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Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: A qualitative study

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Abstract

Background: Current end-of-life care policy and guidance recognises the important contribution of family carers, recommending that their needs should be assessed to support them in their caring role. How regular carer assessment is to be achieved is unclear, particularly because there is no evidence-based tool for directly assessing carers' support needs that is suitable for use in end-of-life home care practice.

Aims: To obtain carers' perspectives of key aspects of support needed during provision of end-of-life care at home and to develop a carer support needs assessment tool suitable for use in everyday practice.

Design: Qualitative using focus groups and telephone interviews. Thematic analysis uses a framework approach.

Setting/participants: 75 adult bereaved carers who were family members/friends of patients referred to five Hospice at Home services in the UK.

Results: Carers' needs fell into two distinct groupings of key support areas or 'domains': support to enable them to provide care for their relative and more direct personal support for themselves. Many aspects of supportive input were common across domains, for example, anticipatory information, explanations or being included in the care process. Therefore, the tool was designed as a screening measure, to identify support needs requiring further detailed assessment.

Conclusions: The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based direct measure of carers' support needs in 14 domains. It is short but comprehensive in approach and thus suitable for both end-of-life care research and practice. Further work has been undertaken to test its psychometric properties.

Keywords

Carers, needs assessment, palliative care, evidence-based practice, qualitative research

Introduction

Most patients with advanced disease would prefer to die at home.¹ Carers (defined as 'lay people in a close supportive role who share the illness experience of the patient and who undertake vital care work and emotion management'²) play a crucial role in enabling this choice to be achieved.^{3,4} However, providing care at home comes at a considerable cost to carers:⁵ there is extensive evidence of negative impacts of care-giving on carers' physical health^{6–8} and emotional well-being.^{8–11} Carers experience social isolation,^{6,12,13} pressures on finances and employment,^{14–16} as well as increased mortality.¹⁷ Given the impact of the care-giving role, recognition of the need to support carers is manifest in government

policy,¹⁸ with guidance stressing that carers' needs should be 'assessed, acknowledged and addressed'.² However, it is not clear how carer assessment is to be achieved and, in particular, there is no evidence-based tool for comprehensive assessment of carers' support needs that is suitable for use in home care practice.

There is an extensive research literature, from the mid 1960s, on carer measures developed to study the impact of long-term care-giving. Many measure care-giver burden, particularly of those caring for relatives with conditions such as dementia and Alzheimer's disease (reviewed by Deeken et al.¹⁹). More recent tools^{20,21} take account of a broader range

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of conditions, but again have been developed and tested in gerontology, in a long-term caring context. In contrast, end-of-life home care is often shorter and more intense, resulting in different demands on carers. In this context of care, a recent systematic review identified 62 measures for use with family care-givers of palliative care patients.²² These encompass a broad range of care-giving experiences, including burden, preparedness and other indicators of care-giving difficulty, such as depression and anxiety. However, despite the range of tools identified, most do not measure support needs directly, rather they act as indicators of carers' need for support.²³

Even where support needs are measured more directly, these tools are not well suited to effective and comprehensive assessment in practice. Some are restricted to psychological needs and understanding of the care-giving situation of the patient²⁴ or are measures of satisfaction with care received.²⁵ More comprehensive instruments, such as the Home Caregiver Need Survey,²⁶ the Problems and Needs in Palliative Care²⁷ and the Caregiving at Life's End Questionnaire,²⁸ are well tested, but their number of items (90, 76 and 73, respectively) raises serious questions about feasibility in practice. Thus, at the outset of this study, no existing research tools for assessment of carer support needs were identified as suitable for use in practice. Since then, one further carer tool has been published, the Needs Assessment Tool-Caregivers (NAT-C).²⁹ Although a shorter tool (32 items), the NAT-C is intended for a different context (general practitioner (GP) consultations) and also incorporates items that act as indirect indicators of needs, such as feelings of burden, meaning and relationship issues.

There is also a dearth of assessment tools developed from and used within a practice context. In 2009, a Help the Hospices Working Group reviewed carer assessment forms used in practice when developing guidance on identifying carers' needs in the palliative setting.³⁰ Reviewed assessment forms varied considerably in content, purpose and comprehensiveness. Accordingly, the Working Group concluded that there was little commonality in how providers currently assess carer needs.³⁰

Thus with no suitable tool identified in either a research or practice context, the need exists for an evidence-based assessment tool for carers' support needs for use in practice. Such a tool is required to fill the gap between validated but overlong research measures and ad hoc assessment forms from practice. The purpose of this paper is to explore perspectives of carers regarding key aspects of support needed during end-of-life care and use these accounts to inform the content of a Carer Support Needs Assessment Tool (CSNAT) that is suitable for use in end-of-life care practice at home. The subsequent psychometric testing of the tool is described elsewhere (paper in preparation).

Methods

The study design was qualitative, using focus groups and interviews with bereaved carers.

Setting

Building on an established research collaboration with the National Association for Hospice at Home (NAHH), five Hospice at Home (H@H) services within its membership participated. H@Hs provide important support for palliative patients and their families, with input associated with better quality home care³¹ and more patient and family needs being addressed.³² A Research Steering Group was established within the NAHH management group.

Recruitment of participants

Participating H@Hs from across the UK identified adult carers (family members/friends) of patients referred to their service, who were six to nine months post bereavement. All carers were invited to participate unless they were under 18 years or the service had concerns about their ability to cope with the research due to exceptionally high distress in bereavement. Services sent carers a recruitment pack containing an invitation letter, information sheet, reply form and pre-paid envelope for its return. Carers who wished to take part returned the reply form directly to the research team with contact details. Bereaved carers were contacted only once: the Research Ethics Committee did not give permission to follow up non-responders.

Carers who returned a reply form were contacted by telephone to answer any questions and to arrange data collection. They were invited to take part in a single focus group (with choice of dates). To include those who had difficulty travelling or did not wish to/were unavailable to take part in a group, an individual interview, conducted by telephone, was offered. From the outset, it was made clear that the study was being conducted by a university-based research team, independent of the local H@H services.

Study sample

Ninety-five carers agreed to take part (19% response rate overall): of these, 75 participated (see Table 1 for participant characteristics). Nine focus groups were conducted

Table 1. Participant characteristics (N = 75).

45 (60%) women
Age range 35–82 years: median 66 years
70 (93%) cared for a patient with cancer diagnosis
Cared for: spouse/partner (59: 79%), Parent (13), Son/daughter (2), Sister (1)
Main cancer diagnoses: Lung (10), Brain (9), Colon (8), Breast (7)
Other diseases: Motor Neurone Disease (1), Fibrosing Alveolitis (2), Chronic Obstructive Pulmonary Disease (1), Parkinson's Disease (1)
Place of death: Home (51: 60%), Hospice (17), Hospital (6), Nursing Home (1)

with 53 carers at five H@H sites. Groups had four to eight participants and lasted between one and a half and two hours. Twenty-two carers took part in individual interviews, ranging from 10 minutes to approximately one hour. Shorter interviews tended to be where carers wished to report satisfaction with support they had received.

Data collection

Focus groups were hosted locally by H@H services and were facilitated by GE and another research colleague. Participants completed consent forms and background details about themselves and the cared-for person prior to the discussion. At each venue a H@H staff member was available if carers became upset by the discussion and wanted support. Participants did become emotional during groups but none felt the need for this additional support. A debriefing follow-up telephone call was made the next day to all group participants to check on their emotional well-being. Individual telephone interviews (also conducted by GE) were arranged at a time convenient to participants. All interviews finished with a debriefing period of general discussion.

Focus groups and interviews explored carers' views on their support needs while they had been caring for a family member/friend at the end of life, focusing particularly on the last two to three months of life. They were recorded digitally, with the permission of participants. Carers were asked about key aspects of support, that is, support needs that were met and input perceived to be helpful, but also shortfalls in provision where needs had not been met. Discussion extended to factors that had aided coping and support (or its absence) that had an impact on them. It was made clear during data collection that although they had been contacted via H@H services, the focus was on support needed by carers during end-of-life care at home, not just support provided by H@H.

Data analysis

All audio files were fully transcribed. They were checked for accuracy, anonymised and imported into Atlas.ti. A thematic analysis was conducted using a framework approach³³ to determine carer-identified aspects of support. This involved initial reading of the data for familiarisation, then an initial broad thematic framework was devised by GE based on both focus group/interview topics and additional issues raised during discussions. This framework was used to index the data set. Then data relating to each support area identified by carers were extracted and analysed by both GE and GG. Analyses were compared and interpretations agreed. In the final part of the analysis process, key aspects of support identified by carers were further reviewed and used to structure the content of the assessment tool.

Findings

Findings are presented in three sections. Firstly, carers' support needs in providing care for their relative are described (although the term relative is used here, those cared for may have been friends rather than family members). The second section describes more direct support needs for carers themselves arising from the impact of their caring role. Illustrative quotations for both groupings are provided in Appendices 1 and 2 and referenced in the text: the abbreviation 'Q' refers to numbered quotations in the appendices. In the third section, the process of developing tool items from the qualitative findings on support needs is described.

Support to enable the carer to provide care

Carers felt a strong sense of responsibility for both ensuring their relative had appropriate care and for carrying out many aspects of caring themselves. These were support needs during the last months of caring for their relative, including through to death itself.

Having a named support contact (Q1–Q4). When study participants had found themselves in a caring role, months or in some cases only weeks before the patient's death, most were unclear about what to do, who could help and how to contact them. They often had little knowledge of health care systems and where to find support. What appeared to distinguish those who described a more positive caring experience from those who did not, was whether they had a contact for support. However, this was not just a telephone number, it was a *person*: someone they could contact who knew *their* situation. Being able to make contact for support was needed both in daytime and out of hours. Carers with a key/named contact person were able to access advice and information and further support services. Carers did not necessarily make use of named contacts a great deal, but reported reassurance from knowing that there was a person they could call if needed.

Managing the patient's symptoms and medicines (Q5–Q9). Carers made a compelling case for the importance of being supported with managing symptoms/medicines. Most had felt competent managing routine oral medications when things were relatively stable. However, they also had to deal with progression in symptoms towards the end of life to ensure that symptom control, particularly pain relief, was achieved. This was a continuous process of checking adequacy of medications, described by one carer as having always to 'be on the ball' (FG: A4).

During this phase carers had different information needs, including more understanding about medications they were left to administer. A recurrent theme was lack of support with knowing how to access help with symptoms out of hours, which could result in patients being admitted to hospital.

Explanations were particularly important during end-stage care with syringe drivers. Where given, explanations were greatly valued but, more often, carers reported no preparation about how syringe drivers may affect communication with the patient.

Carers also identified support needs other than information. In order to achieve better symptom control they needed to contribute their perspective on patient symptoms, particularly where patients themselves were reluctant or less able to do so. Some carers learned new skills, such as giving injections, which enabled them to maintain some normality and keep patients at home. Even when not actively managing medications, carers identified the need to be included: in decision making and particularly being present with the patient during the medication process.

Support with equipment (Q10–Q13). Help and support with equipment was essential in enabling carers to care for their relative at home, through to death if that was their wish. For many, knowing what equipment was available was for them. Their need was for anticipatory guidance about what was (potentially) available and what might be needed as the patient deteriorated.

Carers needed a wide range of aids and pieces of equipment in their caring role, which they often did not know how to source, and appreciated when professionals organised for them. However, this also had to be based on whether it was actually required and would be used (e.g. hoists to move patients). Supply of equipment in itself created further support needs: carers also required explanations and instructions on using specific pieces of equipment, which were not always provided.

Providing personal care (Q14–Q16). Carers' need for support with providing personal care came during later stages of care-giving: as patients deteriorated, mobility became a problem and they were no longer able to self-care. At this stage, patients needed 'hands-on' care. Where patients with limited mobility or self-care abilities had been discharged home from hospital, carers' needs in relation to managing personal care were often reviewed, forming an important and supportive part of the discharge process. However, this did not always happen, leaving carers to manage alone. Although some carers were happy to hand over this aspect of care-giving, others wanted continued involvement in providing personal care, and being excluded caused distress. Sensitivity to this need was a positive support, as was learning new skills such as turning techniques.

Support to understand the illness (Q17–Q19). At the time of diagnosis, carers had wanted to know about the disease and its effects, including patient prognosis. These needs mostly remained through to the last months of life, especially for carers whose relative was diagnosed with advanced disease

only shortly before death. However, information was not always provided, even where carers made clear it was needed and they were left to find out this information themselves. As the disease progressed, carers required this information to know what symptoms to expect, both to be able to care for their relative and to help them deal with the situation in which they found themselves.

Support to understand the dying process (Q20–Q23). Carers needed information about dying and closeness of death. Most had not been through this process before: they wanted information in advance, to be able to anticipate what was going to happen. Explanations by known professionals were an important support, but were not always given. There was also a need to understand the significance of different symptoms, such as changes in breathing and lack of appetite. A few carers who knew the signs were able to recognise the closeness of death, but not knowing the signs of the dying process caused additional worry for carers as they tried to care for their relative.

Talking with the patient about the illness (Q24–Q26). Related to carers' needs in understanding the disease and dying process was being able to talk with their relative about the effects of their illness and closeness of death. Carers described positive experiences of openness in talking about dying. This was valued for different reasons: to ensure wills had been put in place, enable appropriate preparations for funeral arrangements and to allow family members to say their good-byes. However, not all carers were able to have such discussions. Even where they wished to do so, some carers found themselves caught between wishing to remain positive and supportive towards their relative, but also having to deal with the knowledge that their relative was dying and wanting to know what their wishes were.

Carers described the need for more direct help from services to enable them to talk to their relative. Some had experience of nurses initiating such discussions, while others had to ask directly for help to facilitate a conversation. However, where families were unable to talk openly about dying, finding the opportunity to express their need to talk with the patient about the terminal nature of their illness could be difficult.

Support at the time of death (Q27–Q29). Carers identified that they needed information about what to do when the death itself took place at home. As one carer put it, in the run up to her mother's death, she 'didn't have a clue' (Int 22) about arrangements that had to be made. They needed to know what to do, but carers also discussed the important support of having a health care professional present around the time of the death and particularly having help with managing the body. Where this happened, carers described a calm situation dealt with professionally. However, not all carers had this support and this appeared to have a lasting impact on them.

Direct support for the carers themselves

While carers were willing to discuss support needs to enable them to provide care for their relative, there was some reluctance to move the focus of discussion to more direct support for themselves. This appeared, in part, to reflect their own focus during care-giving, where they wanted to concentrate on the patient rather than on themselves. Attention to their relative's needs was more important and in itself supportive. It may also have reflected their experiences of the assessment process. Contacts with health professionals came about because of their relative's illness: the patient, not the carer, was referred to the visiting service, so addressing their own needs may not have felt legitimate. Usually carers were asked how they were, but these were often 'doorstep conversations', rather than a formal assessment of needs:

...but it was like as I was showing them out the door, they'd turn round and say, 'Well how are you?' I think I would have liked if they... When we'd seen [wife], come down and sit down and have a consultation with me. And although they always asked, it was more like, as they went out the door. Sometimes it was a long conversation on the doorstep. FG:C3

Their commitment to care-giving and intensity of their involvement, however, had a considerable impact on many aspects of carers' lives. Thus, from these discussions a set of more direct support needs for themselves as individuals was identified.

Respite support (Q30–Q37). Carers identified respite as a key support for themselves due to the strain of care-giving and associated tiredness. Some could rely on family members for a break, but this was not always feasible if they were living at a distance or where patients required more than just someone to sit with them. Patients could be reluctant about carer respite, not wanting care from anyone else. Carers too did not always recognise their need for respite and often had to be persuaded to accept help. Where it was received, a break that gave them time for themselves was often described as making a great difference. Also valued was having responsibility for the patient relieved for a short time. In the end stages carers did not necessarily want to leave the patient, but even just a short break was important and the positive effects of this remained with them.

In the later stages where patients needed regular assistance during the night, for example, with toileting or managing medications, the impact on carers was great, particularly for those who were non-resident and had other family responsibilities. By this stage, carers said they were exhausted: respite overnight was an essential support, allowing them some sleep. However, the type of respite provision was particularly important: most were reluctant to have respite that required the patient to be admitted to hospice/hospital. They felt able to

accept home-based support because home was where patients wished to remain. However, where patients needed medications administered or equipment such as oxygen pumps required attention overnight, a nurse rather than a care assistant was needed. Otherwise, carers found themselves still with main responsibility for the patient.

Physical health concerns (Q38 and Q39). Effects of care-giving on carers' physical health were not always realised at the time. It was only when they reflected back that they recognised the impact on their physical health. Those who had existing health problems when they became carers had been concerned about how they were going to manage. Others suffered recurrent infections during care-giving or developed injuries by lifting, and this continued to have an impact on them. However, they also identified that it was difficult to attend to their own physical health needs whilst in the midst of care-giving, and in these circumstances, there was a need to 'give yourself permission to be ill occasionally' (FG:J5).

Financial and work issues (Q40–Q43). Juggling caring with work can present considerable challenges. Self-employed carers had some flexibility to organise care-giving around work commitments, others benefited from supportive employers, by being able to take some leave from work. Other carers had been at home full time due to retirement. Many study participants thus had been able to provide care at home, but they acknowledged that their personal, financial and work circumstances had enabled this. They recognised that this was not true for all carers and this was an area where support was needed. For one self-employed carer who worked mostly from home, respite support enabled him to work away for short periods. The pressure of trying to work while also being a carer was difficult, with concerns expressed about not doing the job well and not doing caring well either.

Carers also needed help regarding their entitlement to state benefits in relation to their care-giving role. That was particularly the case for those who had to give up work to look after their relative, but also for full-time carers at home who, despite the amount of care-giving being done, were often unaware of their eligibility for different allowances. Carers needed information and advice on what was available and assistance with applications.

Practical support (Q44–Q46). Carers identified the need for practical help in the home as a means of overcoming the difficulty of accomplishing everyday household tasks that had to be done whilst in a caring role. Lack of this practical help added to the stress for some carers, particularly when they were working outside the home. Some had practical support from friends or family members, helping with meals or enabling them to get out for shopping. A very few were in the position to pay for this support. More commonly, carers used

Table 2. Carer Support Needs Assessment Tool (CSNAT) items and supporting references.

Qualitative data category (key aspects of support identified by carers)	CSNAT items derived : 'Do you need more support with ...'	Examples of supporting references
Having a named support contact	→ knowing who to contact if you are concerned about your relative (for a range of needs, including at night)	27,44
Managing the patient's symptoms and medicines	→ managing your relative's symptoms, including giving medicines	37,45
Support with equipment	→ equipment to help care for your relative	46,47
Help with providing personal care	→ providing personal care for your relative (e.g. dressing, washing, toileting)	6,46
Support to understand the illness	→ understanding your relative's illness	48,49
Support to understand the dying process	↘	
Support at the time of the death	→ knowing what to expect in the future when caring for your relative	50,51
Talking about the illness	→ talking with your relative about his or her illness	52,53
Respite support	→ having time for yourself in the day	54,55
	→ getting a break from caring overnight	56,57
Physical health concerns	→ looking after your own health (physical problems)	7,8
Financial and work issues	→ financial, legal or work issues	58,59
Practical support	→ practical help in the home	39,40
Emotional support	→ dealing with feelings and worries	9,10
	→ your beliefs or spiritual concerns	42,60

the respite time provided, having someone to look after their relative for a few hours, to free them to do practical tasks. Essential shopping, ironing, housework and mowing lawns were all done during this break from care-giving.

Emotional support (Q47–Q50). Carers in the study made clear that they found it helpful to be able to talk to someone about what was happening to the patient, ask questions and check things out. At a different level was support for carers themselves: an opportunity to express their feelings about caring for a dying relative and to be listened to. This was recognised by those who had received this type of support and also those who felt that it had been absent. However, there were also expressions of reluctance to take time away from their relative's care, guilt about wanting to talk about themselves and concerns that need for this type of support was indicative of not coping. For some carers this more focused support came through the church or their personal beliefs and it was important that they had the time for this. However, it was also recognised that some carers may not want spiritual support and respect for this position was important too.

Identifying assessment tool domains

Carers identified a range of key areas of support needs in end-of-life care (such as support with managing symptoms and medicines or support with financial and work issues). The study findings also showed that the specific supportive input required to address each of these (e.g. information,

being included, education, practical input) was both detailed and individual. In terms of tool design, generating items to assess precisely what type of supportive input was required to meet individual needs within each of these areas was not an option, for two reasons. The first was pragmatic: the resultant tool would be too lengthy for use in practice. Secondly, the qualitative findings also showed that there were commonalities in supportive input required across key areas. For example, need for information was a component within each support area carers identified: in the form of anticipatory guidance of equipment available, explanations about symptoms or medications or instructions about performing aspects of personal care. This was also the case for some other support needs, such as learning new skills to care for the patient or being included in different aspects of care. Therefore the tool was designed as a screening measure, structured around support broad areas or 'domains'.

Specific support domains from the qualitative findings, which were also evidenced within the research and policy literature, were conceptualised to form items for the assessment tool (see Table 2). Most items were derived directly from a single support category, for example, the category of having a named support contact translated directly to the item 'knowing who to contact when concerned about your relative'. The two categories of understanding the dying process and support at the time of the death were combined into a single, broader, item of 'knowing what to expect in the future when caring for your relative'. Respite support needs were revised to items on day and night respite. Finally, the category of

emotional support was divided into two separate tool items: 'dealing with feeling and worries' and 'support with beliefs or spiritual concerns'. The decision to combine/divide support categories is addressed further in the discussion below.

The screening format enabled design of a comprehensive assessment tool in terms of the range of support domains assessed, without the burden of it being too lengthy. The intention was that items included on the tool would enable health professionals first to identify domains in which carers required more support. Once identified, a further discussion can take place with carers to find out the specific type of supportive input they need within any given domain. The intention of the tool is to open up discussion between carers and health professionals about support needs. It is not the role of the tool to prescribe actions health professionals may take to support carers, as this will depend on the individual care-giving and service provider context.

Discussion

This paper identifies carer support needs with the specific aim of informing the design of a carer assessment tool for use in practice. Focus groups and interviews with bereaved carers about the end period of care-giving enabled them to identify support they received that they felt was helpful and also support they felt they needed but did not get. Furthermore, having gone through the experience of care-giving, it was by reflecting back that many realised the extent of their support needs, such as in relation to their physical health. The study found two distinct broad groupings of support that carers needed: to enable them to care for their relative and more personal support for themselves. These two groupings of support needs concur with Twigg's³⁴ conceptualisations of co-worker and co-client relationships between carers and social care agencies. In a hospice palliative care context, Stajduhar et al.'s³⁵ analysis of dual family care-giving roles found that carers situated themselves and were situated by health professionals in both of these roles, which could be occupied simultaneously. In the UK, the End-of-Life Care Strategy¹⁸ recognises carers as having their own needs and also that they are central to the team caring for someone at the end of life. The Strategy indicates that carers 'should be treated as "co-workers" with the health and social care team' (p.107), whereas our findings clearly identify their need to be *supported*, not just *treated*, as co-workers.

Carers expressed a strong sense of responsibility for ensuring their relative had appropriate care, as well as for carrying out many aspects of caring: a co-worker role requiring acknowledgement and support. When there is a lack of recognition and valuing of contributions of carers in this role, carers can feel disempowered,¹⁶ which has the potential for further longer term consequences. In this context, Andersson et al.³⁶ highlight the importance of enabling next of kin to remain involved in care-giving, even when there is substantial

formal care support. Other authors have similarly identified the vital role played by carers in symptom assessment and management and their need for supportive input to enable them to fulfil this role.³⁷ Previous research confirms that while carers prioritise their need for support as co-workers, in contrast, they are more reluctant to focus on direct support needs for themselves,³⁸ despite the considerable body of evidence showing the substantial impact that care-giving has on carers.^{6-16,39,40} Ambivalence that carers have been shown to have regarding their own needs⁴¹ provides further evidence that carer assessment should help make explicit carers' needs for support for themselves. Thus, structuring of the tool in terms of support needs of carers as both provider and recipient of care provides a more comprehensive approach to their assessment. Stajduhar et al.³⁵ suggest that individualising interventions (in this case, an assessment tool) to one role or the other may obscure the complexity of palliative care-giving.

Tool items derive directly from the qualitative findings and are endorsed in the research literature (see Table 2 for supporting references for each tool item). Two aspects of support identified by carers, understanding the dying process and support at the time of death, were combined to a single tool item on what to expect in the future. 'What to expect' was terminology that carers themselves used and acknowledges wording used on other tools.^{26,28} This wording was also chosen considering possible use of the tool with carers at different stages of care-giving, both in terms of time period before the patient's death as well as level of acceptance of their relative dying. Both respite support and emotional support were each divided into two separate items. Respite support is provided during the day for a few hours and may be used for different purposes: time for carers to see other family or friends or to accomplish tasks such as shopping that they would be unable to do otherwise. In contrast, overnight respite may not be required until the terminal phase, with a nurse or carer present to care for the patient. Two separate items were also created for support in dealing with feelings and worries and support with beliefs or spiritual concerns. This distinction is also made within policy guidance.² A recently published population survey of former palliative care-givers further supports the need for separate assessment of spiritual support. Hegarty et al.⁴² found a strong association between need for additional spiritual support and other domains where additional support would have been helpful. The authors concluded that the need for additional spiritual support may be a cue for other unmet support needs across a larger number of domains.

The resulting tool, the CSNAT, was designed to measure support needs directly, unlike many existing research measures, where need is inferred from different indicators of care-giving difficulty.²³ Adopting a screening format based on support domains has resulted in a short assessment tool: feasibility issues were a paramount consideration in designing a tool suitable for use in practice.³⁰ Other evidence-based

needs tools are not used routinely in practice²⁶, a possible consequence of the number of items and time taken to administer. Furthermore, the CSNAT provides a structure to the process of carer assessment to aid health professionals in meeting existing recommendations that carers' needs should be assessed. Collectively, the tool items encompass assessment of physical, practical, social, financial, psychological and spiritual support needs that current policy guidance indicates should be delivered to carers during end-of-life care.^{2,18} As well as having benefits for health professionals, the tool's structure itself may also go some way towards introducing carers to the range of areas in which they may require caregiving support. A recurring theme in this study and one that has been previously identified⁴³ is that carers' 'don't know what they don't know'. This assessment tool, with 14 broad domains of support needs, may start to address this difficulty.

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Conflict of interest statement

The authors declare that there is no conflict of interest.

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Appendix I. Illustrative quotes for support needed to enable carers to provide care

Having a named support contact

- Q1 ... guidance as to what is available, how to contact them and for what sort of things they're available. The guidance has got to be given to us in such a way that we retain it. Because our minds are not receptive in the state of anxiety, panic what have you. FG:BI
- Q2 ... but every single time you ring NHS Direct, 'Hello. My name's... My husband has this...' Blah, blah. And you go through the WHOLE story time after TIME AFTER TIME AFTER TIME. And I understand they need to log it, you know, and it's just constantly repeating that and it's so hard. Whereas you know, you have somebody there and they'll go, 'Well actually this would be the best thing.' 'Okay, I'll do that', you know. FG:C5
- Q3 And actually my husband died on a Sunday, so I had to contact them then. But they were always there 24-7, you know. And that was very reassuring, you know, because you just don't know what to do, and what... or sometimes the symptoms they show you don't know whether... how important it is. FG:F7
- Q4 It is just knowing that you've got this, like a safety net, if you're going to... Not necessarily panic, but you know, you perhaps are going through a very depressed period yourself. Or there's something that you don't understand, you can... you can just contact them. I think to me, that was the most important thing. FG:G5

Managing the patient's symptoms and medicines

- Q5 As you say, things often fall apart after five o'clock then they are unfortunately taken into the wrong place, the hospital. My experience of the District Nurse refusing to give the diamorphine, phoned the GP who said you can't give it either. It was absolutely ridiculous in a palliative care situation. FG:J6
- Q6 A1: The medication for the ... you know, the pump, the driver and everything was all there, but no one said to me what ... I found out because I'd looked in the damn thing, you know ... but it was tucked in the corner and it was all there ...
A3: But you see that's very very bad, that is very very very bad. I mean we sat ... we had a big dining table and we all sat at the table, this is what happens when you go on the syringe driver, this is final, and we were aware of that. Everybody should be aware of that. (FG:A discussion)
- Q7 ... he was very poor at explaining it to them, so I think actually when they realised that I was going to be able to give them more information it was helpful on both sides basically, and from that point on the consultant communicated with me directly. I mean we still included dad, but ... you know, she realised we were going to have better results by dealing with each other directly. Int 06
- Q8 ... I think you were talking about looking at your wife's helping with medication. [Husband] had [named] injections for a long time and I was able to give those and was trained to do that. And that... I know it was supporting him, but it enabled me in a very practical way at home, to help with his care, and meant that he didn't have to have a nurse come in every day to do it. And that was huge. FG:G3
- Q9 ... and I asked if I could be in the room with him, and I was told no, and I did bring it up to the nurse and the doctor and I said I felt that right at the very end I'd let him down. Because I only wanted to be there, I only wanted to hold his hand, and sit beside him. Int 10

Support with equipment

- Q10 A catalogue of all the aids you can get, the physical aids, so you can actually see them. Because a number of things they were talking to us about and we'd got no idea what they were and trying to describe them. FG:J1
- Q11 She put everything into place. A wheelchair and fortunately I didn't need a commode, but things... vital things like that, which you don't know how you're going to source them, or who you've got to contact to get all these facilities. FG:F7
- Q12 [Patient had falls and was difficult to lift up from the floor. A special cushion to help with this was found]
She [nurse] only had her kind of training cushion that she had, but she assessed it as being helpful in these circumstances, so she ordered up another one, and then she gave us her training ... the one she used for training... and if she hadn't done that, again, by the time the new one came she [the patient] had gone through the stage ... because she was getting on towards the point of being bed bound then, so it's just that flexibility of people that was ... was fantastic. Int 20
- Q13 [Talking about changing a catheter bag]
I was doing all the wrong things for the first couple of days, and kept changing it and emptying it and things like this, which made sense to me, but evidently every time you do allow infection to get in if you're not careful. And I do think that I should have had some form of ... a lesson or instruction rather than just be ... having to deal with this. Int 18

Appendix I. (Continued)

Help with personal care

- Q14 ... every time I went in hospital they would say there's a care package in place and as soon as I got home there was nothing, so that I would end up on the phone screaming where is my help, bearing in mind that when you're nursing somebody like that it's just ... it's 24/7, it is 24/7, they're incontinent, a lot of the time they're trying to get out of bed and then you'd try and get them back into bed, you can't reason with them at that point with a brain tumour. FG:D5
- Q15 And the hospice nurse ... would come with our GP nurse in order to help wash him, turn him and so on. And what I found really helpful, as far as I was concerned, they let me help as much as I could, as much as I wanted to. Where it was appropriate I would physically help wash him and bathe and change him. FG:H4
- Q16 And I think on the last... probably the last two days of mum's life, they helped to turn my mum, because I couldn't do that on my own. They showed me the technique of how to do that, so I could do it with my brother or my sister-in-law. Int 22

Support to understand the illness

- Q17 With me I think initially it was no information from anybody was given to me about the condition. They gave me a name and the estimated time left which was completely wrong.
[] I had to go on the internet and look up the complaint, what was wrong and went on open forums with other people in the same boat as me worldwide FG:D1
- Q18 I think with something you picked up on before is that because a lot of our anxiety is about the quality of the care for my mum, it was really ... a lot of it was about, you know, trying to understand where the illness was, what we ... what we were experiencing with her, any things we could do that would be ... sort of an improvement on what we were already doing. Int20
- Q19 I would have been able to have dealt with it much more easily because that was the kind of person that I am. I LIKE to know things. If somebody had sat me down and said, 'You realise what's happening with this illness now.' FG:J3

Support to understand the dying process

- Q20 But I felt, backing up what [another FG member] said, sometimes you needed 'Well this is what's likely to happen, and these are the stages, that's likely to happen.' [Several different voices saying 'Yes']. And I think a conversation or two like that would have helped a lot, to set expectations. FG:C3
- Q21 Well it's just knowing that somebody who understood cancers and was able to explain to me what was actually going on. And you know, they didn't precisely say this is the end. [Wife] had recovered so many times that you know, we thought she'd go on and on anyway. FG:G1
- Q22 He was a three meals a day man and once his appetite had gone I knew we were in trouble. And I had nursed my mother. My mother died at home and I knew that once she stopped drinking that it wasn't very long. And when he stopped drinking I knew that our time was pretty close. FG:B7
- Q23 ...when he started to go off his food ... then I was sort of trying all sorts of things to get him to eat, and he was trying to eat them to please me, I know he was, and ... Obviously now I read that over ... in the last week or fortnight, they will go off their food, and not to worry about, but I did really worry. I really did worry that he couldn't eat. Int10

Talking with the patient about the illness

- Q24 And I think what I appreciated was their honesty and right from the beginning we were able to talk about dying. [Mod:You were?]
We were. And we could talk about what... what [husband] wanted for his funeral. What music he liked and poetry and where he would like his ashes. FG:H4
- Q25 Now okay, and we'd done it because it was triggered by the fact that my mother died [a few years earlier]. But I don't know, but nobody ever said to us, 'You know, have you thought about wills?' And I say, I don't know whether anybody has said anything like that to any of you, but it's something which ought to be there, however tactfully it's put. FG:C1
- Q26 Because I didn't know what he wanted, and I suppose secretly in my mind I thought 'Well he just might...[die]'. I did ask the [H@H] nurse if she could bring it up with [Husband] while I was there, so she could introduce it. FG:F6

Support at the time of death

- Q27 Because again we didn't know what was happening, you don't know what to do. When do you call the funeral director, what do you do, you know, this is the first time this ever happened to you. FG:D4
- Q28 She [H@H nurse] did get out of bed and leave her 16 year old daughter and drive over from [Town] to help with [husband] the day that he died. Which is above and beyond the call of anybody's duty to be quite candid. FG:B3
- Q29 I went into her room with the carer [from social care], realised my wife was dead, immediately the carer rushed out and said she wouldn't go in the room and disappeared. I then phoned [H@H] because I was given a number to say 'Contact the duty...' whatever. I got an answerphone. I phoned three times and got an answerphone. I finished up dialling 999 and speaking to the ambulance people.
[] In the meantime, they [H@H] contacted a doctor, the doctor turned up at half past ten. It was a woman, and she ran across my front lawn, came in, looked at my wife. Put a stethoscope on her and said 'Yes, she's gone' and ran out again. I literally chased the woman out saying 'What do I do next?' and she said 'Contact your GP' and then drove off.
[] But that's the one aspect of the whole situation where I could have done with all the help under the sun, and didn't get it. Literally did not get it. FG:F1
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Appendix 2. Illustrative quotes for direct support for carers.

Respite support

- Q30 I couldn't leave him because he was dying, with a friend. You know I had lots of people who would say, 'I'll come and sit with him.' But you can't do it.
[] And he was on oxygen constantly. And you know, it didn't always work and sometimes it broke down, you know. FG:B2
- Q31 It is very, very hard. I had my husband's family and my own family all saying to me you should get more help, and my husband said 'We don't need it'. [Carer] can look after me. [Agreement from group] I only feel safe when [Carer] is here. FG:E5
- Q32 But respite. They gave me time to... If you wanted your hair done or you know, I wanted to go into town, do shopping or to have time with my husband 'cos obviously my husband's very... He relies on me a lot to do things. And we were given that time then because otherwise I wouldn't have been able to cope really. FG:G4
- Q33 .. for me it was such a relief to know that he was going there [respite at hospice day centre], that he was going to be assessed by another set of eyes so to speak, because I was so involved sometimes, you know, you miss things when you're on top of it all the time, and also yeah, just to have a break from him basically, yeah. That was an enormous help for me and for him. Int 06
- Q34 H3: During the day and towards the end they sent [Hospice nurses] and they would be here perhaps for a couple of hours. And I think... You would appreciate that, I... at that point I wouldn't go out into [Town] shopping at that point because he was sort of towards the end, but just to go out into the garden in the fresh air/ H6: Knowing someone was sitting with your husband./ H3: and just doing... It sounds ridiculous really but you could just do something NORMAL (carer emphasis) ... FG:H discussion
- Q35 .. we were doing nightshifts and then we were then obviously doing mum's washing, caring, and then you'd have to go home and suddenly stand there with this smiley little face and act to your two children like nothing had happened...
[] and obviously our husbands as well didn't know what was going on really because they wanted their wives back, but we were caring for mum. Where's your priorities, you just felt so torn, everyone wanted a bit of you and you just wanted to sit there and be with her. FG:D3
- Q36 Carer: Yeah, and I wanted him just to go in [to hospice] for a couple of days so I could have a rest. But when we got there. I mean it was a nice place, but I could tell by his face he didn't want to go in, so ... there was no way we was going to put him in for a couple of days. Int 14
- Q37 [Talking about overnight respite] ... she's coming such and such a time, she said, but of course she's only a care assistant, she won't be able to give any medication, you'll have to give her the medication. [] Which wasn't very clever was it when you think about it, right. Int 01

Physical health

- Q38 In one way I wished I'd have known they [Hospice at Home] were there earlier because what I was doing, I mean I was hoisting on my own, I was turning on my own, I was lifting on my own. I think I might have used them a little bit earlier just to save myself, because now I find that I have got medical problems now and the doctors have said it's just from all the hard work and all the stress that I was under FG:E5
- Q39 A3: And I got tennis elbows during the caring of my girl. Aagh ... I thought why have you given me this now ... why Lord have you given me this now... you know, and I couldn't ... oh, the pain was horrendous, so I was under the GP with that, and it was ... it was all the lifting ...
A4: I know. I've had a frozen shoulder ever since, I've had treatment for because it's the lifting ... I mean even with the best will in the world, you know, people would come in and move him from various places, but during the day ... we'd got one of these reclining chairs for him, but he'd slip right down ... and
A3: Yeah, that's right ... you have to pull them up ... FG:A discussion

Financial and work issues

- Q40 It's got to make a difference as well if it's long term or short term hasn't it? Because I'm a shift worker. And I mean my bosses are super and said basically, just do what you like, when you like. I'm a [names occupation]. [] So I could, you know, I could do that. But we knew it was going to be short-term which if it was going to be years, I wouldn't have asked. FG:J1
- Q41 When you're younger though you have got a working life to cope with... I was retired and you know I just spent 24 hours a day doing it [caring]. It just became my job. FG:J2
- Q42 I didn't know what to do after [patient] had been ill for about 3 months, because I'm self employed and needed to work. [] ... the top and bottom of it was that I got 2 half days a week sort of ... short half days, sort of 3½ hours, in which time I could sort of go out and ... do some work for 3 hours and come back and they would sit and look after [patient] while I was out. Int 19
- Q43 I agree entirely with [other participant], but I was totally unaware that I was entitled to any carer's allowance. I mean I've just always been/ [] /there to look after... one another we had, you know. It wasn't a question of care allowance. And I didn't realise you were entitled to it, or any of the other facilities that were available and that. FG:F7

Practical support

- Q44 I mean probably it's my own fault because I am independent. And so many friends said, 'If there's anything I can do, let me know.' But there were odd ones that sort of turned round, 'I've baked a cake. I thought that would help if you had visitors,' or whatever. But the majority said, 'If I can help, let me know.' But you don't like to say, 'I'll tell you what would really help, if you did the washing for me, or the ironing pile.' You don't like to do that. [Agreement from J3] FG:J4

Appendix 2 (Continued)

- Q45 In a practical situation some of the time I was working, then I was looking after my own family and then I was cooking for my dad and my mum and my, my family. And doing the washing and ironing for both households. FG:B4
- Q46 ... shopping becomes difficult, just ordinary simple things of trying to get the ironing done and the washing and ... you know, to ... it's hard, very hard. [Talking about 2 hours respite provided per week] [] I didn't go out. I normally would tend to go upstairs and get the ironing done or ...Int 18
- Emotional support**
- Q47 I mean before the event, in terms of ... if you're looking after me, effectively that was what the MacMillan nurse did, I mean she would come and she would talk to ME about ME. (carer emphasis) FG:A2
- Q48 I think beforehand all you wanted was to concentrate on your loved one. Not so much you, you were fine, you could cope! Or so you thought you could. And if someone said you couldn't cope that was a reflection as if 'No, but I have to because...'. You know, I must admit a couple of days before [Husband]... Well someone said to me, one of the nurses, 'Stop!' I said 'What do you mean?'. She said 'You can fall apart. You know, you can be upset', I said 'I can't I've gotta be strong for him'. But I must admit she kept on and on and the next minute I balled my eyes out, and I was crying like mad. And probably needed it, because you're... but you feel if someone sort of says 'A help for YOU'. They're sort of saying you can't cope, FG:F6
- Q49 And bumped into this guy [chaplain]. '[Name of carer], how are you?' And 'How are you?' And I told him what was happening. But 'How are YOU, though?' And I said, 'Oh, I haven't got time for me at the moment.' And my son, who was 22 at the time said, 'Yes, you have mum. You go and talk to [chaplain].' And that was an enormous support for me. FG:G3
- Q50 We're not a religious family, in fact my wife dedicated her body to medical science, so there was no funeral, no service or anything like that. The moment she died she was collected and she went to the teaching hospital at [Town S], and that was it, you know? But they knew all this and this nurse went and got a lady vicar. FG:H5
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