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Supporting carers at hospital discharge at end of life: a feasibility study of the Carer Support Needs Assessment Tool (CSNAT) intervention

Summary report
April 2019

Working in collaboration with:

Authors

Dr Alex Hall, Dr Christine Rowland & Prof Gunn Grande
University of Manchester
NIHR CLAHRC Greater Manchester

Dr Gail Ewing
University of Cambridge

Michael Spence
NIHR CLAHRC Greater Manchester

Sarah Shipton
Manchester University NHS Foundation Trust

This study/project is funded by the National Institute for Health Research (NIHR) Collaboration for Leadership of Applied Health Research and Care Greater Manchester. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care

Introduction

Discharge of patients from hospital at end-of-life into the community relies heavily on family carers' ability and willingness to help care for the patient. However, carers often feel uninvolved and unsupported in the discharge process, and palliative care patients are often re-admitted to hospital following discharge because of a breakdown in carer support at home. The Carer Support Needs Assessment Tool (CSNAT) intervention is a novel intervention to facilitate carer-led assessment and support for carers. This project explored the feasibility of using the CSNAT intervention to support carers at hospital discharge home at end-of-life.

1. Background to the Project

1.1 The importance of carers at hospital discharge

Timely discharge from hospital and avoidance of readmissions are major concerns of health services. In the UK, there is guidance about hospital discharge in general from different sources [1-5] and specifically about hospital care at end-of-life [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' suggests their involvement relates more to meeting patients' rather than carers' needs with regard to caregiving after discharge to home.

The majority of patients wish to die at home [11], and 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]. 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 that involved an intervention, none of which focused on the discharge process as directly related to carers [22]. A systematic review of 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) program which involved telephone assessment and support delivered by a dedicated FECH nurse [27]. The trial showed significant improvements for carers enrolled in the program in preparedness to care after discharge and reduction in caregiver strain.

1.2 The Carer Support Needs Assessment Tool (CSNAT) intervention

The Carer Support Needs Assessment Tool (CSNAT) intervention, which formed part of the FECH program, 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 CSNAT intervention identifies the domains of support needs that are important to carers, in order to (a) enable them to support the patient at home (as ‘co-workers’) and (b) preserve their own health and wellbeing whilst doing this (as ‘clients’ in their own right) [28]. These domains have been used to structure a 14 item assessment tool, which has been validated in a palliative home-care setting and shown to be comprehensive [29]. For use in practice the tool itself is incorporated into a five stage person-centred process of assessment and support [30] involving consideration, identification and prioritisation of support domains by carers themselves, discussion with a practitioner to identify the carer’s specific support needs within prioritised domains, agreement about supportive input to meet the identified support needs and a plan for review. This approach 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 together with the practitioner identify supportive input that is tailored to their individual needs. It has been implemented widely in community palliative practice in the UK and abroad.[1]

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[1] Sections 1.1 and 1.2 are taken from Ewing, Austin, Gibson & Grande [35] under the CC-BY-NC licence

2. Project aims

This project aimed to explore the feasibility of using of the CSNAT intervention to support carers of patients discharged from hospital at end-of-life. It followed the MRC Framework for the development and evaluation of complex interventions [34], which outlines a phased approach including development, feasibility/piloting, evaluation, and implementation. The current project built upon earlier work at the first phase of the MRC Framework (‘development’) (see publication by Ewing, Austin, Gibson & Grande [35]). This earlier work involved exploring current practice in discharge planning, and the potential value of the CSNAT intervention in this context. It was undertaken with healthcare professionals involved in discharge of patients with a palliative condition, and bereaved or current carers, some of whom were within what is now Manchester University NHS Foundation Trust (MFT).

In this developmental work, practitioners and carers felt that the CSNAT intervention was likely to help legitimise support for carers, to help educate carers about the support they may require, and to help practitioners introduce conversations about the realities of caring for an end-of-life patient at home. The following factors were highlighted as potentially important for successful uptake of the CSNAT intervention into routine practice within the context of hospital discharge:

- ensure local determination in identifying practitioners best-placed to introduce the CSNAT intervention to carers;
- consider the workload implications for practitioners;
- consider the need for communication skills training for practitioners;
- introduce the CSNAT intervention earlier in the hospital stay than during preparation for discharge;
- link the hospital carer assessment with a follow-up by community practitioners;
- ensure that the CSNAT Tool itself works as a carer-held document within the intervention.

The current project moved this work on to the second phase of the MRC Framework (‘feasibility/piloting’): it explored the feasibility of using the CSNAT intervention to support carers during discharge of patients from hospital at end-of-life.

3. Methods

This project was a case study of implementation of the CSNAT intervention. The CLAHRG GM team worked with MFT's Supportive and Palliative Care Team (SPCT) at Manchester Royal Infirmary, and the Central Manchester Community Macmillan Specialist Palliative Care Service (Central team). Following early discussions with Sue Langley (Director of Nursing, MFT) and Sue Heatley (Matron/Lead Palliative & End of Life Care, MFT), these teams were identified based on the recommendations above, namely that the SPCT would be well-placed to introduce the CSNAT intervention to carers in advance of preparation for patient discharge, and that the Central team would be able to provide post-discharge follow-up assessment and support. Some members of these teams had taken part in the initial development work referred to above [35].

3.1 Project planning

The CLAHRC GM team were keen for the SPCT and the Central team to take the lead in planning the implementation of the CSNAT intervention. This would allow the practitioners to take ownership of the CSNAT work and to make decisions about how it would be workable within their current contexts, rather than have the CLAHRC GM team impose a plan upon them.

Sarah Shipton (Advanced Nurse Practitioner, SPCT) was identified within the clinical teams as the practitioner who would be the champion for the CSNAT project. She was closely supported by Faye Madden (Project Officer, SPCT). Sarah and Faye were supported by their line manager Sue Heatley to dedicate some of their time to the CSNAT project.

At the beginning of the project, the CLAHRC GM team provided face-to-face CSNAT intervention and implementation training to the SPCT and Central team. The training involved two half-day sessions; one focused at practitioner level, about using the CSNAT intervention (attended by all the practitioners), and one focused at a service level, about an implementation strategy (attended by Sarah Shipton, Faye Madden, and the Central team).[2]

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[2] Further detail about CSNAT training can be found at http://csnat.org/online-training/.

The intervention training included an overview of the history of the CSNAT intervention, discussion exercises to help practitioners reflect upon their current practice in supporting carers, and thinking about how the CSNAT intervention may be different to current practice through understanding its five-stage person-centred process of assessment and support.

The implementation training at service level included discussions focused particularly on:

- ***Scope of the project:*** In order to keep the scope of the project manageable in the first instance, the clinical teams decided to offer CSNAT assessments to carers of patients with a cancer diagnosis who lived in Central Manchester.

- ***Handover from hospital to community*****:** The clinical teams decided to make minor amendments to existing referral forms between the SPCT and the Central team, so that the CSNAT work could fit in with their existing practice. They also developed a system of numbered CSNAT 'packs' to allow them to track the handover of CSNAT assessments from hospital to community in order to enable continuity with follow-up assessments.

- ***Recording information about CSNAT assessments*****:** The clinical teams decided to add information about CSNAT assessments into patient notes on the Somerset Cancer Register (national database). They also decided to collate information about carer assessments via Faye Madden (SPCT Project Officer).

- ***Visibility*****:** The clinical teams ensured that they embedded discussion of CSNAT work into existing team meetings such as MDTs (which are attended by the SPCT and the Central team) and team briefs in their own settings. They also used visual strategies to identify carers who were to be offered CSNAT assessments (such as colour-coded markers added to the patient board in the SPCT office).

3.2 Data collection

3.2.1 Research data

The aim of the research, to explore the feasibility of CSNAT implementation, required seeking the views and experiences of the SPCT and Central teams of using the CSNAT intervention. Therefore, patients and carers were not participants in the research.

The CLAHRC GM team explored the views and experiences of 17 practitioners (13 members of the SPCT; four members of the Central team). This involved two rounds of interviews, and some observational work, over a six-month period. The first round of interviews was conducted in May/June 2018, prior to the clinical teams using the CSNAT intervention. The second round was conducted in November/December 2018, after they had been using the CSNAT intervention for around six months. During this time period, the CLAHRC GM team also observed clinical team meetings and reviewed CSNAT implementation procedures.

3.2.2 Practitioners' CSNAT data

The SPCT and Central team collected information about their work with the CSNAT intervention for their own evaluation and reflections. This included numbers of CSNAT assessments that they carried out, and their own feedback about their experiences of using the intervention.

4. Main findings

In total, the SPCT introduced the CSNAT intervention to 12 carers, received completed CSNAT tools from six carers, and carried out CSNAT assessment conversations with three carers. These three were handed over to the Central team for post-discharge follow-up, with one being reassessed in the community.

This section highlights the main findings from the perspectives of the SPCT and Central team members.

4.1 The CSNAT tool: bringing structure and focus to carer support

Practitioners felt that the structure and focus of the CSNAT tool provided a more comprehensive assessment that gave them more confidence in assessing carers' support needs, and also helped the carer to identify their own support needs. At the start of the project, practitioners felt that the structure of the CSNAT could add value to their current practice by helping carers to focus on their own needs, and by helping the practitioners have more concrete evidence of carers' support needs:

> *To have something that [we] can say "this is a relatively short structured, some things that people have previously come across, how does it work for you?" gives them that remit to say it's okay to think of these as concerns… it's alright to have your own concerns (SPCT, interview round 1)*

> *We don't use a tool, so we're aware of all this from experience, but then we've got nothing to validate the difficulties or the concerns. (Central team, interview round 1)*

In the follow-up interviews, practitioners reflected on how the CSNAT intervention had helped them to keep a focus on carers' needs:

> *It also kept in mind those other issues that we hadn't yet resolved to make sure that we brought those back up again. So I thought it gave it more structure, more focus… Because when you're sat with a relative who is worried about taking their loved one home you can say last week these were your worries, but actually you're not worried about this one now because we've done X, Y, Z. So I think it helps for them as well to see that not only are they being supported and that something fairly structured is being done. But actually oh yeah, don't need to worry about that one now. (SPCT, interview round 2)*

The formality introduced by the CSNAT tool and assessment process also seemed to help a number of carers feel that any concerns they had were being taken seriously, whilst also allowing practitioners to highlight and address carer concerns with colleagues:

> *[The CSNAT] really, really helped… the partner to express his concerns. Because he'd said he'd told people but nothing had been done. So because it's in writing as well it gets a little bit more formal, people take more notice of it. Put a copy in the notes, the ward team could see what the issues were. But also it [gave] me some clout to say well, these are his feelings, this is what he's struggling with on the ward, and we need to do something about this. (SPCT, interview round 2)*

4.2 Reflections on CSNAT introduction and assessment conversations

Practitioners felt that as palliative care professionals, they were used to having discussions with carers, and that the CSNAT intervention would not present an unmanageable amount of extra work. There were examples where the introduction of the CSNAT, and the subsequent assessment conversation, had been straightforward:

> *The conversation itself was very easy. It was on the very first [patient] assessment and it started from the view that she [the carer] gave. So I just said to her may we pick that up at the end of the conversation? I said, would you be interested in looking at a more structured way? I think there were about seven or eight issues on there, three of which we got sorted out straight away. (SPCT, interview round 2)*

However, there were other examples that highlighted challenges for the SPCT in identifying the right time to introduce the CSNAT and to have assessment conversations with some carers in the hospital setting. This was not necessarily a workload issue, but rather, related to the context of caring for acutely unwell patients. Some carers may not be as ready to think about their own needs when the patient is very unwell, and it could be difficult for practitioners to judge when would be the 'right' time to introduce the CSNAT:

> *It's the time to complete the CSNAT; it's the right time, like the patient needs to be a bit more stable at that point because [the carer] won't want to focus on themselves... it's hard to try to get them to focus on them. (SPCT, interview round 2)*

There were also some difficulties in finding an appropriate environment to have private conversations with carers in the hospital setting. This was felt to be a general reflection of the hospital environment rather than particular to the CSNAT intervention. However, this is important to highlight because the CSNAT intervention is designed to facilitate a more in depth conversation with carers than the pre-existing practice of a brief "and how are you coping?" conversation in a corridor. There were also instances where carers had not been on the premises during practitioners' working hours, and therefore practitioners had not been able to meet them in person to introduce the CSNAT.

The CSNAT intervention is specifically designed to foreground carers' concerns as separate from patients. Practitioners reflected that the project had stimulated their thinking about their current practice around carer support:

> *It's made me think more about it, I will be honest; it's made me think about assessing them more, than [just] focusing on the patients (SPCT, interview round 2)*

> *I suppose it's challenged, maybe, some of our previous ideas about what sort of support we're offering at the moment, and how that's aimed, and maybe where we need to move to in the future (SPCT, interview round 2)*

However, some practitioners also reflected upon a tension between recognising a need and desire to support carers in their own right, who may want more information about the patient's condition, and a need to respect issues of patient confidentiality. One team member reflected on the experience of supporting a patient who did not want practitioners to speak with her family, but whose family could have benefitted from a CSNAT assessment:

> *I found it difficult because it's almost like she's consenting for somebody else, for us not to contact, when actually it's not her needs we're looking at, we're looking at the needs of her family. (SPCT, interview round 2)*

These challenges partly accounted for the low number of CSNAT assessments that were carried out, and also meant the Central team did not get much experience in working directly with the CSNAT intervention at post-discharge follow-up.

4.3 Potential of CSNAT to provide evidence of work with carers

Practitioners emphasised that the structure and focus of the CSNAT tool had the potential to help them to document the work that they do supporting carers. This was felt to be very important in palliative care settings where supporting carers can often be more complex and time-consuming than looking after patients:

> *I'm finding there's more and more of a psychological input in the care that we deliver, which is very, very time consuming. So, you can't always make, "oh it's an hour, I need to go", it's not about that, sometimes you can be two hours, two and a half hours (Central team, interview round 1)*

This time can be difficult to account for in recording systems and performance metrics that are patient-focused:

> *This week, we've had a young gentleman that's come out for end of life care, not imminently dying, but you know, uncertain, and with a young wife. And when I've discussed him at the MDT, I can honestly say that there's nothing on any of the [palliative care] domains, apart from support for wife. So, if you're going to demonstrate what you've done, well on the Somerset, the MDT discussion, it looks like you've really done nothing. But again, you are spending an hour, easy, of your time, to make sure that everything's there, that you can support somebody to look after somebody else. (Central team, interview round 1)*

The teams acknowledged that the use of the Somerset Cancer Register was not an ideal recording system, as it meant that work with carers was recorded as a sub-category of patient records, but that it was the best option currently available to them.

> *I suppose one thing I have come to realise quite recently actually, though, is the way we assess carers. The carer element kind of falls under our holistic assessment of the patient, so whilst we do assess them in their own right, when it comes to documenting, when it comes to, you know, passing that information on, they're almost part of the patient as opposed to their own individual person. (SPCT, interview round 1)*

The role of Faye Madden (SPCT Project Officer) in providing dedicated administrative support was acknowledged as being vital in maintaining separate recording of CSNAT intervention work.

5. Summary and next steps

- Discharge of patients from hospital at end-of-life relies heavily on family carers' ability and willingness to help care for the patient. However, carers often feel uninvolved and unsupported in the discharge process.

- The Carer Support Needs Assessment Tool (CSNAT) intervention is a novel intervention to facilitate carer-led assessment and consequently more tailored support for carers.

- This project explored the feasibility of using the CSNAT intervention to support carers at hospital discharge at end-of-life. The CLAHRC GM team worked with Manchester University NHS Foundation Trust's Supportive and Palliative Care Team and Central Manchester Community Macmillan Team. The research focused on the practitioners' experiences of using the CSNAT intervention for around six months.

- The practitioners found the structure and focus of the CSNAT intervention helpful in providing a more comprehensive assessment of carer support needs.

- The CSNAT intervention could be accommodated into existing workloads, but sometimes it was difficult for practitioners in the hospital setting to find the right time or private space to introduce the intervention and have conversations with carers.

- Although the SPCT had been identified in the preliminary work as well-placed to offer CSNAT support, they found that patients were often discharged from hospital before they could speak to carers.

- The CSNAT intervention could help the practitioners document the work that they do to support carers. However, the recording of information about carer support needs and activity within patient-focussed NHS systems is challenging. There are currently no obvious solutions to this problem, and dedicated administrative support may be necessary. Sarah Shipton is in discussion with MFT's Information Governance team to explore options for better use of electronic records.

The SPCT and the Central team intend to continue to work with the CSNAT intervention for a further period of nine months, beginning at the end of April 2019. It is anticipated that the CSNAT intervention will continue to be used between the two clinical teams to support carers around hospital discharge, but it will also be implemented separately in the hospital and community settings. In the hospital setting, the SPCT will work with the Hepatobiliary Clinical Nurse Specialists and the Lung Clinical Nurse Specialists. This is to allow them to retain a manageable scope of the work (i.e. carers of patients with a cancer diagnosis in Central Manchester), but to see if CSNAT assessments can be initiated earlier in the patient/carer journey. In the community setting, the Central team will continue to work with the CSNAT so that they can gain more experience of working with it in practice.

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For more information please contact, Dr Alex Hall alex.hall@manchester.ac.uk
Produced by NIHR CLAHRC Greater Manchester, April 2019