Supporting family caregivers to identify their own needs in end-of-life care: Qualitative findings from a stepped wedge cluster trial

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Abstract

Introduction: The Carer Support Needs Assessment Tool encompasses the physical, psychological, social, practical, financial, and spiritual support needs that government policies in many countries emphasize should be assessed and addressed for family caregivers during end-of-life care.

Aim: To describe the experience of family caregivers of terminally ill people of the Carer Support Needs Assessment Tool intervention in home-based palliative care.

Methods: This study was conducted during 2012–2014 in Silver Chain Hospice Care Service in Western Australia. This article reports on one part of a three-part evaluation of a stepped wedge cluster trial. All 233 family caregivers receiving the Carer Support Needs Assessment Tool intervention provided feedback on their experiences via brief end-of-trial semi-structured telephone interviews. Data were subjected to a thematic analysis.

Results: The overwhelming majority reported finding the Carer Support Needs Assessment Tool assessment process straightforward and easy. Four key themes were identified: (1) the practicality and usefulness of the systematic assessment; (2) emotional responses to caregiver reflection; (3) validation, reassurance, and empowerment; and (4) accessing support and how this was experienced.

Conclusion: Family caregivers appreciated the value of the Carer Support Needs Assessment Tool intervention in engaging them in conversations about their needs, priorities, and solutions. The Carer Support Needs Assessment Tool presented a simple, yet potentially effective intervention to help palliative care providers systematically assess and address family caregivers’ needs. The Carer Support Needs Assessment Tool provided a formal structure to facilitate discussions with family caregivers to enable needs to be addressed. Such discussions can also inform an evidence base for the ongoing development of services for family caregivers, ensuring that new or improved services are designed to meet the explicit needs of family caregivers.

Keywords
Family caregivers, home-based palliative care, Carer Support Needs Assessment Tool, support needs, needs assessment

What is already known about the topic?
- There is a lack of suitable tools for assessment of family caregivers’ support needs in end-of-life home care.
- Assessment is often informal and undocumented, making family caregivers’ support needs less “visible.”

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Background

Home-based family caregiving toward the end of life entails considerable emotional, social, financial, and physical cost for family caregivers and may even increase their mortality.1–4 Evidence suggests that good support can improve family caregivers’ psychological outcomes in the longer term5–7 and that specialist palliative care may reduce family caregivers’ morbidity and mortality.8 The UK government palliative care policy and guidelines stress that family caregivers’ needs should be assessed and addressed,9,10 as is the case in Australia11,12 and in Canada.13 However, many factors hinder adequate assessment of family caregivers’ support needs. Service providers focus on the patient, often have little time to undertake comprehensive screening for family caregivers’ problems, and may be reluctant to openly do so in the patient’s presence. A family caregiver’s assessment is often informal and undocumented, making family caregivers’ support needs less “visible.” Family caregivers are also often reluctant to express their own needs and unlikely to feel these are legitimate.4

Furthermore, there is a lack of suitable tools for assessment of family caregivers’ support needs in end-of-life home care. While there are research-based questionnaires for measuring family caregiver needs, their content and length generally make them unsuitable for use in everyday palliative care provision.14,15 Conversely, recent work from the United Kingdom by a Help the Hospices Family Caregiver Assessment Working Group16 showed that family caregiver assessment undertaken by palliative home care services relies on ad hoc, non-validated tools that show little communality in content or format. To address this gap, Ewing and Grande15 have developed an evidence-based, comprehensive Carer Support Needs Assessment Tool (CSNAT) suitable for use in all domains of palliative home care: physical, psychological, social, practical, financial, and spiritual.

Description of the CSNAT

The CSNAT is used to elicit family caregivers’ concerns during end-of-life care in a systematic way. Eliciting any concerns early and focusing on family caregiver needs are likely to lead to better outcomes post bereavement.4,7 As such, the tool is a supportive family caregiver intervention. The CSNAT is based on interviews and focus groups with 75 bereaved family caregivers;15 has good face, content, and criterion validity; and shows sensitivity to change over time.17

The CSNAT adopts a screening format structured around 14 broad support domains derived from qualitative data from family caregivers and endorsed in the research literature. This format allows it to be brief but also comprehensive, enabling carers to identify the domains in which they require further support which can then be discussed with health professionals. Each item represents a core family caregiver support domain in end-of-life home care,15 and these domains fall into two distinct groupings: (1) those that enable the carer to care and (2) more direct support for themselves.

The first group encompasses support that enables the family caregiver to care for the patient at home, such as understanding the patient’s illness, knowing what to expect in the future, knowing whom to contact, managing symptoms and medicines, providing personal care (dressing and toileting), providing support with equipment including information and skills, and talking to the care recipient about his or her illness.

The second group encompasses support for the family caregiver in their caring role (more direct personal support), such as looking after their physical health; dealing with feelings and worries; financial, legal, or work issues; practical help in the home; support with their beliefs and spiritual concerns; and time for themselves in the day and overnight respite.

There are four response options for each of the 14 CSNAT items that allow family caregivers to indicate the extent of their support requirements for each domain: (1) no more, (2) a little more, (3) quite a bit more, or (4) very much more. Once the domain is identified, there would be a further conversation to find out “what the
The problem is—essentially to identify what the individual need the caregiver has within that domain. Once that individual need is identified, then the caregiver and health professional can work together to look at how best to meet that need.

The application in Western Australia

This study was initiated when the Silver Chain Hospice Care Service, a large organization providing home-based specialist palliative care in Perth, Western Australia, identified a need to further address the following organizational standard: “The needs of the primary caregiver(s) are assessed independently and are documented with supportive strategies in the plan of care.” An internal quality action plan has identified this gap against the Australian Palliative Care Standards. This organization identified the CSNAT as potentially useful and sought to work with the authors of this article to test its impact and determine how its use was experienced by family caregivers and the staff.

The overall purpose of the study was to evaluate the CSNAT intervention in this service context. There were three pre-bereavement phases of data collection following a period of pilot testing.

Phase 1. A stepped wedge cluster trial was used to implement the CSNAT with an intervention group using the CSNAT for identification of support needs and a control group using the service standard identification of support needs. Pre- and post-outcome measures were collected for the two groups. Total recruitment was 620. There was 45% attrition for both groups between baseline and follow-up mainly due to patient deaths resulting in 322 caregivers completing the study (233 in the intervention group and 89 in the control group). The intervention group showed significant reduction in caregiver strain relative to controls ($p=0.018$, $d=0.348$).18

Phase 2. Feedback on using the CSNAT was sought from 233 family caregivers in the intervention group through telephone interviews, as each completed the study.

Phase 3. Feedback on using the CSNAT was sought from 44 nurses who participated in the trial (article under review).

This article reports findings from the 233 family caregivers in Phase 2.

Aim

The aim of the study addressed in this article was to describe the experience of family caregivers of terminally ill people of the CSNAT intervention in home-based palliative care.

Methodology

The study was approved by the Curtin University Human Research Ethics Committee (HR 24/2011) and the Silver Chain Human Research Ethics Committee (EC App 068). All aspects of this study conformed to consolidated criteria for reporting qualitative research (COREQ) requirements.

Service context

This study was conducted (March 2012 to February 2014) in three sites of the Silver Chain Hospice Care Service, Australia’s largest provider of home-based palliative care. The service is provided by an interdisciplinary team comprising general practitioners with a special interest in palliative care, medical consultants, registrars, resident medical officers, palliative care specialist nurses, counsellors, chaplains, care assistants, social workers, and volunteers, who work with the patient to control symptoms and address psychosocial needs. Typically, nurses visit patients weekly and increase visits according to client needs for care and symptom management, and care assistants provide personal care visits three times per week to daily depending on patient needs. The average length of stay with the service is approximately 90 days.

In relation to caregiver support during the study, the “standard practice” included the staff meeting with the caregiver during the client visit and discussing caregiver needs on an informal basis. Following this discussion, the staff member would offer services and equipment that Silver Chain was able to provide. These services included social work, counseling, spiritual care, personal care, and in-home day respite. The service was able to access crisis respite from external organizations. The equipment that was provided free of charge included hospital beds and pressure relieving equipment.

Some aspects of the discussion with caregivers would be documented; however, many conversations were “drive way” conversations (outside of the home) and were therefore on an ad hoc basis and not documented as clients’ clinical records are currently paper-based and stored in the home.

Description of the intervention

The CSNAT intervention consisted of at least two visits from nurses (2–3 weeks apart) to identify and review caregivers’ needs. Family caregivers identified the domains where they need support in general and indicated which domains were their main priorities. The CSNAT was either self-completed by the family caregiver or completed jointly with the nurse. Priorities were discussed with the nurse who recorded the actions taken or proposed solutions for each priority need and discussed a shared action plan.
Recruitment

Participants were primary family caregivers of terminally ill patients (with cancer or non-cancer diagnoses) referred to Silver Chain Hospice Care. A primary family caregiver was defined as a person who, without payment, provided physical care (and emotional care) to a person who was expected to die during provision of the caring role. This care could be provided on a daily or intermittent basis. Included family caregivers were all adults, able to read and write in English. Family caregivers with a known cognitive impairment were excluded based on the nurses’ clinical judgment.

At the start of the intervention, family caregivers of clients newly admitted or already receiving palliative care were invited by the nurses to participate at the first feasible opportunity during a face-to-face visit. Nurses obtained written informed consent for the researcher to contact them by phone to undertake the pre- and post-intervention outcome measures (Phase 1) and then audiotaped their feedback on using the CSNAT at the end of the intervention period, as each of them completed it (Phase 2).

Study design and data collection (Phase 2)

This study adopted a qualitative research design using the questions provided below. Participants were interviewed by a research nurse who telephoned at a pre-arranged time convenient to them, within a week after completion of the intervention. Participants were given the opportunity to describe any other benefits or problems and ways of improving their experience of the CSNAT intervention. The questions and the probes to each question were as follows:

- How easy or difficult was it for you to complete the CSNAT assessment of your support needs? For example, Did you identify your needs alone or did the nurse assist you? What was this like for you?
- Did you feel that completing the assessment process was helpful in getting the support you needed? For example, After discussing your needs with the nurse, did you receive the help/support you needed? How did you find this worked for you? Were there things put in place for you after identifying what you needed?
- Did this experience of identifying your needs affect what you did yourself? For example, Were there any changes for you and what did you yourself after going through the CSNAT? Were there things you did yourself after identifying what you needed?
- Did you feel that your needs as a caregiver were acknowledged/listened to in a way that was distinct from the needs of the patient? For example, How do you feel the nurses listened to what you needed for yourself? How did you find the nurses acknowledged your needs?
- Do you think the CSNAT assessment process could be improved in any way? For example, What, if anything, do you feel you would change to improve the assessment process itself?

This set of questions was used with each of the 233 intervention group family caregivers. Interviews from 80 participants were transcribed verbatim, until no new themes arose from the conversations. For the remaining interviews, the interviewer took detailed notes to validate emerging findings from the first 80 interviews. Some participants spoke in detail about their experiences when probed. For others, responses were limited to yes/no with a few additional comments.

Analysis

Data from the interviews were subjected to a thematic analysis. Initial coding was carried out independently by two co-authors, one being an experienced qualitative researcher and the other was the interviewer. Coding was supported by the NVivo 10 software. Transcriptions were read and re-read to identify key words and phrases that were then grouped into categories labeled with codes. To enhance the credibility of findings (as described by Creswell), the interviewer was involved in the analysis process so that consideration of the non-verbal context was assured. Themes emerging after comparisons within and among individual interviews identified key messages. These themes were initially identified independently with differences resolved by discussion and by returning to the data. Exemplars are provided to explain themes and how interpretations have been reached. To further ensure the trustworthiness of our findings, transferability is established by our description of the study’s setting and participants.

Results

A total of 441 family caregivers were enrolled in the intervention arm of the study, and 233 were able to complete two visits to discuss their support needs through the CSNAT intervention and also to complete the feedback interview addressing their experiences in the timeframe of the study.

All 233 family caregivers agreed to participate in a telephone interview to give feedback on their experience using the CSNAT (100% response rate). The mean duration of telephone interviews was 21.34 min (standard deviation (SD) = 8.24 min) with duration times ranging from 9 to 63 min (median = 19 min).

Participants’ characteristics

Table 1 summarizes the profile of participants in the telephone interviews. The majority of family caregivers were
Table 1. Demographic characteristics of family caregivers (N=233).

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>69</td>
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</tr>
<tr>
<td>Female</td>
<td>164</td>
<td>70.4</td>
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<tr>
<td>Age (years)</td>
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<td></td>
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<tr>
<td>Mean ± SD</td>
<td>62.1±12.4</td>
<td></td>
</tr>
<tr>
<td>Median (range)</td>
<td>62 (20–88)</td>
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<tr>
<td>Marital status</td>
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<td></td>
</tr>
<tr>
<td>Never married</td>
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<tr>
<td>Widowed</td>
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<td>Divorced/separated</td>
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<td>4.7</td>
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<td>Married/de facto</td>
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<td>Australian</td>
<td>129</td>
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<td>Other English-speaking</td>
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<td>28.3</td>
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<tr>
<td>Non-English speaking</td>
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<td>Usual employment situation</td>
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<td>Paid employment</td>
<td>74</td>
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<tr>
<td>Pensioner</td>
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<td>41.2</td>
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<td>Self-funded retiree</td>
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<td>15.0</td>
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<tr>
<td>Other</td>
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<td>12.0</td>
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<tr>
<td>Highest level of education</td>
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<td>Secondary</td>
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<td>Tertiary</td>
<td>94</td>
<td>40.3</td>
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<td>Living arrangements</td>
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<tr>
<td>Private residence</td>
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<td>95.7</td>
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<td>Retirement village</td>
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<td>3.0</td>
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<tr>
<td>Other</td>
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<td>Relationship to patient</td>
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<td>Spouse</td>
<td>157</td>
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<td>Parent</td>
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<td>1.7</td>
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<td>Child</td>
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<td>22.3</td>
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<td>Sibling</td>
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<td>2.1</td>
</tr>
<tr>
<td>Other</td>
<td>15</td>
<td>6.4</td>
</tr>
<tr>
<td>How has caring affected your work?</td>
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<td></td>
</tr>
<tr>
<td>Gave up job</td>
<td>41</td>
<td>17.6</td>
</tr>
<tr>
<td>Reduced hours</td>
<td>27</td>
<td>11.6</td>
</tr>
<tr>
<td>No change</td>
<td>22</td>
<td>9.4</td>
</tr>
<tr>
<td>Not working</td>
<td>115</td>
<td>49.4</td>
</tr>
<tr>
<td>Other</td>
<td>27</td>
<td>11.6</td>
</tr>
<tr>
<td>Caring length (median and range in months)</td>
<td>10 (0.1–420)</td>
<td></td>
</tr>
</tbody>
</table>

SD: standard deviation.
*Other: work leave (annual, sick, carers, long service), flexible hours, leave without pay, redundancy, retrenchment, and changed job.

female (70.4%), married or de facto (86.7%), and 62 years of age (median and mean). Two-thirds were spouses and about a quarter were adult children. They had been in this caregiving role for just under a year. Caregiving affected the work situation of 40% of respondents, in that they either gave up or reduced their work commitments.

Table 2 presents a brief profile of the care recipients. Just over a half were male with a median age of 72 years. The majority had a cancer diagnosis, with a median diagnosis length of just over a year and a median period of receipt of palliative care of 1½ months.

**Participants’ experiences of the assessment process and received support**

The process of CSNAT assessment of support needs was found to be straightforward and easy to complete by 94% of the participants. Responses to the questions further addressed how family caregivers experienced the assessment process and the support they received. The themes that emerged were in response to both the assessment and support aspects of the CSNAT intervention. Three themes related to the assessment process are as follows: (1) its practicality and usefulness, (2) the reflection required to undertake it evoked emotional responses, and (3) the validation, reassurance, and empowerment experienced by being asked to complete the process. The final theme related to the supports that were put in place, which were also experienced as empowering. Table 3 summarizes the four themes and their sub-themes.

**Theme 1: the practicality and usefulness of the systematic assessment.** The structured format of the CSNAT offered the caregivers the opportunity to systematically address questions about their support needs. Participants stated that the CSNAT raised issues that may not have otherwise
been identified, their presence being ignored or overlooked. Participant 483 encapsulated this benefit by saying, "There were things I hadn’t thought about that [the nurse] talked about—“knowing what to expect.” I wouldn’t have asked without that form. These participants were appreciative of the service but were not always aware of the additional supports that were available or of what they might need to consider during the caring trajectory:

... if it hadn’t been for this [CSNAT] I wouldn’t have approached the counsellor or accessed services—I wouldn’t have known about them. (P109)

... it brought up issues about what the carers may not be asked and would have been missed. (P137)

In particular, completing the CSNAT provided a vehicle to express support needs for those who found these problematic to articulate:

It formalised what I probably knew I needed, but it’s difficult to articulate when you’re going through it ... so yes it was very good. (P237)

The fact that CSNAT completion was written and could be achieved over several brief periods was also valued, as explained by this participant: Yes it underlined areas—you can go back to the paper work later to refresh your memory and can work on yourself (P132).

One benefit from self-completion was that it allowed a considered response, without necessarily taking time from the patient or sharing caregiving concerns with them. Participant 217 was referring to the CSNAT question that addresses knowledge of what is to come in the future in this response: ... the last one “needed to know more”—I couldn’t ask in front of [my] husband so I phoned [the] nurse and talked in private. Another participant stated,

It’s best if the person does it [CSNAT] themselves. You can sit and reflect and think about the tasks and whatnot that you have been doing, rather than someone sitting there and asking you … and then you have to think about it on the spot. (P330)

Theme 2: emotional responses to caregiver reflection. The need to reflect in order to respond to the CSNAT questions evoked a spectrum of emotional responses. One of these responses was a feeling of confrontation when reflecting honestly on the caregiving situation. As described by this participant, completing the form was a prompt to pause and consider one’s own needs, instead of just trying to cope with caregiving tasks to the extent that consideration of one’s own needs were ignored:

Emotionally—it makes you reflect where you are in process. A little confronting as you had to look at questions and be honest with yourself in where you are in process. … You tend to get caught up in [the] physical aspect but the questions make you think about emotional aspect. (P195)

As expressed by this participant (P195), there was an underlying process of adjusting to, or accepting, the caring situation that influenced how reflection was experienced. The family caregiver needed to be ready to admit that there were or would be needs. This admission was difficult—sometimes impossible at that time—because it involved fully recognizing the impending death of the patient:

It certainly made me think about various things. It made me think about my husband’s illness and how it will affect our

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-themes</th>
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<tbody>
<tr>
<td>Theme 1: the practicality and usefulness of the systematic assessment</td>
<td>Structured format of the CSNAT. Systematically addressed support needs. Raised awareness of available support. Vehicle for those needs problematic to articulate.</td>
</tr>
<tr>
<td>Theme 3: validation, reassurance, and empowerment</td>
<td>Validated the caregiver role. Caregiver role seemed more manageable. Caregiver reassured not being so alone. Empowered caregiver to identify own strategies.</td>
</tr>
<tr>
<td>Theme 4: accessing support and how this was experienced</td>
<td>Supports put in place were responsive to needs. Informational and emotional needs met. Respite allowed sense of perspective. Provided confidence in ability/capacity to cope.</td>
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CSNAT: Carer Support Needs Assessment Tool.
lives now, how it’s affected it now and how it will affect it
down the track. It’s certainly made me think more. (P330)

At the same time, the reflection required during assess-
ment was recognized as a necessary cathartic process:

I don’t think I was ready—not wanting to confront what was
happening—I think I could have handled it a bit better now I’ve
got a clearer mind. Sometimes you go into your own little
world & you just don’t want to hear—you feel like you’ve gone
stone deaf & you don’t want anyone to interfere. Going through
the form was helpful—like someone needs to shake you &
wake you up out of the shock. It’s like bad trauma … (P371)

Reflection could also be humbling because family car-
egivers were called upon to recognize their situation—see
it like it really is (P415) and admit to a need for help. To
this extent, the opportunity to express their needs was
challenging when family caregivers prided themselves on
their independence, but also helped them to recognize that
this was one time when their usual (independent) approach
would not be helpful: It’s hard to admit that you need help.
I’ve always been independent—I felt if I didn’t do every-
th ing I was a failure (P607).

The following participant found that reflection on the
individual domains identified in the tool helped to make
requesting assistance more tenable because it identified
specific support needs:

It just breaks things down a little bit to give you that idea of
where you do need to ask for help, rather than “try to tough it
out on your own” because you think you should. (P316)

**Theme 3: validation, reassurance, and empowerment.** Although
there were emotional challenges resulting from the reflection
required during assessment, the assessment process
was almost universally welcomed, not only because of the
support that was provided in response to it but also because
it validated the family caregiver role, being sensitive
towards the well-being of the carer (P151); reassured the
family caregiver that they were not facing this time alone;
and empowered the family caregiver. The following
responses illustrate the feelings of validation that were
experienced:

At first I felt like I was invisible in the [hospital] system …
no-one gave me information from the hospital. You were the
very first person to ask about my needs. (P492)

… my needs were listened to, [the] nurse listened to me …,
[this helped me to] value my work positively as a family
caregiver and to “go with the flow.” (P138)

Now [they’re] turning to me & asking me how I feel about it
and how I’m coping with it, always both people. Not always
[considering] my husband all the time, but both of us
together.” (P312)

[The] Form is fantastic as the carer is recognised. Often the
carer is forgotten and if [the] carer “goes down” the patient
suffers. (P515)

The process was found to be reassuring because it was
one way in which the nurse could demonstrate their sup-
port for the family caregiver, meaning that the family car-
egiver was not so alone. This was articulated by the
following participants:

It gave me the reassurance I needed. It does make you feel
less isolated, knowing if anything goes wrong, I’m not the
only one making decisions. (P498)

It was just good to … know there was support there and
someone to talk to and that somebody else cares. (P295)

Participant 426 alluded to the benefit experienced from
just sharing a need for help: Doing the questions help you
realise there are areas you need help with and it lightens
the load. Participant 134 noted that some issues might not
be feasible to address, yet just identifying them helped
them to be seen as more manageable: knew some things I
couldn’t get help with—just talking/flagging/raising issues
was useful.

The assessment was seen to empower the family car-
egiver, in that it provided a catalyst for the caregiver to
identify how they could manage their role. As indicated by
Participant 269, this benefit was recognized even by those
reluctant to ask for help:

If it hadn’t been for that form, we probably wouldn’t have
gone over it. I don’t like asking for help. [But] it made a
difference with me coping.

Family caregivers indicated that conversations about
the need for help were facilitated by the CSNAT and that
the assessment helped them see things in a more system-
atic way:

It got [my] husband and I talking about what I needed help in.
It got me to sort my thoughts out and get them in order so I
could think what I really did need help with at this time and
what was important enough to ask for help at this time. (P211)

Responses also suggest that the caregiving role was
suddenly found to be more manageable, not only because
it was no longer such a lonely role but also because the
CSNAT provided a vehicle to express needs and to break
problems down into more manageable components:
going step by step (P312). One respondent stated that she
went suddenly from being overwhelmed to thinking “I’m
going to have some help with this,” indicating that this
was like a little pressure valve [being] released (P416). Another noted that the “lines of communication” were
opened up:
It’s good for both of us—it showed me all the things that may happen in the future. It’s good for the Silver Chain carer—shows she has some understanding about what’s going on. (P258)

Theme 4: accessing support and how this was experienced. The support strategies that were implemented helped to meet family caregivers’ informational and emotional needs. Sometimes the nurses were able to meet these needs, at other times, other professional support was accessed. Participant 259 referred to the meeting of her needs for information about how the disease would progress in its terminal stages: *It’s the not knowing is the big thing—nurse is getting some booklets.* Participant 371 alluded to the provision of counseling support and how this was helpful: *Nurse arranged a counsellor—it lifted me ... talking about it has been much better.*

Nurses, in particular, were reported to provide support in practical ways that were responsive to individuals’ needs. In this way, they supported caregivers’ confidence in their abilities and their capacity to cope. Participant 138 stated, *... [the] nurse listened to me—gave me practical skills,* Participant 193 similarly emphasized practical skills but also the support available via the telephone, and his/her entitlement to this—the “sub-text” of this comment demonstrating the impact upon confidence: *Made me more confident (in giving Ordine medicine). Confident to call Silver Chain for advice any time.*

These support strategies also made family carers aware that they did not need to cope with caregiving alone—that they had a network of support upon which they could rely, as illustrated by this comment: *... feels like I’ve got someone helping me when I need it. It’s good to have someone to reach out to when you need it* (P371).

Prompt responses to clearly identified needs further promoted trust in the system and promoted a sense of validation. Participant 211 explained this experience: *Then nurse organised something and it happened right away. It felt someone really is listening to me now.*

There was also a sense that respite from caring allowed the caregiver to retain a sense of perspective, as illustrated by Participant 600: *Responsibility was taken off me—it was excellent when SC started showering. You don’t feel trapped—when you get a break and step into the real world.*

Sometimes participants indicated that they did not need additional support at this time, because of family networks or pre-existing skills. For example, Participant 595 stated, *No [I don’t need support] because I’ve got a big family and they’re all supportive. Also as I’m a carer at work I have an awareness.* Nonetheless, there was also some recognition that support might be needed in the future, as illustrated in the following response:

*I still have family that I can get support from—I won’t need to go & make an appointment with the counsellor at the moment— not yet. I want it to be in my family & my children—they support me & I’d prefer it that way. But later on when I can’t handle it on my own, the most likely I will need someone to talk to professionally …* (P312)

However, there were times when caregivers felt that they could not take up the support offered, even when it was what they needed—emphasizing the tension between the caregiver’s needs and those of the patient—also the sense that the patient’s needs should always take priority:

*The nurse rang to get respite—Mum found it too much. It was like a Catch 22 in some areas, but it was good knowing support was there if I needed it. Mum couldn’t handle it—whose needs were more important? Under different circumstances I’d take advantage of it. The one thing you need doing it, is a break, because you do tend to “climb the walls” … You have to be happy & uplifted to make them happy.* (P406)

An important point to add is that a subset of family caregivers had already been receiving support from Silver Chain Hospice Care Service and were complimentary about the support they were getting, all be it acknowledging the usefulness of the CSNAT:

*In our case we have had excellent support anyway from Silver Chain. I think the form is excellent though.* (P365)

To be honest Silver Chain is pretty switched on. It [CSNAT] made me more aware of it, but they were already doing all those things. (P297)

**Discussion**

This study has described the experience of 233 family caregivers of terminally ill people who completed the CSNAT in a community-based setting in Western Australia. The reported positive experience on the whole is compatible with this group of caregivers in the intervention arm of the trial experiencing a reduction in strain compared to the control group as a result of feeling more supported.18 While the support that the service routinely provides has been described as excellent, the CSNAT seems to have contributed to augmenting this existing practice by assessing the needs for the support in a more systematic and proactive manner. In particular, the findings highlighted the experience of the needs assessment as being validating, reassuring, and empowering, although confronting at times. More importantly, family caregivers, who are often reluctant to express their own needs and unlikely to feel these are legitimate, have articulated that the CSNAT approach has provided the opportunity to give them the permission to ask for help (as illustrated by P136) and therefore legitimized their own needs as separate from those of the patients. It is evident that the CSNAT has assisted with the reluctance of caregivers to ask for help.
for themselves, which usually has a detrimental effect on their physical and mental well-being.1,2,3

It is apparent that the family caregivers have appreciated the value of the CSNAT intervention in engaging them in conversations about their needs, priorities, and solutions. They felt it gave them the opportunity to consider and express their needs and identify what is important to them in a timely manner. The process certainly prompted them to “lift their heads” from the caregiving tasks and reflect upon what was happening and how they could best be supported. This was not necessarily a comfortable thing to do although there were benefits that flowed from it. Moreover, the process allowed the family caregivers, together with the nurses, to cover all the domains for support and in the one visit. Therefore, it provided them with an early preparation for things to come and introduced them to a range of areas where they may require support, as depicted by Rabow et al.24 “they don’t know what they don’t know.” A number of participants had commented that undergoing the CSNAT intervention would have worked better for them in the early stages when they had a lot of uncertainties.

It seems the solutions undertaken to meet the needs of family caregivers have been within the service capacity, although on many occasions the actions planned were within the realm of what caregivers themselves or their families and other informal networks can provide, or they were facilitated by the service itself or required referral to other agencies. This is reaffirming that support may not need to always come from the service provider, and the opportunity for discussions provided by the CSNAT approach has broadened the sources of support. Burns et al.25 have emphasized the importance of the “invisible network” of caregivers (other than spouses and adult children) to health care providers, in “sustaining high quality of life in the dying process” (p. 614).

Strengths and limitations

To our knowledge, this is the first study nationally and internationally to illuminate the experience of palliative care support needs assessment for family caregivers through a qualitative investigation. The 100% response rate and the large number of participants have helped to ensure that diverse views have been captured. Should budgetary factors allow it, there is a clear advantage to undertaking telephone interviews with family caregivers rather than postal surveys, where in similar studies response rates were about 30%.4,26 It is also worth noting that this group of family caregivers has been engaged through several steps of the research process leading up to this last contact with them and the development of a trusting relationship in which they felt more confident to disclose.

This study has been conducted in one geographical area of Australia, although the three recruitment sites are located in the northern, southern, and eastern suburbs of the metropolitan Perth, thus allowing a varied demographic mix of the population. Nevertheless, it may be that the experiences of family caregivers, elsewhere in Australia and in other countries, could be different depending on the organizational structure of the service provider, the health care system in the country, the availability of support, the type of terminal illness, and profile of family caregivers and their care recipients. However, the indications from the UK study are that the UK family caregivers share similar experiences and perceptions to those in this Australian study.27 Moreover, while cancer was the predominant illness in this study, there was a wide spread in the characteristics of the 233 participating family caregivers, for example, caregiver age ranged from 20 to 88 years, patient age ranged from 28 to 94 years, 16% of caregivers were from a non-English speaking background, caregiving length ranged from 0.1 to 420 months, and period of receiving palliative care ranged from 0.3 to 29 months.

Conclusion

This study provided a comprehensive insight into the experiences of family caregivers of terminally ill people using the CSNAT assessment process. The straightforward, caregiver friendly question format (do you need support with …?) provides practical implementation in informal care. The CSNAT is a standardized assessment tool that ensures that the family caregiver’s own health and support needs are recognized in conjunction with those needs necessary for the care recipient. Caregivers’ needs are not invisible because of the tool’s focus on supporting caregivers and therefore placing them as co-workers with service providers. The tool acts as an incentive for caregivers and service providers to look at many areas affecting the caregiver’s own direct needs as well as their caring needs. While the tool’s testing has predominately been in caregivers of cancer patients, the generic nature of the questions means that the tool may be useful for caregivers of people with other life-limiting illnesses, such as Motor Neurone Disease and Alzheimer’s Disease, and in care settings other than home, such as post-discharge planning from palliative care units.

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The authors declare that there is no conflict of interest.

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