"We Are a Team" Older Patients' and Carers' Shared Views of Hospital Information

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ABSTRACT

Health care providers who view patients and carers as a care partnership during hospital treatment will offer better care experiences, however, this is not always the case. Carers have reported experiences where they are not included in information and communication of their loved one's care. This study aims to explore information seeking, communication and information access requirements and priorities of older persons and carers during hospital engagements from the perspective of "we are a team".

KEYWORDS

Keyword 1, Patients and Carers, Keyword 2, Information Access, Keyword 3, Hospital Care

Introduction

In Ireland, approximately 17.5% of people aged 75+ have severe self-perceived long-standing limitations in usual activities due to health problems with adults aged 65–85+years accounting for 53% of total inpatient bed capacity in 2015 (Health Service Executive, 2016). Good information and communication are essential to aid diagnostics and clinical interventions and is essential for patient support and to aid participation in their care (Ekdahl, 2010; Caswell, 2015).

Family carers bridge the information and communication space between hospital and patient especially when patients are very ill or frail (Gordon et al, 2010) in the complex combination of clinical and relational interactions (Bridges et al, 2010). However, there is evidence that carers often feel their contribution is not considered in the hospital care system beyond the initial diagnostic and medical history, especially for follow up information and communication (Nikki et al, 2012; Gallagher et al, 2014).

Patients and carers seek information and additional support from external sources such as internet searches (Dunne et al, 2017) for cancer (Saleh et al, 2017), dementia (Au et al, 2019), palliative care (Mohamadali et al, 2018) and stroke (Eames et al, 2010). However, there has been limited research exploring how patients and carers seek information to support their shared understanding during hospitalisation.

This study aims to explore information seeking, communication and information access requirements and priorities of older persons and carers during hospital engagements. The results will be used to explore how design can help older patients and carers during hospital care.

Methods

The methodology combines the Double Diamond design process (Design Council, 2004) four stages of development '*Discover, Define, Develop and Deliver*' with Grounded Theory (Robson and McCartan, 2016) to provide a rigorous research framework for data collection and analysis.

Twenty participants (10 older patients and 10 carers) were recruited from two support centres (day care and drop-in facilities) in the South East Region of Ireland. Ethical approval was given by Loughborough University Ethics Committee.

Inclusion criteria were living (or caring for someone) with one or more physical condition(s) associated with the aging process; living independently or semi independently; experience of at least one health event requiring hospital treatment within the last 5 years. Exclusion criteria included mental incapacity (e.g., dementia), non-English speakers, in receipt of professional care, and professional carers (e.g., nurses, therapists).

The Centre Managers were approached to discuss the proposed research with respect to their role, time, resources etc.; this included screening for eligibility based on physical/cognitive abilities and the inclusion/exclusion criteria. Permission was given to introduce the research at group activities and hold interviews with interested participants after informed consent had been given.

Data were collected with semi-structured interviews (audio-recorded) were used to gain an in-depth understanding of older patients and carers experiences of hospital information and communication during their care journey. The interview questions were developed and structured around seven broad themes from a previous literature review.

- How participants view the role of a carer in hospital information and communication
- How illness/emotions affect giving or receiving information
- How participants access information
- What the participants want to know at different junctures
- When information would have been most beneficial
- What was most frustrating about the experience (barriers)
- Participant opinions for improving information and communication exchanges.

The interview recordings transcribed verbatim and analysed thematically (open coding) using NVivo12, followed by axial coding for a more detailed level of analysis to identify relationships between the codes to generate a Grounded Theory as the basis for future design criteria.

Results

The analysis resulted in 7 themes which are described in the following sections.

Carers Role

Theme 1 explored hospital information and communication in terms of a carers perceived role from both perspectives. Figure 1 is a visual representation of the subthemes across both older patients and carers (combined data).
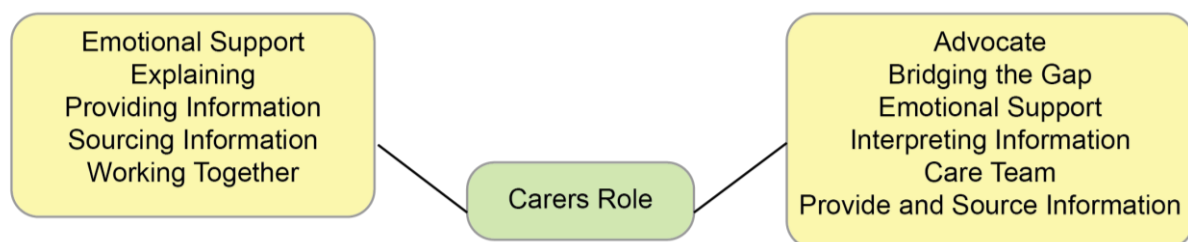

Figure 1: How patients and carers view the carers role in hospital information and communication

Both groups see a carer as a provider of support whether emotional or practical in terms of interpreting and explaining information to the older patient and advocating on their behalf. *"Someone there that you can relate to and rely on". "I could see my aunt was anxious and distressed and so I would use the information to help explain things to her and help her understand and reassure her".*

Practical support is given through providing and sourcing information for hospital care staff and the older patient. *"she was the one who helped me tell them how I was complaining". "My daughters would go and look for a nurse to find out for me". "He is my extra ears… he picks up things that I sometimes can't hear or miss". "Yeah I do that by helping him see what is happening and listening to what he has to say … I am the go between… between what they want and what we want".*

Both older patients and carers viewed themselves as a care team or partnership based on trust and having to work it out together: *"We would then chat about what was going on and that was how we worked it". "I had to do my best to get the answers to help calm her. I did not want to make stuff up but to give her simple accurate information. She trusts me and I could not do anything to compromise that".*

Impact of Illness / Emotions

Theme 2 explored the potential impact of illness and emotions on information and communication (Figure 2).
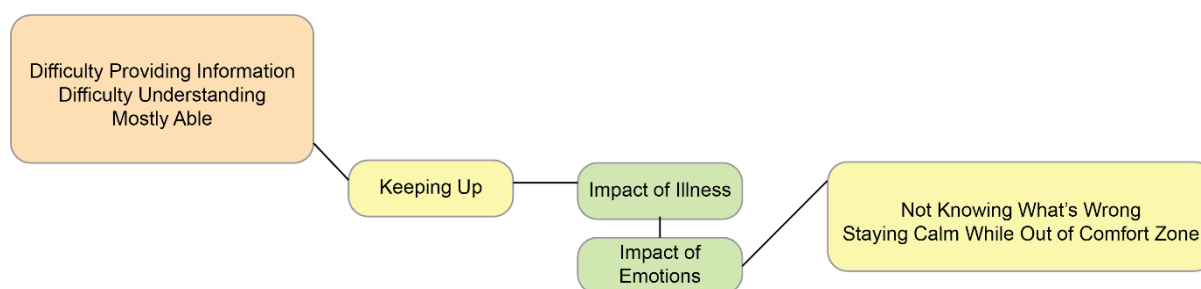

Figure 2: The impact of illness and emotions of information provision

The impact of illness affects how older patients provide and understand information and is described as their ability to keep up*: "There were so many questions and different people seemed to want the same answers over and over. It was very confusing". "I was in so much pain I couldn't answer properly and anyway there were so many of them around me pulling and prodding and talking around me that I was lost in all that".*

Some older patients described how they coped better when they were recovering*: "Well usually I don't need anyone to talk for me… I am more than capable of speaking for myself. But when I was really sick, you could say I wasn't myself really. But as I began to recover again with treatment then I was able to keep up better".*

The quality of the information also effected understanding especially if it was considered to be too technical. *"I mean sometimes I can understand some of the basic information but sometimes it's complicated and they don't take enough time to explain it".*

The carers described the impact of emotions during emergencies and the need to keep calm*: "I think I tried not to let my aunt see how my emotions were affecting me because that would have made things worse" … "But yeah it was hard because you feel out of your own comfort zone too".*

Figure 3: Issues surrounding accessing information
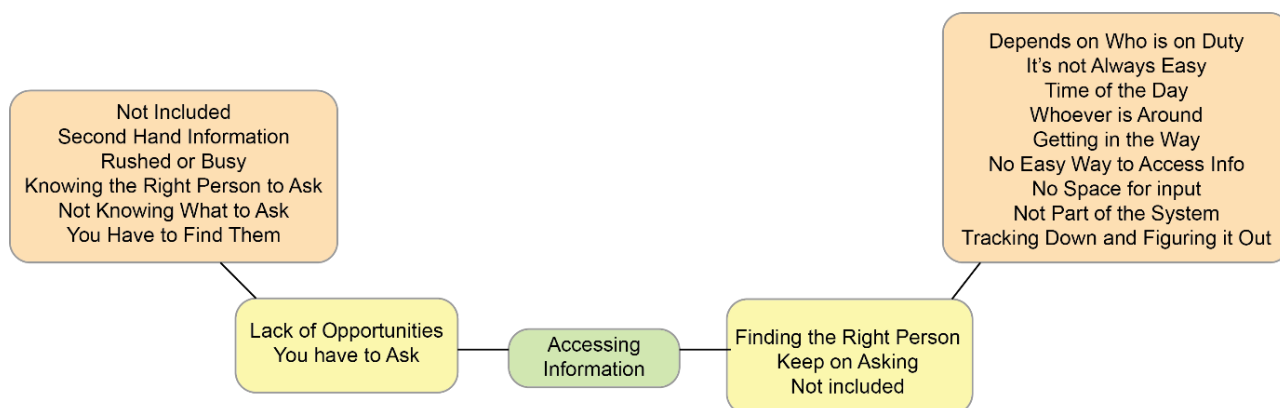
Accessing Information

Theme 3 explored how older patients and carers accessed information about treatment, condition, or progress etc. (Figure 3). Accessing information could be difficult due to several factors; this included feeling excluded from conversations. *"well, they* [my family] *weren't at my bedside. When they* [doctors] *were chatting about it. They were chatting between themselves, about what was going on with me". "You're not in on the full conversation … just the bit they want you to be".*

Information was not offered and had to be requested, which could depend on availability of care staff to deliver information in a timely manner and/or with sufficient detail to support understanding: *"I know they are busy people* [doctors] *and have a lot of patients". "If they told you what you wanted to know early then you wouldn't have to keep asking".*

The older patients also described not knowing what to ask and finding it difficult to articulate their concerns: *"Well yes sometimes I asked questions… like when they were doing their rounds and times like that. But I don't think they understood what I was wanting to know".*

Carers also reported difficulties in accessing information, including finding the right person to ask*: "You just try and grab whoever is around basically". "You always feel like you are somehow interfering or meddling in their work". "They just wanted to do their tasks and not want to deal with questions or concerns we had". "Maybe it's because they don't see it as their job to follow up with you because you are not part of the system".*
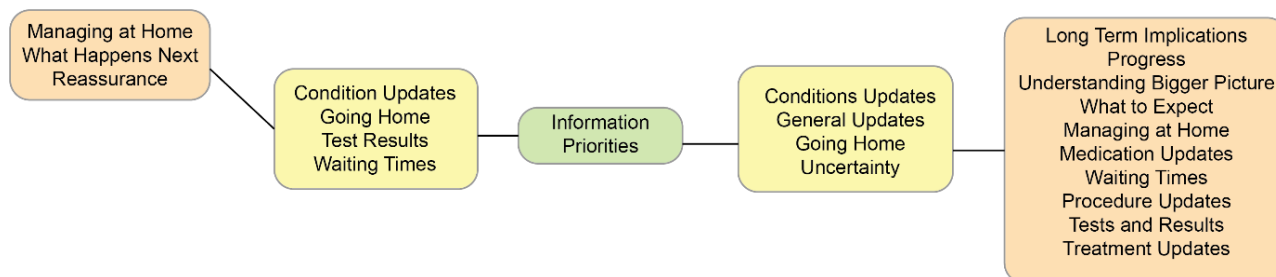
Information Priorities

Figure 4: Patients and carers information priorities

Theme 4 explored what information older patients and carers think they require at different junctures, what they consider important information (Figure 4).

The information priorities of older patients and carers were mostly linked to the progression of their treatment or condition and how they were getting on: *"Mostly how I was getting on… how I was*

doing… what was happening with the treatment". "When I'd ring it was mostly for general information like how he was getting on and how he was through the night and so on you know". Both groups wanted information about test results, and timing of tests and procedures, or signs they were moving to a next level of care: *"… you were left waiting for so long before being told anything and in the mean time you were imagining all sorts of things".*

More information was seen to help reduce anxiety and uncertainty about discharge and managing at home: *"I just wanted to know when I was going home and how I was going to manage". "How long it would be before he was coming home and if we needed anything sorted before that".*

When Most Beneficial

Theme 5 explored the interviewees' perceptions of the most beneficial time to receive information and updates (Figure 5).
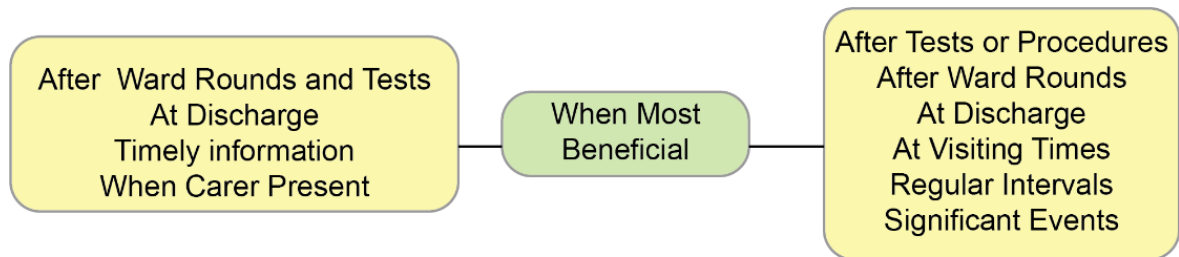

Figure 5: When information was considered most beneficial by both groups

Older patients and carers wanted to receive updated information regularly during their hospital care journey: *"More than once a day. You only see the team in the morning when they do their rounds". "I think you should be informed about all this at regular times during the hospital stay. If not every day, then definitely when significant results or changes occur". "… after the doctors do their rounds to tell you what the plan is going forward because that can change from day to day and you only know much later if you can get hold of the information".*

Information updates before discharge were useful to explain long term care implications and regimen: *" when I was going home would have helped a bit more". " I suppose the time I think I needed good information and I don't feel I got it was when my brother was going home".*

The older patients indicated that having a carer present when receiving information would allow for support and discussion and carers described visiting times as offering the best opportunity: *"when I was under the weather … the information would have been more of a benefit if it was given at a time when my brother was in"* *"*[Visiting Time] *That's when my wife and I had time to talk between ourselves and come up with questions together… that would be the best time really when you have backup so to speak to help you".*

Found Most Frustrating

Theme 6 explored what older patients and carers found most frustrating about being in hospital and their experiences of information and communication (Figure 6).
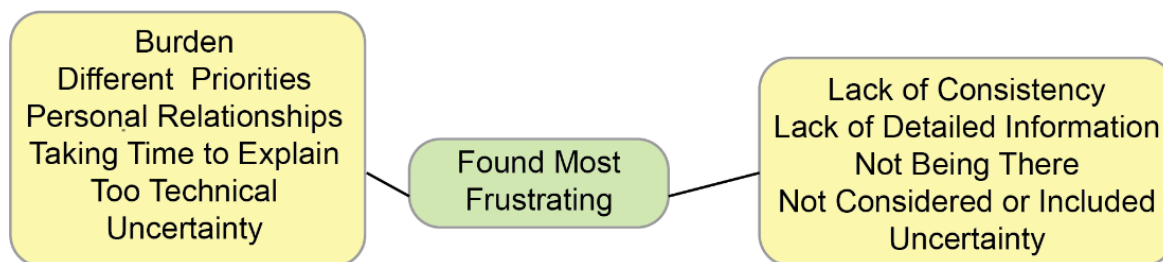
Figure 6: What patients and carers found most frustrating about accessing hospital information

Frustration was expressed by the older patients of their experiences of hospital care: *"you wouldn't be understanding what they were saying to you some of the time so that was hard. If they spoke to you more slowly and well maybe ... I don't know ... took more time to make sure you'd understand or something".* This led to feelings of being a burden both to their carers and to staff: *"Feeling like I was a burden... I didn't like that, I like to be able to do things for myself where I can and being dependent on everyone was horrible". "Having to have my wife chase everything down and follow up on everything".*

Frustration was also expressed due to their perception of the hospital having different priorities to them and their carer which affected care decisions: *"They want to know everything when you first get there and then they forget all about you and tell you very little" ... "Being told about decisions such as going home without letting my wife have an opportunity to talk to the doctors and discuss our concerns".*

Carers expressed frustration at feeling excluded and the lack of consistency for updates in information and communication: *"It was hard to get enough consistent information and updates to reassure both of us". "This isn't easy because you cannot be by his bed all day every day and sometimes it feels like that is what you have to do to be there and involved".*

Making it Better

Finally, theme 7 explored ways of making the information and communication exchanges better (Figure 7).
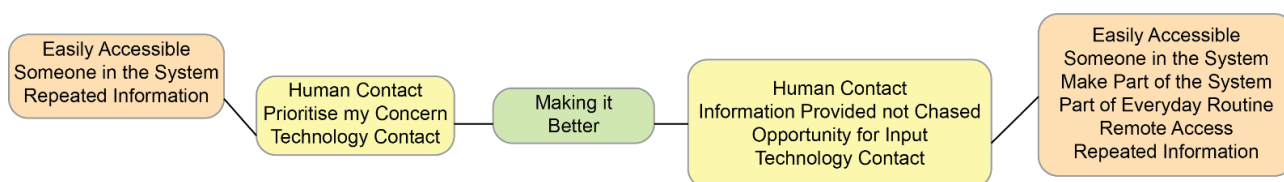

Figure 7: How patients and carers see making information and communication better

Older patients and carers described ways to make their experience of hospital information and communication better including someone who works on their behalf and knows the hospital system: *"Maybe if there was someone who was there just to gather information for you based on your questions" ... "They would be like my niece but actually in the hospital knowing how to work their system" ... "and talk to my daughters too! Maybe talk to all of us when we are all together".*

Technology ideas included: *"Somewhere you can access updates and not feel like you are bothering them...a place where you can look up information yourself". "When I was bed bound it would be useful if I could ring the helpdesk from my phone and talk to someone who had access to the tests and stuff".*

Both groups suggested that some information was generic could be provided in a more accessible way: *"Something that I could access remotely". "Something that would mean that you would not have to keep ringing all the time"* Accessing information remotely was seen as taking pressure off both care staff (especially busy nurses) and themselves. *"Because I am not part of the hospital… so if there was something that didn't involve them having to deal with me when I could just look up what we wanted to know that would be good for everyone".*

Discussion and Conclusion

This paper aimed to explore information seeking, communication and information access requirements and priorities of older persons and carers during hospital engagements. The results have been described as 7 themes: carers role, impact of illness (emotions), accessing information, information priorities, timing (when most beneficial to receive information), frustrating experiences of information and communication, and opportunities for improvement (making it better).

For this discussion, the themes are grouped into 3 categories for:

1. Personal factors: carers role, impact of illness, frustrating experiences
2. Information design: accessing information, information priorities, timing
3. Opportunities for improvements include the design of communication systems and interfaces.

The personal factors related to the perceptions of the carer's role. The patients described this as being someone familiar who knew and understood their physical and emotional concerns and the carers viewed their role as reducing stress and providing reassurance. This has been recognised in previous research on serious health events requiring hospitalisation as vulnerable, ill, older patients feeling anxious, stressed, and fearful (Gordon et al., 2010; Bridges et al., 2010), which can result in difficulty in describing the nature of symptoms and appearing confused by questions medical staff (Farmer et al., 2006).

Previous studies suggest that opportunities for information exchange between care staff and patient may have a narrow window of time within a busy hospital setting and its occurrence may vary from day to day leading to patients expressing frustration at waiting for information (Swenne and Skytt., 2014). To make the most of information access opportunities, the patient and carer will work together as a team, this has been described as 'equal partners in the care process' (Bennett et al., 2017). Communication (including information design) can be described in terms of participation preferences (Ekdahl et al., 2010); for example, some older patients might prefer to take a more passive role in their care, but this should not be confused with not wanting to be informed (Swenne and Skytt, 2014).

Opportunities for improvements (future design) should consider the users (patient and carer) characteristics, for example information recall and understanding of written patient information literature, information integration (Dyrstad et al., 2015) and understanding illness and prognosis (Gerlich et al., 2012).

The results are now being used as the platform for an innovative design solution which will be evaluated in the next phase of research. Limitations included the recruitment criteria (inclusion/exclusion) and experience of participants. This will be explored in future research to test whether the theoretical saturation of themes was related to the scope of experience of the participants or if the proposed improvements can be used more widely.

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