



## Research Briefs

# Leveraging the lived experience of surrogate decision makers of the seriously ill to develop a decision support intervention



Ronald L. Hickman Jr., PhD, RN, ACNP-BC, FAAN<sup>a,\*</sup>, Barbara J. Daly, PhD, RN, FAAN<sup>a</sup>,  
John M. Clochesy, PhD, RN, FAAN<sup>b</sup>, Julia O'Brien, BSN, RN<sup>a</sup>, Mary Leuchtag, MSSA, LISW-S<sup>a</sup>

<sup>a</sup> School of Nursing, Case Western Reserve University, Cleveland, OH

<sup>b</sup> College of Nursing, University of South of Florida, MDC22

## ARTICLE INFO

## Article history:

Received 24 June 2015

Accepted 24 October 2015

## Keywords:

Surrogate decision makers

Seriously ill patients

Intervention development

Qualitative research

## ABSTRACT

**Background:** Surrogate decision makers of seriously ill patients are frequently asked to make healthcare decisions without evidence-based decision support.

**Aims:** To describe the lived experiences of surrogate decision makers who have made advance care decisions and identify relevant features of a decision support intervention from their perspectives.

**Methods:** A convenience sample of surrogate decision makers (n = 10) of seriously ill patients discharged to an extended care facility within the past 6 months participated in focus group discussions. Data were analyzed using content analysis.

**Results:** Three salient themes were identified: (1) limited preparation, (2) decisional and emotional burden, and (3) content and features of a decision support intervention.

**Conclusions:** Surrogate decision makers of the seriously ill are not prepared for their new role, and experience decisional and emotional burden. Effective decision support interventions must address the decisional and emotional needs of surrogate decision makers to enhance the quality of their decisions.

© 2015 Elsevier Inc. All rights reserved.

## 1. Introduction

In the United States, nearly three-fourths of adults are hospitalized with a life-limiting illness (e.g., cancer, diabetes mellitus, heart failure, cerebrovascular disease) that can diminish their ability to participate in shared decision making for health care (Steiner & Friedman, 2013). For almost one-half of older adults (aged >65 years) hospitalized with a serious illness, surrogate decision makers, such as spouses, adult children, and legally designated representatives, abruptly assume the responsibility for making complex healthcare decisions as result of the patient's cognitive impairment (Boustani et al., 2010; Camhi et al., 2009). The culmination of the uncertainty of the patient's illness trajectory and the lack of awareness of the patient's healthcare preferences can result in plans of care that are inconsistent with

the patient's and family's preferences (Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2007).

Prior research has principally focused on helping surrogate–clinician communication; however, there is a shallow evidence base for interventions that provide decisional support for advance care decisions (e.g., cardiopulmonary resuscitation [CPR] and readmission status) that commonly occur with transitions in a patient's care (Schuster, Aslakson, & Bridges, 2014; Sharma et al., 2011; Vig et al., 2007). The transition from hospital to extended care facility marks an opportunity for patients and their families to re-evaluate their preferences for life-sustaining care. Therefore, the purpose of this article is to: (1) describe the lived experiences of surrogate decision makers who have made advance care decisions, and (2) identify pertinent educational content and features for a decision support intervention to enhance the quality of advance care decisions by individuals thrust into the surrogate decision maker role.

## 2. Methods

This study is part of a larger project and was designed as a qualitative investigation using focus group methodology to inform the development of a decision support intervention. Focus group discussions were held in various community settings (e.g., extended care facilities, coffee shops, libraries, and churches) in Northeast, Ohio.

**Financial Disclosure:** This publication was made possible in part by research grant R15NR013569 from the National Institute of Nursing Research (NINR), a component of the National Institutes of Health (NIH), and research grant 72118 from the Robert Wood Johnson Foundation (RWJF). Its contents are solely the responsibility of the authors and do not necessarily represent the official view of the NINR, the NIH, or the RWJF.

**Conflict of Interest:** None for all authors.

\* Corresponding author at: Ronald L. Hickman Jr., PhD, RN, ACNP-BC, FAAN, Frances Payne Bolton School of Nursing, Case Western Reserve University, 2120 Cornell Road, Cleveland, OH 44106-4904. Tel.: +1 216 368 2147; fax: +1 216 368 5989.

E-mail address: [ronald.hickman@case.edu](mailto:ronald.hickman@case.edu) (R.L. Hickman).

## 2.1. Sample

A convenience sampling method was used to identify and recruit eligible surrogate decision makers who have made advance care decision for a seriously ill patient. Eligible surrogate decision makers met the following inclusion criteria: > aged 18 years, able to speak and understand English, and were recognized as the next-of-kin (e.g., spouse, adult child, or other relative) or legal representative responsible for an advance care decision for a seriously ill patient (aged > 60 years and cognitively impaired) discharged to an extended care facility (e.g., skilled nursing home or long-term acute care hospital) within the previous 6 months.

## 2.2. Procedures

Prior to screening and recruitment of participants, this qualitative study was approved by the institutional review board of a university-affiliated medical center. If a surrogate decision maker was interested in study participation, he or she contacted the research staff by telephone for eligibility screening. For those surrogate decision makers who remained eligible to participate, the research staff assessed the surrogate decision maker's availability to participate in a focus group discussion and obtained contact information. Written informed consent was granted by each participant, preceding the focus group discussion.

## 2.3. Data collection

Each focus group discussion was held at various extended care facilities and queried participants on the following three questions: (1) What was it like for you making a decision about CPR and readmission for your loved one?; (2) How did you get the information you needed to make these decisions?; and (3) What would have been helpful to you when you making decisions about your loved one's resuscitation and readmission status? Additionally, the focus group facilitator used probing questions to clarify statements and gather more in-depth information from participants. The focus group discussions were audio-recorded and transcribed verbatim for subsequent content analysis.

## 2.4. Data analysis

A multi-stage collaborative analytic strategy was implemented to identify themes in the focus group data (Floersch, Longhofer, Kranke, & Townsend, 2010). First, each coder (RH, JO, and ML) independently assigned in-vivo codes to the actual words of the participants. Second, the in-vivo codes of each focus group were merged to develop a master codebook. Third, coders worked collaboratively to classify the in-vivo codes into themes that emerged across the groups. Lastly, reliability and validity assessment was conducted by: double-checking the in-vivo codes across the focus groups and verifying that the themes were derived appropriately from the in-vivo codes.

## 3. Results

### 3.1. Participants

In this study, 10 surrogate decision makers participated in one of three focus group discussions. Participants were mostly Caucasian (60%) females who were a spouse (30%), adult child (50%), or legal representative (20%) of a seriously ill patient discharged to an extended care facility. Participants' age ranged from 20 to 80 years. At the time of the focus group, 70% of the seriously ill patients were alive. Each focus group consisted of three or four participants, and the mean duration of the discussions was 64 minutes.

Three salient themes emerged across the focus groups: (1) limited preparation; (2) decisional and emotional burden; and (3) content

and features of a decision support intervention. A description of each theme is presented.

### 3.2. Limited preparation

Participants described that the sudden decline in the patient's health afforded them a limited time to access information and prepare for the multitude of decisions that would ensue. A participant who was responsible for her husband's advance care decisions commented that, "The decisions you have to make, you have to make them very quickly many times, and you don't always have the information you need or you feel that you need, in order to make the best decision or what you would think is a better decision." Similarly, another participant commented, "I wasn't prepared at all."

Participants underscored that there was not just a single decision but a series of decisions that occurred on a daily basis. After her mother suffered from a stroke, a participant expressed her experience making daily decisions for her mother with little preparation and commented that, "You know every level of decisions. I've had to deal with how am I gonna' present this to the siblings. Any decisions... what kind of diapers? Decisions as far as just everything."

### 3.3. Decisional and emotional burden

Of the three themes, participants were most expressive about the persistent burden of making decisions for a seriously ill patient. Participants expressed feelings of stress, guilt, and regret with having to make healthcare decisions on the patient's behalf. A daughter responsible for her mother's healthcare decisions remarked, "Well it was very stressful for me, and I felt very guilty...you always have this expectation that you're going to bring them home and it just doesn't happen because they just get sicker and sicker." Additionally, a wife of a seriously ill patient shared a similar sentiment and expressed that, "As far my feelings, it was terrible guilt and I still feel that way, but I realize that there's nothing I can do."

The decision to transfer a seriously ill patient to an extended care facility was shown to provoke a sense of guilt associated the stigma of institutional care and failure to maintain cultural expectations of end-of-life care. In most situations, participants described making placement decisions under conditions of uncertainty, limited time for deliberation, and the recognition of their inability to remain an informal caregiver. "I don't think you ever get over the decision of putting them into a facility, as important as it is," commented a participant about her decision to transfer her husband to an extended care facility.

In contrast, participants of seriously ill patients with established advance directives or knowledge of the patient's preferences for life-sustaining care reported less decisional and emotional burden. Several participants commented that their decisional and emotional burden was alleviated by prior conversations about life-sustaining care preferences with a seriously ill patient. One participant stated, "Oh that [a written advance directive] relieves a great burden off of me."

### 3.4. Content and features of a decision support intervention

Participants were clear that they desired informational support to make higher quality decisions. Several participants alluded to the lack of understanding of medical terms and commented on the benefits of having a glossary of medical terms and acronyms. Although Internet access and usage varied somewhat among participants, across focus group a preferred method of accessing healthcare information was through the Internet. In addition, several participants commented on a desire for a decision support intervention that was capable of providing customized informational support to meet their specific needs and deliver content through an interactive process.

# دانلود مقاله



<http://daneshyari.com/article/2645033>



- ✓ امکان دانلود نسخه تمام متن مقالات انگلیسی
- ✓ امکان دانلود نسخه ترجمه شده مقالات
- ✓ پذیرش سفارش ترجمه تخصصی
- ✓ امکان جستجو در آرشیو جامعی از صدها موضوع و هزاران مقاله
- ✓ امکان پرداخت اینترنتی با کلیه کارت های عضو شتاب
- ✓ دانلود فوری مقاله پس از پرداخت آنلاین
- ✓ پشتیبانی کامل خرید با بهره مندی از سیستم هوشمند رهگیری سفارشات