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# Does an Intervention Designed to Improve Self-management, Social Support and Awareness of Palliative-care Address Needs of Persons with Heart Failure, Family Caregivers and Clinicians?

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Does an Intervention Designed to Improve Self -  
Management, Social Support and Awareness of Palliative -  
Care Address Needs of Persons with Heart Failure, Family  
Caregivers and Clinicians?

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## Abstract

### Aims and Objectives

To conduct a formative evaluation of the iPad-Enhanced Shared Care Intervention for Partners (iSCIP) among persons with heart failure (HF), family caregivers and clinicians. Together, persons with HF and family caregivers are referred to as partners.

### Background

There is growing awareness of the caregiver's contributions to HF self-management, social support and reciprocal benefits of interventions that involve both partners. The iSCIP engages both partners in a six-session psychosocial intervention to address three preventable causes of poor outcomes in a HF population: poor self-management skills, inadequate social support and underutilisation of palliative care. An iPad app is used to organise the intervention. The goals of the iSCIP are to engage partners in HF self-management, communication about the HF patient's care values and preferences, and future planning.

### Design

A qualitative focus group design was used.

### Methods

Seven clinicians and eight partners participated in focus groups to explore their experiences, needs and reaction to the iSCIP content and technologies employed. Open-ended questions and closed-ended surveys were used to collect data. Deductive content analysis was used to analyse the qualitative data. NVivo software was used for qualitative data analysis. Bayesian statistical models were used to analyse numeric data.

### Results

The iSCIP met partners' and clinicians' needs to improve self-management, communicate about care values and preferences and plan for the future. Quantitative analysis of numeric data supported our qualitative findings, in that both groups rated the intervention components useful to very useful.

### Implications for practice

These findings add to the growing evidence of the feasibility and acceptability of programs that address care values and preferences, and care planning. The iSCIP can be used as a guide for developing interventions and software applications, which involve both partners in care and palliative-care discussions.

What does this paper contribute to the wider global clinical community?

- This study adds to the growing evidence of the acceptability of partner-level interventions that addresses care values and preferences and supports the utility of care planning for a variety of disease groups.
- The iSCIP can be used as a guide to facilitate partner communication about care values and care preferences, evaluate care options and develop a care plan for the future.
- The work reported here, which applies technology to facilitate delivery of the iSCIP, may also serve as a model for development of software applications that go beyond the typical functions of information access and data gathering, to play a more direct and central role in real-time discussions of care values and care preferences, and decision-making about the patient's current and future care.

## 1 INTRODUCTION

The World Health Organization reported that within all noncommunicable diseases, ischaemic heart disease (including HF) is the single greatest cause of fatal and nonfatal global disease burden (McAloon et al., [2016](#)). More than 6.5 million Americans over 20 years of age have heart failure (HF) (Benjamin et al., [2017](#)). People with HF experience distressing symptoms, decreased quality of life and increased mortality risk (Heidenreich et al., [2013](#)). Preventable causes of poor quality of life include poor self-management skills (Annema, Luttik, & Jaarsma, [2009](#)), inadequate social support (Gallagher, Luttik, & Jaarsma, [2011](#)) and underutilisation of palliative care by this population (McIlvennan & Allen, [2016](#)). There is a growing awareness of the person with HF and family caregivers' (who together are referred to as partners from here on) contribution to self-management and social support and of the reciprocal benefits of interventions aimed at improving outcomes for both partners. There is increasing evidence that improving outcomes, such as quality of life, for both partners is important and reduces the global burden of disease in this population (Sherwood et al., [2017](#)).

The iPad-Enhanced Shared Care Intervention for Partners (iSCIP) is a six-session psychosocial intervention developed to address three preventable causes of poor outcomes in a HF population: poor self-management skills, inadequate social support and underutilisation of palliative care. The iSCIP empowers HF partners to improve self-management skills, communication about the patient's care values and preferences and to develop a care plan for the future.

## 2 BACKGROUND

Evidence-based practice guidelines recommend actively involving both partners in self-management and palliative-care planning (Heart Failure Society of America et al., [2010](#); McMurray et al., [2012](#)). However, a recent meta-analysis showed that caregivers were included in less than a third of studies with potential interventions to improve care (Wakefield, Boren, Groves, & Conn, [2013](#)). Despite the recognised importance of caregiver involvement in care and of early introduction of palliative care as a treatment option, the majority of HF

interventions are focused on an individual patient, and palliative care is not introduced until late in the disease trajectory.

## 2.1 Partner-centred intervention

The iPad-Enhanced Shared Care Intervention for Partners (iSCIP) is a theory- and evidence-based intervention that takes a partner-centred approach to address poor HF self-management skills, inadequate social support and underutilisation of palliative care. The iSCIP is an adapted version of the *SHARE for dementia* program (Support, Health, Activities, Resources and Education; formerly referred to as EDDI; Whitlatch, Judge, Zarit, & Femia, [2006](#)). The iSCIP provides a structured protocol of self-management education: communication about patient care values and preferences, decision-making about the future, and strategies to promote reciprocity in the care relationship. Similar to the SHARE program in the iSCIP patients' care values are assessed and discussed with respect to environment, social interactions, autonomy, choosing who helps out and family caregiver issues (Whitlatch, [2010](#)). For the values assessment, the patient rates how important or not important each value indicator is to him or her. However, the caregiver rates how important or not important the caregiver thinks the value indicators are to the patient; in other words, we assess the patient's perception of the patient's values and the caregiver's perception of the patient's values. A care preference, on the other hand, represents the assignment of a particular care task or self-management activity to someone who can assist the person with HF in that regard. The intervention supports the person with HF in defining a set of care preferences and assists the caregiver in understanding those choices. Each partner reflects on how to balance the best interests of the other in developing the care plan. In most cases, and similar to the SHARE program, the person with HF initially prefers that the caregiver provide assistance with all the care tasks, and the caregiver usually agrees to provide that assistance into the future. However, partners are encouraged to reflect on how much one person can be expected to do and the best interests of the other. This strategy of promoting reflection on "best interests" is used to strengthen reciprocity in the care relationship.

## 2.2 Adaptation of iSCIP for heart failure care partners

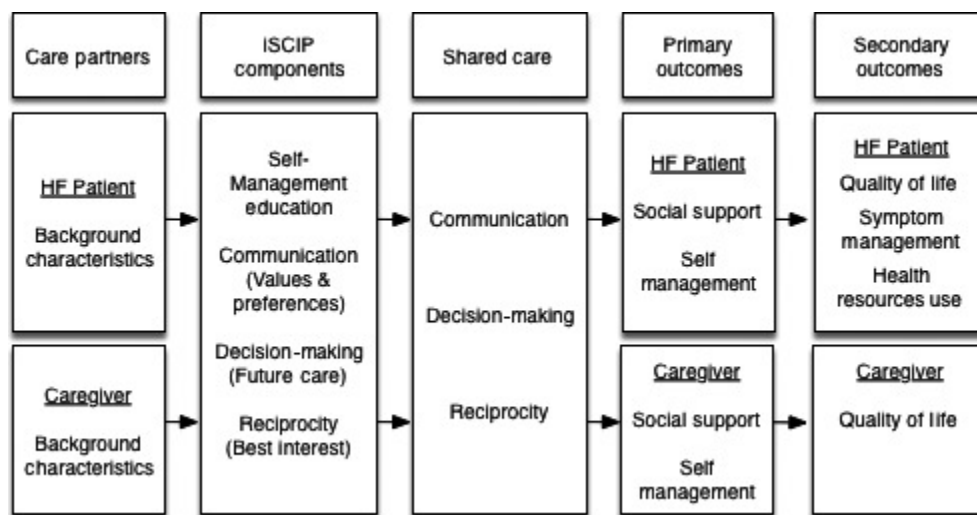
The iSCIP differs from the prior protocols in the following ways. First, HF self-management education is tailored to the partners' needs. Second, we added additional care preferences tasks specific to HF self-management, such as preparing meals that follow dietary restrictions, symptom monitoring, physical activity, walking, climbing stairs, assistance with falls, assistance with appearance and being available 24 hrs (Luttik, Jaarsma, Tijssen, van Veldhuisen, & Sanderman, [2008](#)). Third, the iSCIP incorporates mobile computing devices (iPads), a custom iPad application (commonly referred to as an "app"), and links to network educational resources designed for partners and clinicians. The handheld iPad platform offers direct visual and tactile interaction without the need to manage a separate display, keyboard and mouse; this allows users to focus on concepts and tasks, rather than the mechanics of interacting with the device.

A prototype app was developed to assess and display the care values, preferences and subsequent care planning. For example, using the app, partners complete an assessment of

care values and review their ranking; they are able to arrange the care values spatially, facilitating communication of values and feelings through a visual display of similarities and differences in the value rankings. The partners need not agree, but it is important that they understand each other's perspective and the rationale for their rankings. Next, partners use the care preferences feature of the app to assign self-care and HF self-management tasks to specific persons or resources able to assist them. They use the app's care plan feature to discuss what resources they have now, and what may be helpful for them in the future. The care plan identifies tasks that could be delegated, when more assistance is needed, to family, friends, paid helpers and community resources, thus reassuring both partners.

### 2.3 Theory and evidence base

The iSCIP is based on a construct called shared care. Shared care is an interpersonal interaction system composed of communication, decision-making and reciprocity; it is used by partners to exchange social support (Sebern, 2005). The iSCIP strengthens the three shared-care components, and improved shared care contributes to better self-management and social support. In turn, improved self-management and social support contribute to improved symptom management, quality of life and decreased health resource use (HRU) (see Figure 1). In preliminary studies with over 400 sets of partners, significant positive associations were supported between shared care and self-management, relationship quality and quality of life (Sebern, 2008; Sebern, Brown, & Flatley-Brennan, 2016; Sebern & Riegel, 2009).



**Figure 1** Shared care intervention for partners model

Prior research supported the effectiveness of the *SHARE for dementia program* (Copyright © 2017 The Benjamin Rose Institute on Aging), which the iSCIP has adapted to serve a population of HF partners. SHARE provides a structured protocol of education about communication of care values, care preferences and care planning for persons with dementia and their family caregivers (Orsulic-Jeras, Whitlatch, Szabo, Shelton, & Johnson, 2016). Based on dementia partners' understanding of values and care preferences, they develop a care plan for the future (Reamy, Kim, Zarit, & Whitlatch, 2011). Results from the SHARE program

support our premise that targeted education and communication about care values and preferences can improve self-management and social support, while facilitating planning for the future (Whitlatch et al., [2006](#)).

The adapted SHARE program was evaluated with HF partners. Sebern and Woda ([2012](#)) reported a moderate effect size for the adapted intervention on HF self-maintenance (Cohen  $d = 0.39$ ) and self-management (Cohen  $d = 0.48$ ). Effect sizes for the caregivers were strongest for positive relationship quality ( $d = 1.25$ ) and decrease in relationship strain ( $d = 0.99$ ). The caregivers also improved their communication with the patient ( $d = 0.44$ ) and mutual decision-making ( $d = 0.28$ ).

## 2.4 Proposed iSCIP outcomes

The iSCIP proposes to improve self-management skills. Self-management in heart failure is a complex process that requires partners to monitor and respond to symptoms, modify life styles, mobilise and manage social support, learn to live with a chronic illness and engage in future planning (Schulman-Green et al., [2012](#)). Heart failure self-management often occurs in a family context, and complex self-management regimes cause a significant burden for partners. Inadequate self-management is prevalent in the heart failure population and contributes to unplanned hospitalisations (Riegel et al., [2009](#)).

The iSCIP also proposes to improve social support. Social support emerges in informal care interactions, such as those between partners, and is linked to better self-management (Gallagher et al., [2011](#)). The iSCIP proposes to improve shared care, and shared care is used to exchange social support. Social support is the provision and exchange of informational, instrumental and/or emotional resources, in response to a perception of another's need or a person's perceptions of social resources available or actually provided by nonprofessionals (Holt-Lunstad & Uchino, [2015](#)).

Social support may have a direct effect on self-management behaviour and a stress-buffering effect on physical and mental health. The direct-effect hypothesis proposes that social support directly affects health behaviours like HF self-management. For example, the caregiver provides instrumental support to a patient by setting up a weekly pillbox, which directly affects patient adherence to medication.

The stress-buffering hypothesis proposes that social support moderates the negative effects of stressful life events on individuals (Uchino, Carlisle, Birmingham, & Vaughn, [2011](#)). For example, the quality of the relationships is an important moderator of cardiovascular reactivity, and cardiovascular reactivity is a symptom of stress. Birmingham and colleagues ([2009](#)) reported that supportive social relationships buffered the impact of stress on cardiovascular reactivity. Uchino and colleagues ([2011](#)) reported that perceptions of available social resources moderated the effects of stress on health. In other words, the partner's perceptions that there are available social resources to assist them moderate the stressful effects of managing a chronic illness on health. Statistical evidence for a moderation effect occurs when a causal relationships between two variables (i.e., chronic illness and health) change as a function of the moderator variable (i.e., perception of available social resources) (Baron &

Kenny, [1986](#)). Mobilising social support is considered an essential process for self-management in chronic illness (Schulman-Green et al., [2012](#)). The effects of positive social support are improved behavioural, emotional and physiological functioning, resulting in a person being better able to manage the demands of a chronic illness (Holt-Lunstad & Uchino, [2015](#)).

Practice guidelines recommend introducing palliative care early in HF treatment. The American Heart Association and American Stroke Association (AHA/ASA) define palliative care as patient- and family-centred care that optimises health-related quality of life by anticipating, preventing and treating suffering (Braun et al., [2016](#)). Components of palliative care are shared communication, shared decision-making, advance care planning, attention to distress (physical, emotional and spiritual) and the inclusion of the patient's family and care system. Understanding the person with HF's values and care preferences is essential for care planning and palliative care (Allen et al., [2012](#)). The iSCIP can guide discussions of care values and preferences, and future planning

When adapting an intervention with supporting technology to a new setting, it is important to consider the context, beliefs, attitudes, values, needs and past experiences of the population who will utilise the intervention (Glanz, Rimer, & Viswanath, [2015](#)). To facilitate adoption to practice, it was important to assess whether the intervention was acceptable and valued by partners and clinicians. Thus, the purpose of this study was to engage partners and clinicians, jointly referred to as stakeholders, in a formative evaluation of the iSCIP, to elicit their attitudes, beliefs and needs related to the intervention and supporting technology.

### 3 PURPOSE

The first aim of this study was to evaluate whether the iSCIP approach to improving self-management, social support and palliative care was acceptable to and valued by the stakeholders. The second aim was to evaluate the acceptability of a prototype app used to organise the intervention.

Aim 1. Engage stakeholders in an evaluation of the acceptability and value of the iSCIP.

Research questions were as follows:

1. How useful are the intervention materials for the partners?
2. How useful are the intervention materials for the clinicians?
3. What additional content is needed?

Aim 2. Engage stakeholders in an evaluation of the acceptability of the prototype app.

Research questions were as follows:

1. What were the stakeholders overall reactions to the prototype app?
2. What additional features are needed?



## 4 METHODS

Qualitative methods were used to meet the study's aims and answer our research questions. We engaged stakeholders in a series of three focus groups, over a three-month period, to conduct a formative evaluation of the intervention materials and prototype of the app. Focus group methodology was used to explore experiences, needs and reaction to the iSCIP content and technologies employed. Open-ended questions and closed-ended surveys were used to collect narrative and numeric data.

### 4.1 Ethical consideration

Prior to implementation of the study, we obtained Institutional Review Board approval from the healthcare organisation where the study was conducted. Clinic employees asked potential research participants if they were interested in learning about the research study. Research staff met with potential participants who expressed interest, to explain the study, determine eligibility and obtain consent. Written informed consent was obtained from all research participants prior to the start of the focus groups.

### 4.2 Participants

To be eligible, patients had to have a diagnosis of heart failure, be at least 21 years old and cognitively intact, be medically stable, not require continuous in home or institutional care, be able to read, write and speak English and have a caregiver willing to participate. Caregivers had to be at least 21 years old, cognitively intact and able to read, write and speak English. Potential persons with HF and caregivers were excluded if they reported (i) significant sensory or cognitive impairment, (ii) end-stage renal disease, (iii) need for 24-hr professional care, (iv) an unstable medical condition or (v) enrolment in a conflicting investigational study. Clinician participants were required to be licensed health professionals engaged in providing care to a HF population.

In selecting the size and number of groups, we followed the recommendations of Krueger who suggests a range of six to ten participants per group if the purpose of the group is broad consensus (Krueger, [1994](#)). Our final sample consisted of four sets of partners (8 persons) and seven clinicians. Six of the eight partners participated in all three sessions, and all but one clinician participated in all sessions.

### 4.3 Procedures and measures

Prior to the focus groups, we collected the participants' demographic information. We convened two separate series of focus group meetings, one with partners and one with clinicians. Each series of focus groups consisted of three 1.5-hr meetings. In the first two sessions, we solicited feedback about the usefulness of the iSCIP content and prototype app. The third focus group brought partners and clinicians together so that we could validate our findings from the prior session and provide an opportunity for stakeholders to hear each other's views.

Open-ended survey questions focused on (i) the usefulness of session content to the participants, (ii) whether this approach would meet their needs, and (iii) what additional content is needed. To assure credibility, transferability and dependability of data, all focus group sessions were recorded, transcribed verbatim and subjected to content analysis.

We used closed-ended survey questions to collect numeric data related to the usefulness of the intervention content. The response options were 0 (not useful) to 3 (very useful). A study-specific survey with two scales was used. The first scale asked the participant to rate the usefulness of 13 HF self-management education components. These components included definitions of HF terms, definitions of HF medications, taking daily weights, low-salt diets, healthy eating, how to stay active, symptom monitoring, evaluation and reporting. The second 14-item scale asked the participant to rate the usefulness of the shared-care components: care values, preferences, planning for the future, goal setting and community resources. For this study, the Cronbach alpha for the HF self-management education scale had a standardised  $\alpha = 0.93$ , and the shared-care scale had a standardised  $\alpha = 0.71$ , indicating appropriate reliability for the components.

We used the User Evaluation of an Interactive Computer System (QUIS) to evaluate the acceptability of the iPad technology from the user's perspective (Harper, Slaughter, & Norman, [1994](#)). The QUIS has 27 items and the response options are from 0 to 9; higher scores are better. The QUIS has excellent reliability, Cronbach's alpha = 0.94. The surveys were administered at the end of each focus group.

#### 4.4 Analysis

The software package NVivo version 11 was used to analyse the qualitative data (NVivo, [2016](#)). As our aim was to evaluate the adapted SHARE intervention in a HF population, deductive content analysis was used (Elo & Kyngas, [2008](#); Graneheim & Lundman, [2004](#)). Deductive content analysis is used as a framework for qualitative analysis when the analysis is based on pre-existing categories. For example, usefulness of the care values was a pre-existing category that directed our analysis of the narrative data. Partner and clinician group data were separately analysed, to understand the perspectives of each group. Codes were based on categories of the intervention. Once initial coding was completed, we aggregated coded data under similar themes and content; for example, one theme was *Partners' care preferences—shared activities*. We tracked our analytic process with memos to increase the transparency and confirmability of our findings. We summarised the key themes for the self-management education and shared-care components. We presented our preliminary findings in the third focus group where both the partners and clinicians came together to verify the findings.

We used R 3.3.2 (R. C. Team, [2016](#)) to compute descriptive statistics, including means, medians and standard deviations to describe the study sample and scales. We estimated group mean comparisons and determined group differences between self-management education and shared-care components. Our rationale for separating the intervention components was that the self-management education is considered standard care, while the shared-care components are unique. Thus, we wanted to know whether the participants

perceived the usefulness of self-management and shared-care components differently. Due to our small sample size, we used Bayesian models for group comparisons. The Bayesian analysis is based on the Markov chain Monte Carlo (MCMC) method, which approximates the distribution of the parameters of interest in the population based on the data provided by the sample (Gelman et al., [2013](#)). In small samples, Bayesian analysis is more sensitive to differences compared to a frequentist analysis; frequentist analysis is commonly used with larger samples and based on the null hypothesis significance testing (Gelman et al., [2013](#)). Analysis was conducted using the R package brms (Bürkner, [2017](#)), which specify and run statistical analysis through the general Bayesian program rstan R package (S. D. Team, [2016](#)).

## 5 RESULTS

### 5.1 Demographic characteristics

The mean age of the person with heart failure was 74 (*SD* 8) years ( $n = 4$ ), all were White, non-Hispanic individuals; only one person did not graduate from high school (see Table [1](#)). One person with heart failure was female (25%); all were married to the caregiver and lived in the same residence. The mean number of years the patient was diagnosed with HF was 19 (*SD* 10) years. The mean age of the caregiver was 72 (*SD* 5) years ( $n = 4$ ). All caregivers were White females, and all but one had a high school education. There was no statistically significant difference in age between patients and caregivers. Three sets of the partners (75%) had a computer, one (25%) had an iPad, and all sets of partners had mobile phones.

Table 1. Participants demographic characteristics

	Person with HF	Caregiver	Clinicians
Mean Age	74 ( <i>SD</i> 8) years	72 ( <i>SD</i> 5) years	34 ( <i>SD</i> 12) years
Range	68–86 years	66–79 years	26–55 years
Gender			
Female	25% ( $n = 1$ )	75% ( $n = 3$ )	87% ( $n = 7$ )
Race			
White	100%	100%	100%
Hispanic	0%	0%	0%
Education			
Some High School	25% ( $n = 1$ )	25% ( $n = 1$ )	
High School	25% ( $n = 1$ )	25% ( $n = 1$ )	
College Graduate	25% ( $n = 1$ )	25% ( $n = 1$ )	37% ( $n = 3$ )
Post college	25% ( $n = 1$ )	25% ( $n = 1$ )	62% ( $n = 5$ )
Owns computer	75% ( $n = 3$ )	75% ( $n = 3$ )	100% ( $n = 7$ )
iPad	25% ( $n = 1$ )	25% ( $n = 1$ )	25% ( $n = 2$ )
Mobile phone	75% ( $n = 3$ )	75% ( $n = 3$ )	62% ( $n = 5$ )
Live in same residence	100% ( $n = 4$ )	100% ( $n = 4$ )	NA
Marital status married	100%	100%	NA
Children	75%	75%	NA

The mean age of the clinicians was 33 (*SD* 12) years ( $n = 7$ ), all were White non-Hispanic, with a postcollege education. All but one clinician was female. All clinicians worked full time; three clinicians were advanced practice nurses, two were BSN nurse clinicians, one was a pharmacist, and one was a dietician. All clinicians owned a computer (100%), two owned a iPad (22%), and six reported they had mobile phones (62%).

## 5.2 Deductive content analysis

### 5.2.1 Partners' usefulness of HF self-management education

The context for the partners' perspectives on usefulness of the iSCIP was their own experience living with HF. The partners stated the self-management educational content (monitoring symptoms, mobility and staying active, diets) was useful. However, they had difficulties managing symptoms of fatigue, depression and anxiety. The family caregivers stated they share the emotional burden of managing HF. For example, one caregiver stated that she struggles with her partner's depression, and another caregiver stated that his partner's difficulties have a "ten-fold" impact on him (see Table 2. Partners' content themes).

Table 2. Partners' content themes

Content	Theme	Statements
Self-management education	Shared Burden	Caregiver G. <i>Her difficulties impact me ten-fold</i> Caregiver MH. <i>Sometimes I struggle when he's real depressed you know and he can be more of a challenge</i>
	Fatigue	Patient S. <i>I have more like just yeah severe fatigue would be more me</i> Patient A. <i>I'm horrible because, we used to go to Zumba five times a week. I'm just tired. I have trouble even walking</i>
	Depression	Patient S. <i>All my adult life I've had many bouts of severe depression. But I have to say in all honesty since the last time my defibrillator went off I haven't... I get a little anxious but I bounce back pretty fast</i>
	Anxiety	Caregiver MB. <i>He gets agitated easy, and I get agitated easy. We're trying</i>
	Need for nutritional guidance	<i>The dietitians do talk to you, okay. But really how they explain everything, it really doesn't do very much. You have to basically figure out, 'cause you're doing the cooking, you have to basically figure out how much salt is going to be in everything</i>
Shared Care	Shared communication	Patient S. <i>Before the visits, we kinda go over and like... But what's the questions we wanna ask ... I'm a frequent flier with a lot of different doctors, so... You know how you think of a question, "Next time I see Dr. so and so..." well then I write that down for my next visit, and I ask that question. And then before we go in, then we sit down and confer and... Years ago, I didn't like her going in with me, but it's so complex and so much information, you don't always absorb it all, and I'll hear things she didn't hear. She hears things I didn't hear, and then we confer afterwards...not having her go with me actually makes it harder on her</i>

Content	Theme	Statements
Shared Values	Value Not being a burden	<p>Caregiver MA. <i>When we call, we'll both be on a phone, and then we both hear it, and then maybe... And we say we're both on</i></p> <p>Caregiver G. <i>"Patient" tends to be very inconsistent, so her numbers continuously go up and down (based on Coumadin dose). So we see the doctor quite regularly to make sure that it's within range</i></p> <p>Patient R. <i>I should mention though when I go to the psychiatrist you come along.</i> Caregiver MB. <i>Oh yeah.</i> Patient R. <i>If I miss something she jumps right in and tells the psychiatrist.</i> Caregiver MB. <i>I do all the talking on the phone, and I can call his Medicare. I have that set up 'cause otherwise he wouldn't talk to them. He can't hear. So I have that all set up so I can handle it all</i></p>
	Value Autonomy.	<p>Caregiver MB. <i>Your burden on family, I am very, very against that. I don't want to be a burden on my kids, okay? I mean, they're always saying, "If you need help," I mean, they do come and do our gardening for us. But right now, I still don't want to lose my independence for doing things</i></p> <p>Caregiver. <i>When my mind goes, stick me somewhere (nursing home). I wouldn't want my children to take (care) of me at home, no</i></p> <p>Patient S. <i>I don't want to leave stuff for my kids... if I die or get so infirm, then my kids would have to deal with it</i></p>
	Value activities with family and friends	<p>Caregiver A. <i>Someplace it has to be the importance of the patient taking charge. You know that the caregiver is just there to assist</i></p> <p>Patient S: <i>Yeah like I can get helpful advice from others when dealing with problems. I realize how much emotional support and love I have from family and friends and everything and my wife and, you know like how you know blessed I really am</i></p>
Care preferences	Shared activities	<p>Caregiver A. <i>We always share activities (care preferences tasks)</i></p> <p>Caregiver G. <i>And in the beginning I would say that it was very, very stressful because I didn't really know what I was doing. I'm also well, retired, but then I'm not really because I'm patient's caregiver, which is a full-time job, taking care of her</i></p> <p>Caregiver A. <i>And a lot of it just comes down to kindness whether you're kind to one another...</i></p>
	Shared Symptom Monitoring	<p>Patient S. <i>Probably so many of the things that we do as a couple, we didn't start doing that right away. We kinda learned by trial and error and different... as you go along</i></p> <p>Patient R. <i>When I said, "I feel fine." At home. And you (caregiver) said, "No we better go." ... We found out I had a heart attack</i></p> <p>Patient S. <i>Then sometimes I don't want to tell her things because I don't want her to push the panic button</i></p> <p>Caregiver MA. <i>And we're still learning. I've been working with him for... It's been about, what, 20, almost 25 years since he had his first heart attack, but still, he wasn't worried about it, then as he got worse, he got more and more, but I think this time he really got scared</i></p>

Content	Theme	Statements
		<p>Caregiver MB. ....I keep track...of everything he eats. Now I'm keeping track of all his fluids, and he still has fluid in legs. We have to contact the doctor on that. Basically I'm controlling what he's eating</p> <p>Caregiver MA. I simply tell him he should weigh himself every morning. Sometimes he remembers, and I write it on the top of the page...I also tell him to keep his feet up, and when I walk in the kitchen and he's sitting on the chair with his feet down, I tell him, "Get your feet up." And I know I [irritate] the hell out of him...he'll call me the Gestapo because I say, "You shouldn't eat that." I worry</p>
Barriers to mobilising family and paid resources		<p>Caregiver MA. A daughter thought her mother might be missing her morning pills so they called to find out if they could hire somebody to come in to check on whether she's taking her pills. (The cost of this service) \$35/day is sometimes out of the question</p> <p>Caregiver. Our children live in different states so can not help out</p> <p>Caregiver MA. But I think just important, like for both of us would be like the diet counseling. You know, the dietitian. But that really that's not like covered by insurance, so that's not something that could be offered</p> <p>Patient, Well I visit her (sister) as often as I can but I'm very sad over it. She has no one in her immediate family can take her out of that home and take care of her. But she has to stay in there. It's very sad, very sad</p>
Care planning	Vulnerability of both care partners	<p>Caregiver. But then again right at the end are we still going to think how we thought back here? You know, we finally finalized our five wishes. What happens if the caregiver needs the help more than the other person and all of this factors into how we plan care.</p> <p>Caregiver A. It does not get easier with health issues, I would like a road map on what is ahead</p> <p>Patient S. I have to face the future as I'm going to be able to do less. I'm just trying to kind of hang on to what I have which isn't very much, and my function does keep going down with what I can do</p>
	Communication with family	<p>Patient R. Yeah. So I've been dealing with heart failure for a lot of years, and I think I communicate with everyone about it, and I'm doing what's necessary to stay healthy. You know, I'm not trying to make things worse, and as far as planning the future, sometimes I just take one day at a time</p> <p>Caregiver G. You want to discuss certain things. And yet you have difficulty because you want to try to keep that positiveness up and you want to kind of keep a good spirit up. So, right, there is a conflict there. And several times she said, you know, you're getting too analytical with me, you know, let's not go there. So, you know, so that is a difficult spot for a caregiver</p> <p>Caregiver M. Myself as a caregiver, I want to know what's exactly going on with him. I want straight answers and I want to know what I have to look forward to</p>

Content	Theme	Statements
Palliative care	Request for information about palliative care & prognosis	<p>Patient S. <i>Excuse me. What does (palliative care) mean?</i></p> <p>Patient R. <i>I was on transplant list. I don't know if they have plans for me in the future, I don't know</i></p> <p>Patient A. <i>But it's kind of hard for the patient because somebody will tell you're going to live five months. And then like Dr. says I should be out there Zumba dancing, you know, like I used to. So, you know, that's a conflict and you always have that thought</i></p> <p>Patient A. <i>I mean, I would do a heart transplant or I would do a heart monitor but they can't even do it for me because of my age and my heart problems. So here I am just on drugs</i></p> <p>Patient A. <i>Like when you think of us, we have a congestive heart failure, but yet we are not dying. When people think you're dying right away, you know, stuff like that</i></p> <p>Caregiver M. <i>One question I have is: when you have heart failure and then when you're doing well, are you still considered in heart failure, or having heart failure? I mean, once you have it do you just have it always?</i></p>
	Preference for information about prognosis	<p>Caregiver G. <i>You know, I got to keep this to myself, and we're together so I can't ask the doctor or the nurses certain questions (about prognosis)</i></p>
	Complex decision	<p>Patient S. <i>I'm kinda investigating ....end of life things, you know, like how far do you want somebody to go to keep you alive, etc. etc.? Is that partly what you're talking about?</i></p> <p>Patient A. <i>Do people ever say that you wanna have (life) support? I mean, when you're not doing well, do people actually say they wanna do that</i></p> <p>Patient RB. <i>There are some people out there that no matter how bad, life is better than not being there</i></p> <p>Caregiver M. <i>We don't wanna be on any life support. If there's no help in anything without life support, cut it off. That's the way we both look at it. If his quality of life is not good, what's the sense? If you have no quality of life, you're not there</i></p> <p>Caregiver. <i>Some people will accept the situation with the idea that tomorrow will be a better day. So that's also part of this too. That I will be willing to be with a low quality of life today with the idea that maybe tomorrow I'll be much better. So I don't know how you would work that in</i></p>

Partners identified a need for more information about how to follow low-salt diets both at home and when they eat out. For example, one caregiver stated: *The dietitians do talk to you, okay. But really how they explain everything, it really doesn't do very much. You have to basically figure out, "cause you're doing the cooking, you have to basically figure out how much salt is going to be in everything"* (see Table 2. Partners' content themes).

Partners shared in communicating with clinicians; both partners attended the patient's clinic appointments and both are on the telephone when they call the clinician. Shared

communication with clinicians was important due to the complexity of HF self-management. For example, one patient stated:

Before the visits, we kinda go over and like... But what's the questions we wanna ask ... I'm a frequent flier with a lot of different doctors, ... And then before we go in, we sit down and confer and... Years ago, I didn't like her going in with me, but it's so complex and so much information, you don't always absorb it all, and I'll hear things she didn't hear. She hears things I didn't hear, and then we confer afterwards... not having her go with me actually makes it harder on her (i.e., the caregiver).

(See Table [2](#). Partners' content themes).

#### 5.2.2 Partners: usefulness of shared care – values

Partners agreed that it was important to understand the patient's values. They were surprised that each partner perceived the patient's values differently. Themes related to values that emerged in the qualitative data were (i) not being a burden on the family, (ii) patient autonomy important when providing assistance and (iii) value for activities with family and friends (see Table [2](#). Partners' content themes). For example, one caregiver expressed her value “not to be a burden” in the following statement: *I don't want to be a burden on my kids, okay? I mean, they're always saying, “If you need help.”* Another caregiver stated the value for autonomy in the following way: *Someplace it has to be the importance of the patient taking charge, you know that the caregiver is just there to assist.* A statement supporting the importance of activities with family and friends is evident in the following statement by a person with HF: *I realize how much emotional support and love I have from family and friends and everything and my wife and, you know like how you know blessed I really am.*

#### 5.2.3 Partners: usefulness of shared care – preferences and care planning

A care preference represents the preferred assignment of a particular care task or self-management activity to someone who can assist. An example of a care preference question is: *who would you prefer to help you with taking medications?* The caregiver is asked a similar question: *Who do you think your partner wants to assist him/her with taking medications?* Care tasks can be assigned to identified persons or to categories, such as the caregiver, family and friends, or paid resources. These care preferences are the basis for the care-planning activity (Orsulic-Jeras et al., [2016](#)).

The partners' data supported the usefulness of care preferences and care-planning activities. Similar to past studies using preferences for care, the caregivers provided the majority of assistance (see Table [2](#). Partners' content themes). Partners stated that they mutually share in monitoring symptoms, following low-salt diets, adhering to medications and communicating with healthcare providers. They stated that managing HF was an ongoing process they learned to do together. For example, one person with HF stated: *Probably so many of the things that we do as a couple, we didn't start doing that right away. We kind of learned by trial and error and different... as you go along* (see Table [2](#). Partners' content themes).



Although partners felt it was important to explore assistance from family, friends and paid resources, they identified barriers to asking for assistance with care tasks. Examples of barriers were the value to not be a burden, children who live out of state and family and friends who do not understand the partner's situation. Barriers to paid resources were high cost, concern about quality of services and not meeting eligibility criteria for services. Partners felt that nursing homes were a last resort, if they become cognitively incapacitated. Partners reported negative experiences with family members admitted to a nursing home. For example, a person with HF stated:

Well I visit her (sister) as often as I can but I'm very sad over it. She has no one in her immediate family can take her out of that home and take care of her. But she has to stay in there. It's very sad, very sad (see Table 2).

Care-planning themes that emerged were: (i) vulnerability of both partners and (ii) communication with family. Partners discussed how the care plan will likely change because of the vulnerability of both partners and the possibility that both will need more assistance in the future. They stated it was important to communicate their care preferences to their family. They stated that future planning was useful because (i) things are not getting easier for them, (ii) they did not want to leave things for their children to do, and (iii) the patient's fatigue and dyspnoea make it progressively harder to engage in most care activities (see Table 2. Partners' content themes).

#### 5.2.4 Partners: need for palliative-care information

Although the partners were unclear about what palliative care involved, they were interested in learning more about future planning and palliative care as a treatment option. The following themes in the qualitative data supported the relevance of palliative care to the partners: (i) request for information about palliative care and prognosis, (ii) different needs for information about HF prognosis and (iii) palliative-care decisions are complex. Some participants asked for a definition of palliative care and were not sure about their prognosis. For example, one caregiver stated: *One question I have is: when you have heart failure and then when you're doing well, are you still considered in heart failure, or having heart failure? I mean, once you have it do you just have it always?* The complexity of choosing HF treatment options was evident in the following statements: *There are some people out there that no matter how bad, life is better than not being there.* Another HF person stated: *Do people ever say that you want to have (life) support? I mean, when you're not doing well, do people actually say they want to do that?* (See Table 2).

#### 5.2.5 Partners: acceptability of the iPad

Partners verbalised that they lack experience using computers and iPads, but that their children and grandchildren use them routinely. Partners had difficulties completing the QUIS survey, because they did not understand the questions. For example, one set of partners stated: *It wouldn't be useful to me and my wife to even fill this out.* Caregiver: *Because we don't have any computer tools between the two of us. You know, some of these questions I don't have any idea what they're even asking.* Another patient stated: *I'm almost a computer*

*illiterate*. However, the partners were interested in learning to use the iPad, if it facilitated their self-management and communication with their family. For example, one patient wanted to use the app to keep track of health appointments, this patient stated: *I'm almost a computer illiterate, but as an example, would this program or whatever, would you say, click on, say keep doctor and nurse appointment?* Another patient wanted to know whether other family members could access the shared-care app, this patient stated: *Okay, you've got this app, then you have like, your principal care giver or the very most important caregiver you have or whatever, but other people in the family, would they have access to this app or would they have an app, some way?*

In conclusion, the partners verbalised the self-management and shared-care components of the intervention were useful. Partners mutually engaged in self-management activities without assistance from others. They identified a need for more information about diet. Values (autonomy, not being a burden, activities with family and friends) were relevant to the partners' experience; however, these values can create barriers to asking for assistance. They had several unanswered questions about palliative care, their prognosis and treatment options. They stated that their healthcare decisions were complicated due to conflicting values for survival and quality of life.

#### 5.2.6 Clinicians: usefulness of self-management education

Clinicians' evaluated the iSCIP based on their experience managing heart failure patients. Clinicians stated that educational content was important. They identified that self-management education does not necessarily lead to the better patient self-management (see Table 3. Clinician Themes: Self-management education). Clinicians stated that patients do not recall or remember the patient education they provided. For example, a clinician stated the following: *There's many times that these patients who have been coming to our clinic for years and we go over the same thing every visit and they will say they've never heard of a low sodium diet or fluid restriction. And it's like I don't believe you. You can't say that, but that's how they are* (see Table 3. Clinician Themes: Self-management not ideal). Some identified barriers to self-management were a lack of money for healthy foods and medication, and patients feeling overwhelmed.

Table 3. Clinician content themes

Content	Theme	Statements
Self-management education	Self-management not ideal	<p>Clinician AS. <i>Barrier I think to people with heart failure, I think is the understanding component. I think you can say it until you're blue in the face and they might still not understand it</i></p> <p>Clinician M. <i>Most challenging aspect is because you see them so much, sometimes you get blue in the face and you feel like you're saying things over and over and over again and you're kind of a broken record...understanding that it's really important that they follow the medical treatment guidelines</i></p> <p>Clinician C. <i>There's many times that these patients who have been coming to our clinic for years and we go over the same thing every visit and they will say they've never heard of a low</i></p>

Content	Theme	Statements
Clinician Communication	Communication is not ideal	sodium diet or fluid restriction. And it's like I don't believe you. You can't say that, but that's how they are
		Clinician J. <i>The most frustrating is I feel bad for people who can't afford the healthy foods, who can't afford the medicines</i>
		Clinician T. <i>It's a lot of information. And sometimes I feel like we overwhelm our patients and you don't really take in it</i>
		Clinician Ph. <i>I think frustrating thing is when patients don't show up to appointments and I've done a lot of work to try and figure out what I can help optimize with their meds or what I can answer for them and then they just don't show up...I have yet to encounter a heart failure patient that doesn't have some sort of a question about their meds or at least something to learn about their meds</i>
Values	Useful discussion	Clinician A. <i>I think they don't always have a great understanding of how little things fit all together, right? So they tell one symptom to one person, and another symptom to another. And unless you ask that question directly in a specific way that they think relates to that one symptom</i>
	Clinician S. <i>A nurse is going to ask about how much was my weight, and how much did I take my medicine? And these are the same standard questions if she asks to them they'll answer the same way. Ask on a scale of 1-10 how well are your following your low sodium diet?</i>	
Care preferences and planning	Barrier to asking for help, not being a burden	Clinician A: <i>On the value side of things, I think I like the way that you had it set up, that caregiver one and then caregiver two (separately assess values) and then come together, because I think it's a good topic of discussion</i>
	Use to mobilise support for self-management	<p data-bbox="727 1184 1458 1276">Clinician C. <i>Many patients don't want to ask for help because they think they are being a burden. Afraid to ask family even if family willing</i></p> <p data-bbox="727 1293 1433 1419">Clinician C. <i>In care planning the list of things (care preferences) they haven't assigned, (the partners could) imagine who might help, start the process to get over fear of asking for help</i></p> <p data-bbox="727 1436 1471 1656">Clinician S. <i>Like they might not have anybody looking into healthy diets and they might not have anybody looking into how they're going to take their meds or something like that and they're just kind of doing it on their own. So if they come into the center that might be something where it might trigger the clinician saying okay we need to get a referral to dietary or to social work. I think that could be used as an intervention</i></p> <p data-bbox="727 1673 1471 1795">Clinician L. <i>With a care plan you're assigning these tasks to them or you know if it's all under them where they see problems or barriers ...you know, they know, this is going to be a struggle kind of like red light so we follow up with</i></p>

Content	Theme	Statements
		Clinician AS: <i>Yeah. I was thinking mainly like the future planning question. Like if your partner is not as sick as they could be, is care plan going to change as they get sicker?</i>
	Recommendations to add care preference tasks	Clinician S. <i>I would recommend is this would be a good time to identify who is going to be your healthcare power of attorney</i> Clinician P. <i>Medication management includes, Take medications, pick up medications from pharmacy, fill pillbox</i> Clinician A. <i>The discussion about if you're in hospice care do you want to be at home at the end of your life or in a hospice facility, but I think there's also the discussion would you ever want to be in a long term care facility. Would you ever want to go to a nursing home</i>
Palliative care	Prognostic information	Clinician S. <i>One partner may want to know and the other may not. And so that's an important question (about prognosis) to ask. And we don't have an exact answer, but we can give you a very good guesstimate. And so I think that's really important. It's an uncomfortable question (regarding prognosis) to ask for sure. And it's a uncomfortable answer to give. So it's important to have that discussion at least, ... I still think that it's an important discussion to have with your physician. And it may not be wise to just keep it in an app kind of a setting</i>
	Competing values add complexity to decision-making.	Clinician S. <i>So I think it's more about survival than quality of life. That's the question. Why would I want to do any of this if my quality of life won't improve? But if, you know, there (treatment) will be life-saving, I would think that would be something you'd want them to know</i>
	Palliative-care education	Clinician A. <i>I think maybe putting something in there about palliative care and what the role is? Some people hear palliative care and they think like end of life. Like we're saying you know they get a little confused about that</i> Clinician A. <i>We feel that palliative care should be brought up early on in the discussion and when they first come to the heart failure clinic, just so that the seed is planted that it is a chronic progressive disease</i>
	Deactivating Implantable Cardiac Defibrillator (ICD)	Clinician AS. <i>Yeah, because that's something (ICD) that we don't talk about until we get to that point. I mean it's not something you talk about right in the beginning. I mean they're that sick at that point. That's when we have that discussion. And I don't know that they can grasp it at that point</i>

Clinicians stated that clinician–partner communication is also less than ideal. Communication challenges include patients not showing up for appointments and their inability to correctly report symptoms (see Table 3. Clinician content themes: *Clinician Communication*). Clinicians suggested that patient–provider communication could improve when clinicians consistently asked each patient standard questions about HF symptoms, and when patients write nonurgent questions in a log and ask these questions at their appointments.

### 5.2.7 Clinicians: usefulness of care values

Clinicians stated that patient care values were important for the partners to discuss (see Table 3. Clinician Themes: Values). Similar to the partners, the clinicians reported that the patient's value for not being a burden creates a barrier to asking for help, even when family is willing to assist. For example, a clinician stated: *Many patients don't want to ask for help because they think they are being a burden. Afraid to ask family even if family is willing* (see Table 3. Clinician content themes: Values).

### 5.2.8 Clinicians: usefulness care preferences and planning

The clinicians' data supported the importance of care preferences and care-planning content for partners. Clinicians stated the care plan would help them to assess the person's social support and mobilise support when the person had challenges with adhering to diets, adhering to medications, and unplanned hospitalisations. For example, one clinician stated: *In care planning the list of things (care preferences) they haven't assigned, (they could) imagine who might help, start the process to get over fear of asking for help.* (See Table 3. Clinician Themes: Care preferences and planning). The clinicians stated mobilising social support to improve self-management might well increase the likelihood that the patient could stay at home and decrease unplanned hospitalisation.

The dietician stated the care preferences and plan would help her know who is assisting the patient with meals and to include that person in her teaching. Clinicians recommended that the following tasks be added to the care preference list: healthcare power of attorney, obtaining medications, setting up medications, and monitoring and reporting side effects (see Table 3. Clinician Themes: Care preferences and planning).

The clinicians discussed several benefits of care planning. The care-planning process could start a conversation about palliative care as a treatment option and help the patient get over the fear of asking for help. The care plan would also provide a way to assess the patient's social support and refer partners who lacked social support. For example, if there were inadequate resources to assist the patient with care tasks, a social service referral could be initiated. Clinicians believed that there is no ideal care plan, and care plans will change as situations change. The clinicians believed that the iSCIP could potentially improve self-management and social support and that improved self-management and social support would contribute to cost savings downstream.

### 5.2.9 Clinicians: usefulness of palliative-care discussion

Clinicians agreed that palliative care needed to be introduced earlier in care. Like the partners, clinicians stated that palliative-care decision-making is complicated due to a need to balance the outcomes related to survival and quality of life. For example, one clinician stated:

Why would I want to do any of this if my quality of life won't improve? But if, you know, the (treatment) will be life-saving, I would think that would be something you'd want them to know.

Clinicians stated it was important to start the palliative-care conversation earlier in the treatment of HF. For example, one clinician stated: *We feel that palliative care should be brought up early on in the discussion and when they first come to the heart failure clinic, just so that the seed is planted that it is a chronic progressive disease* (see Table 3. Clinician Themes: Palliative care).

Clinicians stated that palliative-care decision-making requires understanding the patient's prognosis; they use the Seattle Heart Failure Model to predict the patient's survival (Levy et al., 2006). However, not all partners want information about prognosis. For example, one clinician stated: *One partner may want to know (the prognosis) and the other may not*. Thus, it is important to first assess whether the individual wants to know their prognosis, prior to providing this information.

The clinicians also stated a conversation with the patient about implantable cardiac defibrillator (ICD) deactivation needs to be introduced earlier in treatment. The clinicians discussed several empirical indicators that indicated the patient's value for palliative care. For example, one clinician stated she would consider palliative care as an option if a patient preferred their care be provided at home and not in the hospital.

Clinicians made recommendations to add educational materials to the intervention. For example, the dietician recommended utilising the cardiac rehab dietician for recipes, and websites with restaurant menus and food values, and a website related to the Mediterranean diet (i.e., Oldways Mediterranean diet <http://oldwayspt.org>). Clinicians recommended utilising the organisation's educational materials related to prognosis and deactivating an ICD.

#### 5.2.10 Clinicians: iPad usability

In contrast to partners, clinicians had more experience with computers and iPads. Clinicians were able to understand the QUIS survey questions. They felt the prototype app used to organise the iSCIP was acceptable, and it would be helpful to access intervention materials on an iPad. The QUIS average score for acceptability of the prototype app was 6.8 (*SD* 1.8) (range 0–9 higher score better). Clinicians made recommendations for improving the app, such as including partners' names, password protection and user authentication, and the ability to print materials.

In conclusion, clinicians believed the intervention was useful in practice and provided a way to introduce palliative-care conversations earlier. They believed that HF self-management education does not necessarily result in better self-management. However, developing a care plan that mobilised social support for partners having self-management difficulties could enhance self-management, decrease hospital readmissions and decrease healthcare costs. They suggested resources that could be used to enhance self-management education.

#### 5.2.11 Group comparison statistics for self-management education and shared-care scales

To render a more complete understanding of the usefulness of the self-management education and shared-care materials, we analysed the numeric data. Table 4 shows descriptive statistics

(mean, median, standard deviation, range) for the HF self-management and shared-care scales for the whole sample and for each group. The median score for the shared-care scale components was 2.50 (mean = 2.55, *SD* = 0.12) for partners and 2.53 (mean = 2.53, *SD* = 0.29) for clinicians. The HF management median score was 2.62 (mean = 2.58, *SD* = 0.39) for the partners and 2.37 (mean = 2.41, *SD* = 0.37) for the clinicians (see Table 4). These scores support our qualitative analysis, in that they indicated both groups perceived that iSCIP components were useful (2) to very useful (3). The correlation between scales ( $r = 0.45$ ,  $p = .11$ , 95% CI = [-0.11, 0.79]) shows a medium positive linear relation between them; as one component score increases, the other component score also increases.

Table 4. Shared care & HF self-management scale descriptive statistics

Scale	Group	Mean	Median	<i>SD</i>	Range
Shared Care	All	2.54	2.50	0.23	2.08, 3.00
HF self-management	All	2.48	2.50	0.37	2.00, 3.00
Shared Care	Partners	2.55	2.50	0.12	2.44, 2.77
HF self-management	Partners	2.58	2.62	0.39	2.14, 3.00
Shared Care	Clinicians	2.53	2.53	0.29	2.08, 3.00
HF self-management	Clinicians	2.41	2.37	0.37	2.00, 3.00

- 0 = not useful, 1 = a little useful, 2 = useful, 3 = very useful.

Table 5 presents the group comparisons of mean difference and their respective effect size (standardised mean difference, Cohen *d*). As expected with a small sample, the differences are not distinguishable from 0, as their CI (credible intervals) include 0 for both components. Credible intervals (CI) represent the 95% interval of the posterior distribution for each parameter; the posterior distribution is the distribution of the parameter in the population based on the information given by the data. The 95% CI is interpreted as there is 95% probability the parameter in the population is between the CI given the data. Looking at effect size lets us identify how meaningful the differences are. For the shared-care component, both mean difference and effect size indicate that the difference is functionally 0 with a minimum effect size. For the HF self-management component, the effect size indicates a moderate difference between groups ( $d = 0.42$ ,  $SD = 0.53$ , 95% CI = [-0.63, 1.49]), where the partner group perceived HF self-management components more useful than did the clinicians (see Table 5).

Table 5. Group comparisons of mean difference and effect size

Component	MD ( <i>SD</i> )	MD 95% CI	<i>D</i> ( <i>SD</i> )	<i>d</i> 95% CI
Shared Care	0.02 (0.27)	-0.26, 0.32	0.08 (0.53)	-0.98, 1.13
HF self-management	0.17 (0.43)	-0.29, 0.65	0.42 (0.53)	-0.63, 1.49

- MD, mean difference; *SD*, standard deviation; CI, credible interval; *d*, Cohen *d*.
- 0 = not useful, 1 = a little useful, 2 = useful, 3 = very useful.

### 5.3 Limitations

The following limitations of this study are recognised. First, due to qualitative methods used, causality cannot be assumed. However, the results of this study will inform a fully powered clinical trial, to determine the effectiveness of the iSCIP. Second, most participants were a select group of non-Hispanic White individuals, so the usefulness of the iSCIP needs further evaluation with individuals from diverse racial and ethnic populations and with other chronic conditions. This study reflected the experience of partners who have mutually participated in HF self-management for several years. However, other partners who engage in HF self-management may also benefit from exploring their care values, preferences and planning for the future.

Our clinicians were HF specialist and may not represent clinicians in nonspecialty community health clinics. However, other clinicians interested in improving self-management skills and introducing palliative conversations earlier in the HF trajectory may find that assessing the patient's care preferences helpful in mobilising their social support. Clinicians may also find that discussing care values, preferences and future care is a way to start a palliative-care conversation.

## 6 DISCUSSION

This study adds to the growing evidence of the feasibility and acceptability of programs that address care values and preferences and supports the utility of care planning for a variety of partners managing HF and dementia (Orsulic-Jeras et al., [2016](#); Sebern & Woda, [2012](#)). The iSCIP was acceptable and useful to stakeholders. In the current study, clinicians had more confidence in using the iPad app prototype compared to the partners; however, the partners were willing to learn to use the app if it would benefit them. This finding suggests that partners may need more coaching compared to the clinicians in the use of new technologies.

An interesting finding was that partners perceived self-management education as more useful than did clinicians. This finding could be understood as reflecting the different contexts of clinicians and partners. The clinician's context was educating persons with HF; however, better self-management did not necessarily result from their education, and this leads to frustration with self-management education. The partners' context was using the educational materials to assist them in self-management. As both partners shared the self-management activities, they may have viewed the self-management education as more useful. A practice implication from this finding is that clinicians may be reassured that partners value self-management education even when self-management behaviours are less than ideal. In addition, both partners could be included in educational sessions and clinic visits. International practice guidelines support the inclusion of both partners in HF self-management education and palliative-care planning (McMurray et al., [2012](#)).

Partners identified limitations in self-management educational materials related to following low-salt diets and difficulties with symptoms of dyspnoea, fatigue, anxiety and depression. When these difficulties arise in practice, a palliative-care consult could be made to assist the



partners with distressing symptoms and to simplify treatment. Because partners in this study indicated a lack of knowledge about their prognosis and palliative care, it is important to make sure partners want to know their prognosis and understand what palliative care is when a referral is made.

Schulman-Green and colleagues ([2012](#)) reported that mobilising social support is an essential process for self-management of a chronic illness. Clinicians believed care preferences and planning activities could be used in practice to assess the person's social support and to mobilise social support in persons having difficulties adhering to treatment or frequent hospitalisation. For example, if self-management is less than ideal, then social support could be mobilised by asking the person with HF who they prefer assists them with specific self-management activities (i.e., caregiver, family or paid resources) and develop a plan to include that resource in their care.

While evidence-based research supports introducing palliative care early in the trajectory of HF, in actual practice palliative care is seldom introduced until late in the disease (Ghashghaei, Yousefzai, & Adler, [2016](#)). Results from this study suggested that iSCIP strategies could serve as guide for starting the palliative-care conversation earlier in care. In addition to providing standard HF self-management education, clinicians could ask the partners what are their important care values and how their values affect decisions about care now and in the future. For example, if the patient values not being a burden, ask them how this value could influence their decision to rely solely on the caregiver for assistance in the future?

Finally, the work reported here, which applies technology to facilitate delivery of the iSCIP, may also serve as a model for development of software applications that go beyond the typical functions of information access and data gathering, to play a more direct and central role in supporting partners and clinicians in achieving improved quality-of-life outcomes. When new technologies are developed, similar evaluation methods can be used to elicit feedback from stakeholders about the usefulness and acceptability of the intervention and supporting technology.

## 7 CONCLUSION

Improving quality of life for both HF partners is important to reducing the global burden of disease in this population. The iSCIP takes a partner-centred approach to address three preventable causes of poor outcomes in this population: poor self-management, inadequate social support and underutilisation of palliative care. The findings from this study can be used as a guide for developing interventions that involve both partners in care and palliative-care conversations. Further clinical testing of the iSCIP is being conducted to assess partners' ability to use the iPad app and to evaluate the effect of the intervention on self-management, social support, quality of life and utilisation of health resources including palliative care.

## 7.1 Relevance to clinical practice

This study adds to the growing evidence of the feasibility and acceptability of programs that address care values and preferences, and care planning. The findings highlight the importance of engaging both partners in care and palliative-care conversations to improve self-management, social support and utilisation of palliative care. Although our stakeholders were mostly White and from a HF specialty clinic, our findings could provide guidance in developing interventions for stakeholders who are challenged by less than ideal HF self-management and under utilisation of palliative care. For example, if self-management is less than ideal, then social support could be mobilised by asking the person with HF who they prefer assists them with specific self-management activities. Finally, it is important to evaluate the acceptability of technology with stakeholders prior to introduction to practice. One way to do this is to assess perceived usefulness of the technology in a clinical setting. Once benefits and barriers to use of the technology are known, strategies can be developed to facilitate transfer of technology to practice.

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## CONFLICT OF INTEREST

Dr. Margaret Sebern and Dr. Mark Sebern have a significant interest in Ensemble 74 LLC, the company that developed the iPad app for the iPad Shared Care Intervention for Partners.

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