



# The lived experience of informal carers of older adults living in the community

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# Overview

- Motivations for the study
- Background: literature review
- Introducing the study
- Key findings
- Discussion
- Recommendations and implications for practice



## Motivations for the study

- Area of practice
- Assessment of the older adult
- Recognise the role of carers
- Recognise the needs of carers
- Avoid crisis



## Background: literature review

➤ 24 studies: 3 Quantitative, 2 mixed quantitative and qualitative, 19 qualitative of which 10 were Hermeneutic design

➤ Included seminal studies from

Ireland - O Connor & Ruddle 1988, Lane 2000

Europe – Mesthenos & Triantafillou 2003

Lebanon - Seoud et al 2007



Contd/.

- Prevalence of informal caregiving in Ireland  
2006 census – 160,917 documented unpaid carers
- Identified home care by informal carers as a global phenomenon with studies from Ireland, United Kingdom, Europe, America, Australia & Lebanon



Contd/.

All studies recognised varying levels of:

- Carer strain,
- Physical and Emotional burden,
- Sense of loss – time, relationship,
- Inability to cope
- Loneliness



Contd/.

- Need for social supports
- Need for increased awareness of available supports
- Understanding of need to accept supports offered
- Need for education on caring role
- Need for recognition of their value as carers by health care professionals
- Need for caregiver assessment



## Introducing the study

Research question:

What is the experience of informal carers caring for an older adult living in the community?



# Research aims and objectives

## Aim:

- To explore the experience of informal carers who care for and maintain older adults at home.

## Objectives:

- To identify who is caring for older adults at home
- To identify what is the age profile of carers
- To identify what is the health status of carers
- To ascertain how the journey of care can become more pleasing for the carer and the older adult.



## Research Design and methodology

- The research approach is qualitative and is aimed at uncovering and gathering in depth knowledge about how people feel about the circumstances they are in.
- The research method of choice is phenomenology from a Heideggerian hermeneutic approach which will provide an increased understanding of the meaning of the experiences of informal carers and what it is really like for them by allowing the researcher bring previous experience gained in this area to the study.



# Population

- Informal carers of older adults
- Purposively selected from carers of clients attending an outpatient service where the researcher works with at least 6 months experience of caring – need to have experienced the phenomena under study to participate
- Sample size of 6 participants



## Data collection

- Unstructured interviews – 2 – 3 guided questions to start
- Recorded – ensures accuracy and nothing is missed
- Note taking – captures body language, reactions and emotions
- Interviews transcribed – given to participant to verify



# Data analysis

Morse's Framework: four stages

- Comprehending – become familiar with carers experience
- Synthesising – identify commonalities, immersed in data
- Theorizing – Identify links between data and theory
- Recontextualising – development of the emerging theory that is generalized into different settings that supports the literature or claim new contributions



# Profile of participants

	Age of carer	relationship to the older adult cared for	living with the person you are caring for	How is your own health	How old is the person you are caring for
Participant A	56	Daughter	Yes	Good	78
Participant B	52	Daughter	No	Good	92
Participant C	77	Sister	No	Poor	87
Participant D	58	Daughter	No	Good	83
Participant E	70	Daughter	No	Good	93
Participant F	80	Wife	Yes	Good	84



## Key findings: presented under four themes

Time is not your own

Wouldn't have it any other way

Being the one

Support networks



# Time is not your own

*“You are tied down. So much, yeah it is just seven days, its not, you have no day off....it is very frustrating” Participant B*

*“it ties you down completely, apart from being there, it can be mentally...it can be tough, you are just not free to go anywhere” Participant E*

## Tied down

*“I do not mind looking after her she is not a problem. I suppose the usual that you are tied....like having a child in the house” Participant A*

*“...you cannot make any arrangements you would often say now I will do this this weekend and you get a phone call to say there is no one here for Saturday.. It is a big roundabout.” Participant D*



## Time is not your own

*“I got up in the morning at eight o'clock like, I used to leave it till nine, but now I find that she is up sitting waiting in the bed, waiting on me”, “she is always waiting no matter what”*

*Participant B*

*“it is such a worry for me. Half eight I said to her will you go to bed now you would be safer in bed: no not going to bed it is too early. So I said ok. So it was twenty to eleven I got her to bed and then I got to go home.”*

*Participant C*

## Time consuming

*“I am there from ten a.m. till one until her home help comes in until half two, I then go back down until 5pm, it's a long time. The hour and a half goes so quickly, just to have my lunch in my own home or do the shopping. The time is gone” I go back down at night to see her into bed sometimes she says „where were you coming down for or why do you come down at all „I found that a bit hard. “ Participant E*



# Time is not your own

*“life evolves around my mam, that is what it is. Everything, everyday revolves around my mam. I have a sister who comes up once a month on a Friday till a Sunday. And I have to say there is so much relief there, it is the only time I know I will not get a call to say there is no one to cover.” Participant D*

**No me time!**

*“My brother wanted to bring her out for a weekend but she would not go but eventually she went for a day. When she came back I went up to settle her to bed and she said „ why did you not come out for me? I was there for far too long sure they are far too busy where were you?” Participant B*



## Time is not your own

*“even to have lunch at home or do some shopping” Participant E*

### No time for own family

*“I feel I should be able to leave my own house without having to answer to her, where I am or time wise....it is the biggest problem day or night that is very tough....” Participant E*

*“it can be frustrating and she tends not to let my sister do anything for her, you know, there is rows you know to change her pads in the evening..... I have to come back and do it and it is just very frustrating.”*

*Participant B*

**Time is a huge factor in caring for an older adult, time to self, time to care and time for family.**



## Wouldn't have it any other way

*"she is my mam. She is the main person that I am looking at and that is the way I would look at it. Even though it would impact on me. I would still go up because she is my mam."*

*Participant D*

*like I would have a job other than, like always looking after her, oh god I would of course. Definitely"* Participant B

## Duty of care to mother

*"it can be tough at times, you are just not free to go any where but at the same time there is nothing you would not do any other, you know what I mean, you would not have it otherwise."*

*Participant E*



# Wouldn't have it any other way

*"..he is difficult, he is difficult. No doubt what can I do". "What can I do, I just keep going."*

*Participant F*

## Duty of care to husband/sister

*"And the last month has been horrendous absolutely horrendous. Then I kept saying „am I selfish?“ and my doctor said to me you are too old to be taking on all that, he said you do not need it. I said well I know, but what can I do?." Participant C*



## Wouldn't have it any other way

*"I do it for me. You know when I go up even though I am going up for my mam I said I am doing it for me. Where the others do not feel they have to do it, I suppose for themselves"*  
Participant D

*"I think in the future I will never regret it, you know, I wouldn't see her any other way."* Participant B

## Need to do it

*"I do not mind looking after her she is not a problem."* Participant A



## Wouldn't have it any other way

*“she never had any family so there was nobody else , I think her husband might be about 10 years gone, I was concerned for her with the arm.” Participant C*

## Who else would do it

*“I resented the fact I had to do things for her, the more I had to do the more I was resenting having to do it because I was not able.... And there was never any words of thanks.” Participant C*



## Wouldn't have it any other way

*"As long as I am able to look after her, that is the main thing, it would not matter what it would be, that would not bother me at all"... I will organize things differently." Participant E*

Will do it for as long as....

*"I get very tired, I am tired I think now I will start saying stop talking to me, walk out"  
"When he gets annoyed with me, sometimes to get very very bad. I just walk away"  
Participant F*



## Being the one

*“she tends not to let my sister do anything for her.”*

*“she gets upset so you cannot, say too much, it is part of the problem”*

*Participant B*

*“three years now.... The last year she really went down... I mean at a terrible rate the way she has gone down and then when she started to get a bit confused. It is really hard, really hard.” Participant D*

*“you are expected..... go down at night, might be half nine or ten and you get where were you and then for that again she might say what are coming down for or why do you want to come down at all. I find that a bit hard.” Participant E*

**Main carer**



## Being the one

*“I like going up and looking after her, the time I am with her I am washing her, dressing her, feeding her, washing her clothes, making sure everything is adequate.”*

*it bothers me sometimes that I cannot sit down and spend quality time with her.”*

*Participant D*

## Loss of relationship

The stress of caring for a sister by participant C is changing their relationship as all the time she is with her sister, her sister is giving out to her and pushing her away, refusing to eat, refusing to take her tablets and saying; *I will not forgive you for this, you are making me take these*

The only time participant E went to her mothers, was to provide care. She too found care giving frustrating and the lack of mother daughter relationship



## Being the one

*“I wasn’t able to with my own health. I felt so guilty because I wasn’t doing more, I really wasn’t able to do more.” Participant C*

*“I have two, three stents and I need another one, I’ve cataracts done And waiting for another angiogram “  
Participant C*

## Health status

Each participant expressed feelings of stress, frustration, tiring, exhausting, upsetting, worrying, headache which can be detrimental to health over a period of time.

*“and I just keep working doing things in the house, exhausting, I walk away, and I walk into another room or go upstairs. But it still leaves me with a headache... but with difficulty.” Participant F*



# Support Networks

*“when she’d be dressing the leg, she got a little sore, it wasn’t bad but the nurse came in maybe two days, then I did it, when she had cellulites’ and then you’d wonder where you doing it right or not, a bit frustrating”*

*Participant B*

## External Supports

*“our district nurses, they are very good, when needed, they are good. I only need to call them and they come. Like she has an ulcer at the moment and she comes three times a week, the nurse, they are excellent.”* Participant E

*“we had a Public Health Nurse coming in for seven years once a week for the leg ulcer but didn’t find them any support because.....they are too busy as I felt you couldn’t call on them”* Participant A

*“Our clinic is just up the road....I would avail of a nurse coming in to have a chat with him”*  
Participant F



# Support Networks

*“I got to go to mass every night in lent because my son would be there, I found that absolutely great to go out, to walk to the church, just talk to myself and walk back. Thank God, you know” Participant F*

*well I have sisters but they are married they would come in but its not easy either for them you know I mean some of them have young kids. I would not really expect it” Participant A*

## Family supports

*“sister came to visit and we asked her to do things and she said yea I’ll come up on Tuesday and then she doesn’t come up on Tuesday” Participant D*

*“my two sisters very good support, they are always there if I need them for longer times. For holidays one of my sisters comes when I’m going away which is great” Participant E*



# Discussion of findings

## Constraints of caring

Stoltz et al (2004) likens no time due to caring to a lack of freedom, no life anymore resulting in social isolation. Participant F referred to this and feelings of her life being over yet being still alive.

Cheung (2004) alluded to the time consuming nature of caring to that of a feeling of being trapped, for carers in the study this rang through in statements like;

“go up morning, afternoon and again in the evening”

“time is not your own”    “days are restricted”    “give up things – no time to do them.”



Cheung (2004) refers to carers as providing care, attention, supervision and surveillance for up to twenty four hours a day with no break at times. This for anybody would be unsustainable and given the age profile of carers being of similar age to the person they are caring for would be more difficult. Participant F is similar age to her husband and the researcher would identify her role as being all of the above due to her husband having Alzheimer's disease.

Stoltz et al (2004) referred to carers keeping themselves busy doing tasks to keep their mind off the caring situation. Participant F refers to going from room to room keeping busy in order to avoid confrontation.

*“What I find during, we might be just having a meal and he grinds his hands together and he walks with so much tension. And screams, And its so worrying, its so upsetting. I just walk out. I walk away, And I walk out into another room or go upstairs But it still leaves me with a headache. But with difficulty “*



Vellone et al (2002) highlighted that carers had no time to themselves which again was a sub theme in this study recognised as “no me time”.

Schur et al (2005 ) alluded to the need for carers to have “me time” in order to relax and rejuvenate, to recharge the batteries.

Participant D shared the care with her sister and her sister noted;  
*“she was going home and getting straight into bed, she was not getting to see her grand children. So she said I had no me time. Because that was the only time they could visit her. So she said I had no me time, time for me, time to get her hair done time to you know, she said I had no me time at all.”*

This would commonly be encountered by the writer in her area of practice when carers would voice that they would love just one day off.



## Being the one

Despite having other family members there always appears to be a main carer – being the one

For participant F a duty of care to her husband, whom she has promised to mind for better or worse whatever the hardship. For participants A,B,D and E a duty of care to their mother simply because she is their mother. For participant C a duty of care to the sister because she has no one else.

Vellone et al ( 2002) identified this in their Italian study but of other family members who were unable to help due to family commitments without giving a thought to the family lives of the main carer.



In this study the participants all alluded to their caree putting pressure on them not to go out, not to let other members of the family mind them as they had their own lives – “wants me”. “They are happier if I am here so that is all that matters”.

Vellone (2002), noted when asked if the carer became unwell or couldn't give care, other family members could not identify who would take over the role.

The writer from experience recognizes other family members lack of involvement as denial or unacceptance of the illness at hand rather than a direct refusal to give care.



They have lost their identity as wife, daughter and sister and have now become carer or minder due to the nature of their illness.

For participant F her husband has become very childlike and requires constant supervision, “*can not be left alone*”.

Seoud et al (2005) refers to caring for a relation as an emotional affective and relational matter .

More feelings are unearthed as this causes the carer to be torn between the caree and their own family and as participant F recognized it as torn between her husband and “*life*”.



Despite a lot of negative emotions around being the carer, they are all “*happy*” at being able to help and as participant D says “*I will always have that, I did it for my mam and I did it for me*”. She is juggling caring for her mother four days a week, working five afternoons a week, and tending to her own husband and children. The role of the carer takes over and comes first, it has priority.

Samuelsson et al (2001) note carers feel it is their responsibility to care and the main reason for becoming a carer while “being the one” was the second most common reason for caring.

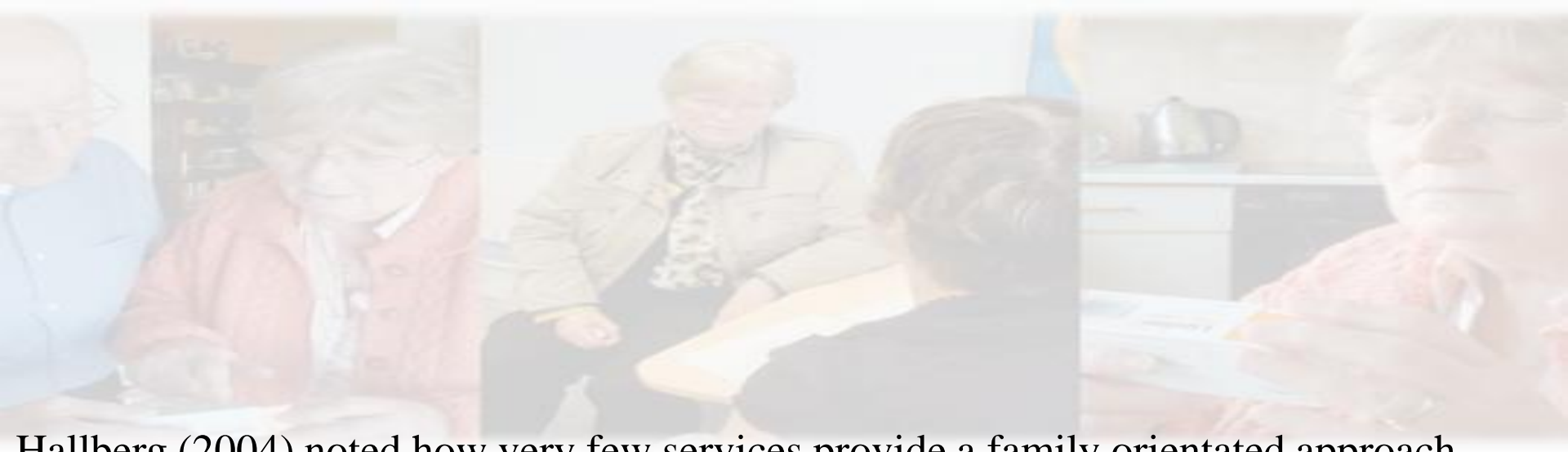


## Support networks

For each of the participants in this study they had no structured network and would randomly ask family members to help out as required.

Three of the participants had support from the Public Health Nurse when their mother had a leg ulcer but their involvement stopped once the ulcer healed.

In a study by Begley et al (2004) they found there were uncertainties around role definition and boundaries of public health nurses and in Ireland they are seen as a generalist with responsibility to provide primary, secondary and tertiary care to people in the community of all ages from birth to old age.



Hallberg (2004) noted how very few services provide a family orientated approach including supports and education for informal carers.

Teel (2005) developed a model, the theory-based self care talk intervention which focused on promoting health among older adults who provide care. It included education on aspects of care including avoiding work overload, focusing on the positive, building self esteem, community and practicing healthy habits all carried out over the telephone to facilitate carers.

In the writers practice the clients have an access to information on any aspect of caring for their loved one by phoning in. Calls are answered punctually and as participant A states *“I know I have here, I can always ring if there is a problem.”* This is seen as a stepping stone by the writer on accessing more supports in the future as the trust will have been developed that then system is there to help.



Reluctance of family caregivers to use services for which they are eligible and the preference for carers to solve problems on their own presents challenges to those trying to provide services to family carers.

By providing supports and education to family carers could go a long way to improving the quality of life of carers. Vellone et al (2002) – it would give a reassurance to carers on if everything is working alright

Overall the support services for carers whether they be family or external are very patchy. There does not appear to be any consistency in who does and who does not get help. This area needs further development in order to meet the needs of carers and the cared for.



## **Recommendations and Implications for Practice**

Nurses and carers of the older adult are on a journey together with the older adult being cared for. To this end it is necessary for nurses to take on board the needs of carers.

Nurses need to gain a better understanding of the informal/family carer and appreciate the time and commitment that they are putting into the care of older adults. It is our duty as nurses to build up relationships with carers as well as clients and acknowledge their roles as carers.

It is vital that the cycle of care that exists is broken to include the health care professional as part of the wheel so the carer does not feel alone and isolated.



There needs to be recognition that the added role of care giving has the potential to have repercussions on the health of the carer and there is a need for the carer to be viewed as a secondary patient even though they may not have any presenting health issues.

Education needs to play a major role in care provision, informing carers on all aspects of the caring role relevant to their individual circumstances. There is a need to involve the whole family, not just the carer and give them the opportunity to become part of the caring process.



There are many support groups in society to assist carers but many are not aware of their existence. The nurse should where possible point the carer in the direction of ones relevant to their situation.

There is also the potential to develop a tool for nurses to help them assess caregiver stress.

Older adults and their carers should attend medicine for elderly services regularly to give nurses the opportunity to identify any signs of carer stress or strain.



*The simple  
act of caring is heroic.*

Edward Albert, 1999