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“It's Not Something That’s Really Been Brought Up”: Advance Care Planning Among Individuals Living with Mechanical Circulatory Support

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A dissertation submitted in partial satisfaction of the
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in Nursing

by

Tiffany Dzou

2021

ABSTRACT OF THE DISSERTATION

"It's Not Something That's Really Been Brought Up": Advance Care Planning Among Individuals Living with Mechanical Circulatory Support

by

Tiffany Dzou
Doctor of Philosophy in Nursing
University of California, Los Angeles, 2021
Professor Huibrie C. Pieters, Chair

Despite the well-established evidence about catastrophic complications in individuals living with durable mechanical circulatory support, little is known about the decision-making processes in advance care planning for this population. While findings from current studies give insights into clinicians' attitudes and protocol development to integrate palliative care specialists in advance care planning, these results do not describe the patients' experiences in managing the uncertain outcomes of living with durable mechanical circulatory support. Therefore, this dissertation research explored the personal experiences of individuals living with mechanical circulatory support to analyze how their complex disease trajectories impact decision-making about advance care planning.

Constructivist grounded theory guided all aspects for this dissertation. In-depth interviews, using a semi-structured guide to navigate the conversations, were conducted with 24 individuals who were implanted with durable mechanical circulatory support devices. Systematic analysis of the interview transcripts led to the identification of emergent categories and the

development of the *Theory of Pivoting Uncertainties*, a situation-specific theory. The first paper, a systematic literature review, points to the dearth of ongoing ACP communication and the potential for nurses to provide primary palliative care for the MCS population. Consistent with the findings from the literature review, the paucity of ACP communication continued to be evident within the sample of participants. In the first data-based paper, participants' perceptions of opportunities for ongoing advance care planning conversations were elucidated in four categories: 1) identifying the optimal context and timing for advance care planning; 2) sharing information with key stakeholders; 3) examining their understanding of advance care planning, and 4) assessing satisfaction with the information that had been received. These four categories were interrelated and occurred simultaneously to present ongoing opportunities for advance care planning across the mechanical circulatory support trajectory. In the second data-based paper on the *Theory of Pivoting Uncertainties* describes the process of decision-making about advance care planning in the context of living with mechanical circulatory support. Within the core category of complexities in decision-making about advance care planning, there were three dynamic subcategories: 1) impediments; 2) uncertainties; and 3) promoters. Collectively, the subcategories in the *Theory of Pivoting Uncertainties* gave insight into participants' patterned responses towards these uncertainties and ultimately decision-making around ACP.

These insights into the experiences of the complicated disease trajectories among individuals with mechanical circulatory support evidence their growing awareness of the uncertainties of living. The awareness of uncertain outcomes holds the potential for clinicians to engage individuals in sensitive advance care planning conversations. Additionally, the current sample highlight the need for clinicians, including MCS-trained clinical nurses and MCS coordinators, to initiate ongoing conversations with mechanical circulatory support individuals and their families. By exploring the firsthand experiences of individuals living with mechanic circulatory support, these findings are useful for informing clinical practice, future research, and policy-making around advance care planning.

The dissertation of Tiffany Dzou is approved.

Lynn V. Doering

Jo-Ann Eastwood

Carol L. Pavlish

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University of California, Los Angeles

2021

Dedication

This work is dedicated to the 24 participants who braved the discomfort of talking about death and dying, and in so doing taught us how to be courageous when facing the uncertainties of living.

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Education

Master of Science in Nursing (MSN)	Charles R. Drew University of Medicine and Science, Los Angeles	2014
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Palliative Care in Mechanical Circulatory Support: A Systematic Review *Poster presentation in the 2020 UCLA School of Nursing Research Day*	2020
Palliative Care in Mechanical Circulatory Support: A Systematic Review *Poster presentation in the Sigma 45th Biennial Convention*	2019
Convergent Procedure: Nursing Considerations *Invited speaker in Cedars-Sinai MD/RN Critical Care Lecture Series*	2018

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Changing attitudes: The Chinese American Senior on End-of-life Decision-Making *Poster presentation in the Gerontological Society of America’s 69th Annual Scientific Meeting*	2016
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The Gerontological Society of America, Member	2014–present
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Professional Service Activities

MD/RN Collaboration *Cedars-Sinai 6NE Unit Co-Chair*	2017–2020

Introduction to the Dissertation

Background and Significance

Cardiovascular disease is the leading cause of mortality, accounting for 23.4% of all deaths in the United States (American Heart Association (AHA) & American Stroke Association (ASA), 2017; Centers for Disease Control and Prevention, 2017). As the population in the United States becomes increasingly older, so increases the prevalence of heart disease, which is now projected to impact 45% of the population by 2035 (AHA & ASA, 2017). Between 2015 to 2035, it is estimated that individuals affected by advanced heart failure will increase from 5.8 million to 8.8 million (AHA & ASA, 2017). Currently, advanced heart failure is managed through three distinct approaches: medical therapy, surgical therapy, and heart transplantation (Van Diepen et al., 2017). When medical and surgical interventions are no longer effective, advanced heart failure patients may be presented with a complex decision to choose life prolongation through the implantation of a mechanical circulatory support (MCS) device (AHA, 2017). Between 2006 and 2016, the population of individuals implanted with a MCS device increased 40-fold (Kirklin et al., 2017).

The use of a MCS device can be categorized into three treatment goals: bridge to candidacy, bridge to transplant, and destination therapy (Teuteberg et al., 2020). Bridge to candidacy is the treatment therapy for individuals who are pending eligibility for heart transplant (Frigerio et al., 2017). The second option, bridge to transplant is the goal therapy for individuals who are eligible for heart transplantation, but need more time to be matched with a suitable donor organ (Kusne et al., 2017). Finally, destination therapy is the treatment goal for individuals who are ineligible for heart transplantation, but receive the MCS device for life prolongation and to improve the quality of life (QOL) (AHA, 2017; Peura et al., 2012). In 2019, 73% of MCS patients were implanted with the MCS device with destination therapy as the treatment goal (Molina et al., 2021). The goal of therapy may evolve over time with 40% of patients reporting a change within two years of MCS implantation (Schramm et al., 2019).

Although MCS therapy is beneficial for many advanced heart failure patients, it is filled with risks and uncertain outcomes. The five-year survival rate of MCS patients is 47% (Teuteberg et al., 2020), and 89.2% of MCS patients report experiencing adverse events such as stroke, gastrointestinal bleeding, and sepsis within the first 60 days of implantation (AHA, 2017; Kirklin et al., 2015, 2017; Kusne et al., 2017; Newsom & Paciullo, 2013). However, the MCS trajectory is different from the steady decline of the advanced heart failure disease trajectory. Prior to the device implant, end-stage heart failure patients experience significant symptom burden at rest, but after MCS surgery individuals may experience improved QOL with prolonged survival (Swetz et al., 2014). Despite the improvement in QOL with less shortness of breath and fatigue, after implantation patients are faced with acute, life-threatening events such as stroke and pump thrombosis. The physical changes after MCS surgery are generally positive, but there are few symptomatic cues to motivate MCS patients and their family members to anticipate future adverse events that require ACP conversations (Swetz et al., 2014). For these reasons, ongoing discussions with MCS patients and their families are needed to examine the personal values that inform advance care planning (ACP) to address the uncertainties of living with the device and the potential complications along the MCS trajectory.

In response to the complexities of the MCS trajectory, the Centers for Medicare and Medicaid Services (CMS) and the Joint Commission recommended ACP for all individuals undergoing evaluation for MCS surgery (CMS, 2013; Sagin et al., 2016). Additional recommendations for ACP among MCS patients accentuate ongoing conversations over time to address potential complications and changes in health (Wordingham & McIlvennan, 2019). However, despite these clear recommendations and the opportunities for these sensitive conversations to happen during the frequent interactions with MCS clinicians, minimal ACP conversations have been reported (Wordingham & McIlvennan, 2019). Furthermore, ACP discussions were found to be primarily focused on the simply completing the advance directives and identification of surrogate decision-makers (Chuzi et al., 2019). In accordance with CMS recommendations, the initial ACP conversations were often conducted by consult-based palliative care specialists (CMS, 2013; Sagin et al., 2016). However, research on the perceptions of bereaved MCS caregivers, following the death of a MCS patient, suggested that the consult-based integration of palliative care specialists led to fragmented ACP communication and perceptions of being abandoned by the MCS team (McIlvennan et al., 2016). Against this background, research is urgently needed to explore the discrepancy between the completion of advance directives and palliative care consultations, and the lack of ongoing ACP communication among individuals living with a MCS device. Finally, in these times of patient-centered care and shared decision-making, it is alarming that no research was found that involved the views of the key stakeholder: the MCS patient.

Purpose of the Study

My dissertation research is focused on the unique and understudied experiences of MCS individuals related to ACP communication. Qualitative research was needed to describe the perceptions of individuals living with MCS in ACP. Constructivist grounded theory guided all aspects of the research as the methodology is especially suited to study dynamic interactions and the reconstruction and interpretation of the past, present, and future (Charmaz, 2014). By examining participants' perceptions and experiences of ACP communication over their MCS trajectory, findings from this study will add to existing knowledge in ACP that will tailor the development of education and resources to meet the needs of the MCS population. Therefore, the overall purpose of this dissertation was to explore how MCS patients evaluated the experiences from their complex disease trajectories and applied them to ACP communication.

Overview of the Dissertation: Three Manuscripts

My dissertation research is comprised of three manuscripts. The first manuscript was a systematic review of literature that examined how nurses can champion sensitive discussions across the MCS trajectory, specifically focusing on the historical convergence between ACP and MCS. Findings in the literature suggested fragmented ACP communication between clinicians, MCS individuals, and the patients' family members. The current consult-based approach to ACP communication, with the primary MCS team handing off ACP discussions to palliative care specialists, was perceived to be an impediment to ongoing conversations across the MCS trajectory (Sinha et al., 2017). Nurses, such as MCS coordinators and MCS-trained cardiac nurses, were identified as ideal candidates to bridge the gap in communicating and facilitating ACP conversations, over time, among the MCS population (O'Connor et al., 2016). However, nurses reportedly felt unprepared to engage patients in ACP communication due to the lack of formal training on discussions around goals of care (Wittenberg et al., 2016). Currently, there are no clear guidelines for nurses to engage MCS patients and families in ACP communication. Thus, additional research is needed to examine MCS patients' perceptions on the role of nursing in shared decision-making around ACP communication (Wittenberg et al., 2016).

In the second manuscript, I examined MCS individuals' perceptions on the opportunities and challenges for ongoing ACP communication. A majority of the current sample reported completing advance directives (n=19); however, they could not recall ACP conversations with clinicians. Grounded in the participants' reflections on conversations around ACP, four dynamic categories were developed: identifying context and timing, sharing information, understanding of ACP, and assessing satisfaction. Most striking from the participants' narratives about the lack of ACP conversations, was one individual's reflection, "it's (ACP) not something that's really been brought up (by the heart team)." Overall, we recognized the dearth of ACP communication across the MCS trajectory and identified potential opportunities and challenges for future ACP conversations among MCS individuals, supportive others, and clinicians.

In the third manuscript, I presented a situation-specific theory that delineated the process of decision-making around ACP in the context of living with a MCS device. I focused on how the complexities of the MCS trajectory were situated over time and understood by the individual through external and internal processes. As MCS individuals experienced uncertainties in their MCS trajectory, they developed an awareness of the precariousness of their health and pivoted from passivity to action in ACP communication. Thus, we found that decision-making about ACP communication pivoted around experiences of uncertainty throughout the MCS trajectory.

Conclusion

Collectively, these three manuscripts provide insight into the experiences of MCS individuals in relation to the opportunities and challenges they face in navigating ACP communication. These participants shared their stories to pave the way for clinicians to enhance ACP conversations with future MCS patients given the uncertainties and complexities of living with MCS. In the words of the participants themselves, findings from this study have important implications for clinical practice on how to enhance and engage MCS individuals in conversations around ACP. Finally, this work also elucidates future research pathways to deepen our understanding and improve ACP communication with the MCS population.

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First Manuscript

Advance Care Planning in Mechanical Circulatory Support: A Systematic Literature Review

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Introduction

Mechanical circulatory support (MCS) is a complex technology used to treat heart failure (HF) patients. In individuals awaiting transplant, MCS can extend time for patients to match with a suitable organ. For patients deemed ineligible for transplant, a MCS device can improve health-related quality of life (HRQOL) (Abshire & Himmelfarb, 2014; Peura et al., 2012). From 2006 to 2016, the MCS population increased from 511 to 22,866 patients (Kirklin et al., 2017). However, MCS technology increases the risk for adverse events, such as strokes, sepsis, and gastrointestinal bleeds (American Heart Association (AHA) & American Stroke Association (ASA), 2017; Kirklin et al., 2015). Furthermore, the aging HF population proliferates catastrophic events and emotional burdens experienced by patients and caregivers. These issues necessitate a greater understanding of patients' preferences to provide care aligned with individual values.

Advance care planning (ACP) ensures that individuals receive medical care in accordance with their goals, values, and treatment preferences (Sudore et al., 2017). ACP is increasingly recognized as a series of decisional processes, not merely the completion of advance directives (Sudore et al., 2017) and represents ongoing communication between patients, families, and clinicians to support shared decision-making (Lovell & Yates, 2014; Swetz et al., 2014). The complex MCS trajectory calls for deeper understandings of the interface between ACP and MCS (Fang et al., 2015). The purpose of this systematic review is to examine the historical development of ACP and MCS to better understand how clinicians, particularly nurses, can champion ACP discussions across this unique trajectory.

Methods

The literature was reviewed to identify research gaps, describe methodological limitations, and make recommendations for practice and future research (Grant & Booth, 2009). CINAHL, PubMed, Medline, and PsycINFO were searched using MESH terms: "heart assist device," "artificial heart," "advance care planning," "palliative care," and "advance directives" with no restrictions on dates to minimize omissions. Only articles written in English were included. Initial article titles and abstracts were reviewed for relevance and appropriateness. Studies on ACP in HF patients, non-specific to MCS, were excluded from the review. Finally, reference lists were searched to identify additional eligible studies.

The search strategy is shown in the flow diagram (Figure 1) according to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (Liberati et al., 2009). A total of 183 studies were identified through database searches and five additional articles from the review of reference lists. Duplicate articles, commentaries, poster abstracts, and non-ACP related papers were excluded resulting in the final 27 articles.

Results

We first present findings on the historical context of MCS, its treatment goals and trajectories, and psychosocial complexities. Subsequently, we offer results on the historical context of ACP and its convergence with MCS. The final section highlights nursing's role in ACP.

Historical Context of MCS Devices

In 1977, the National Institutes of Health called for research on long-term implantable pumps (Peura et al., 2012). Throughout the 1980s, MCS evolved from surgical bypass technology to wearable ventricular assistive devices. Currently, MCS devices are indicated for individuals with advanced and refractory HF and cardiogenic shock (AHA & ASA, 2017; Fang et al., 2015; Van Diepen et al., 2017). The integration of wearable MCS devices was approved by the Food and Drug Administration in 1992 (Stewart & Givertz, 2012). The use of MCS is becoming more widespread and understanding treatment goals is imperative.

Treatment Goals and MCS Trajectories

MCS can be classified into two treatment goals: bridge to transplant and destination therapy. Sadly, only a fraction of HF patients in the United States (N = 3,244) received transplants in 2017 (AHA, 2018). The development of MCS as bridge to transplant has impacted the trajectory of HF patients, in 2016, 31.7% of heart transplant candidates had MCS devices at the time of listing (Colvin et al., 2018). Additionally the benefits of MCS are improved hemodynamics and circulation that can reverse or prevent end-organ dysfunction (Fang et al., 2015; Meredith et al., 2016; Van Diepen et al., 2017) and improve HRQOL and survivability (Peura et al., 2012).

Destination therapy is designated for patients with comorbidities such as irreversible renal, neurological, or hepatic disease (Kirklin et al., 2011; Peura et al., 2012), and has a 6-month mortality rate of 20%-33%, as compared to the 61% of inotropic-dependent HF patients (Peura et al., 2012). However, a positive response to lifestyle changes mitigate some contraindications to destination therapy with approximately 10% of patients later qualifying for bridge-to-transplant (Kirklin et al., 2011). Overall, the use of MCS devices for destination therapy is beneficial to improve HRQOL for advanced HF patients who are ineligible for a heart transplant (Sagin et al., 2016).

MCS Complexities

Despite potential for improved HRQOL, MCS devices are irrevocably linked with life-altering adverse effects that lead to frequent readmissions (Swetz et al., 2013). Within the first 60 days of implantation, approximately 89.2% of patients experience adverse events, most commonly embolic or hemorrhagic strokes, with incidence rates of 7-11% in the first 2 years (AHA & ASA, 2017; Kirklin et al., 2015; Kirklin et al., 2017; Newsom & Paciullo, 2013). Infections have a 30% incidence rate during the first 3 years (AHA & ASA, 2017; Kirklin et al., 2015). Multi-system organ failure occurs in 15.6% of the MCS population (Kusne et al., 2017). Overall, the mortality rate of patients with MCS is 8.8% within 1 year of implantation (Kusne et al., 2017; Sagin et al., 2016). These potential post-implantation complications create complex trajectories that increase physical, psychological, and emotional burdens for patients and families (Wordingham et al., 2016).

Psychosocial Complexities Associated with MCS

Psychological complexities of MCS therapy are linked to patient and family expectations versus the realities of post-implantation outcomes. In a large single-center study, 81.8% of readmissions were unplanned and revealed a discrepancy between anticipated and actual outcomes (Hernandez et al., 2015). This unpredictable nature of the MCS trajectory increased psychosocial and physical burdens on caregivers (Rady & Verheijde, 2014). In a qualitative study, family caregivers reported feelings of anxiety and worry (Marcuccilli et al., 2014). Thus, the psychosocial complexities related to MCS weigh heavily on both patients and families.

Due to the complex trajectories with MCS, patients, caregivers, and clinicians collaborate and develop close relationships. However, as patients transitioned to hospice, family members described feeling loss of support from MCS clinicians when care was transferred to unfamiliar hospice providers (McIlvennan et al., 2016). Some participants described confusion attributed to the fragmented care received during the transition (McIlvennan et al., 2016). On the receiving end of the transfer, palliative specialists lacked technical knowledge about MCS devices, and this amplified caregivers' distrust towards these clinicians (McIlvennan et al., 2016). It is evident that more research is required to examine the support needed to reduce caregivers' experiences of abandonment and confusion at the end of the MCS trajectory.

Historical Context of ACP

The historical context of ACP sheds light on important conversations needed to address difficult health trajectories. In 1975, the concept of patient self-determination emerged around the controversial case on the removal of ventilator support for Karen Ann Quinlan (Miller, 2017). In 1990, the Patient Self-Determination Act was passed by Congress in response to the case of Nancy Cruzan to ensure that patients would receive adequate information on advance directives upon admission to a hospital (Miller, 2017). The enactment of the Patient Self-Determination Act also promoted care aligned with patient values and preferences. These historical events further contribute to ethical values of patient autonomy, and the development of ACP.

Convergence of ACP and MCS

Figure 2 presents the historical convergence of specific landmark events of ACP and MCS. Despite the longevity of research in both these areas of study, their convergence has resulted in limited applications of ACP for MCS individuals. The first of 3 interventional studies was a single-center retrospective study on protocol development for palliative consultation. The collaborative efforts between the palliative care and MCS teams resulted in increased completion of pre-implant palliative consults from 17.2% to 96.6%. This collaboration also increased designation of surrogate decision-makers from 40.6% to 98.3% (Sinha et al., 2017). In the second study, a four-pronged intervention was developed to identify specific stages in the MCS trajectory, standardize the role of palliative care, promote shared decision-making, and facilitate multidisciplinary communication. The intervention resulted in increased preparedness plans from 52% to 73%; advance directive completion increased from 71% to 83% (Woodburn et al., 2019). The third study was a randomized pilot study on the feasibility of using a guided discussion, *Sharing Patients' Illness Presentations to Increase Trust*, as an ACP intervention (Metzger et al., 2016). This intervention demonstrated the acceptability and willingness of MCS patients and families to engage in ACP (Metzger et al., 2016). These 3 studies reflect novel ACP approaches that pertain to palliative consultation, preparedness planning, and completion of advance directives.

In the context of HF, current studies of ACP and MCS are limited both in quantity and depth. The existing evidence focuses on clinicians' perspectives of ACP. In one report, MCS clinicians cited discomfort, lack of education, and prognostic uncertainty as factors that inhibited ACP conversations (Wordingham et al., 2016). Another study specifically examined physicians' attitudes towards the withdrawal of ventricular assistive devices (Swetz et al., 2013). Respondents reported that they were hesitant to withdraw MCS treatment, even in informed patients, because turning off the device was equated with imminent death (Swetz et al., 2013). The paucity of research from the viewpoints of key stakeholders: patients, family, nurses, and social workers presents an opportunity for future research regarding ACP in the unique context of MCS.

The convergence of ACP and MCS also delineates the need for conversations based on the potential for adverse events. ACP is recognized as a continuous process (Sullivan & Kirkpatrick, 2020; Wordingham et al., 2017b), but research with MCS patients were mostly based on one time point (Delmaczynska & Newham, 2019). Furthermore, the consult-based use of palliative care specialists augments the fragmentation of ACP, where the progression of adverse outcomes and nuances of the MCS trajectory were not described (Chuzi et al., 2019; Salomon et al., 2018). Despite the frequent interactions between MCS patients and their clinicians, there are no reports regarding ongoing ACP conversations with patients over time. In the absence of iterative ACP, unexpected deterioration in patients' health generates potential uncertainty in the congruence between patients' values and care preferences. Ongoing ACP conversations promote greater understanding about patients' preferences and support shared decision-making (Wordingham & McIlvennan, 2019). However, the paucity of evidence is insufficient to address the complex care needs of this population and their families. Left with little relevant evidence, clinicians continue to provide initial ACP consultations according to the general guidelines of the Centers of Medicare and Medicaid. The discrepancy between limited ACP conversations and high tradeoffs in health outcomes is particularly alarming, as people with MCS devices have unpredictable disease trajectories. Together, these issues underscore the importance of facilitating iterative ACP conversations for patients and their family (Wordingham et al., 2017b; Wordingham & McIlvennan, 2019).

Role of Nursing in ACP

Patients reported that nursing professionals are the most present at the bedside and most trusted clinicians in end-of-life care (Hebert et al., 2011). Thus, nurses are in a prime position to promote ongoing interactions and conversations with patients and families to help them navigate delicate ACP decisions. However, ACP discussions have primarily been viewed as the responsibility of physicians (Hebert et al., 2011) although the American Nurses Association (ANA) emphasized the need to potentiate nurses' roles in primary palliative care (ANA, 2016). Unfortunately, many nurses described inadequate training to conduct ACP discussions with MCS patients (Casida & Ilacqua, 2011; K. Hebert et al., 2011). This discordance between nurses as the most present clinician and nurses' self-described lack of training reveals an urgent need to equip nurses to initiate and conduct ongoing ACP conversations.

In the sentinel report, *Dying in America,* released in 2014, the Institute of Medicine (IOM) recommended the delivery of patient and family-centered care, and the need to improve clinician-patient ACP communication, development, and public engagement. Nurses, the largest and most trusted profession in health care (Stone, 2019), with approximately 3.9 million members in the United States (Haddad & Toney-Butler, 2018), are aptly positioned to advance these IOM recommendations (Meghani & Hinds, 2015). Nurses' scope of practice includes taking an active role in ACP and shared decision-making with patients and families in a variety of settings and throughout the course of complex and advanced chronic disease management (ANA, 2016). A position statement on end-of-life care by the ANA (2016, p. 1) outlined ACP-related responsibilities as follows: "Establishing goals of care for *this* patient at *this* time may provide a framework for discussion about what care should be provided. This process often involves collaboration with experts in decision-making, such as ethics committees or palliative care teams." The expansive role of nursing generates opportunities for seamless ACP across care transitions to explore and uphold the values and preferences of patients living with MCS. Nurses can conduct preparedness planning conversations (O'Connor et al., 2016) and advocate for the early inclusion of ACP and palliative care to provide ongoing decision-making support through care transitions (Delmaczynska & Newham, 2019; Meghani & Hinds, 2015). In turn, nurse educators should develop nursing curricula and advocate for additional education on iterative ACP conversations (ANA, 2016). Nurses should also spearhead ACP research, as the

National Institute of Nursing Research (NINR) is the lead institute supporting enquiries to promote understanding of decision-making by patients, caregivers, and providers surrounding life-limiting illnesses (NINR, n.d.). In administration, nurses can promote the seamless integration of ACP conversations from the time of initial diagnosis and advocate for excellent care extending throughout the course of chronic, complex disease management (ANA, 2016). Across settings, nurses can develop ACP best practices and measure the quality of support patients and families receive at different stages of the disease trajectory (ANA, 2016; IOM of The National Academies, 2014).

Discussion

Various barriers impede the potential for nurses to champion ACP conversations with MCS patients. Points for discussion center around 3 aspects: current ACP practices in MCS, clinical nursing implications, and future research directions.

Current ACP practices among MCS patients are fragmented (McIlvennan et al., 2016). Although MCS teams are multidisciplinary, ACP discussions are often delegated to palliative specialists (Sinha et al., 2017). Handing-off ACP as a consultation may create silos where patients and families find themselves navigating difficult topics with less familiar specialists. The limited trust may impede deeper conversations and exploration of values and preferences related to unexpected changes in health. Consequently, the palliative consult approach is not feasible without the support of additional clinicians on the MCS team to engage patients in ongoing ACP.

Nurses, as a trusted profession, are capable of facilitating ACP conversations to help patients and families explore personal preferences and values (O’Connor et al., 2016). MCS coordinators and specially trained MCS nurses, who often have longstanding relationships patients and families, are resources to champion ACP in this population. However, the role of nurses in ACP is poorly developed and little education or training is customarily provided to prepare nurses to assess patient values and initiate dynamic goals of care conversations

(Wittenberg et al., 2016). One way to address the increasing ACP need is to prepare all nurses to provide primary palliative care and to facilitate ongoing ACP discussions (Mazanec et al., 2020).

Based on findings from this systematic review and reflections of the authors' clinical and research experiences in cardiovascular nursing, ethics, palliative and hospice care, we believe that the increasingly complex disease trajectories among MCS patients warrant specific research to integrate ACP as part of the treatment plan. Of the 27 articles included in the review, 24 were conducted in United States, with one in the UK, Canada, and China. We look forward to research from other countries that include culture, religion, spirituality, and personal coping styles, and how these components impact ACP in diverse MCS populations. There is also an imminent need to examine the experiences and perspectives of key stakeholders such as MCS patients, their caregivers and families, and clinicians to develop ACP training and conversation guides specific to the MCS trajectory. The timing of ACP discussions is another crucial area for research. Although there are 2 studies on pre-implantation ACP, we found no reports that assessed ongoing ACP interventions. Future research on ACP timing can elucidate events that require additional ACP conversations. Thus, this review identifies nurses as an integral resource to champion ongoing ACP and research for MCS patients.

Strengths and Limitations

A strength of this review is the historical overview of two well-researched, yet separate topics of MCS and ACP. To our knowledge, this is the first review focused on the role of nurses in the convergence of ACP and MCS. A limitation is that the search was restricted to English-only articles and cultural, religious, and spiritual implications from articles written in other languages were excluded. Two other limitations reflect the current state of ACP in MCS. First, the lack of clarity used to define ACP resulted in its interchangeable use with preparedness planning and palliative care. Additionally, the newly standardized definition of ACP has yet to translate into clinical practice and ambiguity persists in whether researchers specifically addressed ACP or broadly referenced palliative care, which was also confounded with hospice and end-of-life care. This review is also constrained by the “MCS” keyword situated in HF literature, where the focus was not specific to MCS.

Conclusions

Ongoing ACP is crucial to promote shared decision-making between all the stakeholders: MCS patients, family members, and clinicians. This systematic review clearly identifies nurses as an underutilized resource. By examining the historical convergence of ACP and MCS, we confirmed that each distinct area of study has received attention on the national level. However, there are no clear nursing guidelines for ACP interventions to meet the unique needs of the MCS population. Potentiating the role of nurses in the ACP discourse and primary palliative care is imperative to enhance quality care for patients across the MCS trajectory. In response to the identification of nurses as potential agents for primary palliative care, this dissertation was purposed to examine the nurses’ role in supporting collaborative decision-making along the unique MCS trajectory. Building on these foundational findings, future studies are needed to enhance the role of nurses, specifically examining nursing interventions to support shared decision-making in the MCS population.

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Figure 1

PRISMA Reporting of Article Review Results

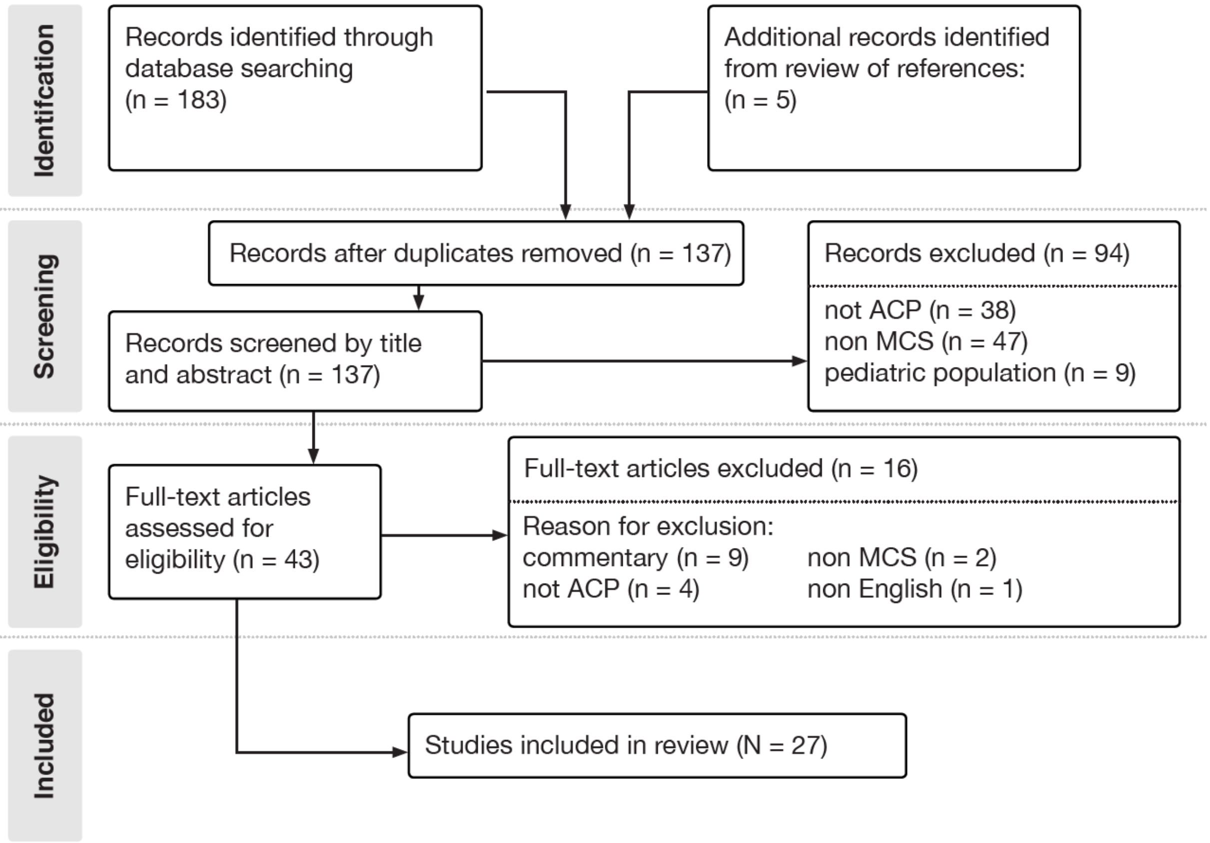
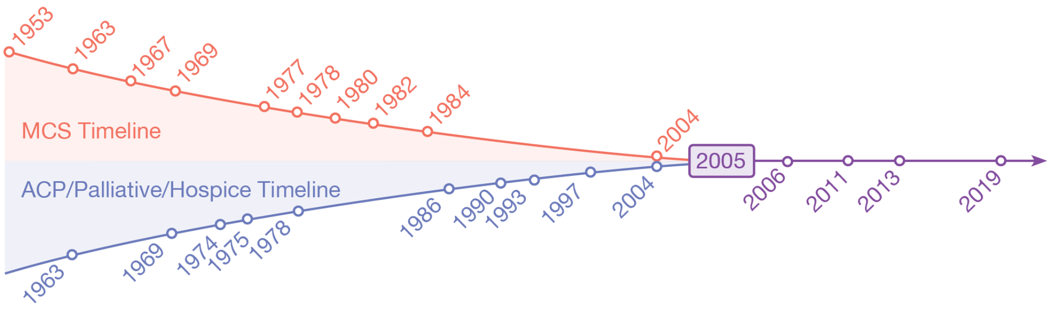


Figure 2

Converging Timelines of Mechanical Circulatory Support and Palliative Care.



MCS Timeline

1953	Dr. Gibbon used the Gibbon IBM heart-lung machine for atrial septal defect closure.
1963	First ventricular assist device implanted; pt died on post op day 4.
1967	First heart transplant performed by Dr. Barnard in Cape Town, South Africa.
1969	Dr. Cooley uses first total artificial heart as bridge to transplant.
1977	NIH first call for research proposals related to components of long-term implantable pumps.
1978	Dr. Norman reports first use of left ventricular assistive device for bridge to transplant.
1980	NIH second call for research proposals focused on long-term implantable left ventricular assistive device.
1982	First implant of total artificial heart.
1984	First successful implantation of electric left ventricular assistive device for bridge to transplant.
2004	FDA approves total artificial heart for in-hospital bridge to transplant.

ACP/Palliative/Hospice Timeline

1963	Dr. Saunders introduces hospice to the United States in a lecture given at Yale University.
1969	Dr. Kübler-Ross publishes *On Death and Dying*. The “death with dignity” movement begins.
1974	Florence Wald creates Connecticut Hospice, the first hospice in the US.
1975	Emergence of patient self-determination surrounding the controversial case to remove ventilator support for Karen Ann Quinlan.
1978	US Department of health, education, and welfare recognizes hospice as a “means of providing more humane care for Americans dying of terminal illness while possibly reducing costs.”
1986	Congress approves Medicare Hospice benefit.
1990	Nancy Beth Cruzan v. Director, a controversial case regarding the discontinuation of tube feeds for patient in persistent vegetative state.
	Congress passed Patient Self-Determination Act to ensure that hospitals would give patients written information on advance directives.
1993	The Clinton administration health care reform guaranteed hospice as a national health benefit.
1997	Oregon voters affirm the right to physician assisted suicide by passing for the second time its “Death with Dignity Act.”
2004	First time 1 million Americans with a life-limiting illness were served by the nation’s hospices.

Converged Timeline

2005	The American Heart Association and the American College of Cardiology recommends hospice care education after heart failure is diagnosis.
2006	The American Board of Medical Specialties recognizes hospice and palliative medicine as a medical specialty.
	Interagency Registry for Mechanically Assisted Circulatory Support established; 511 patients, 89 sites.
2011	Campaign for the National Center for Care at the End of Life Launched by National Hospice Foundation.
2013	Centers of Medicare and Medicaid and the Joint Commissions required palliative care specialists to be integrated as part of the MCS team.
2019	25,145 patients currently enrolled in the Interagency Registry for Mechanically Assisted Circulatory Support.

Note. Synthesized from Kozik & Plunkett, 2011; Miller, 2017; National Hospice and Palliative Care Organization, n.d.; Stewart & Givertz, 2012.

Second Manuscript

Potential Opportunities and Challenges to Ongoing Advance Care Planning Discussions Across the Mechanical Circulatory Support Trajectory

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Introduction

Advance care planning (ACP) among individuals living with a mechanical circulatory support (MCS) device is complex as the trajectory is typified by recurring life-threatening complications. Implantation with a durable device is beneficial for life prolongation, but the three-year survival rate is limited to 57% (Sagin et al., 2016). Additionally, 89.2% of MCS patients report experiencing complications such as gastrointestinal bleeding, stroke, and sepsis (American Heart Association, 2017; Kirklin et al., 2015, 2017; Kusne et al., 2017). Against this background, in 2013, the Centers for Medicare and Medicaid Services (CMS) and the Joint Commission required MCS teams to include palliative care consultations to enhance ACP communication early in the trajectory, specifically during the evaluation for MCS surgery (CMS, 2013; Sagin et al., 2016).

Historically ACP originated in decision-making around end-of-life and hospice care. However, current understanding around ACP has evolved to acknowledge the need for these sensitive conversations to happen earlier in the disease trajectory, specifically around life-prolonging interventions (Sullivan & Kirkpatrick, 2020). In response to ambiguity about the purpose of ACP, a 52-member Delphi panel defined ACP as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences” (Sudore et al., 2017). The ultimate goal of ACP is to ensure that individuals who experience serious and chronic illnesses receive care consistent with their values, goals and preferences (Sudore et al., 2017). Recommendations for ACP among cardiovascular patients, including a subset of MCS patients, involved the early initiation of discussions at the point of diagnosis (Lum & Sudore, 2016). However, there is a persistent lack of ACP communication among MCS individuals (Pak et al., 2020), and no scientific literature was located regarding timing of the early initiation of ACP conversations in MCS population.

Timing for ACP communication is fluid and recognized to be a continuous process (Sullivan & Kirkpatrick, 2020; Wordingham et al., 2017b). Recurring conversations are recommended to take place across the MCS trajectory to address patients' perceptions of new complications (Wordingham & McIlvennan, 2019). An iterative approach to ACP is suggested to promote shared decision-making based on patients' values and preferences (Lum & Sudore, 2016; Wordingham & McIlvennan, 2019). However, despite the frequent interactions between MCS patients and clinicians, there is no evidence of ongoing ACP communication over time. Instead, ACP conversations with MCS clinicians took place at discrete time points before or shortly after implantation (Delmaczynska & Newham, 2019). The current practice of consult-based integration of palliative care specialists was found to further augment fragmented ACP communication (Chuzi et al., 2019; Salomon et al., 2018). There is an alarming disparity between the minimal ACP conversations and the increased risks for complications and complex end-of-life situations for MCS individuals (Wordingham & McIlvennan, 2019). Thus, the recommendations to start ACP discussions early in the disease trajectory followed with recurring communications over time that apply to people with MCS is not practiced. Although the urgent need for research around iterative ACP discussions for the MCS population was published some years ago (Wordingham et al., 2017b), relevant research is lacking.

In the case of MCS, conversations around ACP involve key stakeholders in addition to the patient. Living with a MCS device is filled with the uncertainties of potential complications and unanticipated decisions that involve patients, clinicians, and their supportive others. As such, the complicated nature of MCS trajectories necessitates planning for unexpected events that are addressed through ACP communication between key stakeholders. Although literature specific to the MCS population is lacking, evidence for heart failure patients identified key individuals in ACP discussion included the patient, their family or surrogate decision-makers, and clinicians (Nishikawa et al., 2020). However, there is minimal evidence on shared decision-making in ACP between MCS patients and other key stakeholders as research on perspectives of ACP among the MCS population has primarily focused on a singular group of stakeholders such as health care providers or caregivers. A qualitative study on the collaboration between palliative care specialists and MCS clinicians found that limited palliative care resources contributed to reduced ACP communication between the multidisciplinary clinicians (Sagin et al., 2016). An interventional study on implementing a collaborative protocol between palliative care and MCS clinicians was found to improve pre-implantation consultation by palliative clinicians from 17.2% to 96.6% (Sinha et al., 2017). Research on the caregivers' perspectives on MCS patients' end-of-life experience had findings that included feelings of abandonment by MCS clinicians because of their unfamiliarity with palliative care specialists (McIlvennan et al., 2016).

Currently, no studies were found that examined the perspectives of MCS patients themselves on ACP communication. The paucity of knowledge on MCS patients' attitudes towards these sensitive conversations combined with the lack of iterative ACP communication present a unique challenge to improving ACP conversations and shared decision-making (Braun et al., 2016). Thus, the purpose of our study is to identify and describe perceptions of opportunities and challenges for ongoing ACP communication among individuals living with a MCS device.

Research Design and Methods

Constructivist grounded theory (CGT) directed all aspects of the design and methodology (Charmaz, 2014) to examine participants' experiences of living with MCS. Symbolic interactionism is a foundational philosophical cornerstone of CGT that emphasizes the interactions between individuals to understand symbols and create meaning (Charon, 2009, p. 48). Pragmatism is another philosophical underpinning of CGT that reflects how individuals use adaptive strategies based on personal experiences to enhance the recognition and resolution of everyday challenges (Magee, 2001). The integration of pragmatism in problem-solving prompts individuals to search for outcomes that are most useful (Hammersley, 1989, p. 45). Building upon traditional grounded theory, we utilized a constructivist approach to recognize that knowledge is co-created between the researchers and participants (Charmaz, 2014). A constructivist approach directs that meanings and definitions are co-constructed through the interactions between the interviewer and participants. Furthermore, the researchers' active interface with the data during analysis also constructs meaning (Charmaz, 2014). Thus, we employed CGT with its underlying philosophical tenets to examine ACP processes among MCS patients, families, and clinicians.

Recruitment

Approval from the South General Institutional Review Board from the University of California, Los Angeles, was received before the initiation of recruitment. A total of 24 participants were recruited from outpatient MCS clinics of two Southern California medical centers. Potentially eligible participants were handed recruitment flyers by the first author and clinicians from the MCS team. Criteria for inclusion were English-speaking, adults 18 years or older with current use of a MCS device. Exclusion criteria were comprised of individuals who were cognitively impaired or hospitalized at the time of the scheduled interview. The first author screened participants for eligibility in-person at the MCS clinics or over the phone.

Between February 2019 to October 2020, 29 MCS patients expressed interest in the study. Upon eligibility screening, one individual was excluded because of dementia. Other reasons eligible individuals were not interviewed included: 1) hospitalized at the time of interview (n=2), 2) received heart transplant (n=1), or 3) died (n=1). A total of 24 MCS patients participated in the research, with two follow-up interviews conducted during theoretical sampling for a total of 26 interviews.

Following the first five interviews, it became apparent that the sample was homogeneous with bridge to transplant MCS participants. We recognized a lack of representation of destination therapy MCS individuals whose experiences with the device are prolonged and complex. Subsequently, the IRB approved an amendment that allowed for theoretical sampling (Charmaz, 2014) for focused recruitment of participants with destination therapy. The resultant sample included perceptions from individuals with bridge to transplant (n=14), destination therapy (n=8), and an uncertain goal therapy (n=2) to elucidate opportunities and challenges for ACP discussions.

Data Collection

Informed consent, written or verbal, was obtained by the first author according to the participants' preferences for in-person or phone interviews. Semi-structured interviews and questionnaires to gather demographic and clinical characteristics were employed to collect data. An interview guide with open-ended main and follow-up questions (Charmaz, 2014; Rubin & Rubin, 2012) was used to focus on participants' experiences of living with a MCS device and uncover emergent processes surrounding ACP. The guide was purposefully designed for the current study based on existing literature and input from experts in clinical decision-making, palliative, and cardiovascular nursing. The first author, a full-time registered nurse with 5 years of experience on a cardiac surgical unit, leaned on her clinical expertise to formulate both the content and phrasing of the questions in a way that would stimulate a focused conversation. (See Table 1 for exemplars.)

Anticipating the sensitive nature of discussing ACP (Dempsey et al., 2016), the researchers were mindful to uphold the ethics of doing no harm throughout the interview process (Rubin & Rubin, 2012). To minimize the risk of harm, the first author advised all participants, prior to the start of the interview, that they could stop the conversation at any point if they were uncomfortable with the questions. Additionally, during the interview close attention was paid to the participants' body language and tone of voice to monitor for signs of discomfort. If the interviewer detected uneasiness or distress, she intended to ask if the participant preferred to take a break; however, this situation did not occur during this study. The final question of each interview was directed towards assessing participants' mental and emotional well-being to ensure that no harm was inflicted during the conversation. Despite the sensitive nature of the topic, all participants responded positively to discussing ACP.

Interviews were conducted by the first author in person (n = 5) or over the phone (n= 19) based on the participant's preference and public health regulations during Covid-19. In-person interviews were done at a location of the participant's choosing. To avoid power differentials such as perceptions of authority or influence of participation on quality of care, the location was outside of the hospital clinic setting. Throughout the interviews, the first author used participant's own words to rephrase questions in a language consistent with participants' descriptions. A $50 compensation, in the form of a gift card, was given upon conclusion of the interview. The 26 interviews, with a total average of 52.7 minutes (range: 18.6 – 132.6), were digitally recorded and transcribed by a professional transcription service (http://www.rev.com). The first author de-identified transcripts and cross-checked the raw data with the recordings for accuracy.

Data Analysis

Data analysis was conducted by the first and last authors individually coding each transcript then meeting to compare and discuss the similarities and differences in their codes. As data analysis proceeded, constant comparison was employed to inform successive interviews (Corbin & Strauss, 2015; Charmaz, 2014). As directed in constructivist grounded theory, a systematic approach to data analysis was used: initial inductive, line-by-line coding, followed by focused coding, and then theoretical coding (Charmaz, 2014). Early in the interview process, we generated initial codes to sort the data. As the interviews progressed, categories began to emerge across participants, and we transitioned to focused coding. In the final stages of analysis, theoretical coding served to describe the processes between and among categories, subcategories, and dimensions. Throughout data analysis, we used analytic and reflexive memos, diagramming, and theoretical coding to raise the level of abstraction (Corbin & Strauss, 2015; Charmaz, 2014). Microsoft Word and Atlas.ti software programs were used by the research team to manage the data (Muhr, 2012). Measures taken to establish scientific rigor are presented in Table 2.

Results

Sample Characteristics

The sample consisted of 24 individuals, 16 men (67%) and 8 women (33%), with an average age of 60.6 years (range 24-80 years) at the time of the interview. Our heterogeneous sample included individuals who self-identified as Caucasian (50%), African American (29%), Hispanic (17%), and Asian (4%). Participants reported being implanted with MCS for an average length of 29.8 months (± 26.7), with a wide range of fewer than six months to nine years. Finally, 79% of participants recalled completing their advance directives. A complete list of sociodemographic and clinical characteristics can be found in Table 3.

Overview of Results

The most salient finding about perceptions of ACP communication among these MCS individuals was that ongoing communication was glaringly missing from the narratives. Although the majority of the sample (n=19; 79%) completed advance directives, participants, except for one individual, did not recall revisiting ACP discussions with clinicians or supportive others. Systematic analysis led to the development of four major categories surrounding opportunities and challenges in ongoing ACP communication. Identifying context and timing, the first category, described the circumstances surrounding previous ACP conversations as well as preferred situations for future ACP discussion. The second category, sharing information, represented the key individuals, MCS clinicians, supportive others, and other MCS patients, whom participants perceived to be important to decision-making about ACP communication. The third category, understanding ACP, accounted for participants' vague insights on the purpose and content of ACP communication, specifically highlighting the properties of meaningful living and misconceptions about ACP. The final category, assessing satisfaction, described MCS individuals' satisfaction and dissatisfaction with the information received during ACP communication.

Figure 1 is a diagrammatic representation of the opportunities for ongoing ACP communication with the inherent challenges embedded within the four categories. The outer ring of the circular component of the diagram depicts the realities of living with MCS such as overall changes in health, unexpected hospital readmissions, and changes in the goal of therapy. Against the milieu of context and timing, the participants described sharing information with key individuals to navigate the uncertainties of the MCS trajectory. As the individual continued to make sense of potential complications and complexities of living with the MCS device, there was an evaluation of understanding ACP as well as an assessment of satisfaction with ACP communication. Examining the four main categories through an iterative process gave insight into the glaring dearth of ACP communication for the current sample and identified opportunities to enhance ongoing conversations for the future. The fluidity and interrelation between multifarious components, illustrated in Figure 1, distilled the essence of potential ever-evolving conversation around ACP.

Category 1: Identifying Context and Timing for ACP Communication

The context of ACP was often described in the circumstances surrounding initial conversations or foreseeable discussion from qualifying future events. Participants shared varying contexts in which ACP conversations were applicable, ranging from the implantation consultation to changes in their health status. Among individuals who were relatively more engaged in ACP communication, the process of discussing preferences for care often started before their implant surgery. One individual who recalled a discussion with a palliative care specialist before the MCS surgery advised, “Well, definitely (have ACP discussions) before LVAD (left ventricular assistive device) and before... I mean, actually, everybody should have them (advance directives) period. I mean you should have them in your 30s or whatever.” On the other hand, while some participants welcomed the discussion before the MCS implant, others preferred ACP communication to take place in the context “serious” conditions, with one individual sharing, “(You should have ACP discussions) Before you have a serious surgery. Or when you have a serious illness.” In response to a question about revisiting ACP discussions, a participant anticipated, “Well, I'm sure if my health deteriorated to such a point that there was a real problem or an impending problem that it would be a good time to talk to me about it (ACP).” Other individuals also identified hospitalization or readmissions as the context for discussing ACP conversations. Although many participants focused on the physical aspects of their health, a unique aspect of ACP conversation among individuals implanted with the MCS was the goal therapy of their device. Reflecting on his goal therapy, one participant recalled, “It (ACP discussion) was when we were getting ready to go on the transplant list.” Hence, there were various contexts in which ongoing ACP conversations were deemed appropriate.

At the start of the study, an assumption of the researchers was that participants would describe optimal timepoints throughout the MCS trajectory to introduce or continue ACP discussions. We did not expect that only one participant would describe a specific time for ACP discussions. In planning for ACP communication with his large family, this individual stated that the preferred time was “at least two months prior (to MCS surgery), or maybe a little longer.” This was an example of a specific time point that researchers anticipated participants would recommend in response to questions about the appropriate times to discuss ACP. However, most participants shared general preferences of timing for ACP discussions that varied from “no time is too soon (for ACP discussion)” to “it's never a good time.” Thus, concerning the MCS trajectory, context and timing for ACP communication were fluid, and not dichotomous. Overall, the optimal timing for ACP communication was presented as ideal and non-ideal circumstances that held meaning for ACP discussions.

Ideal Circumstances for ACP Communication

Ideal circumstances for ACP discussions were depicted in significant physical and mental experiences of living with the MCS device. Physical experiences that were identified as meaningful situations to discuss ACP were often related to unexpected changes in physical health. After experiencing the sudden onset of pump thrombosis, one individual recalled his conversation with MCS clinicians as follows:

> Particularly after these two episodes of the clot formation so I told them (clinicians) that deep in my heart, I am a little bit more scared that who knows what can happen at any time because this came so unexpectedly, suddenly stomachache… even today I think that what is the guarantee that it will not come back? They (clinicians) say, “Well, mostly it doesn't, but you never know.”

Thus, the changes in health led to questions that created an opportunity for the participant to ask clinicians about the potential recurrence of complications from living with the MCS device. However, in the latter case, the response from clinicians was close-ended and not specific. Thus, the opportunity to engage in ACP communication was not recognized nor utilized for meaningful discussion.

Additionally, participants pinpointed mental clarity as a prerequisite for engaging in ACP discussions. Thinking back to the mental exhaustion of dealing with a painful recovery from MCS surgery, one participant emphasized, “I think a good time is when a person is fully alert… you should make sure a person is in the right frame of mind to really comprehend what you're saying to them.” Hence, ideal situations that participants indicated as standing out to them in discussing ACP were characterized by physical changes in health and mental clarity.

Non-ideal Circumstances for ACP Communication

Non-ideal circumstances for discussing ACP were marked by emotional turmoil and impaired cognition. Some participants described the highly emotional circumstances immediately preceding MCS surgery as undesirable for ACP discussions. Recalling her family crying at the bedside before her surgery, an individual said, “I just can't tell you, it's so hard to make a (ACP-related) decision like that (to get the MCS surgery) when you're so exhausted.” Other individuals shared the emotional challenges in their recovery from MCS surgery that were less than ideal for engaging in ACP discussions. After identifying the post-operative recovery period as imperfect conditions for ACP discussions, one participant further explained, “Because you can't think straight (right after surgery). For one thing, I can't think straight now… Plus, it's too emotional.” In addition to emotionally charged situations, participants identified that impaired cognition was an unacceptable condition for discussing ACP. Describing the process of ACP communication with clinicians, one individual recalled,

> By the time all of that (ACP discussions) came through, I was not in my right mind. I have no recollection of ever signing it (advance directives) and probably legally that paperwork is not valid. If I was to be honest with the hospital, that paperwork (advance directives) should have never been valid because I was already out of my mind.

Thus, non-ideal conditions for ACP communication were comprised of situations where MCS individuals were emotionally distressed or when their cognitive abilities were limited.

Category 2: Sharing ACP Information with Key Stakeholders

Reflecting on opportunities for ACP communication, participants described their reliance on key individuals to be a resource for greater insight into personal preferences and values surrounding ACP. Grounded in the narratives and social worlds of the current sample, key stakeholders in ACP communication were identified as MCS clinicians, supportive family members, and other MCS patients.

Characteristics of Clinicians Conducive to ACP Communication

In identifying individuals who were important to include in discussions, participants reflected on the characteristics of clinicians that were conducive to facilitating ACP conversations. Many participants emphasized a desire to be well acquainted with their doctors, which accentuated a sense of familiarity and helped individuals feel comfortable in engaging in ACP communication. With the development of relational intimacy over multiple hospitalizations, one individual reflected on the importance of being known by doctors prior to participating in ACP conversations, by saying, “I would hope that they (doctors) would know, especially if I've been in the hospital a lot, kinda my personality and knowing what I want.” Participants also measured their familiarity according to how comfortable they felt with the clinicians. Reflecting on which clinicians were the most well-suited to discuss ACP topics, one participant shared, “I listen to what they have to say and listen to how they listen to me … I make decisions on which doctors that I feel more comfortable with and whose advice I listen to more.” Hence, familiarity was a highly desirable characteristic for doctors who would engage individuals in ACP communication.

Doctors’ generosity with their time was another characteristic that participants deemed important in enhancing ACP communication. Some participants perceived physicians’ availability through physical actions such as, “The one doctor pulled his chair up next to the bed.” While other individuals identified characteristics of availability with time such as, “ (The cardiologist was) very caring. Listens very well. Isn't in a hurry.” The physicians’ willingness to spend time with participants was identified as an important characteristic that was conducive to ACP communication.

Nurses were also identified as appropriate clinicians to have ACP conversations. Similar to the characteristics of physicians, participants described that the qualities of familiarity and generosity with time among nurses were inviting to engage in ACP discussions. When asked about which discipline they preferred to have ACP discussions with, the explanation of an individual who preferred nurses was centered around familiarity when he said, “You get to know a nurse. You have conversations with them and share things.” Another participant identified the MCS coordinator, a nurse, as the most appropriate individual to have ACP conversations with when he said “She (MCS coordinator) knows me...we have a kind of a personal interaction so it makes it very easy to talk to her.” The amount of time nurses spent with MCS individuals was also a characteristic that was conducive to ACP communication. An individual who preferred nurses as the clinician he most preferred to engage in ACP conversations shared, “I always felt very comfortable with them (nurses)… They're really super great at what they're doing and they take an interest in the individual's case. You're not just a number going through there.” Thus, whether it be physicians or nurses, participants described that relational closeness and generosity of time with clinicians were the characteristics that invited ACP conversations.

Perceived Barriers to ACP Communication with Clinicians. In contrast with the characteristics conducive to ACP communication, the perception of clinicians' lack of availability to take time and discuss ACP was considered an impediment to ACP discussions. Although these MCS individuals had multiple encounters with clinicians through clinic visits or hospital readmissions, the onus of initiating ACP conversations remained on the MCS clinician. After a long, unexpected readmission to the hospital, one participant reflected on the nonexistent ACP communication with clinicians, when he said “it's (ACP) not something that's really been brought up (by the heart team).” Reflecting on the difficulties of engaging in ACP communication with clinicians, one participant described a challenging characteristic as clinicians who appeared preoccupied with other responsibilities and “in a hurry to get in and get out.” Another potential obstacle related to time was the importance for clinicians to get to know an individual before engaging in ACP conversations. Reflecting on perceiving insufficient familiarity and empathy with a clinician, a participant recounted, “Like this (ACP communication) is just a job to them... Like all right, well it's (discussing ACP) your job. I know it's just your job, but can you be sensitive?” Thus, perceptions of clinicians’ hurriedness and lack of time to get acquainted with MCS individuals were recounted as barriers to ACP communication.

Another hurdle to ACP communication with clinicians was receiving close-ended answers about ACP-related concerns. Although participants in the current study rarely initiated ACP conversations, they tested the waters by asking questions about ACP-related topics. One individual who waited a long time for a transplant asked clinicians about the possibility of dying from the complications of living indefinitely with the MCS device. The participant recalled clinicians’ response:

> They (clinicians) said yes (other MCS patients have died), but it's different for me. Their (other MCS patients’) problems got complicated because their blood got infections, and that's what got them to pass away. But I'm different. Everybody's different. That's what

> they (clinicians) told me. So, in my mind, when they told me that, I was like, okay, so I could go with this machine.

Thus, rather than exploring this participant's concerns about dying from complications and engaging in a meaningful ACP discussion, she remembered that clinicians simply advised her that she was "different." Although the clinicians answered her immediate question, the invitation to engage in ACP communication was not utilized. Thus, receiving non-specific or close-ended answers from clinicians impeded ACP discussions.

Supportive Others

Selecting most appropriate family members. In accordance with the pre-implant requirements, patients from both recruitment sites identified informal caregivers who would assist with MCS care, such as dressing changes and accompanying the patient to clinic visits. When asked to identify individuals who were essential to include in shared decision-making around ACP, participants named family members, such as spouses (n=18), parents (n=3), adult children (n=2), and siblings (n=1). These supportive family members were commonly tasked to communicate participants' wishes in situations where they might be unable to represent themselves. Reflecting on readmissions to the hospital, one individual recalled, "I've had conversations with them (family)…we bring it up anytime you end up in the hospital again to remind them what my wishes are. And I trust them (family) to follow through with that (decisions from ACP)." Irrespective of the gender of the supportive other, participants' narratives demonstrated a selection process in identifying the most appropriate family member(s) for ACP discussions. In some instances, the caregiver was not the preferred individual to include in ACP communication. Some participants preferred to discuss ACP with family members whom they deemed were most "logical" and capable to make decisions in difficult circumstances. Weighing the differences in personalities between her adult children, one participant decided to delegate shared decision-making about ACP to her son. She explained, "He's (son) going to think things through…He will go ahead and he'll make a decision. He also won't fuddle around. He's not indecisive." Although participants were able to identify a preferred surrogate decision-maker when asked, few discussions with supportive others occurred outside of the initial completion of advance directives. Thus, overall ACP communication with supportive others was limited to the selection of the most appropriate individuals but lacked ongoing conversations about preferences and wishes in relation to complexities in living with the MCS device.

For other participants, ACP communication was motivated out of altruistic concern for their family members. As the individuals reflected on discussing ACP, many shared about the importance of reducing the "burden" on their caregivers. Reflecting on the rationale for completing an advance directive, one participant explained, "So, the family can know what your wishes are and not have to deal with the complete burden of having to try to figure that (ACP) out on their own." Caring for their supportive family members also motivated some individuals to complete their advance directives. Reflecting on the responsibilities of making difficult decisions, one individual recalled,

> My wife and I sat down and decided that, well, we're just going to do it (advance directive) so they (children) don't have to…it's a very emotional time to try to make decisions like that (surrounding ACP). And so, we just decided, hey, we're not going to let our kids have to do that, it'll already be done.

In a rare example, supportive others were also described to initiate ACP conversations. One individual reflected on his wife initiating the discussion and acting as a sounding board for decision-making around ACP. The participant recalled his wife saying:

> Let's talk about this. The only thing that's keeping you alive is your LVAD, but what does that mean? You want to turn it off? And I said, "That's an excellent question. If I have no quality of life, if the LVAD weren't functioning enough to keep my organs functioning, I'm not mentally aware of what's going on and you have to make decisions and there's no hope of me getting to the point of being mentally aware, then no, I think I'd want it turned off."

This uncommon example of an informal caregiver initiating ACP reflects the potential conversations that were not documented or explicitly shared with clinicians.

Overall, ACP communication with supportive others focused primarily on the selection of an appropriate surrogate decision-maker. Participants were more inclined to complete advance directives out of a mutually caring relationship with family members. This was observed as individuals sought to reduce the decision-making burden on supportive others. Occasionally the pivotal caregiver-initiated conversations in the home-setting presented potential opportunities for MCS individuals and family members to engage in ACP dialogue. Thus, supportive others played an integral role in ACP communication by representing MCS individuals' wishes to clinicians, being a motivation for the discussions, and initiating conversations.

Perceiving supportive others as barriers to ACP communication. While supportive others fulfilled essential tasks, they were also perceived, at times, to be barriers to ACP conversations. In some instances, revisiting discussions around ACP were unwelcomed because participants perceived that these conversations would upset supportive others. In the statement, “I don't think my wife likes to talk about that stuff (ACP), so we just remain silent about it” the sensitivity to supportive others' emotional discomfort towards ACP discussions was a potential hindrance to ongoing conversations. Of the few who revisited ACP discussions with supportive others, there was one participant whose spouse was not willing to engage in conversation.

Being able to have personal preferences executed was the desired outcome of ACP communication with supportive others. Supportive others with views on life-sustaining treatment options contrary to MCS participants' preferences, were perceived to pose an impediment to ACP communication. Although uncommon, one participant specifically preferred not to include supportive others in his ACP communication because he felt that they would not carry out his wishes. He explained:

> Sometimes I feel like I cannot always include them (family) in decisions…Sometimes I

> feel like my family wouldn't care if I was on life support, in a coma, laying up there as a vegetable…I wouldn't want to be that way. You see, there are some decisions that I would have to make, that I have made, that have been hard.

In the last example, the participant perceived the supportive others to hinder ACP communication because they would not act in his best interest according to his wishes. Thus, supportive others whose views on ACP were significantly different from MCS individuals posed potential barriers to ACP communication.

Other MCS Patients

Other MCS patients were identified as another group of informative individuals who helped participants navigate ACP topics. Within the sample, it was observed that participants commonly consulted with other MCS patients about their experiences with the device while waiting for clinic visits, during support groups, and during hospital readmissions. The interactions with other MCS patients were sporadic and informal, consisting of unguided conversations. There were also some conversations between the sample participants and other MCS patients that were initiated by clinicians' referral to patients who were willing to share their experiences of living with the device. Consequently, other MCS patients were identified to be potential sources of information for ACP communication.

The information shared by other MCS patients was imbued with subjective experiences that were left to the interpretation of the participant. For some, conversations with other MCS patients gave hope, as one individual recalled, "the two individuals (MCS volunteers) that had the device, they both had type O. So it kind of gave me hope, because I knew going in that type O would be a problem, there'd be a longer wait."

Conversely, the difficult realities of living with a device were substantiated through conversations with other MCS patients. During a support group discussion, one participant reflected on his prolonged wait for a transplant, and stated, "Obviously, the longer you have this thing (MCS device) in you, the greater the risk of something happening." Similar sentiments of increasing uncertainties of living with the device were also shared concerning potential changes in the goal of therapy. One individual recalled a MCS patient candidly sharing the frustrations of potentially becoming ineligible for transplant:

> One of the guys in the support group said I'm being penalized because I've worked out and kept my body in fairly decent shape, now I can't get a transplant. And they (clinicians) said, that's fundamentally true because you're going to age out, you're going to be too old before you really need it for us to do a transplant.

In addition to receiving information from other MCS patients, participants also acted as agents of ACP communication by sharing their experiences with other patients. For some participants, these shared communications included advice on how to engage clinicians in conversation. Thinking back to her own ACP conversations with clinicians, one individual advised other patients, "Hey, make sure you're telling them (clinicians) what you want.” Encouraging other MCS patients to advocate for their preferences was a unique form of ACP discussion that was situated exclusively between participants and other patients.

Overall, the honest giving and receiving of information between participants and other MCS patients increased understanding of ACP. These conversations imparted the realities of living with the device and encouraged ACP communication with clinicians.

Comparing illness trajectories with other patients. Despite the transparent ACP conversations with other patients, participants also often internally compared their illness trajectories with other patients' experiences. For some individuals, this led to a positive outlook as concluded by a participant who said, “I'm not having any problems that a lot of people experience with it (MCS device), haven't had any infections. I don't have any alarms; I don't have any major troubles with my LVAD at all.” However, participants who experienced prolonged MCS trajectories described that the comparison with other patients led to a negative perspective about their future with the device. Particularly among individuals who have waited an extended time for a heart transplant, the news of other patients receiving transplants generated feelings of resentfulness, as one participant shared, “I try not to think about it because it just depresses me and it causes me to become very vengeful. Especially when you hear about people that have gotten hearts and you were there first.” Thus, comparing the personal illness trajectories with that of other patients potentially led to internalized perceptions about one’s future with the MCS device.

Category 3: Understanding of ACP

It was evident that individuals in the sample was not proficient in ACP. This dearth of knowledge was apparent as participants either admitted they did not know what ACP was or they guessed at what ACP encompassed. The vague understanding around ACP manifested through inconsistent descriptions which were often different from clinicians’ comprehension of ACP. Participants’ obscure understanding was evidenced through descriptions of the purpose and content for ACP communication.

Purpose of ACP communication

Large inconsistencies in the perceived purpose and content of ACP communication were evident. Among the few participants who were more engaged in ACP discussions, there was a nuanced understanding that ongoing conversations were needed to address the uncertainties of living with a MCS device. One such individual reflected on his values on the quality of life and potential discrepancies that may arise if these values are not revisited by the clinical team. He said, “When you're put in the hospital, the nature of the medical care is to give you whatever is necessary to keep you alive. And whether that really fits your understanding of how you want to live going forward, may be in conflict.” However, few individuals recognized the purpose of ACP communication to address the potential unknowns in the MCS trajectory.

In contrast, a majority of individuals in the sample viewed the purpose of ACP communication as the selection of a surrogate decision-maker and had difficulty envisioning the complex MCS trajectory with varied health outcomes. For example, in response to a question about the purpose of ACP communication, one participant identified his health proxy and replied, “So, if that (becoming incapacitated) happened to me, I know who's got the first choice to pull (the plug).” For others, the purpose of ACP communication was merely to fulfill a requirement for MCS surgery. Using the terms advance directives and ACP communication interchangeably, one individual explained, “Advance directive is not a big thing in my life and it's just something I have to sign... It was a requirement for me to get surgery.” Thus, among the majority of participants, the purpose of ACP communication was simplified to be the selection of a surrogate decision-maker or to fulfill a requirement for their MCS surgery.

Descriptions of meaningful living. Without being prompted, what was valued in everyday living was embedded in participants’ narratives. While specific reasons were not identified, personal values and preferences were evident in the descriptions of living with the device. For some, meaning was found in being able to enjoy pastimes that were previously abandoned because of advanced heart disease. One participant described the ability to return to his favorite hobbies and said, “So, since the LVAD (left ventricular assistive device), I've been able to get back to those things like tinkering with my old classic car and walking at the park.” The ability to revisit and enjoy hobbies was a source of motivation for continuing on the MCS trajectory. Furthermore, a majority of the participants described finding meaning in having more time with family. Reflecting on the importance of family in ACP discussions, one individual said, “I like to be around to see my grandkids grow up, so they're very important.” For other individuals, simply having additional time to wait for a transplant gave hope and meaning to their existence, as one participant said, “To me, it's another day waking up waiting for it and waiting for a call, someone would call and say, "Come down here (to the hospital), we've got your heart." And transplant means a lot to me.” Hence, many participants' descriptions of personal values and preferences were interwoven with the meaning they found in revisiting hobbies, spending time with family, and simply being alive and eligible for a heart transplant.

Meaningless living. Although less common, few participants also described circumstances of living with MCS device that they perceived to be meaningless. Individuals often attributed the lack of meaning to becoming a “hindrance” to others. Reflecting on her experiences of being a caregiver for a spouse who became increasingly disabled, one participant expressed, “Yeah, if you can't live independently, and I think that's when I made that decision. When you can't live, maybe I don't want to be alive.” Among the few individuals that were able to contemplate future circumstances where living would be futile, becoming an encumbrance on others was perceived to be a meaningless type of living. These descriptions of meaningful and meaningless living can be referenced for future discussions about the purpose of ACP.

Content of ACP Communication

The content included in the minimal descriptions of ACP communication were often interchangeable with advance directives. Despite the majority of the sample having completed an advance directive (n=19), these individuals were unable to describe the content included in their advance directives or ACP conversations. This was exemplified by a participant who, thinking back to the content of his advance directives, admitted, “I don't quite remember what it (advance directives) all said, but I just filed in my filing cabinet, then when someone asks for it, I'd get it out so they can make a copy of it.”

With ample opportunities to discuss the content of ACP during MCS clinic visits, the lack of ongoing conversations with clinicians was particularly apparent. During clinic visits, with the accompaniment of family caregivers, participants were regularly asked about the completion of an advance directive. However, individuals perceived this approach to ACP communication to be close-ended with little room for shared decision-making between the participants, family members, and clinicians. Recalling how clinicians gauged his understanding of ACP, a participant shared, “mostly they (clinicians) ask if you have an advanced care plan or a directive and if you tell them yes, that's the end of it (ACP discussions).” Despite assessing the completion of advanced directions, no clinician was described to use the opportunity to further the conversation with MCS individuals. Reflecting on her routine check-ins at the MCS clinic, one participant shared, “They (clinicians) always ask about advance directives, but I don't have one in place and I don't know anything about advanced care.” Thus, participants’ lack of knowledge about the content of ACP communication was described to be a gap in communication with MCS clinicians.

Misconceptions surrounding ACP communication. The narratives from the sample of participants revealed multiple misconceptions about the purpose and content of ACP communication. The purpose of ACP discussions was often misunderstood to be a concrete decision about post-mortem affairs. Thinking back to the ACP conversations with his wife, an individual who exemplified such a misunderstanding, shared:

> The advanced care, now we've (he and his wife) done everything we can with that (ACP). I mean we've purchased plots and paid for advanced funeral arrangements and stuff because we don't want our kids to have to go through that if something happens to us.

Additional misconceptions about the content of ACP communication included decisions surrounding organ donation. Reflecting on his understanding of ACP, one participant remarked, “As far as I know that when you value, what should be done rather whether certain organs of your body should be donated…So that is what I think that is very advance directive so that they (the adult children) don't have to make a decision.” Although both examples of perceived ACP communication were motivated by the concern for supportive others, the purpose and content of their discussions were incongruent with ACP surrounding personal preferences and values for future healthcare.

Category 4: Assessing Satisfaction with ACP Communication

As participants described their experiences surrounding ACP communication, many reflected on whether or not the information was satisfactory to their needs. For some, ACP communication was deemed satisfactory because it helped them anticipate what to expect from living with a MCS device. One individual who discussed ACP with multiple clinicians from the

MCS team said,

> It's (ACP) been like I said, invaluable as far as kind of letting me see what my directed care would be all about. They (clinicians) give me both good and bad, so I know what's the worst that can happen. I know what's the best that could happen.

Although a majority of participants were poorly informed about the purpose and content of ACP and had not experienced ongoing ACP communication, they were not generally dissatisfied with the information received. Thinking back to an initial conversation about living with a MCS device, an individual shared, “You know, the thing is, they (clinicians) told me what it was going to be like (living with a MCS device). They (clinicians) were really honest with me, and I appreciated that because I didn't have any illusions on what it (living with the device) was going to be like.” Hence, satisfaction with ACP information was described in the context of the perceived congruence of expectations compared with the realities of living with MCS.

Dissatisfaction with ACP Communication

Conversely, dissatisfaction with ACP communication was identified among participants who described a discrepancy between their expectations and the realities of living with a MCS device. For some individuals, feeling unprepared for life with the device was linked with the lack of ACP communication. Hoping that she had received information earlier in her disease trajectory, one participant expressed disappointment when she shared,

> That (having ACP discussions) would have meant a lot to me. Because at that point (needing a MCS device), when something did happen, you would kind of already have an idea what was to come…So to have had pre-knowledge of what was to come would have been really good. I would probably not be feeling the way I'm feeling right now.

Consequently, the lack of conversations to prepare MCS individuals for living with a MCS device was perceived as a source of dissatisfaction in ACP communication.

An unusual example of dissatisfaction with ACP communication arose from discordant views between the clinician and the MCS individual. It is important to mention that this particular participant was implanted at an out-of-state hospital, and the findings here does not reflect the rest of the current sample. Remembering the jarring ACP communication that occurred before her MCS surgery, the participant recounted the doctor saying:

> “You're going to put a lot of stress on your family” and he (doctor) was like he really wanted me to consider not getting the LVAD (left ventricular assistive device)…He was like, “But, why? You know, you're going to be a big hindrance on your family. You're going to cause them a lot of stress, a lot of pain.”… But to me, it was like, why would you want me to die or not live?

This clinician’s forceful approach to ACP communication imposed an antagonistic set of values on the unsuspecting participant. Hence, discussions that infringed on the participants’ values were also perceived to contribute to dissatisfaction with ACP communication.

Summary of Opportunities for Ongoing ACP Conversations

Overall, an outstanding finding across participants was the dearth of ACP communication and particularly of ongoing discussions. Grounded in these reflections, perceptions of opportunities and challenges of ongoing ACP discussions centered around four categories. Identifying the preferred context and timing for ACP communication was focused on health-related changes and mental clarity. The second category centered on sharing information with three groups of key stakeholders. MCS clinicians were identified to be the most preferred, but least available, individuals with whom to have ACP conversations, supportive family members were identified to be essential to ACP communication, albeit the lack of ongoing conversations, and giving and receiving information from other MCS patients provided viewpoints that shaped decision-making. The third category revolved around participants’ understanding of ACP and described a vague understanding of the purpose and content for ACP communication. The final category, assessing satisfaction with ACP information, examined the information participants perceived to be useful in ACP communication and managing expectations of living with MCS. Thus, the process delineated by these four dynamic and interrelated categories described the opportunities and challenges for ongoing ACP communication among individuals living with a MCS device. Considering that the nature of living with MCS was situated within unexpected changes in health and unanticipated complications, the dearth of ACP communication was surprising.

Discussion

The most surprising finding of our novel study was that MCS individuals' descriptions about opportunities and challenges were situated in a complete lack of ongoing ACP conversations. This scarcity of communication was exemplified by a participant in his 30s who received the device two years before the interview. He explained that ACP "is not something that's really been brought up (by the heart team.)" Embedded within this dearth of communication, the systematic analysis resulted in a synthesis of four categories of opportunities and challenges: identifying the context and timing for ACP communication, sharing information with key stakeholders, understanding of ACP, and assessing satisfaction with the information received during communication. Opportunities for ongoing ACP conversations with MCS individuals lie at the intersection of an iterative review of these four categories to engage participants in shared decision-making around the complexities of living with MCS. The diagrammatic representation of the processes and actions between the four categories are represented in Figure 1. Context and timing encircled ACP conversations between the key stakeholders. Situated within the realities of living with MCS, information was exchanged between key stakeholders in shared decision-making to navigate the complexities inherent in the MCS trajectory. As information was shared, the understanding of ACP gradually expanded and created opportunities for further ACP discussions. Ongoing assessments of satisfaction with ACP knowledge and experiences also presented opportunities to further engage MCS individuals in ACP conversations. The combination of the four categories enhanced opportunities for ongoing ACP communication. Collectively, these four categories are inextricably interrelated and present boundless opportunities for ongoing ACP communication as life with MCS continues to evolve. Thus, sharing information with key stakeholders, preferably when initiated by a MCS clinician in the context of changes in health, was identified to be tantamount to having sensitive discussions and enhancing shared decision-making. Furthermore, examining MCS individuals' understanding ACP, including misconceptions, and assessing their satisfaction with ACP information received creates opportunities for ongoing ACP conversations.

It has been well-established that engaging individuals with chronic, debilitating illnesses in ACP conversations about personal values and preferences in the context of disease progression are crucial for shared decision-making (Sudore et al., 2017). However, the finding that ongoing ACP communication was largely missing in our study was surprising for two reasons. Firstly, there are clear protocols for the integration of palliative care specialists in MCS teams (Sinha et al., 2017). Secondly, 70.2% of newly implanted individuals in 2019 received the device for destination therapy (Teuteberg et al., 2020) and will live with the device and the associated unanticipated life-threatening events until their death. Therefore, in a climate of improved integration of palliative care specialists and acknowledged mortality with the device, the extent to which ongoing ACP communication was evidenced to be missing from participants' narratives was unanticipated. Furthermore, this dearth of communication was particularly surprising as recruitment happened at two well-renowned centers, and the absence of ACP conversations was consistently reported by participants across both institutions.

While some MCS individuals in the current sample preferred ACP discussions as early as possible, others shared that these sensitive conversations should only take place when serious changes in health arise. The participants also described that non-ideal conditions for ACP communication were when they experienced emotional turmoil or cognitively limitations. These findings from our study corroborate the recommendations to contextualize ACP communication in the current goals of care and treatment decisions (Sinha et al., 2017; Sudore et al., 2017), such as with serious changes to health, MCS-related hospital readmissions, or changes in the goal of therapy. The experiences of complications with a MCS device, or potential changes related to upcoming surgeries or changes in treatment goal, are opportunities to revisit individuals' values and preferences surrounding ACP. However, current studies within the MCS population have primarily focused on the initial ACP discussion during the pre-implantation evaluation (Salomon et al., 2018; Swetz et al., 2014b). Overall, while it was evident that identifying the appropriate context and timing for ongoing ACP discussions were important, the implementation of conversations individualized to MCS individuals' preferences continued to be lacking.

All the participants in our study echoed sentiments that sharing information with key individuals, such as clinicians, family members, and other MCS patients, was integral to shared decision-making around ACP. Consistent with current literature, the health care provider and supportive family members were identified as the most important individuals to include in the conversation (Nishikawa et al., 2020). A noteworthy finding from our study was that MCS individuals preferred MCS clinicians to initiate the ACP conversation while visits from the palliative care specialist were not recalled. Familiarity was described as a key component of conducive ACP communications, specifically, being known personally by the MCS clinicians who would engage them in these sensitive discussions. Our findings are congruent with recommendations that cardiovascular clinicians have an essential role to play in the provision of practical, "primary" palliative care (Sullivan & Kirkpatrick, 2020). Additionally, the current sample of participants also identified MCS-trained nurses as preferred individuals to engage MCS patients and caregivers in ACP discussions. These narrated reflections of participants support previous findings of nurses as a potential resource for primary palliative care within the MCS population (Delmaczynska & Newham, 2019; O'Connor et al., 2016).

As a MCS-trained nurse, the first author has witnessed the routine integration of palliative care consults following the recommendations of CMS (Centers for Medicare and Medicaid Services, 2013). However, it is noteworthy that the majority of MCS individuals in the current sample (n=23; 96%) did not identify palliative care specialists as key individuals in ACP communication. These insights provided by the sample reinforce findings from previous researchers that suggested the consult-based integration of palliative care specialists was insufficient to address the ACP needs of MCS individuals and their families (McIlvennan et al., 2016). Overall, while the integration of palliative care specialists is useful for the initial completion of advance directives (Sagin et al., 2016), descriptions from participants suggest that MCS clinicians, not palliative care specialists, have an essential role in engaging MCS patients in ongoing ACP communication.

It was not unexpected to find that our MCS participants lacked knowledge because ACP conversations are known to be limited within the MCS population (Wordingham & McIlvennan, 2019). However, these findings contribute to existing knowledge in two ways: these individuals did not have the words to express their concerns and needs surrounding ACP conversations and held misconceptions about both the purpose and content of ACP discussions. Although participants volunteered for the study knowing that the focus was on ACP, when asked what they considered to be ACP their descriptions were vague and oftentimes incongruent with clinicians' understandings. Examples of these misunderstandings were exemplified as participants discussed, with certainty, that ACP was about purchasing funeral plots and deciding about organ donation. Yet no one avoided talking about ACP, nor were they distressed when engaging in conversation about the complexities of living with the device. Overall, participants' misconceptions about ACP led to cursory discussions about planning for the future, while it was evident to the researchers that they had conflated the abstract nature of advance care planning with the concrete nature of completing advance directives and selecting surrogate decision-makers. It is possible, incongruent with clinical knowledge, these individuals thought they knew what ACP was and also considered that they had done what was needed. These novel findings shed light on MCS individuals' misconceptions and reasoning why they did not initiate discussion about ACP. The results also contribute to both opportunities and challenges in ongoing ACP communication.

Clinical Implications

The importance of the appropriate context and timing for ongoing ACP conversations was accentuated when current sample of participants living with MCS reflected on opportunities and challenges for these sensitive discussions. Thus, our first clinical implication for promoting ongoing ACP relates to opportune timing. Congruent with previous findings on the need to revisit ACP with the MCS population at defined intervals (Blumenthal-Barby et al., 2015), promoting ongoing ACP conversations requires clinicians to find the delicate balance between health changes and health crises. Participants were able to give information about the opportune time indicating that MCS patients and their supportive family members can respond to patient-centered questions about ideal or non-ideal circumstances for conversations about their personal values and preferences regarding their experiences with MCS. Hence, specific questions about the preferred context and timing are beneficial to identify appropriate situations to revisit ACP and collaborate with individuals and family members in shared decision-making.

The second clinical implication is associated with the most opportune person to engage with in discussions. The current group of people living with MCS voiced unequivocal preference for their specialized MCS clinicians to be the ones to initiate conversations. Despite recommendations for palliative clinicians to engage patients and family members in ACP (Swetz et al., 2014), findings from our study showed that these 24 participants were waiting for their MCS clinicians to initiate the conversations although some had been implanted with the device years earlier. Comparatively, a study on hospitalized elderly patients and their families reported dissatisfaction related to the lack of discussions with physicians on what to expect regarding end-of-life (Heyland et al., 2013). Despite the important role clinicians play in ACP, it was reported that, from the perception of providers, three quarters of MCS clinicians felt uncomfortable ordering the withdrawal of MCS therapy (Swetz et al., 2013). Hence, an implication for clinical practice includes the incorporation of palliative care education and simulated practice for MCS clinicians, such as MCS cardiologists and MCS-trained nurses.

As participants reflected on clinicians' characteristics that were conducive to ACP communication, they described familiarity and generosity of time as important attributes of clinicians to facilitate these sensitive conversations. Similar to a previous study on seriously ill patients, trusting relationships with the treating physicians were important to enhancing communication around end-of-life expectations (Heyland et al., 2006). Hence, a third implication for clinicians is to develop rapport with MCS individuals before delving into ACP communication. In addition to clinical experts, the inclusion of supportive family members in these sensitive conversations is essential to shared decision-making. Reflecting on MCS choice of the preferred supportive other, it would be prudent for MCS clinicians to consider engaging patients and family members in an unhurried environment, perhaps an appointment specifically dedicated to ongoing ACP communication, separate from hospital rounds or routine clinic visits.

Strengths and Limitations

To our knowledge, this is the first study that examined MCS individuals' perceptions about opportunities and challenges in ACP communication in their own words. Strengths of this novel work include a diverse sample of MCS participants with a wide range of age, adequate representation of female MCS patients (33%), and the inclusion of individuals with various goals of therapy: bridge to transplant (58%), destination patients (34%), and other (8%). Also, representation of individuals of varying ethnic backgrounds were included with Caucasians (50%), African Americans (29%), Hispanic (17%), and one participant who identified as an Asian (4%). Analysis of the descriptive narratives provides insights, from the MCS individual's perspective, on the lack of ongoing ACP communication between MCS patients, supportive family members, and clinicians. The strengths from the development of the four conceptual categories are reflected in the usefulness of identifying opportunities and challenges to ongoing ACP communication and shared decision-making for this MCS sample.

The findings of this investigation are notwithstanding potential limitations. Participants were recruited from two large medical institutions in Southern California and the findings were not representative of MCS patients nationwide. The inclusion of participants potentially introduced sampling bias as individuals who were not comfortable to discuss ACP may not have opted not to volunteer for the study. Also, two participants were implanted in the recent six months, which was a small window of time for ongoing ACP discussions to take place. Thus, few participants from the sample may not have had sufficient opportunities to allow for continuing discussions.

Future Research

Our findings confirm the lack of ongoing ACP communication despite ample opportunities during the frequent, routine interactions with clinicians and extended hospitalizations. Reflecting on the shortage of palliative care specialists (Sagin et al., 2016) and participants' preference that the current sample voiced for their MCS clinicians to initiate ACP communication, a high priority for future research is the development and implementation of ACP education and training materials specific to MCS clinicians. Concurrently, research is needed to evaluate the efficacy of primary palliative care by MCS clinicians in engaging patients' in ongoing ACP conversations.

As participants in the current sample did not report palliative care specialists as key individuals to include in ACP communication, the communication between MCS patients and palliative care specialists requires further exploration. The current protocol of the consult-based involvement of palliative care specialists contrasts with our findings that MCS individuals preferred to share ACP information with clinicians that they were familiar with and felt were unhurried in their approach to sensitive discussions. An important area of future research can be the structured integration of palliative care specialists in the MCS team (Pak et al., 2020). Hence, a future study on MCS clinicians' familiarity with palliative care specialists and their perceptions on strategies for collaborating across specialty teams to promote ongoing ACP communication among MCS patients is warranted.

With a keen awareness of the complexities of living with a device and the potential changes in the goal of therapy, we recognize the importance of revisiting ACP conversations along the MCS trajectory. Similar to prior studies, ACP communication in the current sample typically took place before MCS surgery and was evaluated based on the completion of advance directives (Woodburn et al., 2019). In response to participants' descriptions of ACP communication at a single time point, an important next step is for a future longitudinal study to examine ongoing ACP conversations over the MCS trajectory. Targeted areas of research include ACP communication among MCS patients who experience changes in the goal of therapy, as well as those who experience complications from the device. Although previous studies emphasized the need for ACP communication among destination therapy patients (Allen et al., 2018), the current sample described prolonged wait times for some bridge to transplant patients (n=4), with one particular individual being implanted with the device for over nine years. Interventional studies on ACP education for MCS clinicians are also needed to examine ACP communication related to experiences of changes in health. Overall, we recommend longitudinal and interventional studies on ACP communication between MCS patients, family members, and clinicians across the MCS trajectory.

Finally, future research is needed to examine the influence of culture on ACP communication in the MCS population. Although diverse, the sample only included one individual who self-identified as Asian American. Furthermore, the study was not focused on participants' cultural background and the implications of their customary way of life on ACP communication was not explored. Literature on end-of-life care in African American, Hispanic, and Asian American populations, have cited inaccessibility to care, lack of knowledge, experience of discrimination, fear of being misunderstood by health care providers, and receiving inadequate care as potential barriers to sensitive discussions (Bowman & Singer, 2001; O'Mara & Zborovskaya, 2016; Rhodes et al., 2017b). As our study was not purposed to explore cultural perceptions of opportunities for ongoing ACP communication, the effect of culture in ACP communication among the MCS population remains unexplored. Thus, future research is needed to examine the implications of culture on ongoing ACP communication.

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Table 1

Exemplars from Semi-structured Interview Guide

Subject	Question	Potential follow-up questions
Identifying optimal timepoints for ACP communication	What comes to mind when you think about the situations surrounding your experiences with advance care planning communication?	Can you recall your last ACP discussion? How did the timing of those conversations work for you? in your opinion, as someone living with a MCS device, what would be a good time to discuss advance care planning? Then again, what would not be a preferred time for such discussion?
Sharing ACP information with key stakeholders	Overall, who would you like to include in discussions for advance care planning?	What is meaningful to you about including this individual in advance care planning discussions? Some people have described their loved ones being impacted by advance care planning, if this is the case, how may your decisions around advance care planning impact these individual(s)?
Evaluating ACP knowledge	What have you heard about advance directives?	In your own words, what is advance care planning for you?
Assessing satisfaction with ACP information	How do you feel about the conversations you have had about advance care planning?	What information from your advance care planning conversations did you find most useful? On the other hand, was there something that did you found less useful?
Checking-in with participants on their well being	We just had a pretty lengthy conversation filled with some difficult topics, how are you feeling?	

Table 2

Processes to Establish Scientific Rigor

Quantitative research	Qualitative research	Components in this study	Processes followed in the current study
Internal validity	Credibility	Triangulation	The first and last authors independently read, coded, and discussed emerging themes for all the transcripts.
		Peer debriefing	Repeated discussions with co-investigators who were experts in the fields of decision-making, palliative care, and cardiology throughout the study.
		Reflexivity	Self-reflective memos with a detailed description of potential bias and perspectives about the participants were written and revisited in the course of the research.
External Validity	Transferability	Thick descriptions	Field notes were written to provide detailed descriptions of the sample, including the timing and location of data collection. Memos were written to examine the development of dimensions and properties, and whether they were filled out.
		Purposive sampling	Purposive sampling was conducted to enhance heterogeneity and authentic representation of the MCS population.
Reliability	Dependability		Two authors independently coded all the transcripts to compare and discuss their coding. In case of different opinions, an agreement was reached through discussion.
Objectivity	Confirmability	Audit Trail	An audit trail of digital recordings, transcripts, field notes, reflexive memos, data analysis, and diagrams was maintained throughout the study.

Lincoln & Guba, 1985; Tong, Sainsbury, & Craig, 2007; Levitt et al., 2018; Charmaz, 2014; Lincoln 1995; Erlandson et al., 1993; Elliot et al., 2005

Table 3

Characteristics of the MCS Sample (N=24)

Sociodemographic Characteristics	**n (%)**
Age mean ± SD (range[years])	60.6 ± 16.5 (24-80)
18 - 24	2 (8%)
35 - 44	3 (13%)
45 - 54	2 (8%)
55 - 64	2 (8%)
65 - 74	10 (42%)
75+	5 (21%)
Sex	
Male	16 (67%)
Female	8 (33%)
Ethnicity	
Caucasian	12 (50%)
African American	7 (29%)
Hispanic	4 (17%)
Asian	1 (4%)
Marital status	
Single	4 (17%)
Married	18 (75%)
Divorced	1 (4%)
Widowed	1 (4%)
Religion	
Christian	16 (67%)
Catholic	3 (13%)
Hindu	1 (4%)
Jewish	1 (4%)
Muslim	1 (4%)
None	2 (8%)
Education completed	
Middle school	2 (8%)
High school graduate / GED	1 (4%)
Some college	11 (46%)
Four-year college graduate	5 (21%)
More than four-year college degree	5 (21%)
Household	
Lives alone	1 (4%)
Lives with spouse	13 (55%)
Lives with spouse and children	2 (8%)
Lives with adult children (only)	2 (8%)
Other	6 (25%)
Financial status	
Fixed income	21 (87%)
No fixed income	3 (13%)

Clinical Characteristics	**n (%)**
MCS Device mean ± SD (range[months])	29.8 ± 26.7 (3-112)
< 6 months	2 (8%)
1 year	9 (38%)
2 - 3 years	9 (38%)
4+ years	4 (16%)
MCS therapy goal	
Destination Therapy	8 (34%)
Bridge to Transplant	14 (58%)
Other (transplant pending clearance)	2 (8%)
Future Planning	
Completed advance care directives	19 (79%)
Filled out a POLST form	3 (13%)
Healthcare proxy	17 (71%)
Living will	9 (38%)
Surgical History	
Coronary artery bypass graft	4 (17%)
Prior heart transplant	2 (8%)
Pacemaker / ICD implant	11 (46%)
Other	8 (33%)
Complications from MCS device	
Bleeding - requiring hospitalization	6 (25%)
Nontherapeutic anticoagulation	20 (83%)
Infection (driveline, sternal wound)	3 (13%)
Issues with device charging	3 (13%)
Pump thrombus	1 (4%)
Stroke	1 (4%)
Readmissions since device implantation	
Never	3 (12%)
1 - 3 times	12 (50%)
4+ times	9 (38%)
Days readmitted to the hospital	
<7 days	9 (38%)
1 week	6 (25%)
2 weeks	3 (12%)
>1 month	6 (25%)

Table 4

In-vivos from Individuals Living with MCS

Category	Subcategory	Property	In-vivos
Context and timing of ACP			At least two months prior (to MCS surgery), or maybe a little longer. Because I was lucky to have a big family, so everybody showed up. Plus my wife. Son couldn't get here, but if they don't have the same support system that I have, they probably need three to four months prior to any surgery, once they determine that they're going to need a heart transplant. Make sure they get the right people in place. (P02)
			It (ACP discussion) was after my surgery. It (ACP discussion) was when we were getting ready to go on the transplant list. That (ACP) was part of their (clinicians') protocol. (P15)
			It's never a good time (for ACP). Like now, it's making my anxiety level go up. (P24)
	Ideal circumstances for ACP communication		I think a good time is when a person is fully alert. I think ... And I know you have to discuss things while you're in the hospital, but I think some things I forgot is because I just remember being in a lot of pain. I just was like, "Some of this stuff is just going in one ear and out the other." So I'm thinking maybe when a person is in a ... you should make sure a person is in the right frame of mind to really comprehend what you're saying to them. (P09)
			Particularly after these two episodes of the clot formation so I told them that deep in my heart, I am a little bit more scared that who knows what can happen at any time, because this came so unexpectedly, suddenly stomachache. And I was totally fine for one and a half years, no fever or anything. And I had two trips, one to H (state) and one to B (city) and nothing was there but this came I, even today I think that what is the guarantee that it will not come back? They say, well, mostly it doesn't, but you never know. (P14[2])
			If it concerns my heart, that's where I would say something (ACP) should be planned for future. (P17)
	Non-ideal circumstances for ACP communication		When your two daughters and your husband are all crying around your bedside, they wore me down. But I don't regret it now. I just can't tell you, it's so hard to make a decision like that when you're so exhausted. You're so exhausted you can't even think about how you're going to brush your hair or brush your teeth. You know what I mean? I just had no energy at all. So no, I thought we were in total agreement, and we don't have any fights about it now. Now I'm glad that I had somebody to give me another position on it because I wasn't really in the right frame of mind to decide. I don't know if that makes any sense to you, but I wasn't in the right frame of mind to make a good decision that maybe would help my family and help me. (P06)
			So, if a person is really sick, sometimes explaining things that are very, very important is ... maybe it's not a good time. You should wait until they're more capable of comprehending and understanding what you're saying. (P09)
			Because you can't think straight (right after surgery). For one thing, I can't think straight now. My mind, my eyes, I'm not thinking like I was thinking before. Plus, it's too emotional. (P20)
Sharing ACP information with key stakeholders	Clinicians	Familiarity (doctors)	I would hope that they (doctors) would know, especially if I've been in the hospital a lot, kinda my personality and knowing what I want. So, knowing what they think would be the best kind of (ACP communication.) (P05)

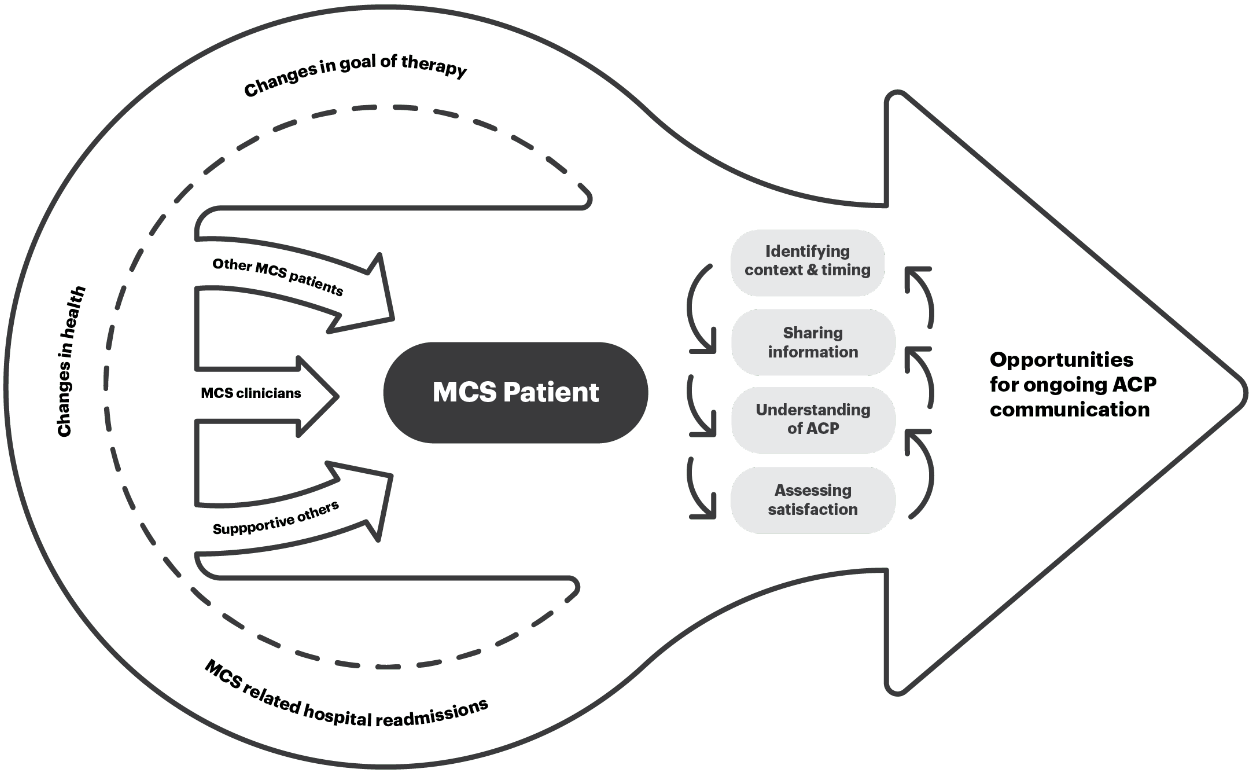
			There's an actual selection process that goes on in my head. When I start talking to doctors, and I listen to what they have to say and listen to how they listen to me, I don't consciously rate them, but I know I make decisions on which doctors that I feel more comfortable with and whose advice I listen to more. (P18)
		Generosity with time (doctors)	There was this one doctor, “Dr. (cardiologist). He and I connected the most, and he would sit and talk to me deeply. I mean, he's a very caring man. (P06)
			Very caring. Listens very well. Isn't in a hurry. We've asked about his family and talked about our family and vacations and stuff like that. It's been really nice. He's more like a friend than a doctor. (P19)
		Familiarity (nurses)	The one nurse practitioner who had followed me for years, when I had to make different decisions on things, I used to ask her opinion and what she thought. So, I would say that I sometimes go to that healthcare professional whom I trust, and I value their opinion. That helps me make decisions sometimes. (P09)
			You get to know a nurse. You have conversations with them and share things. But with somebody who just comes in the door and starts telling you what you need to do, that's different. (P15)
			She (MCS coordinator) knows me. She's actually come down to (city) to speak before a group that I had her come down to speak to. So, we have a kind of a personal interaction so it makes it very easy to talk to her. (P17)
			But yeah, (MCS coordinator) is probably the number one person in my corner. (P17)
		Generosity with time (nurses)	The people at “A” (hospital) are so great and the nurses that we've worked with in the heart unit at “A” (hospital) that asks these questions and initiate the discussions, I always felt very comfortable with them. I don't know. I don't think I'd be any more comfortable with somebody else… Well, they're friendly. They ask questions. They're really super great at what they're doing and they take an interest in the individual's case. You're not just a number going through there. (P16)
	Perceived barriers to ACP communication with clinicians		But it's not something that it's really been brought up with my heart team. (P01[2])
			Like this is just a job to them. You know. Like it’s my job. Like all right, well it's your job. I know it's just your job, but can you be sensitive? Like a doctor, be caring. That goes a long way to a person. (P04)
	Supportive others	Selecting appropriate family members	Figuring out who's going to make your decisions, so that was a big one because my parents are divorced and they don't really think eye-to-eye. But I would have felt bad just to pick one or the other. So thankfully I was able to put both of them down. But I kind of regret putting both of them down only because one of them thinks more realistically and knows me better than my other parent. (P05)
			My son won the lottery (selected to make ACP decisions) because he had a personality very like my husband in the sense that he's very logical. He's going to think things through. He's very emotional. I mean he's not this rock or what have you, but he'll do what has to be done. He will go ahead and he'll make a decision. He also won't fuddle around. He's not indecisive. (P21)
			Like I said, it's my mother. My mother knows how I feel about my health there and she knows my wishes that I want to be carried out. I leave it up to her. I hope that she makes the right choices and will tell the doctors and express my wishes. (P23)

		Motivating conversations	The family can know what your wishes are and not have to deal with the complete burden of having to try to figure that (ACP) out on their own. (P08)
			It is better to make a decision before the end rather than leaving it to the children and giving them all kinds of stresses. And then the son says one thing and daughter says something then there's a difference of opinion and unnecessary heartburn. So better to make a decision before when you are alive and in good condition where you can make a conscious decision basically. (P14[1])
		Initiating conversations	And my wife and I actually have conversations about this because she's (more than a decade) younger than I am and she said, "Let's talk about this. The only thing that's keeping you alive is your LVAD, but what does that mean? You want to turn it off?" And I said, "That's an excellent question. If I have no quality of life, if the LVAD weren't functioning enough to keep my organs functioning, I'm not mentally aware of what's going on and you have to make decisions and there's no hope of me getting to the point of being mentally aware, then no, I think I'd want it turned off." (P18)
		Perceiving supportive others as barriers to ACP communication	Sometimes I feel like I cannot always include them (family) in decisions because what they may want may not be what's best for me. Sometimes I feel like my family wouldn't care if I was on life support, in a coma, laying up there as a vegetable. They just know they kept me around. I wouldn't want to be that way. You see, there are some decisions that I would have to make, that I have made, that have been hard. (P13)
	Other MCS Patients		Another thing that I told patients also, they had me going to talk to patients or whatever. Obviously, the longer you have this thing in you, the greater the risk of something happening. (P03)
			The minute I stopped going to those support groups is when... my wife and I, we were there and there was this one older couple, because all the patients with the total artificial hearts, they had all gotten hearts and going on their way. (P03)
			And I would tell them (other patients) "Hey, make sure you're telling them what you want though". And so, I think hearing another patient telling them what they think that they should make sure that they're getting the right kind of care by telling them what they think they need is definitely helpful because I don't know how else they would. (P05)
			Now I will say this, the two individuals that had the device, they both had type O. So, it kind of gave me hope, because I knew going in that type O would be a problem, there'd be a longer wait. (P13)
		Comparing illness trajectories	I guess older people, they've had such a long life and they're grateful that they get to have an extra five or seven years, I guess because they got an LVAD. Whereas I haven't met anyone my age with an LVAD but for me, it's just been tough. I'm glad that I have it and that I can get the extra time that I want on earth, hoping that the transplant, if I do get one, will work and that I don't have the devices but it definitely puts a different ... Like I said it's harder because I haven't lived a life as free, I guess, as the older people have and so with the VADs, it definitely limits the way I can live it. (P05)
Understanding of ACP	Purpose		Advance directive is not a big thing in my life and it's just something I have to sign. I don't even know how to answer that. Acting like advance directive is great in my life, it's not. It was a requirement for me to get surgery. (P12)
			When you're put in the hospital, the nature of the medical care is to give you whatever is necessary to keep you alive. And whether that really fits your understanding of how you want to live going forward, may be in conflict. So, you have to think very hard about it, I mean, it's easy to say I don't want to be kept alive by artificial means. (P18)

			Well, the purpose of it would be maybe to clarify what to do in the future if I start having problems. (P19)
		Descriptions of meaningful living	Well, I enjoy cooking, so that's all part of who I am. I enjoy eating, obviously being with my family, we come together every night and eat, and sometimes lunches. It's a sociable thing for me a bit and just something that we do. Like I said because I enjoy cooking. I would really miss not being able to eat. The things that I want. It's all fun, the creative side of me, I get to figure out what I want to eat, how I make it, that kind of thing. (P08)
			So, since the LVAD (left ventricular assistive device), I've been able to get back to those things (old hobbies) like tinkering with my old classic car and walking at the park. And actually, we took our RV out in July while I was feeling good between the first surgery. (P11)
		Meaningless living	To me, not being able to walk is a sort of imprisonment, and I didn't like that part. (P06)
			Well, the fact that I can't live by myself is a hindrance. (P09)
	Content		I really don't know that much about them (AD). I know I did it, but... Yeah. (P17)
			I don't even know what's on the advance directive anymore. I don't know. I can't remember. (P20)
		Misconceptions of ACP	As far as I know that when you value, what should be done rather whether certain organs of your body should be donated. My wife wants her whole body to be donated. I'm in the middle or kind of a Twilight zone whether I should go this way or that way. And I think of the children how they will feel and this and that. So that is what I think that is very advance directive so that they don't have to make a decision. The decision is already made by the patient basically. (P14[1])
			I mean, I know when we would be buried, we'd be buried in the military cemetery in San Diego. (P20)
Assessing satisfaction with ACP communication			They've been, again, invaluable. Like I said, when you talk about healthcare professionals, I'm talking the psychologist they provided, the social worker they provided, the whole program itself and the palliative care, and even the doctors, it's been like it said, invaluable as far as kind of letting me see what my directed care would be all about. They give me both good and bad, so I know what's the worst that can happen. I know what's the best that could happen. (P13)
			I did have a session, a very helpful session with a doctor who specializes end of life planning. I'm pretty sure she was a medical doctor, or I think she actually was a medical doctor. She wasn't a social worker, I don't think, per se. And Medicare didn't cover it, but it was worth it to have somebody just really put it out there. (P21)
	Dissatisfaction with information		That would have meant a lot to me. Because at that point, when something did happen, you would kind of already have an idea what was to come. But for things to happen, and then you have to make a decision right then and there, it's kind of difficult. So, to have had pre-knowledge of what was to come would have been really good. I would probably not be feeling the way I'm feeling right now. (P09)

Figure 1

Opportunities for Ongoing ACP Communication Across the MCS Trajectory



Third Manuscript

Theory of Pivoting Uncertainties: Decision-making about Advance Care Planning among People Living with Durable Mechanical Circulatory Support

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Introduction

Cardiovascular disease is the leading cause of mortality in the United States, accounting for 23.4% of all deaths in 2015 (American Heart Association (AHA) & American Stroke Association (ASA), 2017; Centers for Disease Control and Prevention (CDC), 2017). By 2035, the prevalence of heart disease is projected to impact 45% of the population in the United States, affecting 8.8 million individuals (AHA & ASA, 2017). Mechanical circulatory support (MCS) is used to manage advanced heart failure when medical and surgical interventions are no longer effective (Kozik & Plunkett, 2011). From January 2014 through December 2018, 13,787 patients in the United States were implanted with durable MCS devices (Teuteberg et al., 2020).

Durable MCS devices provide hemodynamic support and symptom reduction for advanced heart failure patients (Van Diepen et al., 2017). The most commonly used technology is a left ventricular assistive device (Teuteberg et al., 2020). Recent innovations in MCS technology have led to reduced mortality in the first 30-days (5%), with 1-year survival (82%), and 5-year survival (47%) (Teuteberg et al., 2020). Among individuals living with MCS for five years, only 23% remained implanted with the device, while 34% had received heart transplants (Teuteberg et al., 2020). Furthermore, the MCS trajectory is complex with 89.2% of patients reporting adverse events such as gastrointestinal bleeding, strokes, systemic infections, right heart failure, and end-organ failure (AHA & ASA, 2017; Kusne et al., 2017).

According to the Society of Thoracic Surgeons, the use of MCS is categorized into three distinct therapy goals: bridge to candidacy, bridge to transplant, and destination therapy (Teuteberg et al., 2020). Bridge to candidacy is the treatment strategy for individuals whose eligibility for a heart transplant has yet to be confirmed (Frigerio et al., 2017). Bridge to transplant patients are implanted with MCS devices as an intermediary step prior to heart transplantation (Kusne et al., 2017). Patients implanted with MCS for destination therapy are not eligible for a heart transplant (Kusne et al., 2017), but receive the device to improve their functional status and quality of life (Abshire & Himmelfarb, 2014; Peura et al., 2012). Furthermore, therapy goals may be altered over time according to changes in patients' health. Approximately 40% of MCS patients reported changes in their goal therapy within two years of implantation (Schramm et al., 2019).

Ongoing advance care planning (ACP) is needed to address the complex post-implantation trajectory and evolving MCS therapy goals. Traditionally, ACP was focused on the completion of advance directives in preparation for future states of mental incapacity (Singer et al., 1998; Winzelberg et al., 2005). However, as time progressed, clinicians found the mere completion of advance directives to be ineffective in practice because these documents do little to enhance clinician and surrogate's knowledge of patient preferences and have been found to have minimal affect the quality of end-of-life (Sudore, 2010). The reconceptualized definition of ACP incorporates a series of decisional behaviors over time between patients, clinicians, and family caregivers (McMahan et al., 2013). In 2013, the Centers of Medicare and Medicaid Services along with the Joint Commission required the integration of palliative care specialists to address the complex trajectory of living with a MCS device (Centers for Medicare and Medicaid Services [CMS], 2013). However, the focus in the current literature surrounding ACP among MCS patients has been on the perspectives of clinicians (Meyers & Goodlin, 2016; Sinha et al., 2017) and MCS caregivers (McIlvennan et al., 2016). Findings from the literature confirmed insufficient palliative care training and resources for MCS clinicians (Sagin et al., 2016). Similarly, bereaved caregivers of MCS patients reported experiencing fragmented palliative and hospice care (McIlvennan et al., 2016). However, there are minimal guidelines on conversations surrounding the deactivation of cardiac devices, including the termination of MCS devices and anticipated death (Braun et al., 2016). For these reasons, the purpose of the current study is to understand and describe how patients' perceptions of the MCS trajectory inform decision-making about ACP.

Research Design and Methods

Constructivist grounded theory (CGT) was employed to guide all aspects of this study as the methodology emphasizes exploring patients' subjective experiences and understanding their actions (Charmaz, 2014) when living with a chronic condition such as advanced heart failure. Furthermore, it is historically noteworthy that the first published study utilizing grounded theory, *Awareness of dying,* was also used to explore processes in ACP (Strauss & Glaser, 1966).

Symbolic interactionism, an important philosophical underpinning of CGT, is focused on symbols as the building block of all human interactions (Charon, 2009, p. 48). These symbols are created and give meaning according to socially agreed-upon definitions that allow for the ongoing re-evaluation and adaptations of self to the external world, including experiences of illness (Charon, 2009, p. 72). Applied to this research, the words "heart" and "plug" are examples of symbols that participants used. "Heart" was aptly used to depict the cardiac muscle, yet in other instances, the word symbolized life and love. "Plug" described the object used to connect the MCS device to an electrical outlet. However, being plugged into a wall also denoted a lack of freedom and pulling the plug represented a decision to terminate life support. Pragmatism, another philosophical tenet of CGT, is used in the application of personal experiences to recognize and resolve problems as they arise. Hence, the application of pragmatism encourages individuals to act in a way that leads to the most useful outcomes (Hammersley, 1989, p. 45; Magee, 2001, p.186).

Finally, the incorporation of constructivism diverges from the traditional approach to grounded theory by acknowledging the researcher's interaction with the data (Charmaz, 2014). In constructivism, reality is not objective, rather it is fluid, constructed through personal experiences (Rodgers, 2005). Meaning and definitions are thus constructed through the dialogues, interactions, and the reflexive process between the interviewer, participants, and the data (Charmaz, 2014). Subsequently, CGT, symbolic interactionism, pragmatism, and constructivism are conducive for examining ACP interactions and decisions between MCS patients, families, and health care providers.

Recruitment

Following approval from the South General Institutional Review Board from the University of California, Los Angeles, 24 participants were recruited from outpatient MCS clinics of two large urban medical centers in Southern California. Recruitment flyers were handed to potentially eligible individuals by the first author and key members of the MCS team, including social workers, MCS coordinators, and cardiologists. To reduce power imbalances that might influence potential recruits' decisions to participate in the study, the first author, an employee at one of the medical centers, wore professional attire with her UCLA School of Nursing identification pinned to a visible location during recruitment. Inclusion criteria were comprised of adults 18 years or older, who were English-speaking, and currently implanted with a MCS device. Excluded were individuals who were cognitively impaired or admitted to the hospital at the time of the interview. Screening for eligibility was done by the first author in-person at the MCS clinic or over the phone.

Between February 2019 and October 2020, 29 MCS patients expressed interest. Of these, one was not eligible because of cognitive impairment. Four eligible individuals were not interviewed because they were readmitted to the hospital (n= 2), transplanted (n=1), or died before the interview (n=1). The remaining 24 MCS individuals completed informed consent to participate in the research. Second interviews were conducted with two participants for a total of 26 interviews.

Data Collection

Data were collected with semi-structured interviews, and demographic and clinical characteristics were garnered with questionnaires. The semi-structured interview guide, developed by the first and last authors, was used to stimulate a focused discussion on participants' perceptions of living with a MCS device and how their experiences informed making decisions about ACP. Non-directed questions, based on the research team's clinical experiences and expert knowledge in decision-making, palliative, and cardiovascular nursing, were used to promote rich, emergent information (Charmaz, 2014; Rubin & Rubin, 2012). Open-ended follow-up questions were included in the interview guide to be used if further discussion needed to be encouraged. (See Table 1 for exemplars.)

The first author conducted all the interviews in person (n=5) or by phone (n= 21) according to the participant's preference and California-mandated restrictions during the Covid-19 pandemic. The 26 interviews lasted on average 52.7 minutes (range: 18.6 – 132.6) and were digitally recorded with the participants' permission. The in-person interviews were conducted at a location of the individual's choice. The interviewer obtained written informed consents from individuals who preferred in-person interviews while implied consents were obtained from those who selected phone interviews. After five interviews, homogeneity of the sample became evident, specifically, inadequacies in representing unique experiences of unpredictable complications and frequent hospital admissions. Following an approved amendment by the IRB, theoretical sampling allowed for targeted recruitment of destination therapy patients. As recruitment continued, successive interviews were focused on processes that needed to be further understood to complete the dataset and reach saturation (Charmaz, 2014; Corbin & Strauss, 2015).

Since conversing about ACP was deemed a sensitive topic and to maintain the ethical obligation to do no harm (Dempsey et al., 2016; Rubin & Rubin, 2012), the first author received extensive training and practice in qualitative interviewing. To reduce power differentials, all interviews were conducted outside of the clinical setting. Before the start of the conversation, interviewees were advised that they had a right to stop the interview if they felt uncomfortable with answering any of the questions. Another measure taken to respect the delicate nature of the research topic was that, as an interview progressed, the participant's own words were used to ask questions to maintain language sensitive to the individual's comfort level. The researcher also paid close attention to participants' tone of voice and overall body language to look for signs of discomfort. If any potential reluctance was evident, the interviewer planned to ask the participant if they would prefer to take a break or if they were comfortable continuing with the interview. At the end of each interview, the researcher checked with each participant to assess how they were feeling and to confirm that no harm was incurred. Despite the emotional content of the discussions, all the participants were observed to respond positively to the interview. Upon completion of the interview, participants received a $50 gift card to compensate for their time and emotional availability to reflect and describe sensitive experiences in their MCS trajectory.

The interviews were transcribed verbatim by a professional transcription service (http://www.rev.com). The first author checked for accuracy by comparing the transcripts to the audio recordings of the interviews. Transcripts were de-identified by replacing all names, locations, and organizations with an abbreviation and brief description to protect the anonymity of the participant, treating clinicians, and institutions.

Data Analysis

Data analysis was a systematic process as the principal investigator and the chair of the dissertation committee individually conducted three rounds of coding. Data collection and analysis were concurrent to allow for constant comparison, which informed subsequent interviews as analysis progressed (Corbin & Strauss, 2015; Charmaz, 2014). Categories in the data were identified through systematic analysis, as researchers transitioned from initial coding to focused coding, and finally to theoretical coding (Charmaz, 2014). Initial coding, the first round of the analytic process, utilized gerunds to describe actions and meanings in the data (Charmaz, 2014). Focused coding sorted initial codes into larger, more conceptual categories (Charmaz, 2014). Theoretical coding, the final round of data analysis, elucidated relationships between categories and moved the data in a theoretical direction (Charmaz, 2014, p. 150). Concurrent with coding, the researchers used reflexive memos and diagrams to raise the level of abstraction (Corbin & Strauss, 2015; Charmaz, 2014). In addition, situational analysis was used to enhance our understanding of social processes and emergent analytic directions (Clarke et al., 2018). The social worlds map was particularly useful for examining the interrelatedness of humans and MCS technology and the nature of relationships within health, familial, social, and financial situations. Atlas.ti and Microsoft Word software were utilized for data management and analysis (Muhr, 2012).

Supporting Rigor

The rigor of this study was maintained in accordance with the criteria of credibility, transferability, dependability, and confirmability used in qualitative research (Lincoln & Guba, 1985). Credibility of the findings was upheld through reflexive memos to explore researchers' perceptions and understanding of the themes in the data (Tong et al., 2007). Additionally, the first author deliberately built trust with participants by making sure to arrive on-time to in-person interviews with her UCLA identification badge pinned in a visible location on her attire. Transferability to contextualize the data and its potential application to other populations (Levitt et al., 2018) was achieved through detailed field notes with thick descriptions of participants' characteristics. Memos of emerging themes and categories were kept as an audit trail to delineate the analytic process. Dependability was attained by having two qualitative nurse researchers, the first author with expertise in cardiology and the last author with expertise in decision-making, independently review the transcribed interviews to identify themes and categories (Cypress, 2017). The first and last authors practiced analytic triangulation through independent reading and coding of the transcripts, followed by a discussion on the different views in coding until a mutual agreement was reached (Charmaz, 2014; Lincoln, 1995). Confirmability of the data was achieved through the creation of an audit trail of audio-recordings, field notes, reflexive and analytic memos, and process notes were composed throughout the study to ensure the dependability of the findings (Erlandson et al., 1993; Lincoln, 1995).

Results

Sample Characteristics

The 24 participants in the sample consisted of 16 men and 8 women, who were on average 60.6 years old (with a range of 24-80 years old) at the time of the interview. Self-identified ethnicities of participants included Caucasian (n=12), African American (n=7), Hispanic (n=4), and Asian (n=1). The average duration of MCS implantation was 29.8 months (with a range of 3-112 months) at the time of the interview. Per the participants, the self-reported goal of MCS therapy was identified as a bridge to transplant (n=14), destination therapy (n=8), or uncertain pending the resolution of current comorbidities (n=2). The majority of the sample recalled completing advance directives (n=19). Additional sociodemographic and clinical characteristics are listed in Table 2.

The Theory of Pivoting Uncertainties in Decision-Making about ACP Communication

Grounded in the words of the current sample, The Theory of Pivoting Uncertainties elucidated the process of decision-making about ACP in the context of living with a MCS device. At the center of the theory, the core category reflected that the complexities of these conversations were situated over time and, within the individual, external and internal processes. Over time, the laborious nature of the MCS trajectory was evidenced by the complexities of living with the device. Recognition of the increasing challenges of living with MCS enhanced awareness of the precariousness of health, with one participant sharing, “you never know what's around the corner that can send you back to the hospital for another month and a half.” Weighing the uncertainties of health outcomes pivoted individuals from passivity to action in ACP. These actions were further categorized into external and internal processes. External activities embodied shifting from waiting for information to questioning, communicating, and participating in shared decision-making about ACP with clinicians and informal caregivers. Internal activities promoted shifting attitudes of trust and positivity to a nuanced contemplation of varying health outcomes and the impact on the self and family. Therefore, the Theory of

Pivoting Uncertainties, presented in Figure 1, addressed the dynamic internal and external processes that shaped decision-making about ACP throughout the MCS trajectory.

The core category, complexities in decision-making about ACP communication, was identified through the participants' narratives about their experiences of living with MCS. This core category incorporated the dynamic intricacies of ACP communication from the time of implantation to the emerging health variances. The upward-pointing arrow in Figure 1 symbolizes increasing ACP communication overtime. Overall, the analysis of the core category of complexities in decision-making about ACP communication subsumes the progression of time and the internal and external processes involved in decision-making around ACP.

The three subcategories surrounding complexities in ACP were derived from the participants' descriptions of living with MCS: impediments to discussing ACP, uncertainties in MCS outcomes, and promoters of ACP communication. Fluidity in the subcategories was evident as participants pivoted between uncertainties in their MCS outcomes to impediments or promoters in ACP communication. Additionally, the conversations surrounding decision-making in ACP were never effortless, and the identification of the subcategory, promoters of ACP communication, left much desired as only two participants revisited discussions with clinicians and family caregivers about their ACP preferences after the initial completion of advance directives.

Subcategories were further represented by dynamic external and internal processes. External processes were comprised of behaviors such as anticipating to receive information, asking clarifying questions, and verbalizing concerns to clinicians and supportive others. These external processes were categorized into three properties: aligning self with the best care, living in limbo, and distrust of clinicians. The internal processes, that reflected inner conversations and descriptions of reflective thoughts, were organized into three properties: maintaining a positive outlook, leaning on spirituality, and managing incongruent expectations.

Impediments to Discussing ACP

Impediments to discussions about ACP revolved around the interaction of expectations between the external sources of care and the internal processes of framing the MCS trajectory positively. Aligning the self with the “best care” was an external process in which participants described receiving care at the “best” hospitals from the “best doctors and nurses.” In contrast, framing experiences positively was an internal process used to cope and make sense of various health-related situations.

Aligning self with the best care: “I got the best, so where do I go from here?” Without being prompted, participants spontaneously shared experiences of being at the best hospitals and receiving the best care from clinicians. After transferring from a different healthcare system to the current MCS team, one participant exclaimed: “I mean this is first class. You know, I mean look at this. This is, you can't get any better than this.” Believing that they received the best care, many participants felt reassured about the future of their MCS outcomes. An individual waiting for a heart transplant recalled the reassurance he received from clinicians: “You're at the best place (hospital). We get it (heart transplant) done. It's going to happen.” Confidence in being at the best hospital for a transplant was evident throughout the narratives as individuals minimally reflected on the potential complications of living with a MCS device. For the majority, believing that they received the best care hindered additional questions and communication about their future with MCS. As an example, when asked about how clinicians could have more meaningful ACP conversations with them, one participant described a lack of suggestions, stating, “I got the best, so where do I go from here?” Aligning with the best care was further comprised of positive attitudes towards clinicians that hampered ACP communication: trusting the clinician, feeling grateful, empathizing with providers, and living as a good patient.

Trusting the clinician: “I just kind of wait for them (clinicians) to say, ‘This could be an issue.’” Descriptions of receiving the best care commingled with a deep sense of trust towards MCS clinicians. Under normal circumstances, trust and rapport are conducive to communicating about illnesses and changes in health. However, within the sample of participants, trusting the clinician was reflected in participants' passivity to initiate conversations about the trajectory of living with a device. Despite waiting longer than expected and nearing the cutoff age for a transplant, one individual shared, "I've been on this (transplant list) for a long time. I trust my medical providers. And I really don't know what's going to happen going forward." In trusting clinicians, many anticipated that the MCS team would initiate ACP discussions, as one individual described, "I just kind of wait for them (clinician) to say, 'This could be an issue,' or, 'You might want to think about that,' from their own experiences with other patients that have gone through the same thing I have. I trust their judgment." Overall, trusting the clinician evidenced a passivity to ACP and placed the onus of initiating conversations on the MCS team.

Feeling grateful. Gratefulness appeared in descriptions such as "thankful" and "grateful" that were weaved throughout the narratives. A deep sense of gratitude was observed as many individuals spontaneously expressed gratefulness for receiving the best care from the best clinicians. Overcome with emotion, one individual said, "I was just so grateful for them. They were so kind to me, those doctors. They absolutely mean the world to me. They absolutely do." A majority also described a sense of gratefulness for having extra time to live. An individual who was extremely debilitated before MCS implantation reflected, "Without the LVAD I wouldn't have made it this far. So, I'm pretty thankful." Despite receiving the best care and being alive, a few individuals expressed the tension between feeling grateful and wishing that they did not have the device. A participant who struggled to adapt to living with the device reflected, "On one hand, I'm grateful. On the other hand, I'm not. It's not that I'm not grateful, I just wish I had chosen a different decision, which was not to get it." In balancing gratefulness with the desire to live free of the device, researchers observed as many participants glossed over the difficulties of living with the device, especially when they were in good health. While having a thankful attitude was conducive to maintaining a good rapport with clinicians, the overwhelming sense of gratefulness impeded communicating the adversities of living with MCS.

Empathizing with providers: “I understand they're walking that tightrope.” For a majority of participants, empathy was demonstrated in the trust and gratefulness felt towards clinicians. Subsequently, empathizing with the providers was an impediment to ACP as many participants precluded themselves from the external decision-making process of asking questions about their MCS trajectory. Recalling a situation where one clinician shared information while another clinician shook their head in disagreement, one participant empathized with the clinician to make sense of the discrepancy and said, “The doctor was probably trying to pick me up, keep me positive about going forward and not getting depressed about it.” Participants frequently attempted to understand the discrepancies in ACP communication by putting themselves in the clinicians' shoes. Despite feeling distrust towards clinicians for the inconsistent information about his MCS trajectory, an individual made sense of the situation as he explained, “I understand they're walking that tightrope also, whereas they want you to have hope. They want to give you hope. They don't want to give you expectations that may not come out.”

Despite experiencing inconsistencies in ACP communication, these MCS individuals often empathized with the provider by rationalizing the perceived discrepancies. In a rare example of regretting to be implanted with a MCS device, a participant shared:

> I don't want to seem like I'm saying that they didn't give me all of the information that they should have, because I know they did. That is one of the best hospitals…I know I'm getting the best care I could possibly get.

Although discontent with the life after implantation, this individual was quick to rationalize the deficiency of information received and shifted blame away from clinicians by juxtaposing her dissatisfaction with receiving the best care.

Speaking up about personal care preferences was uncommon as most participants relied on clinicians to begin the ACP conversation. Within the sample, only one participant expressed a preference to self-initiate ACP communication over empathizing with the provider. Spending much of her youth in the hospital after multiple heart transplants, a participant shared, “With me, vocalizing a lot, I show what I want, I can tell them (doctors) what I want instead of just always agreeing with what they think is best. Sometimes you need to tell them what you think is best.” Ultimately, empathizing with providers was depicted by most participants as making sense of the inconsistent information received rather than engaging in direct ACP communication.

Living as a “star patient.” Striving to live up to what was perceived as their clinicians’ expectations, participants aligned themselves with the best care by embodying the role of a “star patient.” This label was created by clinicians and understood by participants as a form of encouragement from providers. One young, independent participant reflected hearing a discussion between clinician about him, said, “It helped that a lot of the team along the way were telling me like, ‘(here is) our star patient.’” However, the concept of a “star patient” also constructed a perceived ideal of clinicians’ preferred patient. A variety of self-descriptions were encompassed in the narratives ranging from “I went to every appointment” to “taking care of myself (not being readmitted to the hospital).” Simultaneously, within these stories emerged descriptions of not being perceived by clinicians as “she’s too much of a problem” and not asking “when is the transplant going to happen?” As time progressed, the uncertainty of a transplant weighed heavily on many, and individuals began to question the purpose of living up to clinicians’ expectations. Frustrated with waiting longer than expected for a heart transplant, one participant responded to a MCS coordinator, "I don't come here to be your (MCS team’s) poster child." Although living as a “star patient” helped participants align with the best care early in their MCS trajectory, it was perceived to be an impediment to ACP communication over time.

Maintaining a positive outlook: “I'm going to try to stay positive, always.” Maintaining a positive outlook throughout their MCS trajectory was valued by a majority of participants. When asked about the process of waiting for a heart transplant, one individual who was implanted for less than six months said, “Just stay positive, it's going to happen. I'm not that type of person like, it (transplant) ain't never going to happen, I'm not that type of person. I'm going to try to stay positive, always.” Although participants who were further along the trajectory faced multiple MCS-related complications, such as bleeding (n=6), infections (n=3), and issues with powering the device (n=3), these events were rarely considered to be adverse effects of living with MCS. Analytic memos reflected that what clinicians see as medical complications were often considered by participants as mere “setbacks” on the road to transplant.

Maintaining a positive attitude was also an impediment to ACP communication as many participants perceived such communication as a negative discussion. An older participant, who had been readmitted to the hospital for longer than two months prior to the interview, reflected such shying away, “but as far as end-of-life or stuff like that, we (participant and wife) haven’t talked about that (ACP). It’s kind of a negative thing, so we’re trying to be positive.”

Thus, although the internal process of maintaining a positive outlook was conducive to coping with uncertainties of living with a MCS device, such as prolonged waiting for the transplant, this approach inadvertently positioned ACP communication as a negative experience. Within the sample, internal processes of maintaining a positive outlook were detailed in three properties: minimizing difficulties, accepting change, and going with the flow.

Minimizing difficult changes: “It’s not so bad.” Difficult challenges, such as readmissions for infections or recurrent bleeding, were commonly recalled by participants. However, through the process of analytic memos and comparing descriptions of difficult changes across multiple interviews, we were surprised to find that the participants did not consider these adverse events as complications of MCS therapy. Instead, these setbacks were compartmentalized as events separate from the complications of living with a device. One participant who reflected on the prolonged wait for a transplant along with a complicated readmission that caused him to be temporarily ineligible for transplant described his setbacks as “it’s not so bad.” Consequently, rather than considering the complications of MCS therapy to stimulate discussions about ACP, participants focused on the positive outcomes. Another individual readmitted for more than a month in the first year of implant, shared, “But things happen and if it has to be from one thing to another, well we’ve got to keep moving on until we get to the right part of life.” Thus, the downplaying of difficult experiences created an impediment to ACP communication because participants did not view these changes as sufficiently important to discuss with clinicians.

Accepting change: "Well, that's just the street I live on." Accepting change, the second dimension of maintaining a positive outlook, was exemplified as participants detailed how they accepted the limitations imposed by living with a MCS device. A frail participant who had survived a previous chronic disease recalled the first months of living with the device and said, “It’s very precarious (living with MCS) … I get it’s very much a tightrope of an existence … But I don't dwell on that.”

Despite improvements in heart failure symptoms after MCS implantation, participants were still considered “very sick” by clinicians, family, and friends. Participants recounted the tension of accepting changes while being cognizant that they were regarded as seriously ill. This was evidenced by an individual who reflected, “Well, that's just the street I live on. That's the new normal for me.” Accepting the permanency of living as a sick individual became an impediment as this acknowledgment did not spur participants to further delve into discussions about ACP. One participant who has lived with the device for eight years divulged, “whatever the outcome is, that's what it's going to be.” Thus, acknowledging that living with the implant went along with still being a sick patient formed a new normal for participants, but did not enhance ACP communication.

Going with the flow: “It is what it is.” Going with the flow, the third dimension of maintaining a positive outlook, represented a passive approach to living with MCS. Rather than advocating for personal care preferences, participants relied heavily on clinicians to guide them through the highs and lows of living with the device. Additionally, participants described a strong reliance on the clinicians to navigate conversations about their MCS trajectory and potential health issues. One participant who had waited an extended time for a transplant shared, “I’m really in their (clinicians) hands. So, I really don't ask them, or tell them, when I want to hear the good news or bad news. It is what it is.” Another participant likened clinicians to the “grandparents” who allowed the patient to feel comforted and supported without pushing them to make decisions about ACP. However, this feeling of comfort fostered ambiguity as participants relied on clinicians to initiate ACP conversations instead of taking a proactive stance to address their concerns. One individual who struggled to adjust to life with a MCS device expressed, “I just go with the flow. Whatever they tell me, I just do it. So, if there was something out there that I should know, I wouldn't even know, because I just only do what they tell me at the doctor's office.” The opposite of going with the flow was to advocate for personal preferences and to challenge the “protocols” that were already in place. Although there were instances of participants speaking up for themselves while hospitalized, these few examples were described in terms of tangible, daily care preferences such as walking, bathing, or getting dressed. Ultimately, going with the flow represented an attitude of not questioning clinicians, not discussing concerns, and not being proactive in advocating for personal preferences associated with ACP.

Uncertainties in MCS Outcomes

Uncertainties in MCS outcomes were crucial for decision-making around ACP communication. In a dynamic and fluid manner, the perceptions within this subcategory pivoted between internal and external processes to promote or impede communication around ACP. Many uncertain MCS outcomes were described by participants who had lived with the device for an extended time. Most reported experiencing some form of a setback (n=21) along with more frequent readmissions of four times or more (n=9). As time passed, individuals described numerous unexpected situations such as receiving the call for a transplant only to learn that the organ was deemed unsuitable by surgeons, being readmitted to the hospital for weeks at a time or discovering that other MCS individuals who received the implant later had already received a heart transplant. Uncertainties about the future were most evident among participants who had waited a long time for a transplant. Some individuals voiced doubts about whether a transplant was going to take place “they (medical team) ain't giving me no heart.” Hence, individuals’ experiences of living with a prolonged MCS trajectory elucidated the external processes of anticipating to receive information from clinicians and the internal processes of making sense of the wait for a transplant. Within the backdrop of varying MCS outcomes, participants’ stories elucidated two properties: “living in limbo” and “leaning on spirituality.”

Living in limbo: “I’m still waiting.” A sense of uncertainty towards the outcomes of living with the device was described as many experienced unpredictable lengths of waiting for a transplant. The majority of MCS participants recalled receiving information from clinicians, before surgical consent or early in their trajectory if the device was placed emergently, that the device would be used as a bridge to transplant (n=17). The resultant focus on transplantation contributed to embedded expectations that the transition to transplant surgery would be quick and smooth. At the time of the interview, participants who self-identified as living a prolonged time with MCS were implanted with the device for one to nine years. After seeing other MCS individuals transplanted before himself, one individual begrudgingly stated, “I’m still waiting.” Many who waited longer than anticipated for a transplant shared sentiments of feeling “stuck” or being in “limbo.” As the wait for a transplant continued, two divergent external dimensions emerged: “changing to destination therapy” and “being consumed by transplant.”

Changing to Destination Therapy. Albeit less common, changes in MCS goals from a bridge to transplant to destination therapy were evident in participants with prolonged trajectories. Individuals who switched to destination therapy because of complications shared feeling “a little discouraged” and “disappointed” at their ineligibility for a transplant. However, while disheartened, the change in goal resulted in direct ACP communication with clinicians about their MCS trajectory. After waiting for two years, one individual recalled receiving news from clinicians that he was ineligible for transplant: “And of course then because of the fact that I’m a big guy and my age being what it is, they (clinicians) told me I’d probably never get a transplant. So, they took me off the transplant list.” For individuals who experienced changes in their goal therapy, the indefinite amount of time to live with MCS prompted ACP-related questions about their future outcomes. A participant who was switched to destination therapy because of multiple re-do sternotomies questioned, “Other than giving me an idea of how long this LVAD will last and what to expect if it goes into failure, would they (clinicians) be able to replace it (MCS device) or would I be too old for it?” Once the new goal of destination therapy was accepted, participants realigned themselves with the best care and were less engaged in ACP communication.

Other individuals with prolonged MCS trajectories described being uncertain of whether they could survive another open-heart surgery. In a unique example, one participant, who was an eligible candidate for a heart transplant, chose to forgo future transplant surgery and requested for his MCS goal to be changed to destination therapy by asserting, “No, no, (transplant) is not for me.” Similar to individuals who became ineligible for a transplant, choosing against transplantation initially enhanced ACP communication with caregivers and clinicians. However, this type of ACP communication was short-lived as the individuals realigned themselves with the best care after changing to destination therapy.

Being consumed by the transplant: "When's my turn to get a transplant?" In contrast to participants whose MCS goals were changed to destination therapy, many individuals were dedicated to continuing their goal of a bridge to transplant and felt “consumed” by the drawn-out waiting time. One individual, who received multiple transplant offers reflected on the disappointment of the failed attempts for transplantation when the organ was deemed subpar by surgeons immediately before surgery. After describing an experience of waking up in the operating room and realizing the transplant surgery was canceled, the participant avowed, “My whole existence is waiting for a transplant.” The constant anticipation for transplant offers also created anxiety in some participants, as one individual shared, “you can be consumed with that aspect to the point to where it interferes with your daily life routine.” Reflecting on the prolonged wait, many shared narratives of apprehension about their likelihood to receive a transplant. As more time passed, some individuals agreed to high-risk donors to expedite the transplant process, often asking, “When's my turn to get a transplant?”

A finer aspect within being consumed by the transplant was the increasing concern with the durability of the MCS device. As participants experienced pressure from the prolonged wait, they became concerned about the durability of the device and asked ACP-related questions about the MCS trajectory. Having waited nine years for a transplant, one individual asked clinicians “Has anybody passed away with the machine by waiting?” Other individuals who had previously aligned themselves with the best care reflected on the doubts of receiving a transplant and losing confidence in clinicians. Nearing the cut-off age for transplantation, one participant admitted, “I do not believe that the medical team that I have right now ... I don’t think their objective is to find me a heart.” Overall, descriptions about being consumed by waiting for the transplant and the lack of confidence in clinicians promoted decision-making about ACP communication.

Leaning on spirituality: “The wish of whatever powers it be.” Leaning on spirituality was an internal process that decreased the need for ACP communication and bolstered individuals’ abilities to maintain a positive outlook in the context of living with the uncertainties of MCS. In the sociodemographic questionnaire, the majority of individuals self-identified as religious or spiritual (n=21). While our initial interview guide did not focus on spirituality, the early interviews spontaneously reflected the influence of religion. Thus, we added a specific question to the interview guide to promote deeper discussions about spirituality. Individuals who identified as being spiritual, but not religious, described gaining acceptance for the uncertainties of MCS outcomes through their belief in the will of a higher being. Reflecting on multiple readmissions for recurrent bleeding, one participant shared, “that is the wish of whatever powers it be. So, let us accept it (the complications of living with MCS).”

Leaning on spirituality also promoted accepting one’s mortality, as expressed by a participant who said, “when the gig’s up, it’s up.” Spirituality in the religious sense also provided a means for coping and accepting changes. Participants shared that their spirituality helped them stay “positive,” as a young expectant father recounted, “God is giving me a chance to understand that nothing’s going to happen to me and hopefully soon I’ll get my heart transplant and everything will be fine.” Thus, overall leaning on spirituality helped participants make sense of the prolonged MCS trajectories and the uncertainties of their future health.

Conversely, the self-acknowledged absence of religious faith was observed to motivate decision-making around ACP. One participant recounted how not having a religious belief impacted her perceptions on death:

> They (people who are deeply religious) have a comfort and belief system that God will take care of them, and I don’t have that belief system anymore, so I don’t have an idea, I haven’t made up my mind what death is. I don’t believe in prayer. I mean, I believe in people sending me good thoughts and things like that, but I don’t believe in prayer, so I don’t have much comfort zone, anything to hold me up on this since it’s so unknown to me, where it used to be I had this firm idea what life after death is.

Also common among the three participants who did not self-identify as religious or spiritual was that they acknowledged their mortality and were highly engaged in ACP communication with their families and clinicians. A self-reported, non-religious individual recalled an ACP conversation when his wife asked how he would react to a heart transplant offer, he responded, “No. I don’t think my life expectancy would be significantly greater and the impact of my daily life would not be improved enough that I would go through the experience again.” Among individuals who denied a preference for spirituality, we observed a greater acceptance of mortality and subsequent engagement in ACP communication.

Promoters of ACP Communication

Over time, the uncertainties of the MCS trajectory played a pivotal role in enhancing or reducing ACP communication. Experiences that contributed to enhanced ACP communication were conceptually organized in the subcategory of promoters of ACP communication. These promoters were comprised of the external process of “distrust of clinicians” and the internal process of “managing incongruent expectations.” Dimensions within promoters of ACP communication were fluid as the distrust of clinicians was described concurrently with incongruent expectations.

Distrust of Clinicians: “Don’t think they (doctor or nurse) just going to drop a load on you.” Distrusting clinicians was described in the prolonged wait for a transplant as well as reflections on the expectations of what MCS trajectory ought to be. The pivotal experiences of uncertainty helped participants identify areas of dissatisfaction in their MCS care, as one disgruntled individual shared, “I can honestly say I really don’t trust what they (clinicians) tell me at the clinic anymore…I think they’ve got predetermined responses for just about everything because they’ve seen it all.” The sense of distrust diverged from being aligned with the best care and prompted individuals to question their clinicians about the MCS trajectory. Reflecting on the discrepant information received about the timeline for transplant, one participant pondered if the clinicians had a hidden agenda to change the goal of MCS to destination therapy:

> No matter what they (clinicians) tell me, I’m going to have questions. I’m going to have suspicions. Instead of focusing on what they (clinicians) did tell me (this is a bridge to transplant), I would say, “Well, you didn’t tell me this (the wait for transplant will be more than three years),” and I’ll focus on the things that I may be picking up (you may be switched to destination therapy) that I don’t think they (clinicians) told me.

Feeling distrust towards clinicians also motivated participants to ask difficult questions and become self-advocates for ACP. A young female participant who experienced distrust after being “passed up” by clinicians shared the following as advice for future MCS patients:

> You have to write down your questions, you have to ask your questions, you have to try to research your own stuff because it’s not just going to all be handed to you, that’s for sure. Don’t think they (doctor or nurse) just going to drop a load on you and they don’t say, “Hey, this is what’s going to go on.”

Overall, the external process of distrusting clinicians provoked participants to ask difficult questions about their MCS trajectories, enhanced self-advocacy, and ACP communication.

Managing Incongruent Expectations. Over time, participants were faced with managing incongruencies between initial expectations at MCS implantation and the realities of living with the device. As individuals acknowledged their growing distrust towards clinicians, they were also faced with their internal recognition of misaligned expectations. After experiencing uncertainties in their MCS outcomes, many individuals reflected on their initial, post-operative outlook of living with a device. Incongruencies in the expectations caused participants to form internal questions that would necessitate ACP-related communication with clinicians and caregivers. After being readmitted to the hospital for the third time, one individual pondered, “This machine, I don’t know how long it will remain, how many years and what if stability stops, all those kinds of things.” Although the participants did not particularly label these internal questions as related to ACP, the ensuing discussion would likely be in the vein of ACP communication.

Managing incongruent expectations was depicted as an internal process of weighing initial expectations against the challenges of living with MCS. The narratives in the sample evidenced internal perceptions along with perceived expectations from family caregivers. Hence, managing incongruent expectations manifested two internal dimensions: “embedded perceptions” and “perceptions of supportive others’ experiences.”

Embedded Perceptions: "I probably envisioned doing things more normally than I am able to." Embedded perceptions were the internal expectations that were not identified or voiced until incongruencies emerged. Early in the MCS trajectory, participants experienced few setbacks and were less cognizant of potential outcomes that were discrepant from their expectations at the time of implant. However, as time progressed, many participants described a divergence between their expectations for life after implant and the reality of living with MCS. An individual who had waited a prolonged time for transplantation articulated, "Hey, you're going to be on there (transplant list) longer than what they're (clinicians) telling you, and what you expected also."

Embedded perceptions dissimilar from participants' initial expectations were expressed through a range of emotions. Some individuals felt hopeless when they recognized the limitations that living with MCS placed on their favorite pastimes. Upon realizing that she could no longer travel on cruises because of the lack of access to MCS clinicians, one participant expressed a sense of hopelessness by stating, "I feel like I have nothing to look forward to, is what I feel like." Participants who had anticipated a return to the lifestyle that they had before surgery, were frustrated by the challenges that they encountered in living with a MCS device. Comparing the positive information that she had received from other MCS individuals with the reality of living with MCS, a participant voiced aggravation by using strong language: "Well, that's *@#!" Finally, some experienced anger at the thought of living the rest of their lives with MCS, as one participant shared, "Even though I had accepted it (the MCS device), but sometimes I'm angry why I wish that it was not there…" Overall, the discordance in embedded perceptions were manifested through participants' emotions.

Managing the divergence between embedded perceptions and initial expectations was occasionally ameliorated through ACP communication with supportive others. Frustrated with the uncertainties in their MCS trajectory, a few individuals were motivated to reevaluate personal preferences and engage in ACP communication with their caregivers. Reflecting on the prolonged wait and potential complications of MCS, such as kidney failure, one participant shared with his wife, “I don’t want to walk around with a piss bag for the rest of my life…I don’t want that. I’d rather die than that.” Perceptions of uncertain outcomes along with divergent expectations evidenced ACP communication between participants and their supportive others.

However, while the recognition of incongruencies between initial expectations and embedded perceptions promoted ACP communication with some family caregivers, none of these participants expressed their feelings and concerns to MCS clinicians. One participant whose MCS goal was switched to destination therapy questioned, “Now that I have this pump, it’s always in the back of my mind. Will it quit? Will it do this or that?” Although he described respect for his MCS team, these internal musings related to ACP were not expressed to clinicians. Many of these individuals described ACP as something that was required by the clinicians in their transplant eligibility process. When asked about their first encounter with ACP, one participant recalled, “It (ACP conversation) was when we were getting ready to go on the transplant list. That was part of their (MCS clinicians’) protocol.” However, ongoing ACP conversations were not preferred, especially among participants who were keenly focused on a transplant. Reflecting on the experience of discussing ACP with clinicians, one bridge to transplant candidate described, “I’m like wow, can y’all talk about something positive or make it (ACP) positive or something? … I don’t like to be teared up.” Thus, while divergences in embedded perceptions promoted internal questioning about the future trajectory of living with MCS, as well as conversations with supportive others, it did not enhance ACP communication with clinicians.

Individuals whose goal therapy was designated as destination therapy were more aware that they would live with the device until they died. The knowledge that MCS therapy was an intimate life-giving connection and its termination were equivalent to death was acknowledged by one individual who said, “your (MCS device) sunset is my sunset.” For the number of individuals who were informed that their outcome was destination therapy (n=8), the acknowledgment of one’s own mortality prompted deep thought about ACP. One of the destination therapy participants reflected on the external discussion with a specialist about anticipating poor outcomes when he was hospitalized for a recurrent infection. Internally pondering this communication, the participant shared,

> I’ve got all kinds of artificial means attached to me that are addressing both the quality and quantity of my life. So, say I don’t want to be kept alive by artificial means, I already am… So you have to dig a little deeper about what that means.

For some destination therapy individuals, the external information about the trajectory of their goal promoted internal reflections around ACP.

Perceptions of supportive others’ experiences: “I’m a liability.” Unexpected burdens were perceived to be placed on family caregivers as participants recalled the difficulties of living with a MCS device. A participant who struggled to adapt to life with the device shared, “Sometimes I feel like I might be a burden to my mom because she has to do so much for me…I feel like I’m a liability.” Although participants did not explicitly describe their pre-implant expectations of how the device would affect their families, the narratives later in their MCS trajectories expressed a deep concern for placing undue burdens on their caregivers. One participant who was concerned about becoming ineligible for a transplant questioned, “Is it really worth it all?…Do I want to keep putting my family through this?” As participants experienced more uncertainties of living with MCS, the internal reflections and questions about the impact of the device on their families promoted opportunities for ACP discussions.

There were also some participants who fully entrusted communications about ACP to the family members who were the main informal support person. This subset of participants described this family member as being the primary individuals who made decisions on their behalf and communicated with clinicians. An individual who acknowledged the importance of involving caregivers in decision-making, especially in potential circumstances of incapacitation, also expressed his indifference towards being actively involved in ACP conversations. He stated, “Really, there’s nothing to it (ACP). If it’s something I need to have done and stuff like that and take care of me. She (wife) will. She’ll make the right decisions. I trust her.” Individuals who were less engaged in ACP described their reliance and trust towards their caregivers and clinicians to discuss ACP.

Conversely, the perceptions of supportive others’ experiences impeded ACP communication for a handful of MCS participants. For some, the hesitation to engage in ACP communication was related to the perceptions of their caregivers’ preferences. When asked about applicable situations to revisit ACP discussions, one individual responded, “I don’t know if that’s (revisiting ACP) something my wife would like to do or not. But she isn’t here, so I can’t ask her.” Although this participant identified his wife as an important individual to include in conversations about his care, he did not engage in ongoing ACP communication with her. Thus, for this person, decision-making around ongoing ACP conversations hinged on the perception of his wife’s receptivity to engage in this form of communication. In another example, a participant whose goal therapy was changed from bridge to transplant to destination, shared, “I don’t know if my wife would like me talking about that stuff or not...I think she gets very discouraged about that (ACP) kind of talk.” Thus, the varying individual responses to the perceptions of supportive others’ experiences evidenced a dynamism in the internal and external processes surrounding ACP communication.

Decision-making about ACP communication: “A gut punch.” Within the core category, complexities in decision-making about ACP communication, the arduous nature of external and internal processes were observed in the limited conversations between participants and clinicians. Additionally, impediments and promoters were both evidenced in decision-making around ACP communication. External impediments in deciding about ACP communication were described by a few individuals who perceived constraints in the clinicians’ time. In a reflexive memo written during recruitment, the first author remembered observing what she called “a feeding frenzy” in the outpatient clinic setting when clinicians converged in the patients’ room for a short period. Similarly, one participant described the experience in the clinic as “fielding questions” from multiple clinicians. These copious interactions and assessments by a team of multidisciplinary clinicians, subjected to the external time constraints of the clinic visit, did not leave time for individuals to gain information about the internal questions that they were mulling over. When asked about the difficulties of engaging in ACP conversations with clinicians, one participant responded, “He (cardiologist) seems to just want to get in and get out. Always seems to be in a hurry.” Overall, participants’ consciousness of clinicians’ time constraints was perceived to be an external impediment to ACP communication.

In contrast with the sensitivity towards clinicians’ limited time, later in their trajectory, individuals described external promoters of uncertainties and distrust towards clinicians, which enhanced proactive approaches to ACP communication. As participants reflected on uncertainties arising from the longevity of living with the device, some questioned clinicians about the future of their MCS trajectories. One individual who had been readmitted to the hospital for more than three months, self-initiated ACP communication, when he recalled, “I asked (MCS coordinator) about the longevity of (the device) ...You know, what could I expect.” Although less common, the proactive stance of directly asking clinicians ACP-related questions promoted ACP communication. Similarly, proactive questions directed towards clinicians were observed among participants who experienced distrust towards clinicians. One individual who experienced being “bypassed” by clinicians shared,

> If you have any questions for the doctors or anything going on, you write it down ahead of time, have your list written down ahead of time because you don't want to get there and forget…You have to almost get ready to fight when you come into the doctor. Fight for your healthcare because they will absolutely pass you up.

Overall, the fluidity in external processes was perceived to impede ACP conversations for some but promote the initiation of ACP communication for others.

Particularly evident among participants who had been implanted longer with MCS, was the internal impediment that ACP communication should be initiated by clinicians. Researchers reached this understanding whilst comparing MCS individuals' active participation in conversations around medical and surgical interventions with their reserved approach as they waited for discussions about ACP. In a post-interview memo, researchers noted that the participant's internal views of ACP appeared to be a non-medical concern. After analyzing the meaning ascribed to ACP conversations, the researchers perceived undertones of empathy for clinicians, which was exemplified by participants' respect for clinicians' valuable time. This internal impediment was further exemplified when one participant described how individuals without a medical background, including the participant and his caregivers, should "stay in your own lane." The culmination of internal impediments manifested in individuals who shied away from ACP discussions until clinicians initiated the conversation.

In contrast, the internal promoter was described as a growing awareness of the need to engage in ACP communication. Faced with the uncertainties of their MCS trajectories, few individuals acknowledged the challenging internal process of making sense of difficult information. Recalling a prior hospital readmission, an older individual processed the sobering news that he would not survive if he was placed on a ventilator one more time, by saying:

> I want to really know what you (clinicians) think. I may not listen to what you (clinicians) think, but I want to know. Then I'll make my own judgment...It was a gut punch…That was eye-opening. And maybe a good view into my own mortality that I needed to confront.

The internal willingness to confront one's own mortality promoted the initiation of ACP communication. Thus, overall decision-making about ACP communication was fluid, interrelating internal and external processes, which manifested over a spectrum of behaviors from hesitation to self-advocacy.

Discussion

Grounded in the words of people living with MCS devices, decision-making about ACP communication pivoted around experiences of uncertain outcomes in their disease trajectories. The subjective experiences of participants revealed multifarious complexities in the decisional processes surrounding ACP conversations. Although expansive and interrelated, these complexities were systematically organized into three main subcategories: impediments, uncertainties, and promoters. The relationships between these subcategories were fluid and dynamic with simultaneous interactions between internal and external processes. Subsequently, the synthesis of study findings led to the development of the Theory of Pivoting Uncertainties. This situation-specific theory presents a framework for understanding the experiences of a specific clinical population (Im & Meleis, 1999). Furthermore, the researchers utilized a nursing perspective in their dialogued approach to examine participants' lived experiences (Im & Meleis, 1999).

Although our methodology of constructivist grounded theory precluded the incorporation of an initial framework in the research design, our resulting theory reflected similarities to concepts presented in the Uncertainty in Illness Theory (Mishel, 1988) and the Reconceptualized Uncertainty in Illness Theory (Mishel, 1990). Mishel's middle-range theory emphasized uncertainty in illness as a source of a change that moved individuals from an initial state through a bifurcating point towards a new state (Mishel, 1990). An essential difference between the Theory of Pivoting Uncertainties and the Uncertainty in Illness Theory is found in the targeted clinical implications for ACP communication among the MCS population in the current study. However, the theories also share similarities in process of shifting individuals living with chronic uncertainty from an initial state of limited ACP conversations to a higher level of initiating ACP communication. Thus, our situation-specific Theory of Pivoting Uncertainties explains MCS individuals' patterned responses towards uncertainties in their trajectories and provides clinical implications for decision-making around ACP communication.

A main finding in the current study is that ACP discussions between MCS individuals and clinicians were sorely lacking. Although participants described frequent communication with clinicians about the management of their devices and medications, this close working relationship did not translate to ACP communication. A relevant clinical observation by the first author, in accordance with recommendations from the Joint Commission and CMS, was the integration of palliative care consultation for pre-implantation counseling at both sites of recruitment. In a study on the routine integration of palliative care services, pre-implantation consultation rates with palliative care specialists increased from 35% to 71% (Salomon et al., 2018). However, these rates are much higher than the current sample's reported communication with only 4% (n=1) recalling such a discussion with a palliative care specialist. Instead, we found that individuals primarily identified MCS clinicians as the most appropriate individuals to initiate ACP conversations. However, while participants waited on their MCS clinicians to initiate conversations, previous research reported that cardiologists relied on other specialists, such as primary care or palliative care, to discuss ACP (Chandar et al., 2017). In the Chandar et al. study, only 15% of cardiologists felt responsible to engage patients in ACP communication.

Having worked for five years at the bedside with MCS patients from the main recruitment site, the first author has overheard many effective communications between patients and MCS clinicians about sensitive matters, such as poor prognoses or invasive healthcare treatment options. Against this background, it was unexpected to come across the lack of communication about ACP that was so repeatedly witnessed during the interviews. One possible explanation of the perceived dearth of ACP communication was the emphasis placed on transplantation. For many individuals, discussions about the prognosis centered around the timeline for a heart transplant with minimal conversations about complications until issues occurred. Participants in the current study only described self-initiated ACP conversations after a prolonged MCS trajectory, when they reached a tipping point – the distrust of their MCS clinicians. These descriptions were similar to previous findings, that ACP conversations occur late in the course of heart failure (Chandar et al., 2017). Overall, while the incorporation of palliative care specialists, who are recommended by national bodies, was in place, the source that patients were expecting communications from, i.e. MCS clinicians, were not recalled to engage in the delivery of ACP conversations.

Advance directives were completed by the majority of participants in the current sample (n=19). However, a gap persisted in understanding the purpose of ACP communication. We were surprised to find that participants had forgotten about the ACP conversations they had during the process of completing their advance directives and could not recall what they had decided upon. A potential explanation for the discrepancy between the rate of completion of advance directives and the recall of ACP conversations was the varying language that clinicians may use to describe the discussion. Nonetheless, the completion of advance directives did not lead to clarification about the future complications of living with MCS. Hence, our research confirmed previous findings that the completion of advance directives was inadequate to prepare individuals with advanced heart failure for the clinical scenarios they may encounter throughout their disease trajectory (Wordingham et al., 2016a).

It has long been acknowledged that conversations about progressions of severe disease, end-of-life, and death are sensitive and challenging for all parties involved (Dempsey et al., 2016; R. S. Hebert et al., 2009). There persists a need for ongoing conversations that lie at the heart of effective ACP communication (Lovell & Yates, 2014; Swetz et al., 2014b). Participants' stories acknowledged a strong reliance on family caregivers for daily care as well as communication with the MCS team. Despite the closeness with family members, we were surprised to find major gaps in ACP communication between the patient and their informal caregivers or key family members. Although including key family members and informal caregivers in ACP conversations has been emphasized (Blumenthal-Barby et al., 2015), according to participants in our study, ACP discussion among MCS individuals and their caregivers is lacking. Instead, with time passing and faced with uncertainties in their MCS trajectories, participants internally reflected on the impact of potentially negative outcomes on their families. However, these concerns were internally contained and did not lead to direct ACP communication with family caregivers. Thus, our findings are consistent with recommendations for clinicians to facilitate ACP communication, particularly the discussion of family interests (Winzelberg et al., 2005).

Clinical Implications

Awareness from this study around the pivotal role of uncertainties in ACP communication elucidated specific topics for discussion between clinicians, MCS individuals, and their informal supportive caregivers. The integration of probabilistic thinking (Mishel, 1990), helping patients to consider the changing nature of their MCS trajectory, is useful for fostering ongoing communication around ACP. A recent study by Land et al. (2019) found that clinicians could support terminally ill patients' preferences and prepare them for the uncertainties of their disease trajectory by revisiting hypothetical plans and expectations to enhance decision-making. A first implication for practice in the MCS population is to shift away from focusing on transplantation as an end goal, with clinicians' revisiting the potential adverse events that may impact patients' expectations and plans for receiving a transplant. Internal questions arising from prolonged wait times for transplants revealed the need for clinicians to address concerns around the durability and longevity of MCS devices. Asking targeted questions about unmet expectations can present opportunities to initiate ACP conversations. One such focused question that is specific to MCS patients' and family can be around the changed nature of the trajectory. While these key stakeholders have experienced the progressive deterioration of heart failure, the MCS trajectory is markedly unique in the acute onset of adverse events. Thus, ACP conversations with patients and family should emphasize the sudden and life-threatening risks of living MCS.

The fast-paced setting of MCS clinic visits was perceived to be a suboptimal environment to engage in ACP communication. From the primary investigator's clinical experiences, the opportunity for ACP discussion in these settings competed with physical assessments, medication teachings, and inspection of the MCS device. As MCS individuals respected clinicians' valuable time during clinic visits, they were unlikely to initiate ACP communication to ask the internal questions that they may have been pondering. A second implication is for future ACP conversations to be scheduled separately from routine clinic visits with a clear intent to discuss areas of potential uncertainties in MCS trajectories and incongruent expectations about living with MCS. Potential opportunities to engage MCS patients in ACP communication include readmissions for non-life-threatening complications. During these hospitalizations, clinicians have the opportunity to reinforce the uncertainties of the MCS trajectory and examine patients' understanding of these setbacks. This is also a potential opportunity to engage key family members and caregivers in shared decision-making around ACP, to identify patients' preferences for care, and address the patients' internal concerns about the impact of their device on the family.

The third implication for practice is for MCS clinicians to extend the invitation to initiate ACP conversations. Clinicians should be careful to avoid labeling MCS individuals as "star patient" or "poster child" because it created a perceived ideal of clinicians' preferred patient, which included descriptions of not asking questions about one's MCS trajectory. Although few participants described feeling "passed up," maintaining the image of an ideal patient outweighed the importance of self-initiated ACP communication. Hence, MCS clinicians must embrace what the participants metaphorically described as the "gut punch," and tailor these discussions according to each individual's preferences (Hall et al., 2019). One way to uphold patients' preferences is to assess the individuals' attitudes and readiness to engage in ACP discussion. The fourth clinical implication is for clinicians to ask patients about their preferences of who to include in the conversations and how to approach these discussions. Clinicians may also ask the patient if they prefer a direct approach to ACP or if discussing hypothetical situations would be more beneficial. Furthermore, clinicians may use more deliberate language to educate patients about the meaning of ACP and to establish a common understanding that they are actually participating in ACP communication. Not only do our findings suggest that MCS clinicians are the most appropriate individuals to engage patients in a dialogue about ACP, they also support previous findings that recommend ongoing ACP at defined intervals (Blumenthal-Barby et al., 2015).

Strengths and Limitations

To our knowledge, the findings from the current study are the first to examine decision-making about ACP communication from MCS individuals' first-hand experiences. Our findings among MCS individuals are novel in the exploration of internal and external processes contributing to ACP over time. The identification of uncertainties in the MCS trajectory is pivotal for enhancing ACP communication and filled with implications for clinical practice and future research.

Strengths of our investigation include a heterogeneous sample with a wide age range, varying lengths of living with the device, and varying goals of MCS therapy. Analysis of MCS individuals' nuanced narratives offered novel insights into the sensitive topic of ACP communication. Through the participants' rich descriptions and the fulfillment of theoretical data saturation, researchers developed a theoretical framework (Charmaz, 2014), the Theory of Pivoting Uncertainties. The strengths of this situation-specific theory include the usefulness in recognizing clinical implications for the future of ACP communication among the MCS population.

Despite the novel nature of this research, the findings are subject to several methodological limitations. First, the purposive sampling of participants from two large medical centers in Southern California does not represent the nationwide population of MCS individuals. Sampling bias may have potentially skewed our findings because individuals who were more open to discussing ACP were more likely to agree to participate than those who did not volunteer. Finally, the qualitative design of our study relied on participants' retrospective reporting of their experiences, which potentially introduced recall bias to our findings.

Implications for Future Research

Our study showed that, in their own words, MCS individuals are exposed to unpredictable changes and uncertainties throughout their trajectories that require ongoing ACP communication but that these discussions rarely happen. Hence, future investigations are needed on successful interventions that support ongoing ACP communications among individuals living with MCS. Future research can also be focused on clinical interventions surrounding ACP communication at various time points throughout the MCS trajectory. The completion of advance directives is currently considered an indicator of ACP communication (Woodburn et al., 2019). Given the limited scope of ACP communication, sometimes solely targeted at the identification of surrogate decision-makers (Sinha et al., 2017), future research needs to focus on a more holistic approach to ACP communication.

Additionally, investigation on spirituality in ACP communication is needed to elucidate the processes individuals used to make sense of the uncertainties of living with MCS. Although the purpose of our current study did not include comparing experiences of religiosity before and after the MCS implant, it was evident that participants spontaneously associated spirituality as part of their understanding of the uncertainties faced in the MCS trajectory. Thus, a future study on the larger aspects of spirituality can provide a holistic approach to understanding how MCS individuals navigate the uncertain outcomes of their trajectory.

Although palliative care specialists have been incorporated in pre-implantation consultations, participants did not recall these discussions. It is unclear whether participants' preferences for MCS clinicians to initiate conversations are related to their familiarity with the clinicians or the perceived expertise of the clinicians in managing the device. Future research on the seamless integration of palliative specialists, as opposed to the current consult approach, is needed to determine if familiarity with palliative care specialists enhances ACP communication. Another suggestion to address potential concerns with familiarity and MCS expertise is to mobilize nurses at the bedside, specifically MCS-trained nurses, to engage patients and families in ongoing ACP communication. While previous studies have explored scripted nurse visits for pre-implantation consultation (O’Connor et al., 2016), we recommend future research to examine nursing interventions that can be implemented at the bedside throughout the MCS trajectory. Another key stakeholder who is likely the most familiar to the MCS patient is the family member who was preferred to be included in ACP conversations. Studies are needed to examine this preferred family members’ perceptions of ACP and their participation in these sensitive conversations. Overall, future research is needed to identify appropriate key stake holders and interventions to provide ongoing ACP communication over the MCS trajectory.

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Table 1

Examples of Interview Questions and Potential Follow-up Prompts

Subject	Question	Follow-up
Experiences of living with a MCS	How has living with a MCS device influenced your life?	Could you tell me about how this process has lived or not lived up to your expectations?
ACP sources of information	Who did you first hear about advanced care planning from?	Some patients have described preferring to talk about advanced care planning with certain clinicians over others, what has your experience been like?
Purpose of ACP conversations	For you, what is important about advanced care planning conversations?	If you could use a picture to describe the role of advanced care planning in your experience with the device, what would it be?
Experiences with clinicians	Can you think of an example of a conversation with your clinician that helped you manage the expectations for your care?	How were these expectations managed over time?
Shared decision-making around ACP	When you think about your future with the MCS, who should be included in the conversations around advance care planning?	How is this individual(s) important to your process of making decisions?

Table 2

Characteristics of the MCS Sample (N=24)

Sociodemographic Characteristics	**n (%)**
Age mean ± SD (range[years])	60.6 ± 16.5 (24-80)
18 - 24	2 (8%)
35 - 44	3 (13%)
45 - 54	2 (8%)
55 - 64	2 (8%)
65 - 74	10 (42%)
75+	5 (21%)
Sex	
Male	16 (67%)
Female	8 (33%)
Ethnicity	
Caucasian	12 (50%)
African American	7 (29%)
Hispanic	4 (17%)
Asian	1 (4%)
Marital status	
Single	4 (17%)
Married	18 (75%)
Divorced	1 (4%)
Widowed	1 (4%)
Religion	
Christian	16 (67%)
Catholic	3 (13%)
Hindu	1 (4%)
Jewish	1 (4%)
Muslim	1 (4%)
None	2 (8%)
Education completed	
Middle school	2 (8%)
High school graduate / GED	1 (4%)
Some college	11 (46%)
Four-year college graduate	5 (21%)
More than four-year college degree	5 (21%)
Living arrangement	
Own house	16 (67%)
Renting apartment	2 (8%)
Living at the family home	6 (25%)
Household	
Lives alone	1 (4%)
Lives with spouse	13 (55%)
Lives with spouse and children	2 (8%)
Lives with adult children (only)	2 (8%)
Other	6 (25%)
Financial status	
Fixed income	21 (87%)
No fixed income	3 (13%)

Clinical Characteristics	**n (%)**
MCS Device mean ± SD (range[months])	29.8 ± 26.7 (3-112)
< 6 months	2 (8%)
1 year	9 (38%)
2 - 3 years	9 (38%)
4+ years	4 (16%)
Type of MCS Device	
Heartmate II	3 (13%)
Heartmate III	8 (33%)
Heartware	11 (46%)
Uncertain	2 (8%)
MCS therapy goal	
Destination Therapy	8 (34%)
Bridge to Transplant	14 (58%)
Other (transplant pending clearance)	2 (8%)
Future Planning	
Completed advance care directives	19 (79%)
Filled out a POLST form	3 (13%)
Healthcare proxy	17 (71%)
Living will	9 (38%)
Medical Diagnoses	
Atrial fibrillation	11 (46%)
Congenital heart defect	1 (4%)
Cardiomyopathy	1 (4%)
Cancer	2 (8%)
Diabetes	8 (33%)
Heart Failure	22 (92%)
Hypertension	16 (67%)
Other	5 (21%)
Surgical History	
Coronary artery bypass graft	4 (17%)
Prior heart transplant	2 (8%)
Pacemaker / ICD implant	11 (46%)
Other	8 (33%)
Complications from MCS device	
Bleeding - requiring hospitalization	6 (25%)
Nontherapeutic anticoagulation	20 (83%)
Infection (driveline, sternal wound)	3 (13%)
Issues with device charging	3 (13%)
Pump thrombus	1 (4%)
Stroke	1 (4%)
Readmissions since device implantation	
Never	3 (12%)
1 - 3 times	12 (50%)
4+ times	9 (38%)
Days readmitted to the hospital	
<7 days	9 (38%)
1 week	6 (25%)
2 weeks	3 (12%)
>1 month	6 (25%)

Table 3

In-vivo Quotes from the Narratives of People Living with Durable MCS

Subcategory	Property	Dimension	In-vivo Quotes
Impediments to ACP	Aligning self with best care (external)		My wife and I, we're just giggling and sniggling. We're like, we're like loving like, "Oh, now I see why everybody goes to "A" (hospital) now and why "B" (hospital) hates "A" (hospital), God, look at what, and then look at their accommodations. My goodness. I mean the waiting room is bigger than the whole cardiomyopathy over there in that building for "B" (hospital). I'm like wow, you know and I've already been in the Rehab Center, I know where that is. I mean this is first class. You know, I mean look at this. This is, you can't get any better than this. I've been meeting all these people that have had heart transplants and all I'm telling you, that's the way to go da-da-da-da-da, you know, keep the faith. (P03)
			I said, "Honey, we've hit the lotto. We've come to "A" (hospital), we've hit the lotto." (P03)
			Before this, year, year and a half at the max with getting this done, "A" (hospital) is the number one facility in the nation. You're at the best place. We get it done. It's going to happen. (P13)
			I can't ask for a better service than they give. (P16)
		Trusting the clinician	I don't think like that, I just kind of wait for them (clinician) to say, "This could be an issue," or "You might want to think about that," from their own experiences with other patients that have gone through the same thing I have. I trust their judgment. (P01^2)
			I don't know that I've had discussion with any of my doctors on advance healthcare specifically. I think where they maybe tie in would be in just the trust that I have with their guidance and care. (P08)
		Feeling grateful	Well, that's almost a double question, it makes me feel thankful that I'm able to rise up and see the sunrise again, so I'm very thankful. (P02)
			They've all lifted me up and carried me through it. I'm so grateful to the nurses and the doctors. (P06)
			I would want to say that even though a patient, so I'm going to say me, even though I'm having ... and I said this so many times, even though I'm having a difficult time accepting the fact that I have the LVAD, I'm still very grateful that I have the LVAD. I want you to realize that. And I know you already do because you said it. How you feel conflicts. How I feel conflicts. On one hand, I'm grateful. On the other hand, I'm not. It's not that I'm not grateful, I just wish I had chosen a different decision, which was not to get it. (P09)
			Well, it's a strange dichotomy because you know that you're blessed. You know that you have a lot to be thankful, because the alternative is you wouldn't be here. There are other people that are in my same health condition that want this and can't get it. You got to feel grateful for having it, at the same time I want it gone. (P13)
			I'm absolutely going to cry, but she was. She was everything. Those doctors absolutely made a huge difference in my life. Yeah. Even when I got out of the hospital, I couldn't even walk that well yet. And I took lunch up there too. I was in five units. I was in three ICU units and two floor units. I took lunch out there to everybody in all of those units because I was just so grateful for them. They were so kind to me, those doctors. They absolutely mean the world to me. They absolutely do. (P23)
		Empathizing with providers	And, like I said, I don't want to seem like I'm saying that they didn't give me all of the information that they should have, because I know they did. That is one of the best hospitals. Everyone there is very knowledgeable. I know I'm getting the best care I could possibly get. I know all of that. (P09)

			That's a very difficult question, and I would answer it like this, is that give an honest evaluation. Try to take out all biases. They do an excellent job. They do an excellent job. Because I understand they're walking that tightrope also, whereas they want you to have hope. They want to give you hope. They don't want to give you expectations that may not come out. (P13)
			I remember a time seeing a doctor say something and I was looking over the doctor's shoulder at one of the other clinicians that were in there and they were shaking their head no, like they didn't agree with the doctor. I'm feeling a little, hmm, this is interesting. But I think everybody was being honest. The doctor was probably trying to pick me up, keep me positive about going forward and not getting depressed about it. But some of the others might have a view of, don't get your hopes up too much. (P18)
		Empathizing with providers (opposite)	And they definitely realize with me, I definitely like to speak a lot about my care so it definitely helps and it shows the doctors ... With me, vocalizing a lot, I show what I want, I can tell them what I want instead of just always agreeing with what they think is best. Sometimes you need to tell them what you think is best. (P05)
		Living as a star patient	It helped that a lot of the team along the way were telling me like, it's our star patient. (P01^1)
			I've been good at taking care of myself and the nurses even said, "The people we see, we see over and over again," and since it was the first time in two years that I had been back, other than for checkups, they were kind of surprised. (P01^2)
			I'm a wonderful patient because I'm clean and I don't ask myself or the people who deal with me, the team that deals with me, okay, when is this going to happen? When is the transplant going to happen? I haven't done that. And they haven't put me on top of the list. So, for months if something comes, I can get it. But they promised me a couple of times. (P10)
			I went to every appointment to get the information they needed to see if I qualified or if I was a candidate to be on the heart transplant list. (P20)
			And I just felt if I added one more problem on to whatever the mountain of problem that's going on with me, that they were just going to say, "She's too much of a problem." (P23)
		Living as a star patient (opposite)	I said, "You know what? Give me this equipment and I could do this at home. Me and my wife we could do this at home, because this is what you do every time I come in." He said, "Well, Mr. "U", but you're our poster child." I said, "You know what, M (MCS coordinator)?" I said, "I appreciate it, but I don't come here to be your poster child." (P03)
	Maintaining a positive outlook (internal)		No, just be grateful. Just stay positive, it's going to happen. I'm not that type of person like, it ain't never going to happen, I'm not that type of person. I'm going to try to stay positive always. (P04)
			I have a positive attitude of this one, a very positive attitude. So that has helped I think. (P14^1)
		Minimizing difficult changes	But then when it starts to cool off and it's not as hot, you're like, "Oh, you know what? I can wait again." It's like a pendulum. It kind of swings back and forth, it's not so bad or yeah, I really wish we got this over with. (P01^2)
		Accepting change (internal)	It's very precarious. It's very precarious. The device could malfunction, I could have the cord ripped out of me in an accident. I get it's very much a tightrope of an existence. At any time I could fall. But I don't dwell on that. (P06)
			I have to remind myself, because I tell them, "I'm a tough kid, tough individual." I'll try to do things that may be pushing the limits or the boundaries. They have to remind me, "You're still a very sick individual." I've even been told this by the doctors. (P13)

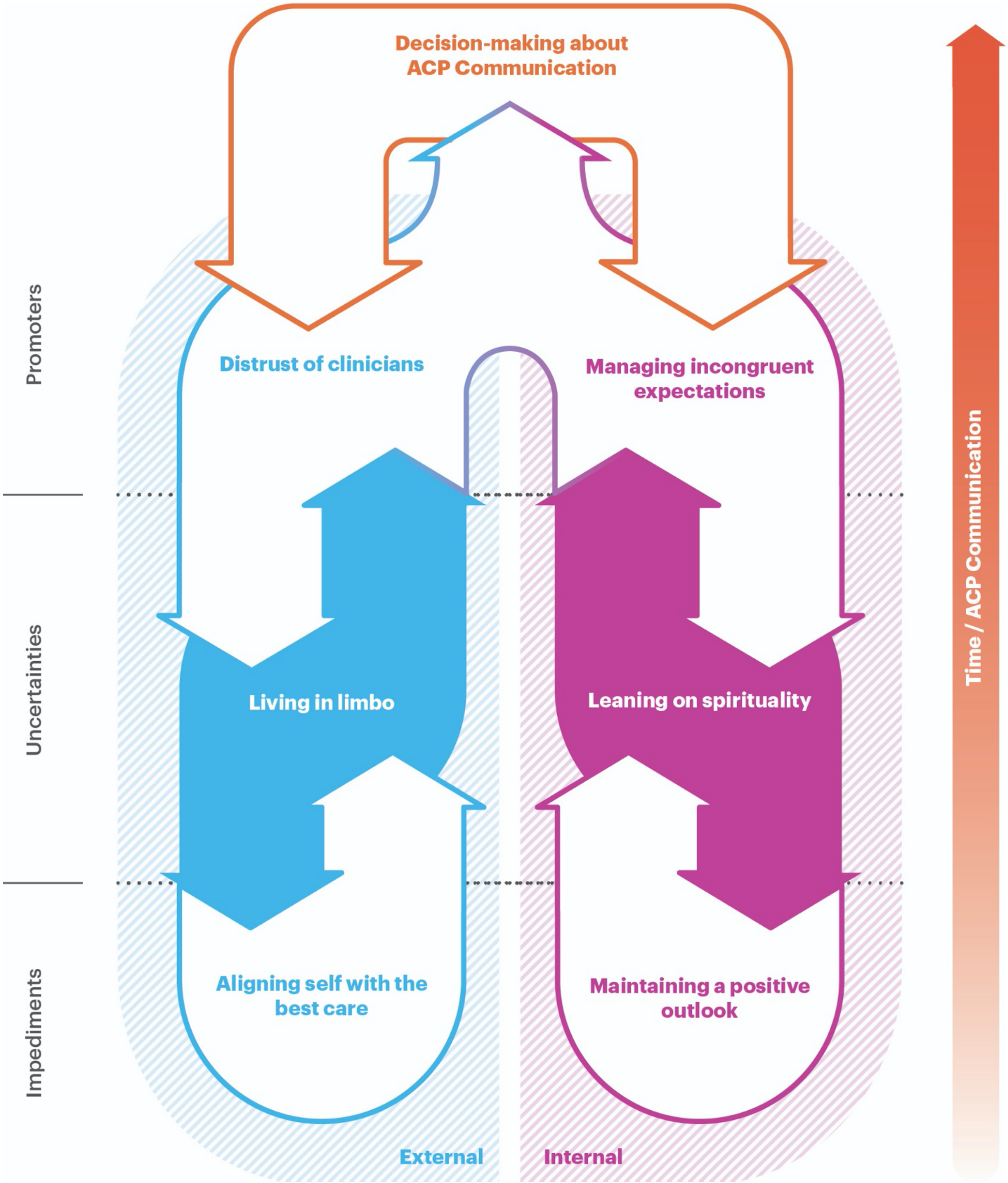
			You start looking at these things when you do have a palpitation here or there, or when you do go up the stairs and you start getting winded, or you bend down you get dizzy, the approach I take is, "Well, that's just the street I live on." That's the new normal for me. (P13)
		Going with the flow (internal)	(The clinicians are like) my grandparents never answered questions for me, they always just supported it. (P01^{2})
			Honestly, I haven't really done any extra research on it. I just go with the flow. Whatever they tell me, I just do it. So if there was something out there that I should know, I wouldn't even know, because I just only do what they tell me at the doctor's office. (P09)
Uncertainties in MCS outcomes	Living in limbo (external)		After I got through that, I really feel like I am living a normal life until I'm waiting for the transplant. But I do feel like my life is in limbo while I'm waiting. (P01^{1})
			I'm stuck, but I tried stuff (to lose weight) that should help me out, and I'm just hanging in there. (P22)
		Changing to destination therapy	It was a little discouraging (transition to DT), but I think it was way more discouraging to my wife. But just a little bit to me. I mean, I feel good that I don't know. This is fine with me. (P11)
			Other than giving me an idea of how long this LVAD will last and what to expect if it goes into failure, would they (clinicians) be able to replace it (MCS device) or would I be too old for it? That part, I guess, they (clinicians) should talk to me about. (P11)
			“Well, it's a 10 hour or eight hour surgery and open the chest and God knows how many things, lungs and all this, which I went through.” Then I said, “No, no, it's (transplant)not for me.” (P14^{1})
			Well, I was a little disappointed at first, but I got over it and it is what it is. (P16)
		Being consumed by transplant	I do not believe that the medical team that I have right now ... I don't think their objective is to find me a heart, I think the objective had turned to where, "Okay. As long as we can keep Mr. "U" convinced that he'll have a heart sooner than later, but our main purpose is to keep him stabilized and sustained on the LVAD, because he's doing so well." (P03)
			You can be consumed with the issue of the transplant to where it'll really throw your life off the rails, and you have to constantly be reminded, "Don't dwell on it. I'll happen when it happens. Live your life." (P13)
			Now, when you get the device, for me, when I get the device, the hardest thing, and again, they do a very good job with trying to help my mindset, but the hardest thing is when you are thinking about a transplant, you're thinking about an offer and you will be consumed by just thinking on that, when it's going to happen, how long am I going to wait? How long do I have to wait? Will it happen tomorrow? Will it not happen? Will I provide until it happens? You can be consumed with that aspect to the point to where it interferes with your daily life routine. (P13)
			I asked the question what happen if I don't end up getting my heart, and they just said they just adjust the machine. They just keep adjusting the machine. But I asked the question has anybody... I also asked the question have anybody passed away with the machine by waiting. (P22)
	Leaning on spirituality (internal)		You know, I talked to a lot of people, and “B’s” (city) a very deeply religious community, and I found that people that are deeply religious, they do better in situations like this. They (people who are deeply religious) have a comfort and belief system that God will take care of them, and I don't have that belief system anymore, so I don't have an idea, I haven't made up my mind what death is. I don't believe in prayer. I mean, I believe in people sending me goof thoughts and things like that, but I don't believe in prayer, so I don't have much comfort zone, anything to hold me up on this since it's so unknown to me, where it used to be I had this firm idea what life after death is. (P06)

			And then it’s an extra little heart that god is giving me a chance to understand that nothing’s going to happen to me and hopefully soon I’ll get my heart transplant and everything will be fine. (P07)
			The only big basic question that constantly came was why, (am I bleeding) again and again, this thing is happening to me. This is the third time (I was readmitted for bleeding), but then again, you have to accept it. You know, they say, what is it, that is the wish of whatever powers it be. So let us accept it (the complications of living with MCS). (P14^{2})
			But my wife asked me about six months in after the surgery, she says, "If they called you today and said we've had a change of heart, you are eligible and we have a heart available for you, would you have a transplant?" And I said, "No." I don't think my life expectancy would be significantly greater and the impact of my daily life would not be improved enough that I would go through the experience again. (P18)
			It probably doesn't in that I think because I'm not a believer of the literal pie in the sky heaven and all that, my spirituality more than my religion guide my decision in palliative care. I'm a big believer when the gig's up, it's up. Thanks for the memories and thanks that you had it. (P21)
Promoters of ACP communication	Distrust of clinicians (external)		Even though, at this point, I can honestly say I really don't trust what they tell me at the clinic anymore. I just don't, you know, I just don't. I think that they've seen every situation you could think of and consequently as a result, I think they've got predetermined responses for just about everything because they've seen it all. (P03)
			Don't expect the doctor or nurse to give you all your answers, you know? Um do your own research and due diligence. You have to write down your questions, you have to ask your questions, you have to try to research your own stuff because it's not just going to all be handed to you, that's for sure. Don’t think they just going to drop a load on you and they don't say, “Hey, this is what's going to go on.” You have to do your own research. (P23)
	Managing incongruent expectations (internal)		You can call it a negative expectation in the sense that I did talk to my daughter and wife that you know, this machine, I don't know how long it will remain, how many years and what if stability stops, all those kinds of things. There is an apprehension, basically. (P14^{2})
		Embedded perceptions	I try to keep everything positive. I like to talk to talk about positive things. Always something down, down, down, down. I'm like wow, can y'all talk about something positive or make it positive or something? I hate to make a person feel down. I won't try to be teared by, I don't like to be teared up. (P04)
			I'm scared of the unknown, and I'm really scared of other organs failing. I don't want to walk around with a piss bag for the rest of my life. I mean, those people smell, they go in for dialysis, whatever. I don't want that. I'd rather die than that. And I told my wife, if it comes to that, I really don't want to live that life. I don't want to be in a wheelchair with the piss bag. And even if I have, down my pants, I don't want it. There are always accidents. You always end up smelling, and anyway, ask me another question. (P10)
			It took about two, three weeks and I would be very honest, even just when I completed two years, I wrote a letter “Dear LVAD.” And I put all my feelings and those that email, that letter I emailed to my son, daughter, my wife, explaining that … Even though I had accepted it, but sometimes I'm angry why I wish that it was not there, but then I said, “I'm not angry at LVAD don't worry you are my friend and you'll be remaining with me until the end of my life. (P14^{1})
			When you're put in the hospital, the nature of the medical care is to give you whatever is necessary to keep you alive. And whether that really fits your understanding of how you want to live going forward, may be in conflict. So, you have to think very hard about, I mean, it's easy to say I don't want to be kept alive by artificial means, but my body is full of equipment. I've got an ICD and I've got an LVAD, I wear an insulin pump. So, I've got all kinds of artificial means attached to me that are addressing both the quality and quantity of my life. So, say I don't want to be kept alive

			by artificial means, I already am. I would have died long ago without some of this equipment. So you have to dig a little deeper about what that means. (P18)
			I Several times people, including one person that I interview, I talked with, that had an LVAD is that eventually you won't even know that you have... “It'll feel like you won't even notice it's there.” Well, that's *@#! You will always. Every second I am aware of it, 24/7. I am never, ever not aware of that LVAD. (P21)
	Perceptions of supportive others' experiences (internal)		Sometimes I feel like I might be a burden to my mom because she has to do so much for me. So that's one of the things that depresses me because I feel like I'm a liability. (P09)
			Is it really worth it all? Is it worth going through this? Worth continue to doing this? If they put the finality on a hope for a transplant, do I want to stay like this forever, however many years I may have? Do I want to keep putting my family through this? (P13)
Initiating ACP communication		External impediments	They come in and there's doctors and nurses and coordinators and people taking different information and different people asking you questions. My wife's fielding half the questions and I'm fielding the other half, it's all going on at the same time, which that is an interesting process in itself. (P18)
		External promoters	And when I asked the MCS coordinator about the longevity of (the device). You know, what could I expect, and she said, "Well, we don't have any data on anybody that's had one more than ten years." (P19)
			Also, if you have any questions for the doctors or anything going on, you write it down ahead of time, have your list written down ahead of time because you don't want to get there and forget. And then you think, “Oh, what was I going to say?” I even had doctors, even with stuff going down they try to bypass you and just do the 30 seconds come in a room and get out the room and you're just like, “Hey, I have questions.” I had a lot of doctors, whatever you put on paper, you're coming in. “Oh, you have headaches.” Yeah. I'm going to prescribed Tylenol,” blah, blah, blah. Out the door. It's like, “Hey, I have some other questions. I want to know about this.” Or “Can I talk to you about this?” You have to almost get ready to fight when you come into the doctor. Fight for your healthcare because they will absolutely pass you up. (P23)
		Internal impediments	I'm following what they say because they are trained, I'm not. Like I have a saying, "Stay in your own lane," and I believe in staying in my own lane, because I'm not a doctor. (P02)
		Internal promoter	I don't want to be told things in a way that is not clear to me. Tell me what you mean or what you're saying. Let's not worry about bedside manner at this point. I want to really know what you (clinicians) think. I may not listen to what you (clinicians) think, but I want to know. Then I'll make my own judgment. That's how I felt at the time. It was a gut punch. My wife and I were sitting there with our mouths open thinking, we certainly didn't expect to hear this. Like I said, I've always recovered from things pretty well in the past, and I did recover from the pneumonia but it took a while. It was somewhat debilitating. But we didn't expect a doctor to say, "Hey, you're in a serious situation here, so you'll have to figure out if you really want to do this again." That was eye-opening. And maybe a good view into my own mortality that I needed to confront. (P18)

Figure 1

Pivoting Uncertainties: Process of ACP Decision-making Among MCS Patients



Note. A situation-specific theory on decision-making about ACP conversations among individuals living with MCS.

Conclusion to the Dissertation

Over the last decade, MCS technology has continued to evolve as a treatment for the rapidly increasing population of advanced heart failure patients (Kirklin et al., 2017). Despite the life-prolonging benefits of MCS, recipients are continually faced with the potential for catastrophic events, yet major gaps in communication about ACP continue to persist (Wordingham et al., 2017). While perceptions of MCS clinicians and palliative care specialists have been examined (Swetz et al., 2013; Wordingham et al., 2016), there is scant research surrounding the ACP experiences of a group of key stakeholders involved in the decision-making: MCS patients themselves. The uncertain outcomes of living with MCS are well established and acknowledged by MCS clinicians (Frigerio et al., 2017; Wordingham & McIlvennan, 2019), yet MCS patients' and family members' understanding of the complex trajectory and how they should plan for the future are poorly researched. Although the findings of this qualitative dissertation do not represent all MCS patients, our study resulted in crucial insights. First and foremost, as evidenced across the participants of two prominent medical centers, the superficial communications around ACP and the dearth of ongoing conversations were alarming. Subtle invitations that participants posed to clinicians to engage in ACP discussions such as ACP-related questions about the longevity of MCS and raising concerns about future adverse events, went unrecognized by MCS clinicians. Furthermore, participants specifically voiced a preference for MCS clinicians to initiate ACP conversations to address the shifting uncertainties in their MCS trajectory. Hence, the sample of individuals provided a deeper understanding of MCS individuals' perceived complexities in engaging in ACP conversations that are useful to guide clinical practice, future research, and policy.

Implications for Clinical Practice

These MCS individuals preferred that ACP conversations be initiated by MCS clinicians, specifically MCS cardiologists, nurse coordinators, and MCS-trained clinical nurses. This insight into MCS individuals' preferences towards ACP will provide practical guidelines for MCS clinicians to initiate these sensitive communications and revisit the planning across the MCS trajectory. Surprisingly, ACP discussions with palliative care specialists were not recalled by the individuals of the current sample. This finding has important implications for clinical practice because current ACP conversations are conducted by palliative care specialists on a consult basis as a requirement for pre-implantation evaluation. It is important for MCS clinicians to be cognizant that, while palliative care specialists may be more skilled in navigating sensitive discussions, MCS patients did not recall the palliative care specialist as a familiar clinician with who they could be engaged in ACP communication. Therefore, our findings showed that the integration of consult-based palliative care was insufficient to provide ongoing ACP communication for MCS individuals and their family members. Despite the Centers of Medicare and Medicaid (CMS) recommendation for palliative care consultation during patients' evaluation for MCS implantation (CMS, 2013), a more structured integration of palliative care specialists was needed to enhance ACP communication. Thus, it was important for all members of the MCS team, to be prepared to engage MCS patients and their family members in ACP conversations.

Another clinical implication is the importance of clinicians' availability to engage in ACP communication. We found that ACP discussions were described to be most conducive when participants in the current sample perceived that the clinician had time to discuss the sensitive topics encompassed in ACP. Fast-paced settings, such as in MCS clinic visits or rounding during hospitalizations, were perceived to be suboptimal environments for ACP conversations. Particularly in the present study, MCS individuals demonstrated a strong inclination to respect MCS clinicians' valuable time and were less likely to ask questions or bring up ACP-related concerns when clinicians were perceived to have a busy schedule.

Even when clinicians are available, there may be internal factors in the patient that may inhibit open discussion. MCS individuals' misconceptions around ACP may contribute to a sense of knowing and having completed ACP through cursory discussions of selecting a surrogate decision-maker. Individuals in the sample demonstrated that they simply may not have the knowledge to initiate conversations. These misconceptions and limited ACP knowledge confounded with the strong desire to respect clinicians' valuable time solidly places the responsibility of ACP conversations on MCS clinicians. Thus, an important implication for clinical practice was to engage patients and family members in ACP communication in a designated appointment outside of the routine MCS clinic visit or rounding in the hospital.

As ACP requires shared decision-making between key stakeholders, the identification and inclusion of suitable family members are essential. This is in line with current literature in advanced heart failure that recommends the inclusion of supportive family members in ACP communication (Nishikawa et al., 2020). However, there is nuance in the identification of supportive family members whom the MCS individuals perceive to be most appropriate to include in ACP communication. Findings from the current study suggested that the caregiver and the supportive family member in ACP communication may be different individuals. Additionally, some family members were perceived to be a hindrance to discussions while others may hold values that conflicted with participants' wishes. Hence, clinicians need to ask MCS individuals about who they prefer to include in ACP communication and to engage these important family members in shared decision-making.

In addition to identifying the most important family members to include ACP conversations, the current sample also described the optimal context and time for these sensitive conversations across the MCS trajectories. While MCS participants reported changes in health as a precursor for ACP discussions, some also emphasized the importance of not revisiting these conversations during times of emotional distress. Furthermore, individuals accentuated mental clarity as a prerequisite for ACP communication. Assessing MCS individuals' mental status, in terms of mental exhaustion from pain and mental capacity from dealing with emotional stressors, is crucial to determining the appropriate situation to engage patients in ongoing ACP conversations. An implication for clinical practice is to ask MCS patients and their families specific questions about their perceived opportune times for revisiting ACP conversations, and to individualize ongoing discussions according to patient preferences.

Another aspect of an optimal time to initiate ACP conversations was when MCS individuals developed a growing awareness of uncertainties in their MCS trajectory. The *Theory of Pivoting Uncertainties* is a situation-specific theory that elucidates this sample of MCS individuals' responses towards the uncertainties in their trajectories and how these uncertainties shape decision-making around ACP communication. Similar to the Reconceptualized Uncertainty in Illness Theory (Mishel, 1990), findings from our study have implications for clinical practice that include the integration of probabilistic thinking, considering the potentially complex outcomes of the MCS trajectory, to enhance ongoing ACP communication. While the majority of the participants emphasized that their goal of MCS treatment was a bridge to transplant, those who experienced prolonged wait times for transplantation described heightened levels of anxiety that was potentially relieved by direct ACP communication. Interventions tailored to discuss the uncertainties associated with a prolonged wait for heart transplantation are needed to address the complexities of the MCS trajectory. Additionally, training and simulation for clinicians on identifying the appropriate contexts and engaging MCS patients' and family in ACP communication may be beneficial to enhance self-efficacy. MCS coordinators and MCS-trained nurses may be instrumental in assisting MCS individuals and family members to navigate the uncertainties of a complex MCS trajectory and engage them in ongoing ACP communication.

Implications for Future Research

Our findings make a novel contribution to MCS literature by examining the reflections of a sample of MCS individuals' experiences around ACP communication. Conversations with these participants demonstrated the lack of ongoing ACP communication, along with the superficial initial discussions. This dearth is particularly concerning as it occurs despite the inherent opportunities by frequent interactions with clinicians in the MCS clinic and readmissions to the hospital. The amalgamation of MCS individuals' preference for MCS clinicians to initiate ACP conversation along with the shortage of palliative care specialists (Sagin et al., 2016), indicated a need for future MCS research to develop, implement, and evaluate ACP education and training for MCS clinicians. While prior studies have examined protocol development for palliative care consultation in the MCS population (Sinha et al., 2017), an important next step in MCS research is to examine clinician-initiated ACP communication and to critically evaluate whether these interventions enhance ongoing ACP conversations, improve documentation of ACP, and increase MCS patient and family satisfaction.

Palliative care specialists are consulted during pre-implantation evaluations (Sinha et al., 2017), yet the participants in the current sample did not recall these discussions. Although these individuals identified MCS clinicians as the most preferred individuals to initiate ACP conversations, it was unclear whether the conversations with palliative care specialists were not preferred or simply not remembered. As participants valued familiarity with clinicians, the lack of recalling discussions with palliative care specialists may be contributed to the silo-ed nature of a one-off consult rather than an objection to engage in ongoing communication with palliative care specialists. Findings from research on the bereaved caregivers of MCS patients also described the importance of family members' familiarity with clinicians in planning for end-of-life (McIlvennan et al., 2016). As supportive family members are also key stakeholders in shared treatment decision-making, both patients and family members need to develop relationships and familiarity with palliative clinicians to better engage in ACP communication. Hence, an important area for ongoing research is the seamless, structured integration of palliative care specialists into the MCS team (Pak et al., 2020) and additional knowledge around the effects of familiarity with multidisciplinary clinicians, outside of the MCS team, on the engagement in ongoing ACP communication.

As these MCS individuals described the uncertainties of unpredictable changes and missed opportunities for ACP conversations throughout their MCS trajectories, our findings were confronted by the reality that ACP communication currently took place at a single time point, typically before device implantation. These descriptions echoed findings from previous studies in the United States where ACP conversations were limited to selecting surrogate decision-makers and completing advance directives before MCS surgery (Sinha et al., 2017). As the participants in our study reflected on the uncertainties of living with MCS, prolonged wait times for transplantation, and changes in the goal of therapy, there was an apparent need to revisit ACP discussions at various time points along the MCS trajectory. Although a specific focus has been placed on ACP communication for destination therapy patients (Allen et al., 2018), bridge to transplant individuals may also experience prolonged, complex trajectories that require ongoing ACP conversations. Additional research is needed to examine ACP communication among bridge to transplant individuals with prolonged wait times, and also for individuals who experience changes in their MCS treatment goal. In the light of the complex and protracted MCS trajectories, longitudinal research, at multiple time points, is needed to enhance knowledge and develop interventions that promote effective, ongoing ACP communication.

Lastly, in the era of patient-centered care, a holistic approach is essential to enhance quality care for patients. The scarcity of research on two important components of shared decision-making, spirituality and culture, in ACP communication among MCS individuals inhibits patient-centered care. The guidelines to caring for stage D advanced heart failure patients recommend incorporating nonmedical considerations, such as spirituality and societal obligations to ensure that decision-making reflects the true preferences of the individual (Fang et al., 2015). Some of the narratives of this study evidenced that spirituality played an important role in making sense of the uncertainties of living with MCS. Hence, future research is needed to elucidate the larger aspects of spirituality and its impact on how MCS individuals navigate uncertainties in the MCS trajectory. Another important, nonmedical consideration is the influence of culture on decision-making. Although some participants alluded to their MCS experience from a cultural perspective, our study was purposed to focus on the cultural aspects of ACP communication. However, the literature on African Americans' perceptions of advance care planning (Rhodes et al., 2017) and nurses facilitating end-of-life discussion with Hispanic patients' (O'Mara & Zborovskaya, 2016) have highlighted the importance of integrating individuals' cultural background in ACP. Thus, an essential next step in research is to examine the influence of culture in ACP communication among the MCS population.

Implications for Policy

In consensus with the recommendations from the American Nurses Association (ANA, 2016), findings from the current study corroborate the need to potentiate nurses' roles in primary palliative care. Policies should be reviewed and amended to provide financial incentives for MCS clinicians to participate in continued education for literacy and self-efficacy around palliative care, specifically the initiation of ACP communication.

Summary

Living with a MCS device was described to be complex and riddled with uncertainties. Participants accounted for uncertain outcomes, potentially catastrophic adverse events, and changes in goal therapy that required ongoing ACP communication to ensure that the life-sustaining interventions of MCS are aligned with patients' preferences and values. Despite these complexities and opportunities for ongoing conversations around ACP, there is a dearth of knowledge about ongoing ACP communication among the MCS population. Our study provided firsthand knowledge about the ACP needs of individuals living with MCS.

Furthermore, findings from the present study confirmed the ongoing need for ACP communication: the first manuscript identified the current gap in ongoing ACP communication, the second paper described the opportunities and challenges to ACP, and the third manuscript reported the dynamic processes of pivoting uncertainties in ACP communication. Together, these three manuscripts provide crucial insights into the need for ongoing ACP communication over the MCS trajectory and opportunities to enhance shared decision-making, future research, and implications for policy. In the words of the current sample, nurses, specifically MCS coordinators or MCS-trained nurses at the bedside, are well-positioned to engage patients in ongoing ACP communication, guide research, and advocate for ACP to enhance shared decision-making over the MCS trajectory.

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