

ORIGINAL ARTICLE

# Preparedness and Mutuality Affect Quality of Life for Patients With Mechanical Circulatory Support and Their Caregivers

## A Qualitative Analysis

See Editorial by McIlvennan and Matlock

**BACKGROUND:** Clinical and US regulatory guidelines for patients with mechanical circulatory support (MCS) require the identification of a caregiver to assist with MCS care. There is limited understanding of the impact of MCS caregiving on patients and caregivers. The purpose of this study was to examine how living with MCS affects the quality of life (QoL) of patients and their caregivers through the lens of preparedness and mutuality.

**METHODS AND RESULTS:** The sample included 30 MCS patients and their caregivers. Semistructured qualitative interviews about factors contributing to QoL were conducted with patients and caregivers and analyzed using a 2-phase thematic process. Caregiving impacts QoL of MCS patients and their caregivers long term. When there was limited time to engage in decision-making about MCS implantation, people entered MCS caregiving relationships naive to its full demands. Although most people adjusted to the task demands, MCS caregiving had a significant impact, both positive and negative, on interpersonal relationships. We applied the concepts of preparedness and mutuality to help frame the understanding of the emergent themes of forced choice, adjustment, gratitude, relationship change, strain, and burden (both caregiver and patient perceived). Availability of networks of support was identified as a crucial resource.

**CONCLUSIONS:** MCS caregiving affects QoL for both patients and caregivers. Specifically, preparedness, mutuality, and availability of supportive networks influence QoL of MCS patients and their caregivers. Caregiving relationships change over time. Long-term support by the MCS clinical team can help ensure that physical and emotional needs of MCS patients and caregivers are identified and addressed.

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## WHAT IS KNOWN

- Clinical and regulatory guidelines for patients with mechanical circulatory support (MCS) require the identification of a caregiver to assist with MCS care.
- There is increasing recognition that MCS caregiving can adversely affect health-related quality of life of both MCS patients and their caregivers.
- Preparedness and mutuality have been shown to influence caregiving outcomes across diverse clinical populations.

## WHAT THIS STUDY ADDS

- To our knowledge, this is the first study that seeks to understand MCS patient and caregiver experiences within the broader conceptualizations of preparedness and mutuality (and the negative impact when these conditions are absent).
- By building on and learning from the established body of caregiving evidence, MCS researchers and clinical teams can help develop supportive resources and interventions to promote health-related quality of life for both MCS patients and their caregivers.

During the past 2 decades, over 25 000 patients with advanced heart failure (HF) received mechanical circulatory support (MCS).<sup>1</sup> Adverse events have decreased and outcomes, including survival and health-related quality of life (HRQoL), have improved among MCS patients.<sup>2,3</sup> The availability of a well-trained caregiver plays a pivotal role in adjustment and HRQoL among MCS patients.<sup>4</sup> Indeed, clinical and US regulatory guidelines require identification of a dedicated caregiver to assist with MCS self-care.<sup>5</sup>

For many MCS patients and caregivers, caregiving does not begin at device implantation but rather is a continuation of long-term caregiving related to HF management. Although caregivers for both HF and MCS patients offer emotional and logistical support, HF caregiving is characterized by high levels of monitoring symptoms and adherence with HF care regimens to reduce symptom burden and slow disease progression.<sup>6</sup> In contrast, post-MCS implantation, most HF symptoms abate relatively quickly, and caregiving responsibilities tend to be more technical, related to changing driveline dressings and stabilizing drivelines, charging and changing batteries, troubleshooting alarms, and dealing with emergency and urgent situations (both environmental, such as power failures, and clinical, such as infections, at the driveline exit site).<sup>7,8</sup> Because of activity restrictions imposed by MCS, caregivers may also take on more household chores and financial responsibilities, especially if the patient is unable to return to employment. Caregiving is demanding and can have

a significant impact on caregivers' HRQoL.<sup>9–12</sup> Caregivers may experience anxiety, depression, posttraumatic stress disorder, burden, and worsening physical function.<sup>9,11,13–17</sup> As a result, there is increasing recognition of the need to support MCS caregivers, both at implantation and long term.

Two concepts that may facilitate understanding MCS caregiving are preparedness and mutuality. Preparedness, the caregiver's readiness to provide care,<sup>18</sup> has been shown to have a positive impact on outcomes among caregivers for diverse populations, including HF. Lack of preparedness is related to caregiver role strain, fatigue, and mental health across various patient populations.<sup>18–22</sup> Mutuality (the positive quality of the patient-caregiver relationship characterized by love and affection, shared pleasurable activities, shared values, and empathy) is an indicator of the strength of the patient-caregiver relationship.<sup>18</sup> Mutuality is associated with increased patient and caregiver confidence in care, as well as less perceived stress, depression, role strain, and burden for caregivers.<sup>6,17,18,20,22–26</sup>

Although preparedness and mutuality have been shown to be strongly related to caregiver burden across diverse clinical population, to our knowledge, these 2 concepts have not yet been examined in MCS patients and their caregivers. Thus, we sought to examine the concepts of mutuality and preparedness within the context of MCS caregiving to enhance our understanding of the impact of MCS caregiving on MCS patient and caregiver QoL. Knowledge gained from this study has important clinical implications on how to best support MCS patients and their caregivers.

## METHODS

### Design

We conducted a secondary analysis of cross-sectional semi-structured qualitative interviews of MCS patients and their caregivers.<sup>4</sup> The purpose of the parent study was to develop a conceptual framework of HRQoL, followed by development of a measurement system to assess adjustment and HRQoL among MCS patients. We conducted extensive qualitative interviews of multiple stakeholders, including expert clinicians, patients with HF scheduled for MCS implantation, MCS patients, and caregivers. Analysis of those data underscored the importance of caregiving to HRQoL for both patients and caregivers. Consequently, the available data from MCS patients and their caregivers were reanalyzed to address the research questions in this report. Only patients whose caregivers participated in the study are included in this analysis. The data that support the findings of this study are available from the corresponding author on reasonable request.

### Site and Sample

Advanced HF patients, who received continuous flow left ventricular assist devices (LVADs) for MCS, were recruited into a larger qualitative study as described above.<sup>4</sup> MCS patients were

recruited at a single site in the Midwest using a maximum variability sampling strategy based on implant strategy (bridge to transplant versus destination therapy) and time since implantations (HF/preimplantation), early postimplantation (within 6 months of implantation), and long-term since implantation (>6 months) to capture different phases of adjustment and expectations. We also set recruitment targets for lower incidence subgroups that we conceptualized to offer alternative points of view, especially women and people of color. As part of the parent study, MCS patients were asked to identify their primary caregivers and gave the research team permission to contact them. MCS caregivers who were approached were screened for eligibility and invited to participate during clinic visits. Eligibility criteria for MCS caregivers, included age  $\geq 21$  years, identified as the primary caregiver, was an unpaid family member or friend, and was able to communicate in English. All participants provided written informed consent in accordance with the Northwestern University Institutional Review Board. Thirty-seven patients identified caregivers all of whom consented to participate; 2 failed the eligibility screen (were not the MCS patient's primary caregiver), 3 could not be scheduled, and 2 MCS patients ultimately refused to participate. Our final sample included 30 MCS patients and their caregivers (n=30).

## Development of Interview Guides

Semistructured interview guides for both patients and caregivers were developed for the parent study, based on a review of the literature, findings from qualitative interviews with expert MCS clinicians, and the clinical expertise of the principal investigator (Dr Grady). Draft interview guides were reviewed and revised by a separate group of expert MCS clinicians in a focus group setting at our medical center. Questions progressed from open elicitation to obtain unbiased perspectives to targeted probing related to physical, mental, and social health. Caregiving was not the focus of the parent study but emerged spontaneously within the context of the parent study.

## Interviews

Semistructured interviews were conducted by the lead author (Dr Magasi) who has extensive expertise as a qualitative methodologist, the primary investigator (Dr Grady), and the research coordinator (S. Buono) who had expertise in conducting qualitative interviews with other chronically ill patient populations. Dr Magasi trained both Dr Grady and S. Buono in qualitative data collection.

All participants were interviewed individually in person or by telephone per participant preference and lasted 30 to 60 minutes. Interviews were audio-recorded and transcribed verbatim with identifiers removed. No data were shared between patients and caregivers. Accuracy of transcription was verified by the research team. All participant recruitment and data collection were conducted as part of the parent study. No new participants or data were collected for this study.

## Qualitative Analysis

Deidentified transcripts were imported into Atlas-ti 7.0 (Scientific Software Development GmbH) for data management and qualitative analysis. We used a 2-phase thematic

analysis to analyze the qualitative data<sup>27,28</sup> and created a detailed audit trail to track analytic decisions.<sup>29</sup>

First, as part of the parent study, we (Drs Magasi, Grady, and S. Buono) conducted descriptive coding by attaching meaningful labels to blocks of text using a preliminary coding dictionary based on our literature review. Two independent raters initially coded each transcript, adding to the coding dictionary as necessary. Disagreements between coders were reconciled through extensive in-person discussion. We used the code frequency spreadsheet feature in Atlas-ti to track emergent themes and monitor data saturation. Issues around caregiving emerged as an important theme warranting further in-depth analysis.

Thereafter, we conducted conceptual coding to refine a large number of descriptive codes into conceptual categories to identify the overarching themes related to caregiving in a subset of the data from MCS patients whose caregivers also participated in the parent study. Specifically, we used Archold et al's<sup>18</sup> conceptualization of preparedness and mutuality to frame our understanding of emergent themes. These concepts were expanded as appropriate to capture the nuances of MCS caregiving. To establish the trustworthiness of our findings, we triangulated the patient and caregiver data to explore caregiving from multiple perspectives.<sup>29,30</sup> Throughout the analytic process, we tracked emergent themes using a saturation grid. Based on our analysis, we are confident that we achieved data saturation, the point of redundancy when new cases no longer lead to the identification of new themes.<sup>31,32</sup> Data saturation is a marker of rigor of qualitative research as it demonstrates the adequacy of the sample.

## RESULTS

### Participant Characteristics

The final sample included 30 patients and their caregivers. MCS patients were predominantly middle-aged, male, and white, whereas caregivers were primarily middle-aged, female, and spouses of the patients (Table 1). The accrued patient sample reflects the population of LVAD recipients which is skewed toward more male (80%) and white (82%) patients.<sup>33</sup> Patients received MCS as either a bridge to heart transplantation or permanent implantation (ie, destination therapy). Most patients had been living with an LVAD for more than 6 months and could reflect on changes to the caregiving relationship over time.

### Qualitative Findings

Caregiving after MCS had a profound impact, both positive and negative, on patient and caregiver QoL. Regardless of demographic and social characteristics, LVAD implantation has been identified as a major life change and disruption<sup>34</sup>; therefore, we do not examine our findings by these categories. The concepts of preparedness and mutuality framed our analyses and deepened our understanding of the following themes

**Table 1. Participant Characteristics**

Characteristics	Patients (n=30)	Caregivers (n=30)
Age, y, mean (range, SD)	57.7 (19–78, 17.1)	56 (21–76, 14.3)
Sex (% male)	27 (90)	20 (66.7)
Race and ethnicity, n (%)		
White	21 (70)	24 (80)
Black	7 (23.3)	4 (13.3)
Hispanic/Latino	1 (3.3)	2 (6.7)
Other	2 (6.7)	2 (6.67)
Current marital status, n (%)		
Married/partner	18 (60)	21 (70)
Single	8 (26.7)	3 (10)
Divorced/separated	3 (10)	4 (13.3)
Widowed	1 (3.3)	1 (3.3)
Not reported	...	1 (3.3)
Highest level of education, n (%)		
Less than high school	1 (3.3)	1 (3.3)
High school graduate	8 (26.7)	5 (16.7)
Some college	8 (26.7)	10 (33.3)
College graduate	6 (20)	6 (20)
Postgraduate	7 (23.3)	8 (26.7)
Current work situation, n (%)		
Full time	2 (6.7)	9 (30)
Part time	3 (10)	4 (13.3)
Not working	25 (83.3)	17 (56.7)
Living alone, n (%)	2 (6.7)	3 (10)
Relationship to patient, n (%)		
Spouse or partner	...	20 (66.7)
Parent	...	4 (13.3)
Other family	...	6 (20)
Diagnosis at implant, n (%)		
Ischemic cardiomyopathy	16 (53.3)	...
Dilated cardiomyopathy	8 (26.7)	...
Valvular cardiomyopathy	2 (6.7)	...
Other	4 (13.3)	...
Implant strategy, n (%)		
Bridge to transplant	14 (46.7)	...
Destination therapy	16 (53.3)	...
Time since implant, n (%)		
Early (<6 mo since implant)	9 (30)	...
Late (>6 mo since implant)	21 (70)	...

that emerged from the data: forced choice, adjustment, gratitude, burden, relationship change, and networks of support. Representative quotations are provided to support these themes. Table 2 shows the number and percentage of participant interviews wherein themes were identified. Endorsement of individual themes

ranged from 30% for forced choice to 73% for adjustment (total sample percentages).

### Preparedness

Preparedness within the context of MCS caregiving is the belief that one has the knowledge and skills needed to assume and competently fulfill the caregiver role. This requires both the technical skills of managing LVAD care at home and emotional preparedness to cope with the psychosocial demands of long term caregiving. The themes of forced choice and adjustment strongly influenced preparedness both at the time of implantation and long term.

### Forced Choice

LVAD implantation, and thus the onset of MCS caregiving, was described as a forced choice between life and death. Some patients described having limited time to engage in the decision-making process.

*“They said either you get a VAD (ventricular assist device) or you go on palliative care...I think he kind of felt trapped.” Caregiver*  
*“I didn’t really have a choice, you know what I mean? You got two choices. Do you want to live or do you not want to live? That was my choice.” Patient*

Framing the decision to receive an LVAD as life over death limited the opportunity to fully contemplate and comprehend the demands (physical, emotional, logistical, technical, and time) required of full-time caregiving. As a consequence, some caregivers entered the long-term caregiving relationship relatively naive to the task demands, with a small number of caregivers reporting feeling pressured into the decision.

*“I was not completely on board and the surgeon felt that... I wasn’t completely understanding the situation....I felt like I was backed up against a wall...we had to accept it and do it because I was being told he really had no other choice.” Caregiver*  
*“I think we often underestimate how demanding caregiving is.” Caregiver*

The promise of more time and decreased HF symptoms were rationalized as outcomes worth the demands of full-time caregiving by both patients and caregivers.

### Adjustment

All participants characterized the early post-LVAD period as one of adjustment as new roles, and relationship changes had to be negotiated within the high stakes context of LVAD care. The early post-LVAD period was also a time of heightened anxiety as both patients and caregivers adjusted to a new set of life circumstances and task demands related to managing LVAD-related care (eg, driveline dressing changes, maintaining a power supply, and reporting device-related complica-



**Table 2. Emergent Themes: Indicates the Frequency (n/%) That Themes Were Identified in Participant Interviews**

	Patients (N=30) n (%)	Caregivers (N=30) n (%)	Both* (N=30) n (%)	Total (N=60) n (%)
Forced choice	8 (27)	10 (33)	4 (13)	18 (30)
Adjustment	21 (70)	23 (77)	16 (53)	44 (73)
Gratitude	15 (50)	17 (57)	8 (27)	32 (53)
Relationship change	12 (40)	7 (23)	5 (17)	19 (32)
Burden	12 (40)	12 (40)	8 (27)	24 (40)
Networks of support	17 (57)	21 (70)	13 (43)	39 (65)

\*When both the patient and caregiver within a matched pair discussed a particular theme and is included to show overlapping issues.

tions). Patient safety, survival, and ability to remain out of the hospital required a high degree of vigilance on the part of patients and caregivers alike.

*“Uncertainty initially with he and I, both. Thinking Oh my God are we going to be able to do this...but once you incorporate it into your daily life and just schedule the things you do it is just not that big a deal.” Caregiver*

The tasks of LVAD management became routinized relatively quickly over a matter of days or weeks yet the need for vigilance continued long term. Contingencies for unexpected events (both emergency situations, such as power failures, and routine occurrences like grocery shopping) needed to be carefully planned in advance or actively problem solved at the moment. Over time, the majority of caregivers and patients described a normalization process as they established caregiving routines and became confident in completing tasks related to LVAD care.

*“It is to the point with us that I don’t really even notice it. I mean I always listen for the beep in the morning and at night you know when he unplugs and stuff. You are always kind of tuned into that. Other than that we are just used to it...I don’t even think about it anymore.” Caregiver*

**Mutuality**

Mutuality is the degree to which the MCS dyads felt their relationship was characterized by positive feelings for each other, empathy, shared values, and activities. Within the context of the MCS caregiving relationship, mutuality further included a sense of coming to a shared understanding about both the organization of MCS-related care and importance caregiving has on the MCS patient’s day-to-day activities, as well as long-term health and survival. Individual caregiving needs and decisions about how care is structured and organized varied across individuals and frequently changed over time. As a result, caregiving relationships must often be negotiated and renegotiated as needs and expecta-

tions change. Themes associated with mutuality include gratitude and relationship change, specifically positive changes (ie, strengthening of relationships).

**Gratitude**

Caregivers and patients described a profound sense of gratitude for more time to live and enjoy their lives and loved ones. Appreciation for the advantages conferred by the LVAD, such as decreased HF symptomatology and increased life expectancy (ie, more years together), helped patients and caregivers cope with the demands of caregiving. Gratitude and appreciation did not minimize those demands but afforded MCS patients and caregivers the opportunity to reframe them as not only necessary but acceptable.

*“It blesses both of us with hope and it gives him the opportunity to go on living and instead of feeling like he only has a certain amount of time left to live he feels like he’s been given a second chance at life and he knows that I can’t live without him so it has saved my life as well. It is the greatest blessing that we have ever received in our life.” Caregiver*

**Relationship Change**

Both MCS patients and caregivers described changes to their interpersonal relationship, positive and negative. Participants described both shared and unique responses based on their roles and responsibilities.

**Positive Change**

Closely related to feelings of gratitude was the recognition that the interdependence created through the caregiving relationship, as well as the intimate nature of the care itself, actually strengthened the relationship between caregiver and care recipient and enhanced QoL. Positive relationship changes were gleaned both from the day-to-day exchange of care and from the recognition that the LVAD provided more time together to pursue shared and individual experiences.

*“I don’t think she feels like a burden ... I am like her shadow and basically we have grown closer... she doesn’t feel that way and I don’t feel that way.” Caregiver*  
*“There were many, many things I couldn’t do myself and I had to rely on my wife to take care of that and, you know, I can’t express the amount of appreciation for that and what she had done for me...We are best friends and we love to hang out with each other but you know I think this has brought us closer together.” Patient*

**Lack of Mutuality and Preparedness**

The impact of the LVAD on interpersonal relationships and HRQoL was not uniformly positive. When MCS patients and caregivers were unprepared for the reali-

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ties of caregiving or were unable to come to a shared understanding and appreciation of the value, demands, and organization of caregiving, participants reported negative outcomes, including relationship strain and burden, both caregiver burden and self-perceived burden.

### Strain

Both caregivers and patients reported negative or stressful aspects of caregiving. Negativity was associated with relationship strain, and caregiver and self-perceived burden and often represented a lack of mutuality between caregivers and patients. Mismatched expectations between patient and caregiver resulted in relationship strain which exacerbated a sense of burden for the caregivers and loss of autonomy for the patients. Power struggles and over-protectiveness about care management and control, although rare, led to the most significant examples of strain and dissatisfaction.

*"Have you ever seen that movie Misery with James Caan and you know how she wouldn't let him leave. That's what it's like really actually. You're pretty much in the hands of this other person and you can't go anywhere unless they go... That's what causes the anxiety and depression."* Patient

Both patients and caregivers recognized that lack of alone time and loss of autonomy also created relationship strain and caused LVAD patients to view the caregiving relationship as confining.

*"Knowing that I have to be there to do the dressing change every day has taken a toll on probably both of us."* Caregiver

### Caregiver Burden

Some caregivers felt overwhelmed by the demands of caregiving and recognized the profound impact that caregiving had on their physical and emotional health and QoL.

*"[Caregiving] actually affected my mom's health because she came down here and would plop her butt in the lazyboy and weight started coming on and now she's still got this weight issue that I feel is kind of my problem or my fault because she sat here with me for 2 years with nothing really to do at my house."* Patient

*"If he didn't have a VAD he might be dead so that is the tradeoff. It got him alive but it has affected my quality of life more than his."* Caregiver

Perceptions of caregiver burden were intensified if caregivers experienced a sense of role loss or felt forced to abandon social and leisure activities to meet caregiving demands. Caregiver burden was most acute when

an individual was the sole caregiver for the MCS patient. Assuming sole caregiving responsibilities were related to limited trust in a diverse set of caregivers, limited availability of alternate caregivers, and patients' expressed desires not to burden other people, such as children, and outside friends and family. Caregiver burden was discussed by ≈43% of the caregivers.

*"That 24-hour somebody with you is so hard on the family. It's just an incredible amount of pressure, you know? I mean my son was a young man and sowing his oats and doing his own thing... It was just really, really hard, and it caused a lot of tension and upheaval amongst the family."* Patient

### Self-Perceived Burden

Equally important were patients' self-perceptions and expressed concerns with being a burden to their caregivers. Self-perceived burden was described by patients even when caregivers denied feeling burdened by the role.

*"It's put more of a burden on her [my wife] than myself as far as she works like three 10-hour days."* Patient

*"I feel that she is overworked sometimes, but she claims she doesn't mind... But there is extra work I cause my wife because she does everything."* Patient

Participants, both patients and caregivers, described the emotional toll that perceived burden had on MCS patients.

*"I think at first he felt he was a burden on me and I didn't look at it as a burden, but you know when you are more emotional in the beginning and there were days we would just sit and cry because he felt bad because I had to do so much."* Caregiver

*"I feel like I'm a burden when they have to change the bandage for me or do something that I can't do that I used to do but I can't do it now. Then there is depression. I get depressed because I really can't do much. Sometimes I just feel like pulling the cord out and let it go."* Patient

### Networks of Support

Mutuality does not imply that the MCS patient and a single caregiver is or should be responsible for addressing all caregiving needs. The demands for 24-hour supervision were onerous, and people developed elaborate plans to ensure constant coverage and care. Indeed, the creation of an infrastructure of support was identified as critical to successful long-term LVAD management and was an effective strategy in reducing both caregiver and patient self-perceived burden. The mobili-

zation of networks of support provided caregivers with time to step out of their caregiver role to pursue other roles and responsibilities.

*"I don't know how people deal with it who don't have...that strong network, I think it's critical... because you are going to need that with the VAD." Caregiver*

*"If you don't have enough caregivers, you do feel like a prisoner that can never go out and do anything alone." Caregiver*

The availability of a stable, yet flexible, network of support also provided MCS patients with greater autonomy by decreasing dependence on a single individual and increasing choice and control over LVAD management and participation in social activities. Patients and caregivers who did not reach out beyond a single caregiver reported greater burden and relationship strain.

## DISCUSSION

We found that despite limited time to engage in decision-making, especially when patients were most acutely ill, both patients and caregivers generally adjusted to life with a device and were grateful. Our findings validate existing literature that both patients and caregivers often perceive the MCS implantation decision-making process as a forced choice between life and death.<sup>10,35,36</sup> As a consequence of this forced choice, we found that individuals often entered the caregiving relationship naive to the practical, logistical, and emotional demands that the need for sustained caregiving has on patients and caregivers alike. One of the most salient findings was the impact that the caregiving relationship has not only on the 2 parties individually but on the relationship as a whole.

After implant, although most patients and caregivers were able to work together to learn about and adapt to the practical aspects of LVAD care, such as dressing changes and monitoring the device, the sustained and often intimate nature of caregiving had both a negative and positive impact on interpersonal relationships. Lack of preparedness (ie, urgent decision-making and naivety to caregiving processes) has been associated with anxiety, burden, strain, and mood disturbances among caregivers for diverse clinical populations, including patients with HF.<sup>18–20,22,37,38</sup> Relationship strain was more common among nonspousal caregivers, such as siblings or parents of adult patients. Such relationships are outside of societal normative roles and may be more challenging to negotiate in adulthood.

Caregiver burden and self-perceived burden amongst MCS patients and caregivers were identified. Caregiver burden was reported when the demands of caregiving exceeded the individual's capacity to provide care or forced the curtailment of other meaningful life

roles. Consistent with existing research,<sup>10,11,15,39</sup> our participants described anxiety, role loss, despondency, and feelings that they had given up their lives as negative consequences of caregiving. These findings reinforce calls for greater clinical attention to the psychosocial and emotional support needs of MCS caregivers.

Self-perceived burden represents patients' concerns that they were asking too much of caregivers. Patients who described themselves as burdens to their caregivers expressed more feelings of despondency and negative self-worth and affect. To our knowledge, self-perceived burden is not discussed in the existing MCS literature. Self-perceived burden is associated with decreased help-seeking, decreased QoL, as well as psychological and existential distress in other serious chronic medical conditions.<sup>40–43</sup> Although our study did not include objective evaluation of depression and distress, these findings may point to the need for greater psychosocial screening and intervention to help patients manage feelings of decreased autonomy and role loss.

MCS patients and caregivers who came to mutually agree upon interdependent processes for MCS care reported that the experience brought them closer together and enabled them to appreciate each other in new ways. This finding resonates with a larger body of caregiving research on the buffering effect that mutuality has on caregivers' HRQoL.<sup>18,20,23</sup> Mutuality emphasizes the positive interpersonal and reciprocal nature of caregiving relationships.<sup>18</sup> Its salience has been supported in diverse clinical populations, such as dementia, oncology, stroke, and HF.<sup>20</sup> Anchoring MCS caregiving within this larger body of evidence can help inform evidence-based interventions and support, while addressing the unique clinical needs of MCS patients and their caregiver. MCS clinicians can help to facilitate negotiation of caregiving roles and responsibilities for these MCS patients and their caregivers postimplant over time.

Finally, the ability to mobilize networks of support was described by both patients and caregivers as helping to offset some of the negative consequences on interpersonal relationships. Networks of support helped disperse the emotional and physical demands that caregiving placed on any one individual but did require time and effort to coordinate and manage. As patients expanded their networks of support, it was important to ensure that critical aspects of care were not compromised. When individuals within social networks failed to meet their responsibilities as caregivers, tension and relationship strain occurred not only between MCS patients and caregivers but also among caregivers in the network. This again highlights the need for ongoing psychosocial support of MCS patients and caregiving teams. Clinical team members with expertise in care coordination and social support, including social workers and psychologists, can play

**Table 3. Recommendations to Enhance Preparedness, Mutuality, and Support for MCS Caregiving Dyads**

During evaluation for MCS
Shared decision-making about MCS includes discussion of the emotional, interpersonal impact of caregiving for both patient and caregiver, in addition to discussion of MCS and device management.
During early follow-up
MCS training includes tailored discussion of the emotional and interpersonal impact of caregiving for both patient and caregiver, in addition to training on device management. This includes discussion of caregiving as an evolving process that often changes over time and strategies to adjust to these changes.
Psychosocial interventions, such as those provided by social workers and psychologists, should include strategies focused on enhancing communication and mutuality between partners in the MCS caregiving dyad. Particular emphasis should be paid to the changing nature of the caregiving relationship.
Caregiving dyads are encouraged to develop a flexible VAD management and caregiving plan of action that address the needs of both MCS patients and their caregivers.
During long-term follow-up
Each clinical encounter includes specific actionable questions about interpersonal relationships and role strain for both patients and caregivers, including discussion of caregiver burden. It may be helpful to ask these questions of each dyad member individually to promote disclosure of challenging issues.
Caregiving is a role that requires the development of new habits and routines. Facilitation of engagement in meaningful life roles and activities should be promoted. Referral to applied health professionals, such as vocational rehabilitation or occupational therapy, should be considered as appropriate. To promote a sense of autonomy and independence, these roles and activities should span the domains of self-care, productivity, leisure, self-care, as well as alone time, as defined and desired by the individual.
Supportive interventions are provided as indicated by identified needs, including actively supporting a network of support.

MCS indicates mechanical circulatory support; and VAD, ventricular assist device.

an important role in helping individuals establish, negotiate within, and sustain networks of support over time. Incorporation of supportive interventions for MCS caregivers is supported by strong bodies of evidence across diverse fields including gerontology,<sup>44</sup> dementia care,<sup>35</sup> and stroke rehabilitation.<sup>45</sup>

This study has some limitations. First, participants were recruited from a single site; thus, findings may need to be replicated at other institutions to evaluate the generalizability to more geographically diverse settings. However, our sample size was large and relatively diverse demographically, clinically (ie, by implant strategy), and geographically as the hospital has a large catchment area. We enrolled participants from urban, suburban, and rural settings. Although the parent study used a maximum variability sampling approach based on clinical and demographic factors, our approach for recruiting caregivers was based on patient outreach which may have impacted the diversity of our sample. In spite of this limitation, our sample is reflective of the population of LVAD recipients.<sup>33</sup> Lastly, because the interview guides were designed to reflect the parent study's emphasis on development of a measurement system on adjustment and HRQoL for MCS patients, standardized questions related to caregiver QoL were not included. Therefore, issues related to the negative impact of caregiving on caregiver QoL emerged spontaneously and may be underrepresented in our findings.

## Clinical Implications

Based on our findings, we recommend that MCS clinical teams help prepare individuals for the demands of caregiving (both immediate and long term), facilitate dialogue between patients and caregivers to set real-

istic expectations for both parties, and encourage inclusion of >1 caregiver. It is further recommended that clinicians offer ongoing support and assistance based on challenges that can develop within the MCS patient-caregiver relationship over time (Table 3).

## Conclusions

Caregiving is a dynamic interaction between patients and caregivers which is vital to long-term outcomes, including QoL, for patients with MCS and their caregivers. Caregiving can have both positive and negative consequences on interpersonal relationships which may affect individual psychosocial well-being and QoL. Caregiving relationships can change over time. Long-term support by the MCS clinical team can help ensure that physical and emotional needs of MCS patients and caregivers are identified and addressed.

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