Title: Identifying and assessing the needs of carers of patients with palliative care needs: An

exploratory study

Abstract

Background: Carers of patients with palliative care needs require careful assessment and support to

undertake their role effectively. The carer component of palliative care is embedded in complex

situations that necessarily focus on the patient.

Aim: To explore experiences of specialist palliative care nurses (SPCNs) in identifying, assessing and

planning care to support carers of patients with palliative care needs.

Methods: Qualitative study with two face-to-face group interviews of SPCNs (n = 11) and descriptive

content analysis.

Findings: Findings articulated gaps in identifying carers and their role, and assessing the carers'

needs.

Conclusion: This study confirmed the complexity in assessing carers' needs within the palliative care

context, existing practice gaps and positive outcomes when routine processes were adopted. Future

research should explore how to systematically make improvements in supporting carers in all

palliative care contexts including specialist and non-specialist settings.

Keywords

palliative care; carer; care planning; nurses; quality.

Introduction

Carers[1] of patients with palliative care needs require careful assessment and support to ensure they can effectively and confidently undertake their caring role (Alvariza et al. 2018). A carer is someone "who provides personal care, support and assistance to another individual who needs it …" (ACSQHC 2015, 32). This study worked with specialist palliative care nurses (registered nurses who specialise and work in palliative care contexts). Thus, the carers they interacted with, and about whom they shared their perceptions and described their experiences with, had all been referred to a specialist palliative care service. The carer component of palliative care may seem obvious, but this component is embedded in complex situations that necessarily focus on the patient. Therefore, although the assessment and planning for carer support requires its own specific focus, it is often added on to assessments and planning performed for the patient. Palliative care guidelines (Hudson, Remedios et al. 2010) and standards (PCA 2018) acknowledge the need to plan support for carers; however, gaps in practice continue (Ates et al. 2018; Henderson 2014; Thomas et al. 2018; Wiles et al. 2018). In response to these gaps, this study explored the experiences of specialist palliative care nurses in identifying, assessing and planning care to support carers of patients with palliative care needs.

Literature Review

Although carers are often drawn from the patient's closest family members, the carer role may not be assumed "merely because they are the spouse, de facto partner, parent, child, other relative or guardian of an individual, or live with an individual who requires care" (ACSQHC 2015, 32). When the carer role is performed by a close family member, the provision of palliative care also affects the broader family unit (Alvariza et al. 2018). Numerous barriers – associated with the individual carer, the health system and inadequate communication – challenge the provision of timely and effective support for carers (Ates et al. 2018; Thomas et al. 2018; Wiles et al. 2018). In recognition of these

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[1]To avoid awkwardness and repetition, the terms 'carer' and 'carers' are used interchangeably and are understood to include both the singular and plural forms, as appropriate.

issues, some systematic reviews have documented interventions and clinical tools that target the needs of carers (Hudson, Trauer et al. 2010; Candy et al. 2011; Bostanci et al. 2012). Increased focus has been given to interventions supporting carers, for example, the use of evidence-based psychosocial interventions (Harding et al. 2012; Applebaum and Breitbart 2013; Hudson and Aranda 2014; Aoun et al. 2015) and use of targeted and validated needs assessment tools (Alvariza et al. 2018; Thomas et al. 2018). However, systematic implementation of relevant tools to assess carers' needs and facilitate personalised careplans and/or regular screening for carer distress remains challenging within current service delivery models (Alvariza et al. 2018). Although caring for a loved family member can be both rewarding and fulfilling, the evidence repeatedly suggests that some carers suffer negative health consequences because of their role (Ates et al. 2018; Hudson and Payne 2011; Hudson and Aranda 2014; Ullrich et al. 2017). Hudson and colleagues systematically reviewed instruments related to family caregivers of patients with palliative care needs (Hudson, Trauer et al. 2010). Their review noted that "there is a lack of consistency in the way needs are assessed, few longitudinal studies to examine the impact of caregiving, and a dearth of evidence-based interventions" (Hudson, Trauer et al. 2010, 1). Although research has progressed in this area (Alvariza et al. 2018), systematic implementation of useful tools in practice, remains a key challenge (Ates et al. 2018; Thomas et al. 2018; Wiles et al. 2018). The carers' needs should be acknowledged as an extension of the care provided to the patient; carers need to be given information to enable them to work in partnership with health professionals (Ates et al. 2018; Virdun et al. 2016).

In 2013, an Australian project, the Continuous Quality Collaborative Project: Support for Carers, was commissioned by Palliative Care Australia to review and improve the identification, assessment, planning and delivery of support to meet the needs of carers of palliative care patients (Henderson 2014). Specialist palliative care services evaluated the identification of carers, assessment of the carers' needs, and planning support for carers. A patient record audit evaluation confirmed gaps in all these areas (Henderson 2014). A limitation of the evaluation was that the audit of patient records

did not capture the experiences of health professionals in identifying and planning care for the carers. Specialist palliative care nurses are key stakeholders in identifying and assessing the needs of carers to plan their support. Hence exploring their experiences in this domain is a step towards understanding these gaps that potentially hinder the integration of carers' needs into assessment and planning practices.

Participants, ethics and methods

Study design

A qualitative design was used to explore specialist palliative care nurses' experiences with and opinions about assessing carers' needs and documenting a plan to support the carers of patients with palliative care needs. This study used a pragmatic framework which focused on pre-identified practice gaps in the identification, assessment, planning and delivery of support to meet the needs of carers of patients with palliative care needs (Henderson, 2014; Creswell, 2013, p. 28). Five semi-structured interview questions were framed based on the work completed for the above-mentioned collaborative quality improvement project of the National Standards Assessment Program (Henderson, 2014). The semi structured questions explored: 1) identification of patients' carers; 2) identifying the carers' role; 3) assessing the carers' needs; 4) potential difficulties experienced when assessing and planning support for carers; and 5) positive experiences in planning carers' needs. Two face-to-face group interviews were held to explore the interview questions, encouraging participants to provide detailed information about their experiences in order to better understand the processes and activities undertaken by these specialist nurses to support carers.

Ethics

This study design was approved by the local university Human Research Ethics Committee (Reference number: A/13/484). Participation in the study was voluntary and all participants signed written informed consent forms before the interviews were conducted.

Participants

A purposive sample of Australian specialist palliative care nurses who attended an annual National Standards Assessment Program workshop hosted by Palliative Care Australia on 2 December 2014 were invited to participate in the group interviews. All the workshop participants were sent email correspondence regarding the study before the workshop. A total of 11 specialist palliative care nurses from Australian states and territories agreed to participate in two group interviews (n = 6, 5; average interview time: 33 minutes).

Data analysis

The group interviews were audiotaped and the data were transcribed verbatim. In addition, scribed notes were completed at each interview, and key responses from the interviews were summarised with participants at interview closure. The descriptive content analysis undertaken to interpret the data preserved the study questions (Creswell 2013, p. 185). An analytical framework using the study questions was used to organise and report the qualitative responses (Patton, 2002, p. 439). All participants were offered the opportunity to review both the summary information and the results from the data analysis, and were invited to discuss any queries or concerns about the data. Consensus by all authors confirmed the analysis of the group interview data. The consolidated criteria for reporting qualitative research (COREQ) guided the report on this study (Tong et al. 2007).

Results

The results of the study articulated participants' experiences of identifying and assessing the needs of carers of patients receiving palliative care in order to plan their support. De-identified quotes from participants taken from the interview transcripts are used to illustrate these experiences. Quotes from participants in Group Interview 1 are presented as G1 and those from Group Interview 2 as G2.

Identification of the patients' carers

Participants confirmed that identification of the patients' carers is not always a straightforward process. Participants suggested that identifying the carer of a patient with palliative care needs could be confirmed by a number of means. For example, explicitly asking who the carer is on admission; asking the next of kin to confirm the carer (it is important not to assume that the next of kin is the carer); avoiding assumptions that a particular person is the carer; recording details of the carer within the documentation system; and confirming if there is more than one carer. Example responses follow:

> G1: In our service the patients and carers are asked on admission to the service and once the carer has been identified the role is discussed on admission and it has been changed on our database according to who is then the primary carer, who has been identified.

> G2: People make the mistake of thinking the next of kin is their carer. That's not always the case. So really the only way is to ask.

> G2: In our admission form we say, do you have a carer? Who is it? Spouse? So we ask all those questions. Now I just try and word it differently. We'll say, who do you identify as your carer?

> G2: Sometimes there can be multiple carers too, sort of like a shared-care with two daughters is probably the more common one.

Identifying the carer's role

Participants confirmed the complexities of discussing and identifying the carer's role with the carer. Participants stated that different members of the patient's care team could conduct the conversation about the role with the carer. There was no consistent approach to confirming the role with the carer; the process was often ad hoc rather than formally addressed. In some instances, the role was not confirmed with the carer. Examples of participant responses illustrate current practice for

identifying and confirming the expectations of the carer with the person who would undertake this role. Example responses follow:

> G1: I don't necessarily believe that we do it in a systematic way. I think we make a lot of assumptions about it … we don't actually specifically say do you understand your role and do you know about the requirements of your role in a systematic way.

> G1: So we've got a system in place where once the carer's been identified through the admission process, it's usually within the second week after the patient's been admitted, that our Allied Health, a member of our Allied Health team, rings the carer, the identified carer, and as part of the carer needs assessment tool we ask the questions and discuss the role and ask the questions about whether they're able to accept the role and they're agreeable. Sometimes it comes up that in actual fact I didn't agree to that and no, I'm not the carer, I'm just the neighbour and so it's sort of like a check and balance in a way that what happened at the admission process is they are actually agreeable to that role …

> G1: Ours is more ad hoc. We've got a network facilitator position dedicated to the role of the caregiver, so any patient that comes through our early introductory clinic to palliative care actually does get that whole level of assessment and it's kind of exploring about their role and that they're agreeing to participate and take on that position of carer. It's a confronting conversation, because often they haven't even switched their heads to the fact that they've shifted from wife to carer. But to say that everyone gets it wouldn't be fair ... so there's no way everybody gets it. It's certainly not rolled out unanimously through the community programme.

Assessing the carers' needs

Again, complexities in assessing the carers' needs were highlighted by participants. The responses confirmed that inconsistent practices exist in the approach to the carer assessment process .

G1: There's questions surrounding it all, but we don't do a proper care assessment.

G1: Basically it happens, but it doesn't happen in a formalised way, because ultimately we couldn't manage it [if] we didn't look after the carer, so there's a lot of informal assessment going on every single visit.

Some services use formalised carer assessment tools while other services employ less formal approaches.

G1: It's a paper-based tool, so we keep a record for each carer. We phone them all, so it's all phone based, initially phone-based assessment, and then we scan that tool into our electronic record so that everyone has access to it.

G1: And again … we have quite an extensive carer needs assessment tool, which is an amalgamation of a few tools. It was developed years ago when we actually did research around putting in that position, so we've continued to use it. We've divvied up the cancer needs assessment tool amongst that group so that's there's components of that. So if they come through that clinic then, yes, they get that assessed, but again once they get into other parts of the service it's ad hoc, it's hit and miss.

G2: Our service has actually a carers' assessment document. So these things are virtually identical in that. If the carer is frail, elderly, got multiple comorbidities themselves, or want to add – also identify as the other people who may be able to help them.

Difficulties experienced when assessing and planning carer support

Participants articulated difficulties experienced when assessing and planning carer support; carers being unaware of the true requirements of their role; assumptions about the role of a carer who is a health professional; the need for flexibility due to patients' changing care needs; the carer's views not aligning with the patient's views; carers feeling bound by duty but not actually wanting to be a carer; unrealistic expectations; and no support available for the carer. Example responses follow:

G2: I'll give you another [example] … this fellow was diagnosed with [bulbar] onset motor

   neurone disease … hadn't had any contact with family for years. They found a sister

   … who he hadn't had any contact with for eight years. They put him on the plane,

   sent him to [x]. She said he could come and live with her. Two days later she turned

   up at the outpatients department …

G2: When the daughter of the man is a nurse and we virtually expect her to wash her father

   or things like that. I think if they're nurses we expect them to give S8s [restricted

   drugs], which may be out of their practice even because they might be an enrolled

   nurse. I think that's a real special group of carers too, that we don't often look after.

G1: Only in people just objecting at the time that I don't need a carer and I don't want to be

   the carer, I'm the wife, I'm their father or their son or daughter, I'm not the carer.

G1: Our negatives are when the carers has agreed to be the carer and the patient's agreed

   that that's the carer, but then you find out later that the agendas of the two parties

   are quite different. So the adult son says I'm the carer, that was fine, but he actually

   really wanted active treatment for mum, who previously had said I don't want any

   active treatment, and come to us for terminal care. But then the son might discharge

   mum from out of hospital, we find later that all the things you'd set in place and all

   the things he agreed to, he actually really didn't want. So that was where it all fell

   down. But we'd had all the discussions.

G1: We find it very hard to support the carers who are stuck and who can't get out of the

   situation. They don't want to be the carer, but they actually can't do anything about

   it … Ex-wives, even some ex-husbands, ambivalent relationships, there's quite a few

   of those. Maybe we did support them well, maybe we didn't support them enough, I

   don't know …

G1: I think when expectations are not realistic. Carers expect that they've come onto the

   programme, they might have been promised something and they do everything and

we recalibrate them down to their one hour extra help a week or something and that

in itself is often where they start to see difficulties.

Positive experiences in planning a carer's needs

Participants could identify positive experiences in planning a carer's needs, which deserve

acknowledgement. Positive experiences confirm the importance of planning support for carers.

Positive examples included carers being supported within the family unit; having clarity for the carer

about the requirements of the caring role; and early planning to support carers. Example responses

follow:

> G2: She knew she had a very short prognosis. She lived with her husband who had quite
>
> advanced dementia. The family were very committed … They set up a roster system
>
> where one of them was always at home with the mother and the father with
>
> dementia. During the day the father used to go off to like a day centre to do stuff
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> because it was just too much for him and made sure they had the right drugs in the
>
> house. I told them the risk that she might have a major bleed. They had the advance
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> care directive at the hall table. So they didn't say, look, if she suddenly bleeds –
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> please don't call an ambulance but make sure they know that she's not for
>
> resuscitation ... She died very peacefully at home and it just worked really well.

> G1: I think of times where we've thought we had a carer and that person has said, no, I'm not
>
> the carer, but that's actually a positive, that we wouldn't have known about had we
>
> not gone through this process, and then it's brought up a whole lot of other issues in
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> the family that were there already but we've brought them to the fore and from that
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> it's helped to plan the care a lot sooner, rather than waiting until it all falls into a
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> heap because we never identified that this person actually doesn't have a carer. It's
>
> helped us to put things in place to … So although that might seem a negative, it's
>
> actually been a positive from a care planning point of view.

G1: Because often with our nursing team they wait until the family is in tears or they need referral to a counsellor, rather than getting – so that's been positive for our service in planning support a lot earlier than we normally would.

Discussion

This study sought to explore how specialist palliative care nurses identify, assess and plan support for carers of patients with palliative care needs. The findings confirm the complexities of identifying and planning appropriate support for carers. Identifying the carer is the first step in being able to assess and plan support for them (Hudson, Remedios et al. 2010). Participants confirmed the importance of not assuming who the carer is; for example, the next of kin is not necessarily the carer. Furthermore, participants acknowledged that documenting a carer's name does not necessarily translate to preparing a carer for their caring role, nor to supporting them in the role (Hudson and Aranda, 2014). The participants also acknowledged they were often faced with difficult situations when the identified carer felt they had no choice but to undertake that role. These difficult situations further confirm the importance of assessing the carer's needs, providing information, and planning targeted support to prepare the carer for the realities of the caring role (Alvariza et al. 2018; Thomas et al. 2018).

Caring for a patient with palliative care needs can be burdensome, with carers prone to social isolation and physical, psychological and financial disadvantage (Ates et al. 2018; Hudson and Payne 2011; Hudson and Aranda 2014; Ullrich et al. 2017). To minimise the carer's burden, assessing and planning interventions to meet the carer's needs is vital (Alvariza et al. 2018; Hudson and Aranda, 2014; Thomas et al. 2018). Although supporting carers now receives increased focus and more carer-specific interventions are available (Alvariza et al. 2018; Applebaum and Breitbart 2013; Harding et al. 2012; Hudson and Aranda 2014; Thomas et al. 2018; Wiles et al. 2018), the limited scope of systematic implementation means that all carers' needs and preferences are not necessarily met (Ates et al. 2018). Health professionals need to engage the carer to give them permission to

articulate their needs and understand their role, which allows assessment and planning of appropriate support (Alvariza et al. 2018; Ates et al. 2018; Thomas et al. 2018). This study's findings suggest that gaps in documenting a plan of action to support carers' needs continue to exist. These findings are consistent with those of an Australian National Standards Assessment Program collaborative project (palliative care), which showed that the percentage of patient records with evidence of a documented plan of action to support carers' needs increased from 19% at the start of the project to 52% at project completion (Henderson 2014, p. 22). An embedded process that addresses the needs of carers is critical for effective carer support. This process should use validated tools such as the Carers Support Needs Assessment Tool (CSNAT) (Aoun et al. 2015; Alvariza et al. 2018), with the assessment conducted individually with the carer only (Alvariza et al. 2018; Ates et al. 2018; Thomas et al. 2018). The process must also respond to unexpected challenges that affect the caring role.

Health professionals are critical in identifying the carer, confirming that the carer is aware of the requirements of the caring role, assessing the carer's needs, and planning individualised support for the carer. If an assessment of a carer's needs is not adequately completed, how can the carer be appropriately supported to provide safe care for a patient with palliative care needs? This study confirms the complexity and varied approaches to assessing carers' needs within the palliative care context. Although gaps in current practice have been identified, the findings also confirm the positive outcomes of appropriately identifying, assessing and planning support for carers of patients.

Strengths and limitations

A strength of this study includes that the exploratory questions were not unfamiliar to the participants, and their experiences in working with carers of patients requiring palliative care were current. A limitation of the study is that the results are limited to the experiences of practitioners working in specialist palliative care settings only. The small number of participants, with all those involved also attending a concurrent workshop focusing on meeting national palliative care

standards, is potentially biased towards practitioners who are energised and committed to excellence in palliative care. However, this also affirms our results in that even these specialist practitioners describe complexities in identifying, assessing and planning care for carers of people with palliative care needs.

Conclusion

The aim of this study was to explore the experiences of specialist palliative care nurses in identifying, assessing and planning care to support carers of patients receiving palliative care. Specialist palliative care nurses confirmed that practice gaps exist in these aspects of supporting carers. These gaps are consistent with previous work completed in the Australian context. Confirmation of gaps in the specialist palliative care services also raises the potential difficulties in assessing and planning care for carers of patients with palliative care needs not managed in specialist palliative care settings across the health sector. Further research is needed to explore how to systematically make improvements in supporting carers in all palliative care contexts including specialist and non-specialist settings. This consistency is critical to both carers and patients with palliative care needs: a well-supported carer is better prepared for their role in the delivery of quality palliative care.

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Reflective questions

1. Supporting carers of patients requiring palliative care is embedded in complex contexts necessarily focussed on the patient. When you think about current clinical practice, do you formally identify the carer for a patient requiring palliative care and confirm the requirements of the carers' role?

2. Guidelines for assessment and planning of carer support are published, but translation into practice varies. What are the barriers and enablers of assessing and planning support for carers?

3. Interviews with specialist palliative care nurses confirmed that practice gaps exist in planning support for carers, and highlighted the contextual difficulties contributing to these gaps. How could the findings of this study be used to evaluate the assessment of the carers' needs in your clinical setting?