I) Title: Understanding the hospital discharge planning process for medical patients with dementia

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V) Key Words

Dementia, Systems Approach, Discharge Planning, Hospital

Title: Understanding the hospital discharge planning process for medical patients with dementia.

Abstract

Background

Poor hospital discharge processes can result in the readmission of patients and potentially increase the stress levels of carers. Therefore, this study sought to understand factors related to the discharge planning process for patients with dementia.

Methods

The researchers interviewed 32 carers of patients with dementia and 20 hospital staff who worked on medical wards in a United Kingdom (UK) hospital. The semi-structured interviews were analysed thematically using a systems theory (patient-carer-staff relationships, hospital equipment and policies).

Results

The findings indicated that the following factors could either have a positive or negative impact on discharge planning: patient (e.g. cognitive capacity), carer (e.g. preconceived ideas about care homes), staff (e.g. communication skills), policy (e.g. procedures such as discharge meetings), equipment (e.g. type of service provider delivering the equipment) and the wider social context (e.g. availability of specialist dementia beds in care homes).

Conclusion

It is important for hospital staff to adopt a systems perspective and to integrate the different elements of the hospital system when planning for patients' discharge.

Impact statement

A systems approach can help to improve the discharge planning process for patients with dementia in hospital.

Plain Language Summary

Using a systems based semi structured interview guide, staff and carers were given the opportunity to discuss the discharge planning process. The discharge planning process starts with in-patients. The findings identified the barriers and facilitators of the discharge planning process through the lens of a systems framework. The results can support discussions amongst patients, staff, hospital managers, policymakers, academics, researchers and the wider general public on the best discharge practices.

Introduction

Patients who are discharged before they are fit to go home run the risk of being readmitted into hospital (Knutsen Glette, Kringeland, Røise, & Wiig, 2019). Those who encounter delayed discharges may end up contracting nosocomial infections and experience functional decline (Rojas-García et al., 2018). This makes it necessary to ensure that patients are discharged in a timely manner. Another issue that emanates from the discharge planning process is an inadequate staff-carer communication about the patient's discharge details (e.g., time of discharge) which can result in discontentment of family carers (Jurgens, Clissett, Gladman, & Harwood, 2012).

Carers of patients with dementia have found it difficult to understand discharge instructions because staff used medical terms (Sawan et al., 2021). Difficulties in understanding discharge instructions can subsequently result in a failure to adhere to drug therapy and missed hospital appointments (DeSai et al., 2021). A descriptive, explorative qualitative study in Australia found that poor communication about the patient's follow up care can also increase the stress levels of carers at home and lead to post-discharge complications (e.g. drug overdose) (Kable, Chenoweth, Pond, & Hullick, 2015). A descriptive qualitative study involving patient navigators who were mainly senior nurses in Singapore found that carers feeling unable to cope without additional support may have patients readmitted (Mohd Razali et al., 2017).

Other researchers have reported that in comparison to people without dementia (3.7%), patients with a diagnosis of dementia and Covid-19 (22.2%) are likely to die at home following their discharge from hospital (Roig-Marín & Roig-Rico, 2021). This finding was attributed to the

fact that patients with dementia were likely to be older and have more co-morbidities than their peers without dementia (Roig-Marín & Roig-Rico, 2021). In response to the Covid-19 pandemic, hospitals have made various organisational changes to maintain the flow of patients (Juvet et al., 2021) and free up hospital beds (McCabe et al., 2020). Indeed, Covid-19 has brought greater attention to the need for efficient but careful hospital discharge policies. In the UK attention to this issue has been heightened due to the policy to discharge older people who were potentially Covid positive back into care homes without testing for Covid-19 (Iacobucci, 2020).

Given the current need to increasingly improve discharge policies, and particularly for patients with more complex needs, the current research explored the barriers and facilitators to effective hospital discharge for inpatients with dementia. This research used systems theory that is a multi-dimensional approach to patient care as it looks at hospital procedures and protocols, staff-patient-carer interactions, hospital atmosphere or environment and the use of hospital equipment (Duah-Owusu White, Vassallo, Kelly, & Nyman, 2020). A systems approach is advantageous because it seeks to address all the factors (e.g. team working skills) that influences the patient journey (Komashie et al., 2021). While this approach has been used in other areas of hospital care (Moazez, Miri, Foroughameri, & Farokhzadian, 2020), this is the first study to use a systems perspective to understand the discharge process. Therefore, the aim of the study was to understand factors related to the discharge planning process for patients with dementia through a systems perspective.

Methodology and methods

A qualitative constructivist (multiple interpretation) methodology was used for this research (Given, 2008). This methodology was used because the researchers wanted to compare and

contrast the views of carers and staff. The interviewer had a nursing background and was empathic with participants. The semi-structured interviews that were used in this study centred on staff-patient-carer relationships in regard to the discharge process, discharge policies and the patient's discharge equipment (Duah-Owusu White, 2021). Issues regarding the hospital's discharge environment were not raised because patients were still in-patients and had not yet been transferred to the discharge lounge. The interviews took place in a quiet room on the ward, lasted for approximately 20 minutes and were audio-recorded.

We interviewed staff and carers of patients with dementia on medical wards because of the fact that they are likely to spend a longer period of time on such wards when compared to other units (e.g. surgical) (Scerri, Scerri, & Innes, 2020). Data saturation was reached as there was no new information being generated from the 52 interviews. We excluded patients with dementia from the research because of their potential to experience fluctuating capacity to consent to participate.

Ethics

This study was approved by North West-Greater Manchester Central Research Ethics Committee. All participants provided written informed consent prior to taking part in an interview.

Sample and sampling

A total of 20 staff (1 male and 19 females) from a UK hospital (nursing staff (i.e., specialist and general health care workers), an allied health professional and administrative staff) as well as 32 carers (11 males and 21 females) were recruited into the research to share their

experiences on dementia care. Participants were recruited through the use of flyers and posters. Staff identified carers of patients with dementia. The participant information sheets were then passed onto potential participants. Staff and carers were included in the study if they could provide informed consent. In addition, staff were required to have a present/past experience of caring for a patient with dementia. Carers of patients with dementia were recruited into the study if they visited the ward at least once a week. Six members of staff (Occupational health therapist, Domestic assistant, 3 doctors, 1 support worker) and 13 carers refused to take part in the interviews.

Analysis

The audio files were transcribed by the first author. A sub-set of the transcripts were cross-checked by the research group leader. The data were managed with Nvivo 11 and analysed using Ritchie, Spencer, and O'Connor's (2003) approach (i.e. familiarisation with the data, labelling and sorting out data generated from the transcript, and summarising the research findings). The overarching themes were created deductively using systems theory (Marks & Yardley, 2004). Sub-themes were created inductively (codes were generated without theory) (Marks & Yardley, 2004). The themes and subthemes were generated separately for staff and carers and then merged. Research meetings were held at regular intervals to discuss the analysis process and the research team cross-checked the themes and sub-themes.

Results

Thirty-two carers and twenty hospital staff participated in the research. The findings will be presented together using a systems framework (i.e. patient, carer, staff elements, hospital policies, equipment and the wider social context).

Patient element

The patient element refers to patient's characteristics such as their co-morbidity etc. Staff stated that a patient's condition could deteriorate whilst awaiting a discharge package. Patients with dementia may be taking different types of medications and may find it difficult to remember the right dose, time etc. Staff felt that patients may sometimes not be able to discern staff concerns regarding their preferred discharge location. Staff therefore responded to this by organising best interest meetings that included the multi-disciplinary team, the patient's next of kin, lasting power of attorney etc. The following quote illustrates the challenges of discharge planning for a patient with fluctuating capacity:

It can be quite difficult when it comes to discharging people with dementia. From a capacity point of view. And also putting the right care into place. There is a bit of a gap sometimes in the care that is available for older people generally but those with dementia as well.

(Staff, participant 3).

Staff and carers stated that patients with dementia may have other co-morbidities.

But then of course say since this last stroke that has all gone out of the window. I don't think I can manage him. It's very difficult to do that.

(Carer, participant 15).

The key points are that the poor physical health of patients, low cognitive capacity and complex medical treatment can potentially slow the discharge process. This is because of the need to involve a wide range of professionals in the care of patients with complex needs.

Carer element

Keeping patients well at home after hospital discharge can depend on the carers' ability to effectively utilise community resources (e.g. Alzheimer's charity) to help with dementia care. Whilst some family carers had access to paid carers to help with personal care, other carers were closely involved in the provision of this type of care.

Staff stated that family carers may not be aware of the various funding streams that are available to the patient (e.g. social services and NHS continuing health care). Carers may also be facing financial difficulties:

Much of the reason that they stay the amount of time here is because there are not enough money for care for the elderly people [sic]. Much of the family don't have enough money too [sic] (Staff, participant 10).

Carers may be stressed as they have to make difficult decisions (i.e. discharge to an institution or the patient's home environment with care package). One carer was stressed about the provision of dementia care in the home environment because of the fact that she had nervous anxiety. Other carers may not be receptive to the idea of placing relatives in a nursing home:

It's like a lot of these care homes. There are terrible things that go on in there. I wouldn't trust them. If my husband had to go in a care home, I will be turning up anytime of the day to see what was going on. Different times: early morning, mid-day, late at night, afternoons. Just to make sure that I knew what is going on. As I say in here, I sit here what from 1 o'clock till 6, half past 6. And I have just seen nothing but niceness (Carer, participant 2).

Some patients may not have family carers and therefore require the support of an Independent Mental Capacity Advocate or care agency. The involvement of these professionals help to support the best interest decision making process of a patient. A carer stated that he did not have detailed knowledge of the hospital's discharge policies and therefore could not make well informed decisions.

The key points are that the financial status of the patient's family, the carer's preconceived ideas about care homes, the carer's psychological state (e.g. stress), the carer's life and social skills (e.g. accessing community resources) can affect the discharge planning process. Some patient's may not have family carers. The implications for discharge planning are that staff need to be aware of pressures that carers face and sign post them to relevant supportive services.

Staff element

Staff arranged discharge planning meetings with family members of patients with dementia or their lasting power of attorney. Staff had to work with other members of the multidisciplinary team (e.g. occupational therapist, discharge planners, social workers etc.) in order to ensure the safe discharge of the patient.

Staff cognitive errors (e.g. forgetting to pack some of the patient's belongings) can affect the discharge process. Staff had to assess the patient's suitability/readiness for discharge using care diaries, behaviour charts and simulation sessions:

The care diaries, we document every detail. I mean, if the patient can go to the toilet. Clean himself properly or herself properly. If they need help with personal care. I mean hygiene, brush your teeth. Simple things but they are important for them (Staff, participant 15).

The key points are that staff cognitive errors (e.g. remembering to pack the patient's belongings), observational and team working skills, communication skills (i.e. working with family members and the multidisciplinary team) affects discharge planning. The implications

for discharge planning is that staff need to regularly update their discharge planning knowledge.

Policy

Services

Community services available to patients with dementia included a referral to the Community Mental Health Team and the Intermediate Care Service for Discharge. Staff stated that outreach services were provided for patients with delirium. Interim measures were implemented when staff and patients disagreed on the discharge destination. Carers and staff stated that carers had been provided with details of the hospital's brokerage program.

We ring, we ring. It's a brokerage first. Because you have to find the appropriate care so that delays things (Staff, participant 8).

Home visits

Staff stated that they were required to conduct home visits to ascertain the suitability of the home environment for discharge. Home visits also provided staff with an opportunity to train family carers.

I go in and agree with the patient that we can move this rug or we can move this table because it is in the way. And then I go back to review it and the family's come in and moved it all back again because they haven't realised. So stuff like that is really important. (Staff, participant 20)

Staff-related policies

A member of staff felt that hospital policies were more useful to inexperienced colleagues. Carers felt that policies geared towards the introduction of specialist dementia nurses and wards was useful in addressing the needs of patients.

We discussed what the options were with the dementia nurse and the other staff when he first came in and that has been helpful because basically it was the end of the road so far as him living at home was concerned (Staff, participant 19).

Documentation

Staff had to ensure that the property of patients were within their possession by completing the checklist. Other documents that staff used in relation to discharge included Transfer letters to care homes and Manual handling care plans, as illustrated by this practitioner:

If the patient is going to a nursing home or a care home you have to fill in a transfer letter. And that helps the next person who's going to look after the patient with the information[sic]. Maximum information we can give which will assist them, you know [sic]. For example you have to write down the mobility, how independent they are, if they have got like catheters, if they are continent, incontinent[sic]. We have to explain everything. Likewise, in order to have all that information, you also liaise with the doctors to make sure that the patient is medically fit[sic] (Staff, participant 16).

Delays

A carer stated that they had to remain in hospital for several hours because of delays in the dispensation of medication. Booked hospital transport did not sometimes arrive on time (this therefore delayed discharges by a day or two). Another carer made mention of her infection prevention concern (i.e. soiled linen from a co-patient put on her husband's bed space). Poor adherence to infection prevention policies could potentially delay discharge. Carers mentioned meeting with staff to discuss patient care plans, discharge destinations and funding arrangements for social care (although this is essential it could add further delays to the discharge process):

I had a meeting with the discharge nurse, physiotherapist and a lady called D… (Name). She looks after four hospitals in trying to find places for, with social services. She was very helpful very nice. They were all very nice. They were amazed that I could actually look after my husband for so long without any help (Carer, participant 14).

One carer did not however understand medical terms used during a multi-disciplinary meeting.

The key points are that the availability of community resources and hospital transport can affect the discharge planning process. Hospital documents such as property checklists and hospital procedures such as discharge meetings and home visits are important in discharge planning.

Equipment

Staff stated that the delivery of equipment in the south-western region of the UK was quicker than the south-east. Despite the quickness, the delivery of equipment to the patient's home could sometimes be delayed if there was no one available to receive it.

Other times there is nobody to let the equipment delivery in the person's house or the care home may need something additional to buy. So it is not in our control as a hospital, so that can slow things down (Staff, participant 1).

A carer mentioned that discharge progressed slightly slowly because the patient needed a hospital bed at home.

If you've already got a bed in the bedroom. And they want you to have a hospital bed in it. You've got to empty the room so that there is space for the hospital bed, you know. So I don't know how you speed that up. Because you don't know in advance that you need the hospital bed. Its only when they get assessed on discharge you know that you realise you need a special bed for him. That he can't manage in the bed at home (Carer, participant 12).

Whilst equipment for one of the patients was provided by social services, another carer stated that a specific clinical commissioning group facilitated their receipt of equipment. An example of a specialist hospital equipment needed to facilitate patient care at home is as follows:

The fall-back position is that at home he was using a molift to transfer between commode, bed and tilt in space wheel chair. So he was doing molift stands at least every time the carers were there (Carer, participant 25).

The key points are that the delivery of the equipment can be affected by the type of service provider (e.g. social services), patient's locality (e.g. south west versus south east) and residents not being at home. It is also necessary to make space in the house for new equipment.

Wider social context

Some care homes refused to accept patients because they could not meet the needs of the patient (i.e. manage aggression).

The last time he was here and needed to be discharged. I found a home for him and they took him. But this time they won't take him back because they have had experience of not coping with him (Carer, participant 10).

One carer mentioned that discharge was slowed down because a patient required a social services care package. A carer had a positive experience with social services whilst another did not. Carers and staff stated that nursing and care home costs were very high. This means the patient cannot be discharged if the family cannot pay for it, thereby delaying discharge.

There is the funding as well. Some families turn the homes down because they say it cost too much. You have to keep looking so they are here with us even though they are medically fit (Staff, participant 17).

The key points are that the availability of specialist dementia beds in care homes, community care costs due to government policies and the involvement of social services can delay the patient's discharge from hospital.

Discussion

This is the first UK study to attempt to understand the discharge planning process from a systems perspective. The current study attempts to shed more light on the influence of the patient (e.g. cognitive capacity), carer (e.g. preconceived ideas about care homes), staff (e.g. communication skills), policy (e.g. procedures such as discharge meetings), equipment (e.g. type of service provider delivering the equipment) and the wider social context (e.g. availability of specialist dementia beds in care homes) on the discharge planning process for people with dementia. The use of discharge lounges (i.e. environment) was not highlighted in the interviews as patients were still on the ward.

Previous researchers have found an association between patient factors (e.g. frailty), social factors (e.g. the arrangement of new social care for patients) and delayed discharge (Moore, Hartley, & Romero-Ortuno, 2018). Findings of this research helps to explain how patient and social factors identified in Moore et al.'s (2018) study affect the discharge planning process. A scoping review has attributed the causes of delayed discharges to the following factors: organisational influence, patient/family characteristics and wider social issues (Modas, Nunes,

& Charepe, 2019). In terms of organisational factors, the scoping review by Modas et al. (2019) found that administrative processes could delay discharges. Some of the administrative processes found in the present study were discharge meetings and delays in the dispensation of medication. Wider social issues discussed in Modas et al.'s study (2019) also included the low availability of care home placements. This finding complements the results from our research which also found that some care homes refused to accept patients because they could not meet the patient's needs (e.g. manage aggression). Other researchers have found that a diagnosis of dementia in addition to needing a nursing or care home placement significantly contributed towards delayed hospital discharges (Aaltonen et al., 2021). This finding can be supported by the results of the present study. Carers for example had to visit care homes to ascertain its suitability for the patient thereby delaying the patient's discharge. The hospital also provided multi-disciplinary meetings for staff and carers to discuss funding arrangements and discharge destinations. Although staff adherence to hospital protocols (e.g. multidisciplinary meetings) could potentially delay discharges by a few days, a novel finding of this research is that some delayed discharges are necessary to maintain patient safety in the community.

Strengths and limitations

A large number of staff and carers were interviewed. A limitation of this study is the fact that the research was conducted on medical wards in one acute hospital. Some principles and perspectives from this work may be relevant to other healthcare systems. Another limitation is

that hospitals may have changed their policies since the work was conducted, but the lessons from this study are still relevant in the Covid-19 world.

Conclusion

Ensuring the safe discharge of patients with dementia in hospital is important as they do not only have memory difficulties but also grapple with other issues such as having additional co-morbidities. Improving the discharge planning process for patients with dementia therefore requires a careful consideration of how the various aspects of the hospital system interacts to influence this activity. We therefore recommend the need to integrate the different elements of the hospital system when planning a successful discharge.

Impact Paragraph

A systems approach can help to improve dementia care. Therefore, hospital managers need more awareness on the use of systems theory so that they can identify locally with ward managers the barriers and facilitators in discharge planning. Policy makers need to support the integration of community and hospital care.

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Interview guide for carers using a system framework (human interactions, environment, equipment, paperwork):

Introduction

Researcher: My name is Mary Duah-Owusu White. I am a student from Bournemouth University. How should I address you?

Carer: Wait for response.

Researcher: How are you today?

Carer: If the person is feeling OK, the researcher will continue with this introduction. If the person is not feeling too great, the research will ask if it is ok to continue or rebook the meeting).

Researcher: I am currently researching on how to improve the health concerns or the positive aspects of care for people with dementia. This interview will take approximately 30 minutes. Please interrupt this interview at any point should you

feel uncomfortable. In the event that you say something that indicates significant harm such as abuse, I will be obligated to report to the hospital safeguarding team. I would like to record this interview on a tape if that is ok. The recorder will be securely locked and the researcher will delete everything after she has transferred results on to paper. “You can refuse to answer any questions that you are uncomfortable with. Your name will not be linked to what you say. Is that OK?”

Carer: If the carer accepts, then I will proceed.

Researcher: I will read through the study’s information sheet with you so you know in detail what the research is all about. Please stop me at any point whilst I read if you have any concerns. I will go through the consent sheet with you to confirm that you are happy to continue with this study.

What has been your experience of being a carer for a patient with dementia on a hospital ward?

What has been your experience of discharge planning and what slows it down?

Prompts

Do you find it helpful involving staff in the discharge planning process?

How can the hospital environment be improved to help with the discharge planning process?

How does the use of patient equipment affect the discharge planning process?

Do Trust documents help with the discharge planning process?

Are you aware of any Trust (hospital) document on the care of patients with dementia?

Interview guide for staff (nursing, medical, allied healthcare professionals, support staff) using a system framework (human interactions, environment, equipment, paperwork):

Introduction

Researcher: My name is Mary Duah-Owusu White. I am a student from Bournemouth University. How should I address you?

Staff: Wait for response.

Researcher: How are you feeling today?

Staff: If the person is feeling OK, the researcher will continue with this introduction. If the person is not feeling too great, the researcher will ask if it is ok to continue or re-book the meeting).

Researcher: I am currently researching on the discharge planning process and the reduction of falls amongst people with dementia. This interview will take

approximately thirty minutes. Please interrupt this interview at any point should you feel uncomfortable. In the event that you say something that indicates significant harm such as abuse, I will be obligated to report to the hospital safeguarding team. I would like to audio-record this interview if that is ok. The recorder will be locked in a cabinet and the researcher will delete everything after she has transcribed the interview herself. The researcher's supervisors will cross-check a sub-set of the transcripts for accuracy. "You can refuse to answer any questions that you are uncomfortable with. Your name will not be linked to what you say. Is that OK?"

Staff: If the member of staff accepts, then I will proceed.

Researcher: Please read through the study's information sheet so that you know in detail what the research is all about. Please ask me questions if you have any concerns. Please sign the consent sheet to confirm that you are happy to continue with this study.

What is your role in the hospital?

How long have you worked in this role in the hospital?

What has been your experience of talking with or meeting patients who have dementia in this hospital?

Do you find it helpful involving family or paid (home) carers in the discharge

planning process?

In what ways do you utilise other members of staff in order to help with the discharge planning process?

How can the hospital environment be improved to help with the discharge planning?

How does the use of patient equipment affect the discharge planning process?

Are you aware of any Trust (hospital) document on the care of patients with dementia?

Do Trust documents help with the discharge planning process?