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Research Article

The Rhetoric and Reality of Choice and Autonomy When Older People Are Discharged from Community Hospital at the End-of-Life in England: A Constructivist Grounded Theory Study

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There has been an increasing acknowledgement in the UK of the importance of recognising frailty as a condition that leaves older people vulnerable to dramatic, sudden changes in health triggered by seemingly small events. In policy, the approach to managing frailty is often an emphasis on staying well with limited consideration to frailty as an end-of-life phase. Meanwhile, discharge from hospital continues to be complex. Overstretched acute hospitals are juxtaposed with community and social services that struggle to keep up with the demand of those being discharged and the labelling of older people as "bed blockers" at the centre of delayed discharges. This paper reports a study underpinned by constructivist grounded theory methodology, with the aim of exploring the experiences and perceptions of stakeholders. Semistructured interviews were conducted with 57 participants including patients, their informal carer(s), community hospital staff, community health professionals, and care home managers. The core category of "the drive to discharge conveyor belt" was derived from data analysis. A significant finding of this study was that of the carer, their burden, and their intrinsic role in facilitating discharge, filling in gaps in services, coordinating services, and enabling the patient to stay at home, with little consideration of their choices or autonomy. The "drive to discharge" impacts older people, their informal carers, and health professional. This study suggests how they may be supported, through an ethical lens.

1. Introduction

Globally, there has been an increasing acknowledgement of the importance of recognising frailty as a condition that leaves older people vulnerable to dramatic, sudden changes in health triggered by seemingly small events such as a minor infection, change in medication, or environment [1]. Older people with frailty are those who are at highest risk of adverse outcomes such as falls, disability, admission to hospital, and the need for long-term care. Internationally, there has been an emphasis on "ageing well" with the World Health Organisation (WHO) stating it "must be a global priority" to deal with the burden of chronic illness as the population ages [2, 3]. In England, a recent policy such as the NHS Long Term Plan addresses the growing demand on the NHS due to the ageing population by setting out how older people will be supported to "age well" [4]. This involves a reorganisation of acute and community services aimed at reducing hospital admission through frailty assessment and same-day discharge and in the community through setting up cross-sector frailty teams, which also include same-day assessments. However, no guidance is given on how frailty and end-of-life should be managed and what care an older person might expect at the end of their lives as they "dwindle" [5]. Community hospitals' purpose has evolved primarily to relieve acute care pressures [6]. Meanwhile, end-of-life policy emphasises choice and goes as far as saying that choice "should play the greatest role" in end-of-life care and that choice is "inextricably bound up with quality," and it is "vital to offer people choice and control over the things that are important to them at this point of maximum vulnerability in their lives" [7]. The WHO identified that effective palliative care delivery should have patient choice at its centre; yet, little is known about how choice is understood

and enacted [8]. In policy, "control" was previously only mentioned in terms of symptom or pain control but takes on new meaning in later documents such as ambitions for palliative and end-of-life care: a national framework for local action 2021–2026 where it is seen as vital in the personalisation of care [9]. It also acknowledges that choice is hard to enable when there are tight resources and calls on organisations and care professionals to facilitate and innovate in order to provide choice. Wilson et al. [8] critique the concept of choice as decision-making can be constrained by a range of intrinsic and extrinsic factors. They identified the immense reliance on informal carer support to help realise the patient's choices/preferences of dying at home, and an awareness of this burden could influence choices. Gott et al. [10] were critical of the notion of "control" and found that older people were less concerned with control and more concerned that financial affairs were in order. For example, older people were also keenly aware of the burden that may be placed on informal carers. Meanwhile, discharge from hospital continues to be contentious, with overstretched acute hospitals juxtaposed with community and social services that struggle to keep up with the demand of those being discharged. There is a recurrent global theme of discharging ageing patients "quicker and sicker," with the average length of admission decreasing [11]. As a result, healthcare providers have less time to coordinate services across settings and to prepare patients for their situation at home, particularly as they may be more unwell than they were prior to hospital admission [11]. Statistics show that hospital admissions can increase in the last 3 months before death with most of those having three or more emergency admissions being over 70 years old [12]. Meanwhile, research shows that carers often feel uninvolved and unsupported in the discharge process, with staff not routinely identifying carers and supporting them [13]. Many informal carers report not being asked about their needs or whether they can cope after the patient is discharged. Often health professionals do not realise that what appears routine to them is challenging to carers [13–15]. Salifu et al. [16] similarly found that informal carers were "overburdened" where there is a lack of community resources to adequately support them in the caring role. There is also scant literature on how the biomedical ethical principles of authority, nonmaleficence, beneficence, and justice could/ should be applied to informal carers in the same way it is to patients [17]. Previous studies looking at frailty, end-of-life, and hospital discharge are few. There is a tendency to focus on perceptions of health professionals or patients and informal carers, but not a range of stakeholders. Studies that look at the combination of frailty, end-of-life, hospital discharge, and a range of stakeholder views were also limited, with only one study including a range of stakeholders' perspectives of discharge at the end of life [14]. While Hanratty et al. [14] did not include frailty as such, they did include stroke and heart failure. Consequently, this study sought to explore the experiences of those involved in the discharge from community hospital of an older person living with frailty who is nearing the end-of-life. This included the patient, their informal carer(s), community hospital staff, and health and social care staff in the community. The purpose of this study was to explore the perceptions and experiences of stakeholders involved in the discharge from the hospital of an older person living with frailty approaching the end-of-life. The research questions were as follows: (1) How is discharge perceived and understood by stakeholders? (2) How is discharge experienced by stakeholders? (3) What structures and processes are in place to facilitate discharge?

2. Methodology

The choice of qualitative methods was guided by the research question and the exploratory nature of the study. A constructivist grounded theory methodology was used, and semistructured interviews were conducted with 57 participants. Constructivist grounded theory was chosen as it encourages the development of analyses into theory construction, which "sees people as active beings engaged in practical activities in their world and emphasises how they accomplish these activities. This perspective produces a dynamic understanding of actions and events" ([18], p. 263).

2.1. Sampling and Recruitment. The study was submitted to the National Research Ethic Service (NRES) and gained approval in June 2017 from the Research Ethics Committee (REC), reference number 17/LO/0854. Sampling was purposive, and inclusion criteria were created to identify appropriate participants (Table 1). Theoretical sampling was then used to "seek and collect pertinent data to elaborate and refine categories" in the emerging theory, see Tables 2 and 3 [18]. Fifty-seven participants were recruited through community hospitals in the southeast of England according to inclusion criteria (see Table 1). Clinical staff identified eligible patients and invited them to participate in the study. The researcher then contacted the patient after discharge from the community hospital. During the consent process, the patients were asked for their permission for the researcher to talk to their informal carers and any hospital or community health professionals involved in the discharge process (see Table 2).

All participants provided written informed consent prior to interview. Twelve informal carers, 21 community hospital staff, and 12 community staff involved in discharge of the 10 patients were interviewed. Only 2 of the informal carers were male. One participant and their daughter were interviewed twice as the patient was admitted and discharged again during the interview phase of the study. All patients were aged over 75, and two had cancer in addition to a diagnosis of frailty. A letter was sent to the patient's GP to inform them of participation in the research.

2.2. Data Collection. Data were collected over a period of 3 months, from July 2018 to September 2018. Semistructured interviews were conducted at participants' place of residence (2 care homes; 8 own home). All participants had been living at home prior to the relevant hospital admission.

TABLE 1: Inclusion criteria.

(i) NHS patients who were being discharged from a community hospital to a "community setting"
(ii) The "community setting" may be their own home, a nursing home, a hospice, or a family member's home
(iii) Health professionals consider that it would not be a surprise if the patient were to die within the next six months
(iv) Carers were defined as whomever the patient regards as their main source of practical and/or emotional support; they may live with the patient or visit regularly
(v) Hospital and community staff were defined as those who were directly involved in caring for the patient preceding and postdischarge

2.3. Data Analysis. In line with constructivist grounded theory, coding and analysis were iteratively carried out during data collection. Pseudonyms were used to protect the participants. Messy maps were created for each patient, and their informal carer and health professionals were used to capture the complexity of hospital discharge and the relationality of the lives of older people [19]. Each patient and those involved in their discharge were conceptualised as "cases." Data were analysed after three "cases" which consisted of 16 participants, and themes were becoming apparent at that point. After a further seven "cases" were analysed, no new themes were found with fresh data no longer sparking new theoretical insights; therefore, it was considered that data saturation was reached [18].

The semistructured interviews were transcribed verbatim. The interview data were analysed and interpreted using the constant comparative method, and situational analysis was used as an analytical framework during data analysis to ensure reflexivity and rigour. Constructivist grounded theory uses reflexivity to ensure groundedness and acknowledges researcher subjectivity [18, 20]. Transcripts were coded, and the constant comparison method was used together with the situational analysis technique of maps as memos to sort and organise the raw data [18, 19]. As interviews progressed, the maps grew and developed. The maps enabled complexity to be captured while developing codes. This iterative process helped to construct the major category of the "drive to discharge conveyor belt" which overarched and influenced the other key codes (which were interlinked) and had a profound impact on the choices of all stakeholders. Mapping the cases enabled the researcher to be conscious of their occupational therapy background while enabling the categories to be created from "shared experiences and relationships with participants," thus providing rigour [18, 21].

3. Findings

The perpetual push to discharge patients was conceptualised as the "drive to discharge conveyor belt." Participants' experiences of discharge were complex and interlinking but were dominated by the core category "drive to discharge" [22]. The drive to discharge dominated and influenced the choices and autonomy of all involved. A significant finding of this study was that of the carer, their burden, and their intrinsic role in facilitating discharge, filling in gaps in services, coordinating services, and enabling the patient to stay at home, with little consideration of their choices or autonomy.

3.1. Drive to Discharge. The drive to discharge conveyor belt represented the dynamic process that was experienced by all stakeholders in the discharge. The pervasive push to

discharge patients as quickly as possible dominated the discharge process and influenced the categories. The general practitioner described the drive to discharge as being an effort to relieve pressure on acute hospital beds.

> There's a delay in discharging people [from the community hospitals] which means there's a delay in getting people out of the acute trust. (General Practitioner)

As a result of the pressure to relieve acute hospital beds, the community hospitals are compelled to create space for those patients who cannot return home. The consultant community geriatrician described what had happened since the frailty team had taken over the medical care of the community hospitals.

> Since we have started the length of stay has significantly gone down in the areas where we've worked . . . So now we see around 200 more patients in the community hospitals in a year in comparison to previously. (Consultant Geriatrician)

This gave rise to a tension between the hospital and community staff when discharge was seen as the priority rather than meeting patient needs. The findings showed that the quick discharge of patients caused therapists to feel unable to provide the rehabilitation they used to (which at one point was six weeks). There was anxiety around discharging people so that they met minimum safety standards rather than maximising mobility and independence. While there is an assumption that community rehabilitation will commence soon after discharge, this is not always the case.

> So what we're actually doing now is getting them to a point where they are safe to return home but not necessarily as good as they could be and this seems to be because of a push towards getting patient's home quicker and then having more rehab within the home environment. What we're finding though, is that the community teams are not able to pick patients up quick enough and we have had situations . . . over the last year to 18 months, where patients have gone home and we've told them we are going to refer them on, 12 weeks have gone by and their phoning saying, "I haven't seen a physio in the community," and it's just been because waiting times have been horrendous. (Physiotherapist, community hospital)

The drive to discharge pushed patients into the community, where services were not able to support them, with a wait of several weeks for rehabilitation to continue, sometimes leading to readmission. One participant felt the drive to discharge originated with pressures felt by the acute hospitals.

TABLE 2: Initial sample September 2018–February 2019 (pseudonyms, names are not those of the participants).

Patient	Age range	Informal carer(s)	Community hospital health professionals	Community health professionals	Number of participants
Hazel Unable to mobilise Hoisted	100+	Brother-in-law Family friend	Nurse Occupational therapist	Care home manager	6
Amy Mobilising short distances with wheeled Zimmer frame (wzf)	80–90	Daughter Grandniece	Occupational therapist Physiotherapist nurse	Hospice nurse	6
Alastair Standing transfers only	70–80	Daughter	Consultant nurse	Nursing home manager	4
Zoe Mobilising with wzf in bedroom only	90–100	Friend and sister	Occupational therapist nurse	Occupational therapist	6
Mae Mobilising with wzf and close supervision	80–90	Nil	Physiotherapist nurse	Physiotherapist care home manager	5
Ivy* Mobilising independently short distances. Frequent falls	80–90	Daughter*	Occupational therapist	Rapid response nurse Physiotherapist	5
Jane Unable to mobilise Hoisted	90–100	Neighbour	Occupational therapist Physiotherapist nurse	Frailty nurse	6
Claire Mobilising with wzf and close supervision	90–100	Niece	Occupational therapist Physiotherapist nurse	Care home owner/manager Physiotherapist	7
Andrew Mobilising with wzf and close supervision	80–90	Daughter and wife	Therapy assistant	Physiotherapist	5
Iris Mobilising with wzf and close supervision	80–90	Son	Occupational therapist Physiotherapist	Not referred for community support at the time of interviewing	4
					Total 54

*Interviewed twice: after first and second discharge from hospital.

Table 3: Theoretical sample summary.

Role	
Consultant geriatrician	
General practitioner	
Therapies lead	Total 3

because the pressure's on the Acute to discharge everybody and it's just everyone's pressured isn't there, and it's like a revolving door, you're just going in a circle all the time and people are going to be readmitted. (Ivy's community nurse)

They went on to describe how this exacerbated distrust felt by community teams towards the community hospital.

we're actually doing someone else's job because the rehab hospitals should be making sure these patients are medically stable to go home and they can actually rehab properly, you know, if they think that in 2 weeks they're going to go backwards then they shouldn't be discharging. (Ivy's community nurse)

The push of the drive to discharge created a situation that was at odds with the choice and autonomy rhetoric in policy.

There is a real emphasis on getting people home but our pathway for rehab doesn't mean we're going to pick them up the next day after they get home, that pathway's not there so it could be week or two before someone comes out of the [community hospital] and I then picked up (Ivy's community physiotherapist)

Community services are not always available to pick the patient up immediately after discharge, thus limiting their choices regarding further rehabilitation and independence, while increasing their reliance on informal carers.

3.2. Drive to Discharge and Choice. Choice is limited to the services available; for example, a patient may want to go home as per the "home is best" rhetoric, but there are not the services available to support someone with their physical limitations and lack of social network. This rhetoric fails to consider the complexities of people's lives and social networks. Hazel wanted to go home but was not able to due to a lack of informal carer support and needs too great for social care to meet. She had to go into a care home but described being allowed to go home as "heaven." There is then a double-bind choice of which care home to live in, neither of which is the patient's actual choice of accommodation. Her hospital nurse made it clear she was aware of how unfair the system was when she said,

It's very difficult for these frail elderly patients that we have that come out of their own homes into hospital and then all of a sudden they're not going back and I always feel quite strongly that they don't get the opportunity to say goodbye to their homes, to see the things in their homes ever again and that always kind of hits me really,

I think that's really harsh, it's really harsh. (Hazel's community hospital nurse)

However, the discharge progressed as usual, and Hazel never saw her home again. She died in the care home she was discharged to.

Alastair's daughter was desperate for her father to be discharged to a care home as he had lost the ability to care for himself, had multiple failed hospital discharges, and lacked trust in social care. She felt hospital staff were "determined to send him home."

So he's got a brain tumour on the left side of his head and they were taking him in to rehabilitate him back into home life, which really concerned me after all the admissions and the times he's been discharged before. And we kind of had a worrying conversation that they were claiming he was independent and I said, "he's not." (Alastair's daughter)

Aggressive advocacy required for her father and felt "pushed to the limit" with "doors slammed [in her] face" and that nursing staff were "laughing at us" for wanting the discharge to be to a care home. Lost trust in the system and staff due to the seemingly blinkered aim of discharge home.

3.3. Drive to Discharge and the Informal Carer. The findings showed that the informal carer was intrinsic to the discharge process but was often seen as a resource to facilitate discharge rather than an autonomous individual with other burdens. The informal carers in the study were looking after other older relatives/spouses with advanced frailty and neurological conditions, as well as children. They also had jobs and had to get signed off due to the physical and mental burdens of caring.

3.4. Choice and the Informal Carer. Paradoxically, respecting the older person's choice often resulted in a lack choice and control for the informal carer. For example, several patients did not want to live in a care home even though remaining at home was becoming dangerous due to increasing frailty, loss of mobility, frequent falls, and regular hospital admissions. The patient choice created a significant mental and physical burden for their informal carer who was intrinsic in helping her patient to remain at home. The drive to discharge meant that one patient did not receive enough rehabilitation to be independent before going home and rehabilitation did not commence in the community. After the discharge, the daughter was angry and had lost trust that the hospital staff were making decisions in her mother's best interests.

I should have said I'm not happy about it but I didn't and I could kick myself now and, but then I didn't know if that would have made any difference, if I'd have sort of said, you know "can you keep her in longer? I don't feel she's ready"... So how I feel about my mum coming out of hospital now is I feel really angry actually because, you know, when I was going in to visit her she looked as bright

as a button because she was getting round-the-clock care, she had people around her all the time which keeps her buzzing as it were. (Ivy's daughter)

The informal carer felt her mother would benefit from further rehabilitation in the hospital setting as it was also benefiting both her mother's mental and physical health. In addition, it was common that these struggling (female) carers had other family available, but all the responsibility fell to them.

We've got a massive family but you always find that people just don't want to know do they? They just don't want to bother. (Ivy's daughter)

Informal carers described the pressure of the drive to discharge when trying to choose the right care home for her relative.

I was feeling pressured, not bullied . . . but I felt pressured. I was like no, no you're not, it's not going to happen, and I am really nice about it but, "I'm sorry, no you're not going to get away with this one." (Claire's niece)

Finally, in the case of patients who had no family members, there were instances of (female) nonfamily members being recruited to the role of informal carer due to assumptions made during the discharge process.

She didn't want carers, she didn't want anybody coming in to see to her. (Jane's neighbour)

While this arrangement started as facilitating hospital discharge, it then followed that nonfamily members were responsible for everything, right up to funeral planning. Here, the patient choice has had a significant impact on the life of a nonfamily member

Planning was started to get her home to her own home which was her choice, with a package of care, and the support of her neighbour. (Jane's community hospital nurse)

The patient had the maximum social care input regarding informal carers. However, she was relying heavily on her neighbours all day and all night.

ringing every hour, [her neighbour was] not getting any sleep at night. (Jane's neighbour)

When the neighbour was interviewed, she said

Nobody's listening to me, I can't get the help that she needs from anybody. (Jane's neighbour)

This example illustrates how the drive to discharge uses people to meet the needs of the system without consideration of the context of the patient and their informal carer, how they intersect, and what other burdens the carer may have outside of the patient/carer dyad.

4. Discussion

The drive to discharge dominated and influenced the choices and autonomy of all involved despite these concepts being considered important for good end-of-life care and biomedical ethics [17]. Patients were caught between a hospital system that was driving for discharge and a community system that was ill-equipped to respond to the quick discharges. The drive to discharge combined with the need for older people living with frailty to be seen sooner than four weeks postdischarge (to continue the rehabilitation started in hospital and to prevent deterioration) was creating a gap in the service that caused the discharge to fail or for patients to be unable to rehabilitate and further burden their informal carer. This corresponded with other research where carer burden was increased at the end-of-life due to a lack of community resources [16].

The illusion of choice that was offered to older people that was not really a choice, and the patient's "choice" is used by the drive to discharge to coerce carers into a caring role, presenting the carer with no choice. The findings highlighted the role of informal carer for an older person was a stressful burden that required a high level of vigilance and aggressive advocacy, while the older person, somewhat overwhelmed by the number of services and health professionals, surrendered control to their carer, thus further burdening them. Feelings of guilt that they are not doing enough or failing the person they care for, as well as gendered assumptions regarding care and the nuance of family dynamic, provide a carer context that is complex and vulnerable. A loss of trust was observed as patients and carers in particular felt that in the face of the drive to discharge, their context and best interests were not at a consideration in discharge decision making.

It has been discussed internationally how older people living with frailty are a disadvantaged group [23]. This study found informal carers were further disadvantaged, particularly when overwhelmed by the power of the drive to discharge and set adrift by lack of resources in the community. Choices made by patients are based on many different factors that the drive to discharge may not allow for or anticipate [10]. People will not always behave and/or may not have the social network or confidence that policy expects; therefore, home is not always the preferred option for the patient and may seem utterly overwhelming to the carer. The drive to discharge causes a burden to the carer, which is exacerbated by a focus on patient-centeredness rather than the patient/carer intersection. The carer needs to be taken into account as they are intrinsic to the discharge process and to ensuring that the patient remains in their place of choice postdischarge. Broom and Kirby [24] described "family-centred" care that takes into account the relationality of dying preferences that are a combination of individual preference and collective desire. They recommend a focus on individual preferences and that the management of disease is augmented with a "sophisticated and nuanced understanding of the family context," because the exclusive focus on patient choice and needs exclusively increases "the severity of the consequences for carers" [24, 25].

The carer is a valuable resource that is not inexhaustible. They are also a future NHS user and the drive to discharge risks becoming a loop that creates more patients and inequities. From an ethical perspective, the concepts of autonomy, nonmaleficence, beneficence, and justice could be applied to informal carers as much as they are to patients [17]. This would ensure the informal carer is not coerced into a caring role they are not prepared for, they are fully informed of the burden they are taking on and consent to participate in this role, fully informed of what life may be like postdischarge, and freely able to reduce or leave the caring role. An ethical framework that takes into account the relationality of ageing and dying could form the basis for care planning and carer support.

5. Conclusion

The lack of availability of resources within the hospitals (acute and community) triggered the drive to discharge process. Combined with resource limitation in the community, a system-wide inability to enable a genuine choice is created, which ultimately leads to a dissatisfying experience for all stakeholders. Poor or unfair outcomes are a result of prioritising discharge and not embracing the complexity of the patient/carer dyad. Informal carers are not viewed through the same ethical lens as the person they care for. However, an ethical framework that takes into account the relationality of ageing and dying could form the basis for care planning and carer support that improves the justice experienced by informal carers.

6. Limitations

A limitation of the study was that interview data were collected at only one point in time, shortly after discharge. However, the impact of the discharge process could be felt for some time after the event, and a longitudinal approach would have enabled a deeper understanding of what happens after the discharge, what caused readmissions, and how the carer burden may change over time. Further investigation of the role of nonkin carers is also required as these friends/neighbours were relied upon just as heavily as family members, but with none of the authority, and were never offered carer assessments and therefore received no support. While formal social care workers, such as formal, paid caregivers, were not interviewed, care home employees were. The study was conducted in southeast England. Participants were illustrative of the geographical area but not of the wider population. However, the drive to discharge is felt across health and social care throughout the country. How this affects other communities merits further investigation.

Data Availability

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Additional Points

What is already known about the topic? (i) The UK population is ageing rapidly with an increasing number of people living with complex long-term conditions, frailty, or dementia. (ii) Hospitals are experiencing a record level of emergency activity and delayed transfers of care. (iii) "Choice" and "autonomy" are key concepts in policy and are associated with good end-of-life care. *What this paper adds?* (i) Stakeholder experiences were varied and complex but were united by the power of the drive to discharge that overrode choice and autonomy. (ii) Despite policy rhetoric, older people living with frailty have varying amounts of influence on care decisions and choice or autonomy can be limited. (iii) The concepts of choice and autonomy were rarely extended to informal carers, with an assumption that they would undertake the care burden during the discharge process, and beyond, without being fully informed about the demands of the role beyond the hospital discharge and as the older person deteriorates.

Disclosure

The manuscript is based on a PhD thesis which is available on the Kent Academic Repository at https://kar.kent.ac.uk/89468/.

Conflicts of Interest

The authors declare that there are no conflicts of interest.

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