks a pure clarification question about something they've said.

  "Does that make sense?"

  "Do you understand where I'm coming from?"

  "Are you familiar with Highway 40?"

- Patient/CP asks a pure clarification question about something they've said that's more of a personal question (not related to illness).

  "Have you been to Nashville before?"

- Patient/CP asks about how to pronounce something.

  "How do you say that again?"

- Patient/CP says "right?" at the end of a sentence simply because they are seeking validation or support for a feeling or opinion.

  "It's just hard because we know she wants to stay at home, right?"

- Patient/CP asks a question about something that is strictly personal, not to get information that is related to care

  "Did you hear that Tom's Bar is closing this year?"

Notes about coding a section that appears to have more than one question as one, two, or multiple questions:

- Code as one question if the two questions represent two sides of the same coin (e.g., "Are you the person who I should call? Or is there someone else I should call?"). These should only be considered one question because the clinician could offer the same answer to both questions (i.e., the questions are not asking two different things).

- Code as two questions if the question starts small and get bigger, or vice versa. For example, if the patient says, "What medication will I take when I go on hospice? When will I go on hospice?" These two questions are both about the same topic and refer to "when" the patient goes on hospice, but the patient is sort of trying to zoom out with the question asking.

Assertions

We are interested in the total number of assertions—specifically, requests and decisions—made by patients and care partners as part of this study.

Requests

Patient or care partner asks for something from member of palliative care team. This will often be phrased like a question but may not always be phrased like a question.

"Can you call Dr. X and let him know we want to see him?"

"Can you write the prescription for XYZ medication?"

"Please speak louder, we can't hear you."

Decisions

Patient or care partner makes a choice and states it to the clinician.

- Has a tangible action tied to it and an actual outcome (i.e., something material, something tangible would happen as a result of making the decision).

- Reflects a decision or choice that was made in the context of the appointment based on information that was discussed during the appointment.

- Could include expressing a change in one's attitude toward something related to care, if the change in attitude occurred during the appointment and/or as a result of conversation that occurred during the appointment, and if that change in attitude would be linked to changes in behaviors.

  "After talking, I think I would not want to be on the ventilator." **Counts because attitude change happens within context of appointment AND would lead to an actual behavior change based on changing that attitude.**

What *does not* count as a decision?

- Patient or care partner states a decision that was made outside of the appointment or prior to the appointment.

  "He's told us for years that he doesn't want a feeding tube."

"Yes, we talked about it, and he wants to do the treatment."

- Acknowledging that some action should or ought to be taken, or contemplating/ rephrasing that something a clinician on the palliative care team mentioned should be done.

  "I should call Dr. X and ask about going up on that medication."

  "I'll think about whether I want that form."

- Simply expressing an attitude

  "Yes, I want everything done."

IMPORTANT NOTE FOR DECISIONS

Consider patient's ability to communicate. Normally, saying "yes" or "no" would not count as a decision, but if the patient has ALS or another neurodegenerative condition that affects speech, one-word answers may end up counting as decisions, if they meet the other criteria of a decision and simply reflect how a patient with that type of impairment would communicate a decision.