



Northern Ireland
Assembly



Queen's University
Belfast



The Open University



University of
ULSTER

Knowledge Exchange Seminar Series (KESS)

Policy Briefing

A time of transition: family caregiving, older people and long-term care.

Dr Assumpta Ryan

Reader

School of Nursing and Institute of Nursing Research

University of Ulster

Cromore Road

Coleraine

BT52 1SA

Phone 028 70124256 (Direct Line)

028 70124094 (Research Secretary)

E mail aa.ryan@ulster.ac.uk

A time of transition: family caregiving, older people and long-term care.

Introduction

Northern Ireland has experienced a transition to an older population profile over the last century and this reflects a world-wide demographic trend. An ageing population raises questions about the future provision of health and social care with a particular focus on reducing morbidity and improving the quality of life and functional independence of older people. Clearly, there is a challenge in identifying what type of care provision will be necessary to respond to these demographic changes. Of equal significance are questions pertaining to who will provide the care required and moreover where this care will be provided. The changing philosophy surrounding the provision of health and social care across Europe has resulted in a shift in policy from institutional to community based care. This shift lies at the heart of the 'Transforming Your Care' policy in Northern Ireland.

Family caregiving

While there is strong evidence to suggest that older people wish to remain in their own homes, it is important to acknowledge the needs of family carers who support older relatives to stay at home and age in place. Caring involves many sacrifices; physical, psychological, financial and social. It is exhausting, frustrating, expensive and isolating. The positive aspects of caring clearly exist but accounts of carer satisfaction are overshadowed by strong evidence of caregiver strain and burden. Decreased functional abilities of the care receiver, interrupted sleep of the caregiver and the presence of multiple stressors within the caregiving situation have been positively correlated with caregiver burden. However, factors outside the caring relationship have also been identified including a lack of flexibility in community support services (McCann et al, 2005), pressure to release hospital beds (Davies & Nolan, 2004) and inadequate or inappropriate respite services (Ryan *et al*, 2009). In the end, home care becomes unsustainable, particularly for those caring for a relative with dementia, and admission to a nursing home is the only option. However, the end of family caregiving is usually a fairly gradual process and the final decision is often precipitated by some sort of crisis either on the part of the older person or the carer. This, coupled with shorter lengths of hospital stay means that there is often little time for identifying a suitable home or establishing relationships with nursing home staff. As a result, instead of receiving support during this difficult period, families find themselves 'working in the dark' (Davies & Nolan, 2003) and the

need for healthcare professionals to support families in the decision-making process has become a recurrent theme in the literature on entry to care (Ryan & McKenna, 2013a).

Entry to a nursing home.

Moving into a nursing home is a major decision, probably one of the most difficult and stressful decisions a person is likely to have to make. The social stigma attached to residential care placement has been identified in the literature as a factor influencing decisions about entry to long-term care (McCann *et al*, 2005). For example, in Northern Ireland, Heenan (2000) conducted in-depth interviews with farming wives responsible for the care of older relatives and concluded that residential care was heavily stigmatised and that there was an unquestioned, intrinsic assumption that care would take place entirely within the family. Considering the reports of neglect or abuse in care homes in the media, it is easy to understand why families have concerns about their relatives' welfare. Finding a legitimate reason for having placed a relative, a reason sanctioned by professional carers, has been identified as a strategy which some family carers adopt in trying to accommodate change during the transition and early post-placement phase (Ryan *et al* 2011). Others have suggested that negative perceptions about care homes may be related to the promotion of community care and the literature advocating the superiority of home care over residential care (Davies & Nolan, 2003).

Despite the volume of literature on the experience of entry to long-term care, few studies have investigated the factors influencing the choice of home. There is a general consensus in the literature that information about long-term care facilities is extremely limited and often reduced to a list of homes, further compounding the stress experienced by relatives (McGarry & Arthur, 2001). This was supported in research by Davies & Nolan (2003) which concluded that family carers were largely unprepared for the realities of nursing home life and that health and social care practitioners had enormous potential to influence relatives' experiences of entry to nursing home care.

Knowledge Exchange Seminar Series (KESS)

Impact of the placement

There is a general consensus in the literature that admission to a nursing home is a stressful experience for older people and their relatives. Research findings indicate that, for relatives, the experience is associated with conflicting emotions such as guilt, anger, sadness, and relief and in the case of spouses a strong sense of loss and separation (Davies & Nolan, 2006; Ryan & McKenna, 2013b). Therefore, although the physical burden of caring is relieved following nursing home placement, the emotional turmoil often continues and is exacerbated by the circumstances surrounding the decision to end home care. In an attempt to cope with this and to maintain contact with their relatives, many carers wish to remain involved in some aspects of their relative's care. However, communicating this request to nursing home staff is problematic and as a result there is a degree of misunderstanding about each other's role. Furthermore, in failing to recognise the actual and potential contribution of families, nursing homes run the risk of alienating the very people who need a sense of belonging and attachment to the nursing home community.

In Northern Ireland, Ryan & McKenna (2013a) interviewed 29 rural dwelling family carers and concluded that having a sense of familiarity with the nursing home staff, residents and history was a key factor influencing rural family carers' experience of the nursing home placement of an older relative. Most of the respondents were drawn from family owned homes and the owners lived within the same community as residents, relatives and staff. Perhaps because of this, these homes appeared to be perceived as extensions of the community, a sub-culture within a culture. The findings of this study emphasise the importance of familiarity, continuity, stability and social capital in the lives of older people.

The role of families in nursing homes.

Perhaps because of the emotional turmoil associated with the placement or because carers find it difficult to fill the gap left by their relative, many, particularly spouses, wish to continue their caring role after admission to a nursing home. The value of maintaining family relationships following the move to a nursing home, both for resident and relative has been well documented (Bauer 2006, Brown-Wilson, 2009). Various studies have recommended the need for change in the relationship between care home staff and relatives. These include clarifying the roles and responsibilities of groups (Brown-Wilson 2009, Lee 2010), valuing and accessing carer knowledge

Knowledge Exchange Seminar Series (KESS)

and biographical expertise (Robinson *et al* 2010) and helping carers to perceive the transition in a more positive light (Davies & Nolan 2004; Ryan *et al* 2011). However, Williams *et al* (2012) argued that antagonistic relationship can develop between staff and relatives as the former seek to take over care and the latter to develop new roles. Other studies suggested that nursing home placement provides a new set of challenges for family carers such as, how much help to provide, how to initiate relationships with staff, how to negotiate boundaries, how to sustain their relationship with their relative and how to redefine their own identity and role (McCormack & McCance 2006).

Based on interviews with 48 people who had assisted a close relative to move into a nursing home, Davies & Nolan (2006) described three discrete roles for families in care homes. These were: 'maintaining continuity' through the continuation of loving family relationships and by helping staff to get to know the residents as an individual; 'keeping an eye' by monitoring and participating in care provision within the home; and 'contributing to community' by interacting with other residents, relatives and staff and providing a link with the outside world. However, it is important to note that even though there is strong evidence to suggest that family involvement positively affects the care of residents and the emotional health of residents and family members (Robison *et al*, 2007), others (Andershed 2006) caution that staff need to be sensitive in determining why, how and how much families want to be involved. Whether they are providing care to residents because of a personal desire to do so or based on their perceptions of the quality of care in the nursing home are key issues in terms of their emotional and physical health outcomes (Williams *et al*, 2012).

Older people in care homes are a vulnerable population group with limitations to their physical and mental functioning resulting in the need for nursing care. The extent to which their nursing care needs are met is an important quality indicator from the perspective of families. Respecting the older person's former routine and lifestyle, responding to food preferences and paying attention to the clothing and physical appearance of their relatives have been identified by families as examples of the 'little things' that are important indicators of the quality of care provided in nursing homes (Ryan & McKenna, 2013b).

Knowledge Exchange Seminar Series (KESS)

Implication for policy and practice

The population of the world is ageing and this poses major challenges to health and social care systems and to families. When a caregiving situation arises, family members provide most of the support, yet frequently find that they are unprepared for their new roles as caregivers and decision-makers. A lack of knowledge and skills can be a significant factor in increasing caregiver stress and information and support tailored to meet the needs of the individual can have a powerful influence on caregivers' self-efficacy and confidence.

The early literature on family caregiving identified the typical family carer as middle aged and female. Today, changes in family size and structure, the impact of divorce, technological advances, an increasingly migrant population and the changing role of women in society has influenced recent literature in this field. This is evidenced by a shift in focus to male caregiving (McDonnell & Ryan 2011,2013), caregiving for older people with intellectual disabilities (Taggart *et al* 2012) and the use of technology in supporting older people and their families (Delaney *et al* 2010). This 'new' population of ageing family carers will pose a major challenge to health and social care providers and intellectual disability services. However, this challenge can be effectively met by future planning and by the allocation of appropriate resources to meet the needs of this growing population.

'Ageing in place' is a broad term for a concept, which recognises the deep attachments that older people have to their homes. Home, for many older people, is a powerful symbol of autonomy and independence whereas institutions are associated symbolically with the loss of autonomy and independence (Andrews *et al*, 2005). Across Europe and Northern Ireland, current policy is to support older people to live independently in their own homes for as long as possible. A key strength of this policy lies in its recognition of the importance that many older people attach to their homes and communities and the centrality of 'ageing in place' in the lives of these people. Critics may refute this in their argument that care *in* the community is a contrived policy designed to maximise care *by* the community. While this argument has some support as evidenced by the plethora of studies on family caregiving, it is important that obvious flaws are considered in the context of a policy, which continues to respect the wishes of many older people who want to stay at home.

Knowledge Exchange Seminar Series (KESS)

At a policy level, the literature raises questions about the geographical distribution of care homes. The proportion of older people in local populations is higher in rural areas than in urban areas in most countries in the world (Wenger, 2001). Policy makers need to think more carefully about the social consequences of the locations of care homes and the impact of their location on older people and their families. A need for a rural model of health and social care services is required. Recognising this and the importance of ageing in place, it is recommended that care homes, albeit smaller in size, are located in these rural communities and that this social policy stance is reflected in government agendas. Therefore, rather than clustering homes in certain areas, a wider distribution would facilitate people to maintain their community connections and to 'age in place'. Over the past decade, the provision of care to people with learning disabilities or mental health problems has been characterised by a shift from large scale institutional care to smaller, locally based accommodation units. Consideration should be given to a similar model of care provision for older people.

Accepting the sensitivities associated with families addressing the issue of long-term care, it appears that health and social care professionals have a key role to play in this regard. As objective professionals, they are ideally placed to initiate discussions with the older person without fear of reprisal. Such discussion should not be deferred until the older person becomes ill but rather comprise part of the annual health checks undertaken by GPs, district nurses or health visitors. Equally the assessment of older people in acute care settings could also address these issues as an integral part of the assessment process. Questions such as 'Where would you choose to live if you were no longer able to manage on your own?' could be used to 'sow the seed' about long-term care arrangements.

Admission to a nursing home is a sad and regrettable experience for most older people and families require information and support from health and social care professionals. Families need time to consider all their options and health and social care professionals need to recognise the importance of familiarity, among other things, when assisting with the selection of a care home. Quality of care should be less about the physical environment and more about the extent to which older people actually feel 'at home' as evidenced by the provision of person-centred care in nursing home settings. Although older residents have psychological and social needs, these often remain unmet as a result of a preoccupation with the physical aspects of care or the failure

Knowledge Exchange Seminar Series (KESS)

of staff to understand the significance of the 'little things' from the perspective of the resident and relative. This suggests that care home staff would benefit from educational opportunities designed to facilitate a greater emphasis on ways of making residents and their families feel 'at home'. For their part, nursing home owners need to recognise the importance of investing in the education of their staff as many have a weak track record in this area.

Many families wish to continue providing care to their relatives after the placement and nursing home staff need to recognise this in order to provide them with a sense of belonging and attachment to the nursing home community. Developing caring partnerships is crucial if the resources of care home staff and families are to be maximised for the benefit of residents. However, this is unlikely to occur unless both parties recognise each other's unique contribution to the care of the older person and work in partnership to maximise this. Care home staff need to be aware of the factors influencing the decision about entry to care and be sensitive to the range of feelings and emotions associated with this transition. Families have biographical expertise, which they should be encouraged to share with staff with the aim of providing high quality holistic care to residents. Care home staff have technical expertise and a wide range of experience caring for older people and this can be shared with families to enable them to make a more complete contribution to the care of their older relative.

Clearly, good communication must underpin any staff/family relationship. Good quality care is best delivered by care home staff who have gained a deep understanding of the resident and a good working relationship with the family. For family carers to play as full a role as possible, they need to be involved in the assessment, planning, implementation and evaluation of care. They need encouragement and information to continue their participation in care. 'Time' for the resident and the family is the most important contribution that care home staff can make in building and maintaining a caring relationship. This time can be used to discuss problems, thoughts and feelings and to provide stimulating activities for the resident. However, the availability of more time has major implications for staffing levels. Relatives require patience and understanding from staff in nursing homes. Their actual and potential contribution should be recognised and valued. However, carers also need to demonstrate sensitivity to staff difficulties and concerns. Improved communication and sharing of information between family carers and staff has the potential for an improved working relationship that can only prove beneficial to all concerned.

Knowledge Exchange Seminar Series (KESS)

References

- Andershed, B (2006) Relatives in end of life care-part 1: A systematic review of the literature the five last years, January 1999-February 2004. *Journal of Clinical Nursing*, 15, 1158-1169
- Andrews, G. J., Holmes, D., Poland, B., Lehoux, P., Miller, K. L., Pringle, D. and McGilton, K. S. (2005) 'Airplanes are flying nursing homes': geographies in the concepts and locales of gerontological nursing practice. *International Journal of Older People Nursing* 14(8b): 109-120
- Bauer, M (2006) Collaboration and control: nurses' constructions of the role of family in nursing home care. *Journal of Advanced Nursing*. 54(1), 45-52.
- Brown-Wilson, C. & Davies, S (2009) Developing relationships in long-term care environments: the contribution of staff. *Journal of Clinical Nursing*, 18(12), 1746-1755.
- Davies, S. and Nolan, M. (2003) 'Making the best of things': relatives' experiences of decisions about care home entry. *Ageing and Society* 23: 429-450.
- Davies, S. and Nolan, M. (2004) 'Making the move': relatives' experiences of the transition to a care home. *Health and Social Care in the Community* 12(6): 517-526.
- Davies, S. and Nolan, M. (2006) 'Making it better': Self-perceived roles of family caregivers of older people living in care homes: A qualitative study. *International Journal of Nursing Studies* 43: 281-291.
- Delaney S, Ryan A, Barron B, Ferguson H & Truesdale-Kennedy M (2010). *Assessing Telecare for Carers of Older People: A Research Network*. Dublin: Work Research Centre.
- Heenan, D. (2000) Expectations and attitudes affecting patterns of informal care in farming families in Northern Ireland. *Ageing and Society* 20: 203-216.
- Lee, G.E (2010) Predictors of adjustment to nursing home life of elderly residents: A cross – sectional study. *International Journal of Nursing Studies*, 47(8), 957-964.
- Mc Cann, S. Ryan, AA & Mc Kenna, HP (2005). The challenges associated with providing community care for people with complex needs in rural areas: a qualitative investigation. *Health and Social Care in the Community*. 13(5)462-469
- Mc Cormack, B. & McCance, T (2006) development of a framework for person-centred nursing. *Journal of Advanced Nursing*, 56(5), 472-479.

Knowledge Exchange Seminar Series (KESS)

McDonnell E & Ryan A. (2011) Male caregiving in dementia: A review and commentary. *Dementia: The International Journal of Social Research and Practice*, 12 (2), 284-250

McDonnell E. & Ryan, A (2013) The experience of sons caring for a parent with dementia. *Dementia* published online 16 April 2013. DOI: 10.1177/1471301213485374

McGarry J & Arthur A (2001) Informal caring in later life: a qualitative study of the experiences of older carers. *Journal of Advanced Nursing* 2001, **33**(2): 182-189.

Robinson, C.A., Reid, R. C. & Cooke, H.A. (2010) A home away from home: the meaning of home according to families of residents with dementia. *Dementia*, 9(4), 490-508.

Robison, J., Curry, L., Gruman, C., Porter, M., Henderson, C.R., Jr., & Pillemer, K (2007) Partners in caregiving in a special care environment: Cooperative communication between staff and families on dementia units. *The Gerontologist*, 47, 504-515.

Ryan , A & McKenna, H. (2013a) Familiarity as a key factor influencing rural family carers experience of the nursing home placement of an older relative: a qualitative study. *BMC Health Services Research*, 13:252. DOI: 10.1186/1472-6963-13-252

Ryan, A & McKenna, H (2013b) "It's the little things that count". Families experience of roles, relationships and quality of care in nursing homes. *International Journal of Older People Nursing* (in press)

Ryan AA, Mc Cann, S & McKenna H (2009) Users' perspectives on the impact of community care in enabling older people with complex needs to remain at home. *International Journal of Older People Nursing*, 4, 22-32.

Ryan AA, Mc Kenna HP and Slevin, O. (2011) Family caregiving and decisions about entry to care: a rural perspective. *Ageing and Society* 32, 1, 1-18.

Taggart, L, Truesdale-Kennedy, M, Ryan, A & McConkey, R (2012) Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, 16 (3), 217-234

Wenger, C. G. (2001) Myths and realities of ageing in rural Britain. *Ageing and Society* 21: 117-130.

Williams, S.W., Zimmerman, S & Williams, C.S (2012) Family caregiver involvement for long-term care residents at end of life. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 67 (5), 595-604.