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## **"The day is long you know?" Older people's voices on their homecare experiences in Ireland**

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The population of people aged over 65 years in Ireland is increasing, creating an expanding homecare market with over 60,000 older people in receipt of homecare in 2015. Yet lack of regulation and legislation within the homecare market in Ireland causes unpredictability in service provision, while lack of research further compounds the issue of inconsistency in homecare services. Adopting a qualitative methodology, 14 older people in receipt of homecare and two family members of recipients were interviewed for this study. Two focus groups with older people in the community were also undertaken. Findings suggest that participants were largely satisfied with the homecare they received and value the social contact this provides. Fear and hesitation in relation to retaining the service appeared evident from the data collected. Older people in receipt of homecare place profound value on the relationship they develop with their homecare worker and this relationship largely dictates their level of satisfaction with the service.

### **Introduction**

Older people in Ireland are a growing cohort of social care service users. By 2041, the number of people aged over 65 years is predicted to reach 1.4 million and represent 22% of the population of Ireland (Mc Gill, 2010). In 2016, 94% of people aged over 65 were living in the community as opposed to nursing home settings (Central Statistics Office, 2019). Homecare is essential to ensuring older people can age in their own homes for as long as possible (Alone, 2017). There is a dearth in the literature relating to older people and homecare in Ireland (Lundstrom & Mc Keown, 1994; Murphy, Whelan, & Normand, 2015). Lundstrom and Mc Keown (1994) published what is considered a cornerstone paper relating to homecare in Ireland, which sought older people's views in relation to their homecare service. Participants were largely satisfied with their homecare and noted the value of the social contact element of the service. Respondents further reported that increased time for the home-help visit would be beneficial to their care needs (Lundstrom & Mc Keown, 1994). However this issue appears to be a continuing challenge of homecare provision in Ireland, with public protests pertaining to home-help hours being cut occurring as recently as 2012

(Holland, 2012). Yet since 1994 older people in Ireland have not been consulted specifically pertaining to their experiences of care in the home.

The Irish Government surmise that the homecare market in Ireland is problematic at present due to lack of regulation and the discretionary nature of the service (Houses of the Oireachtas, 2012). High staff turnover is also common within the homecare market (The Institute of Public Health Ireland, 2018). In 2011, the Irish government stated that homecare provision in Ireland was to be regulated and subject to Health Information and Quality Authority (HIQA) inspections, consistent with those undertaken within residential settings for older people (National Economic and Social Council, 2012). Yet to date, no legislation exists in Ireland to govern this sector resulting in inconsistencies in service provision and standards in homecare delivery to older people (Kiersey & Coleman, 2017; Timonen, Doyle, & O’ Dwyer, 2012). Ireland’s homecare sector remains unregulated, placing older people at risk and prompting the development of a ‘black market’ relating to homecare provision (Home Instead Senior Care, 2015). The black market refers to individuals providing homecare who are working independently and not affiliated with any organisation (Home Instead Senior Care, 2017)

Tasks undertaken by Health Service Executive (HSE) home-helpers include assistance with personal care, positioning of the service user (to prevent pressure sores for people with limited mobility), assisting with meals and essential household tasks (Citizen’s Information, 2013; Migrant Rights Centre Ireland, 2015). The Irish Research Board (IRB), in 2017, conducted a review of legislative frameworks for homecare provision in four other countries, as the first step towards planning for the regulation of homecare in Ireland (Kiersey & Coleman, 2017). This review found that homecare in Germany, Netherlands, Scotland and Sweden has been created based upon robust regulations and supported by legislation. Homecare providers must achieve accreditation based on minimum levels of quality standards created by each country, in order to be able to provide care to older people. Monitoring bodies undertake inspections of homecare services and investigate complaints. Compliance information is then made available to the public (Kiersey & Coleman, 2017).

## **Literature Review**

Originating from the Health Act of 1970, homecare provision in Ireland is a discretionary service provided by the HSE (formally the Health Board) (Health Act, 1970). The primary objective of the home-help service within the HSE was viewed as enabling older people to

remain in their own homes rather than residing in long-stay care facilities (Lundstrom & Mc Keown, 1994). Yet there has been a lack of consistency and transparency in relation to the allocation of homecare hours and the individual experiences of older people in receipt of care (Timonen & Doyle, 2008). The homecare market continued to evolve in to the current quasi market of both state and private providers, with the HSE outsourcing care to private homecare providers throughout the country (Timonen & Doyle, 2008).

Policies relating to the importance of providing homecare for older people to support them to remain living in their own communities emerged throughout the 1980s and 1990s in Ireland. Such policies made recommendations to expand the existing home-help service and offer training to homecare workers. While also acknowledging the underfunding of the home-help service and the need for a more comprehensive provision of service (Department of Health, 1994; Department of Health and Children, 1998, 2001). Yet it was not until 2010, when an undercover documentary illustrated the provision of homecare to older people in Ireland by multiple private providers, that this sector began receiving nationwide attention. The footage highlighted the lack of training, education and experience of care workers and further showed older people being subjected to abuse and neglect (Gantly, 2012). This prompted the development of the dialogue relating to the regulation of homecare in Ireland which is now being created by the HSE (Kiersey & Coleman, 2017). An aim of this paper is to add the voice of the older person to such dialogue.

Holroyd-Leduc et al. (2016, p. 3) argue that the voice of the older person is imperative when planning service provision relating to their care as older people possess unique and expert knowledge relating to their homecare experiences and are "directly affected by the service". Davis, Sylvester, Barnett, Farndon, and Ismail (2019) argue that older people participating in research relating to their care highlights their priorities as service users and can be used to inform policy and enhance outcomes for older people. There is a lack of research pertaining to the effectiveness of care in the home in Ireland and the lived experiences of homecare recipients (Delaney, Cullen, & Dolphin, 2008; Mc Gill, 2009; Timonen et al., 2012). The primary aim of this paper is to report on the factors that impact homecare for older people in Ireland, based on their unique perspectives and experiences. Key objectives of the research conducted was to:

- Ascertain the views of older homecare recipients on what contributes most to satisfaction and dissatisfaction with their homecare services;
- Explore the impact of the homecare experience for older people.

## **Methodology**

A qualitative methodology was employed and semi-structured interviews were undertaken with sixteen older people, fourteen of whom were in receipt of homecare, and two participants who were family members of an older person in receipt of homecare. Semi-structured interviews enabled the exploration of the individual experiences of older people (Litchman, 2014). Two focus groups were also undertaken with active retirement groups, containing seven and eight participants respectively. Focus group participants had not themselves been in receipt of homecare services. However all had friends or family members who had been in receipt of homecare provision and wished to share their views. The location of the study was limited to one city and county area in Ireland.

## ***Sampling***

Gatekeepers such as homecare provider supervisors and non-profit organisations were used to disseminate letters of invitation to participate to potential participants. Older people were contacted with information about the study and invited to take part. Willingness to participate initially was low, as seen in previous research (Harris & Dyson, 2001). Focus groups with older people active in their community were employed to generate discussion around homecare provision and to demystify the research process. This resulted in snowball sampling which was indispensable in the recruitment of the subsequent participants. Due to health and mobility issues older people may be less likely to participate in research (Liljas et al., 2017). Multi-morbidity of health conditions further reduces the likelihood of participation (Galenkamp & Deeg, 2016). Liljas et al. (2017) suggest that gathering data at a place of familiarity to the person and creating a supportive environment conducive to their needs may increase the participation of older people in research. Consequently, offering potential participants the option to have interviews undertaken in their own homes was employed as this incorporated their familiar surroundings and reduced access barriers. Table 1 summarises details of the participants.

Table 1

*Participant demographics*

Interview participants	n = 16 All aged over 65 years Two male and 14 female 14 in receipt of homecare Two family members of person in receipt of homecare
Focus group participants	Group 1: n = 7; all female; all aged over 65 years Group 2: n = 8; one male and seven female; all aged over 65 years

*Data Collection*

Data collection began in January 2017 and was completed in July 2017. Interview data were collected in the homes of interviewees and interviews lasted from fifteen to forty five minutes. Focus groups took place in the researcher's university and in a local community resource centre, based on the preference of each group and each lasted approximately one hour. A dictaphone was used to record both interviews and focus groups while field notes were also taken. An interview assistant was present for focus groups to assist in taking field notes. Interviews and focus groups were transcribed verbatim, continuously as the data was collected.

*Data Analysis*

Nvivo software was used to open code the data and thematic analysis was used to generate significant themes. Thematic analysis provides a more "flexible approach to analysing qualitative data" while inductive in nature (Braun & Clarke, 2006, p. 78). The data were analysed and reanalysed to locate patterns within the responses (Braun & Clarke, 2006). This culminated into the generation of three key related themes: social contact, consistency and the relationship with the homecare worker. One additional broader theme was identified that related to fear of losing service.

*Ethical Considerations*

This study was given ethical approval from the Ethics Committee of the University of the Ph.D. candidate. Given the vulnerability of the population being studied (in receipt of home-

help/support) and the age range of greater than 65 years, specific ethical considerations included permission to contact the public health nurse of participants should they have become distressed within the interview process. Participants were given information via letter and then face to face about the rationale for this research and their right to withdraw their participation at any time, so that informed consent could be provided.

As interviews were undertaken in the homes of potentially vulnerable older people, the researcher used her extensive practice experience in the field of homecare to support participants to feel safe and at ease. It was envisaged that gatekeepers extending the invitation to participate in this study, would further contribute to the feelings of safety of participants when allowing the researcher to come to their home. Time was taken for introductions and questions in order to develop rapport with the participants and enable them to feel comfortable when the interview commenced.

Confidentiality was guaranteed to all participants. Within the research, participants' identities were protected with the use of letters as pseudonyms. Based on the recommendations of the Ethics Committee, individuals living with a diagnosis of dementia were supported by a family member or carer to participate if they so wished. This occurred in relation to one interview.

## **Findings**

The findings indicated that all recipients of homecare and the family members interviewed expressed satisfaction with their homecare experiences. Participants had between one and 17.5 hours of care per week, with the average hours of care provided being 5.4 hours per week. Twelve of the sixteen interviews are cited within the results as some participants elaborated more than others. Equally, some participants were hesitant in their answers and these interviews were quite short, which is considered within the results. A key theme identified through the analysis of the data related initially to the importance of social contact. Subsequently as homecare provision progressed and continued, consistency in care delivery and the relationship with the homecare worker emerged as significant. Finally, fear of losing their homecare service was a recurrent theme throughout the data collection process, which warranted further exploration. Interviewees are assigned a letters (A-N) to identify them. Focus group participants are identified with: FG for focus group and then the letter they were assigned (e.g. FG. Participant M refers to focus group member M).

### ***Social contact***

When asked about what makes homecare a positive experience for them respondents identified the issue of loneliness and placed significant value on the social contact element of homecare provision. Many older people reported that the homecare visit was something they very much looked forward to and gave them a focus point in their day. Some respondents reported that knowing someone would be calling in to see them was reassuring as they spend much of the day alone:

The fact that you can talk to someone, tell them that such a thing happened in town yesterday, and oh that interesting kind of thing you know? In other words I suppose human contact.

(Participant A)

The home-help is a bit of fulfilment for me you know. I'm grateful for it.

(Participant B)

Having someone visit the older person at home on a regular basis, or indeed if the homecare worker does not visit, greatly impacts the person in receipt of care as explained by one participant who stated that homecare "does sort of give you a quality of life" while another interviewee explained that "one week nobody came at all... it really was upsetting, I mean I was watching the door" (Participant M).

### ***Consistency***

All respondents agreed that consistency is a significant element of a positive homecare experience. This was reported in response to questions about satisfaction, choice and both positive and negative experiences of homecare. Of the 16 participants, ten reported that having multiple homecare workers providing care was an issue they had encountered. However older people reported that the issue of multiple homecare workers providing care presented when they first began receiving homecare, and is not as problematic once care is provided for an extended period of time. Having a regular homecare worker enables older people to connect with the person, feel comfortable allowing this person in to their home, and have stability and regularity of care provision.



Having the same person all the time is great because you know who's coming in to you, but also, having the same person coming in regularly, you build up a relationship with them and it's almost like having a friend coming in.

(Participant C)

I think, it's quite essential that whatever arrangement is there, that it has a big element of continuity attaching to it. Just because we're elderly.

(Participant M)

The sense of the rapport with the person, confidence with the person... the same person where possible.

(FG Participant A)

Equally, lack of consistency and having multiple homecare workers had a negative and distressing effect on some older people. Participants reported that inconsistency relating to their homecare workers was a key factor relating to more negative experiences. In particular having multiple homecare workers was noted as being problematic:

It was one of the things that annoyed me about the agencies was because there were several people coming.

(Participant L)

The replacement wasn't great. I had a different person every day and they would come at a different time. And I was very sick at the time, and I wouldn't know what time they would be coming at.

(Participant D)

Well the first month I think I must have had about six different people.

(Participant N)

### ***Relationship***

In response to questions asking if the older person had a regular homecare worker for an extended period of time; and what makes homecare a positive experience for them, many participants reported that building a relationship with one or two homecare workers had a positive impact on their lives. The older people interviewed were very enthusiastic when discussing their relationship with their regular homecare worker. Recipients described their homecare worker as a friend and knowing their needs, wants and eccentricities like no-one else:

Terrribly important to have someone that's regular, someone that you know. As they get to know maybe your eccentricities. And you don't have to say would you mind doing this or would you mind doing that.

(Participant A)

The one woman that takes care of me is very good. She's always here like and she gives me homecare and everything when she calls. And she likes the dogs, and that's a good one 'cos no one else likes the dogs (laughs).

(Participant G)

She was going to her African church for some service and she'd showed us photographs of herself it was gorgeous in her African dress. And she said will I call in in the morning? Do I said and she arrived with two of her children. So you do get that sort of relationship.

(Participant D)

A sense of connectedness and almost familial bond with their homecare worker was described by some participants:

We would be closer to her (homecare worker) than some of our cousins and other relations you know. She was such a marvellous person and really caring. She used to be able to get them to do things that we couldn't as family couldn't get them to do you know? She had a way about her. So there are people out there who are really gifted.

(FG Participant M)

The sense of familiarity older people feel with the homecare worker appears to contribute directly to their level of satisfaction with their homecare service:

Whereas [name of homecare worker] knows exactly what I need, what I need having done. And as well as that, when you get to know somebody, you ask how their grandchild is, if they've been ill or if they've started school how are they getting on and... they almost become a part of your extended family. So it makes it a much nicer thing, I'm extremely lucky so I am.

(Participant C)

Having a cup of tea was a recurrent element of care provision which emerged as particularly important to older people in relation to building and maintaining the unique relationship with their homecare worker:

Mark is a gas man altogether, about my own age, well he's in his late fifties. He'll have a cup of tea and take time you know?

(Participant B)

It's lovely to have a young person around the house. Even for the hour. And you get all sorts of news about their families and sometimes they'll have a cup of tea.

(Participant D)

Reliability and dependability on their regular homecare worker further created a positive homecare experience for recipients:

Well I have a good relationship with her, we get on really well, we seem to just pull well together you know. She will do anything for me.

(Participant I)

I think it's very important that you have a rapport with whoever it is coming. I think it's important that there's continuity in terms of the personnel calling and caring. They're two things which I think are quite vital.

(Participant M)

### *Fear of losing service*

Participants expressed hesitation and apprehension when asked about any negative experiences they have had in receiving homecare or if they had ever made a complaint. Notably, when the recording had finished two participants went on to explicitly disclose fear of losing their homecare hours, should they report anything negative about their experiences or complain about their homecare service. Apprehensiveness was evident in more than half of the interviews. Participants paused, shifted uncomfortably in their seats, and struggled to word negative experiences. It was evident that although confidentiality had been assured to all participants, that the fear that their interviews would be shared with their homecare providers remained an issue:

Yes usually, yeah.. it is a pity but most of them are okay.. I won't say anything derogatory. So it's completely confidential is it?

(Participant A)

Fear of losing the service was further evident with participants alluding to an understanding that keeping the service required them to accept whatever level of service is being provided, as the latter may result in a discontinuation of their homecare:

I said to my daughters a few months ago I think I'll cancel this altogether. But they said if you do you probably won't get anyone again. So it's kind of a threat you know.

(Participant N).

Well....I...I don't like really being critical... it's a difficult job. And I'm sure it's difficult for the girls doing it too.

(Participant M)

The focus group participants were more vocal and unambiguous in their responses concerning poor practice in homecare:

They're often afraid to say anything you see their hands are in the dog's mouth. They're afraid they'll get nothing at all. They're not the ones to do it.

(FG Participant F)

Because they are frightened. They're on their own and they're vulnerable and you have to be very very careful.

(FG Participant C)

I don't know whether that's included... he might have been lucky again and should keep his mouth shut.

(FG Participant D)

## Discussion

Overall, participants expressed satisfaction in broad terms with the homecare they receive. Consistency in the care provided and building a meaningful relationship with their homecare worker were key factors for older people creating a positive experience of homecare. Having multiple different homecare workers was a notable issue which contributed to more negative experiences of homecare. Loneliness, social contact and relationships with homecare workers, were cited as particularly key for older people in relation to their homecare.

The importance of social contact was very evident in the data. Participants reported that knowing someone would be calling to see them, and simply having someone to talk to or have a cup of tea with is very important to them. Having identified the importance of social contact for older people, befriending services may possibly meet the older person's need for company and could possibly reduce the need for homecare hours. The Central Statistics Office (2017) report that 27% of people over 65 years of age in Ireland live alone. Loneliness can have devastating effects on both physical health and the mental health and wellbeing of older people, from cardiovascular health to depression (Hemmingway & Jack, 2013).

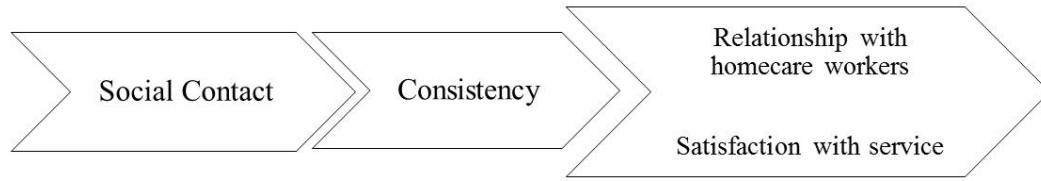
Initiatives aimed at responding to loneliness experienced by older people could potentially reduce their need for more intensive support services going forward. Alone is a voluntary organisation which provides a befriending service for older people living alone. Volunteers visit the older person in their home on a weekly basis (Alone, 2019). Friends of the Elderly provide a visiting service to isolated individuals over the age of 60. A telephone befriending service in addition to social outings and intergenerational projects are also provided throughout Ireland (Friends of the Elderly Ireland, 2019).

All participants agreed that consistency in care provision to older people in their homes is of major significance. Starfield, Shi and Macinko (2005) argue that effective

primary care is long term and person focused. March (2006) contends that lack of consistency and continuity of care results in poorer outcomes for service users and further reduces the effectiveness and quality of service provision. Pembroke (2017) indicates that homecare workers in Ireland are difficult for private providers to recruit and retain. The willingness to work flexible hours, travel between the homes of clients and work for minimum wage are some of the reasons cited (Pembroke, 2017). HIQA (2016) in their quality standards for nursing homes for older people stipulate the need for continuity in staffing to support and maintain relationships between staff and older people. Yet in the absence of legislation and regulation pertaining to homecare in Ireland, such consistency in home care is not always afforded to older people. Patmore (2004) found that some homecare providers in the UK assigned a keyworker to the older person in receipt of care and aimed to facilitating this worker to attend to the older person as a matter of preference. However other providers actively discouraged the development of relationships between older people and individual homecare workers, as this causes upset if the homecare worker leaves (Patmore, 2004). Yet this study found that older people value consistency immensely concerning their homecare provision and the subsequent relationship which may then develop.

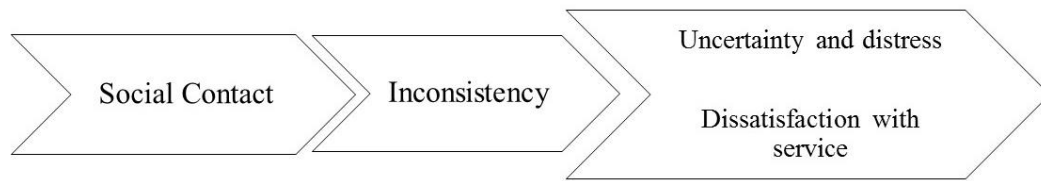
Many participants became enthusiastic when talking about their regular homecare worker. The connection to one or two regular homecare workers and the subsequent close bonds that developed, undoubtedly enhanced the older person's day. Interviewees reported sharing stories about their families and notable life events with their homecare worker. The relationship between the older person and their homecare worker appeared much more important to them than the amount of time or tasks completed. Familial terms were used by some participants when describing their homecare workers, while other respondents explained that when their care worker arrives they bring cheer and enthusiasm in to their home. Previous research concluded that homecare workers reported a deep connection with the older people they cared for and highlighted that it required the effort of both parties to be a successful and sustainable relationship (Walsh & Shutes, 2013).

Each of these themes are significant within the sequence of building and maintaining a relationship between both parties. A care path may be actively built based on the premise of these optimal factors. The social contact element of homecare provision is quite significant and welcomed. While consistency in the homecare worker provided, enables the development of a strong caring relationship, which is profoundly valued by the older person (illustrated in Figure 1 below).



*Figure 1.* Optimal homecare path

However the opposite may also occur, where lack of such optimal conditions results in a more negative care pathway. The initial social contact may not be welcomed if consistency is not maintained. When different homecare workers attend to the home of the older person each day, this causes distress and apprehensiveness for the older person resulting in dissatisfaction with the service. This may then hinder or prevent completely the development of a strong caring relationship (illustrated in Figure 2 below):



*Figure 2.* Inconsistent homecare path

The final theme identified in the data is concerned with fear in relation to loss of service. Interviewees appeared apprehensive in relation to saying anything negative about their homecare experiences, reported feeling grateful and that there were many other older people in far worse circumstances. Similar conclusions are evident elsewhere which reinforce the findings of this study relating to fear when contemplating complaining about service provision. One qualitative study in the UK found that older people tend not to voice concerns in relation to their care: “recognising their vulnerability, will bend over backwards not to offend the people in whose hands they find themselves” (Woolhead, Calnan, Dieppe, & Tadd, 2004, p. 167). A report by the Parliamentary and Health Service Ombudsman (PHSO, 2016), also in the UK, found that older people are less likely to complain about their care due to: being unaware about how to make a complaint, living alone and lacking social networks while Rabiee and Glendinning (2014, p. 8) reported that many older people are “reluctant to complain” and “didn’t want to make a fuss”.

Life course theory is one possible avenue for explanation in relation to the theme of fear or hesitation to complain. Life course theory proposes that the societal and historical timing of one's life may impact the trajectories across the life course (Elder, 1998). Generational time contends that the values, beliefs and understanding of a specific generation are shaped by the timing of their births and subsequently the societal structure they were encultured within (Elder, 1998). Indeed older people in Ireland report that their parents' generation never complained and that the influences of the Catholic Church prompted them not to voice their concerns or complaints (Timonen et al, 2012; Walsh & Harvey, 2013). Vulnerability, fear of repercussions and acknowledging that "you just don't rock the boat" were reasons cited by older people for not complaining (Walsh & Harvey, 2013, p. 59).

### **Limitations**

One notable limitation is geographical location of the participants, which was limited to one city and county in Ireland. Also, the fear of losing hours possibly inhibited participants in their willingness to share information about their homecare. Equally, fear of losing hours may have prevented other older people in receipt of homecare from participating.

### **Conclusion**

The overall aim of this study was to ascertain the factors which impact homecare for older people in Ireland. This paper focused on what older people perceive contributes most to satisfaction and/or dissatisfaction in relation to their homecare provision. The overall impact of homecare for older people was also discussed.

Older people in receipt of homecare have expressed satisfaction with the care they receive. Social contact emerged as an important factor which contributes to this satisfaction in relation to homecare provision. Participants noted feelings of loneliness and expressed the significance of their homecare worker's visit to their day. The interviewees reported that having someone to talk to and knowing someone would visit them was particularly beneficial. Satisfaction with homecare was further reported in relation to the relationships older people form with their regular homecare worker. Participants described their homecare workers in familial terms and expressed profound care and a sense of connectedness to them. Having a cup of tea was reported throughout the interviews as a very significant event and contributing to the building and maintenance of this caring relationship between the older person and their homecare worker.



In relation to what contributes most to dissatisfaction concerning their homecare services, older people cited inconsistency in care provision. Having different and sometimes multiple homecare workers providing care was described as problematic. However most participants reported that this problem occurred when they first began receiving homecare, but improved after the initial few months. The impact of homecare for older people was evident in each of the interviews and both focus groups. Participants expressed profound gratitude for the care they receive and some older people described their homecare as essential. This study found that older people, value, need and benefit greatly from the homecare services they receive.

Fear of losing their homecare service makes older people apprehensive or not likely to complain should they have negative experiences. This may be due to the generational timing of their lives as suggested within the life course theory. Older people in need of homecare are often vulnerable, living alone and living with chronic health issues. This study has found that social contact is a significant need of many older people. Such older people may benefit from accessing visiting or befriending services available locally. The development of a strong relationship with their regular homecare worker contributes to enhanced satisfaction with their homecare services. This research concluded that consistency is a key factor in creating a space for this caring relationship to develop. Having one or two regular homecare workers as opposed to multiple providing care enables the establishment and progression of this relationship which older people value immensely.

Greater research is needed to examine in detail the experiences of older people in Ireland relating to homecare provision. Yet this study concludes that homecare is a much needed, valued and beneficial service based on the experiences of older people.

### **Conflicts of Interest**

This research presented no conflict of interest.

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