



## Knowledge Exchange Seminar Series (KESS)

*...is a forum that encourages debate on a wide range of research findings, with the overall aim of promoting evidence-based policy and law-making within Northern Ireland*



# A Time of Transition:

## Family caregiving, older people and long-term care

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# Researcher Background

Research interest in community care, family caregiving and long-term care.

Presentation brings together the main findings from 20 research studies carried out across the Island of Ireland including an EU funded study. Quotations from NI research participants.

Policy implications

Publications >80. Conference presentations > 60



# What is a carer?

Carers are people who, without payment, provide help and support to a family member or a friend who may not be able to manage without this help because of frailty, illness or disability (DHSSPS, 2013)

214,000 family carers in Northern Ireland saving the NI economy over £4.4 billion year



# Why the focus on family caregiving and entry to long-term care?

Demographic trends-changes in family size and structure

Prevalence of long-term conditions

Older people want to stay at home and ‘age in place’

Family support is necessary for this to happen



# Physical Impact

“I did it all myself. I knew that he wouldn't want anyone else. It was me he wanted. He didn't know it but it was me” (wife)

“He can be very aggressive.....that's very hard” (daughter)

“When it's time to get up, I'm exhausted. I've only been asleep for about an hour but I have to get up...no choice” (wife)

“I would get up in the morning and she would be soiled and she would have to have a shower. I would be sick after it” (son)

# Psychological Impact

“Kyle (son) would say that I wasn’t there for him. I have really neglected him in the years that I shouldn’t have...those teenage years. I just wasn’t there for him” (daughter)

“Things are really bad now because he doesn’t know me, It is the toughest things...me there 24 hours a day, no sleep and he doesn’t even know me” (wife)

“I look back and see how I have neglected my own family over the years. It doesn’t help me looking back. Help was needed and there was nobody else to provide it. You were left in the middle trying to balance everything. It has its effects” (daughter )



# Social Impact

“You just feel abandoned....you feel that there is nobody out there”  
(daughter)

“I find that the worst days are the days that I can't get out” (husband)

“I don't do lots of things that I used to do. I don't say I miss them. I miss the ability to do them more than I actually miss them” (daughter)



# Living with risk

“Your fear for years is that you would go in some morning and find her dead but you know that she would not have wanted to move out of her home” (daughter)

“She had candles lit all around the house and near the curtains in the hall. God knows what would have happened if I hadn’t walked in!” (son)

“ She does potter about. She has fallen but she is more content with a bit of freedom. You have to come to some happy medium” (son)





# Needs of Family Caregivers

## Information

“I think that one of the biggest thing is the lack of information....sometimes you feel that they are putting you round in circles” (wife)

“I think that it is important to know what you are dealing with. There are decision to be made and if you don't have the right information, you can't make the decisions” (son)

## Support

“The nurse came to me on Monday morning and said that I had to send him back to the home. She said that I was going to keep going until I took a heart attack” (wife)

“They kept cutting the home help hours and I couldn't manage” (son)

# Views on Respite

- Not a consideration
- A life line that enables families to continue caring role
- Unsuitable/stigma

“Not as long as there is breath left in me to cope, I would just be happy carrying on they way we are going... I feel as if I am in control. If he was put into respite, that he would not just get the same care ” (daughter)

“I certainly appreciate it, it gives me a chance to clear my head, sit down and maybe read the paper” (wife)

“I just want a holiday...I don't want to go anywhere or do anything...I just want a holiday in my own home” (daughter)

“She never settled in that whole fortnight...it was just awful” (daughter)



# Factors influencing the transition to long-term care

**Increasing dependency of the older person** -  
deterioration in condition, wandering, aggression,  
incontinence, need for 24 hour care, degree of risk

**Reduction in the carers ability to cope**  
- evidenced by exhaustion, carer illness, family illness,  
conflicting roles.

# Thoughts and feelings

- “You feel so guilty that you were inadequate as a daughter or as a child of a parent who has to go into a nursing home...the guilt is terrible and it doesn't get any easier as time goes by” (daughter)
- “John used to come home and cry. For the first couple of weeks that she was in there, he used to wonder if he had done the right thing. As time went on, he says he realised we have” (daughter in law)
- “Every time the phone rang at night, you fear the worst....it has been a tremendous relief” (daughter)
- “I just contented myself that I wasn't fit to look after him. He needs nursing care. It's not home care.....it is nursing care that he needs now” (wife)

# Thoughts and feelings

“We were sad that it had come to this...that she was never going to go back to her flat. We had to clear her flat out then and that was a very sad part of it. It was almost as if she was dead and we were clearing out her flat and yet she wasn't”  
(daughter)

“I am both a wife and a widow”

*Married widowhood* (Rollins et al, 1985)

# Post placement adjustment

Four stages (Woods et al, 2008)

- Guilt and loss
- The building of trust
- Increasing confidence in negotiating with staff
- Spouses begin to build their lives around their relative's care and adult children start to develop other areas of their lives

# The role of families in nursing homes

- Maintaining contact with the older person
- Maintaining contact with the community
- Advocate
- Involvement in relatives care
- Blurring of boundaries

# Easing the transition

- An inherently difficult experience for older people and their families
- Provision of support to families and quality care to residents
- Importance of ‘the little things’ and respecting lifetime routines
- Communication and information.
- Sharing expertise and working as partners in care (resident, relative and care home staff)



# Policy Implications

Ageing in place

Recognition, information and support for carers.

In NI, only 44% of older carers have their needs assessed compared to 89% of older carers in England. Why?

Older people with intellectual disabilities and their carers...a mutually dependent relationship

Rurality, familiarity and social capital

Advocacy role of health and social care practitioners during transition

Partnership working and sharing expertise in nursing homes

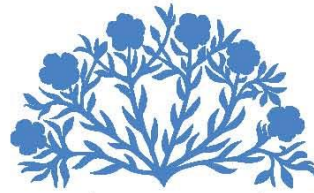


**Never lose sight of the fact that old age needs so little.....but needs that little so much!**

*A word of caution*

**Services should not support caregivers beyond the point at which their own health suffers**





Northern Ireland  
Assembly



The Open University



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