Enabling successful hospital discharge to home at end of life: how can we support family carers?

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Background

Why carers and the discharge process?

• Successful patient discharge from hospital often depends on having a carer at home
• Prevention of patient readmission also often depends on carers’ ability to support them at home
Aim

- To investigate how carers are supported during patient discharge from acute care towards the end of life

- To assess the suitability of a Carer Support Needs Assessment Tool (CSNAT) to improve carer support at discharge
### Carer Support Needs Assessment Tool (CSNAT)

<table>
<thead>
<tr>
<th>Enabling carers to care (co-worker role)</th>
<th>Direct support for carers (client role)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowing who to contact when concerned</td>
<td>Own physical health concerns</td>
</tr>
<tr>
<td>Understanding the patient’s illness</td>
<td>Dealings with their own feelings and worries</td>
</tr>
<tr>
<td>Knowing what to expect in the future</td>
<td>Beliefs or spiritual concerns</td>
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<tr>
<td>Managing symptoms and giving medicine</td>
<td>Practical help in the home</td>
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<tr>
<td>Talking to the patient about their illness</td>
<td>Financial, legal or work issues</td>
</tr>
<tr>
<td>Equipment to help care for the patient</td>
<td>Having time for them themselves in the day</td>
</tr>
<tr>
<td>Providing personal care for the patient</td>
<td>Overnight break from caring</td>
</tr>
</tbody>
</table>
CSNAT as a tool for practice tool

<table>
<thead>
<tr>
<th>Do you need more support with</th>
<th>No</th>
<th>A little more</th>
<th>Quite a bit more</th>
<th>Very much more</th>
</tr>
</thead>
<tbody>
<tr>
<td>understanding your relative's illness</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>having time for yourself in the day</td>
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<tr>
<td>managing your relative's symptoms, including giving medicines</td>
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</table>
Methods: qualitative

Focus Groups
- 40 HCPs
- Hospital and community

Topic areas
- Discharge process for palliative patients and their carers
- Current methods of assessing and supporting carers
- Views of the CSNAT
  - Tool content
  - CSNAT Approach
Methods: qualitative

Focus Groups
• 40 HCPs
• Hospital and community

One to one Interviews
• 22 Bereaved carers and current carers
Methods: qualitative

Focus Groups
- 40 HCPs
- Hospital and community

One to one Interviews
- 22 Bereaved carers and current carers

Final Workshops
- 14 HCPs
- 5 bereaved carers
Results

• Carers and current discharge processes

• Views of the CSNAT and its use within hospital discharge

• Practitioner and carers views of the person centred CSNAT Approach to support carers

• Advice on feasibility of using the different stages of the CSNAT approach at hospital discharge
Carers and the discharge process

• 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]” (FG)

• Process driven by funding agenda and putting practicalities in place
• Carers consulted but on patients’ needs
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.” (Ca)
Views of the CSNAT content

• Entirely positive

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

“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’” (Ca)
Practitioners’ views

- Relevant

“*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*” (FGs).
Using the CSNAT at discharge

Facilitating end of life conversations
Patients and carers were not always aware of EOL situations, making eliciting concerns and enabling support problematic.

Managing carers’ expectations

Of caregiving at the EOL:
“they don’t realise until they get home the physical and emotional demands that that then brings.” (FG)

Of how much support is likely to be available: [Mistaken impressions] “that a Macmillan nurse will be in that house 24 hours a day.” (FG)
Responses to The CSNAT Approach

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

[Currently] “the ball’s put in your court of what you need to ask.” (Ca)
The CSNAT Approach at discharge

CSNAT Approach

Stage 1: Introduction of CSNAT
14 domains
- Enabling the carer to care (7)
- Direct support for the carer (7)

Stage 2: Carer consideration of needs

Stage 3: Assessment conversation

Stage 4: Shared action plan

Stage 5: Shared review
Stage 1: introduction

• How introduced is crucial
  • Words used (practitioners)
  • Reluctance; especially current carers
  • Set aside as another leaflet

• Introduction ≠ 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.” (Ca)

CSNAT approach in practice
Stages 2 and 3

• Carers consideration of needs
  • Time to reflect
  • Helpful to have a written format

• 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.” (Ca)

• Challenge of the transition to home
  • Review process by a different team
  • CSNAT – a carer held record?
Conclusions

The CSNAT Approach shows good potential to enhance carer support at hospital discharge and play a role in preventing readmissions towards the end of life.

Moving forward: further work to prepare for a study of implementing the CSNAT Approach within hospital discharge
Thank you

To carers and practitioners who took part in the study and to our funders

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