

Original Article

Cite this article: D'Angelo D, Mastroianni C, Artico M, Biagioli V, Latina R, Guarda M, Piredda M, De Marinis MG (2019). Validity and reliability of the Palliative Care Transition Measure for Caregivers (PCTM-C). *Palliative and Supportive Care* **17**, 202–207. <https://doi.org/10.1017/S1478951517001225>

Received: 14 June 2017

Revised: 18 November 2017

Accepted: 28 November 2017

Key words:

Care transition; palliative care; family caregivers; psychometrics; measurement

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Abstract

Objective. Patients suffering from advanced disease face different care transitions. The transition from acute to palliative care is challenging and may lead to the discontinuity of care. Family caregivers become important sources of information, as patients begin to experience difficulties in coping with emotional transition events. The Care Transition Measure was developed to evaluate care transitions as experienced by the elderly. It has never been used in palliative care. The aim of this study was to test the validity and reliability of a modified version of the Palliative Care Transition Measure, specifically the Palliative Care Transition Measure for Caregivers (PCTM-C).

Method. The study included two main phases. Phase I focused on the construction of a modified version of the Palliative Care Transition Measure through two focus groups and by computing the content validity index. Phase II focused on testing the psychometric properties of the PCTM-C on 272 family caregivers through confirmatory factor analysis.

Result. The content validity index for each of the items was higher than 0.80, whereas that for the scale was 0.95. The model tested with confirmatory factor analysis fitted the data well and confirmed that the transition measures referred to communication, integrated care and a trusting-relationship, and therefore the core dimensions of continuity according to existing conceptual models. The internal consistency was high (Cronbach's alpha = 0.94).

Significance of results. The PCTM-C proved to be a suitable measure of the quality of such transitions. It may be used in clinical practice as a continuity quality indicator and has the potential to guide interventions to enhance family caregivers' experience of care continuity.

Introduction

Patients with complex care needs are often required to be cared for by different health professionals in multiple settings (Coleman, 2003). Changes in the setting and/or the clinicians involved in the healthcare process are classified as transitions (Schumacher & Meleis, 1994). The transition of patients from acute care to palliative care is one of the most challenging aspects for health services because transition can lead to the discontinuity of care, service duplication, medical errors, and inappropriate care (Coleman & Boulton, 2003).

In particular, the transition from curative to palliative care merits greater attention because of the extreme vulnerability of the patients involved (Ryndes & Emanuel, 2003). The World Health Organization defines palliative care as “a multidisciplinary approach that improves the quality of life of patients and their families facing the challenges associated with a life-threatening illness” (WHO, 2017). Palliative care should begin at the earliest stages of the trajectory of a life-threatening illness simultaneously with treatments that are intended to extend life. Palliative care can be delivered at primary and secondary care levels, or in specialist palliative care services that include integrated services such as medical consultation, home care, and residential care (Payne & Radbruch, 2009).

Despite the imperative to provide palliative care throughout the course of an illness, it certainly has a more prominent role when a patient's disease advances and there is less to be achieved in terms of life prolongation (Robinson et al., 2016). The transition to a specialist palliative care service is necessary to ensure the maximum focus on meticulous symptom control, comfort, psychosocial and spiritual support, and bereavement care (Sutherland, 2009).

During the transition from acute to palliative care, patients and families usually experience a shift of focus from the hope for a cure, to a hope for the elimination of suffering, as the patient suddenly faces a progressive and fatal illness. This change in expectation can be associated with feelings of a loss of control for both patients and families (Back et al., 2009).

Although clinical evidence has demonstrated the benefit of a well-managed and smooth transition to palliative care in terms of quality of life and psychosocial well-being (Kirby et al., 2014), the transition to palliative care is a process that has not been studied extensively (Marsella, 2009; Rocio et al., 2017) and the transition of terminally ill patients is a challenging aspect of clinical work. However, current evidence suggests that continuity of care is the best way to ensure effective palliative care transitions, while also enhancing the quality of the time left to live for patients and their caregivers (Gardiner et al., 2015; Hamano et al., 2017).

Several studies have focused on the continuity of care at life end (Bakitas et al., 2010; Corrales-Nevedo et al., 2012). In particular, a conceptual model (D'Angelo et al., 2015) exists that captures the elements of continuity of care during end of life (Haggerty et al., 2003). This model explains how the quality of a transition can be enhanced through careful information transfer, a trusting relationship, and by guaranteeing that flexible care is able to meet patients' and caregivers' changing needs throughout the progression of a life-threatening illness.

To implement an appropriate plan of care, there is a need for a better understanding of the transition phenomenon through its accurate appraisal. However, to date, no instrument has been available to evaluate the transition from curative treatment to palliative care (Hanson et al., 2010; Lofmark et al., 2007; Schenck et al., 2014).

Among the tools developed to assess transition, the Care Transition Measure (CTM) was psychometrically tested and extensively used with older patients who had experienced care transitions (Coleman et al., 2002, 2005). It was used to evaluate the quality of "transitional care" in a large number of American centers, although it has not been specifically tested for use in the transition to palliative care (Hanson et al., 2010). The CTM was developed as a patient self-report measure. It underlines that discussion between healthcare professionals and patients is essential to foster an anticipatory preparation based on clarifications on what to expect during the transition (Broom et al., 2013; Schofield et al., 2006).

Because the communication between terminally ill patients and healthcare providers is often less than optimal (Coleman et al., 2015), clinicians find it difficult to communicate bad news (Horlait et al., 2016); therefore, family caregivers, who are closely involved in patient care, represent a reference point for healthcare providers, to plan advanced care. Moreover, often when direct patient information is hard to collect, it is the caregivers that are the most reliable source of information (Coleman & Roman, 2015; Peruselli et al., 1997). When this situation arises, assessing the quality of a palliative care transition from the caregiver's perspective is of paramount importance. Furthermore, in Italy, although specialist palliative care services are progressively increasing the application of the "continuum of care" model during illness progression, further improvement is required. Hence, it is not surprising that for those patients who require palliative care, the transition to a specialist palliative care setting represents the predominant way to be cared for (Italian Ministry of Health, 2015).

The purpose of this study was to test the psychometric properties of the Palliative Care Transition Measure for Caregivers (PCTM-C), as modified from the Care Transition Measure as used for patients.

Methods

To establish the psychometric properties of the CTM as modified for palliative care, two main phases were followed. Phase I focused on the

construction of the modified Italian version of the instrument, whereas Phase II focused on testing its psychometric properties.

Phase I

Development of the PCTM-C

In the first phase, the original CTM was translated into Italian. Content validity of this Italian version was evaluated through focus groups and by calculating the content validity index. A first focus group was conducted with two caregivers who had recently experienced palliative care transitions, two oncology nurses, two palliative nurses, and two palliative physicians. The participants evaluated whether, in their opinion, the items of the CTM appropriately addressed the family caregivers' experiences of the transition from acute care to palliative care. After feedback from the panel of experts the CTM was modified.

In a second focus group, the same participants were asked to judge whether the items of the modified CTM were understandable and clearly defined.

Standard focus group techniques were adopted and the discussion was moderated by the principal researcher (DD), who encouraged participants to share their experiences. The scale was modified by rewording the items to assess the caregiver's perception rather than that of the patient (e.g., "before I left the hospital" was changed into "before my relative left the hospital"). Whenever possible, the sentences that focused on the self-care aspects that did not fit with the caregivers perspectives, were reformulated (e.g., "I had all the information I needed to be able to take care of myself" was changed into "I had all the necessary information about palliative care"; "I clearly understood the purpose for taking each of my medications" was changed into "I understood the general purpose of medications that would be prescribed in palliative care to my relative").

The items that detailed information such as how to take medications, the side effects of medications, the written list of appointments, and the written care plan were removed.

When patients are referred to a palliative care center, the information gathered should not be provided by the discharging team, but by the team that enrolls them. Because a paternalistic approach in which the clinical team usually takes health-related decisions by itself is still broadly used in Italy, we removed items that stressed the sharing of decision-making, and this reality may hinder the applicability of those items in our context.

In an effort to better address transitions from acute to palliative care, caregivers were asked about the timeliness of transitions, their feelings after a patient's discharge, and the negotiation process in regard to the goals of the care provided. More emphasis was given to feelings of trust towards the palliative care service with specific items focused on the patient's symptom management, and the caregiver's relief and support.

Content validity

The second step consisted of establishing the content validity of the pre-final version of the PCTM-C, using a rigorous judgment quantification process (Lynn, 1986), and the pre-final version of the scale was sent for content validity to an independent panel of eight experts (two palliative physicians, two oncologists, two nurses, a social worker, and a psychologist). They were asked to evaluate the relevance of each item of the modified CTM and of the whole CTM, using a Likert Scale from 1 = not relevant to 4 = very relevant, and to give comments and/or suggestions for modifications when appropriate. The response options were dichotomized according to the procedure by Lynn to compute the Content Validity Index (CVI) (Lynn, 1986).

Phase II

Psychometric testing

In the second phase of the study, the PCTM-C was tested for its psychometric properties. To evaluate the construct validity of the scale, confirmatory factor analysis (CFA) was used with MPlus (Muthén & Muthén, 1998-2012). The assumption underlying the transition model is that the quality of the transitional process is strongly connected with the continuity of the care experience (Gardiner et al., 2015). Thus, the components of the continuity of care model (D'Angelo et al., 2015), specifically communication, a trusting relationship, and integrated care, were hypothesized as the main dimensions of the scale to be confirmed through CFA. In addition, a second order factor was hypothesized to account for the holistic nature of the concept of continuity.

CFA was performed using the robust maximum likelihood estimator method, which produces standard maximum likelihood parameter estimates with corrected standard errors and chi-square test statistic robust to non-normality and to non-independence of observations. To evaluate the adequacy of the measurement model, the following fit indices and indicators of good fit were considered: Comparative Fit Index >0.95; Tucker and Lewis Index >0.95; root mean square error of approximation 0.05 to 0.08, $p < 0.05$; and standardized root mean square residual: <0.08 (Barbaranelli et al., 2015). The internal consistency was examined through the Cronbach's alpha coefficient.

Design

This was a cross-sectional validation study.

Setting and participants

The second phase of the study was conducted between July 2015 and April 2016 in three Italian palliative care centers in the north and center of Italy, respectively named "Madonna dell'Uliveto," "Antea Network," and "San Marco."

The participants were family caregivers of the patients that had transferred from an acute care to either of the palliative care centers involved in the study. Family caregivers were recruited if the patient was admitted to a palliative service for at least five days, and were identified by the healthcare providers who cared for the patient. In particular, given the specificity of the instrument to investigate factors related to the transitions from acute care to palliative care, the healthcare providers were instructed to pay careful attention to identify the primary caregiver involved in the transition process.

Other inclusion criteria included the requirement to be aged 18 years and older, a willingness to participate in the study, and the provision of a signed informed consent. Each caregiver completed the 15 items of the PCTM-C on a scoring system ranged from 1 (completely disagree) to 4 (completely agree). Lower scores indicate a poorer quality transition, and higher scores indicate a better transition experience. To obtain a user-friendly 0 to 100 score, we used the same formula outlined by Coleman et al. (2002).

Results

Phase I

Content validity of the PCTM-C

The pre-final version of the PCTM-C encompassed 15 items. The CVI for each item was higher than 0.80, whereas the average CVI

for the whole scale was 0.95. These results indicated a satisfactory agreement among the participating experts.

There was, however, a general concern voiced by the expert panel who evaluated the content validity regarding "not applicable" as a response choice combined with "do not know/do not remember." The researchers discussed these comments in depth and agreed that the presence of too many response choices might hinder the clarity and comprehensiveness of the items. It was felt that the term "not applicable" could cause confusion, and that it would be preferable to remove it.

Based on these comments, the researchers decided to withhold the pre-final version of the PCTM-C and to remove only the term "not applicable" from the response choices. The PCTM-C scale was finally drafted based on these results.

Phase II

Confirmatory factor analysis of the PCTM-C

Participants. A total of 272 family caregivers completed the questionnaire. The demographic characteristics of the sample are summarized in Table 1. The mean (SD) age of the participants was 54 (14); the majority (62%) were the patients' children or nephews. More than half of the respondents (64%) were employed and

Table 1. Socio-demographic characteristics of caregivers ($n = 272$)

Variable	Frequency (%)
Age (mean \pm SD; range)	54 \pm 14; 24-95
Gender	
Male	91 (33.7)
Female	179 (66.3)
Marital status	
Married-cohabitant	192 (71)
Unmarried	79 (29)
Relation to patients	
Spouse	69 (23.2)
Child/nephew	168 (61.8)
Other relative	41 (15.1)
Education	
< High school	53 (23)
High school	123 (53)
University graduate	56 (21)
Employment status	
Employed	163 (64)
Unemployed	91 (35)
Discharge destination in PC	
Residential care (hospice)	176 (66)
Home care	92 (34)
Relatives' diagnosis	
Cancer	225 (91.8)
Noncancer	20 (8.2)

PC, palliative care; SD, standard deviation.

had a high educational level (77%); their relative was diagnosed with cancer (91.8%).

Construct validity. The CFA confirmed that the data from the transition measure referred to the three dimensions of the continuity of care model with a good fit: chi-square (degrees of freedom 86, $N = 272$) = 158, $p < 0.001$; Comparative Fit Index = 0.95; Tucker and Lewis Index = 0.94; root mean square error of approximation = 0.056 (confidence interval_{90%} = 0.042–0.069) $p = 0.237$; standardized root mean square residual = 0.047. Figure 1 shows the CFA model with the statistically significant factor loadings for each individual item.

The correlations between each dimension were positive, high and significant at $p < 0.001$ (relationship with communication, $r = 0.61$; relationship with integrated care, $r = 0.66$; integrated care with communication, $r = 0.55$). Therefore a second-order factor including these dimensions was specified and named PCTM-C.

Reliability. Cronbach’s alpha coefficient was estimated at 0.94 for the total scale and for each factor: 0.88 (communication), 0.87 (integrated care) and 0.93 (trusting-relationship). Table 2 shows in detail the mean scores, skewness, and kurtosis for the PCTM-C items.

Discussion

Poorly negotiated palliative care transitions are the cause of avoidable medical errors, discontinuity of care, and re-admissions to hospital (Kaur & Mohanti, 2011). Health providers’ efforts to realize the transition to palliative care can lead to significant resistance from patients who are often reluctant or not yet ready to give up hope of a cure. Consequently, caregivers occupy a central position in motivating patients to begin the transition process from acute care to palliative care (Broom et al., 2015).

Although caregivers’ support has been advocated for quality palliative care, and Coleman (2015) recently developed a tool focused on family caregiver self-efficacy (Coleman et al., 2015), instruments that assess their perspectives are lacking (Hudson et al., 2010). To fill this critical gap, we have modified and tested

a measure to evaluate the quality of palliative care transition from the family caregivers’ perspectives. During the process of revising the CTM scale (Coleman et al., 2002) it was decided to significantly change it, and therefore perfect statistical comparisons among the new and the original version are no longer possible.

The items of the new measure (PCTM-C) were directly built on those factors that may influence the caregivers’ experience of palliative transitions (D’Angelo et al., 2015; Marsella, 2009), and careful attention has been paid to emphasize the collaborative efforts between team members (Back et al., 2009; Broom et al., 2013; Kirby et al., 2014). Because the overall palliative transition experience is more than simply a passage from one care setting to another (Duggleby & Berry, 2005), the coordination of interventions as well as smooth referrals may contribute to increase its quality. The new measurement of items such as the flow of information, sharing in decision-making, feelings of confidence, empowerment, and negotiation allows the level of care integration to be fully understood.

In accordance with these assumptions, the CFA confirmed the possibility of grouping the items into three factors (communication, a trusting relationship, and integrated care), which represent the essential elements for guaranteeing a high-quality transition (D’Angelo et al., 2015; Lofmark et al., 2007). This view embodies the three types of continuity of care; informational, relational, and managerial (Haggerty et al., 2003), and is a good continuity indicator (Breton et al., 2012) because it enables the capture of all aspects contributing to the overall sense of continuity (Gulliford et al., 2006). In line with the findings from other studies (Medigovich et al., 1999; Wong & Chan, 2007), this research included caregivers involved in the transition who were in their midlife and were facing different challenges, from meeting their relative’s changing needs to dealing with the demands of their social role (i.e., family, job).

Preventing caregivers’ physical and emotional strain is paramount, and it is also one of the best strategies for managing high-quality improvement in transitional care.

The aspects of care that family members rated as the poorest were those regarding communication. It is worth noting that breakdowns in communication mechanisms significantly predicted whether patients and caregivers experienced feeling

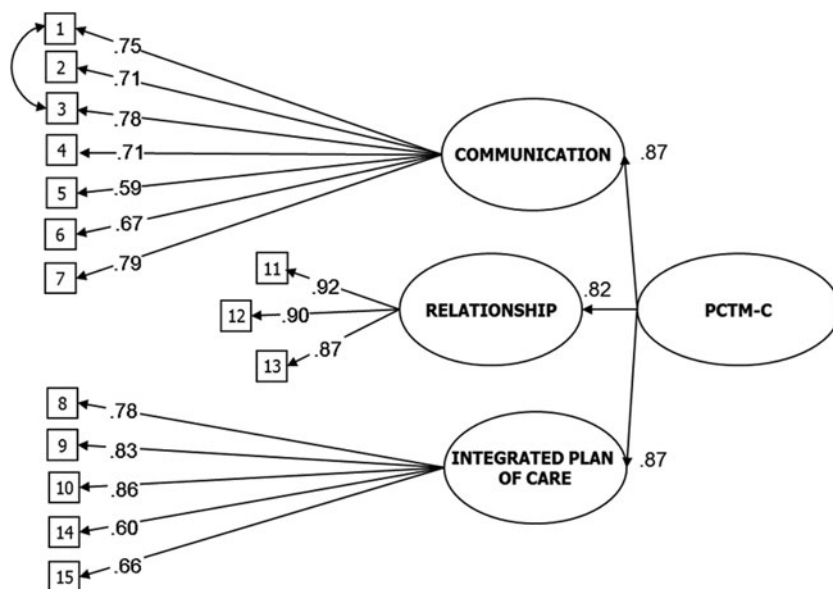


Fig. 1. Confirmatory factor analysis of the Palliative Care Transition Measures for Caregivers (PCTM-C).

Table 2. Item scores of PCTM-C for the total sample

	Mean (SD)	Skew	Kurt
1. When my relative left the hospital, I had all the necessary information about palliative care	2.9 (0.7)	-0.47	0.43
2. Before my relative left the hospital, I had readable and easily understood written information about palliative care	2.6 (0.9)	-0.25	-0.69
3. When my relative left the hospital, I understood how my relative would be cared for in palliative care	3.0 (0.7)	-0.53	0.83
4. When my relative left the hospital; I understood that his/her signs and symptoms would be controlled	3.1 (0.6)	-0.46	1.24
5. When my relative left the hospital, I had a good understanding of his/her health condition and what could improve or worsen	3.0 (0.8)	-0.42	0.30
6. When my relative left the hospital, I understood the general purpose of medications that would be prescribed in palliative care	3.0 (0.8)	-0.58	0.21
7. When my relative left the hospital, I was aware of how I would be involved in his/her care	3.0 (0.7)	-0.49	0.68
8. My relative's referral to palliative care was agreed with health professionals	3.1 (0.7)	-0.38	0.44
9. Before my relative left the hospital, health professionals took my preferences and those of my relative into account in deciding the place of referral to palliative care	3.0 (0.7)	-0.59	0.42
10. Before my relative left the hospital, health professionals took my preferences and those of my relative into account in organizing the referral to palliative care	3.1 (0.7)	-0.53	0.29
11. When my relative left the hospital, I was confident that his/her symptoms would be managed as well as possible	3.2 (0.6)	-0.19	0.10
12. When my relative left the hospital, I was confident that we would receive all the help needed	3.2 (0.6)	-0.08	0.56
13. When my relative left the hospital, I was confident that I would receive the support for his/her caring	3.2 (0.6)	-0.29	0.79
14. The timeliness of referral to palliative care fitted our needs	3.2 (0.6)	-0.45	0.752
15. Health professionals supported us throughout the referral to palliative care	3.1 (0.7)	-0.54	0.556

Kurt, kurtosis; PCTM-C, Palliative Care Transition Measure for Caregivers; SD, standard deviation; skew = skewness.

abandoned, and may negatively affect their confidence in health-care providers (Lofmark et al., 2005; Schofield et al., 2006). Several studies have shown how patients within an official network of organizations were less likely to feel abandoned by the healthcare system (Haggerty et al., 2012).

Although the PCTM-C is a useful measure focused on the transition to palliative care, it does not help to overcome the uncertainty regarding when such transition should occur (Krishnasamy et al., 2007). Despite this, the PCTM-C has the utility to lead healthcare providers to reflect on those elements that facilitate a sensitive transition and to consider the emotional burden and subjectivity underpinning the transition to palliative care. For instance, to ensure tailored communication and trusted relationships, a small number of key health professionals should be identified, whereas multidisciplinary collaboration should be enacted behind the scenes.

Finally, healthcare providers should use the information gathered during the caregivers' transition experience to guide decision-making in regard to future resource management and to assist caregivers when they face emerging problems. Improving the quality of the transition has the potential to increase an early and smooth referral to palliative care as well as to enhance caregivers' physical and psychological well-being and satisfaction levels (Casarett et al., 2008).

Limitations and future directions

The findings from this study need to be viewed in the light of some limitations. First, the study provides data only about one type of transition, from acute care to palliative care. Thus, future research is needed to confirm these findings in larger and more

varied samples of family caregivers who are involved in different types of transitions to palliative care (e.g., from a long-term setting to palliative care).

Second, we addressed the caregiver's perspective without having an insight into that of the patient. Further research efforts might include the patients' perspective with the aim of finding the right communication channels congruent with patients' care preferences and awareness levels. Finally, our results present only initial evidence for the PCTM-C validation, so future research needs to better establish its psychometric proprieties by using a more rigorous approach, especially with regard to reliability.

Conclusion

PCTM-C allows the evaluation of the quality of care delivered during the transition to palliative care from a caregiver's perspective. It can assist in bridging the gap during the transitional process by offering insights into various interaction elements, such as those between caregivers and the healthcare providers involved in the transition. It has the potential to improve the continuity of care for an early and timely referral to palliative care, while focusing on the coordination of individual elements of the plan of care. This aspect may contribute to other desirable palliative care outcomes, such as the decrement of palliative service abandonment and the reduction of unnecessary transitions.

Acknowledgments. There are no commercial associations neither conflict of interest to disclose from any of the authors. We would like to thank all the healthcare providers and the family caregivers who participated in the study. We are also grateful to Ralph James Holland for the English editing of the manuscript.

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