Original Article

Emerging Collaboration Between Palliative Care Specialists and Mechanical Circulatory Support Teams: A Qualitative Study

Alana Sagin, MD, James N. Kirkpatrick, MD, Barbara A. Pisani, DO,
Beth B. Fahlberg, PhD, RN, AGPCNP-BC, CHPN, Annika L. Sundlof, and Nina R. O'Connor, MD
Palliative Care Program (A.S., A.L.S., N.R.O.), Department of Medicine, University of Pennsylvania Perelman School of Medicine, Philadelphia, Pennsylvania; Division of Cardiology (J.N.K.), Department of Medicine, University of Washington School of Medicine, Seattle, Washington; Division of Cardiology (B.A.P.), Department of Medicine, Wake Forest Baptist Medical Center, Winston-Salem, North Carolina; Division of Continuing Studies (B.B.F.), University of Wisconsin-Madison, Madison, Wisconsin; and School of Nursing (B.B.F.), Johns Hopkins University, Baltimore, Maryland

Abstract

Context. Despite national requirements mandating collaboration between palliative care specialists and mechanical circulatory support (MCS) teams at institutions that place destination therapy ventricular assist devices, little is known about the nature of those collaborations or outcomes for patients and families.

Objectives. To assess how Centers for Medicare & Medicaid Services' regulations have changed collaboration between palliative care and MCS teams and how this collaboration is perceived by MCS team members.

Methods. After obtaining verbal consent, members of MCS teams were interviewed using semistructured telephone interviews. Interviews were transcribed, and content was coded and analyzed using qualitative methods.

Results. Models for collaboration varied widely between institutions. Several expected themes emerged from interviews: 1) improvements over time in the relationship between palliative care specialists and MCS teams, 2) palliative care specialists as facilitators of advance care planning, and 3) referral to hospice and ventricular assist device deactivation as specific areas for collaboration. Several unexpected themes also emerged: 4) the emergence of dedicated heart failure palliative care teams, 5) palliative care specialists as impartial voices in decision making, 6) palliative care specialists as extra support for MCS team members, and 7) the perception of improved patient and family experiences with palliative care team exposure.

Conclusion. Although the structure of collaboration varies between institutions, collaboration between MCS teams and palliative care specialists is increasing and often preceded the Centers for Medicare & Medicaid Services requirement. Overall impressions of palliative care specialists are highly positive, with perceptions of improved patient and family experience and decreased burden on MCS team members. J Pain Symptom Manage 2016;■:■–■. *© 2016 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words
Palliative care, ventricular assist devices, mechanical circulatory support, qualitative research

Introduction

Destination therapy ventricular assist devices (VAD-DT) have been shown to improve functional status and quality of life as well as survival.[1–3] However, patients are still faced with the potential for daunting complications such as infection, stroke, gastrointestinal bleeding, and device malfunction, and caregivers can experience significant burdens.[3,4] Furthermore, patients may develop complications or disability

---

Address correspondence to: Alana Sagin, MD, 3400 Spruce Street, White Building, 2nd Floor, Philadelphia, PA 19104, USA. E-mail: alana.sagin@uphs.upenn.edu

Accepted for publication: April 27, 2016.

0885-3924/$ - see front matter
http://dx.doi.org/10.1016/j.jpainsymman.2016.03.017

from comorbid conditions. Overall, three-year survival for patients with VAD-DT is 57%, and voluntary withdrawal of ventricular assist device (VAD) support is the third most common cause of death.[3]

Given the high morbidity and mortality with mechanical circulatory support (MCS), practice guidelines support palliative care specialist involvement for all patients undergoing evaluation for VAD placement.[4,5] Advocates of palliative care for MCS patients cite advance care planning, symptom management, and assistance with end-of-life transitions as potential benefits.[6–9] Swetz et al. have advocated for "preparedness planning," a specialized type of preimplantation advance care planning to address specific complications that might arise after VAD implantation, and since that time, further decision-making aids and recommendations have been described.[10–15]

In October 2013, the Centers for Medicare & Medicaid Services (CMS) issued a new National Coverage Determination requiring all programs that implant VAD-DT to include a palliative care specialist as a member of the MCS team.[16] The National Coverage Determination specifies that "team members must be based at the facility and must include individuals with experience working with patients before and after placement of a VAD," but they do not specify how the palliative care specialist should collaborate with MCS team members. In addition, CMS does not provide guidance on what role the palliative care specialist should play in the care of patients who are considering or have received VAD-DT.

Given these ambiguities, our study was designed to explore collaboration between MCS teams and specialty palliative care, with particular attention to ways in which collaboration has changed since implementation of the CMS guideline. Through qualitative investigation, we sought to determine the following: 1) models for MCS team-palliative care specialist collaboration, 2) MCS team perceptions of this collaboration, and 3) MCS team perceptions of the impact of such collaboration on patients and families.

Methods

A qualitative study design using conventional content analysis was used, appropriate to exploring this emerging area of clinical care and identifying overarching themes in MCS team collaboration with specialty palliative care.[17] A semistructured interview tool was designed by the study team with input from literature and members of a local MCS program (Appendix, available at jpsmjournal.com). Questions in the tool included program characteristics, structure of palliative care resources, challenges and successes of MCS team and specialty palliative care collaboration, and impact of palliative care specialist involvement on patient care. Additional information was obtained using open-ended prompts. The University of Pennsylvania institutional review board approved this study and provided a waiver of written informed consent.

Prospective participants were identified by convenience sampling using known contacts from MCS programs. All participants were members of MCS interdisciplinary teams. MCS team members trained in palliative care and MCS team members from the primary study institution were excluded. No compensation was provided for study participation. Verbal informed consent was obtained from all study participants followed by telephone in-depth semistructured interviews. All interviews were conducted by a single study team member for consistency. The interviews were recorded and transcribed.

Transcripts were analyzed using conventional qualitative content analysis. Conventional content analysis is "generally used with a study design whose aim is to describe a phenomenon … when existing theory or research on a phenomenon is limited."[17] This method of analysis was appropriate as no previous studies have addressed the MCS team's perception of collaboration with specialist palliative care. Using this methodology, transcripts were studied and coded for key concepts, and major themes were identified. Continuous coding and identification of themes was done by a single researcher who also performed the interviews. Interviews were conducted until no new themes emerged. Themes were then discussed by members of the core study team until consensus was reached on final themes for inclusion. To improve credibility, debriefing sessions were held periodically throughout the interview process by the core study team to review emerging themes and discuss the overall process. Credibility was further enhanced through peer scrutiny of the process and interview tool.

Results

Interviews were conducted between July and September 2015. All 13 MCS team members who were successfully contacted agreed to participate in the study. Overall, 13 interviews were performed with MCS team members from eight institutions, including seven VAD coordinators, three VAD nurse practitioners, one social worker, one psychologist, and one physician. Seven of the programs were based in academic institutions; one was based in a community-based institution. Programs were geographically diverse. Programs included one pediatric and seven adult MCS programs that implanted anywhere from