*Original Article*

# Use of the Preparedness for Caregiving Scale in Palliative Care: A Rasch Evaluation Study

Anette Henriksson, PhD, RN, Peter Hudson, PhD, Joakim Öhlen, PhD, Kristina Thomas, DPsych, Maja Holm, PhD(C), Ida Carlander, PhD, Peter Hagell, PhD, and Kristofer Årestedt, PhD

*Palliative Research Centre and Department of Health Care Sciences (A.H., J.Ö., M.H.), Ersta Sköndal University College, Stockholm, Sweden; Centre for Palliative Care (P.Hu., K.T.), St. Vincent's Hospital and Collaborative Centre of The University of Melbourne, Fitzroy, Victoria, Australia; Department of Learning, Informatics, Management and Ethics (I.C.), Karolinska Institutet, Stockholm, Sweden; The PRO-CARE Group (P.Ha.), School of Health and Society, Kristianstad University, Kristianstad, Sweden; and Center for Collaborative Palliative Care (K.Å.), Linnaeus University, Kalmar, Sweden*

## Abstract

**Context.** Studies have shown that family carers who feel more prepared for the caregiver role tend to have more favorable experiences. Valid and reliable methods are needed to identify family carers who may be less prepared for the role of supporting a person who needs palliative care.

**Objectives.** The aim of this study was to evaluate the measurement properties of the original English version and a Swedish version of the Preparedness for Caregiving Scale (PCS).

**Methods.** The sample ($n = 674$) was taken from four different intervention studies from Australia and Sweden, all focused on improving family carers' feelings of preparedness. Family carers of patients receiving palliative home care were selected, and baseline data were used. The measurement properties of the PCS were evaluated using the Rasch model.

**Results.** Both the English and Swedish versions of the PCS exhibit sound measurement properties according to the Rasch model. The items in the PCS captured different levels of preparedness. The response categories were appropriate and corresponded to the level of preparedness. No significant differential item functioning for age and sex was detected. Three items demonstrated differential item functioning by language but did not impact interpretation of scores. Reliability was high (>0.90) according to the Person Separation Index.

**Conclusion.** The PCS is valid for use among family carers in palliative care. Data provide support for its use across age and gender groups as well as across the two language versions. J Pain Symptom Manage 2015;50:533–541. 

***Key Words***

*Family carer, palliative care, preparedness, psychometrics, Rasch, validation studies*

## Introduction

Most people with incurable illness prefer to be cared for at home. Home care is largely dependent on family carers who provide a substantial part of the caregiving,[1–3] and without this support, their relatives would typically not be able to remain at home. Family carers, therefore, play a vital role. Within the context of palliative care, they have been defined as a relative, friend, or partner who has a significant relationship with, and provides physical, social, and/or psychological assistances to, a person with incurable illness.[4]

Supporting a family member requiring palliative care at home is a complex role involving new tasks

*Address correspondence to:* Anette Henriksson, PhD, RN, Palliative Research Centre, Ersta Sköndal University College and Ersta Hospital, Folkungagatann 121, Box 11189, 10061 Stockholm, Sweden. E-mail: anette.henriksson@esh.se

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and responsibilities for which family carers often feel insufficiently prepared. This commonly results in negative effects on their health and well-being, such as stress, anxiety, fear, guilt, and sleep disturbances.[3,5–9] Studies have shown that feelings of preparedness can influence the caregiving experience and protect against negative consequences for family carers.[10,11] Preparedness has been defined as something done before a crisis to improve the response. It has been described as a condition or activity to foresee potential problems and project possible solutions and involves the building of abilities and capabilities.[12,13] Preparedness for caregiving involves a perceived readiness to manage the domains of the caregiving role, such as providing physical care and emotional support, setting up care in the home, and dealing with the stresses of caregiving. It is an anticipatory concept that allows family carers to assess their readiness in advance.[14,15] Recent studies demonstrate that preparedness for caregiving should be seen as an ongoing and nonlinear process that takes place continuously, as changes in the patient's condition force family carers to prepare for additional contingencies.[16,17] In palliative care, it has been found that more prepared family carers feel more rewarded by their caregiving role, with a higher sense of hope and less anxiety.[18–20] Family carers who feel prepared experience less worry, fewer mood disturbances, and decreased levels of depression and burden.[14,19–22] Feelings of preparedness also may protect carers from perceiving caregiving as becoming increasingly difficult as demand increases.[10]

Valid and reliable methods are needed to identify those family carers who may be less prepared for the role of supporting a person who needs palliative care. One promising scale to assess needs and also to evaluate interventions to meet these needs is the Preparedness for Caregiving Scale (PCS).[14] It was originally developed in the U.S. for use among family carers of frail elderly persons living at home but has been used among family carers of patients within the context of palliative care.[23,24]

The PCS has demonstrated good measurement properties; however, previous studies primarily evaluated the factor structure and internal consistency.[25,26] For an increased understanding and interpretation of the PCS scores, other significant aspects of measurement properties need to be evaluated. It is important to ensure that items in the scale capture different levels of preparedness and that response categories correspond to the level of preparedness. Another aspect, often overlooked, is to evaluate if group belongings bias item responses. In addition, international comparisons concerning these aspects are needed to determine if the PCS is valid across different countries and languages. Given this background, the aim of this study was to evaluate measurement properties of the original English version and a Swedish version of the PCS using the Rasch model.

## Methods

### Design

This was a psychometric evaluation study, comparing the original and a Swedish version of the PCS in Australian and Swedish samples.

### Sample and Procedure

The sample for the present study was taken from four different intervention studies focusing on improving the family carers' feelings of preparedness. Two of the studies were conducted in Australia and included a total of 361 family carers.[20,27] The other two took place in Sweden and included a total of 317 family carers.[16,23] In summary, the samples comprised adult English- or Swedish-speaking family carers of patients receiving home-based palliative care. Time in the caregiving role varied between samples, with a median of four and 12 months in Australia and four and four months in Sweden. Palliative specialist multiprofessional teams provided care 24 hours per day. The studies had ethical approval from the St. Vincent Health Human Research Ethics Committee (095/07) in Australia and the Ethical Review Board in Stockholm, Sweden (2008/341 and 2012/377). For this study, baseline data were used to evaluate the PCS. Four of the participants from the Australian studies had missing data in all items of the PCS and were excluded. Therefore, the final sample consisted of 674 family carers.

### Data Collection

Data were collected using self-reported questionnaires including the PCS. The PCS comprises eight items, each responded to on a five-point Likert-type scale, ranging from not at all prepared (0) to very well prepared (4). A total score ranging from 0 to 32 is calculated by summing the responses for all items, with a higher score indicating more feelings of preparedness.[14] Sociodemographic information also was collected regarding sex, age, education, living conditions, and relation to the patient.

### Psychometric Evaluation

Descriptive statistics were used to evaluate data quality in terms of scored distribution and patterns of missing data. To test if data were missing completely at random (MCAR), Little's MCAR test was conducted.[28]