

## QUALITATIVE PAPER

# The work of older people and their informal caregivers in managing an acute health event in a hospital at home or hospital inpatient setting

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## Abstract

**Background:** There is limited understanding of the contribution made by older people and their caregivers to acute healthcare in the home and how this compares to hospital inpatient healthcare.

**Objectives:** To explore the work of older people and caregivers at the time of an acute health event, the interface with professionals in hospital and hospital at home (HAH) and how their experiences relate to the principles underpinning comprehensive geriatric assessment (CGA).

**Design:** A qualitative interview study within a UK multi-site participant randomised trial of geriatrician-led admission avoidance HAH, compared with hospital inpatient care.

**Methods:** We conducted semi-structured interviews with 34 older people (15 had received HAH and 19 hospital care) alone or alongside caregivers (29 caregivers; 12 HAH, 17 hospital care), in three sites that recruited participants to a randomised trial, during 2017–2018. We used normalisation process theory to guide our analysis and interpretation of the data.

**Results:** Patients and caregivers described efforts to understand changes in health, interpret assessments and mitigate a lack of involvement in decisions. Practical work included managing risks, mobilising resources to meet health-related needs, and integrating the acute episode into longer-term strategies. Personal, relational and environmental factors facilitated or challenged adaptive capacity and ability to manage.

**Conclusions:** Patients and caregivers contributed to acute healthcare in both locations, often in parallel to healthcare providers. Our findings highlight an opportunity for CGA-guided services at the interface of acute and chronic condition management to facilitate personal, social and service strategies extending beyond an acute episode of healthcare.

**Keywords:** older people, informal caregivers, admission avoidance hospital at home, inpatient hospital, qualitative research

## Key points

- Older people and their caregivers ensure continuity of healthcare beyond an acute event.
- Older people and their caregivers play a substantial role in managing relational structures and navigating healthcare systems.
- The involvement of caregivers in assessment and discharge preparations could be strengthened to enhance coherence of healthcare.
- Personal, relational and environmental factors facilitate or challenge adaptive capacity and ability to manage.

- Collaborative self-management support is limited if these factors are not recognised within comprehensive geriatric assessment.

### Background

Providing acute healthcare in the home, otherwise known as hospital at home (HAH), is not new; in 1958, the benefits of receiving healthcare in a familiar home environment were advocated as bringing about more rapid recovery with support from the family [1]. Although the emphasis on care for older people in the home continues to be reflected in policy [2], implementation is variable. Admission avoidance HAH for older people provides an alternative to admission to hospital for selected patients; core features include a geriatrician-led multi-disciplinary team, comprehensive geriatric assessment (CGA) and direct access to elements of acute hospital-based healthcare [3]. CGA, an effective system of care for hospitalised older people, is a multi-dimensional, multi-disciplinary, co-ordinated assessment and plan for treatment and follow-up [4], with an assumption that older people and families are actively involved in the processes [5]. Combining acute care in the home with CGA has the potential to improve health outcomes for older people. Despite service innovations seeking to expand the application of CGA [5, 6, 7], older people's and family caregivers' participation in managing acute illness and their interface with professionals in a HAH or hospital setting has not been explored [8].

In this paper, we report the findings from an interview study conducted alongside a UK multi-site participant-randomised trial of geriatrician-led admission avoidance HAH, compared with hospital inpatient healthcare [9, 10]. Older people were recruited to the randomised trial from hospital acute assessment units and randomised within 24 hours of being referred to HAH. The presence of a caregiver was not a requirement for participation in the trial [10]. Our objective was to explore the work of patients and caregivers at the time of an acute health event, the interface with health professionals in hospital and HAH and how their experiences related to the principles that underpin CGA.

### Methods

#### Sampling

Each trial site was geographically defined by the catchment area for the established HAH service, and between June 2017 and July 2018, three of the trial sites contributed to the interview study (see table in supplementary material, Appendix S1). We purposefully selected participants for variation in characteristics that might impact on managing illness [11]. These included socio-demographic characteristics, living alone or with family members, with or without social care and presenting with a range of health conditions that included cognitive impairment.

#### Recruitment

The qualitative researcher (PM) approached participants following initial contact by the trial research nurse or coordinator at each site, who confirmed that participants were medically stable, were not receiving end of life care and that there was no reason why it might be inappropriate to invite them to participate. The research nurse or coordinator provided written information about the interview study and confirmed the participants' or caregivers' agreement for further contact.

#### Consent

The researcher obtained informed consent for the interview study. The consent process took into account implications of the Mental Capacity Act (2005) in England and the Adults with Incapacity Act (2000) in Scotland. A personal consultee was involved in making a decision in the best interests of individuals if they did not have capacity to consent to taking part.

#### Data generation

We developed interview guides from previous research findings from focus groups with older people and caregivers who had received acute healthcare, and from a logic model of the professional elements of CGA (see supplementary material, Appendix S2 and S3) [5]. A female qualitative researcher, independent of clinical and trial recruitment processes (PM), interviewed patients alone or with family caregivers prior to or within 4 weeks of discharge from either setting. The researcher conducted interviews in participants' homes or hospital wards and recorded field notes as a means of documenting contextual information on settings and interactions [11]. Interviews lasted 30–90 minutes, and audio-recordings were professionally transcribed. Data were managed in NVivo 12 (QSR international). We replaced all names with pseudonyms and changed identifying details.

#### Analysis

Our analytic framework was guided by four interlinked concepts from normalisation process theory (NPT) to explain the work associated with healthcare and its integration into daily life [12–14] (see supplementary material, Appendix S4): (1) sense-making work (understanding what is happening); (2) relational work (interpersonal aspects of determining needs); (3) enacting work (undertaking and coordinating collective tasks) and (4) appraising work (reflecting on change and ongoing processes of adjustment).

**Table 1.** Patients participating in the interview study

	Hospital at home <i>n</i> = 15	Hospital inpatient <i>n</i> = 19
<b>Age (years)</b>		
Mean	83	84
Minimum–maximum	74–92	76–96
<b>Gender</b>		
Female	12 (80%)	12 (63%)
Male	3 (20%)	7 (37%)
<b>Ethnicity</b>		
Black British	1 (6.5%)	0 (0%)
White British	13 (87%)	18 (95%)
White European	1 (6.5%)	1 (5%)
<b>Living arrangements pre-admission</b>		
Alone	7 (47%)	8 (42%)
With caregiver	6 (40%)	7 (37%)
Sheltered accommodation	2 (13%)	4 (21%)
<b>Local Authority domiciliary care pre-admission*</b>		
No	12 (80%)	14 (74%)
Yes	3 (20%)	5 (26%)
<b>Primary reason for acute presentation**</b>		
Fall	3 (20%)	5 (26%)
Delirium	2 (13%)	5 (26%)
Exacerbation of chronic obstructive Pulmonary disease	2 (13%)	4 (21%)
Back pain	2 (13%)	0 (0%)
Leg pain	0 (0%)	2 (11%)
Cellulitis	2 (13%)	0 (0%)
Abdominal pain	2 (13%)	1 (5%)
Chest infection	1 (7%)	0 (0%)
Heart failure	0 (0%)	1 (5%)
Other	1 (7%)	1 (5%)
<b>Functional scores on admission: Mean (SD)</b>		
Barthel Index: scored 0–20; lower scores indicate lower level of functioning in activities of daily living	15 (3.1)	15 (2.5)
Montreal Cognitive Assessment (MoCA): scored 0–30; ≤26 indicates cognitive impairment. Data available for 13 HAH and 12 hospital patients	19 (5.6)	19 (4.8)
<b>Length of stay in acute service (days)</b>		
Mean	6.8	8.1
Minimum–maximum	1–19	1–27
<b>Interviewed alone</b>	6	5
<b>Interviewed with caregiver</b>	9	14
<b>Interviewed at home</b>	15	15
<b>Interviewed in hospital</b>	0	4

\* Domiciliary care comprised formal carers' visits to patients' homes, to provide support with activities of daily living such as washing and dressing. \*\*Primary reason for acute presentation identified from discussions with patients, caregivers and site research nurses.

We expanded the analysis to identify factors that influenced patients' and families' capacity to undertake this work [12, 15]. We reviewed the interview findings until we considered that we had reached sufficient understanding of CGA-guided acute healthcare in each setting and no longer identified additional perspectives [16]. We used the Consolidated Criteria for Reporting Qualitative Research checklist as a reporting guide [17] (see supplementary material, Appendix S5).

### Ethical review

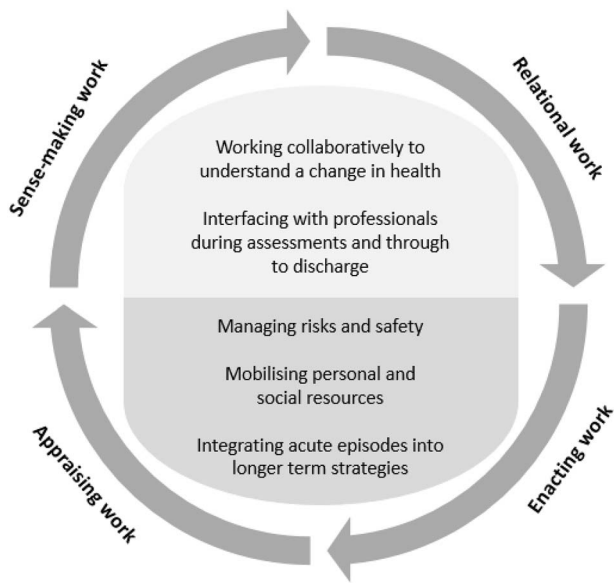
The design of this study was included within the ethics application and protocol for the randomised trial [10]. Ethical approval was given by the Research Ethics Committee

England, Wales and Northern Ireland (14/WA/1081) and Scotland (14/SS/1046).

## Results

### Participants

In total, 34 patients were interviewed, 11 alone and 23 with family caregivers. Falls, delirium and exacerbation of long-term conditions were frequent reasons for acute admissions. A minority were receiving local authority domiciliary care (see Table 1). Twenty-nine caregivers were interviewed (12 HAH, 17 hospital), who were the spouse (7), son, stepson or son-in-law (7), daughter (10), sibling (2), or grandchild (3) of the patient. The majority of caregivers were female (19).



**Figure 1.** Older people and family caregivers' participation in acute healthcare across the four domains of NPT.

**Findings**

Across the four NPT domains, we identified related forms of work: negotiating within personal and professional networks, and health and personal care-related work. Relationships between the NPT constructs and aspects of work identified are illustrated in Figure 1.

**Patients' and caregivers' sense-making and relational work**

*Working collaboratively to understand a change in health*

Patients and caregivers described working together and recurring interactions with healthcare services; during the interviews, they did not confine themselves to the study related episode of healthcare. The significance of an acute health event was shaped through previous experiences, and when discussing the study-related health event, they described a desire to avoid a stay in hospital and how they had sought advice. Many were familiar with the triage and advice line 'National Health Service (NHS) 111' [18] and had used it as a strategy to access immediate guidance.

It got so bad that I thought, 'I'll have to call a general practitioner' but I couldn't, because of the time in the morning. So I thought, 'I've got a pendant [personal alarm], but I know what they'll do, first is you go into hospital'. I had a big think and I asked one of the boys. Between us, we decided to ring 111. They rang me back, eventually. . . 'We'll have to send you a doctor'. The doctor came and says, 'You have to go into hospital.'

(Meg, HAH)

I kept saying, 'Tomorrow, it will get better', and [my son] told me off and my sisters told me off. So, I rang 111, because I really couldn't breathe, and then they just took me straight in.

(Imogen, Hospital).

Decision-making became more complex when patients developed acute confusion, and caregivers described negotiations with their relatives about seeking care before taking action on their behalf. Patients were willing to defer urgent decision-making to family members, who described the challenges if a patient experienced fluctuating confusion. Although generally expressing a preference to remain at home, many patients later reflected on decisions by taking into account opinions of family members.

If it was a doctor saying 'Do you want to go into hospital or do you want to stay at home?' I would say, 'Yes, I want to stay at home'. But if I was delirious then I wouldn't mind my daughter or my son saying, 'Take her into the hospital'.

(Ailsa, HAH)

*Interfacing with professionals during assessments and through to discharge from hospital or HAH*

Patients and caregivers did not recognise CGA as a process of assessment and planning that involved them. Family caregivers, even when involved in providing personal care and having daily contact with their relative, perceived they had not been invited to contribute to assessments on acute units, and that their knowledge of cognitive, communicative and physical functioning could have informed decision-making. Where hospital clinicians' assessments had been conveyed to families, many described discrepancies with their own observations. Caregivers monitored their relatives and identified changes that were not necessarily considered significant by professionals who lacked personal knowledge of the patient.

They said he was too well to be on the ward. . . When I went to see him, he was confused. He says, 'Will you get me some caring food . . . so we can feed the goats'. We haven't got any goats. I say, 'He's still confused, because he said some strange things to me', and [the nurse] says, 'Well, we haven't noticed that'.

(David's son, Hospital)

Caregivers described being aware of discrete elements of assessments in hospital, which did not seem to form part of a personally tailored process and described limited opportunity to contribute or to gain specific information.

I was asking whether I should get a carer but they said, because she passed all the tests, like she can make a hot drink, she can go upstairs and stuff, that she doesn't need one.

(Violet's granddaughter, Hospital)

Many caregivers expressed reluctance to challenge hospital staff if their concerns were not acknowledged: '*You don't like to interfere and you don't like to be a nuisance*' (Jessie's daughter, Hospital). Some described how they had learned to become assertive following repeat hospital admissions.

We did have to actually have a standoff because they were sending her home, she was still unable to walk properly, she was falling around.

(Iris's daughter, Hospital)

Patients and caregivers frequently assumed HAH's remit would be confined to tasks for the patient's presenting health condition: *'They come in, done their job, as far as what their job entailed, and then went out the door'* (Irene's son, HAH). This extended to not raising concerns about competing care needs within assessments at home, even when caregivers were providing significant levels of support.

I do worry about [my husband] a bit really, because he's 86 and I don't want to tire him out. . . I have another daughter but she's got MS and she walks with a stick so we can't just call on her.

(Betty, HAH)

No one said, 'Oh, do you need any help'. Now I'm getting back to work, I need. . . well, I've got my daughter and my son. . . the days that they're not working.

(Irene's son, HAH)

Patients and family members described the contributions by the different healthcare professionals in hospital, for example, *'The physios tried to get you on your feet, and different things like that'* (Bridget's daughter, Hospital). They described questions asked by HAH staff about mobility and functional activities, which had not been directly observed.

[HAH] is mostly blood tests and urine tests. It's nearly all about bloods. Nobody's been, they could have been when, they were probably observing what was going on, and that I wasn't living in the house all turned upside down.

(Meg, HAH)

Nobody has asked me to actually walk. . . One of the pages, it says 'Walk, out of 5' and they've put '5 out of 5', as though I could walk. Well, I can't.

(Betty, HAH)

Many considered that HAH progress folders were not intended for their use, although stored in their home. None were aware of goal documentation contained in folders and, on reading out goal statements from staff assessments, they did not find the content personally accessible: *'Mobilise independently to toilet in 2/52 with a stick' . . . Joyce was thrown by the numbers'* (Field notes, Joyce, HAH).

Patients conveyed a lack of involvement in planning discharge from hospital, generally perceiving this to be an irreversible decision made by a doctor. Perceptions of an NHS imperative to *'empty beds'* were considered to have shaped actions of hospital staff: *'They need to get you out, need the bed, and suddenly you're gone and there's things missing'* (Imogen's step-son, Hospital). Some linked subsequent readmission with their previously unacknowledged concern that the timing of discharge had seemed premature.

The doctor came round, looked at the chart, and says, 'Well, you can go home now'. I was just amazed. I came home, I couldn't swallow anything. . . The ambulance came out and they took me back.

(Susanne, Hospital)

Assumptions about support structures and caregiver roles were not always explored before discharge from hospital

and could result in a perception that care planning was unrealistic.

It's a big tick factor if there is somebody there to care for him but that's not good enough, because I live next door, and I can't be there 24 hours.

(David's son, Hospital).

Ambiguity about the timing of discharge from different visiting HAH staff suggested decision-making occurring away from the home. Many described not knowing how long to expect HAH to be available or had not anticipated imminent discharge: *'That just came out the blue'* (Elizabeth's husband, HAH). Others described a period of uncertainty over whether HAH input had finished or not. Patients and families often detected the end of an episode when the HAH folder had been removed from their home: *'They didn't tell me but I knew they'd come and got the folder'* (Matilda, HAH).

Last Friday, a male [HAH] nurse that came said, 'Oh, we won't be coming in anymore' and took their book away. A nurse turned up on Saturday, she said 'Where's the book?' . . . I've heard nothing since.

(John's wife, HAH)

### Patient and caregivers' enacting and appraising work

Sense-making and relational work took place alongside patients' and caregivers' work of managing potential risks, mobilising personal and social resources to cope with changes and strategies to integrate the acute episode into longer-term ways of managing fluctuating conditions.

#### Managing risks and safety

Patients and caregivers recognised safety as a priority for hospital staff, while HAH required them to be more involved in monitoring and maintaining safety: *'It's like sleeping with one eye open, it's almost like sleeping with one ear open'* (Irene's son, HAH). Patients considered risks in the context of the suitability of their home and accessibility of personal support. Although environmental adjustments, equipment and reablement visits often facilitated the episode of acute HAH, caregivers considered longer-term limits to sustaining care while managing risks.

[HAH] said 'You can't sleep on the settee', because the night before he slept on the settee but he slid off. She said, 'I think we can get a bed in' . . . But he got worse so he did have to go into hospital.

(John's wife, HAH)

Quite a lot of work isn't it, running up and down, for me. I'm worried if she falls. . . I don't think I could lift her.

(Betty's husband, HAH)

The personal setting of home could become particularly significant for patients experiencing acute confusion, if combined with family availability to provide supervision. Aisla's

daughter valued avoiding additional distress from the unfamiliar surroundings of hospital, describing her own strategies for managing when her mother was being treated for delirium at home:

There's bits where this isn't her house and then all of a sudden, yeah, it is. . . if you're here and you get confused that this isn't the house, then we can talk about familiar things and it's almost like you're back in the room again.  
(Aisla's daughter, HAH)

Within this family's '*rota*' to sustain 24-hour support, Aisla's son had been staying one night when their mother '*didn't recognise him and she tried to get out the window*', demonstrating precariousness for the family in containing risks at home. Those living separately from the patient were concerned about a need to substitute for 24-hour hospital care when relatives had lost confidence in managing alone while unwell, particularly at night when '*your imagination runs riot*' (Imogen, Hospital):

People just need to have those few days to get themselves better in hospital, to have all the treatment and have the 24 hour care that they have there, which they wouldn't have at home. . . you try and give as much support as possible but it's difficult from a distance. . . she hasn't got real support, 24 hour sort of thing.

(Imogen's step-son, Hospital)

### **Mobilising personal and social resources**

Although most patients depended on partners or close family for health-related support during an episode of acute healthcare and when continuing after discharge, those living alone often displayed determination in finding ways to manage. Patients who maintained their personal activities of daily living while unwell described how HAH had enabled continuity in their established routines, in the familiar setting of their home.

You're in your own environment and people come in to check that you're all right. I mean at least you can do what you want to do where in hospital you're confined to a certain amount of space.

(Rose, HAH)

Others relied upon distributed social connections, for example neighbours, friends, private cleaners, formal carers, sheltered accommodation wardens, personal alarm responders and befrienders and described diverse pre-existing support networks.

I have got a couple of good neighbours all come in. He comes in the morning to give me an inhaler and she comes in at night to give me another hit.

(Phyllis, Hospital)

I've got a good cleaner and if there's anything I just ask her to do it, and then [a friend of my son], he lives around the corner there, they were good friends for years and years, but he's there if I need him.

(Anne, HAH)

I know Sally very well but I don't have a lot [of contact] because she's very busy. . . She comes from Age UK.

(Joyce, HAH)

Caregivers described limited opportunities for discussion with hospital or HAH staff on how to manage beyond the acute episode, or '*what I can do to change, if anything, the conditions of what mum's living with*' (Irene's son, HAH). Withdrawal of the acute service often meant continuing with a pattern of fluctuating symptoms and functional capabilities. Caregivers described adapting through their own knowledge and relational network to avoid further emergency healthcare.

After she'd been discharged out of [HAH] care a couple of weeks, she took another UTI [urinary tract infection]. But I'd taken a sample up to the doctors. . . I think it's just me being a bit wary now, because you get to know little signs [of delirium starting].

(Aisla's daughter, HAH).

### **Integrating acute episodes into longer-term strategies**

Caregivers frequently considered that transfer to HAH facilitated immediate post-discharge care.

This [HAH] has been the best hospital experience from other times because there seems to be aftercare. . . normally you'd have to phone your doctor and go through whole loop again.

(Patricia's daughter, HAH)

They reflected on the unstable trajectory of the older person's health needs and considered that proactive reviews would be useful after discharge from either setting. Many commented on the lack of a written record, from both hospital and HAH, that could support their appraisal of change. Where copies of summaries had been received, they were typically viewed as communication between professionals that did not seem to address their needs.

All [HAH] did was wrote down on a piece of paper, took it away, we never see it no more. . . The doctor's been given a copy, but surely we should have a copy so we've got an account of it.

(Irene's son, HAH)

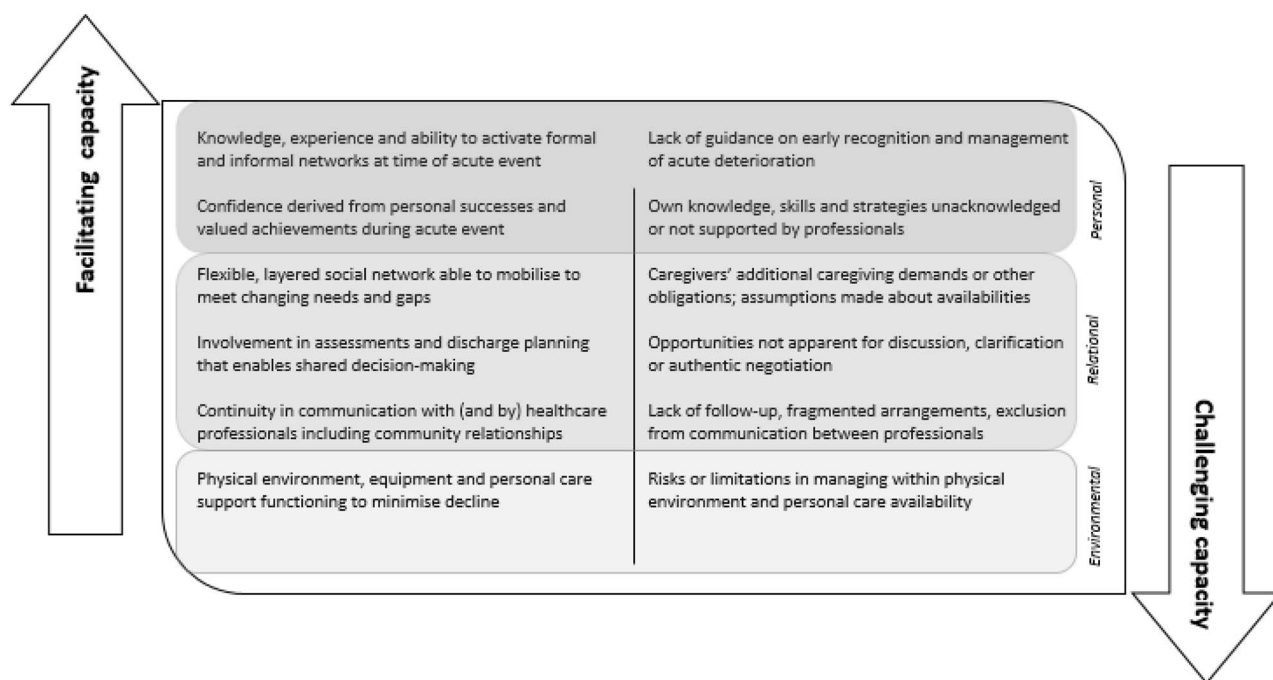
Some hospital patients discovered a need to re-establish arrangements with familiar community services after discharge and perceived gaps in information provision from hospital staff to community services: '*There always seems to be that lapse when people come out, there's no coordination at all of various areas*' (Imogen's stepson, Hospital). District nursing visits that continued alongside HAH maintained established longer-term routines for some. Continuity through community services became particularly important in regaining confidence when uncertainties persisted following withdrawal of the acute service.

I've got the number for district nurses there. . . I know what to do if there's anything happens, you know. Yeah, got all the numbers there, keep it handy.

(Anne, HAH)

I'm very, very fortunate with my family doctor. She takes quite an interest in people and she could sort of fill in the gaps for me [after HAH discharge].

(Martha, HAH)



**Figure 2.** Factors facilitating and challenging older people’s and caregivers’ adaptive capacity to undertake acute healthcare-related work (HAH and hospital).

**Factors moderating patients’ and caregivers’ adaptive capacity**

Prior personal experience, caregiver involvement in the delivery of health and social care, and an environment that was modified to support limitations in functioning were important factors in determining older people’s capacity to adapt and sustain daily routines (Figure 2). Support networks had a crucial role in managing health events and safety at home, where continuing relationships with primary care healthcare professionals and social networks were easier to maintain. However, this was dependent on the extent of caregiver support, particularly at night.

**Discussion**

There is evidence of the significant role played by informal caregivers in managing chronic illness [19, 20, 21] but little is known about how older people and their caregivers manage at the interface between acute and chronic illness. This evidence is crucial to understanding how to minimise a loss of independence experienced by older people from an acute change in health. We have shown in each setting how the relationships between older people, their support networks and healthcare services impacted on their capacity to manage and adapt to a deterioration in health and functional activities. While the importance of healthcare professionals’ understanding of caregivers’ challenges is widely established, the work required of patients and families for managing an acute change in health at home, in contrast to hospital, has received limited recognition [22, 23]. Our findings highlight an opportunity for healthcare professionals to develop skills

to support older people maintain adaptive capacity beyond the acute episode of healthcare.

Caregivers’ contributions were frequently required to facilitate an episode of HAH, and the relational resources of family and social networks acted as a bridge to continuity of healthcare. Close to half of those we interviewed lived alone and received informal care from caregivers living elsewhere, confirming previous research on complex informal care arrangements [23, 24]. Caregivers who were able to provide support in older people’s homes valued continuity of the familiar environment and routine, particularly during patients’ experiences of confusion. Sustaining routines might support the maintenance of an older person’s independence [25].

None of the participants, in either setting, perceived that they had been included in assessing and goal-setting processes of CGA and, in each setting, documentation produced by staff was perceived to be professionals’ use. This was reinforced by the removal of patient folders from the home and for some symbolised the end of an episode of HAH care. Similarly, patients and caregivers described decisions about discharge from inpatient hospital as being irreversible rather than an opportunity for a collaborative discussion to identify how adaptive capacity might be supported [26].

**Strengths and limitations**

A distinctive feature of this study was the inclusion of older people who had recently experienced acute health crises, including those living with cognitive impairment and who had experienced acute confusion. Older people’s and caregivers’ perspectives are rarely included in research on acute

healthcare at home, or at the acute/chronic illness interface, and yet provide insights into service improvement [27].

Our findings might be limited by caregivers who had significant caregiving responsibilities declining to be considered for the interview study and by interviewing patients and family caregivers together. Although joint interviewing can allow sharing of perspectives, this format might have influenced people's willingness to talk openly about concerns and difficulties [28]. In addition, we used single timepoint interviews while a longitudinal approach with observational methods could explore influences on patients' and caregivers' adaptive capacity to undertake healthcare-related work over time.

## Conclusion

Older people and informal caregivers have a substantial role in managing the complex relational structures and decision-making that support autonomy and the provision of healthcare during an acute health event. Our findings align with previous research that suggests that patients' and families' continuous adjustments support the quality and safety of healthcare [29], as they adapt to changing health conditions within fragmented health and social care services and deal with care at night if the older person is at home. Reliance on this informal support underpins the feasibility of achieving policy intentions on prevention, self-management and the shift of healthcare to the community [30]. Future research might explore how CGA-guided acute healthcare can facilitate individuals' adaptive capacity, in contrast with an emphasis on frailty, reduce fragmentation of care and strengthen collaboration with older people and their caregivers.

**Supplementary Data:** Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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