

Who cares for the carers at hospital discharge at the end of life? A qualitative study of current practice in discharge planning and the potential value of using The Carer Support Needs Assessment Tool (CSNAT) Approach

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Abstract

Background: Carer factors prevent patients achieving timely and appropriate hospital discharge. There is a lack of research into interventions to support carers at hospital discharge.

Aim: To explore whether and how family carers are currently supported during patient discharge at end of life; to assess perceived benefits, acceptability and feasibility of using The Carer Support Needs Assessment Tool (CSNAT) Approach in the hospital setting to support carers.

Design: Qualitative.

Setting/participants: Three National Health Service Trusts in England: focus groups with 40 hospital and community-based practitioners and 22 carer interviews about experiences of carer support during hospital discharge and views of The CSNAT Approach. Two workshops brought together 14 practitioners and five carers to discuss implementation issues. Framework analysis was conducted.

Results: Current barriers to supporting carers at hospital discharge were an organisational focus on patients' needs, what practitioners perceived as carers' often 'unrealistic expectations' of end-of-life caregiving at home and lack of awareness of patients' end-of-life situation. The CSNAT Approach was viewed as enabling carer support and addressing difficulties of discussing the realities of supporting someone at home towards end of life. Implementation in hospital required organisational considerations of practitioner workload and training. To enhance carer support, a two-stage process of assessment and support (hospital with community follow-up) was suggested using the CSNAT as a carer-held record to manage the transition.

Conclusion: This study identifies a novel intervention, which expands the focus of discharge planning to include assessment of carers' support needs at transition, potentially preventing breakdown of care at home and patient readmissions to hospital.

Keywords

Carers, needs assessment, palliative care, discharge planning, qualitative research, person-centred care

What is already known about the topic?

- Family carers are essential in making it possible for patients to remain at home towards the end of life and play an important role in achieving hospital discharge.
- The multiple impacts on carers of taking on this role and their need for support are well recognised in end-of-life care policy guidance.
- Palliative-care patients are often re-admitted to hospital following discharge due to breakdown in carer support at home.

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What this paper adds?

- A novel intervention for hospital discharge: expanding the focus of discharge practice to include assessment of carers' support needs at transition to help prevent breakdown of care at home and patient readmission to hospital.
- Identification of carers' lack of awareness of the realities of 24-h caregiving and of patients' end-of-life situation as a major barrier for practitioners wishing to support carers during discharge.
- The potential of The Carer Support Needs Assessment Tool (CSNAT) Approach to facilitate conversations about the realities of caregiving at home towards the end of life, thereby eliciting carer concerns and enabling the provision of support.

Implications for practice, theory or policy

- Enabling successful discharge of palliative-care patients to home and prevention of readmissions is a key issue for health services.
- To date, the focus of interventions to achieve this outcome has been on patients, yet we know that carers are crucial in enabling palliative-care patients to remain at home.
- This study identifies key issues to be considered in turning current policy 'aspirations' for person-centred care for carers into practice realities within a hospital context.

Background

Timely discharge from hospital and avoidance of readmissions are major concerns of health services. In the United Kingdom, there is guidance about hospital discharge in general from different sources¹⁻⁵ and specifically about hospital care at end of life (EOL).⁶⁻¹⁰ In both contexts, guidance makes clear the need to involve carers in discharge where they are involved in supporting patients at home. However, guidance references to involving carers 'with the patient's permission' suggest their involvement relates more to meeting patients' rather than carers' needs with regard to caregiving after discharge to home.

We know from research that the majority of patients wish to die at home¹¹ and that family carers are essential in making home-care possible.^{12,13} Carer factors are an important contributor to difficulties in achieving timely and appropriate hospital discharge.^{14,15} The odds of discharging patients from hospital to die at home are considerably reduced if carers are reluctant to support discharge.¹⁶ However, such reluctance may stem from lack of preparation and information.¹⁷

Discharge is not a single event, but a process that includes prevention of breakdown of home-care and readmission.¹⁴ Likelihood of remaining at home until death is reduced by two-thirds if carers prefer otherwise, even if patients are supported by palliative home-care,¹⁸ and a major reason for hospital admission is breakdown of informal care at home, even where carers willingly take on care.¹⁹ Carers therefore form a crucial component in successful discharge: ensuring they are prepared for home-care is likely to increase likelihood of discharge and decrease that of readmission.

However, research reviews show that carers often feel uninvolved and unsupported in the discharge process and that staff do not routinely identify and support carers.²⁰⁻²² The majority of carers report not being asked about their

needs or whether they can cope after the patient is discharged.^{14,20-25} Often health professionals do not realise that what appears routine to them is challenging to carers.¹⁴

There has been a lack of research into interventions to support carers at hospital discharge in general: a scoping review of service provision for carers around hospital discharge found only five studies involved an intervention, none of which focussed on the discharge process as directly related to carers.²² A systematic review of randomised controlled trials (RCTs) of discharge planning interventions found only 14 separate studies conducted over a 19-year period.²⁶ The review concluded that integration of caregivers into discharge planning reduces risk of hospital readmission, but was unable to determine the most effective method of caregiver integration. An Australian trial has tested a specific carer intervention at discharge: the Further Enabling Care at Home (FECH) programme which involved telephone assessment and support delivered by a dedicated FECH nurse.²⁷ The trial showed significant improvements for carers enrolled in the programme in preparedness to care after discharge and reduction in caregiver strain.

The Carer Support Needs Assessment Tool (CSNAT) Approach, which formed part of the FECH programme, is an intervention developed, tested and implemented in hospice home-care as a comprehensive, person-centred approach for assessing and supporting carers.²⁸⁻³³ The aim of this study is to focus on carers in the discharge process: (1) to explore whether and how carers of palliative-care patients are currently supported at discharge from hospital at EOL and (2) to assess perceived benefits, acceptability and feasibility of using The CSNAT Approach in the hospital setting to support carers during discharge. This is the first development stage of the

In palliative-care, carers and family are part of the ‘unit of care’: therefore in this context practitioners describe their role as ‘being there for the carer as well as the patient’. Practitioners provide carers with support alongside their care of the patient using an informal practitioner-led process.

The Carer Support Needs Assessment Tool (CSNAT) was developed to provide an evidence based, holistic assessment for carers in the absence of any comprehensive framework used in practice. The CSNAT identifies the support domains of importance to carers to (a) help them support the patient at home (as part of their co-worker role) and (b) preserve their own wellbeing whilst doing this (their client role) [28]. These domains have been incorporated into a 14 item assessment tool which was validated in a palliative home-care setting and shown to be comprehensive, with good face, content and criterion validity [29].

For use in practice the tool itself is incorporated into a five stage person-centred process of assessment and support: The CSNAT Approach [30]. This entails a shift from current practitioner-led identification of carer needs to one that is practitioner facilitated but carer-led. As such it is intended to open up conversations with carers, enabling them to consider, express and prioritise their support needs and have support provided that is tailored to their individual needs. It has been implemented widely in community palliative practice in the UK and abroad.

Figure 1. The CSNAT Approach.

Medical Research Council (MRC) Framework for Evaluation of Complex Interventions³⁴ to develop an intervention to facilitate discharge. Figure 1 provides an overview of The CSNAT Approach.

Methods

Qualitative design: focus groups, interviews and workshops

Ethical approval was received from NRES Committee Northwest–Greater Manchester West on 9/10/14 (REC reference no. 14/NW/1311). All participants provided written consent.

Setting and scope

The study was conducted between December 2014 and November 2015 across three National Health Service (NHS) Trusts in England serving a diverse population in terms of social deprivation, ethnicity and urban/rural areas. The primary NHS site recruited practitioners and carers. The other sites recruited practitioners.

The study focussed on discharges to home of patients with a palliative condition who had a carer (see Figure 2 for criteria of discharges). ‘Family carer’ or ‘carer’ may not always be a conventional family member, but denotes a lay person who provides a close, supportive role.

Recruitment and data collection

Focus groups with healthcare professionals

Practitioners were purposively sampled from teams involved in discharge of patients with a palliative condition to home (specialist palliative care, complex discharge, community Macmillan and district nursing teams) aiming for broad representation of different healthcare professionals (HCPs). A

lead contact in each Trust facilitated recruitment by distributing study recruitment packs to teams containing an invitation letter, study information leaflet, reply form and freepost envelope for its return. Interested HCPs responded directly to study researchers.

In total, 40 practitioners took part, 29 from hospital, 11 from community. Participants are described in Table 1.

Eight focus groups (FGs) were conducted, lasting 35–105 min, facilitated by two researchers (L.A./G.E., L.A./D.J. or G.E./D.J.). Discussions were recorded with participants’ permission. The topic guide covered four broad areas: (1) current assessment processes leading up to patient discharge including involvement of carers, (2) exploration of carer-related concerns surrounding discharge, (3) initial views of the CSNAT and its person-centred approach and (4) when/how The CSNAT Approach may be used at discharge to improve carer support.

Interviews with carers/next of kin

Bereaved and current carers/next of kin (hereafter called carers) were invited to participate. Carers of patients discharged from the Trust shortly before death and who were 6–18 months post-bereavement were eligible and were identified by the Trust’s Information Team together with the specialist palliative-care team (SPCT) and complex discharge team (CDT). Current carers were identified at weekly hospital multidisciplinary teams (MDTs). The SPCT highlighted any instances of concern about carers’ ability to participate in an interview. All invitation packs to carers were sent by the SPCT: interested carers responded directly to the study researcher (L.A.) who provided further information, arranged an interview with them at home and took informed consent prior to interview. Table 2 summarises recruitment and characteristics of 22 carer participants.

Interviews with carers were recorded with their permission. Discussions began with an exploration of carer’s experience of the discharge process and any concerns they

To allow examination of the discharge process including whether it was suitable and feasible to use the CSNAT with carers, the following criteria for discharges were used:

- *'Fast track' discharges where there was an expectation that patients going home had "weeks to months" to live (as described by R1FG1) and therefore there was likely to be involvement of the carer in the process. It should be noted that the term 'fast track' here refers to access to a national funding stream in the UK, NHS Continuing Healthcare, not speed of discharge.*
- *Complex discharges involving either the Complex Discharge Team (CDT) and the Specialist Palliative-care Team (SPCT) or both*

Excluded were:

- *'Rapid discharges' where patient were in the last days of life*
- *Routine discharges of palliative-care patients by ward teams*

Figure 2. Scope of palliative-care discharges.

had about the planned discharge. Carers' views about the CSNAT were sought: asking them to reflect back on their caring experiences and say whether they felt it would have helped them discuss any concerns.

Workshops with HCPs and carers

Workshops were mentioned to participants at the end of FGs and interviews. Carers who expressed an interest in further participation were invited to the workshops. All practitioner participants were also invited. Two workshops took place with 14 HCPs (7 SPCT, 4 CDT, 2 district nurses and 1 community nurse team leader) plus five carers (all bereaved). Attendance was dependent on availability on days scheduled for workshops.

Workshops lasted 2.5h (including lunch/refreshments) and were recorded with participants' permission. Each workshop began with a brief overview of the study, key findings and a reminder of The CSNAT Approach. This was followed by (1) whole group discussion of the tool itself and then (2) small group discussions of how this new approach might be used with carers at hospital discharge towards EOL.

Data analysis

All recordings were fully transcribed, checked and anonymised. A thematic analysis was conducted, based on the framework approach.³⁵ The analysis process involved two researchers (D.J./G.E.). Initial transcripts were read and re-read by the researchers to gain familiarity with the data. Then each researcher, independently, developed an indexing framework of key issues arising from both data and topic guides. Key issues identified were compared and discussed, and a coding framework agreed to organise the data. Atlas/ti was used to facilitate data management. The coding framework was applied to all transcripts by D.J., checked by G.E. and minor additional codings were added. Both researchers wrote notes/

memos throughout the process of data collection and analysis. Broad themes derived from the data were identified and interpretations discussed and agreed.

Findings

Findings are organised into three sections, representing practitioners' and carers' perspectives: (1) current barriers to supporting carers at hospital discharge, (2) utility of The CSNAT Approach for hospital discharge and (3) fit of The CSNAT Approach within a hospital context. Italics indicate verbatim quotations. ID numbers beginning with P indicate responses from practitioners and those with C are from carers. We have also indicated which FG (e.g. FG1) or workshop (e.g. W1a) the quotation came from.

Current barriers to supporting carers at hospital discharge

Organisational focus on patients' needs, not carers'. Needs assessments on discharge naturally focussed on patients: *'... because the patient and the duty of care that we have to the patient is uppermost in our mind'* (P2FG3). Emphasis was placed on practical aspects of discharge (e.g. equipment needs and services for patients) often driven by getting NHS Community Healthcare (CHC) funding in place: *'so the care is planned and I think it's a very physical approach, a practical approach, I don't think the emotional element sits in with it really'* (P2FG2). Services had no procedures for identifying carers' support needs at patient discharge as unlike hospice contexts, services were not formally 'there for the carer as well as the patient'. While carers participated in discharge conversations, this often depended on them being present when the patient was assessed. The assessment therefore focussed on *patients'* needs: any carer concerns were picked up informally. The following quotation exemplifies the lack of a carer remit *'Honestly, the carers are my second thought and they're only my thought if there*

Table 1. Healthcare professional participants.

Sites	Number invited	Roles	Number who took part	Roles
Trust 1				
Members of the SPCT MDT	11	Chaplain, manager, palliative medicine consultant, CNSs, EOLC facilitators, AHPs	9	Chaplain Manager 4 CNSs 2 EOL facilitators 1 AHP
CDT MDT	15	Manager, AHPs, social workers, nurses	7	Manager AHP manager 5 CDT nurses
Community-based team 1	6 ^a	Community Macmillan nurses	2	2 Community Macmillan nurses
Community-based team 2	^b	DNs	7	6 DNs 1 Student nurse
Trust 2				
Teams dealing with palliative care and discharges within the acute hospital	23 ^c	Palliative medicine consultants, specialist cancer nurses, palliative CNSs and discharge planning nurses and assessors	7	3 Palliative-care CNSs 4 CDT nurses/assessors
Trust 3				
Hospital- and community-based practitioners most involved in palliative-care discharges	9 ^d	Palliative medicine consultant SPC and case managers SPC CNSs CDT nurses AHPs	8	1 Consultant 3 SPC CNS (2 hospital and 1 community) 1 Case manager 1 SPC community manager 1 CDT nurse 1 AHP
Total	64+		40	29 Hospital-based 11 Community-based

SPCT: specialist palliative-care team; MDT: multidisciplinary team; CNS: clinical nurse specialist; EOLC: end-of-life care; AHPs: allied health professionals; CDT: complex discharge team; DN: district nurse; SPC: specialist palliative care.

Managers/service leads in each Trust facilitated recruitment. They were asked to invite staff most involved in discharge of palliative-care patients to home.

^aTeam not fully staffed at recruitment due to sick leave and posts vacant.

^bInformation on district nurses invited by the facilitating nurse manager not available.

^cThe facilitating service lead sent out a general invitation to all staff who might be involved in discharge of palliative-care patients and their carers to home, including tumour-specific CNSs.

^dFacilitating service lead identified key staff involved in discharge planning.

becomes a difficulty, so as long as they're happy with everything and everything is going along, I don't consider their [needs]' (P5FG7). Carers' experiences reflected this: none of those interviewed described any formal assessment of their needs. However, carers had very a strong sense that they needed support at this time: 'I think that's what they need, people need support when they come out. The carer needs the support as much as the patient, because without the carer where does the patient go?' (C5).

Carers' 'unrealistic expectations' of caregiving at EOL and support at home. Further problems could occur if carers had what practitioners described as 'unrealistic expectations' about caregiving at home. Practitioners found that carers often just wanted the patient to go home, but they did not necessarily have a clear idea of the reality of 24-h caregiving: *You try and make them aware of the sort of responsibility as well that*

they're going to have at home and how they're going to deal with the situation and get their thoughts about how they feel they'll cope when they get home. (P4FG7) This was echoed by district nurses who cared for patients post-discharge: '[carers] don't realise until they get home the physical and emotional demands that that then brings, and quite often within 24 or 48 hours of being home, you get a bit of a crisis going on' (P2FG5). Others recognised that as the process itself was designed to help facilitate discharge, the level of detail carers needed got missed.

Mistaken impressions had also to be managed regarding level of nursing support likely to be available at home: '*that a Macmillan nurse will be in that house 24 hours a day. They will order all the care, they will order all the medications, they will sort all the financial stuff out*' (P3FG1) or that district nurses could be expected to respond instantly if symptoms change. Expectations of

Table 2. Characteristics of carer participants.

Recruitment	N=201 bereaved carers identified n=19 responded and agreed to take part ^a N=4 current carers identified n=1 responded and agreed to take part	
Participants	N=22 (21 bereaved, 1 current carer) All but one patient had a cancer diagnosis	
Relationship with patient	Wife/husband	9
	Daughter/son	9
	Niece	3
	Friend	1
Sex	Female	19
	Male	3
Age range (years)	21–30	1
	31–40	1
	41–50	9
	51–60	6
	61–70	4
	71–80	1
Ethnicity	White British	19
	Black British	1
	Black African	1
	Not recorded	1

^aTwo interviews involved two carers.

availability of support at night were a particular difficulty because *'nights are often the thing that tip people over the edge'* (P5FG5). Practitioners felt that conversations about expectations needed to happen earlier in the process: *'someone explaining the actual nitty-gritty of things to people might be a bit more realistic for them to make that informed choice rather than get home and have the shock of it'* (P6FG5).

Lack of awareness of EOL situations. A significant barrier to preparing carers for patients' discharge expressed by all practitioner groups was when carers had limited awareness that patients were approaching EOL. This posed difficulties for practitioners with eliciting carer concerns: they described not having skills for EOL conversations and for some this resulted in them *'trying to backtrack'* (P4FG4) or *'backpedalling'* (P5FG7) to avoid these discussions altogether. Furthermore, lack of carer awareness meant practitioners were unable to put in place certain supports on discharge: *'... denying them, for example, Hospice at Home, you know, and Macmillan, denying them all sorts of services'* (P1FG2).

Utility of the CSNAT for comprehensive, carer-centred assessment in hospital

Given absence of any assessment process for carers at discharge and problems associated with this, initial practitioner responses to using the CSNAT were very positive: *'I think it looks good'* (P2FG1). They said it covered

everything they would expect to see: *'Yes, definitely the right questions'* (group agreement FG8), with one group reflecting on its usefulness: *'because we've got nothing at all in place and also I am aware that there are quite a few things on here that we don't do very well'* (P3FG5). Carers too were entirely positive: *'it's a good tool'* (C21); *'I think that would be very useful'* (C22). They reflected: *'They should be asking all these questions, you know, to the carers'* (C11); *'I think all those are something that need dealing with, don't they'* (C6). Potential benefits were also identified, outlined below.

Legitimising support for carers themselves. Carers identified their own reluctance to consider support for themselves at this time: *'because I think you put yourself on the back burner, you do, all carers put themselves on the back burner'* (C21). The CSNAT was therefore seen as valuable: *'[it] gives the carer permission to think about themselves'* (C21W2a). Practitioners concurred, *'relatives feel that they need the permission to say, do you know what, I can't do this and I need help'* (P2W1b). Furthermore, practitioners felt that using the CSNAT would clearly indicate their interest in supporting carers: *... with the best will in the world, they're also very focused on that individual, and then a 'How are you?', it's polite and it's respectful and it's cursory, but it's not like this. It actually says we actually care about how you are feeling.* (P4FG5)

Visibility of support needs. Carers found actually being able to see the CSNAT questions useful in enabling them

to consider support needed as most had no idea what caregiving towards EOL involved. One carer explained, *because you're completely at sea, you've no idea, you're going home with your family member with their bag of drugs and if somebody said, 'what kind of help do you need?' you wouldn't know, you need to have ... in a situation like that you've got to have prompts and suggestions, would you need help with this, would you need ... and that's perfect.* (C20) This contrasted with the current situation where *'the ball's put in your court to think of what you need to ask'* (C3), which was unhelpful when carers felt they did not know what to ask. Giving carers the opportunity to see the CSNAT domains made a few practitioners worry that carers might be upset: *'I worry as well is whether the main people absolutely panic and think what's going to happen. They've given me this, I haven't even thought of half of this one'* (P2FG6). However, this view was not expressed by carers.

Assisting communication of support needs. The CSNAT Approach was seen as enabling carers to communicate their needs: *'And I think because it does give people the opportunity to say, "No I don't need that, I don't need that, actually I really do need this"'* (C20). Having a copy of the tool itself further enabled this: *'... sometimes you don't know what to ask and you can't remember. Whereas if you've got something written down that you can go back to, you can make notes or you can gather your thoughts'* (C7). This was particularly pertinent when carers were becoming overwhelmed or feeling emotional. This view was shared by practitioners: *'when it's on paper'. 'You can put down your thoughts and feelings on a piece of paper when you're on your own'* (P1W2a).

Facilitating discussion with carers of caregiving at EOL and support at home. Importantly, practitioners felt that The CSNAT Approach would help address carers' lack of awareness about caregiving at home which was a significant barrier to providing support, for instance: *You could actually hand it to them and say, 'I want you to look at this, and the next time we come back, we're going to talk about it'. Because sometimes you haven't got, like, time to spend going slowly through something. But if they've had a chance to just have a quick look, to look at it when they were quiet, and think, right, I just need that. And then the next time the nurse comes, you can say, 'Have you had a look at that, and what did you think?' And then it just, sort of, like, opens things up.* (P6W1d) Having a 'way in' to these types of conversations was valuable: *You know, sometimes that [the CSNAT] could perhaps be a really good prompt for that scenario. And I have to say, as a practitioner, those scenarios where you have someone saying no, I'm going to take them home, I'm doing it all myself, are the hardest ones to work through.* (P5W2a)

The 'way in' to opening up discussions was also made easier by the questions: *'none of [the questions] say that you're dying, do they?'* (P2W1b) but *'a lot of them are what they should be discussing on discharge anyway'* (P3W1b).

Fit of The CSNAT Approach within a hospital context

Practitioners and carers identified organisational issues to be addressed to implement this approach.

Organisational factors

Responsibility for the process of carer assessment. The many practitioners potentially involved in hospital discharge towards EOL may diffuse responsibility for supporting carers. There was no consensus on who would be best placed to assess and support carers, each role having advantages and disadvantages. For example, it was considered well suited to SPCT members, but they may see only a small percentage of hospital palliative-care patients. Thus, responsibility for carer support would need to be determined within each hospital setting.

Time and workload capacity. Consideration of workload implications for assessment was required, as carer assessment is not usual hospital practice: *'I don't think it's the time to do that. I honestly don't. They don't have time to do the drug rounds let alone anything else'* (P2W1a). Carers' experiences reflected this: *Nurses are running round like blue-arsed what's-its, so you don't want to ask them either. So you end up with this, 'It'll be alright, It'll be alright'. And you don't ask because you know everyone's so busy. So you need to have something built in.* (C21W2a)

Skills and training. Implementation of a new way of working had implications for training. Most hospital staff are generalists unlikely to have skills in EOL communication or awareness of carers' situation, so training was seen as essential. In addition, hospital practitioners are not necessarily familiar with community resources, particularly around carer support: *'it's about the information, it's about what's out there. And if you don't know what's happening, you can be talking about home, and people have this lovely rosy view, but the practicalities are very different'* (P9W2b). There was also recognition of the need for more education of staff in person-centred care *'actually identifying what is important to that person and then supporting [them]'* (P2W1b), given this underpins the CSNAT approach.

Incorporating The CSNAT Approach into routine practice

In addition, consideration of how carers could be included in the discharge process was required, including when the

process was initiated, and how it could follow patients and carers through to the home-care setting.

Earlier engagement with carers. A clear message was that the CSNAT needed to be introduced early in the patient's hospital stay, not when preparing for discharge as this was 'a bit too late [...] I think it's great that it's there for discharge but I think it needs to be more thought about earlier on' (C17). Practitioners agreed, reflecting that carers are too focussed on getting patients home at this stage; this reality summed up as 'Just get him home, stop giving me forms' (P5aW2d). Instead, it was felt that the CSNAT could be used even before discharge was discussed: ... to actually pick up any carer concerns, and then if discharge was then an option I think and kind of refer back to that. So it's almost like a two part thing, it's assessing the concerns but then checking out those concerns in relation to proposed discharge. (P1W1a) Advantages of its earlier use included making more time available for discussions, rather than rushing conversations immediately prior to discharge. Importantly, it would also provide an opportunity to 'manage carers' expectations'.

A two-stage process of assessment. To ensure meaningful support for carers at discharge, a hospital-based assessment alone was viewed as insufficient. Rather, a two-stage process linking hospital carer assessment with follow-up by community staff was viewed as essential as the full impact of caregiving was only realised once at home. One carer explained, 'because until she was home we hadn't realised we'd have a problem at night. [...] we thought she'd go to bed and she'd be able to go to the toilet like she always could before and she couldn't' (C4). Thus, a further review was seen as crucial: P3: '... maybe even a couple of days later, because until they're actually at home they don't'. P2: 'They don't know what they don't know'. P1: 'A lot of people just have no idea what it's like' (W1a). Incorporation of the CSNAT into referrals to community nursing would enable the two stages of the process to be linked to alert community staff to the carer's situation and act as prompt for completing a home-based assessment: 'So if that [the CSNAT] [...] came through with the initial discharge and then we would have a copy of the notes with maybe something on it, redo on such and such a date' (P3W1a).

CSNAT as a carer-held record. To manage transition between hospital and home, workshops discussed the CSNAT as a carer held-record: 'if the carer was to take ownership of this document, then it would be their continuity of care wouldn't it, for them to take from the hospital to the community, to get the answers along the way' (P1W2a). Others agreed: 'I think

ideally it would go with the carer' (P4W1b), but were sceptical about how this might work 'in the real world', identifying that 'it would work in a percentage of cases and then in other cases it wouldn't work because people have different lives and lifestyles' (P1W1b). Carers themselves felt it was a realistic option: *I think it starts there with a normal mini meeting in the hospital, things are discussed, the person [patient] moves out, the carer takes the CSNAT [...] home with them and the link happens where the practitioners say, right, okay, district nurses or community need to come in and help but then it starts again.* (C4W1c)

Discussion

This article examines carer support during hospital discharge of palliative-care patients. Within current hospital practice, barriers to supporting carers were an organisational focus on patients' needs, carers' 'unrealistic expectations' of EOL caregiving at home and lack of awareness of patients' EOL situation. Given absence of any routine process for identifying carers' support needs at patient discharge, The CSNAT Approach was viewed positively by both practitioners and carers. Anticipated benefits included legitimising carer support, providing visibility of support needs and assisting their communication. Importantly, practitioners felt The CSNAT Approach could facilitate conversations about the realities of supporting someone at home towards EOL. In order to achieve its implementation within discharge planning, organisational factors were highlighted: which practitioners would undertake the assessment and workload and training implications. Incorporation into practice required engaging carers earlier in the hospital stay and managing transition between hospital and home through a two-stage process of assessment of carers' support needs using CSNAT as a carer-held record.

We found little evidence from carers or practitioners that carers' needs were identified and supported within the discharge process. On one hand, this is perhaps unsurprising in the hospital setting where the majority of practitioners would identify their role as caring for patients, unlike in hospice care where the ethos also includes supporting carers. However, the End of Life Care Strategy³⁶ has long recognised the impact on carers of caregiving, and National Institute for Health and Care Excellence (NICE) has Quality Standards for end-of-life care³⁷ and transitions between hospital and home⁹ which include comprehensive assessment and holistic support for carers and family according to their needs and preferences. Failure to implement these standards would appear to be a missed opportunity to better prepare carers for caregiving at home and so reduce the likelihood of readmissions.

A common difficulty for practitioners was preparing carers for the realities of EOL caregiving. Consequently, when introduced to The CSNAT Approach, practitioners'

reactions were very positive. As in previous CSNAT studies,³² anticipated benefits included giving carers permission to consider their own needs, opening up conversations, assisting communication about support needs and offering a 'way in' to difficult discussions. As such, The CSNAT Approach may enable practitioners to achieve the 'honest, informed and timely conversations' which are one of the building blocks identified for achieving the Ambitions for Palliative and EOL Care for carers as well as patients.³⁸

While recognising the utility of the CSNAT, participants were clear about practicalities to be addressed including who should undertake the assessment and the implications for workload. In addition, training reinforcing person-centred approaches to assessment and support would be required. The current vision for EOL care³⁸ is based on the House of Care model which puts person-centred care at its core. Implementation of person-centred-care with *patients* is not without difficulty, requiring re-consideration of professional roles.³⁹ The challenge of this approach for carers is even greater, particularly in acute hospitals where carers are not within the remit of the majority of services. A value of this study is that it identifies what is required to turn current policy 'aspirations' for carers into practice realities within acute hospitals and provides a foundation for further work on implementation in this context.

Carers and practitioners identified how carer assessment and support could be facilitated through the transition between hospital and home. This involved a two-stage process: (1) starting assessment early in the hospital stay, in keeping with the principles of effective discharge planning⁴⁰ and (2) follow-up review by community practitioners at home, using the CSNAT as a carer-held record to manage the transition. This is a novel intervention, focussed on supporting carers, to enhance the discharge process. There is existing evidence that both transition-care planning and coordination⁴¹ and integration of informal carers in discharge planning²⁹ are factors affecting hospital readmissions. In addition, we know that interventions which assist transition from hospital to home are effective in reducing hospital readmissions and that those starting during the hospital stay and continuing after discharge are more effective than those starting after discharge.⁴² This potential intervention puts these factors into practice, underpinning further work on intervention implementation.

Limitations of the study

This was an initial exploratory study; however, it was conducted within three large hospitals with key staff involved in discharge planning. Due to the difficult and sensitive subject area, many carers did not respond to the invitation to take part. Those who did take part provided highly valuable insights into current practice and potential use of The CSNAT Approach. The study was limited

to perceptions of acceptability and feasibility of The CSNAT Approach as an intervention: the real test comes when it is implemented in practice. Nevertheless, the consistency and agreement between both practitioners and carers provides a strong underpinning for a future implementation study.

Implications for practice

Enabling successful discharge of palliative-care patients to home and prevention of readmissions is a key issue for health services. To date, the focus of interventions to achieve this outcome has been on patients. Yet we know that carers are crucial in enabling palliative-care patients to remain at home. This study shifts the focus of current practice of discharge planning to include whether and in what way the support needs of carers might be assessed and addressed during the transition to home-care. In so doing, it offers a new direction for intervention development for hospital discharge with the potential to improve support for carers over the transition to home and prevent breakdown of care at home which is often a cause of readmission of patients to hospital.

Accessing the CSNAT

The CSNAT is a copyright tool available free of charge to the NHS and not-for-profit organisations. Registration and a licence are required for its use. For further details about obtaining an inspection copy, please contact Dr Gail Ewing at the University of Cambridge (ge200@cam.ac.uk) or Professor Gunn Grande at the University of Manchester (gunn.grande@manchester.ac.uk).

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Data management and sharing

The primary data for the study consist of a corpus of audio-recorded focus groups, interviews and workshops. The authors do not have participants' consent to share these data with third parties. This includes person-identifiable data within interview transcripts.


Declaration of conflicting interests


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References

- Department of Health. *Achieving timely 'simple' discharge from hospital: a toolkit for the multi-disciplinary team*. London: Department of Health, 2004.
- Department of Health. *Ready to go? Planning the discharge and the transfer of patients from hospital and intermediate care*. London: Department of Health, 2010.
- British Medical Association. *Hospital discharge: the patient, carer and doctor perspective*. London: British Medical Association, 2014.
- Queen's Nursing Institute. *Discharge planning: best practice in transitions of care*. London: Queen's Nursing Institute, 2016.
- Carers UK. *Coming out of hospital*. London: Carers UK, 2015.
- Department of Health. *End of Life Care Strategy: quality markers and measures for end of life care. Part 3 – quality markers for acute hospitals*. London: Department of Health, 2009.
- NHS England. Transforming end of life care in acute hospitals: the route to success 'how to' guide, <https://www.england.nhs.uk/wp-content/uploads/2016/01/transforming-end-of-life-care-acute-hospitals.pdf> (accessed 16 August 2017).
- National Institute for Health and Care Excellence. *Transition between inpatient hospital settings and community or care home settings for adults with social care needs (NICE guideline)*. London: National Institute for Health and Care Excellence, 2015.
- National Institute for Health and Care Excellence. *Transition between inpatient hospital settings and community or care home settings for adults with social care needs (quality standard)*. London: National Institute for Health and Care Excellence, 2016.
- The National Council for Palliative Care. *Getting serious about prevention: enabling people to stay out of hospital at the end of life*. London: The National Council for Palliative Care, 2015.
- Gomes B, Calanzani N, Gysels M, et al. Heterogeneity and changes in preferences for dying at home: a systematic review. *BMC Palliat Care* 2013; 12: 7.
- Grande GE, Addington-Hall JM and Todd CJ. Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med* 1998; 47(5): 565–579.
- Gomes B and Higginson I. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 2006; 332: 515–521.
- Association of Directors of Adult Social Services. *Carers as partners in hospital discharge: improving carer recognition, support and outcomes within timely and supported discharge processes (a review)*. London: Association of Directors of Adult Social Services, 2010.
- Connolly M, Grimshaw J, Dodd M, et al. Systems and people under pressure: the discharge process in an acute hospital. *J Clin Nurs* 2009; 18: 549–558.
- Alonso-Babarro A, Bruera E, Varela-Cerdeira M, et al. Can this patient be discharged home? Factors associated with at-home death among patients with cancer. *J Clin Oncol* 2011; 29(9): 1159–1167.
- Stajduhar K, Funk L and Outcalt L. Family caregiver learning – how family caregivers learn to provide care at the end of life: a qualitative secondary analysis of four datasets. *Palliat Med* 2013; 27(7): 657–664.
- Grande G and Ewing G. Death at home unlikely if informal carers prefer otherwise: implications for policy. *Palliat Med* 2008; 22(8): 971–972.
- Gott M, Frey R, Robinson J, et al. The nature of, and reasons for, 'inappropriate' hospitalisations among patients with palliative care needs: a qualitative exploration of the views of generalist palliative care providers. *Palliat Med* 2013; 27(8): 747–756.
- The Princess Royal Trust for Carers 'Out of Hospital' Project: learning from the pilot projects, final report, London, 2010, <http://static.carers.org/files/out-of-hospital-final-report-6-may-2010-5221.pdf>
- Bauer M, Fitzgerald L, Haesler E, et al. Hospital discharge planning for frail older people and their family: are we delivering best practice? A review of the evidence. *J Clin Nurs* 2009; 18: 2539–2546.
- Borthwick R, Newbronner L and Stuttard L. 'Out of Hospital': a scoping study of services for carers of people being discharged from hospital. *Health Soc Care Community* 2009; 17(4): 335–349.
- Hanratty B, Holmes L, Lowson E, et al. Older adults' experiences of transitions between care settings at the end of life in England: a qualitative interview study. *J Pain Symptom Manage* 2012; 44(1): 74–83.
- Carers UK. Pressure points: carers and the NHS (research summary), <https://www.carersuk.org/for-professionals/policy/policy-library/pressure-points-carers-and-the-nhs> (2016 accessed 8 September 2017).
- Carers UK. State of caring 2017, <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-report-2017> (accessed 8 September 2017).
- Rodakowski J, Rocco PB, Ortiz M, et al. Caregiver integration during discharge planning for older adults to reduce resource use: a metaanalysis. *J Am Geriatr Soc* 2017; 65: 1748–1755.
- Toye C, Parsons R, Slatyer S, et al. Outcomes for family carers of a nurse-delivered hospital discharge intervention for older people (the Further Enabling Care at Home Program): single blind randomised controlled trial. *Int J Nurs Stud* 2016; 64: 32–41.

28. Ewing G and Grande GE. Development of a Carer Support Needs Assessment Tool (CSNAT) for end-of-life care practice at home: a qualitative study. *Palliat Med* 2013; 27(3): 244–256.
29. Ewing G, Brundle C, Payne S, et al. The Carer Support Needs Assessment Tool (CSNAT) for use in palliative and end-of-life care at home: a validation study. *J Pain Symptom Manage* 2013; 46: 395–405.
30. Ewing G, Austin L, Diffin J, et al. Developing a person-centred approach to carer assessment and support. *Br J Community Nurs* 2015; 20(12): 580–584.
31. Grande GE, Austin L, Ewing G, et al. Assessing the impact of a Carer Support Needs Assessment Tool (CSNAT) intervention in palliative home care: a stepped wedge cluster trial. *BMJ Support Palliat Care* 2017; 7(3): 326–334.
32. Ewing G, Austin L and Grande G. The role of the Carer Support Needs Assessment Tool (CSNAT) in palliative home care: qualitative study of practitioners' perspectives of its impact and mechanisms of action. *Palliat Med* 2016; 30(4): 392–400.
33. Austin L, Ewing G and Grande G. Factors influencing practitioner adoption of carer-led assessment in palliative home-care: a qualitative study of the use of the Carer Support Needs Assessment Tool (CSNAT). *PLoS ONE* 2017; 12(6): e0179287.
34. Craig P, Dieppe P, Macintyre S, et al. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ* 2008; 337: a1655.
35. Ritchie J and Lewis J. *Qualitative research practice: a guide for social science students and researchers*. London: SAGE, 2003.
36. Department of Health. *End of Life Care Strategy: promoting high quality care for all adults at the end of life*. London: Department of Health, 2008.
37. National Institute for Health and Care Excellence. *Quality standard for end of life care for adults: quality statement 7: holistic support – families and carers*. London: National Institute for Health and Care Excellence, 2011.
38. National Palliative and End of Life Care Partnership. *Ambitions for Palliative and End of Life Care: a national framework for local action 2015–2020*, p. 11, <http://end-of-lifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf> (accessed 8 September 2017).
39. Coulter A, Roberts S and Dixon A. *Delivering better services for people with long-term conditions: building the house of care*. London: King's Fund, 2013.
40. Lees L. The key principles of effective discharge planning. *Nurs Times* 2013; 109(3): 18–19.
41. Feigenbaum P, Neuwirth E, Trowbridge L, et al. Factors contributing to all-cause 30-day readmissions: a structured case series across 18 hospitals. *Med Care* 2012; 50(7): 599–605.
42. Baert A, Weltons C and Sermeus W. Effectiveness of discharge interventions from hospital to home on hospital readmissions: a systematic review. *JBIC Database System Rev Implement Rep* 2016; 14(2): 106–173.