

# Development of a supportive care intervention for caregivers of patients undergoing hematopoietic stem cell transplantation: The Ready to CARE program



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## BACKGROUND

Hematopoietic stem cell transplantation (HSCT) is a lengthy treatment for cancer that requires the presence of a family caregiver. Existing interventions for caregivers provide education on caregiving or self-management training on fixed topics. Unfortunately, those programs generally have low uptake and modest effects.

## OBJECTIVE

The goal of this research is to develop a pragmatic, replicable intervention that promotes the health and well-being of the caregiver-HSCT patient dyad.

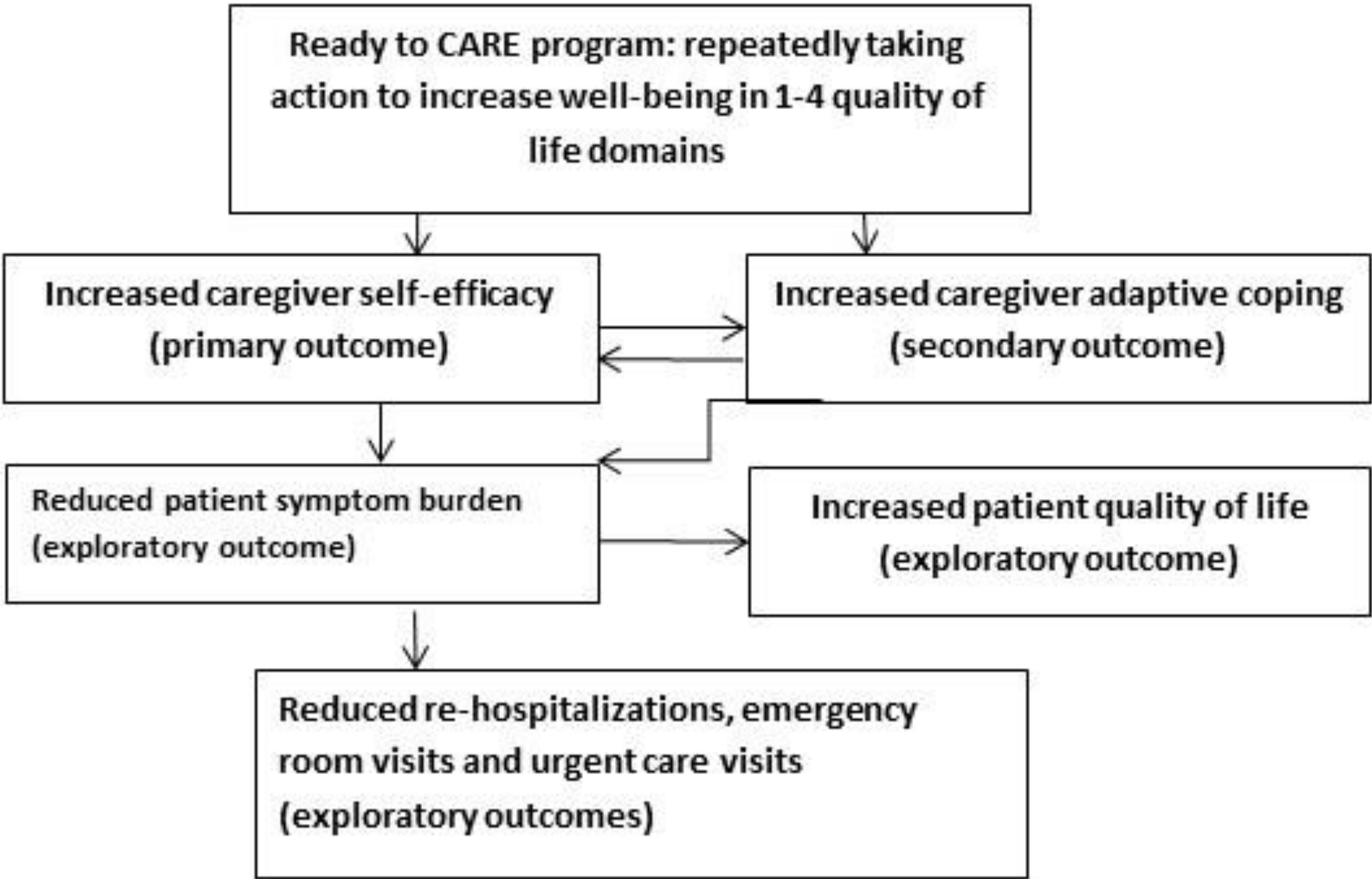
## INTERVENTION DEVELOPMENT

In the first phase of this study, 17 caregivers participated in a semi-structured interview to explore their needs and preferences for supportive care. The participants uniformly reported receiving adequate information about how to monitor symptoms and complications and how to support the HSCT patient.

However, they reported distress related to commuting, nutrition, housekeeping, uncertainty, helplessness, worry, organization, planning, and social isolation. Many reported neglecting their own self-care because of the time demands and “all encompassing” nature of caregiving. In order to meet the needs of our caregivers we designed an intervention that was:

- Participant-directed: Instead of a fixed curriculum, allow the caregiver to identify what he or she wants to work on
- Experiential: Instead of purely didactic include: Practice and action planning for independent practice

## INTERVENTION TARGETS AND OUTCOMES



### The Ready to CARE Program

**CARE: Connect, Actively Relax and Exercise**

- Connect to information, resources, and social support
- Encourage active stress management
- Encourage exercise

Program consisted of:

- 6 sessions (primarily while patient is hospitalized for re-infusion)
- Individual goal setting, action planning, and practice of activities to minimize stressors and maximize buffers in areas of:
  1. Physical well-being
  2. Psychological well-being
  3. Social well-being
  4. Spiritual well-being

### Building Buffers and Reducing Stressors



Taken from the Ready to CARE Intervention Manual: “Stressors are a natural part of life. Every day is guaranteed to contain small challenges to which we need to respond. Of course, when anyone in our family is experiencing a health issue, we often have more stressors, and they can be bigger or more troubling to us. Buffers are a natural part of life, too. Buffers are like stockpiles of energy, hope, or power that can help you deal with the stressors that come up. Buffers, such as good physical or mental health, provide a “cushion” so that stressors do not affect you as greatly. In this program, we want to “inflate” your core buffers so that you have a healthy stockpile of well-being and resilience to draw upon when dealing with stressors.”

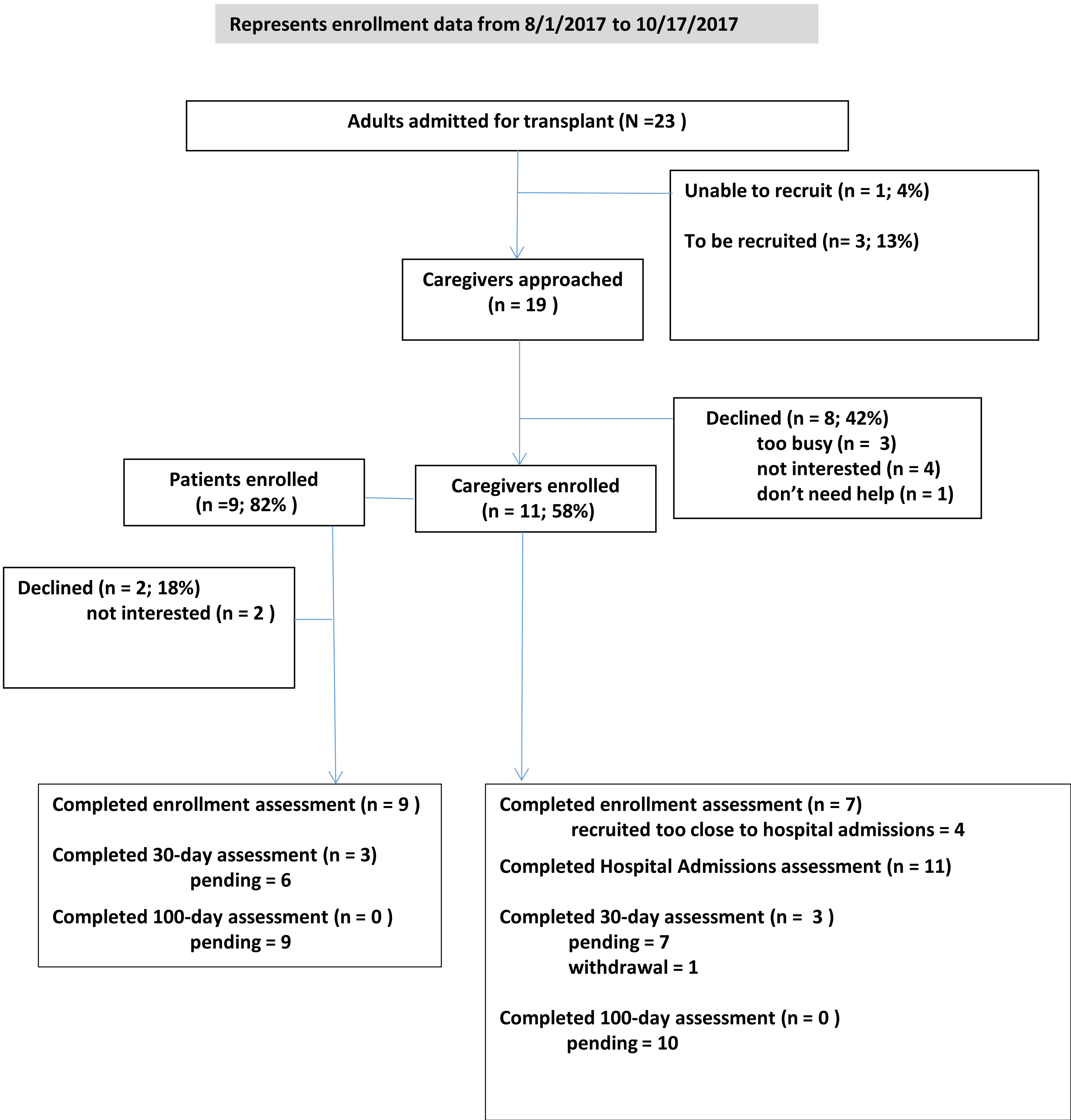
### ACKNOWLEDGEMENTS:

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## METHODS

In the current pilot study, 20 caregiver and patient dyads will test the Ready to CARE program. The aims of the second phase are to determine (1) the program’s feasibility and acceptability and (2) if there is evidence to suggest it increases caregivers’ self-efficacy and adaptive coping skills and improves patients’ health and wellness. Enrollment and data collection are ongoing.

### Feasibility of Study Procedures



## SUMMARY

Many caregivers of HSCT patients report elevated distress and strain as they fulfill their usual and new roles within the family. Literature review and caregiver feedback were used to develop the Ready to CARE intervention. The person-directed, experiential, self-care intervention is currently being pilot tested. Quantitative outcomes will be compared to historical controls, and the intervention will be refined to maximize feasibility and acceptability before efficacy testing.