

AMERICAN UNIVERSITY OF BEIRUT

ASKING QUESTIONS CAN HELP
DEVELOPMENT AND PRELIMINARY EVALUATION OF A
QUESTION PROMPT LIST AND A PALLIATIVE CARE
TRIGGER LIST FOR CHRONICALLY ILL PATIENTS

by
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ABSTRACT OF THE PROJECT OF

Rim Ibrahim Itani

for

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Title: Asking questions can help: development and preliminary evaluation of a question prompt list and a palliative care trigger list for chronically ill patients.

Background: Discussing disease trajectories with patients living with chronic illnesses is recommended in clinical guidelines worldwide. This open communication in chronic illness management is not commonly implemented in practice leading to patient prolonged suffering and unnecessary hospital admissions and invasive procedures. Providers are unsure how much patients want to know, and patients are unsure what, how, and who to ask. This illness trajectory communication can be improved when patients are able to ask questions that are of greatest concern to them and can discuss them; therefore, engaging actively in their healthcare decisions. A wide range of approaches have been employed and one such approach is the use of communication tools such as Question Prompt Lists [QPL] along with an early palliative care team consult.

Aim: The aims of this project are to develop a 1) culturally sensitive QPLs designed to improve communication about chronic illnesses trajectories particularly in chronic organ failure patients [in patients living with Heart Failure and End Stage Lung and Kidney Diseases], and 2) palliative care team consult trigger list. These two culturally sensitive tools are expected to improve communication in chronic illness management, promote questions asking about prognosis and illness trajectory, and ensure early palliative care consult.

Methods: This project presents a thorough discussion of the available, yet scarce, literature on QPLs and early palliative care team consults in non-oncology chronically ill patient populations. When QPLs were unavailable, this review addressed the needs, questions, and concerns of these patient populations. Then three initial QPLs and three Palliative Consultation Trigger lists were created for patients living with Heart Failure, End Stage Renal Disease and End Stag Lung Disease. A Delphi survey inviting interdisciplinary team of palliative and healthcare providers caring for organ failure patients was used to seek expert consensus regarding the drafts. Ratings of the individual QPLs were aggregated and analyzed to determine the level of consensus. Questions that received less than 80% favorable answers were moved for discussion in the second round of Delphi. A final zoom meeting with all the expert committee members was planned and three final QPLs and Palliative Consultation Trigger lists were reached.

Results: After the second Delphi round, we ended up with final lists comprising of 42 Heart Failure QPL questions, 44 End Stage Renal Disease QPL questions, and 41 End Stage Lung Disease QPL questions. Questions were grouped in categories/themes, 6 categories were generated for each QPL: Disease Specific Information; Treatment Options; Self-Care: What is my role?; Quality of life; Palliative and End of Life care; Questions family members may want to discuss. Eleven final triggers were reached for the Heart Failure and End stage Renal Disease Palliative Consultation Trigger Lists and twelve triggers were reached for the End Stage Lung Disease Palliative Consultation Trigger List.

Conclusion: Future research should assess the impact of the Disease Specific QPLs on short-term, intermediate, and long-term health outcomes as well as assess the impact of Palliative Consultation Trigger Lists on early referral to palliative care. We suggest a follow up Delphi Survey that combines patients and healthcare provider and seeks joint perspectives on these lists. We hope that implementation of these QPLs and palliative care trigger lists will guide patients in asking essential questions during consultation.

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ABBREVIATIONS

Question Prompt Lists (QPLs)

CHAPTER I

INTRODUCTION

A. Background

Extended chronic phases of life-limiting illnesses present growing challenges for healthcare providers (Gadoud, Kane, Macleod, Ansell, Oliver, & Johnson, 2014; MacLeod & Block, 2019)). In line with patient-centered care, it is crucial to keep patients well informed about their illness trajectories. This guarantees their active participation and ensures that patients and their informal caregivers are equipped to make informed decisions about their care, prognosis, treatment options given associated risks and benefits, self-management, and adherence (Low et al., 2020). This is truer in life threatening illnesses such as malignant neoplasms where decisions regarding treatment may have far reaching outcomes.

Researchers have reported varying needs of oncology patients in terms of quality and quantity of information and satisfaction with involvement in their healthcare as well as major unmet needs (Bouleuc et al., 2021; Faller et al., 2015; Gaston & Mitchell, 2005). Information requirements are common in chronic as well as acute illnesses, in oncology and beyond, where it is equally essential that patients get the chance to receive enough information about their disease trajectory and therapy plans (Lukaszczik, Gerlich, Wolf & Vogel, 2020; Clarke et al., 2017). Communication between healthcare providers and their chronically ill patients have long been identified as one of the most important aspects of healthcare, yet providers tend to underestimate the information needs of their patients (Degner et al., 1997).

Discussing disease trajectories with patients living with chronic illnesses is recommended in clinical guidelines worldwide (Holley, 2007; Jaarsma et al., 2009; Partridge, Khatri, Sutton, Welham, & Ahmedzai, 2009; Ruggiero & Reinke, 2018; youberkhof et al., 2018). Yet, these discussions are usually centered around disease management and less on illness trajectory including prognosis, symptom management, treatment options, patient preferences, advanced care planning, and goals for end of life (Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011; Byrne et al., 2013; Saiki, 2017). This open communication in chronic illness management is not commonly implemented in practice leading to patient prolonged suffering and unnecessary hospital admissions and invasive procedures (Lefkowitz, Henry, Bottoms, Myers, & Naimark, 2016; You, Fowler, & Heyland, 2013). Providers are unsure how much patients want to know, and patients are unsure what, how, and who to ask (Trice & Prigerson, 2009). This illness trajectory communication can be improved when patients are able to initiate discussions and ask questions that are of greatest concern to them; therefore, engaging actively in their healthcare decisions (Lukaszczik et al., 2020).

B. Significance and Aims

A wide range of approaches have been employed to promote patient participation and empowerment (Kinnersley et al., 2008). These can be patient or healthcare provider centered, or both. Such approaches can include patient and caregiver health education material (Sustersic, Gauchet, Foote & Bosson, 2017), patient education (Stenberg et al., 2016), decision aids (Madden & Kleinlugtenbelt, 2017) and communication skill training for healthcare providers (Berkhof, Van Rijsseen, Schellart,

Anema & Van der Beek, 2011). One such approach is the use of communication tools such as Question Prompt Lists [QPL] along with an early palliative care team consult.

A QPL is a list of prepared and standardized questions that encourage patients' active involvement in their disease management and decision making and offer a standard framework for patients to ask about their disease (Sansoni, Grootemaat, & Duncan, 2015). QPLs involve patients directly, establish a practical patient-physician relationship, and promote active information seeking (D'Agostino et al., 2017). Moreover, they can help primary healthcare providers in providing pertinent information about the active disease, the available treatment options among other aspects (Sansoni et al., 2015; Low et al., 2020; Schwarze et al., 2020).

QPLs are widely available for oncology and palliative care patients and have been shown to increase patient questions and decrease unmet information needs (Clayton et al., 2007; Dimoska, Tattersall, Butow, Shepherd, & Kinnersley, 2008). Studies have demonstrated that their application is linked with more questions asked by patients or their caregivers and that this increased their satisfaction with care and reduced unmet information needs (Lukaszczik et al., 2020; Sansoni et al., 2015). Actually, patients rated questions prompt lists as useful and are much satisfied with consultations where QPLs are used (Lukaszczik et al., 2020). These tools helped cancer patients and their caregivers to frame their questions, be better prepared for clinic visits, and be more involved in decision making (Ekberg et al., 2020; Sansoni et al., 2015). Despite the huge acceptance of QPLs among cancer patients worldwide, they are less commonly used in non-oncology contexts (Lukaszczik et al., 2020; Shepherd et al., 2011) and not available at all in Lebanon. Health system differences and cultural factors

may influence content, delivery, and impact of QPLs and as such cross-cultural adaptation of such communication tools is essential (Caminiti et al., 2010).

In order to expand comprehensive palliative care services to non-cancer patients, prevailing standards of healthcare provision will need to be revisited (Traue & Ross, 2005). The concept of palliative care was first introduced in oncology. The World Health Organization [WHO] defines palliative care as prevention and relief of suffering of adult and pediatric patients and their families facing problems associated with life-threatening illness (WHO, 2002). While the advantages of offering palliative care to non-cancer patients have been highly recognized, and despite the recommendations of international societies to endorse integration of palliative care, this is not yet common practice (Gadoud et al., 2014). Compared to cancer patients, referrals to palliative care services in patients with chronic illnesses are very low, as well as the timing of consultations is usually late (Gadoud et al., 2014). As low as one fifth of non-cancer chronically ill patients get referred for palliative and end of life care compared to 75% referrals for cancer patients (Chen, 2019). In 2019, the palliative care team at the American University of Beirut Medical Center was consulted on about 400 patients (Personal communication with Janane Hanna, Pain and Palliative Care). Thirty percent of their consults were for non-oncology adult patients mostly at the end-of-life stage.

Thus, the aims of this project are to develop a 1) culturally sensitive QPLs designed to improve communication about chronic illnesses trajectories particularly in chronic organ failure patients [in Heart Failure, and End Stage Renal and Lung Diseases Patients], and 2) palliative care team consultation trigger lists for the three mentioned diseases. These two culturally sensitive tools are expected to improve communication in

chronic illness management, promote questions asking about prognosis and illness trajectory, and ensure early palliative care consult.

CHAPTER II

LITERATURE REVIEW

Research supports the importance of Question Prompt Lists [QPLs] and early palliative care team consult in overcoming communication barriers in patients with chronic illness. A QPL is a list of preprepared standard questions that encourages patients' active involvement in their disease management and decision making and offers a standard framework for patients to ask about their disease (Sansoni et al., 2015). Despite the huge acceptance of QPLs among cancer patients worldwide, they are less commonly used in non-oncology contexts (Lukaszczik et al., 2020; Shepherd et al., 2011).

The concept of palliative care was first introduced in oncology. The World health Organization [WHO] defines palliative care as prevention and relief of suffering of adult and pediatric patients and their families facing problems associated with life-threatening illness (WHO, 2002). While the advantages of offering palliative care to non-cancer patients have been highly recognized, this is not yet common practice (Gadoud et al., 2014). Compared to cancer patients, referrals to palliative care services in patients with chronic illnesses are very low, as well as the timing of consultations is usually late (Gadoud et al.). As low as one fifth of non-cancer chronically ill patients get referred for palliative and end of life care compared to 75% referrals for cancer patients (Chen, 2019).

This review will discuss the available literature on QPLs and early palliative care team consults and their effect on outcomes such as patient experience, knowledge

recall, and communication between patients and their healthcare providers. We will also allude to the availability of such tools in the Lebanese healthcare systems.

A. Question Prompt Lists (QPLs)

Patients living with chronic illnesses and their informal caregivers can benefit from tailored information from their healthcare providers related to treatment options including benefits and risks. QPLs enhance the communication between patients and their healthcare providers (Sansoni et al., 2015). More importantly discussing the impact of the disease and treatments on illness trajectory allows chronically ill patients and their informal caregivers the aptitude to make informed clinical decisions and provide an informed consent (Shepherd et al., 2011). Thus, open communication and information sharing can ameliorate outcomes of care (Davidson, 2007).

1. Evidence Supporting the Use of Question Prompt Lists

Existing literature supports the need to provide prognostic information in end-of-life conversations, including evaluating the individual's need for information and deciding on the timing, setting, content of the dialogue, and approaches to promote adjustment and coping (Clayton et al., 2003). Essentially, serious illness conversations and communicating bad news is a complex process for everyone involved, including the healthcare professionals themselves (Jacobs et al., 2016). Thus, mastering efficient communication skills, fostering a team spirit approach, and applying strategies for debriefing may reduce the burden of serious illness conversations on healthcare professionals (Shepherd et al., 2011). Successful interventions in treating patients with organ failure require not only communicating treatment decisions but initiating

symptom management as well as managing social, existential, and psychological concerns (Davidson, 2007).

Researchers explored the effect of asking three simple generic questions [What are my options? What are the possible benefits and harms of those options? How likely are the benefits and harms of each option to occur?] on the quality and amount of information that patients and caregivers receive from physicians while discussing treatment alternatives. These three straightforward questions were successful in eliciting information needed for decision making when uncertainty is predominant. The questions helped in organizing the information provided to patients (Shepherd et al., 2011). When integrated with an approach that allows patients to incorporate information with their personal preferences, these questions should support the purposes of evidence based shared decision making (Barratt, 2008).

Literature related to shared decision making and the use of QPLs [among other communication aids] suggests a small yet significant increase in question asking (Kinnersley et al., 2007) and provision of prognosis information (Gaston & Mitchell, 2005) as well as a positive effect on recall of medical information and an increase in patient knowledge (van der Muelen et al., 2008). Clayton and colleagues (2007) provided their experimental group patients with a QPL prior to their consultation visit and results showed that patients in the experimental group discussed five more topics with their healthcare provider compared to the topics raised by the patients in the control group. Similarly, caregivers who used the QPL discussed three more topics when compared to their control group counterparts. This suggests that QPLs can be efficient in prompting serious illness conversations and advancing communication through engaging in complex, high-stake dialogues, like end-of-life care. Evidence

strongly supports the notion that when QPLs are used they are perceived as beneficial by patients in both framing questions and enhancing the consultation (Sansoni et al., 2015). QPLs improve the quality of questions asked in consultations like diagnosis, symptom management, and prognosis topics (Dimoska et al., 2008; Eggly et al., 2013). Evidence is not conclusive if a QPL that is actively endorsed by healthcare providers has more effect on *total questions asked* (Cegala, McClure, Marinelli, & Post, 2000; Sansoni et al., 2015) but research suggests that using QPLs has led to an increase in consultation time by around 3 minutes (Albada, Van Dulmen, Ausmes, & Bensing, 2015; Sansoni et al., 2015).

There were no consistent findings concerning a QPL's effect on *knowledge recall*, *anxiety levels*, and *patient satisfaction*. But these are complex variables with known interaction effects such as the broader aspects of physician relational communication and patient satisfaction (Sansoni et al., 2015). Of importance, the use of QPLs did not cause or aggravate patient's level of anxiety.

Undeniably, there are many variables that affect the acceptability, usage, and potential effect of QPLs. It may be preferable to give the patients the QPL material immediately prior to the consultation or immediately adjacent to it. QPLs that are specific to the consultation type are preferred over a QPL that covers all phases of treatment or care (Charles, Gafni, Whelan, & O'Brien, 2005; Langbecker, Janda, & Yates, 2012). Other issues such as the optimum length of a QPL were investigated. Many QPLs are quite lengthy (over 50 questions to 112 questions) and include redundant and/or rare questions. Researchers stress the need to pilot test QPLs and examine patient endorsement rates by reporting how many questions were used in the consultation (Sansoni et al., 2015). As such, it is suggested that established methods for

survey and questionnaire design are utilized where appropriate. Moreover, when patients and their informal caregivers are given the choice, usage of QPLs range between 40 to 50% which is much less than what we see in research. This is an important finding, when considering clinical implementation of QPLs, as it would suggest that in routine practice only half the patients would utilize this resource (Sansoni et al., 2015).

In conclusion, there is suggestive evidence that an appropriately designed and relevant QPL, actively endorsed by healthcare providers particularly the physician, and provided immediately before the index consultation, may increase patient question asking in consultations, and may lead to more information being provided by the healthcare providers in these consultations (Sansoni et al., 2015).

2. Available Question Prompt Lists in Organ Failure Patients

QPLs have been developed for chronically ill populations particularly in oncology (D'Agostino et al., 2017). However, these lists are scarce in other chronic diseases. Literature reveals only a few QPLs related to non-oncology diseases including one in heart failure (Hjelmfors et al., 2018), one in chronic kidney disease (Lederer et al., 2016), one in liver cirrhosis (Low et al., 2020), one in Gastrointestinal Reflux (Kamal et al. 2020), one for surgical consultations (Schwarze et., 2020), and one for parents of children with Attention Deficit-Hyperactivity Disorder (Ahmed, McCaffery, & Aslani, 2015), one in dementia (Bavelaar et al., 2020, Van Der Steen et al., 2021), one for women with polycystic ovaries (Khan et al., 2018), one patients with spine surgery (Renovanz et al., 2019), one for parents of critically ill infants (Lemmon et al., 2018) and one for palliative patients (Clayton et al., 2003). Conversation guides or

QPLs that help patients and families to begin discussions about lung diseases or lung failure trajectory are scarce.

Lederer and colleagues conducted a two-phase mixed-methods study recruiting patients on dialysis, with an estimated glomerular filtration rate of less than 60 ml/min/1.73 m², or post kidney transplant (2016). They started by asking patients about their information needs and then created a preliminary QPL with 67 items. In phase two, participants rated the significance of asking each of the 67 questions on a 5-point Likert scale and then provided open feedback as well as their readiness and acceptance of this QPL. Patients reported needing more information about their diseases, transplant, dialysis, and the association between comorbid medical condition and kidney disease. The final QPL included 31 items divided into 7 topics. The majority of participants stated being very willing to utilize a chronic kidney disease QPL during physician's visits in the future (Lederer et al., 2016).

Hjelmfors and colleagues recruited patients, caregivers, and healthcare providers including physicians and nurses to participate in two focus groups (2020). In the first stage, participants highlighted the necessity for a communication tool addressing heart failure trajectory. Based on this the first version of the QPL was developed and the participants suggested helpful questions. Later, the QPL was revised by the researchers based on literature and participant suggestions. Following the final revision of QPL, a 45-items grouped into five sections was developed: Heart failure and impacts on daily life, support and help when illness deteriorates, Heart failure and end of life, questions that family members want to discuss, and questions for patients with a cardioverter defibrillator or cardiac pacemaker. This QPL was later revised for cultural fitness in Netherlands and Sweden through two more rounds Delphi survey including heart failure

patients with their family members and healthcare providers working in cardiac care units (Hjelmfors et al., 2020).

No QPLs were done in Lebanon and the other Arabic speaking countries of the Middle East and North Africa region.

3. Identified Self-Care Needs in Organ Failure Patients

Several studies explored the needs of patients and their informal caregivers. Patients living with chronic illnesses and their informal caregivers perceived that sufficient advice, satisfactory information, and emotional assistance were not adequately accessible to them (Hwang, Luttk, Dracup & Jaarsma, 2010; Imes, Dougherty, Pyper, & Sullivan, 2011). Caregivers accept their roles with the intention of offering care without possessing the skills required to address the difficult decisional, interpersonal, and medical challenges ahead (Sullivan et al., 2016). Particularly informal caregivers reported the need to be reassured by healthcare providers that they were adequately performing daily tasks required of them and that they were making proper decisions particularly around emergencies. Answers to such questions and support in clinical decision-making by healthcare providers might lessen caregiver anxiety, vulnerability, and unnecessary emergency department visits (Kreuter & Holt, 2001). Competence concerns including making a serious mistake, maintaining empathy despite the frustrations, and doing steps correctly were considered major obstacles in offering care to chronically ill patients (Sullivan et al., 2016). Informal caregivers are expected to know more nursing and medical skills and knowledge to perform caregiving tasks (D'Agostino et al., 2017). Because of the mandates of their new caregiving responsibilities, informal caregivers reported a mix of emotions ranging from frustration,

anger, to being overwhelmed due to interpersonal dynamic modifications imposed by the new role (Chung, Moser, Lennie, & Rayens, 2009). They verbalized needing significant amount of patience to maintain the basic compassion and care needed to deal with the various frustrations related to caregiving.

Literature suggests that patients living with Heart Failure have poorer quality of life and unmet needs for information about their illness, how it would affect them and how they could get better. Their experience and interpretation of symptoms influenced their healthcare seeking behaviors (Kimani, Murray, & Grant, 2018). Patients valued information on the nature of their illness, prognosis, self-care, lifestyle changes and prevention strategies, but this was rarely available. They described uncertainty around diagnosis and delays in communication from their healthcare providers and as such facilitation of access to healthcare, through good communication between services and having a strong support network of both family and clinicians can reduce the impact of heart failure on the lives of the patient and those around them (Fry et al., 2016). Similarly, people living with chronic kidney disease reported the need for more information on the disease, symptoms management, treatment options, lifestyle changes, access to educational resources, and family-level support (Havas, Bonner, & Douglas, 2015). Patients living with End Stage Lung disease also report needing disease specific education, symptom management, autonomy, clinical test education, medications adherence, oxygen requirements education, and palliative counseling (Morisset et al., 2016).

As such, healthcare providers should seek to engage patients and caregivers in a therapeutic dialogue and enhance coaching. This will be crucial to prepare both family and patients as the chronic illness progress and to potentially ease the transition role for

patients and family members (Hjelmfors et al., 2020; Kamal et al, 2020; Lederer et al., 2016; Sullivan et al., 2016).

4. Living with chronic Diseases in Lebanon

In the absence of validated QPLs, it is imperative to explore what are the self-care needs of Lebanese patients. Self-care is known for its potential to improve the care of patients with chronic diseases; yet the engagement in and definition of self-care varies between cultures and countries (Massouh, Abu Saad, Meek, & Skouri, 2019). Self-dependence and personal responsibility are western concepts encountered in healthcare systems across the world. This is contrasted with codependence, collectivism, and paternalism in the Arab communities. These pertain to the cultural perspectives of self-care (Massouh et al., 2020). In Lebanon, patients living with chronic illnesses often present to the healthcare facilities accompanied with family. Arabs rely on a huge repertoire of family bonds where the strongest social institution is the extended family (Dumit, Abboud, Massouh, & Magilvy, 2015). Particularly, the Lebanese family is typically overprotective where family members will exchange turns while providing care. Thus, patients and their families are seen as one unit and hence, it is impossible to create QPLs without addressing family needs and concerns.

B. Palliative Care Trigger Consultation Tools

Palliative care interventions are becoming more common in acute care settings (O'Reilly et al., 2016). While initially intended to assist end of life patients, palliative care medicine have expanded their responsibility and are regularly consulted for difficult symptom management such as pain complaints (Trout, Krish, & Peppin, 2012).

The aim of this consultation is to deliver adequate disease information and interventions, providing help and involving patients and family members in decision making while ensuring cost benefit for the healthcare system (Passik et al., 2004). Yet, palliative care services are underutilized (Rodriguez, Barnato, & Arnold, 2007; Gemmell, Yousaf, & Droney, 2019) and reliance on palliative medicine varies (Walshe, Chew-Graha, Todd, & Caress, 2008). In one study, receiving palliative care consultations in the intensive care units was significantly associated with more frequent Do Not Resuscitate code status and hospice referrals as well as significant length of stay and direct cost reductions (Zalenski et al., 2017).

Palliative consults and discussions of goals of care are taking place late in the disease trajectory (Bakitas et al., 2013). This is also supported by low frequency of palliative care team consultations to discuss topics which should be addressed preferably in early illness (O'Mahony, Blank, Zallman, & Selwyn, 2005).

1. Evidence Supporting the Use of Palliative Trigger Consultation Tools

Literature supports discussions of prognostication and sheds light on the importance of planning end-of-life conversations, including evaluating the patient's wishes and the need for information; deciding on the timing, setting, and content of the dialogue; and choosing approaches to promote adjustment and coping with the diagnosis and the imposed changes in clinical situations (Clayton et al., 2003). Fundamentally, serious illness conversations and communicating bad news is taxing for everyone involved, including healthcare professionals and this has been cited as one of the difficult roles' healthcare professionals perform (Jacobs et al., 2016). Practicing effectual communication skills, fostering a team approach, and applying strategies for

debriefing may reduce the burden on healthcare teams (Shepherd et al., 2011). Thus, serious illness conversation is the first step in advanced care planning. Holding successful conversations require not only agreeing on treatment decisions but on initiating symptom management and providing support in terms of social, existential, and psychological issues (Davidson, 2007).

A standardized validated systematic consultation trigger tool improves the accuracy and efficacy of assessments and can ameliorate patient outcomes by ensuring timely palliative team consultation (Trout et al., 2012; Rauenzahn, Schmidt, Ali & Tenner, 2017; Schneiter et al., 2019). Palliative care trigger consultation tools have shown to be effective in improving patients and family members' quality of life, reducing patient suffering, and decreasing cost of stay by being available as early as possible (Trout et al., 2012; Chen, 2019). In fact, undesirable symptoms were shown to be significantly reduced after having a palliative care consultation (Chen, 2019). Despite the absence of consistency and standardization in function, interventions related to palliative care have been revealed to be advantageous both financially and clinically (Passik et al., 2004; Penrod et al., 2006; Ciemins, Blum, Nunley, Lasher & Newman, 2007). Moreover, medical providers' satisfaction and caregivers' satisfaction have as well been manifested (O'Mahony et al., 2005). However, precisely how and when a consultation should take place has not been well evaluated (Chen, 2019). Since the best use of palliative care program is still not identified, a simple disease specific trigger consultation tool could be helpful and will provide nurses and physicians with signs that necessitate palliative care team consultations.

Chronically ill organ failure patients particularly Heart Failure and End Stage Renal and Lung Disease continue to have significant distress affecting their quality of

life and survival even with access to diverse medical, surgical, and technical advancements (Psofka, Mckee, Liu, Elia & De Marco, 2017; Nenova & Hotchkiss, 2019). In their final phase, patients with the above diseases require palliative interventions and have both mental and physical problems. They frequently present with complex signs and symptoms that can be variable over time (Barclay et al., 2011). Hence, knowledge of symptoms through a special palliative assessment tool filled on admission for patients with organ failure can be a prerequisite or trigger for palliative care consultation (Rauenzahn et al., 2017). In fact, initiating early palliative consultation and advanced care planning can decrease symptom burden and be helpful for clients with an unpredictable disease trajectory that are prone to unanticipated periods of life-threatening deterioration and decompensation (Smith, Coyne & Cassel, 2012). Furthermore, with the huge accessibility to advanced therapies for organ failure patients, detailed examination of patients' preferences and goals for medical care can assist both clinicians and patients discern more effectively and professionally the array of alternatives offered (O'Mahony et al., 2005; Bekelman & Havranek, 2008). From a research viewpoint, there is obviously an important chance to fill a gap regarding how to recognize the requirements and timing for providing palliative care interventions to patients with organ failure. Palliative care initiatives in this context should be compatible with the sudden chronic disease exacerbations and adequate to patients who are not imminent, however, wish to better handle their symptoms and maintain their health and well-being (Chen, 2019).

The choice of an ideal tool to aid in the palliative screening must be guided by the importance to be brief in order to avoid burdening the patient but detailed enough to allow coverage of areas needed. It should also be validated for use in the palliative care

field. The outcome of this assessment tool is ideally a prioritized list of warning signs necessitating interventions; hence, a care plan will be created leading to an alarming sign to consult the palliative care team (Rauenzahn et al., 2017).

2. Palliative Trigger consultation Tool in Organ Failure Patients

Multiple guidelines for patients with Heart, Renal and Lung failure supported the involvement of palliative care for chronically ill patients who acquired the above diseases. As an example, the American Thoracic Society and the Global Initiative for Obstructive Lung Disease have called for increased palliative care services for patients living with Chronic Obstructive Pulmonary Disease (Lanken et al., 2008). The American Heart Association Guidelines for the Management of Heart Failure and the 2013 American College of Cardiology highlighted the importance of palliative care considerations throughout hospitalization, prior to discharge, at the initial visit following discharge, and on the follow-up day in select patients (Jessup et al., 2009). The 2013 International Society for Lung and Heart Transplant recommended the consideration of palliative care referral while evaluating patients prior to mechanical circulatory support implantation (Frigerio, Cipriani & Feldman, 2017). The 2016 ESC Guidelines for Diagnosing and Treating Acute and Chronic Heart Failure, suggested early palliative approaches introduction in the illness trajectory before disease progression (Psotka et al., 2017). The KDIGO (Kidney Disease: Improving Global Outcomes) recommended palliative/ supportive care for kidney disease patients because of their high physical and psychological burden, comorbidities, and poor prognosis, but mentioned that palliative care is underused (Diamond et al., 2021). In addition, the European Association for Palliative Care Task Force released recently an expert

position statement that clearly states the importance of using need-based conditions rather than time-based conditions for consultations (Sobanski et al., 2019).

Yet, literature is in agreement that there is a major lack of consensus regarding referral criteria for the involvement of palliative care in patients with Heart Failure and End Stage Lung and Renal Diseases. In one systematic review on Heart Failure palliative care, authors were able to identify 18 categories of referral criteria, including 7 needs-based criteria and 10 disease-based criteria. The most commonly discussed criterion was physical or emotional symptoms, followed by heart failure stage, hospital utilization, prognosis, and advanced cardiac therapies (Chang et al., 2020). In one study involving palliative care in Chronic Kidney Disease Patients, authors mentioned some reasons that necessitate palliative care referral and advance care planning. These reasons include multiple hospitalizations for symptoms management, having multiple comorbidities such as cardiovascular diseases, advanced age and malnutrition (Corbett, 2018). Another systematic review analyzing palliative referral criteria for respiratory non oncologic diseases revealed the most frequently discussed factors: Hospital use (69% of studies), Poor respiratory status (47% of reviewed studies), Emotional and Physical deterioration (37% of reviewed studies), Functional Decline (29% of reviewed studies), requiring Advanced Pulmonary Therapies (27% of reviewed studies) and Illness Progression (26% of reviewed studies) (Philip et al., 2021).

3. Palliative Care in Lebanon

The number of chronic diseases within a rapidly aging population is getting higher making palliative care an important element in Lebanese healthcare settings (Soueidan, Osman, El-Jardali, 2018). Estimates from 2017 revealed that 15,000 patients

can receive help from palliative care services every year and the need is certainly expected to increase. Although palliative interventions have become key components of healthcare structures in several developed countries, it has yet to be founded in developing countries like Lebanon (Osman, 2015). One of the barriers to early integration of Palliative Care in Lebanon is equating Palliative care with End-of-Life care. This misconception is encountered worldwide but more so in our culture since Palliative Care concept is relatively new, it was recognized as a specialty in 2013. In addition, Lebanon does not have enough palliative care health providers/ specialists who can assess and intervene in meeting our population needs (Osman, 2015). Although these services are growing in Lebanon, it remains difficult to access its impact due to system, organizational, professional, and patient level barriers (Huijer, Dimassi, & Abboud, 2009). As such palliative care in Lebanon is subject to many challenges which need to be addressed and these include lack of knowledge and lack of access to multidisciplinary training and awareness campaigns for healthcare providers. This will likely increase awareness and potentially affect earlier palliative care consults (Huijer, Saab, & Hajjar, 2016). Key recommendations to improve palliative care in Lebanon is to integrate these services within healthcare facilities, provide palliative care at patients' residence, strengthen education and training of healthcare professionals, and improve public awareness on palliative care (Soueidan et al., 2018).

CHAPTER III

METHODS

Literature confirms the lack of any Question Prompt List [QPL] or Palliative Care Trigger List done in Lebanon and the other Arabic speaking countries of the Middle East and North Africa [MENA] region. Thus, the aims of this project were to develop a 1) culturally sensitive QPLs designed to improve communication about chronic illnesses trajectories particularly in chronic organ failure patients [in Heart Failure, and End Stage Renal and Lung Diseases patients], and 2) Palliative Care Team Consultation Trigger Lists. These culturally sensitive tools are expected to improve communication in chronic illness management, promote questions asking about prognosis and illness trajectory, and ensure early palliative care consult (Lukaszczik et al., 2020).

A. Settings

This project, which utilized a 2-step modified Delphi method, was performed between April and August 2021 at the American University of Beirut Medical Center [AUBMC]. This is the largest tertiary medical center in Lebanon and includes a 420-bed hospital that serves over 360,000 patients annually. It offers comprehensive tertiary/quaternary medical care and referral services in a wide range of specialties together with medical, nursing, and paramedical training programs at the undergraduate and post-graduate level. Its effect on the medical sector and on improving people's lives is without equal in Lebanon and the region. AUBMC housed the first inpatient

Multidisciplinary Palliative Care Team and the first Heart Failure Multidisciplinary Disease Management Program in Lebanon and the MENA region.

B. Delphi Survey

The Delphi method is a technique based on the outcomes of several rounds of questionnaires referred to a panel of experts. Following each round of questionnaires, the experts are offered with an aggregated data summary of the previous round, allowing each expert to modify their answers and suggest new ideas based on the group responses and judgements. This method combines the experience of experts with elements of the wisdom of crowds (Niederberger & Spranger, 2020).

C. Expert Panel Recruitment

The professional network of multidisciplinary experts was recruited through the project lead's professional networks and included nurses [cardiology, nephrology, pulmonary, pain, and palliative care], clinical nurse specialists [adult health, oncology, and pain and palliative care], physicians [cardiology, nephrology, pulmonary and intensive care, anesthesiology, and palliative care], and academic researchers [palliative care and community nursing]. The panel members were recruited based on their lead roles in treating end organ failure patients [Heart Failure, End Stage Lung Disease, and End Stage Renal Disease] as well as in palliative care. [Appendix A] includes details about the expert panel.

A total of 19 multidisciplinary experts from AUBMC and two Lebanese Palliative Care Non-Governmental Organizations (Balsam and Sanad) were initially contacted directly by phone and email invitation, following which the goals and

methods of the project were explained. Experts were asked to reply back if interested and were immediately enrolled in round 1. Seventeen out of the nineteen experts we initially contacted agreed to participate. Sixteen experts answered the Heart Failure and the End Stage Renal Disease QPLs Delphi, fifteen answered the End Stage Renal Disease Delphi, and 4 members were chosen for the Palliative Trigger Consultation Tool focus group.

D. Development of Three Question Prompt Lists

Questions included in the first draft of the QPLs were initially generated from two sources. We started with a scoping review of the available literature on the needs of patients living with organ failure [heart, lungs, and kidney] as well as a review of the available QPLs from the international literature. Available QPLs were then critically evaluated for cultural sensitivity and applicability in this healthcare setting by the project's lead and two adult health nurses with experience in caring for patients with organ failure. During this review, the drafts were appraised for cultural sensitivity and the team reflected on what their patients mostly *asked*, what they wished their patients *would* ask, and what they thought patients *should* ask. The purpose behind this was to leverage on experts' experience and scholarly knowledge in these chronic diseases, prompting a set of questions reflecting current guidelines and scientific data. Drafts went back and forth until the team finalized the initial draft in preparation for the Delphi Survey: Similar questions were merged together and duplicated ones were eliminated. In the end, a list of 41 questions for the heart Failure QPL, 45 questions for End Stage Renal Disease QPL in addition to 41 questions for End Stage Lung Disease were generated. Questions with similar concepts/subject matter were grouped to create 6

categories for each QPL: *Disease specific information; Treatment options; Self-care: What is my role?; Quality of life; Palliative and End of Life care; Question family members may want to discuss.* [Appendix B] includes the initial draft of the Heart Failure QPL, [Appendix C] includes the initial draft of the End Stage Lung Disease QPL, and [Appendix D] includes the initial draft of the End Stage Renal Disease QPL].

E. Modified Delphi Survey for Question Prompt Lists

A modified Delphi survey was done to evaluate the importance of questions to fit into three-disease specific QPLs. The Delphi process comprised of 2 rounds, led by an MSN student [RI] and the project lead [AM], both were not voting members of the panel. [Figure 1 details the steps of the Delphi process followed].

In the first round, panelists were asked to rate the relevance and clarity of each question in the QPL as well as to decide on the need to rephrase and/or drop the question using an online survey. All panelists received a detailed email [Appendix E] that explains the purpose of the project, their role, what is expected of them to submit, and the proposed dates for the second round of the Delphi survey. Panelists were provided 10 days to complete the survey. The MSN student [RI] monitored responses and sent a reminder email to panelists 4 days before the submission deadline. In this round, panelists were asked to rate the relevance of each question in the QPLs on a Likert scale from 0 to 4 [0: I Do Not Know; 1: Very relevant; 2: Relevant; 3: Not so Relevant; and 4: Not Relevant at All]. They were also asked to comment by Yes/No on the clarity, need to rephrase, and the need to drop the question. They were given the chance to write comments and were asked to suggest additional questions to be included in the QPL. The panelists sent their answers via email to RI.

RI and AM aggregated the data and analyzed them to determine the level of consensus for each of the questions in the 3 QPLs. Questions that received less than 80% favorable answers were put for discussion in the second round of Delphi. Questions that were rated as *Very Relevant* or *Relevant* were considered favorable answers [as opposed to *I Do Not Know*, *Not so Relevant*, and *Not Relevant at All*]. Answering by *Yes* on clarity and *No* for the need to rephrase and need to drop were considered a favorable response. During the Zoom discussions, feedback was obtained to evaluate the questions rated unfavorably, the comments provided on some questions, questions that were suggested for deletion because they were perceived as not relevant, as well as the questions that were added by the panelists. Clarity of questions and suggestions for wording improvements and avoidance of repetitive questions was ensured. Finally, panelists were asked to state for each question whether the question should be kept, deleted, or added. Finally, questions that did not get the approval of the panelists during the discussion meetings, were considered of low importance, and therefore were excluded from the QPL. Three revised QPLs were developed after the second round.



Figure 1. Modified QPL Delphi

F. Development of Three Palliative Care Trigger consultation Tools

The literature was thoroughly reviewed for trigger lists for palliative care consults in Heart Failure and End Stage Renal and Lung Diseases by RI and AM with support from the Pain and Palliative Care Clinical Nurse Specialist at AUBMC. The developed Trigger Lists included 1 simple question if answered with a yes, healthcare providers [Primary Attending Physicians from Cardiology, Nephrology, or Pulmonary; Specialty Clinics, Inpatient Coronary Care Unit, Hemodialysis, Or Respiratory Care Unit Registered Nurses; and/or Clinical Nurse Specialists] will be directed to do a detailed Palliative Care needs assessment. The Heart Failure Palliative Care Trigger List is activated if the healthcare providers answer with a Yes on the below: *Does the Patient have Heart Failure and New York Heart Association [NYHA] Functional Class III or IV?* The End Stage Renal Disease Palliative Care Trigger List is activated if the

healthcare providers answer with a Yes on the below: *Does the Patient have End Stage Renal Disease and Karnofsky Performance Scale score of 50% or less?* The End Stage Lung Disease Palliative Care Trigger List is activated if the healthcare providers answer with a Yes on one of the below: *Does the Patient have End Stage Lung Disease and Modified MRC score greater or equal 3?* However, if the answer on the lead question is No, the palliative trigger list will not open for assessment, meaning that the patient is not eligible yet for palliative screening. This will be reassessed at every visit/encounter.

A total of 10 frequently cited triggers were selected for each disease. Common triggers between the three diseases were as follows: *Decision Support; patient and/or family wishes for no resuscitation; Multiple hospitalizations (≥ 2 admissions in the last 3 months due to disease exacerbation); Multiple Emergency Department visits due to Heart Failure exacerbation (≥ 3 ED visits in the last 6 months); presence of 3 or more chronic comorbidities; Disease cachexia of $\geq 10\%$ of body weight over the last 6 months; functional and/or cognitive decline as compared to baseline; social withdrawal and/ or caregiver burnout; reported poor quality of life by patient or family.* Disease specific triggers were also added. For Heart Failure, the presence of a current or planned *Ventricular Assist Device, being a cardiac transplant recipient, listed on a transplant list, or ineligible for or uninterested in advanced therapies* was one. Additionally, *poorly controlled symptoms despite treatment [Chest Pain, Shortness of Breath, Palpitations, Dizziness, Fatigue, and/or Insomnia] or dependence on inotropes or other intravenous therapy.* For End Stage Renal Disease patients, *being on or planned to start dialysis in the next 6 months, having refused to start dialysis, or decides to stop dialysis in addition to poorly controlled symptoms of uremia despite treatment* was added as triggers. In End Stage Lung Disease, *being a lung transplant recipient, being listed on a*

transplant list, or being ineligible for or uninterested in advanced therapies as well as *persistent dyspnea at rest* and/or with minimal exertion *while maintained on oxygen therapy* or *persistent hypercarbia* were added as potential triggers. All these triggers were weighted and a patient with a weighted score of more than or equal to 2 of the above indications will be eligible for Palliative Care consultation [Please refer to Appendix F for the Initial Heart Failure Palliative Consultation Trigger List, Appendix G for the Initial End Stage Renal Disease Palliative Consultation Trigger List and Appendix H for the Initial End Stage Lung Disease Palliative Consultation Trigger List].

G. Palliative Consultation Trigger Lists Delphi Survey

The Delphi Survey of the Palliative Care Consultation Trigger Lists followed the same steps of the QPLs Delphi survey. We sent an email [Appendix I] explaining the purpose of the Palliative Care Consultation Trigger Lists and the role of the experts chosen. Four experts were chosen (One Palliative Care and Anesthesia Attending Physician, One Oncology and Palliative Care Clinical Nurse Specialist, One Palliative Care Registered Nurse, and One Assistant Professor of Nursing). Panelists were provided 10 days to complete the survey. The panelists sent their answers via email to RI who monitored their responses, aggregated the ratings and the comments, and modified some questions according to the panelists' answers. Clarity of questions and suggestions for wording improvements and avoidance of repetitive questions was ensured. Three revised Palliative Consultation trigger Lists were developed.



Figure 2. Modified Palliative Care Consultation Trigger Lists Delphi

CHAPTER IV

RESULTS

A. Expert Panel Description

As previously mentioned, nineteen experts were initially invited; of them, seventeen members participated. Sixteen experts answered the Heart Failure and the End Stage Renal Disease QPLs, fifteen answered the End Stage Renal Disease, and 4 members were chosen to answer the Palliative Trigger Consultation Tool. The majority of the panel members were female individuals (n=15); in addition, the mean years of total medical experience for the experts is 12.5 years (Range: 3 years to 32 years), and mean years of total experience in the current specialty is 7.8 years (Range: 3 to 25 years). Four healthcare providers were physicians and the rest of the members were nurses from different educational and clinical backgrounds. Please refer to [Appendix A] for more information about the panelists.

B. Results of the Delphi Survey of the QPLs

The panel had positive feedback regarding the need for such QPLs as these are lacking in Lebanon and healthcare providers struggle to find easy and cost-effective communication tools. During the Zoom Call, RI presented averaged scoring of the QPLs and obtained feedback on the low scored questions. Feedback was ensured on questions that were suggested for deletion because they were perceived as not relevant, as well as the questions that were added by the panelists. As per the expert panel, some questions were impractical to answer as is and suggested modifications to the questions. Such questions were eliminated or rephrased based on voting. Clarity of questions,

suggestions for rewording, and avoidance of repetitive questions was ensured. Finally, panelists were asked to state for each question whether the question should be kept, deleted, or added. Questions that did not get the approval of the panelists during the discussion meetings, were considered of low importance and therefore were excluded from the QPL. Questions that were discussed for Heart Failure, End Stage Renal Disease and End Stage Lung Disease with their modifications are included in [Appendix J], [Appendix k] and [Appendix L] respectively.

In the Heart Failure QPL: 12 questions were rephrased, 1 question was dropped and 1 question was added. For the End Stage Renal Disease QPL: 9 questions were rephrased, 1 question was dropped and 1 question was added. As for the End Stage Lung Disease QPL: 9 questions were rephrased, 1 question was dropped and 1 question was added [please refer to Table 1].

| QPL | Rephrased | Dropped | Added |
|-------------------------|------------------|----------------|--------------|
| Heart Failure | 12 | 1 | 1 |
| End Stage Renal Disease | 9 | 1 | 1 |
| End Stage Lung Disease | 9 | 1 | 1 |

Table 1 QPL Survey Results

Examples of rephrased questions included replacing “Is it [my disease] a serious illness?” by “How serious is my illness?” in the three QPLs. “Why it is important to me to check my ABGs” was replaced with “What does high CO₂ in my Arterial blood gases (ABGs) result means?”. “How can I deal with fatigue? Trouble breathing? Fast heartbeats? Bloating sensation? Swelling?” was replaced with “How can I deal at home with the most recognized symptoms related to my Heart Failure?”.

C. Meeting Results of the Palliative Care Consultation Tools

One meeting took place with two palliative experts from the panelist after aggregating the data and the comments. During the Zoom Call, RI presented averaged scoring of the Palliative Care Consultation Trigger Lists and obtained feedback on some triggers. One Anesthesia and Palliative Care Physician with one Palliative Clinical Nurse Specialist had positive feedback regarding the need of the created Palliative Care Consultation Trigger Lists. Since disease specific Palliative triggers were lacking in Lebanon and the Gulf countries and since triggers found in literature were general and not precise, the palliative experts showed interest and support. Four triggers in the three Disease Specific Palliative Consultation trigger tools were reworded. Triggers that were discussed with their modifications are included in [Appendix M], [Appendix N] and [Appendix O] for Heart Failure, End Stage Renal Disease and End Stage Lung Disease respectively.

In the Heart Failure Palliative Care Consultation Trigger List: 4 triggers were rephrased, one of these triggers were split into two. The same applies for the End Stage Renal Disease Palliative Care Consultation Trigger List. However, for the End Stage Lung Disease Palliative Care Consultation Trigger List, one trigger was added and 4 triggers were rephrased, one of these triggers were split into two [Please refer to Table 2].

| Palliative Care Consultation Trigger List | Rephrased | Dropped | Added |
|--|------------------|----------------|--------------|
| Heart Failure | 4 | 0 | 0 |
| End Stage Renal Disease | 4 | 0 | 0 |
| End Stage Lung Disease | 4 | 0 | 1 |

Table 2 Palliative Care Consultation Trigger Lists Survey Results

D. Final Question Prompt Lists and Palliative Care Consultation Trigger Lists

The result of these Delphi Survey meetings for the QPLs and the one-on-one meeting for the Palliative Consultation Trigger Lists was the production of three final QPLs and 3 final Palliative Care Consultation Trigger List that aim to keep the patients well informed about their illnesses' trajectories and guarantees active participation of both patients and healthcare providers. After the Delphi survey and the modifications done, we had a Heart Failure QPL with 42 questions [Appendix P], an End Stage Renal Disease QPL with 44 questions [Appendix Q] and an End Stage Lung Disease QPL with 41 questions [Appendix R], a Heart Failure Palliative Care Consultation Trigger List with 11 Triggers [Appendix S], an End Stage Renal Disease Palliative Care Consultation Trigger List with 11 Triggers [Appendix T], an End Stage Lung Disease Palliative Care Consultation Trigger List with 12 triggers [Appendix U]. Final QPLs were divided into 6 categories each: Disease Specific Information; Treatment Options; Self Care: What is my role?; Quality of Life; Palliative and End of Life care; and Questions family members may want to discuss.

New paragraph goes here double-spaced. In this chapter, we will explain how to insert figures and tables, with their captions.

CHAPTER V

DISCUSSION

In this project, three QPLs and Palliative Care Consultation Trigger Lists have been developed through a detailed literature search followed by a focus group discussion by academic and clinical experts in Palliative Care and Heart Failure, End Stage Renal Disease and End Stage Lung Disease. To our knowledge, this is the first application of the Delphi method to systematically develop adult specific QPLs and Palliative Care Consultation Trigger Lists for patients with Heart Failure, End Stage Renal Disease, and End Stage Lung Disease in Lebanon and the region.

Among the 17 multidisciplinary experts participating in 2 rounds of a modified Delphi method, our project identified 42 questions in the Heart Failure QPL, 44 questions in the End Stage Renal Disease QPL, 41 questions in the End Stage Lung Disease. Likewise, our team developed three Palliative Care Consultation Trigger Lists of 11 triggers for the Heart Failure and End Stage Renal Disease and 12 triggers for the End Stage Lung Disease that aim at increasing early palliative care referrals.

A. Implementation Plan

Since the developed tools in this project are intended to improve communication about disease trajectories and ensure early and timely referral to palliative care, it is crucial to ensure community participation and feedback. In fact, relying on patients' judgments is essential, as strategies that promote patients/ healthcare providers' communication like QPLs should be ideally developed in collaboration with patients, rather than relying on input obtained from literature and clinicians only (Low et al.,

2020). Patients living with chronic diseases will be the main group benefiting from these tools; hence, creating such type of communication tool should be characterized by an equitable input between community representatives, academic researchers, and clinicians. Engaging patients in creation of such QPLs maximizes the probability that these reflect the patients' needs and consequently increases the odds of utilization of such tools, a crucial factor in tackling hospital disparities related to these special populations. We plan to perform the same Delphi survey with Heart Failure, End Stage Lung and Renal Diseases' patients who, in their role, will rate the questions and will comment on the clarity, need to rephrase, and the need to drop the questions. Since the created QPLs address also the caregivers' needs, it is crucial to involve them in this Delphi survey. Ten patients and ten caregivers from each of the three previously mentioned chronic diseases will be asked to participate in the study where focus groups will be generated. The concept and the importance of QPLs and Palliative Consultation Trigger Lists will be explained to the patients and their caregivers. After clarifying the goal of the study, the focus groups will receive the tools for rating. Supported by a Research Assistant (RA), the participants will choose the way they want to provide their answers: Zoom meetings, Face to Face meetings or any way that suits their interests. After receiving the ratings and aggregating the data, the project lead will check the questions which received less than 80% favorable answers and discuss it with the initial committee members where modifications will take place accordingly. In the final phase, we recommend combining clinicians, academicians, patients and caregivers' ratings together and discuss the answers with a bigger interprofessional group. This group will include patients, caregivers, psychologists, social workers, and healthcare providers from different backgrounds (Lebanon and the Kingdom of Saudia Arabia). This will

ensure that the QPLs are connected to clinical practice and have the potential to be used in the real world.

B. Evaluation Plan

After these QPLs and Palliative Care Consultation Trigger Lists are finalized and feedback from patients, caregivers, and the multidisciplinary team are integrated, we will have 3 final QPLs and 3 Palliative Care Consultation Trigger Lists to pilot. The pilot study will be planned with a focus on outcome assessment. Outcomes for the success of these QPLs and Palliative Care Consultation Trigger Lists will include: the number of questions asked by patients and their caregivers during their visits globally and by topic. In addition, quantity and quality of topics addressed by doctors and communication improvement during high stakes dialogues will be also evaluated. Secondary outcomes can include the impact of the QPL on psychological symptoms, quality of life, satisfaction with care, and patient and caregiver coping styles. This can be done by assessing these outcomes in experimental (patients and caregivers who received the QPLs prior to the physician clinic visit) and control (patients and caregivers who did not receive the QPLs prior to the physician clinic visit) groups.

For the Palliative Care Consultation Trigger List Evaluation Plan, we suggest assessing the number of Palliative care consults in the hospital over one year period, in addition to assess the time taken to consult palliative care team after applying the tools at AUBMC compared with the same time period one year prior. Hence, after finding out the efficiency of this tool, it can be applied and used to enhance palliative care consultation, improving in that way patients' quality of life and satisfaction.

C. Strengths and Limitations

The strengths of this project are that it offers a comprehensive overview of two types of interesting tools that we lack in Arab countries: Question Prompt Lists and Palliative Care Consultation Trigger Lists. Additionally, the tools we created were disease specific; this is considered an advantage since such disease-specific tools are lacking in literature and general tools were found only. Moreover, using Delphi Survey to complete this project was very beneficial. In fact, relying on this method allowed equal sharing of thoughts, opinions and suggestions by the experts who, in their roles provided different analysis and efficient variety of options that we can use in order to create our tools. We relied on the statement that a group of experts and the multitude of associated perceptions will lead to a more valid outcome than a judgment offered by one expert, even if this experienced clinician is the best in his/her field.

The results of this project are not without specific process limitations. First, our multidisciplinary panel size was overall small ($n = 17$) compared with other Delphi methods surveys. Second, our panel was all healthcare providers from Lebanon which will likely limit the generalizability of these QPLs and Trigger Lists to patients and providers in Lebanon. Moreover, the total number of questions meeting expert agreement returned high even in the initial Delphi survey which could be explained by the possibility that these multidisciplinary healthcare providers have had similar training and attitude to palliative care and illness trajectory discussions.

CHAPTER VI

CONCLUSION

This project concludes with the development of three Disease Specific QPLs and Palliative Consultation Trigger Lists by a group of experts using a modified Delphi Survey. These are the first Disease Specific QPLs and Palliative Consultation Trigger Lists developed in the MENA region. More importantly, there are only a few, if any, Disease Specific QPLs and Palliative Consultation Trigger Lists targeting specific patient populations like patients living with Heart Failure, End Stage Renal Disease, and End Stage Lung Disease. The aim behind this is to address their unmet information needs, engage them in healthcare discussions, and facilitate patient-centered care. Evidence supports that using such tools in the primary care setting will definitely facilitate earlier referral to palliative care and provide patients and their caregivers with the needed aptitude to open discussions related to illness trajectory.

Future research should assess the impact of the Disease Specific QPLs on short-term, intermediate, and long-term health outcomes as well as assess the impact of Palliative Consultation Trigger Lists on early referral to palliative care. After merging patient and healthcare provider perspectives toward these lists as well as validating improved perceived involvement in care among patients, we hope that the implementation will guide patients in asking essential questions during consultation.

APPENDIX A

| Initials | Gender | Profession | Years of Experience | Years in Specialty | Reason for inclusion in the study |
|----------|--------|---------------------------|---------------------|--------------------|--|
| J.H. | Female | Clinical Nurse Specialist | 16 | 10 | Pain and Palliative Care Experience |
| R.A. | Female | Clinical Nurse Specialist | 17 | 10 | Oncology and Palliative Care Experience |
| M.I. | Male | Clinical Nurse Specialist | 13 | 13 | Adult Health and Heart Failure Experience |
| R.Y. | Female | Anesthesiologist | 9 | 6 | Anesthesia and Pain and Palliative Care Experience |
| G.H. | Female | Assistant Professor | 32 | 25 | Community Experience |
| M.O. | Female | Registered Nurse | 9 | 9 | Critical Care and Pulmonary Rehabilitation Experience |
| S.D. | Female | Clinical Instructor | 15 | 10 | End of Life Care Researcher; PhD Student |
| H.H. | Female | Registered Nurse | 3 | 3 | Nephrology Experience |
| M.C. | Female | Registered Nurse | 4.5 | 4.5 | Cardiology Experience |
| Z.J. | Female | Clinical Educator | 8 | 8 | Cardiology Experience |
| K.F. | Male | Intensivist | 15 | 6 | Pulmonary Critical Care and Palliative Care Experience |
| R.M. | Female | Registered Nurse | 10 | 3 | Palliative Care Experience |
| S.K. | Female | Nephrologist | 17 | 8 | Nephrology Experience |
| H.M. | Female | Nurse Manager | 15 | 9 | Nephrology Experience |
| R.C. | Female | Cardiologist | 12 | 8 | Cardiology Experience |
| M.O. | Female | Registered Nurse | 8 | 3 | Palliative Care Experience |
| S.M. | Female | Registered Nurse | 9 | 8 | Pulmonary Experience |

APPENDIX B

How to make the most of your time with the Doctor

Most people who see their Physicians have concerns and questions. Often these get forgotten in the rush of the moment, only to be remembered soon after. To enhance your consultation visit with the Doctor, we have compiled a list of questions people frequently ask. We suggest that you tick those you want to ask and then write down any additional questions you have in the space provided.

You can keep this list of questions with you when you see your Doctor. Your Doctor might answers your questions without you even ask, but this sheet can serve as a checklist so that you know you have covered every matter essential for you.

| Type | Questions | |
|------------------------------|-----------|---|
| Disease Specific Information | 1 | What is Heart Failure? What caused my disease? |
| | 2 | Is it a lifelong disease? |
| | 3 | Is it a serious illness? |
| | 4 | How much function is left in my heart? |
| | 5 | What are the signs and symptoms that I may experience at this point? |
| | 6 | How do I know that my Heart Failure is getting worse? |
| | 7 | What are the alarming signs that I need to see so I come to the emergency department? |
| | 8 | How can I deal with fatigue? Trouble breathing? Fast heartbeats? Bloating sensation? Swelling? |
| Treatment Options | 9 | What are my available treatment options? |
| | 10 | What are the medications that I need to take? Are there any special side effects I should monitor? |
| | 11 | Do I need to use oxygen at home? |
| | 12 | Is there anything I can do to relieve my symptoms? |
| | 13 | Will I need a heart transplant or an artificial heart or a pacemaker? If I do, when should I expect this? |
| | 14 | What happens if I don't choose to go aggressively with treatment? |
| Self-Care | 15 | What diet should I follow? |
| | 16 | What are some high salt foods should I avoid? |
| | 17 | How much fluid should I drink per day? |
| | 18 | What is a healthy body weight for me? What is my Dry Weight? |
| | 19 | Which over the counter medications should I stay away from? |
| | 20 | What medications should I take? |
| Quality of Life | 21 | How do Heart Failure and my other diseases affect each other? |
| | 22 | What kinds of activities am I allowed to do? How much should I exercise? |

| | | |
|---------------------------------|-----------|---|
| | 23 | What type of work should I avoid? |
| | 24 | Am I healthy enough to have sex? |
| | 25 | What symptoms will I experience when my condition deteriorates? |
| Palliative and End-of Life Care | 26 | Who can I talk to about things that worry or bother me? |
| | 27 | Who can help me make decisions about my care? |
| | 28 | What treatment/support is available to me when I deteriorate? |
| | 29 | What support is available to me if I choose to be cared for at home? |
| | 30 | Who will have the overall responsibility for my care if I deteriorate? |
| | 31 | Is it ok to spend my last days at home? |
| | 32 | Can I discuss goals of care with my primary care provider? Can I refuse treatment? |
| | 33 | Is there a program that helps me manage my symptoms if I choose to stop all treatments? |
| | 34 | Will someone tell me when I am approaching the end-of-life? |
| | 35 | Is it possible to predict how long someone has left to live? |
| | 36 | How will I feel during my last days of life? |
| Family Concerns | 37 | Are breathing problems common at the end-of-life? |
| | 38 | Is pain common at the end-of-life? |
| | 39 | How do I best help the person who is ill if they deteriorate? |
| | 40 | Who can I turn to if I have concerns about the care given to the person who is ill? |
| | 41 | Who can we talk to about things that worry or bother us? |

Additional Questions you may want to ask:

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APPENDIX C

How to make the most of your time with the Doctor

Most people who see their Physicians have concerns and questions. Often these get forgotten in the rush of the moment, only to be remembered soon after. To enhance your consultation visit with the Doctor, we have compiled a list of questions people frequently ask. We suggest that you tick those you want to ask and then write down any additional questions you have in the space provided.

You can keep this list of questions with you when you see your Doctor. Your Doctor might answers your questions without you even ask, but this sheet can serve as a checklist so that you know you have covered every matter essential for you.

| Type | Questions | |
|------------------------------|-----------|--|
| Disease Specific Information | 1 | What is End Stage Lung Disease? |
| | 2 | Is it a lifelong disease? |
| | 3 | Is it a serious illness? |
| | 4 | How much function is left in my lungs? |
| | 5 | What are the signs and symptoms that I may experience at this point? |
| | 6 | How do I know that my lung failure is getting worse? |
| | 7 | What does high CO ₂ in my Arterial blood gases (ABGs) result means? |
| | 8 | What are the alarming signs that I need to see so I come to the emergency department? |
| | 9 | How can I deal with trouble breathing? Fast heartbeats? Bloating sensation? Feeling tired? |
| Treatment Options | 10 | What are my available treatment options? |
| | 11 | What are the medications that I need to take? Are there any special side effects I should monitor? |
| | 12 | Do I need to use oxygen at home? |
| | 13 | Do I need to use bronchodilators at home? |
| | 14 | Is there anything I can do to relieve my symptoms? |
| | 15 | Will I need lung transplant? If I do, when should I expect this? |
| | 16 | What happens if I don't choose to go aggressively with treatment? |
| Self-Care | 17 | What diet should I follow? |
| | 18 | What is a healthy body weight for me? |
| | 19 | Which over the counter medications should I stay away from? |
| | 20 | What are the options that help me quit smoking? |
| Quality of Life | 21 | How do End Stage Lung Disease and my other diseases affect each other? |
| | 22 | What kinds of activities are allowed? How much should I |

| | | |
|---------------------------------|-----------|---|
| | | practice? |
| | 23 | What type of work should I avoid? |
| | 24 | Am I healthy enough to have sex? |
| | 25 | What symptoms will I experience when my condition deteriorates? |
| Palliative and End-of Life Care | 26 | Who can I talk to about things that worry or bother me? |
| | 27 | Who can help me make decisions about my care? |
| | 28 | What treatment/support is available to me when I deteriorate? |
| | 29 | What support is available to me if I choose to be cared for at home? |
| | 30 | Who will have the overall responsibility for my care if I deteriorate? |
| | 31 | Is it ok to spend my last days at home? |
| | 32 | Can I discuss goals of care with my primary care provider? Can I refuse treatment? |
| | 33 | Is there a program that helps me manage my symptoms if I choose to stop all treatments? |
| | 34 | Will someone tell me when I am approaching the end-of-life? |
| | 35 | Is it possible to predict how long someone has left to live? |
| | 36 | How will I feel during my last days of life? |
| | 37 | Are breathing problems common at the end-of-life? |
| | 38 | Is pain common at the end-of-life? |
| Family Concerns | 39 | How do I best help the person who is ill if they deteriorate? |
| | 40 | Who can I turn to if I have concerns about the care given to the person who is ill? |
| | 41 | Who can we talk to about things that worry or bother us? |

Additional Questions you may want to ask:

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APPENDIX D

How to make the most of your time with the Doctor

Most people who see their Physicians have concerns and questions. Often these get forgotten in the rush of the moment, only to be remembered soon after. To enhance your consultation visit with the Doctor, we have compiled a list of questions people frequently ask. We suggest that you tick those you want to ask and then write down any additional questions you have in the space provided.

You can keep this list of questions with you when you see your Doctor. Your Doctor might answers your questions without you even ask, but this sheet can serve as a checklist so that you know you have covered every matter essential for you.

| Type | Questions | |
|------------------------------|-----------|--|
| Disease Specific Information | 1 | What is Kidney Failure? What caused my kidneys to fail? |
| | 2 | Is it a lifelong disease? |
| | 3 | Is it a serious illness? |
| | 4 | How much function is left in my kidneys now? |
| | 5 | What are the signs and symptoms that I may experience at this point? |
| | 6 | What do Glomerular Filtration Rate, Creatinine and Urine Proteins mean? |
| | 7 | Is my blood pressure in the normal range? |
| | 8 | How do I know that my Kidney Failure is getting worse? |
| | 9 | What health problems can Kidney Failure cause? |
| | 10 | What are the alarming signs that I need to see so I come to the Emergency Department? |
| | 11 | How can I deal with Swelling? Shortness of breath? Fatigue? Nausea? |
| Treatment Options | 12 | What are my available treatment options? |
| | 13 | What are the medications that I need to take? Are there any special side effects I should monitor? |
| | 14 | Is there anything I can do to relieve my symptoms? |
| | 15 | Will I need dialysis or kidney transplant? If I do, when should I expect this? |
| | 16 | What happens if I do not choose to continue on dialysis or get a transplant? |
| | 17 | What happens if my kidneys stop working completely? |
| | 18 | What happens if I don't choose to go aggressively with treatment? |
| Self-Care | 19 | What diet should I follow? |
| | 20 | What are some high salt foods should I avoid? |
| | 21 | How much fluid should I drink per day? |

| | | |
|---------------------------------|-----------|--|
| | 22 | What is a healthy body weight for me? What is my Dry Weight? |
| | 23 | Which over the counter medications should I stay away from? |
| Quality of Life | 24 | How do Kidney Failure and my other diseases affect each other? |
| | 25 | How does Kidney Failure affect my day-to-day life? |
| | 26 | How will my quality of life be like if I choose dialysis? How long do patients live on dialysis? |
| | 27 | How will my quality of life be like if I choose kidney transplant? |
| | 28 | Am I healthy enough to have sex? |
| | 29 | What symptoms will I experience when my condition deteriorates? |
| Palliative and End-of Life Care | 30 | Who can I talk to about things that worry or bother me? |
| | 31 | Who can help me make decisions about my care? |
| | 32 | What treatment/support is available to me when I deteriorate? |
| | 33 | What support is available to me if I choose to be cared for at home? |
| | 34 | Who will have the overall responsibility for my care if I deteriorate? |
| | 35 | Is it ok to spend my last days at home? |
| | 36 | Can I discuss goals of care with my primary care provider? Can I refuse treatment? |
| | 37 | Is there a program that helps me manage my symptoms if I choose to stop all treatments? |
| | 38 | Will someone tell me when I am approaching the end-of-life? |
| | 39 | Is it possible to predict how long someone has left to live? |
| | 40 | How will I feel during my last days of life? |
| | 41 | Are breathing problems common at the end-of-life? |
| Family Concerns | 42 | Is pain common at the end-of-life? |
| | 43 | How do I best help the person who is ill if they deteriorate? |
| | 44 | Who can I turn to if I have concerns about the care given to the person who is ill? |
| | 45 | Who can we talk to about things that worry or bother us? |

Additional Questions you may want to ask:

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APPENDIX E

Dear healthcare provider,

I hope my email finds you well.

First, I would like to thank you for your precious time and the support you are providing me to complete my project: Asking Questions Can Help: Development and Preliminary Evaluation of a Question Prompt List and a Palliative Care Trigger List for Chronically Ill Patients.

Please find the attached the three **Question Prompt Lists** [Heart Failure, End Stage Renal Disease, and End Stage Lung Disease] shared on excel.

What are QPLs?

A QPL is a list of preprepared standard questions that encourage patients' active involvement in their disease management and decision making and offer a standard framework for patients to ask about their disease. QPLs involve patients directly, establish a practical patient-physician relationship, and promote active information seeking. Moreover, they can help primary healthcare providers in providing pertinent information about the active disease and available treatment options. These are widely available for cancer and palliative care patients and have helped patients and their caregivers frame their questions, be better prepared for clinic visits, and be more involved in decision making. Despite the huge acceptance of QPLs among cancer patients worldwide, they are less commonly used in non oncology contexts; and not available at all in Lebanon.

What are you expected to do?

There are 2 things asked of you [I hope you can do both so we have some consistency]. You will receive in this email an excel sheet with 3 QPLs. Each QPL has 40 questions approximately. You will be asked to rate the **relevance** of each question in the QPLs on a likert scale from 0 to 4 [0: I Do Not Know; 1: Very relevant; 2: Relevant; 3: Not so Relevant; and 4: Not Relevant at All]. Then you will be asked to comment by yes or no on the **clarity**, **need to rephrase**, and the **need to drop the question**.

You will have 10 days to fill the QPLs and to send it by email to me at rii04@mail.aub.edu. I will be sending you an email reminder two days before the deadline.

After all QPLs are rated, we will meet through Zoom [a doodle link with 2 dates will be provided. Please pick 1 slot and make sure you attend it so that we do not miss your input]. In the Zoom meeting, I will share the calculated averaged scores and we discuss. This will take an hour.

The dates are:

- Option 1: June 7 at 5pm Beirut Time
- Option 2: June 8 at 4pm Beirut Time

Doodle Link:

https://doodle.com/poll/2dtug9v8ur3ydcub?utm_source=poll&utm_medium=link

Zoom links are listed below:

Topic: QPL Delphi Survey 1

- Time: Jun 7, 2021 05:00 PM Beirut
- Join Zoom Meeting

- <https://zoom.us/j/97363979933?pwd=QUF0Wjl4TDhqa3daQXJwYms5OXlhUT09>
- Meeting ID: 973 6397 9933
- Passcode: 575419

Topic: QPL Delphi Survey 2

- Time: Jun 8, 2021 04:00 PM Beirut
- Join Zoom Meeting
- <https://zoom.us/j/92879116962?pwd=SE9oN3N2K1RSQ2RSZ3pFNmJ3cC9mZz09>
- Meeting ID: 928 7911 6962
- Passcode: 601874

Please feel free to ask any questions you may have about this project. Dr. Massouh and I are ready to assist you all.

Please don't forget to reply on the doodle link the meeting date that suits your schedule. Thank you again for your time and help. Much appreciated.

Rim Itani, MSN Student

APPENDIX F

Specialty Clinics or Coronary Care Unit Registered Nurses, Cardiology Clinical Nurse Specialist, or the Primary Attending Physician answers the below:

- Does the Patient have Heart Failure and New York Heart Association [NYHA] Functional Class III or IV?

If the answer is **yes to any** of the above, the palliative care trigger list is opened, and further assessment is warranted.

| Heart Failure Palliative Care Trigger Items | Scores | |
|---|--|---|
| 1 | Decision Support: Discussion of advanced care planning and/or goals of care [and/or <i>possible</i> conflict among the multidisciplinary team[s], or between the multidisciplinary team and patient or family, or between family members]. | 2 |
| 2 | Patient and/or family members verbalized wishes for no resuscitation in case of clinical deterioration [please specify who is providing this information]. | 2 |
| 3 | Multiple Emergency Department visits and/or multiple hospitalizations due to Heart Failure (≥ 3 visits/admissions in the last 12 months), Critical Care Unit Admission, and/or prolonged length of stay. | 2 |
| 4 | Presence of a Ventricular Assist Device [VAD] or a plan for one in the next 6 months OR Status post Cardiac Transplant or listed on a Transplant List OR ineligible for or uninterested in advanced therapies. | 2 |
| 5 | Presence of 3 or more chronic comorbidities that require self-care [Diabetes; Valvular Heart Disease; Lung Disease; Cardiorenal Syndrome...]. | 1 |
| 6 | Unintentional weight loss of $\geq 10\%$ of dry body weight over the last 6 months [cardiac cachexia], frailty, loss of muscle tone, and/or poor appetite. | 1 |
| 7 | Poorly controlled symptoms despite treatment [Chest Pain, Shortness of Breath, Palpitations, Dizziness, Fatigue, and/or Insomnia] or dependence on inotropes or other intravenous therapy. | 2 |
| 8 | Functional and/or cognitive decline as compared to baseline or 6 months back or as per family/healthcare provider observations. | 1 |
| 9 | Social withdrawal [or any reported increase in signs and/or symptoms of Depression and/or Anxiety] in patients and/or caregiver burnout. | 1 |
| 10 | Reported poor quality of life or increased care dependency by patient or family. | 1 |

A patient with a weighted score of ≥ 2 of the above indications will be eligible for Palliative Care consultation. Please notify the primary attending physician of the screening result for consultation initiation.

APPENDIX G

Specialty Clinics or Hemodialysis Unit Registered Nurses or Adult Clinical Nurse Specialist or the Primary Attending Physician answers the below:

- Does the Patient have Kidney Failure and Karnofsky Performance Scale Index 1 or 2?

If the answer is **yes to any** of the above, the palliative care trigger list is opened, and further assessment is warranted.

| End Stage Renal Disease Palliative Care Trigger Items | Scores | |
|---|--|---|
| 1 | Decision Support: Discussion of advanced care planning and/or goals of care [and/or <i>possible</i> conflict among the multidisciplinary team[s], or between the multidisciplinary team and patient or family, or between family members]. | 2 |
| 2 | Patient and/or family members verbalized wishes for no resuscitation in case of clinical deterioration [please specify who is providing this information]. | 2 |
| 3 | Multiple Emergency Department visits and/or multiple hospitalizations due to Renal Disease (≥ 2 visits/admissions in the last 3 months), Critical Care Unit Admission, and/or prolonged length of stay. | 2 |
| 4 | On dialysis or plan to start dialysis in the next 6 months. Refuses to start dialysis or decides to stop dialysis. | 2 |
| 5 | Presence of 3 or more chronic comorbidities that require self-care [Diabetes; Valvular Heart Disease; Lung Disease; Cardiorenal Syndrome...]. | 1 |
| 6 | Unintentional weight loss of $\geq 10\%$ of dry body weight over the last 6 months [Cachexia], frailty, loss of muscle tone, and/or poor appetite. | 1 |
| 7 | Poorly controlled symptoms of uremia despite treatment [Nausea, Vomiting, Pruritis, Confusion, Obtundation, Restlessness, and/or Lethargy]. | 2 |
| 8 | Functional and/or cognitive decline as compared to baseline or 6 months back or as per family/healthcare provider observations. | 1 |
| 9 | Social withdrawal [or any reported increase in signs and/or symptoms of Depression and/or Anxiety]. | 1 |
| 10 | Reported poor quality of life by patient or family. | 1 |

A patient with a weighted score of ≥ 2 of the above indications will be eligible for Palliative Care consultation. Please notify the primary attending physician of the screening result for consultation initiation.

APPENDIX H

Specialty Clinics or Hemodialysis Unit Registered Nurses or Adult Clinical Nurse Specialist or the Primary Attending Physician answers the below:

- Does the Patient have End Stage Lung Disease and Modified MRC score greater or equal 3?

If the answer is **yes to any** of the above, the palliative care trigger list is opened, and further assessment is warranted.

| End Stage Lung Disease Palliative Care Trigger Items | Scores | |
|--|--|---|
| 1 | Decision Support: Discussion of advanced care planning and/or goals of care [and/or <i>possible</i> conflict among the multidisciplinary team[s], or between the multidisciplinary team and patient or family, or between family members]. | 2 |
| 2 | Patient and/or family members verbalized wishes for no resuscitation in case of clinical deterioration [please specify who is providing this information]. | 2 |
| 3 | Multiple Emergency Department visits and/or multiple hospitalizations due to Lung Disease (≥ 2 visits/admissions in the last 12 months), Critical Care Unit Admission, and/or prolonged length of stay. | 2 |
| 4 | Status post Lung Transplant or listed on a Transplant List OR ineligible for or uninterested in advanced therapies. | 2 |
| 5 | Presence of 3 or more chronic comorbidities that require self-care [Diabetes; Valvular Heart Disease; Heart Disease; Cardiorenal Syndrome...]. | 1 |
| 6 | Unintentional weight loss of $\geq 10\%$ of dry body weight over the last 6 months [Cachexia], frailty, loss of muscle tone, and/or poor appetite. | 1 |
| 7 | Persistent dyspnea at rest and/or with minimal exertion while maintained on oxygen therapy or persistent hypercarbia ($PCO_2 \geq 50$ mm Hg). | 2 |
| 8 | Functional and/or cognitive decline as compared to baseline or 6 months back or as per family/healthcare provider observations. | 1 |
| 9 | Social withdrawal [or any reported increase in signs and/or symptoms of Depression and/or Anxiety]. | 1 |
| 10 | Reported poor quality of life by patient or family. | 1 |

A patient with a weighted score of ≥ 2 of the above indications will be eligible for Palliative Care consultation. Please notify the primary attending physician of the screening result for consultation initiation.

APPENDIX I

Dear healthcare providers,

I hope my email finds you well.

First, I would like to thank you for your precious time and the support you are providing me to complete my project. Till now, we completed the Question Prompt lists for Heart failure, End Stage Renal Disease and End Stage Lung Disease. The second aim of the project is to create 3 palliative care trigger lists for the 3 chronic diseases previously mentioned. After reviewing the literature, we came with 10 triggers for each Palliative trigger list that needs your review. Please find the two attached documents: The first document is the official format of the palliative care trigger lists. The second document involves the questions shared on excel sheets that need to be rated and sent back to me (Same rating method we used before in the QPLs). Please provide me with your comments.

Feel free to ask any question you may have about this project. Dr. Massouh and I are ready to assist you all.

Thank you again for your time and help.

Much appreciated.

APPENDIX J

| Questions discussed | | Relevance | Action | | | Modifications done post meetings |
|---------------------|---|-----------|---|--|--|---|
| | | | Number of participants who rated Relevance by 1 OR 2 | Number of Participants who answered by: Unclear | Number of Participants who answered by need to Rephrase | |
| 3 | Is it a serious illness? | 14 | 3 | 4 | 1 | Rephrase: How serious is my illness? |
| 4 | How much function is left in my heart? | 11 | 6 | 5 | 4 | Rephrase: How how well is my heart working now? |
| 8 | How can I deal with fatigue? Trouble breathing? Fast heartbeats? Bloating sensation? Swelling? | 14 | 1 | 4 | 1 | Rephrase: How can I deal at home with the most recognized symptoms related to my Heart Failure? |
| 13 | Will I need a heart transplant or an artificial heart or a pacemaker? If I do, when should I expect this? | 14 | 5 | 7 | 3 | Rephrase: Am I good candidate for Heart Transplant, Left Ventricular Assist Device, or Pacemaker? When should I expect this? |
| 14 | What happens if I don't choose to go | 15 | 7 | 10 | 0 | Rephrase: What other options do I have if I don't choose any of the |

| | | | | | | |
|----|---|--|---|---|---|---|
| | aggressively with treatment? | | | | | indicated invasive therapies? |
| 20 | What medications should I take? | 14 | 4 | 3 | 1 | Rephrase: What medications should I take? What are the possible side effects I should expect? |
| 21 | How do Heart Failure and my other diseases affect each other? | 16 | 4 | 4 | 1 | Rephrase: How would my Heart Failure affect other medical conditions that I have or I may develop? |
| 25 | What symptoms will I experience when my condition deteriorates? | 15 | 3 | 4 | 1 | Rephrase: What are the symptoms that would require me to contact the clinic? When would these require an ED visit? |
| 28 | What treatment /support is available to me when I deteriorate? | 15 | 3 | 5 | 0 | Rephrase: What treatment/support is available to me/my family if my disease progresses? If I choose to stop all treatments? |
| 30 | Who will have the overall responsibility for my care if I deteriorate? | 14 | 6 | 4 | 1 | Rephrase: How can I assign someone to make healthcare decisions on my behalf if I no longer can? |
| 32 | Can I discuss goals of care with my primary care provider? Can I refuse treatment? | No low scores for this question, but during the meeting it was suggested to use instead: | | | | Rephrase: Who would be the right person to communicate my wishes related to end of life to in case I no longer can make decisions? |
| 33 | Is there a program that helps me manage my symptoms if I choose to stop all treatments? | 13 | 3 | 4 | 0 | DROP |

| | | | |
|----|--|--|---|
| 36 | How will I feel during my last days of life? | No low scores for this question, but during the meeting it was suggested to use instead: | Rephrase: What are the signs I should look for when I have limited time to live? |
| | | | Added question: I am worried about suffering at the end of life; will there be ways to manage my symptoms? |

APPENDIX K

| Questions discussed | | Relevance (Scoring) | Action | | | Modifications done post meetings |
|---------------------|---|---|--|--|--|--|
| | | Number of participants who rated Relevance by 1 OR 2 | Number of Participants who answered by: Unclear | Number of Participants who answered by need to Rephrase | Number of Participants who answered by need to Drop | |
| 3 | Is it a serious illness? | 16 | 2 | 4 | 2 | Rephrased: How serious is my illness? |
| 4 | How much function is left in my kidneys now? | 18 | 3 | 4 | 0 | Rephrased: How well are my kidneys functioning? |
| 18 | What happens if I don't choose to go aggressively with treatment? | 18 | 4 | 9 | 0 | Rephrased: What to expect if I don't choose to start kidney dialysis? |
| 20 | What are some high salt foods should I avoid? | 17 | 1 | 7 | 1 | Dropped (can be added to question 19) |
| 22 | What is a healthy body weight for me? | 16 | 3 | 5 | 0 | Rephrased: What is a healthy body weight for me? |

| | | | | | | |
|----|--|--|---|---|---|---|
| | What is my <i>dry weight</i> ? | | | | | |
| 24 | How do kidney failure and my other diseases affect each other? | 19 | 4 | 6 | 0 | Rephrased: How would my end stage renal disease and my other medical conditions affect each other? |
| 32 | What treatment/support is available to me when I deteriorate | No low scores for this question, but during the meeting it was suggested to use instead: | | | | Rephrased: What treatment/support is available to me/my family now and if my disease progresses or if I choose to stop all treatments? |
| 34 | Who will have the overall responsibility for my care if I deteriorate? | 18 | 6 | 5 | 2 | Rephrased: How can I assign someone to make healthcare decisions on my behalf if I no longer can? |
| 36 | Can I discuss goals of care with my primary care provider? Can I refuse treatment? | No low scores for this question, but during the meeting it was suggested to use instead: | | | | Rephrased: Who would be the right person to communicate my wishes related to end of life to in case I no longer can make decisions? |
| 37 | Is there a program that helps me manage my symptoms if I | 15 | 2 | 5 | 1 | Dropped |

| | | | | | | |
|----|--|--|--|--|--|---|
| | choose to stop all treatments? | | | | | |
| 40 | How will I feel during my last days of life? | No low scores for this question, but during the meeting it was suggested to use instead: | | | | Rephrased: What are the signs I should look for when I have limited time to live? |
| | | | | | | Added question: I am worried about suffering at the end of life; will there be ways to manage my symptoms? |

APPENDIX L

| Questions discussed | | Relevance | Action | | | Modifications done post meetings |
|---------------------|--|--|---|---|---|--|
| | | Number of participants who rated Relevance by 1 OR 2 | Number of Participants who answered by: Unclear | Number of Participants who answered by need to Rephrase | Number of Participants who answered by need to Drop | |
| 3 | Is it a serious illness? | 13 | 4 | 4 | 1 | Rephrased: How serious is my illness? |
| 7 | What does high CO2 in my Arterial blood gases (ABGs) result means? | 13 | 3 | 2 | 3 | Rephrased: Why is it important for me to check my Arterial blood gases (ABGs) result means? |
| 15 | Will I need lung transplant? If I do, when should I expect this? | 12 | 4 | 4 | 2 | Rephrased: Am I a good candidate for lung transplant? |
| 16 | What happens if I don't choose to go aggressively with treatment? | 14 | 4 | 7 | 0 | Rephrased: What other options do I have if I don't choose any of the indicated invasive therapies? |
| 20 | What are the options that help me quit | No low scores for this question, but during the meeting it was suggested to use instead: | | | | Rephrased: What are the available supports for smoking cessation? Are there any special programs that I can refer to? |

| | | | | | | |
|----|---|--|---|---|---|---|
| | smoking? | | | | | |
| 28 | What treatment/support is available to me when I deteriorate? | 14 | 3 | 5 | 0 | Rephrased: What treatment/support is available to me/my family now and if my disease progresses or if I choose to stop all treatments? |
| 30 | Who will have the overall responsibility for my care if I deteriorate? | 13 | 4 | 4 | 0 | Rephrased: How can I assign someone to make healthcare decisions on my behalf if I no longer can? |
| 32 | Can I discuss goals of care with my primary care provider? Can I refuse treatment? | No low scores for this question, but during the meeting it was suggested to use instead: | | | | Rephrased: Who would be the right person to communicate my wishes related to end of life to in case I no longer can make decisions? |
| 33 | Is there a program that helps me manage my symptoms if I choose to stop all treatments? | 13 | 3 | 4 | 0 | DROPPED |
| 36 | How will I feel during my last days of life? | 13 | 0 | 1 | 2 | Rephrased: What are the signs I should look for when I have limited time to live? |
| 37 | Are breathing problems | 12 | 1 | 2 | 1 | Keep the Question. |

| | | | | | | |
|--|----------------------------|--|--|--|--|---|
| | common at the end-of-life? | | | | | |
| | | | | | | Suggested Question: I am worried about suffering at the end of life, will there be ways to manage my symptoms? |

APPENDIX M

| Triggers discussed during the meeting for Heart Failure Palliative Care Consultation Trigger List: | | Relevance | Action | | | Modifications done post meeting |
|--|---|--|---|---|---|---|
| | | Number of Participants who rated Relevance by 1 OR 2 | Number of Participants who answered by: Unclear | Number of Participants who answered by need to Rephrase | Number of Participants who answered by need to Drop | |
| 3 | Multiple Emergency Department visits and/or multiple hospitalizations due to Heart Failure (≥ 3 visits/admissions in the last 12 months], Critical Care Unit Admission, and/or prolonged length of stay. (Score: 2) | No low scores for this question; Question was rephrased during the meeting. | | | | Rephrased: *Multiple Emergency Department visits (≥ 2 admissions in the last 3 months due to Heart Failure exacerbation * (≥ 3 ED visits in the last 6 months) (Score: 2) [It was suggested to separate these 2 criteria] |
| 6 | Unintentional weight loss of $\geq 10\%$ of dry | 3 | 0 | 1 | 0 | Rephrased: Cardiac cachexia $\geq 10\%$ of dry body weight over the last 6 months [Unintentional weight loss], frailty, loss of |

| | | | | | | |
|-----------|--|--|---|---|---|---|
| | body weight over the last 6 months [cardiac cachexia], frailty, loss of muscle tone, and/or poor appetite. (Score: 1) | | | | | muscle tone, and/or poor appetite. (Score: 1) |
| 8 | Functional and/or cognitive decline as compared to baseline or 6 months back or as per family/healthcare provider observations. (Score: 1) | No low scores for this question; Question was rephrased during the meeting. | | | | Rephrased: Functional AND/OR memory decline as compared to baseline or 6 months back or as per family/healthcare provider observations. (Score: 1) |
| 10 | Reported poor quality of life or increased care dependency by patient or family. (Score 1) | 4 | 1 | 1 | 0 | Rephrased: Reported poor quality of life and increased care dependency by patient or family. (Score: 1) |

APPENDIX N

| Triggers discussed during the meeting for End Stage Renal Disease Palliative Care Consultation Trigger List: | | Relevance | | Action | | Modifications done post meeting |
|--|---|---|--|--|--|---|
| | | Number of Participants who rated Relevance by 1 OR 2 | Number of Participants who answered by: Unclear | Number of Participants who answered by need to Rephrase | Number of Participants who answered by need to Drop | |
| 3 | Multiple Emergency Department visits and/or multiple hospitalizations due to End Stage Kidney Disease (≥ 3 visits/admissions in the last 12 months], Critical Care Unit Admission, and/or prolonged length of stay. (Score: 2) | No low scores for this question; Question was rephrased during the meeting. | | | | Rephrased: *Multiple Emergency Department visits (≥ 2 admissions in the last 3 months due to End Stage Kidney Disease * (≥ 3 ED visits in the last 6 months due to End Stage Kidney Disease). [It was suggested to separate these 2 criteria] (Score:2) |
| 6 | Unintentional weight loss of $\geq 10\%$ of dry body | 3 | 0 | 0 | 1 | Rephrased: Disease cachexia $\geq 10\%$ of dry body weight over the last 6 months [Unintentional weight loss], frailty, loss of |

| | | | | | | |
|-----------|---|---|--|--|--|--|
| | weight over the last 6 months [Disease cachexia], frailty, loss of muscle tone, and/or poor appetite. (Score: 1) | | | | | muscle tone, and/or poor appetite. (Score: 1) |
| 8 | Functional and/or cognitive decline as compared to baseline or 6 months back or as per family/healthcare provider observations. (Score: 1) | No low scores for this question; Question was rephrased during the meeting. | | | | Rephrased: Functional AND/OR memory decline as compared to baseline or 6 months back or as per family/healthcare provider observations. (Score: 1) |
| 10 | Reported poor quality of life or increased care dependency by patient or family. (Score 1) | No low scores for this question; Question was rephrased during the meeting. | | | | Rephrased: Reported poor quality of life and increased care dependency by patient or family. (Score: 1) |

APPENDIX O

| Triggers discussed during the meeting for End Stage Lung Disease Palliative Care Consultation Trigger List: | | Relevance | Action | | | Modifications done post meetings |
|---|---|---|--|--|---|----------------------------------|
| | | Number of Participants who rated Relevance by 1 OR 2 | Number of Participants who answered by: Unclear | Number of Participants who answered by need to Rephrase | Number of Participants who answered by need to Drop | |
| 3 | Multiple Emergency Department visits and/or multiple hospitalizations due to End Stage Lung Disease (≥ 3 visits/admissions in the last 12 months], Critical Care Unit Admission, and/or prolonged length of stay. (Score: 2) | No low scores for this question; Question was rephrased during the meeting. | | | Rephrased: *Multiple Emergency Department visits (≥ 2 admissions in the last 3 months due to End Stage Lung Disease). * (≥ 3 ED visits in the last 6 months due to End Stage Lung Disease. [It was suggested to separate these 2 criteria]) (Score:2) | |

| | | | | | | |
|----|--|---|---|---|---|---|
| 6 | Unintentional weight loss of $\geq 10\%$ of dry body weight over the last 6 months [Disease cachexia], frailty, loss of muscle tone, and/or poor appetite. (Score: 1) | 3 | 0 | 1 | 0 | Rephrased: Disease cachexia $\geq 10\%$ of dry body weight over the last 6 months [Unintentional weight loss], frailty, loss of muscle tone, and/or poor appetite. (Score: 1) |
| 8 | Functional and/or cognitive decline as compared to baseline or 6 months back or as per family/healthcare provider observations. (Score: 1) | No low scores for this question; Question was rephrased during the meeting. | | | | Rephrased: Functional AND/OR memory decline as compared to baseline or 6 months back or as per family/healthcare provider observations. (Score: 1) |
| 10 | Reported poor quality of life or increased care dependency by patient or family. (Score 1) | 3 | 1 | 1 | 0 | Rephrase: Reported poor quality of life and increased care dependency by patient or family. (Score: 1) |

| | | | |
|--|--|--|--|
| | | | Added trigger: Poorly controlled symptoms despite treatment [Chest Pain, Shortness of Breath, Pain Palpitation, Dizziness, Fatigue, and/or Insomnia] OR dependence on inotropes or other intravenous therapy. (Score: 2) |
|--|--|--|--|

APPENDIX P

How to make the most of your time with the Doctor

Most people who see their Physicians have concerns and questions. Often these get forgotten in the rush of the moment, only to be remembered soon after. To enhance your consultation visit with the Doctor, we have compiled a list of questions people frequently ask. We suggest that you tick those you want to ask and then write down any additional questions you have in the space provided.

You can keep this list of questions with you when you see your Doctor. Your Doctor might answers your questions without you even ask, but this sheet can serve as a checklist so that you know you have covered every matter essential for you.

| Type | Questions | |
|------------------------------|-----------|--|
| Disease Specific Information | 1 | What is Heart Failure? What caused my disease? |
| | 2 | Is it a lifelong disease? |
| | 3 | How serious is my illness? |
| | 4 | How well is my heart working now? |
| | 5 | What are the signs and symptoms that I may experience at this point? |
| | 6 | How do I know that my Heart Failure is getting worse? |
| | 7 | What are the alarming signs that I need to see so I come to the emergency department? |
| | 8 | How can I deal at home with the most common symptoms related to my Heart Failure? |
| Treatment Options | 9 | What are my available treatment options? |
| | 10 | What are the medications that I need to take? Are there any special side effects I should monitor? |
| | 11 | Do I need to use oxygen at home? |
| | 12 | Is there anything I can do to relieve my symptoms? |
| | 13 | Am I good candidate for Heart Transplant, Left Ventricular Assist Device, or Pacemaker? When should I expect this? |
| | 14 | What other options do I have if I don't choose any of the indicated invasive therapies? |
| Self-Care | 15 | What diet should I follow? |
| | 16 | What are some high salt foods should I avoid? |
| | 17 | How much fluid should I drink per day? |
| | 18 | What is a healthy body weight for me? What is my Dry Weight? |
| | 19 | Which over the counter medications should I stay away from? |
| | 20 | What medications should I take? What are the possible side effects I should expect? |
| Quality of | 21 | How would my Heart Failure affect other medical conditions that |

| | | |
|---------------------------------|----|--|
| Life | | I have or I may develop? |
| | 22 | What kinds of activities am I allowed to do? How much should I exercise? |
| | 23 | What type of work should I avoid? |
| | 24 | Am I healthy enough to have sex? |
| | 25 | What are the symptoms that would require me to contact the clinic? When would these require an ED visit? |
| | 26 | What symptoms should I expect to develop as my condition deteriorates? |
| Palliative and End-of Life Care | 27 | Who can I talk to about things that worry or bother me? |
| | 28 | Who can help me make decisions about my care? |
| | 29 | What treatment/support is available to me/my family if my disease progresses? If I choose to stop all treatments? |
| | 30 | What support is available to me if I choose to be cared for at home? |
| | 31 | How can I assign someone to make healthcare decisions on my behalf if I no longer can? |
| | 32 | Is it ok to spend my last days at home? |
| | 33 | Who would be the right person to communicate my wishes related to end of life to in case I no longer can make decisions? |
| | 34 | Will someone tell me when I am approaching the end-of-life? |
| | 35 | Is it possible to predict how long someone has left to live? |
| | 36 | What are the signs I should look for when I have limited time to live? |
| | 37 | Are breathing problems common at the end-of-life? |
| | 38 | Is pain common at the end-of-life? |
| | 39 | I am worried about suffering at the end of life, will there be ways to manage my symptoms? |
| Family Concerns | 40 | How do I best help the person who is ill if they deteriorate? |
| | 41 | Who can I turn to if I have concerns about the care given to the person who is ill? |
| | 42 | Who can we talk to about things that worry or bother us? |

Additional Questions you may want to ask:

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APPENDIX Q

How to make the most of your time with the Doctor

Most people who see their Physicians have concerns and questions. Often these get forgotten in the rush of the moment, only to be remembered soon after. To enhance your consultation visit with the Doctor, we have compiled a list of questions people frequently ask. We suggest that you tick those you want to ask and then write down any additional questions you have in the space provided.

You can keep this list of questions with you when you see your Doctor. Your Doctor might answers your questions without you even ask, but this sheet can serve as a checklist so that you know you have covered every matter essential for you.

| Type | Questions | |
|------------------------------|-----------|--|
| Disease Specific Information | 1 | What is Kidney Failure? What caused my kidneys to fail? |
| | 2 | Is it a lifelong disease? |
| | 3 | How serious is my illness? |
| | 4 | How well are my kidneys functioning? |
| | 5 | What are the signs and symptoms that I may experience at this point? |
| | 6 | What do Glomerular Filtration Rate, Creatinine and Urine Proteins mean? |
| | 7 | Is my blood pressure in the normal range? |
| | 8 | How do I know that my Kidney Failure is getting worse? |
| | 9 | What health problems can Kidney Failure cause? |
| | 10 | What are the alarming signs that I need to see so I come to the Emergency Department? |
| | 11 | How can I deal with Swelling? Shortness of breath? Fatigue? Nausea? |
| Treatment Options | 12 | What are my available treatment options? |
| | 13 | What are the medications that I need to take? Are there any special side effects I should monitor? |
| | 14 | Is there anything I can do to relieve my symptoms? |
| | 15 | Will I need dialysis or kidney transplant? If I do, when should I expect this? |
| | 16 | What happens if I do not choose to continue on dialysis or get a transplant? |
| | 17 | What happens if my kidneys stop working completely? |
| | 18 | What to expect if I don't choose to start kidney dialysis? |
| Self-Care | 19 | What diet should I follow? What are some high salt foods should I avoid? |
| | 20 | How much fluid should I drink per day? |

| | | |
|---------------------------------|----|--|
| | 21 | What is a healthy body weight for me? |
| | 22 | Which over the counter medications should I stay away from? |
| Quality of Life | 23 | How would my Kidney Failure and my other medical conditions affect each other? |
| | 24 | How does Kidney Failure affect my day-to-day life? |
| | 25 | How will my quality of life be like if I choose dialysis? How long do patients live on dialysis? |
| | 26 | How will my quality of life be like if I choose kidney transplant? |
| | 27 | Am I healthy enough to have sex? |
| | 28 | What symptoms will I experience when my condition deteriorates? |
| Palliative and End-of Life Care | 29 | Who can I talk to about things that worry or bother me? |
| | 30 | Who can help me make decisions about my care? |
| | 31 | What treatment/support is available to me when I deteriorate? |
| | 32 | What support is available to me if I choose to be cared for at home? |
| | 33 | How can I assign someone to make healthcare decisions on my behalf if I no longer can? |
| | 34 | Is it ok to spend my last days at home? |
| | 35 | Are there any symptoms I can expect near the end of life? |
| | 36 | Will someone tell me when I am approaching the end-of-life? |
| | 37 | Is it possible to predict how long someone has left to live? |
| | 38 | How will I feel during my last days of life? |
| | 39 | Are breathing problems common at the end-of-life? |
| | 40 | Is pain common at the end-of-life? |
| | 41 | I am worried about suffering at the end of life, will there be ways to manage my symptoms? |
| Family Concerns | 42 | How do I best help the person who is ill if they deteriorate? |
| | 43 | Who can I turn to if I have concerns about the care given to the person who is ill? |
| | 44 | Who can we talk to about things that worry or bother us? |

Additional Questions you may want to ask:

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APPENDIX R

How to make the most of your time with the Doctor

Most people who see their Physicians have concerns and questions. Often these get forgotten in the rush of the moment, only to be remembered soon after. To enhance your consultation visit with the Doctor, we have compiled a list of questions people frequently ask. We suggest that you tick those you want to ask and then write down any additional questions you have in the space provided.

You can keep this list of questions with you when you see your Doctor. Your Doctor might answers your questions without you even ask, but this sheet can serve as a checklist so that you know you have covered every matter essential for you.

| Type | Questions | |
|------------------------------|-----------|--|
| Disease Specific Information | 1 | What is End Stage Lung Disease? |
| | 2 | Is it a lifelong disease? |
| | 3 | How serious is my illness? |
| | 4 | How much function is left in my lungs? |
| | 5 | What are the signs and symptoms that I may experience at this point? |
| | 6 | How do I know that my lung failure is getting worse? |
| | 7 | Why is it important for me to check my Arterial blood gases (ABGs) result means? |
| | 8 | What are the alarming signs that I need to see so I come to the emergency department? |
| | 9 | How can I deal with trouble breathing? Fast heartbeats? Bloating sensation? Feeling tired? |
| Treatment Options | 10 | What are my available treatment options? |
| | 11 | What are the medications that I need to take? Are there any special side effects I should monitor? |
| | 12 | Do I need to use oxygen at home? |
| | 13 | Do I need to use bronchodilators at home? |
| | 14 | Is there anything I can do to relieve my symptoms? |
| | 15 | Am I a good candidate for lung transplant? |
| | 16 | What other options do I have if I don't choose any of the indicated invasive therapies? |
| Self-Care | 17 | What diet should I follow? |
| | 18 | What is a healthy body weight for me? |
| | 19 | Which over the counter medications should I stay away from? |
| | 20 | What are the available supports for smoking cessation? Are there any special programs that I can refer to? |
| Quality of | 21 | How do End Stage Lung Disease and my other diseases affect |

| | | |
|---------------------------------|----|---|
| Life | | each other? |
| | 22 | What kinds of activities are allowed? How much should I practice? |
| | 23 | What type of work should I avoid? |
| | 24 | Am I healthy enough to have sex? |
| | 25 | What symptoms will I experience when my condition deteriorates? |
| Palliative and End-of Life Care | 26 | Who can I talk to about things that worry or bother me? |
| | 27 | Who can help me make decisions about my care? |
| | 28 | What treatment/support is available to me/my family now and if my disease progresses or if I choose to stop all treatments? |
| | 29 | What support is available to me if I choose to be cared for at home? |
| | 30 | How can I assign someone to make healthcare decisions on my behalf if I no longer can? |
| | 31 | Is it ok to spend my last days at home? |
| | 32 | Can I discuss goals of care with my primary care provider? Can I refuse treatment? |
| | 33 | Will someone tell me when I am approaching the end-of-life? |
| | 34 | Is it possible to predict how long someone has left to live? |
| | 35 | Are there any symptoms I can expect towards the end of life? |
| | 36 | Are breathing problems common at the end-of-life? |
| | 37 | Is pain common at the end-of-life? |
| | 38 | I am worried about suffering at the end of life; will there be ways to manage my symptoms? |
| Family Concerns | 39 | How do I best help the person who is ill if they deteriorate? |
| | 40 | Who can I turn to if I have concerns about the care given to the person who is ill? |
| | 41 | Who can we talk to about things that worry or bother us? |

Additional Questions you may want to ask:

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APPENDIX S

Specialty Clinics or Coronary Care Unit Registered Nurses, Cardiology Clinical Nurse Specialist, or the Primary Attending Physician answers the below:

- Does the Patient have Heart Failure and New York Heart Association [NYHA] Functional Class III or IV?

If the answer is **yes** to the above, the Palliative Care Trigger List is opened, and further assessment is warranted.

| Heart Failure Palliative Care Trigger Items | Score |
|---|-------|
| 1 Decision Support: Discussion of <i>advanced care planning</i> AND/OR goals of care OR <i>possible conflict</i> [either among the multidisciplinary team[s], between the multidisciplinary team and patient or family, or between family members]. | 2 |
| 2 Patient and/or family members verbalized <i>wishes for no resuscitation</i> in case of clinical deterioration [please specify who is providing this information]. | 2 |
| 3 2 or more Heart Failure Related <i>Hospitalizations</i> in the last 3 months. | 2 |
| 4 3 or more <i>Emergency Department visits</i> due to Heart Failure Exacerbation in the last 6 months. | 2 |
| 5 Presence of a <i>Ventricular Assist Device</i> [VAD] OR a plan for one in the next 6 months OR status post <i>Cardiac Transplant</i> OR listed on a Transplant List OR ineligible for or uninterested in advanced therapies. | 2 |
| 6 Presence of 3 or more chronic <i>comorbidities</i> that require self-care [Diabetes; Valvular Heart Disease; Lung Disease; Cardiorenal Syndrome...]. | 1 |
| 7 <i>Cardiac Cachexia</i> [loss of 10% or more of dry body weight over the last 6 months], <i>Unintentional Weight Loss</i> , <i>Frailty</i> , <i>Loss of Muscle Tone</i> , AND/OR <i>Poor Appetite</i> . | 1 |
| 8 <i>Poorly Controlled Symptoms</i> despite treatment [Chest Pain, Shortness of Breath, Palpitations, Dizziness, Fatigue, and/or Insomnia] OR dependence on inotropes or other intravenous therapy. | 2 |
| 9 <i>Functional</i> AND/OR <i>Memory Decline</i> as compared to baseline, 6 months prior, or as per family/healthcare provider observations. | 1 |
| 10 <i>Social Withdrawal</i> or any reported increase in signs and/or symptoms of <i>Depression</i> AND/OR <i>Anxiety</i> in patients AND/OR <i>Caregiver Burnout</i> . | 1 |
| 11 Reported poor quality of life AND increased care dependency by patient or family. | 1 |

A patient with a weighted score of ≥ 2 based on the above triggers will be eligible for a Palliative Care Consultation. Please notify the Primary Attending Physician of the screening result for consultation initiation.

APPENDIX T

Specialty Clinics or Hemodialysis Unit Registered Nurses or Adult Clinical Nurse Specialist or the Primary Attending Physician answers the below:

- Does the Patient have End Stage Renal Disease and Karnofsky Performance Scale Index 1 or 2?

If the answer is **yes** to the above, the Palliative Care Trigger List is opened, and further assessment is warranted.

| End Stage Renal Disease Palliative Care Trigger Items | Score |
|---|-------|
| 1 Decision Support: Discussion of <i>advanced care planning</i> AND/OR goals of care OR <i>possible conflict</i> [either among the multidisciplinary team[s], between the multidisciplinary team and patient or family, or between family members]. | 2 |
| 2 Patient and/or family members verbalized <i>wishes for no resuscitation</i> in case of clinical deterioration [please specify who is providing this information]. | 2 |
| 3 2 or more Renal Disease Related <i>Hospitalizations</i> in the last 3 months. | 2 |
| 4 3 or more <i>Emergency Department visits</i> due to Renal Disease Exacerbation in the last 6 months. | 2 |
| 5 On <i>dialysis</i> OR plans to start dialysis in the next 6 months OR is refusing to start dialysis OR decides to stop dialysis. | 2 |
| 6 Presence of 3 or more chronic <i>comorbidities</i> that require self-care [Diabetes; Valvular Heart Disease; Lung Disease; Cardiorenal Syndrome...]. | 1 |
| 7 <i>Disease Cachexia</i> [loss of 10% or more of dry body weight over the last 6 months], <i>Unintentional Weight Loss</i> , <i>Frailty</i> , <i>Loss of Muscle Tone</i> , AND/OR <i>Poor Appetite</i> . | 1 |
| 8 <i>Poorly Controlled Symptoms</i> despite treatment [Nausea, Vomiting, Pruritis, Confusion, Obtundation, Restlessness, and/or Lethargy]. | 2 |
| 9 <i>Functional</i> AND/OR <i>Memory Decline</i> as compared to baseline, 6 months prior, or as per family/healthcare provider observations. | 1 |
| 10 <i>Social Withdrawal</i> or any reported increase in signs and/or symptoms of <i>Depression</i> AND/OR <i>Anxiety</i> in patients AND/OR <i>Caregiver Burnout</i> . | 1 |
| 11 Reported poor quality of life AND increased care dependency by patient or family. | 1 |

A patient with a weighted score of ≥ 2 based on the above triggers will be eligible for a Palliative Care Consultation. Please notify the Primary Attending Physician of the screening result for consultation initiation.

APPENDIX U

Specialty Clinics or RCU Unit Registered Nurses or Adult Clinical Nurse Specialist or the Primary Attending Physician answers the below:

- Does the Patient have End Stage Lung Disease and Modified MRC score greater or equal 3?

If the answer is **yes** to the above, the Palliative Care Trigger List is opened, and further assessment is warranted.

| End Stage Lung Disease Palliative Care Trigger Items | Score |
|---|-------|
| 1 Decision Support: Discussion of <i>advanced care planning</i> AND/OR goals of care OR <i>possible conflict</i> [either among the multidisciplinary team[s], between the multidisciplinary team and patient or family, or between family members]. | 2 |
| 2 Patient and/or family members verbalized <i>wishes for no resuscitation</i> in case of clinical deterioration [please specify who is providing this information]. | 2 |
| 3 2 or more Lung Disease Related <i>Hospitalizations</i> in the last 3 months. | 2 |
| 4 3 or more <i>Emergency Department visits</i> due to Lung Disease Exacerbation in the last 6 months. | 2 |
| 5 Status post Lung Transplant or listed on a Transplant List OR ineligible for or uninterested in advanced therapies. | 2 |
| 6 Presence of 3 or more chronic <i>comorbidities</i> that require self-care [Diabetes; Valvular Heart Disease; Lung Disease; Cardiorenal Syndrome...]. | 1 |
| 7 <i>Cardiac Cachexia</i> [loss of 10% or more of dry body weight over the last 6 months], <i>Unintentional Weight Loss</i> , <i>Frailty</i> , <i>Loss of Muscle Tone</i> , AND/OR <i>Poor Appetite</i> . | 1 |
| 8 <i>Persistent Dyspnea</i> at rest and/or with minimal exertion while maintained on Oxygen Therapy AND/OR <i>Persistent Hypercarbia</i> (PCO ₂) ≥ 50 mm Hg. | 2 |
| 9 <i>Poorly Controlled Symptoms</i> despite treatment [Chest Pain, Shortness of Breath, Palpitations, Dizziness, Fatigue, and/or Insomnia] OR dependence on inotropes or other intravenous therapy. | 2 |
| 10 <i>Functional</i> AND/OR <i>Memory Decline</i> as compared to baseline, 6 months prior, or as per family/healthcare provider observations. | 1 |
| 11 <i>Social Withdrawal</i> or any reported increase in signs and/or symptoms of <i>Depression</i> AND/OR <i>Anxiety</i> in patients AND/OR <i>Caregiver Burnout</i> . | 1 |
| 12 Reported poor quality of life AND increased care dependency by patient or family. | 1 |

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