"We don't have the infrastructure to support them at home": How health system inadequacies impact on long-term care admissions of people with dementia.

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Abstract

Objectives: The influence of healthcare system factors on long-term care admissions has received relatively little attention. We address this by examining how inadequacies in the healthcare system impact on long-term care admissions of people with dementia. This is done in the context of the Irish healthcare system.

Methods: Thirty-eight qualitative in-depth interviews with healthcare professionals and family carers were conducted. Interviews focused on participants' perceptions of the main factors which influence admission to long-term care. Interviews were analysed thematically.

Results: The findings suggest that long-term care admissions of people with dementia may be affected by inadequacies in the healthcare system in three ways. Firstly, participants regarded the economic crisis in Ireland to have exacerbated the under-resourcing of community care services. These services were also reported to be inequitable. Consequently, the effectiveness of community care was seen to be limited. Secondly, such limits in community care appear to increase acute hospital admissions. Finally, admission of people with dementia to acute hospitals was believed to accelerate the journey towards long-term care.

Conclusions: Inadequacies in the healthcare system are reported to have a substantial impact on the threshold for long-term care admissions. The findings indicate that we cannot fully understand the factors that predict long-term care admission of people with dementia without accounting for healthcare system factors on the continuation of homecare.

1. Introduction

The aging population across Europe has the potential to create considerable strain on long-term care service provision in the coming decades, particularly for people with dementia. In light of this, there is great interest in identifying the factors which predict transition of people with dementia to long-term care (LTC) services. Gerontological researchers have conventionally focused on the characteristics of the older person that influence the transition from community to LTC use (1-4). These largely emanate from what has been termed the 'geriatric giants' of ageing (5). They include immobility, falls, incontinence as well as dementia (5-7). However, meta-analyses in the area have acknowledged that this research contains a considerable degree of unexplained variance in the prediction of LTC admissions (ranging from 50-60%) (6, 8, 9).

The psychological health effects on family carers responding to a care recipient's needs have also been recognised. Such work has led to the belief that, as family carers are critical to homecare, if the level of stress carer's experience as a consequence of providing care becomes too great, the homecare arrangement may break down (10-12). Indeed, a recent study of factors associated with long-term institutional care of people with dementia across Europe concluded that '"caregiver burden appeared the most consistent factor associated with institutionalisation" (13p.9).

However, a recent systematic review and meta-analysis indicates that family carer stress does not have as strong an effect on LTC admissions as was previously believed. Although a significant association was found, the effect size was negligible (SMD= .05, 95% CI .04-.07) (14 p.12). The results of this review suggest the need to look wider than the needs of the care recipient or the carer that mitigate against the continuation of homecare.

Despite the provision of homecare taking place within the context of the wider healthcare system, comparatively little attention has been concentrated specifically on healthcare system factors that influence the transition to LTC (15, 16). As Muramatsu et al. acknowledge "the most understudied factors of nursing home admission are those related to the healthcare system" (16 p.S170). Where studies have examined healthcare system factors, they have identified the importance of community care services for people with dementia, options for service reconfiguration and potential costs savings (16-21). However, they have not addressed the implications of the interconnection between community and acute hospital care together in the transition to LTC (16, 19, 22). Therefore, this study aimed to develop an in-depth understanding of how community and acute hospital care, along with the interconnection between the sectors, impact admissions of people with dementia to LTC. To the best of our knowledge, this present study is the first to examine this.

This issue has been examined in this study in the context of the Irish healthcare system. The national health service agency, the Health Service Executive (HSE), provides the majority of public acute hospital and community care services in Ireland. Acute hospitals provide services for medical and surgical treatment. These services include inpatient scheduled care, emergency care, maternity care and outpatient care and diagnostic services (23, 24). The

main state-funded community support services for older people are homecare package schemes which include community health nursing, home-help for domestic tasks or personal care assistants for intimate personal care. Respite may also be provided, depending on the person's needs and where they live. Other HSE services for older people in the community include Physiotherapy, Occupational Therapy, Speech and Language Therapy and Social Work. The Nursing Home Support Scheme provides access to LTC facilities (known as nursing homes, residential care homes, assisted living facilities and care homes in different countries) (17). The scheme provides financial assistance towards the cost of long term care services. It is administered by the HSE through the 'Fair Deal' scheme (25). This scheme means that, depending on income or resources, applicants contribute towards the cost of LTC and the State pays the balance.

Following the economic crisis in Ireland in 2008 and the subsequent government programme of austerity, there have been continuous cuts to HSE staff numbers and budgets (26, 27). For example, HSE funding has fallen by 22% from 2009 to 2013 (28). Consequently, community care services have been reduced since the crisis. Data on home help hours are one of few measures of healthcare system activity in the community (29). Home-help hours have decreased by 18% between 2008 and 2012 (28). However, it should be noted that community care services were fragmented and under-funded prior to the economic crisis (30). In terms of LTC, the number of LTC beds decreased from 25,209 in 2008 to 23,026 in 2013, despite the population aged over 85 increasing by 21.6% between the Census 2006 and 2011 (31). This ageing population in Ireland is expected to result in an increased demand for LTC, assuming levels of community care supports remain consistent and age-standard disability rates continue to fall (32).

2. Methods

2.1 Study design

This study aimed to develop an in-depth understanding of the role of healthcare system factors in LTC admissions of people with dementia, thus a qualitative approach was adopted. This allowed for the nuances and complexities within the healthcare system to be analysed. We obtained ethical approval for the study from the Research Ethics Committee (REC) of the Royal College of Surgeons in Ireland (RCSI) (Ethics Reference number: REC1057b).

2.2 Sample

Participants included healthcare professionals and family carers. Both hospital and community-based healthcare professionals that were key decision-makers regarding the transition to LTC were interviewed. Family carers were those providing care to a loved-one with dementia. They and their family had decided that homecare was no longer sustainable and so had started the process of applying for LTC for their family member, or had gone through the process in the last six months.

2.3 Data collection

Interviews were conducted from May to August 2015. In compliance with REC requirements, participants were not contacted directly. Therefore, a number of simultaneous recruitment strategies were employed. Healthcare professionals identified eligible family carers, informing them of the study and passing on study information which included the researcher's contact details. Family carer support organisations advertised the study. The study was also advertised through a press release from RCSI, and in various healthcare and gerontological websites and newsletters.

All participants received information on the study prior to the interview. Once consent forms were signed, the data were generated through semi-structured individual interviews. Interviews were conducted by the first author and lasted an hour on average. They explored what participants perceived to be the critical factors influencing LTC admissions of people with dementia. Interviews were audio recorded and transcribed verbatim for analysis. All participants were provided with the opportunity to review the interview transcript, one participant did. Data saturation determined the final number of interviews conducted (33). A total of thirty-eight interviews were conducted; twenty-two with healthcare professionals and sixteen with family carers of people with dementia.

2.4 Analysis

Data analysis was supported with the data management software NVivo10. Interviews were analysed thematically. Themes were developed using the 'One Sheet of Paper' (OSOP) method, developed by the Health Experiences Research Group (HERG) at the University of Oxford (34). This enabled comparison of codes within a theme to ensure consideration for nuances in the analysis. The coding framework was reviewed and discussed by the research team and is presented in Fig 1 below.

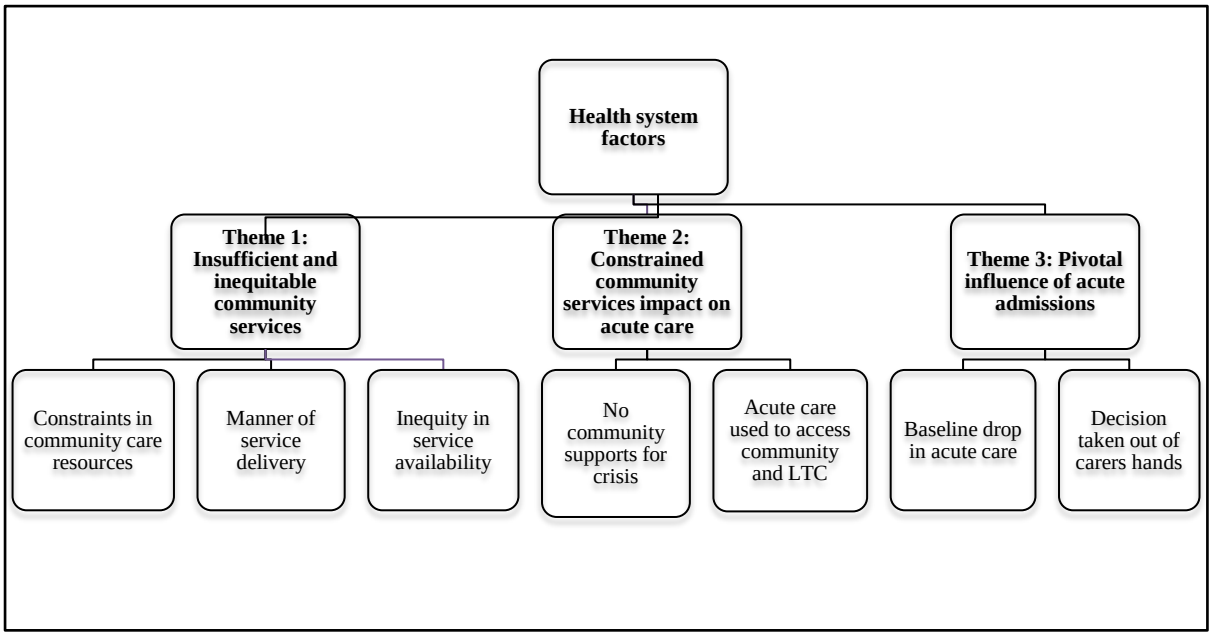

Fig 1. Framework of health system factors which influence LTC admissions

3. Results

3.1 Profile of respondents

All family carers interviewed were providing care to a person with dementia. Thirteen women and three men participated. Nine participants were providing care to a spouse, while seven were providing care to a parent. Family carers were on average 60 years of age and were providing care to a loved-one who was on average 78 years of age.

A total of twenty-two healthcare professionals (HCPs) were interviewed, eighteen of whom were female. The largest group of professionals (n=13) worked in nursing and included Public Health Nurses, Community Registered General Nurses, Clinical Nurse Managers and Clinical Nurse Specialists. The other professional groups interviewed were Social Workers, GPs, a Geriatrician, Psychologist, Occupational Therapist and Manager for Older Person's Services. These professionals were based both in the community and in hospitals.

3.2 Overview of findings

The study findings indicate that admissions of people with dementia to LTC may be affected by inadequacies in the healthcare system in three ways. Firstly, participants regarded community care services to be substantially constrained as a result of the economic crisis. These services also appear to be inequitable. Both these factors were believed to limit the effectiveness of community care in supporting sustainable homecare. Secondly, such limits in community care services were seen to increase acute hospital admissions. Finally, the findings suggest that admission of people with dementia to acute hospitals can accelerate the journey towards LTC.

3.3 Constraints in community care services

The under-resourcing of community care services as a consequence of cuts within the Health Service Executive (HSE) emerged quite strongly in the analysis. Both family carers and healthcare professionals perceived these cuts to have been detrimental to the provision of community care services. Family carers frequently described how they received little to no direction or support from community care services. This led one family carer to describe the community care services provided as *"appalling"* (Family carer 2). Professionals were clearly frustrated by the constraints in services as a result of this under-resourcing. They described how over-stretched they were, limiting time available to visit families. They felt these constraints had undermined their professional practice and consequently their role in homecare.

> *"It's counterproductive…we go out and we do an assessment for home help...We submit all the paperwork and then it doesn't happen…because there is no money*

there… then we're the people at the frontline having to say to somebody "Yes I do understand what you're saying. I do identify the needs of your loved-one but sorry we don't have the resources to put it in". It's like, well why are you here?...it's very hard to be asked to do a job and then not have the tools to do it." (HCP 15)

3.4 Manner of service delivery can undermine quality

As described above, the main State-funded support service for community care in Ireland is the homecare package scheme. This involves personal care assistants providing support with the care recipient's personal care, such as washing and dressing. Given pressure to reduce the cost of the homecare package, there is a growing trend for the Health Service Executive (HSE), to outsource the service to private care providers. Often private providers have high staff turnover rates. Consequently, families reported to have different care assistants from private providers calling to the house to support them. This family carer, who cared for her husband, demonstrated how distressing it was when the care assistants constantly changed:

"You wouldn't know who you were going to get at the door that morning…So he didn't know where he was…The whole situation was like a time bomb when they were here because I was trying to keep my husband calm, because he would get very agitated and be shouting and roaring and everything and then they'd [the care assistant] look at me…as if they were afraid and I would try and keep them calm and I am trying to keep him calm…they were more trouble than they were worth." (Family carer 1).

However, four family carers reported positive experiences. For those who had positive experiences there was continuity in the personal care assistant. This provided routine and

stability and helped reduce some of the stress they experienced. These families had a more positive outlook on the quality of the homecare package scheme compared to those families who did not have continuity in the personal care assistant. Continuity in personal care assistants was also perceived by healthcare professionals as an important component of home care packages. Professionals were frustrated when it was not possible to have continuity in the personal care assistant calling to care recipient's homes.

3.5 Inequity in service availability

Respondents perceived a considerable degree of inequity in availability of community care services nationwide. They emphasised that this inequity did not arise as a result of the economic crisis. The inequity was apparent in the substantial variation in the availability of services between even small geographical areas. Respondents also felt that there was also a lack of transparency in relation to factors influencing waiting times to access services, with some professionals questioning if this was based on priority of need. As this professional described:

> *"The other problem is it depends where you live… in one area I had home help immediately and in the other area, the other side of the road, there was a waiting list…the other bit is if you shout really loud you get it…the people who actually sit there on the waiting list, sit on the waiting list."* (HCP 8)

4. Constrained community services impact on acute hospitals

The second major study finding indicates that constraints in community services were reported to impact on acute hospitals in two main ways, each of which are described below.

4.1 At times of crisis families are forced to go to acute hospitals

Community care services were regarded as so over-stretched that they do not have capacity to respond to families who are experiencing a crisis in care provision, however short-term this crisis may be. This crisis may involve the carer being unwell or otherwise unable to provide care. Healthcare professionals described how, in such circumstances, they have no option but to advise the family to go an acute hospital.

> *"If they can't manage they are forced into an acute hospital…it's not advice anyone wants to give…there is no emergency nursing home beds, emergency respite beds. There is nothing out there for people that if they're really struggling at home there is nothing to support them through that."* (HCP 1)

4.2 Acute hospital admission used as a means to access both community and long-term care

It is not just at times of a family crisis that constrained community services appear to affect acute hospital utilisation. The under-resourcing of community care means there are substantial waiting lists to access homecare packages. Consequently, carers described using acute hospital admissions as a means to access community care.

> *"You find yourself almost in a situation of not taking your elderly parent home from an acute hospital service because there is nothing there. So you have to bed block here, to wait for somebody to put a package in place…there is not joined up thinking."* (Family Carer 2).

Healthcare professionals echoed this not only in terms of accessing community care, but also LTC beds given the considerable length of time it can take to access LTC beds through the Nursing Home Support Scheme (reported to be between 6 and 18 months). Healthcare professionals described advising families to bring their loved-ones to an acute hospital to force them on the healthcare system to accelerate accessing these services.

> *"Quite often, I unfortunately would have to suggest to them that they go into hospital…They've a different budget…So it's easier to get a homecare package or, em, a nursing home placement through the hospital…you have to get the family to say "No I'm not taking them home until it's in" and that's, unfortunately, the way it is."* (HCP 8)

5. Pivotal influence of acute hospital admissions

The third major study finding suggests that there are multiple paths to LTC, presented in Fig 2. The first is what could be referred to as the 'ideal scenario'. That is, the person with dementia transitions from the community to LTC. This scenario is what is most often assumed when researchers analyse the care recipient factors that influence LTC admissions. However, healthcare professionals and carers reported that admission to LTC rarely happens this way. Rather, an admission to acute hospital care was regarded as pivotal, often acting as a catalyst to the LTC transition. Study participants suggested that the person with dementia may return home from acute hospital care, but are on the path to LTC as a result of the admission (Scenario 2, Fig 2). Alternatively, participants reported experiences where it may be impossible for the person with dementia to return home and so the transition happens from acute hospital care (Scenario 3, Fig 2).

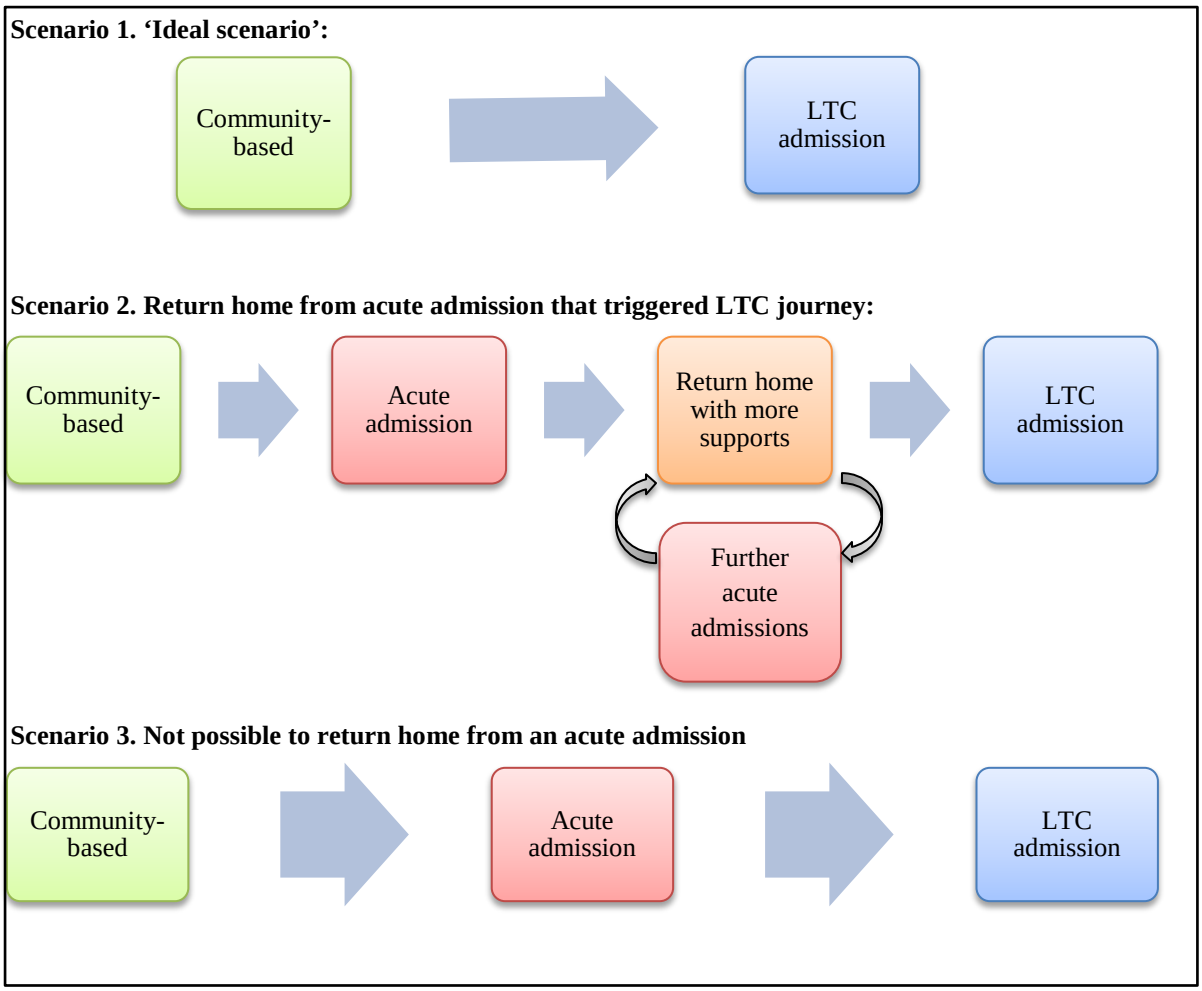

Fig 2. Multiple paths to LTC

There were two reasons an acute hospital admission was regarded as pivotal. Firstly, the participants reported that the baseline status of the person with dementia can drop in acute hospital care. Secondly, the decision to go to LTC appears to be taken out of the carer's hands.

5.1 Drop in baseline status

Participants spoke about how they perceived A&E and acute hospital wards to be inadequate for a person with dementia. The hospital is an unfamiliar environment, involving interactions with many different healthcare professionals. Consequently, people with dementia can become quite confused and distressed in acute hospital care. Healthcare professionals repeatedly emphasised how in their experience, an acute hospital admission can result in a drop in the functional and/or cognitive baseline status of the person with dementia. When this occurs it can accelerate the LTC journey.

5.2 LTC decision taken out of family carer's hands

Family carers have an immense commitment to the caregiving role. They experience feelings of guilt and grief at the thought of ending this role and handing over the care of their loved-one to a LTC facility. Consequently, carers appear to resist embarking on the LTC journey for as long as possible. The difficulty this family carer faced in starting the Nursing Home Support Scheme application form illustrates how coming to the decision that LTC is necessary is a complex and difficult process for family carers.

> *"I couldn't even look at that form. Sometimes I'd peep at it and I'd read one question and I'd shove it back into the envelope… you'd think it was hot coal I was putting my hand on because mentally I could not put him away."* (Family carer 1)

However, an acute hospital admission was reported to often drive the decision and take it out of the family carer's hands. This was regarded as being partly due to the reduction in the functional and/or cognitive baseline status of the person with dementia during the admission. It also appears to be as a result of the influence of healthcare professionals in acute hospital care. Family carer's repeatedly spoke about how they perceived healthcare professionals to have lead on the LTC decision.

> *"It was the hospital decided for me…I really, I knew the way he was in the hospital I couldn't take him home… It was just that he got so sick and my GP said to me "you can't take him home" and in the hospital they said you can't."* (Family carer 7)

Community-based professionals felt that while they may advise families to start planning for the future care of their loved-one, it is the validation of this advice by hospital-based professionals during an acute hospital admission that often triggers the LTC transition. Such professionals appear to play a huge role in supporting families in the decision. By taking the lead on the decision they can help remove some of the guilt family carer's experience in coming to the decision. They can also help the family carer to see that the need for LTC is not based on an inability on their part, but that the care needs of their loved-one exceed that which can be met by the carer in conjunction with the limited support of the community care system.

> *"The majority of families don't want long-term care….they feel that they've failed. And you try to explain that it's not a failure on their behalf, it's just the fact that, you know, we don't have the infrastructure to support them at home."* (HCP 17)

6. Discussion

6.1 Summary of findings

LTC admissions of people with dementia appear to be affected by inadequacies in the healthcare system. This was shown in participants' experiences of limitations in community care services. How such limitations in community care were seen to increase acute hospital

admissions and how admission of people with dementia to an acute hospital may accelerate the journey towards LTC for people with dementia.

The insufficiency and inequitability of community care services was seen in how constrained these services were for participants. Such constraints were apparent both in terms of staff and resources. These constraints undermined the extent that services were available. As others have noted, community services were under-funded and fragmented prior to the recession (30). However, this under-funding was considered to have been exacerbated as a consequence of the economic crisis.

Concurrently, the manner of service delivery appears to have resulted in great variation in the quality of services. This was most apparent for those families where the personal care assistants constantly changed. As the care assistants provide intimate personal care, when there's no continuity of care this was reported to result in very distressing situations. Such a service appears to be counter-productive to supporting families in homecare. Participants also described significant inequity in service availability. The combination of these aspects appears to limit the effectiveness of community care services for people with dementia.

The limitations in community care services were believed to have a knock-on effect on acute hospital admissions. Healthcare professionals reported that the under-resourcing of community care services means these services do not have the capacity to respond to families in crisis. In these circumstances, an acute hospital admission was regarded as the only option for families. Acute hospital admissions were also reported as a means to access both community and LTC. This is of concern considering acute hospital admissions appear to often act as a catalyst to the LTC journey.

Overall, the findings suggest that the factors influencing the admission of an older person with dementia into LTC are more multifactorial than the care recipient's needs or the family carer's ability to respond to these needs. Healthcare system factors appear to be critical. However, healthcare system factors have received little attention in the LTC literature when compared to the extensive literature on the influence of care recipient or family carer factors in the transition to LTC. The present study suggests that not taking into account healthcare system factors means that vital components of sustainable homecare are missed. As dementia is a progressive disease, the care needs of the older person escalate. To meet these care needs, family carers rely on the healthcare system. However, it would appear that, in Ireland, inadequacies within community and acute hospital services along with poor interconnection between the sectors limit the ability of the healthcare system to effectively support people with dementia and their families. The capacity of the healthcare system to provide this support appears to have been further diminished as a result of economic crisis.

6.2 Findings in the context of other research

The under-resourcing of community care services are not unique to Ireland. Studies across the OECD and more recently in Australia, Canada, the UK and other EU countries have also found community care services were limited due to resource constraints (35-39). A recent systematic review of LTC admissions in dementia found "in most countries resources available in the continuing care system are limited" (4 p.19). However, the economic crisis in Ireland appears to have aggravated this under-resourcing. Such constrained resources can be unfavourable for the care recipient and family carer. For example, Allen et al. found unmet need for services can have adverse outcomes for care recipients (40). The constraints in resources have also been found to disempower healthcare professionals (37, 41). It is thus

understandable that professionals in this study expressed such frustration at being prohibited in the degree of support they could offer families due to resource limitations.

The findings suggest that if community care services cannot adequately support families in the provision of homecare; this may have a substantial impact on the decision thresholds for admission to LTC. Indeed, Donnelly et al. found difficulties in community care services availability as a consequence of this under-resourcing meant "older persons were regularly obliged to go into LTC prematurely" (42 p.5). In tandem with this, Muramatsu et al. found state support for community care may prevent or delay nursing home admissions in families where caregiving resources are constrained. However, this analysis, along with similar analysis in the literature, focused on the transition from community to LTC without accounting for the impact of acute care in this transition.

The implications of community care on acute hospital care have recently been noted by a number of authors. A number of studies have highlighted lack of access to out of hours primary care or community nursing, making acute hospital care the only option for patients and families (43, 44). In this study we have widened the scope of analysis by demonstrating the 'vicious circle' between constrained community care services and increased accessing of the acute hospital sector, and also how acute hospital admissions can then accelerate LTC admissions of people with dementia.

A number of international studies have also found that the LTC decision is made at a time of crisis, which is often during an acute hospital admission (45, 46). However, this study provides further insight as to why it takes an acute hospital admission to drive the decision. The findings indicate that family carers resist transitioning to LTC for as long as is possible.

The reported deterioration of the cognitive and/or functional status of the person with dementia while in acute hospital care results in increased care needs. Following re-assessment of the needs of the person with dementia, healthcare professionals may recommend LTC to the family. Such advice from healthcare professionals was perceived by participants as critical to the decision. In many respects, healthcare professionals help to legitimise the decision for families (46, 47). This points to what Mamier et al. describe as the need for healthcare professionals to provide 'anticipatory guidance' to avoid crisis situations which make the LTC admission urgent (48).

6.3 Limitations

While this study included the voice of family carers and healthcare professionals, it did not include people with dementia. Inclusion of people with dementia was considered at the outset. However, as discussed above, the LTC decision is often forced as the care needs of the person with dementia have increased to the extent that they cannot be met by the family carer alone or with the support of the community care system. Thus, by the time the LTC decision has been made, the person with dementia has substantial cognitive and functional care needs. Therefore, it would not have been appropriate or ethical to have undertaken an in-depth interview with a person with dementia under such circumstances.

Another limitation may be the generalisability of the findings. However, mapping of dementia care services across European countries suggests the nature of care services for people with dementia in Ireland is similar to other EU countries (49). This analysis found availability and access to community care may vary between countries. Nonetheless, across European countries access and utilisation of care services for people with dementia was problematic (49). As discussed above, a recent systematic review of LTC admissions in

dementia found resources available for continuing care are limited in most countries (4). Others have also found budget allocation for dementia lags behind other chronic diseases in many countries (30). The economic crisis in Ireland appears to have intensified the under-resourcing of care services for people with dementia. Consequently the study demonstrates how critical these services are in LTC admissions of people with dementia.

7. Conclusions

Overall the findings suggest that the healthcare system is critical in the journey to LTC for people with dementia. This has implications for health policy makers and health services researchers. Firstly, in term of health policy, the apparent fragmentation and under-resourcing of community care services conflicts with Government Policy to support older people to remain at home for as long as possible and has a substantial impact on acute hospital admissions and LTC admissions of people with dementia.

It would be constructive to see if there are options for lesson-learning on community care approaches from other jurisdictions that could be transferred to the Irish context. For example, the 'Partnerships for Older People Projects' (POPPs) in the UK aims to alter the focus of resource utilisation from LTC and acute hospital care settings to community settings. These projects provide person-centred integrated care to promote health and well-being in older people. Review of the POPPs programme indicates that for every £1 spent on POPPs an average of £0.73 is saved per month on the cost of hospital bed days (50). Another example of an opportunity for lesson-learning can be found in the Netherlands where older people have an option for personal budgets. This means older people then have a choice to decide from whom they would like to purchase their care. This could give greater consistency in the care assistants that provide support with homecare (51). Increasing the supply of emergency

respite beds could also support families that are experiencing a crisis in the provision of homecare and mitigate utilisation of acute hospital admissions due to the lack of care options for families.

Finally, it is critical for health services researchers to recognise that analysing care recipient factors or family carer factors on LTC admissions, in the absence of healthcare system factors, means we are missing critical components to sustainable homecare. We cannot fully understand the factors which predict LTC admissions of people with dementia without accounting for healthcare system factors on homecare.

Conflict of interest

The authors declare that there is no conflict of interest

Funding

This work was funded by the Health Research Board (HRB) in Ireland under Grant No. PHD/2007/16. The funder had no role in the study design, data collection, analysis, interpretation, write-up of the data or the decision to submit the article for publication.

Acknowledgements

The authors are grateful to all the individual who participated in the study as well as those who assisted with recruitment, particularly the Institute of Community Health Nursing, Care Alliance Ireland and Family Carers Ireland.

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