The Barriers and Facilitators to Implementing the Carer Support Needs Assessment Tool in a Community Palliative Care Setting

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Corresponding Author:	Zoe Amber Horseman, Ba (Hons), MPH University of Edinburgh Edinburgh, Midlothian UNITED KINGDOM
Corresponding Author Secondary Information:	
Corresponding Author's Institution:	University of Edinburgh
Corresponding Author's Secondary Institution:	
First Author:	Zoe Amber Horseman, Ba (Hons), MPH
First Author Secondary Information:	
Order of Authors:	Zoe Amber Horseman, Ba (Hons), MPH
	Libby Milton, MPH, BN, RN, PGDip
	Dr Anne Finucane, BSc, MSc, PhD (Psych)
Order of Authors Secondary Information:	
Abstract:	Background Family carers play a central role in community-based palliative care. However, caring for a terminally ill person puts the carer at increased risk of physical and mental morbidity. The Carer Support Needs Assessment Tool (CSNAT) enables comprehensive assessment of carer support needs (Ewing & Grande, 2013). Aim Identify barriers and facilitators to implementing the CSNAT in a community specialist palliative care service. Methods Semi-structured interviews with 12 palliative care nurse specialists from two community nursing teams in Lothian, Scotland, June 2017. Data was audio-recorded, transcribed and analysed. Findings Palliative care nurse specialists acknowledge the importance of carers in palliative care and encourage carer support practices. Nurses perceived the CSNAT as useful, but used it as an 'add-on' to current practice, rather than as a new approach to carer-led assessment. Conclusion Further training is recommended to ensure community palliative care nurses are familiar with the broader CSNAT approach.
Suggested Reviewers:	Dr Gail Ewing Senior Research Associate, University of Cambridge ge200@cam.ac.uk Gail is the creator of the CSNAT which is the subject of my paper. Professor Gunn Grande Professor of Palliative Care, The University of Manchester Gunn.Grande@manchester.ac.uk

Morag Farquhar
Senior Lecturer in Nursing Studies, University of East Anglia
M.Farquhar@uea.ac.uk
Morag has worked in health services research for over 30 years, predominantly in palliative and supportive care.
Morag leads a research program on improving care and support for patients and carers living with advanced disease and has developed several programmes to support carers and patients.

Jonathan Totman
Research Clinical Psychologist, Anglia Ruskin University
totman@alumni.ucl.ac.uk
Experience conducting research in the community-based palliative care setting with family caregivers.

Dr Erna Haraldsdottir, BSc, MSc, PhD
Senior Lecturer in Nursing, Queen Margaret University Edinburgh
eharaldsdottir@qmu.ac.uk
Erna has a background in clinical palliative care and research in the palliative care field. She is the Director of the Education and Research department at the St Columbas Hospice. She has dedicated her career to palliative care development and research, with one of her key interests being family support in palliative care.

Response to Reviewers:

1. The discussion and conclusion could be strengthened by a consideration of the relevance of the research to the district nursing workforce rather than just the CNS workforce. It would be good if there is a clear message for the BJCN readership in the conclusion ie how might the CSNAT be used by the district nursing workforce etc.....

We have added a paragraph above 'further research' to address this feedback. Thank you.

2. There is occasional lapses in verb tense consistency; eg see Discussion para Use of the CSNAT where present instead of past tense.

We have addressed the lapses in verb tense consistency in the discussion paragraph Use of the CSNAT, and have checked the rest of the paper for this. Thank you for this feedback.

Reviewer #2: I think this is a clearly written and interesting paper about an important issue. I only have some minor comments

Abstract
Background
3. I think it would be more accurate to say that the "The Carer Support Needs Assessment Tool enables comprehensive assessment of carer support needs" rather than "-provides a comprehensive measure - ", as it is an assessment tool rather than a measurement tool.

Thank you for this comment, we have made this amendment.

Aim
4. From the paper I was not sure whether the aim was really to identify barriers to "implementing the CSNAT" or to "implementing the CSNAT Approach".

We have clarified this in the 'Aims'and 'Setting' section.

Background and reference list
5. The Ewing & Grande reference is 2013 rather than 2012.
Apologies, we have corrected this reference, thank you.

6. The reference Ewing, Brundle, Payne, Grande (2013) should probably be mentioned alongside Alvariza et al, 2019, as a reference for CSNAT validity.

We have added this reference in alongside Alvariza, thank you.

7. There have been some recent papers published on implementation of the CSNAT approach. These do not make the current paper less relevant in any way, as they look at slightly different things, but they should probably be mentioned

Thank you for highlighting these papers to us, we now include these two references in our Introduction/Background.

Diffin J, Ewing G, Harvey G, Grande G (2018). Facilitating successful implementation of a person-centred intervention to support family carers within palliative care: a qualitative study of the Carer Support Needs Assessment Tool (CSNAT) intervention. BMC Palliative Care; 17:129. https://doi.org/10.1186/s12904-018-0382-5

Diffin J, Ewing G, Harvey G, Grande G (2018). The influence of context and practitioner attitudes on implementation of person-centred assessment and support for family carers within palliative care. Worldviews on Evidence-Based Nursing; 15(5): 377-385.
DOI: 10.1111/wvn.12323; http://dx.doi.org/10.1111/wvn.12323

Methods
8. Did the CSNAT training prior to the study explain only the tool or also the CSNAT approach to members of teams?

The training explained the tool and the CSNAT approach. We have explained this in our Methods 'Setting' paragraph. Thank you.

9. I wonder if the Sample table could be summarised more (for instance, mean and range of years of experience, percentages that were more or less experienced for each team)?

We have summarised the table, thank you for the feedback.

10. It would help to have more information on the role of the researcher, for instance was this a member of the team or someone from outside the team, a practitioner or an academic?

We have added a sentence to the Methods 'Setting' paragraph about the background of the researcher. Thank you.

11. Please also explain more about the recruitment process, were all team members approached and how, was the voluntary nature of the research explained and so on.

We have explained this in the 'Sampling' section. Thank you.

12. Please also give some details of the interview protocol.

We have given information about the topic guide used for interviews in the 'data collection' section. Thank you.

13. Some more detail on how rigour was built into the study would be helpful.

We have expanded on how rigour was built into the study in the 'Rigour' section. Thank you.

Findings
14. The findings are clearly written and interesting, but quite brief. I would have liked some more quotes and examples if possible.

Thank you for making this point, we have added more quotes to the 'findings' section.

Discussion
15. This is also clearly written. It does not always seem that the content of the themes in the Findings fully matches the content of the themes in the Discussion. For instance lack of self-identification by carers was part of barriers in the Findings but not in the Discussion. This may be worth reviewing for a final edit.

We have checked the content of themes in the findings against the discussion and corrected mismatched aspects, thank you.

16. On page 14 it is stated that "the CSNAT would be better at identifying carer support needs if it had a greater uptake by carers". Was there an indication how this may be improved?

There was no indication on how this may be improved, and we have added this as a point on page 14, we have also added it to the 'future research' section. Thank you.

17. The Law et al's (2011) theory on page 17 needs more detail and explanation regarding how it fits with the study findings.

We have removed this reference and added a more relevant reference to this section. Thank you.

18. "Further research" on page 18: this recommends research into carers' views of being asked to complete the CSNAT, but presumably this needs to be about carers' views of engaging with the whole CSNAT approach, where the focus is less on completing a form, and more on facilitating communication and support.

Thank you for making this point. We have amended the 'Further research' section to reflect this.

Additional Information:	
Question	Response
Please enter the **word count** of your manuscript	4000

Table 1

Step	Explanation
Introduction of the CSNAT	The practitioner administers the CSNAT, by introducing and explaining it at the earliest opportunity in the caregiving journey.
Carers consideration of needs	The practitioner allows time for the carer to consider their needs using the CSNAT.
Assessment conversation	An assessment conversation takes place, in which the carer highlights their support need priorities.
Shared action plan	The assessment conversation leads to development and documentation of an action plan, which summarizes actions required from the carer and practitioner.
Shared review	Regular review of the carers support needs.
Table 1: Steps to CSNAT Approach	

Table 3

Step Number	Action Involved in Each Step	Details of the Action	Relation to this Study
1	Verbatim Transcription	Undertaken by the researcher.	An ongoing process during data collection.
2	Familiarisation	The researcher must become familiar with the transcripts and be immersed in the data.	Completed by researcher by conducting and transcribing the interviews, and subsequent reading through the transcripts for initial coding.
3	Coding	Reading the transcripts line-by-line, applying codes to summarise important parts of each passage.	The researcher coded the transcripts by hand. Codes referred to behaviours, values, emotions, and more abstract or impressionistic elements of the data.
4	Drafting a Theoretical Framework	Grouping important and recurring codes into categories.	A draft theoretical framework table was created using Microsoft Word, in which recurring and important codes and categories were clearly defined and labelled.
5	Indexing	Application of the draft theoretical framework to the transcript, using qualitative data analysis software.	NVivo 11 was used to apply the framework to each transcript. Appropriate codes were linked to sections of transcript that they were reflected in. The draft theoretical framework was adjusted for clarity.
6	Charting a Framework Matrix	Insertion of recurrent codes and categories into a Framework Matrix.	Microsoft Excel was used to create a matrix for each theme. The codes developed in NVivo 11 were entered into a matrix, with participant quotes reduced to a succinct summary for each code of each theme.
7	Context Checking	Checking themes against original transcripts and field notes to ensure context is appropriate.	The researcher compared the findings in the framework matrix to original data, the audit trail and the field notes to ensure the context was congruent.
Table 3: Steps of Framework Analysis			

ABSTRACT

Background

Family carers play a central role in community-based palliative care. However, caring for a terminally ill person puts the carer at increased risk of physical and mental morbidity. The Carer Support Needs Assessment Tool (CSNAT) enables comprehensive assessment of carer support needs (Ewing & Grande, 2013).

Aim

Identify barriers and facilitators to implementing the CSNAT in a community specialist palliative care service.

Methods

Semi-structured interviews with 12 palliative care nurse specialists from two community nursing teams in Lothian, Scotland, June 2017. Data was audio-recorded, transcribed and analysed.

Findings

Palliative care nurse specialists acknowledge the importance of carers in palliative care and encourage carer support practices. Nurses perceived the CSNAT as useful, but used it as an 'add-on' to current practice, rather than as a new approach to carer-led assessment.

Conclusion

Further training is recommended to ensure community palliative care nurses are familiar with the broader CSNAT approach.

KEYWORDS

Palliative Care; End of Life; Community Care; Carers; Carer Support; Needs Assessment; Nursing

KEY POINTS

1. Palliative care nurse specialists acknowledge the importance of the role played by informal carers in palliative care, and encourage carer support practices.

2. Nurses accepted the Carer Support Needs Assessment Tool (CSNAT), and perceived it as useful, but used it as an 'add-on' to current practice, rather than as a new approach to carer-led assessment.

3. Barriers to CSNAT use included carers self-deprecating attitudes and feeling that their own needs were much less important than those of the terminally ill person they were caring for.

4. Facilitators include having a CSNAT Champion, and the provision of time and space to use the tool.

5. Education and training are recommended for shared action planning and review phases.

INTRODUCTION

For many people with a terminal illness, home is their preferred place of care (Gomes et al, 2013). To enable this, informal carers, in particular family members and friends, need to provide physical, emotional and practical support to the terminally ill person (Epiphaniou et al, 2012). Such support can include practical assistance with activities of daily living, including; personal care, household tasks, financial assistance, and social and emotional support (Rowland et al, 2017). Caring is associated with increased risk of physical and mental morbidity (Williams & McCorkle, 2011). In a palliative care context, the demands of the caring role can become all-encompassing. Support for carers can be limited as carers don't recognise themselves as carers, and often feel their needs are not legitimate in comparison to those of the cared for person (Carduff et al, 2014). To ensure that wellbeing of carers is maintained, and to enable the care for the terminally ill person, it is important that their needs are assessed (Ewing et al, 2018).

Background

The Carer Support Needs Assessment Tool (CSNAT) assesses the support needs of informal carers of people with a terminal illness (Ewing & Grande, 2013). This is a 14-item tool that assesses: (a) support needs for the carer themselves, and; (b) support to enable the carer to provide care to the terminally ill person. The CSNAT was found to be valid and reliable for supporting family caregivers in a palliative care setting (Alvariza et al, 2018; Ewing et al, 2013).

The CSNAT Approach consists of five steps (CSNAT, 2016; CSNAT, 2013). Each step is facilitated by the practitioner, but is carer-led (CSNAT, 2016). The five steps are documented in Table 1.

Step	Explanation
Introduction of the CSNAT	The practitioner administers the CSNAT, by introducing and explaining it at the earliest opportunity in the caregiving journey.
Carers consideration of needs	The practitioner allows time for the carer to consider their needs using the CSNAT.
Assessment conversation	An assessment conversation takes place, in which the carer highlights their support need priorities.
Shared action plan	The assessment conversation leads to development and documentation of an action plan, which summarizes actions required from the carer and practitioner.
Shared review	Regular review of the carers support needs.
Table 1: Steps to CSNAT Approach	

The CSNAT can enable carer support in the transition to end of life care at home (Ewing et al, 2013). It also enables practitioners to focus on carer needs upon discharge home for palliative care, and helps to prevent readmission towards end of life (Ewing et al, 2018).

Implementation in clinical practice can be challenging (Ahmed et al, 2015; Grande et al, 2009). Barriers include; practitioner beliefs and attitudes; lack of knowledge or training regarding any new tool and issues it may raise, and; lack of time or resources (Antunes et al, 2014; Ahmed et al, 2015; McIlfatrick & Hasson, 2013). The provision of education and evidence-based knowledge for practitioners is an important facilitator in the implementation

of new tools in palliative care settings (Thomas et al, 2010). Regular use of the intervention and opportunities for staff to interact with other practitioners to support learning, can promote successful implementation of an intervention (Diffin et al, 2018). There is often a fear that a new tool might replace or negatively impact the relationship between carer and practitioner, so it is important that any tool is seen as being complementary, and enhancing the therapeutic relationship (Antunes et al, 2014).

Diffin et al (2018a) explored the influence of practitioner attitudes on the implementation of the CSNAT. They found that services with a higher proportion of internal CSNAT facilitators to staff members were more likely to be high adopters of the CSNAT, thus being more successful at implementing it. Diffin et al (2018b) found that the success of the implementation of the CSNAT was also determined by how the internal facilitator role was enacted within the service. The establishment of a team of internal facilitators, and giving them authority to manage the implementation process both positively influenced the success of CSNAT implementation.

Austin et al (2017) identified factors influencing CSNAT use in a community specialist palliative care context based on interviews conducted between February 2011 and January 2012. Barriers included practitioners' preference for existing carer support practices, and concern about those practices changing with CSNAT introduction. Facilitators of CSNAT implementation included practitioners' positive attitudes towards the CSNAT, and the perception that the CSNAT may enhance existing practice. However, the CSNAT was a new tool at the time of data collection and was just being developed. Since, there has been a plethora of publications on the need for support for carers, for example; Ewing et al. (2018), Jack et al. (2014), and the Carers (Scotland) Act 2016, along with a growing recognition amongst clinicians, service managers, educators and policy-makers that carers play an

essential role in providing care at home and need to be enabled and supported in their role. Consequently, more recent studies on the implementation of the CSNAT as a tool to identify the support needs of carers were warranted.

METHODS

Aims

This study explores the use and acceptability of the CSNAT, and the barriers and facilitators to implementing the CSNAT ==approach== in a community palliative care setting. The research questions are:

1. Is the CSNAT perceived as useful in a community specialist palliative care setting?
2. Is the CSNAT acceptable in a community specialist palliative care setting?
3. What are barriers and facilitators to the use of the CSNAT in a community specialist palliative care setting?

Setting

Data collection was undertaken with two-community specialist palliative care nursing teams in Lothian, Scotland. Both teams were attached to a local hospice. The CSNAT ==approach== had recently been introduced within the community service. The present study was designed to explore CNS perceptions of the CSNAT ==approach== and to identify any recommendations to improve CSNAT implementation. ==Data was collected by a postgraduate student researcher, ZH, as part of a Masters of Public Health dissertation. ZH is a Registered Nurse by training had no professional connection to the Marie Curie team==.

CSNAT Training Prior to the Study

The Hospice Lead Nurse and two Community Clinical Nurse Specialists (CNS) (one per site) attended an official CSNAT training day facilitated by the CSNAT developers, in June 2015. They each subsequently hosted CSNAT-training meetings at their respective sites,

using CSNAT training materials to introduce and explain the tool and its approach to all members of both teams. Follow-up conversations occurred at team meetings thereafter, and the CSNAT was an agenda item at weekly team meetings. The CSNAT was launched in October 2015, and the CSNAT has been used routinely in the Hospice's practice since then. Any CNSs who have joined the team since the CSNATs introduction have received CSNAT training from their induction supervisor, typically a member of the community nursing team that has received CSNAT training.

Design

A qualitative study design, using semi-structured interviews.

Sample

All fourteen CNS team members were invited to take part; two declined due to holiday and work commitments. A purposive sample consisting of 12 Community Palliative Care Clinical Nurse Specialists was recruited. The recruitment process involved the researcher visiting both teams to explain the study and invite them to participate. Participants volunteered to take part during the researchers site visit.   A participant information sheet and consent form were provided, and informed consent was sought prior to interview. A summary of the characteristics of sample participants are shown in Table 2. All participants were female with an average age of 43 years.

Site	Number of CNS Participants from Team	Gender	Average Number of Years in Community Palliative Care CNS role	Range of Number of Years in Community Palliative Care CNS role	% of Staff with 3 or more years palliative care experience
Team 1	5	Female	3.5	3.0-4.0	100%
Team 2	7	Female	5.3	1.5-9.0	57%
* More experienced = Three or more years in the Community palliative care CNS role					
**Less experienced = Less than three years in the Community palliative care CNS role					
Table 2: Summary of characteristics of the Sample					

Data Collection

Interviews were conducted in June 2017, and lasted between 25 and 55 minutes. The interviews were carried out in pre-booked, private meeting rooms located at the two sites, during participants' working hours, for their convenience and comfort. All interviews were audio recorded and transcribed. Participants signed informed consent forms prior to participation.

For the interviews, a topic guide was designed to explore four main areas: use, accessibility, barriers, and facilitators of the CSNAT. The main body of each interview focussed on the barriers and facilitators of the CSNAT approach. An open, non-presuming questioning style was adopted, with a focus on understanding participants' perceptions and situational experiences of using the CSNAT.

Ethical approval was obtained from the Usher Ethics Committee at the University of Edinburgh, and the study was approved by the Marie Curie Hospice Research Governance Committee.

Data Analysis

A Framework Analysis approach was adopted. The steps of Framework Analysis and their application in this study is detailed in Table 3.

Step Number	Action Involved in Each Step	Details of the Action	Relation to this Study
1	Verbatim Transcription	Undertaken by the researcher.	An ongoing process during data collection.
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Table 3: Steps of Framework Analysis			

Rigour

Rigour was built into this study using the COREQ 32-item checklist for qualitative studies (Tong et al, 2007). Framework analysis involves several processes that enhance

rigour (Ward et al, 2013). In Step 5 of Framework Analysis, the draft theoretical framework was adjusted for clarify following researcher reflection on categorisation of some codes in order to avoid repetition of data across themes (Ward et al, 2013). In Step 7, context checking was undertaken to ensure participants' meaning was visible through the final emerging themes (Smith & Firth, 2011). Cross-validation was used to validate emerging themes, through participant checking which involved a discussion of the findings between CNS participants and the Lead Nurse (Tong et al, 2007).

FINDINGS

Use of the CSNAT

Most participants introduced the CSNAT to new patients at the end of the first visit. Generally this involves giving it to the carer and explaining it.

> *"At the end of every first visit, we offer carer support, and we always give out*
>
> *the CSNAT. I always present the CSNAT as a tool that has been formulated*
>
> *because we are aware that carers require support."* (P1)

None of the participants reported using the CSNAT to develop carer action plans, and none reported that they used it to regularly review carer needs over time. Most participants gave the CSNAT as an '*add on*' to supplement existing carer support practice, allowing carers time to reflect on CSNAT content alone, to identify issues that had not already been covered.

Half of the participants revisited the CSNAT on subsequent visits, whilst the other half never revisited it, leaving it to the carer to raise any issues they may have.

> *"I have been using it as an add-on, to try and identify the gaps I have not met"* (P2)

> *"I introduce it by saying 'this is a tool to help me make sure that I am not assuming your needs' and 'we have talked about a lot of things, but there may be other things that come from this'"* (P6)

All participants strongly expressed the perception that carer support is a hugely important aspect of their job, central to patient and carer well-being, and making possible the patients wish to stay at home for palliative care.

> *"Carer support is important as any other aspect of the job we do, their needs are important"* (P5)

> *"If the carer isn't being looked after it can have a major impact on the patient and on their wishes to remain at home"* (P8)

Acceptability of the CSNAT

Participants were positive about the CSNAT as a carer support tool. Many participants could appreciate how it could potentially improve carer support.

"I'd like to think it does enable carer support, it very much puts that

conversation on the table" (P4)

"I think it is a good tool…it is not too invasive, it is quite generalist, and it is

covering many aspects of the carers role. I do think it is appropriate and fairly

easy and self-explanatory to follow" (P12)

Some participants expressed lack of confidence in using the CSNAT and a desire to improve their knowledge and understanding of it, in order to improve their use of it.

"I'd be interested to know about how I could improve using it…have I just got

the wrong end of the stick with it and I am the barrier?" (P2)

"It is a privilege that we are part of this vulnerable time with many

families…if there is something that can help us deliver our care better,

obviously we will want to try and use it better to ensure that happens." (P10)

Barriers to Using the CSNAT

Participants perceived carers to have self-deprecating attitudes, including; not valuing their own worth or identity as a carer, and consequently, not wanting to discuss their needs. Many participants were keen to help the carer acknowledge their role as a carer, and the additional responsibilities that come with that.

"I think it is just carers needing to acknowledge that they are a carer, and

they are important, because they don't see themselves as important" (P7)

A few participants expressed the view that they are '*already doing*' carer support without the CSNAT, and that the CSNAT is *'extra, burdensome documentation'*.

"We don't need any more documentation, we have enough" (P1)

At the time of the study only a poor quality photocopied version of the CSNAT was available to the CNS team. All participants expressed concern with the unprofessional appearance, lack of colour, and poor quality printing. CNSs found this embarrassing when administering the tool, and worried that the poor appearance may seem representative of the services' approach to carer support.

"It is awful! It is photocopied and the copies are on a slant, they are fuzzy,

have no colour...it looks like a scrap bit of paper" (P5)

Facilitators for Using the CSNAT

CNSs felt encouraged to use the CSNAT when given workplace support through a local CSNAT Champion, provision of training and updates, and through hearing success stories and positive feedback. Equally, participants felt ample time and space was available to use the tool.

"Having someone in the team who owns it and makes it their bag makes it

easier to use, because if it just came from senior management saying 'this is a

new tool and this is what we are doing, get on with it' that would be bland.

Whereas, here you have got the teaching and hearing the feedback from

other areas about how successful it is and actually how unsuccessful it is

where we are, so that is good to hear." (P9)

"Hearing about good experiences and how it has worked really well for other

areas previously helped you to kind of have belief in the tool" (P5)

Many participants created a space for using the CSNAT with carers, through relationship building, and by revisiting the tool.

"Immediately showing carers that they are a priority too is good support for

them...if they have questions we suggest setting aside a separate

appointment for them, sometimes away from the house if it is easier for

them" (P12)

"I offer to meet carers in cafes to have a chat away from the home, and the

information you get there is immense compared to what you would get in the

house" (P5)

DISCUSSION

Use of the CSNAT

Overall, the majority of participants found the CSNAT useful, and nearly all used it to explore carer support needs. Most participants reported introducing the CSNAT towards the end of the first visit with the carer. This is congruent with recommended CSNAT practices, which advise that the CSNAT is delivered as early as possible in the caregiving journey, to capture carers initial support needs (CSNAT, 2016).

Acceptability of the CSNAT

CNSs found the CSNAT acceptable, and perceived carers to review and consider the tool, too. However, CNSs felt that the CSNAT would be better at identifying carer support needs if it had a greater uptake by carers. Given that carers are often reticent to self-identify as such (Carduff et al, 2014), gentle reminders by CNSs at follow-up visits may encourage CSNAT completion, or the commencement of a conversation focused on their needs. Some CNSs expressed lack of confidence in using the CSNAT, and would appreciate more training on the recommended five-step CSNAT Approach.

Valuing Carer Role and Validation of Carer Support

All CNSs expressed a strong, consistent recognition of carer support as important, central, and fundamental to their role. Palliative care CNSs have an in-depth understanding of the additional responsibilities that come with being a carer, and believe that their nursing role involves recognising carers and helping carers address any needs that arise. In line with previous research (Carduff et al, 2014), this study found that CNSs feel carers do not self-identify as carers, ask for support, or, value their own needs. Carduff et al (2014) found that

rather than self-identifying as carers, carers they see themselves in the context of their relationship with the cared-for person, ie as a spouse, sibling, child, or friend. This lack of validation of the carer role, along with the all-encompassing demands, often means they do not have time to address their own needs. This lack of self-recognition is further compounded by a societal and cultural demand for relatives to adopt the role of family caregiver (Rezende et al, 2017; Sharma et al, 2016). These pressures on carers increase their risk of morbidity and mortality (Epiphaniou et al, 2012). There is a need to encourage carers to self-identify, and recognise their own needs as valid and important, and to encourage society to recognise the pressures of caregiving. This requires a change in healthcare professionals' practices, to identify formal carer support opportunities and mechanisms (Epiphaniou et al, 2012). The CSNAT helps convey to carers that their needs are important, legitimate and distinct from patients (CSNAT, 2016; Ewing et al, 2016a). This, combined with the finding from this study, that CNSs' are passionate and keen to support carers, could help address this need. Therefore, further training to highlight the usefulness of the CSNAT in helping carers recognise their own needs might be beneficial.

The CSNAT Approach

The recommended five-step CSNAT approach is person-centred and carer-led. However, many participants described methods of using the CSNAT that are inconsistent with the recommended approach, such as, using the CSNAT as an *'add-on'* to existing nurse-led practice, and not revisiting the CSNAT. Austin et al (2017) also found that the CSNAT was used as an *'add on'* to existing practice in their study of its use in palliative home care. This may have been because practitioners did not fully appreciate that CSNAT implementation requires a shift in their carer support approach from being practitioner-led, to practitioner-facilitated

but carer-led assessment. Similarly, findings from this study suggest that CNSs added the CSNAT to their existing practice, rather than changing their carer support approach. Many used it as a one-off assessment tool, and generally the planning and review stages, which are part of the broader CSNAT approach were not carried out.

Further training would improve CNS understanding of the principles of the CSNAT approach. Findings from this study suggest that such training would be well received by staff, as several expressed a desire for more knowledge on the CSNAT approach.

Barriers to Using the CSNAT

Participants expressed that they are '*already doing'* carer support, and that the tool adds *'extra documentation', 'duplicating'* their existing practice. However, the recommended CSNAT approach suggests that the tool should form the basis of carer needs assessment, rather than being an add-on (CSNAT, 2016). McIlfatrick & Hasson (2013) found aspects of a palliative assessment tool can duplicate what is already being done as part of the clinicians existing role, and that the approach taken to using a tool by the practitioner can disable the efficacy of the tool, if the tool is not used as proposed. Instances described by CNSs in the present study suggest that the CSNAT is used more as a one-off assessment, rather than part of a broader process.

All CNSs mentioned the physically unattractive appearance of the CSNAT; expressing concern about it being representative of the services approach to carer support. The CSNAT's appearance should be reviewed to reflect the necessary improvements reported by participants. This finding has implications for the implementation of service documentation beyond the palliative care setting. It is important to ensure documents are professional and well-presented to engage target audiences (Pearson, 2003).

Facilitators for Using the CSNAT

Positive workplace support can enable CSNAT use. Hearing positive messages about the CSNAT, and workplace provision of time and space to use the tool, motivated participants to implement the CSNAT. Having a CSNAT Champion within the team promotes and encourages team members to use the tool. <mark>Similarly, Diffin et al (2018b) found successful CSNAT implementation was associated with having internal facilitators within each team. Particularly when the internal facilitator is given sufficient 'leverage' to implement the CSNAT, such as; authority to change practice, being on a supportive team of facilitators, and having effective positioning within the service.</mark> Thus suggesting that the workplace positivity described by participants encouraged engagement with the CSNAT. This has implications for the introduction of tools in practice, as having a local champion may facilitate acceptance of new tools in healthcare settings.

Creating space for carer support and CSNAT use was described as a facilitator by many participants. They described creating opportunities for carer support, by proactively arranging individual meetings with carers, where they encouraged them to use the CSNAT. Nelson et al (2017) state that meeting with carers is important to allow time for them to discuss their needs. This enables carer support by providing the opportunity for the CSNAT assessment to occur. These facilitators were also identified by Ewing et al (2016a), who identified that the CSNATs mechanism of action is the creation of space for carer support.

Relevance of the Study to District Nursing

Supporting carers of people at the end of life is relevant to healthcare beyond the hospice setting, particularly in primary care, given the growing number of people projected

to die in community settings over the next two decades (Bone et al, 2018). District Nursing teams are well-placed to support family carers at home, and often carry out carer support in an informal manner during home visits (Griffiths et al, 2013). The CSNAT approach could be adopted by District Nurses as a formal method of addressing carers' needs at home, and our findings could usefully guide the implementation of the CSNAT approach in a District Nursing team. Furthermore, the CSNAT could be evaluated for use by the District Nursing workforce not just for carers of individuals with a terminal diagnosis, but also to identify support needs for carers of elderly individuals with increasing frailty, dementia and complex needs. The CSNAT is currently being promoted as part of the new Daffodil Standards, which are care standards for primary care team delivery of end of life care, which includes online training (RCGP, 2019).

Further Research

Further research to examine the carers views of engaging with the CSNAT approach, and the extent to which implementation of the CSNAT approach improves support for the carer, and indirectly for the terminally ill person, is recommended.

Limitations

The data was generated by interviewing CNSs who are highly knowledgeable and experienced in the palliative care setting. Twelve participants (86%) of the potential fourteen were recruited, giving a good representation of the majority of views from these two sites. However, given the hospice-based context of this study, the findings may not be directly transferrable across all settings.

CONCLUSION

CNSs view carer support as an essential element of their role. CNSs encourage carers to acknowledge their own needs as valid and important. The CSNAT was deemed acceptable by CNSs, and they find it useful for legitimizing carer support, but there is potential for improvement in way the tool is administered, by moving from using the CSNAT as an 'add-on' to adopting the CSNAT Approach. Further training and education using the five-step approach is recommended, as is the identification of a CSNAT Champion within the nursing team. These recommendations are relevant and applicable to the introduction of the CSNAT to the District Nursing workforce.

CPD REFLECTIVE QUESTIONS

What learning have you identified regarding carers and carer support using tools?

How aware are you of carers and their support needs in your daily practice?

How could you incorporate and use carer support tools in your team?

REFERENCES

AHMED, N., HUGHES, P., WINSLOW, M., BATH, P., COLLINS, K., & NOBLE, B. (2015) A

Randomised Controlled Trial of a Holistic Needs Assessment Questionnaire in a Supportive

and Palliative Care Service. *Journal of Pain and Symptom Management. 50*(5) 587-599

doi: https://doi.org/10.1016/j.jpainsymman.2015.05.010

ALVARIZA, A., HOLM, M., BENKEL, I., NORINDER, M., EWING, G., GRANDE, G., HAKANSON,

C., OHLEN, J., & ARESTEDT, K. (2018) A person-centred approach in nursing: Validity and

reliability of the Carer Support Needs Assessment Tool. *European Journal of Oncology

Nursing. 35* (2018) 1-8. doi: 10.1016/j.ejon.2018.04.005.

ANTUNES, B., HARDING, R., & HIGGINSON, I. (2014) Implementing patient-reported

outcome measures in palliative care clinical practice: A systematic review of facilitators and

barriers. *Palliative Medicine. 28*(2) 158-175 doi: 10.1177/0269216313491619

AUSTIN, L., EWING, G., & GRANDE, G. (2017). 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. 12*(6) doi:

https://doi.org/10.1371/journal.pone.0179287

BONE., A, E., GOMES, B., ETKIND, S, N., VERNE, J., MURTAGH, F, EM., EVANS, C, J., HIGGINSON, I, J. (2018) What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliative Medicine. 32* (2) 329-336. Doi: https://doi.org/10.1177/0269216317734435

CARDUFF, E., FINUCANE, A., KENDALL, M., JARVIS, A., HARRISON, N., GREENACRE, J., &

MURRAY, S, A. (2014) Understanding the barriers to identifying carers of people with

advanced illness in primary care: triangulating three data sources. *BMC Family Practice.*

15(48) doi: https://doi.org/10.1186/1471-2296-15-48

CARERS   (SCOTLAND)   ACT   (2016).   (PDF)   Retrieved   from:

http://www.legislation.gov.uk/asp/2016/9/contents/enacted

CARER SUPPORT NEEDS ASSESSMENT TOOL (CSNAT) (2016) *Resources*: *The CSNAT Approach*

(PDF). Retrieved from http://csnat.org/resources/

CARER SUPPORT NEEDS ASSESSMENT TOOL (CSNAT) (2013) *The CSNAT approach (summary)*

(PDF) Available: http://csnat.org/files/2012/07/CSNAT-approach-October-2015.pdf

DIFFIN, J., EWING, G., HARVEY, G., GRANDE, G. (2018b) Facilitating successful implementation

of a person-centred intervention to support family carers within palliative care: a qualitative

study of the Carer Support Needs Assessment Tool (CSNAT) intervention. *BMC Palliative Care*

17:129.doi: https://doi.org/10.1186/s12904-018-0382-5

DIFFIN, J., EWING, G., HARVEY, G., GRANDE, G. (2018a). The influence of context and

practitioner attitudes on implementation of person-centred assessment and support for

family carers within palliative care. *Worldviews on Evidence-Based Nursing. 15*(5) 377-385.

doi: http://dx.doi.org/10.1111/wvn.12323

EPIPHANIOU, E., HAMILTON, D., BRIDGER, S., ROBINSON, V., ROB, G., BEYNON, T., HIGGINSON, I., & HARDING, R. (2012) Adjusting to the caregiving role: the importance of coping and support. *International Journal of Palliative Nursing. 18*(11) 541-545 doi: 10.12968/ijpn.2012.18.11.541

EWING, G., AUSTIN, L., & GRANDE, G. (2016a) The role of the carer support needs assessment tool (CSNAT) in palliative home care: a qualitative study of practitioners perspectives of its impact and mechanisms of action. *Palliative Medicine. 30*(4) 392-400 doi: https://doi.org/10.1177/0269216315596662

EWING, G., AUSTIN, L., GIBSON, D., & GRANDE, G. (2016b) Enabling successful hospital discharge to home at end of life: can a carer support needs assessment tool (CSNAT) help improve support for family carers? *BMJ Supportive and Palliative Care*. *6* 384-408 doi: http://dx.doi.org/10.1136/bmjspcare-2016-001204.21

EWING, G., AUSTIN, L., JONES, D., & GRANDE, G. (2018) Who cares for carers at hospital discharge et 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. *Palliative Medicine. 32*(5) 939-949 doi: 10.1177/0269216318756259.

EWING, G., BRUNDLE, C., PAYNE, S., & GRANDE, G. (2013) The carer support needs assessment tool (CSNAT) for use in palliative care and end of life care at home: A validation

study. *Journal of Pain and Symptom Management. 46* (2013) 395-405 doi:

10.1016/j.jpainsymman.2012.09.008

EWING, G., & GRANDE G (2013) Development of a Carer Support Needs Assessment Tool

(CSNAT) for End-of-Life Care Practice at Home: A Qualitative Study. *Palliative Medicine. 27*

(3) 244-256 doi: 10.1177/0269216312440607

GOMES, B., CALANZANI, N., GYSELS, M., HALL, S., & HIGGINSON (2013) Heterogenity and

changes in preferences for dying at home: a systematic review. *BMC Palliative Care. 12* (7)

doi: https://doi.org/10.1186/1472-684X-12-7

GRANDE, G., STAJDUHAR, K., AOUN, S., TOYE, C., FUNK, L., ADDINGTON-HALL, J., PAYNE, S.,

& TODD, C. (2009) Supporting lay carers in end of life care: Current gaps and future

priorities. *Palliative Medicine. 23* (2009) 339-344 doi: 10.1177/0269216309104875.

GRIFFITHS, J., EWING, G., & ROGERS, M. (2013) Early support visits by district nurses to cancer

patients at home: A multi-perspective qualitative study. *Palliative Medicine. 27* (4) 349-357.

Doi: https://doi-org.ezproxy.is.ed.ac.uk/10.1177/0269216312451949

JACK, B., O'BRIEN. M., SCRUTTON, J., BALDRY, C., & GROVES, K. (2014) Supporting family

carers providing end-of-life home care: a qualitative study on the impact of a hospice at

home service. *Journal of Clinical Nursing. 24* (1) 131-140 doi: 10.1111/jocn.12695

MCILFATRICK, S., & HASSON, F. (2013) Evaluating an holistic assessment tool for palliative care practice. *Journal of Clinical Nursing. 23* (2013) 1064-1075 doi: 10.1111/jocn.12320

NELSON, D., MANSFIELD, P., & KANE, R. (2017) Carers of people affected by cancer and other long-term conditions at end of life: A qualitative study of providing a bespoke package of support in a rural setting. *Palliative Medicine. 31* (2) 158-161 doi: 10.1177/0269216316648073.

PEARSON, S. (2003) Promoting sexual health services to young men: findings from focus group discussions. *Journal of Family Planning and Reproductive Health Care. 29* (4) 194-198 doi: http://dx.doi.org/10.1783/147118903101198079

REZENDE, G., GOMES, C, A., RUGNO, F, C., EVA, G., LIMA, N, K, C., & DE CARLO, M, M, R, P. (2017) Burden on family caregivers of the elderly in oncologic palliative care. *European Geriatric Medicine. 8* (4) 337-341 doi: https://doi.org/10.1016/j.eurger.2017.06.001

ROWLAND, C., HANRATTY, B., PILLING, M., VAN DEN BERG, B., & GRANDE, G. (2017). The Contributions of family care-givers at end of life: A national post-bereavement census survey of cancer carers' hours of care and expenditures. *Palliative Medicine. 31* (4) 346-355 doi: 10.1177/0269216317690479

ROYAL COLLEGE OF GENERAL PRACTITIONERS (RCGP) (2019) Daffodil Standards: Standard 3: Carer Support – before and after death. Available: https://www.rcgp.org.uk/clinical-and-

research/resources/a-to-z-clinical-resources/daffodil-standards/the-daffodil-standards/standard-3-carer-support-before-and-after-death.aspx

SHARMA, N., CHAKRABARTI, S., & GROVER, S. (2016) Gender differences in caregiving among family - caregivers of people with mental illness. *World Journal of Psychiatry. 6* (1) 7-17 doi: 10.5498/wjp.v6.i1.7

SMITH, J., & FIRTH, J. (2011) Qualitative data analysis: the framework approach. *Nurse Researcher. 18*(2) 52-62

THOMAS, K., HUDSON, P., OLDHAM, L., KELLY, B., & TRAUER, T. (2010) Meeting the needs of family carers: an evaluation of three home-based palliative care services in Australia. *Palliative Medicine. 24* (2) 183-191 doi: 10.1177/0269216309351467

TONG, A., SAINSBURY, P., & CRAIG, J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Healthcare. 19* (6) 349-357 doi: https://doi.org/10.1093/intqhc/mzm042

WARD, D, J., FURBER, C., TIERNEY, S., & SWALLOW, V. (2013) Using Framework Analysis in Nursing Research: a worked example. *Journal of Advanced Nursing. 69*(11) 2423-2431

WILLIAMS, A., & MCCORKLE, R. (2011) Cancer family caregivers during the palliative, hospice and bereavement phases: a review of the descriptive psychological literature. *Palliative and supportive care. 9* (2011) 315-325 doi: 10.1017/S1478951511000265.

Table 2

Site	Number of CNS Participants from Team	Gender	Average Number of Years in Community Palliative Care CNS role	Range of Number of Years in Community Palliative Care CNS role	% of Staff with 3 or more years palliative care experience
Team 1	5	Female	3.5	3.0-4.0	100%
Team 2	7	Female	5.3	1.5-9.0	57%
* More experienced = Three or more years in the Community palliative care CNS role					
**Less experienced = Less than three years in the Community palliative care CNS role					
Table 2: Summary of characteristics of the Sample					

The Barriers and Facilitators to Implementing the Carer Support Needs Assessment Tool in a Community Palliative Care Setting.

Short running title: CSNAT use in a Community Setting

Zoe Horseman, Research Assistant [1]   BN, RN, MPH

Libby Milton, Lead Nurse [2]   MPH, BN, RN, PGDip

Anne Finucane, Research Lead [1, 2] BSc, MSc, PhD (Psych)

1. Usher Institute of Population Health Sciences and Informatics, College of Medicine and Veterinary Medicine, University of Edinburgh, Old Medical School, Teviot Place, Edinburgh, EH8 9AG
2. Marie Curie Hospice Edinburgh, 45 Frogston Road West, Edinburgh, EH10 7DR

Corresponding author: Zoe Horseman, [zoehorseman@hotmail.co.uk,](mailto:zoehorseman@hotmail.co.uk) 07827521616

Abstract

Background
Family carers play a central role in community-based palliative care. However, caring for a terminally ill person puts the carer at increased risk of physical and mental morbidity. The Carer Support Needs Assessment Tool (CSNAT) provides a comprehensive measure of carer support needs (Ewing & Grande, 2012).

Aim
Identify barriers and facilitators to implementing the CSNAT in a community specialist palliative care service.

Methods
Semi-structured interviews with 12 palliative care nurse specialists from two community nursing teams in Lothian, Scotland, June 2017. Data was audio-recorded, transcribed and analysed.

Findings
Palliative care nurse specialists acknowledge the importance of carers in palliative care and encourage carer support practices. Nurses perceived the CSNAT as useful, but used it as an 'add-on' to current practice, rather than as a new approach to carer-led assessment.

Conclusion

Further training is recommended to ensure community palliative care nurses are familiar with the broader CSNAT approach.

Conflict of Interest:

None.