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"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 to 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" ([13] p.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 = 0.05, 95% CI 0.04–0.07) ([14] p.12). The results of this review suggest the

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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.

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

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