

Adapting hospice-based carer support needs assessment to an acute inpatient care context: a UK study to support carers during discharge home

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Aims

- To investigate the content, timing and format of support required by family carers at patient discharge from acute care at end of life
- To use the findings to adapt the CSNAT to the acute care setting to facilitate timely and appropriate patient discharge

The focus was on discharges where there was an expectation that patients going home had *“weeks to months”* to live

Methods

**Focus groups with 40
healthcare professionals
from acute and
community settings**

**Interviews with 22
bereaved and
current carers**

**Workshops with 14
practitioners and 5
bereaved carers**

Results

- Current context of the discharge process
- Carers and the discharge process
- Views of the CSNAT
- Feasibility of the CSNAT approach
 - Practitioner and carer perspectives

Teams in the discharge process

- No separate palliative care ward



Carers and the discharge process 1

- A focus on patients

“Honestly, the carers are my second thought and they’re only my thought if there becomes a difficulty, so as long as they’re happy with everything and everything is going along, I don’t consider their [needs]”

- Process driven by funding agenda and putting practicalities in place
- Carers consulted but on patients’ needs

Carers and the discharge process 2

- A focus on patients but carers involved on agreed discharge to home
- Putting practicalities in place – positive for some but for others a ‘standard set of supports’

A carer assessment process?

- No systematic process - informal, practitioner-led conversations
- No carers described assessment of THEIR needs – they were ‘on their own’

“nobody ever really kind of said, ‘Would you like...you know’, it was just, there is all sorts of support there for you, and then nothing.”

Views of the CSNAT

| Your support needs now | | | | |
|--|----|---------------|------------------|----------------|
| We would like to know what help you need to enable you to care for your relative or friend and what support you need for yourself. Please tick the box that best represents your needs now for each statement below. | | | | |
| Do you need more support with... | No | A little more | Quite a bit more | Very much more |
| ...understanding your relative's illness | | | | |
| ...having time for yourself in the day | | | | |
| ...managing your relative's symptoms, including giving medicines | | | | |
| ...your financial, legal or work issues | | | | |
| ...providing personal care for your relative (eg dressing, washing, toileting) | | | | |
| ...dealing with your feelings and worries | | | | |
| ...knowing who to contact if you are concerned about your relative (for a range of needs including at night) | | | | |

| (continued) | | | | |
|---|----|---------------|------------------|----------------|
| Do you need more support with... | No | A little more | Quite a bit more | Very much more |
| ...looking after your own health (physical problems) | | | | |
| ...equipment to help care for your relative | | | | |
| ...your beliefs or spiritual concerns | | | | |
| ...talking with your relative about his or her illness | | | | |
| ...practical help in the home | | | | |
| ...knowing what to expect in the future when caring for your relative | | | | |
| ...getting a break from caring overnight | | | | |
| ...anything else (please write in) | | | | |

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- Entirely positive

“They should be asking all these questions, you know, to the carers”

“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”

Practitioners' views

Your support needs now

We would like to know what help you need to enable you to care for your relative or friend and what support you need for yourself. Please tick the box that best represents your needs now for each statement below.

| Do you need more support with... | No | A little more | Quite a bit more | Very much more |
|--|----|---------------|------------------|----------------|
| ...understanding your relative's illness | | | | |
| ...having time for yourself in the day | | | | |
| ...managing your relative's symptoms, including giving medicines | | | | |
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| ...dealing with your feelings and worries | | | | |
| ...knowing who to contact if you are concerned about your relative (for a range of needs including at night) | | | | |

(continued)

Do you need more support with...

| No | A little more | Quite a bit more | Very much more |
|----|---------------|------------------|----------------|
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- *“Yes definitely, the right questions”*
- *Useful “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”*

Responses to the CSNAT approach

Practitioners

- Seeing questions will stress carers
- A framework to guide practitioner discussion
- Raising expectations – concerns about being unable to ‘fix’

Carers’ responses

- Visibility useful – currently *“the ball’s put in your court of what you need to ask.”*
- Involving carers; not prescriptive – *“[carers will already know what would help them, what would really benefit them.]”*

Stage 1: introduction

- How introduced is crucial
 - Words used (practitioners)
 - Reluctance; especially current carers
 - Set aside as another leaflet
- Introduction \neq job done

I've done my job, tick, I've talked about care planning because I've given you the nice leaflet, and I've told you about the different sections in it." (Carer)

Stages 2 and 3

- Carers consideration of needs
 - Time to reflect; written format
 - Help to 'manage expectations'
- Assessment conversation
 - CSNAT questions – a trigger
 - A separate space; a separate focus
 - A conversation even without a ✓

Stages 4 and 5

- Action planning and review
 - Plan is expected part of the process
 - Review as part of the process of support
“Shall we just revisit this again.”
- Challenge of the transition to home
 - Review process by a different team
 - CSNAT – a carer held record?

Feasibility in discharge planning?

- Timing – in two part

- Earlier in the process

I think it's great that it's there for discharge but I think it needs to be more thought about earlier on."

- Follow up at home – to review

Still to be resolved

Which practitioners?

- No consensus
 - SPCT?
 - CDT?
 - Ward teams?
- Skills; confidence; time
- Training considerations

Summary and conclusions

- The CSNAT intervention was viewed as relevant and valuable in discharge process
- Addresses a clear gap in carer assessment and support
- This initial study has highlighted a number of ways to facilitate implementation
- Hospital discharge context raises new challenges that require further work before testing the intervention in practice

Thank you

- to carers and practitioners who took part in the study



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