



Home & Community
Care Ireland

AN INQUIRY INTO THE LIVED EXPERIENCE OF COVID-19 IN THE HOME CARE SECTOR IN IRELAND

CLIENTS' EXPERIENCES

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Further, we wish to express our gratitude and appreciation to nine people availing of home care – all clients of HCCI members - who generously welcomed us into their worlds and shared their experiences of home care provision during the pandemic and beyond. Thank you for your time, patience and honesty. We are hopeful that your thoughtful and reflective insights will illuminate the importance of home care in enabling independent living and initiate positive changes in the landscape of social and health care.

ABOUT HOME AND COMMUNITY IRELAND (HCCI)

Founded in 2012, Home and Community Care Ireland (HCCI) is the national representative body for home care providers in Ireland. It includes twenty-four members across the country, who between them employ over 10,000 frontline care staff, provide medical and non-medical support to more than 20,000 clients and who have over 100 offices throughout the country. Most of these clients are elderly people, though a significant volume of care is also provided to people with disabilities and those with complex needs. While HCCI represents many of the largest home care providers in the country, most of our members are small and medium-sized enterprises (SMEs).

The mission of the HCCI is to advocate for, and represent, a unified professional home care service in Ireland to enable independent living at home. HCCI does that through representation, leadership, good governance, and enforcement of the HCCI standards.

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Executive Summary

This research is a qualitative study on the impact of Covid-19 on home care clients. Through 9 interviews, HCCI examined the impact of Covid-19 on home care provision, the medical and physical effects and the coping mechanisms used to get through the pandemic. This builds on HCCI research on providers experience during Covid-19.

The robust infection prevention and control (IPC) measures provided great reassurance to clients, with most continuing care without interruption. Home care proved to be the safest model of healthcare delivery in Ireland during the pandemic, with cases peaking at 193 cases in the week ending January 24th, 2021.

Participants reported feeling a strain on their mental well-being. Social isolation was a significant factor. The requirement to cocoon and the closure of shops, recreational and day services meant participants had few social and leisure outlets, leading to reports of “cabin fever” and a loss of motivation. There was a noted difference in participants mental well-being in the summer compared to the dark weather and short days of the winter months.

The primary impact on participants physical well-being was on their physical mobility. Cocooning meant many participants were unable to exercise and some felt a loss of motivation. The long-term effects of sedentary behaviour are well-documented but it is premature to comment on the impact of the closure of non-urgent medical care and how it relates to the true physical impact of Covid 19.

Having strong personal relationships was an important coping mechanism for participants. They pointed to family, friends, volunteer networks and carers as key sources of comfort, companionship and support.

Participants used technology and the internet to maintain social connections, shop online and play video games. Platforms like Zoom, FaceTime and WhatsApp were invaluable during the pandemic. Statistics from the EU and Ireland show that older people are embracing technology and the internet at a significantly higher rate. Offline, participants struggled with the closure of recreational and support services, with laborious activities like needlework being a popular activity.

Participants spoke about the importance of keeping a positive mindset when coping with the pandemic. They demonstrated commendable mental resilience and adaptability, developed through their life experiences, bereavements, illness, and religious faith.

In conclusion, the IPC measures put in place by providers reassured participants that their home was safe and helped make home care the safest method of care during Covid-19 Pandemic. While cocooning and social isolation placed a mental strain on participants, personal relationships, technology and a positive mentality helped them adapt and persevere.

There are several recommendations emerging from this research. Clients should receive a full medical check-up, with social and care services reopened with additional capacity. HSE and providers should build on increased digital literacy and introduce new technology to improve quality of life and standard of care. Home care is established as the safest and most preferential method of care. The Statutory Home Care Scheme should be implemented as a matter of urgency and should include a holistic, patient centred model of care.

1. Introduction

On March 11th 2020, the World Health Organisation (WHO) declared the novel coronavirus, Covid-19, a pandemic. What followed was a set of worldwide severe public health restrictions that included travel restrictions, facility closures, quarantines, as well as national and regional lockdowns. Ireland announced its first full lockdown on March 27th. These restrictions were eased in the Summer until a second wave led to another lockdown, beginning October 19th. Restrictions eased on December 1st until a sharp rise of cases forced a third lockdown on December 30th. As progress continues with Ireland's vaccination programme, restrictions are set to be eased throughout May, June & July 2021. As of May 4th, 2021, Ireland has recorded 251,087 confirmed cases and 4,915 deaths (HSPC 2021).

Most clients in the home care sector are older persons, with a substantial minority being people with disabilities or people with pre-existing conditions. This puts them at a high risk of morbidity from Covid-19 (Bailey et al 2021). Those at high risk were advised to cocoon at home. This meant they remain in their homes and avoid all non-essential contact. Home care is considered an essential service. To mitigate risks, HCCI providers and the HSE introduced numerous infection control measures including PPE training, cough etiquette, hand hygiene, remote monitoring, social distancing, temperature checks and self-monitoring. This proved to be successful as home care recorded less cases and deaths than other care sectors including long term residential facilities and nursing homes. The rate of Covid-19 within HCCI providers peaked in January 2021, at 1% or 193 cases. Carers have been hit harder with an average potential exposure rate to the virus of 8%-10%.

2. Research Methods

2.1. Research Objectives

This research is the second part of a two-wave qualitative study on the impact of Covid-19 on the home care sector in Ireland. This research builds on a previous HCCI study, which examined the experiences of home care providers during Covid-19. Through semi-structured interviews with 9 clients, this study will examine the lived experience of Covid-19 from the perspective of HCCI clients. Interviews took place over the phone during November and December 2020. This research explores how clients were cared for during the pandemic, the effects of Covid-19 and cocooning on clients mental and physical wellbeing and the coping mechanisms used by clients throughout the pandemic.

The findings of this study will explore the lessons that can be learned from the Covid-19 pandemic. The primary objective of HCCI is to advocate for the highest standard of care to clients. This research will inform the future of care in the home care sector; have implications for the work of HCCI and providers and inform policy debates with health partners including the HSE and the Department of Health; and will be of interest to academia and research institutes contributing to research on Covid-19, home care and the wider literature on health policy.

2.2. Research Questions

The overarching question guiding this study is: What are the lived experiences of home care clients during the Covid-19 pandemic in Ireland? To address this broadly defined question, the study was guided by these three questions:

1. What impact has Covid-19 had on home care provision?
2. How has Covid-19 affected participants mental and physical wellbeing?
3. What coping mechanisms have participants used to lessen the impact of Covid-19?

3. The Impact of Covid-19 on Home Care Clients

3.1. Home Care Provision during Covid-19.

For most participants, home care provision continued without disruption. This contrasts with other forms of care, with over 70's reporting cancelled appointments and closure of services (Bailey et al 2021). Working with the HSE, providers implemented a series of infection prevention and control measures including PPE training, cough etiquette, hand hygiene, social distancing, temperature checks and self-monitoring.

Carer's duties vary according to the clients wishes and level of dependency. These include personal care, meal preparation, medication prompting, housework and companionship.

The infection control measures practised by carers were widely praised by participants. Measures like enhanced PPE and strict hygiene not only reduced the spread of the virus, but reassured clients that their home remained safe. As one client explains.

They're very good, they're always washing their hands, they wear a mask... and they're very mindful of it. I'm much more relaxed now. I feel more comfortable with them. I don't have the same [fear] that I would have had in March, at the start of the pandemic and I think they're being very careful. I feel they're being mindful..

Two participants paused their home care at the onset of the pandemic. One client deferred after her "doctor said both myself and my husband are at a very high risk". Without home care, this participant had to adjust her routines and reported feelings of loneliness. She expressed a strong desire to have her carer back after the pandemic.

The other participant decided that her husband, who began working from home, could temporarily substitute for home care. When her husband returned to the workplace, she resumed care and continued to do so during the second wave.

And when they started to come back in, I was grand then. Sure, we laughed about it. I'm fine with it now – even though the numbers are higher this time and it's more contagious – I'm not nervous.

Participants described home care as being invaluable to their physical and mental wellbeing. For participants who have been strictly cocooning themselves, their carers became an important social outlet. One client who did not see his family, referred to his carer as a "friend" and expressed his appreciation of having company during lockdown.

It's nice to have company. And the lockdown, I feel it mentally, very severely, the loneliness of it.

3.2. Mental Health Impact of Covid-19

The negative effects that this pandemic is having on mental health are well-documented. The United Nations (2020) has warned of a global mental health crisis. Past pandemics have caused significant and long-term mental health problems, with the SARS outbreak being labelled as a “mental health catastrophe” (Mak et al 2009).

In Ireland, the pandemic has contributed to a high rate of mental health issues and an increase in referrals to specialised services (Mental Health Reform 2020, College of Psychiatrists 2020). The pandemic has created “a perfect storm”, given underfunded mental health services, high risk of morbidity, and increased isolation. (Mental Health Commission 2020). The same study notes that mental health issues among older people tend to be underreported, as they struggle with stigma around seeking help.

Participants reported no clinical mental health illnesses but did report negative effects on their mental and emotional wellbeing. Participants reported having the “odd bad day” and sometimes feeling “a bit down in yourself”. Another participant expressed concern for other older people:

“In my age group there are people who have nobody. They are there dependent totally on the home care coming in and chatting to them.

Social isolation, brought on by participants cocooning, was a significant strain on their mental well-being. Participants missed activities like shopping with their families and seeing friends. One participant states:

“It's just everyday things, like just going out, going to the shops... just those little things. Just walking around, meeting people and socialising.

The closure of social services and recreational and leisure facilities also impacted participants. Without these facilities, participants had few social outlets, with one describing the experience as “cabin fever”. One participant lamented the closure of a day centre that brought social interaction and a sense of fulfilment. Another participant used to frequent a local pitch and putt course. He noted the lack of options open to him now:

“If you think about it, you get into a car – where do you go? There is nowhere to go!”

Several participants noted the difference between the first lockdown, the following summer months and the second lockdown during October and November 2020. Participants had benefited from the good weather, which allowed them to tend to

their gardens and go for outdoor walks. However, the winter weather made any outdoor activity more challenging.

“It’s very hard now in the lockdown, with the weather being bad and that. With the first lockdown I could at least get out to the front, get out to the garden with my walking frame, walk around and do the flowers. But this time it’s very hard not being able to get out.”

Participants also cited their life experiences, from bereavement to illness, that has allowed them to build up a degree of resilience that helps them combat poor mental health. One participant reflected on her experiences with cancer and her mental resilience:

“So, my mental health wouldn’t be affected. I’m kinda not that type of person. Even when I got cancer, it never got me down. I just got on with it.”

While no participant reported a clinical mental health diagnosis, social isolation, worry about the pandemic, and an interruption of their routines did negatively affect their mental wellbeing. Participants recruited for this study all had outgoing personalities, which is not representative of the wider population and may impact this study’s findings.

3.3. Physical Health Impact of Covid-19

While it is too soon to assess the long-term physical health impacts of the pandemic, research suggests that it will have ramifications for people’s health. In Ireland, 70% of respondents reported exercising less or not at all (Bailey et al 2021). The effects of prolonged sedentary behaviour, brought on by cocooning and the closure of services, are well documented. These include increased risk of type 2 diabetes, heart disease and mortality (McBride and Chilcot 2021).

Participants reported that the requirement to cocoon has meant that they have not been able to engage in daily exercise and physical activity. This has impacted their physical mobility and motivation:

“I would have to say probably my mobility wouldn’t be as good because I’m not getting out anymore. Sometimes the carer would bring me out for a walk, and I would get more exercise. I’m not as good at walking as I was. And I’ve gotten a bit lazier, I might give into it a bit more. Before the pandemic I was more determined to get up and get on my feet. Now I’m kinda ‘Oh, whatever, I can’t go out anyway.”

One participant, who survived cancer, reports changes to routine check-ups.

“I still go to the hospital, but I haven’t been out lately, so what they do is they send me out a letter with a date and time, and the doctor rings me from the hospital, and we have a chat about my old problem.”

Then I go to my own doctor, get a full range of bloods done, and when [the results] are back they send a copy to my doctor in the hospital, and they can keep an eye on me that way.”

Covid-19 has stopped many routine appointments and non-urgent care. As explained above, medical professionals have, in certain cases, developed new methods to monitor patient's health. However, it is possible that conditions have been left undiagnosed or untreated. It is imperative that as the pandemic subsides, care recipients and cocooners are given full medical examinations to establish if any conditions have been missed.

Likewise, physical exercise and movement are crucial for the overall wellbeing of disabled and older people. It is concerning that cocooning has affected participants physical mobility. The long-term consequences of this may not be apparent and should be monitored going forward.

4. Coping Mechanisms

4.1. Relationships

Literature suggests that having close personal contacts during a crisis is an important coping mechanism (Van Tilburg 2021). The negative impact of prolonged isolation and loneliness on people's mental health is well documented (Banerjee 2020). Older people with strong social support during the pandemic were found to be less susceptible to depression (Levkovich 2021).

When asked about coping mechanisms during the pandemic, participants pointed to strong social connections with family, friends, neighbours, carers and voluntary organisations. When asked if relationships were the key to getting through the pandemic, one participant responded:

“Oh, of course, yes. If I hadn't [had] someone else at the other side of the phone... I would be lost.”

Participants cocooning showed caution when seeing other people. They practised social distancing and wore masks to safely conduct visits. This participant received window visits from family and friends.

“And I have people coming in and visiting me, but they only come as far as the door, and they wear masks, and they wear gloves. And some of them only talk to me through the window. I open the window and I talk there.”

Several participants reflected on the importance of their spouses as a source of comfort and support. Older participants benefited from their marriages, built over several decades, “Nearly forty years! We are soulmates.”

For this participant who paused their home care, her husband was not just a source of support but her primary caregiver.

“he becomes more like your carer. He's helping you wash and get dressed. I don't want that, you know? I want him to be my husband. And we have that loving relationship. And that's important – that we have that relationship. I don't want him to have to do [personal care] for me.”

Another participant, whose spouse is deceased, benefited from his large family and helpful neighbours.

“I have been coping fairly well because I have a strong family link up here. And my neighbours are here beside me. They all look after me. If I have any problems, they help me out, the neighbours especially, with keeping the house, the back of the house, the garden, cutting the grass. I have two daughters, they look after me very well. I have four grandchildren and two great grandchildren.”

This participant was active in a voluntary organisation that supports people who have experienced the same injury as he did.

“I have a good network around me. There’s an organisation I deal with because I had a head injury a couple years ago. It’s an organisation that helps people with [a specific type of] injuries. So, I go with them and they [are based] close as well. So, it’s easy for me – I have a network that I can offload to. I can talk to people.”

Relationships evidently played an important role in mitigating the negative effects of Covid-19, particularly social isolation. Participants greatly valued the assistance and companionship of their family, friends and carers.

4.2. Going Online

Before the pandemic, older people in Ireland had significantly lower levels of digital literacy compared to similar EU countries (Age Action 2020). Nevertheless, internet use among older people increased significantly in 2020 (Eurostat 2020), as Covid-19 quickly moved communication, leisure and entertainment online. Participants embraced this change, using the internet to keep in touch with family and friends, shop online and develop new hobbies.

The ability to use platforms like Zoom, FaceTime and WhatsApp to maintain communication was invaluable to many participants, as one explains:

“I Like to talk. My sisters are great, so we do a Zoom call a couple of times a week – I’ve three sisters. I do a lot of Zoom calls. (...) I do keep in contact with my family. My friends are great for FaceTime, we do group calls together. I bet you can’t see anything what’s going on, on a WhatsApp call when it’s a group call, and everyone is talking over one another, but it’s a bit of fun. I try to do a good few of them a week.”

Some participants used tablets and laptops to play online games while communicating with other players:

“I play scrabble. I play with people from all over the world. I play with people in England, America... Who else? I had someone else in Africa. It’s a word game. It’s fun to see who wins it. I play before I go to bed. I enjoy it. We have a little bit of banter with people I play with as well. They’re all strangers to me. We discuss the game”.

Another participant reflects that cocooning has encouraged her to develop her technology skills and discover the virtue of retail therapy:

“I’ve become an expert in shopping online! Let me tell you [chuckles]! I did all my Christmas shopping online. [My husband] said [that] for somebody who couldn’t use the computer, I learned very quickly

when it came to shopping [laughs]! So, I'm an expert now. I said: 'I'm cocooning – it's very hard.' And it is very hard."

One participant reflected on the comfort that technology brought her throughout the pandemic:

"I have a very comfortable house. My lights are operated by Google and I have Netflix and YouTube and anything I want. "

Participants embraced the internet and technology. The ability to communicate online with family and friends played a role in combatting social isolation. Access to the online games and streaming services were important to bring stimulation to those who were cocooning. As providers implement new technologies to facilitate remote working and telecare (Bedenik 2020), all clients should be supported in using technology to improve their care and quality of life.

4.3. Positive Mindset

Studies have suggested that older people have greater emotional resilience and are better placed to withstand the pressures that Covid-19 has brought on their mental health (Petretto and Pili 2020, Czeisler et al 2021) A study in Israel found that optimistic older people, with good social support, were less prone to depression (Levkovich 2021).

When asked about how they coped during the pandemic, participants spoke about having a positive mindset and a psychological adaptability beyond their control, as one participant reflected:

"I suppose I adapt to things. It is what it is. You have to cope with what you have to cope with. And you get on with it. We were brought up very much like that...You just have to accept that's the way it is at the moment."

Participants accepted changing circumstances that are beyond their control. They spoke of the belief that things will improve and the importance of being optimistic:

"We will get through it. And it might be difficult, and it is difficult at the moment. But I look forward to coming into the spring now, things are going to be better, and I am going to be able to get out a bit more. That's the way I look at things."

For some participants, life experiences such as injury and bereavement has led to them developing resilience and adaptability to adverse events:

"Well, I'll tell you, I don't allow myself [to get down], not since my husband died, and I had to raise four children on my own. I made a conscious decision then that I was not going to worry. And that was that."

Religious faith played a role for some in keeping a positive mindset during the pandemic. When asked if their faith was important to them, one participant replied:

“Oh definitely. It is very important to me. I am a firm believer in God. I am a Catholic. Even to this day when I got for my walks, when I am able, I would go down to the church and say my prayers. That is about a quarter of a mile away. It gives me consolation... my faith has been a great support to me.”

4.4. Leisure & Hobbies

With sports clubs, day centres and leisure facilities closed, there have been limited opportunities for recreation outside of the home. While digital technology proved to be useful for socialising, participants outlined alternative hobbies and leisure activity.

As discussed, participants found cocooning in the autumn and winter more difficult than the summer. Two participants, with mobility issues, discussed their passion for gardening:

“I love my garden and I love being out. I find that it helped me in the summer. That really helped me when the weather was good. And I’m very much a summer person.”

Another participant went driving without leaving her car, an activity that allows her to leave the house without any physical contact with other people:

“I go out, I get my car and I go out and drive. I drive about eight or ten miles. And I live in the town. I come back and I drive all through the town. I come back home then – I haven’t gone out.”

Although cautious about leaving his house, one participant’s primary leisure activity was dog walking:

“I have two dogs and that that’s what gets me out. So, I have to, as much as I don’t want to go out, sometimes I just have to go out with them. They’re my motivation to get out now.”

A useful hobby for passing the time was needlework and craftwork. This is a laborious activity, requiring time, patience and dedication. One participant describes creating a tapestry:

“The needlework is great for passing the time. I’ll just give you an idea of the sort of time a needlework project would take me. I did a tapestry for my son, for my son’s house, and he said to me ‘How long does it take ‘till it’s done?’ I didn’t know because I was picking it up and leaving it down. So, the next one I did I actually made a note of the time I spent on it. So, a picture, a tapestry say of 14x20 inches would take me about 200 hours. Because it’s meticulous work. You have to have patience. So, that’s a help.”

5. Conclusions

Most participants continued to receive home care without disruption, and none contracted Covid-19. This was achieved through strictly adhering to the cocooning guidelines and the enhanced infection prevention and control measures practised by carers and providers. Participants commended their carers for their rigid adherence to the protocols of strict hand hygiene and application of PPE equipment for the safety and peace of mind it bestowed upon them. With participants cocooning and cut off from family and friends, the companionship that carers offered was an invaluable tool in combatting social isolation. That strong level of satisfaction that participants experienced supports HCCI research that private home care providers and the HSE developed strong working relationships and lines of communication during the pandemic that facilitated the continuation of care and robust infection control measures.

Two participants, who had family support, paused their care. One participant resumed care after the first wave of the pandemic and reported feeling reassured so continued her care during the second wave. The other participant who paused care, had not yet resumed it. She had to adjust care routines and expressed feelings of loneliness, with the intention of resuming care when she received her vaccination.

Participants who paused care expressed discomfort at the thoughts of their spouse performing certain aspects of care, particularly around washing and hygiene. Participants appreciate the boundaries that home care affords between their family and carers. This is something that should be considered when implementing the statutory home care scheme. The fact that a potential care recipient has family support should not be used as a barrier to securing home care when they are being assessed.

The pandemic affected participants mental wellbeing, although none reported clinical mental illness. Social isolation had a substantial impact on participants, as cocooning meant they had few social contacts. The closure of everyday services like shops, social clubs and leisure facilities left participants feeling that there was nothing for them to do and nowhere to go. Nevertheless, participants should be commended for adopting an optimistic outlook. Participants had a wealth of life experiences and relationships that allowed them to develop resilience to the changes that the pandemic brought them.

The primary impact on participants physical health was the effects of cocooning on their mobility. With some participants unable to exercise without assistance, it was difficult to maintain their previous levels of physical activity and motivation. Participants commented on the contrast between cocooning during the summer, when the weather suited more outdoor activities, and cocooning during the winter, when poor weather and closed services reduced their options for physical activity. As Covid-19 has stopped many routine check-ups and non-urgent care, there is a possibility that conditions have been left undiagnosed. Moving forward, there is an opportunity to expand the role of a home carers/home care providers to undertake

extra medical responsibilities, such as routine check-ups and physical rehabilitation. This in turn will facilitate better career pathways for carers, making the industry more attractive and assist meeting the estimated demand for an additional 7,000 carers.

Several factors contributed to participants positive mentality. They relied on their personal relationships, by way of their family, friends, neighbours and carers. Those who were cocooning alone in their homes availed of window visits and the companionship that their carers offered. The appreciation of the companionship offered by carers should be recognised in the statutory support scheme and moves should be made towards a holistic model of care that gives carers flexibility to deliver patient centred care.

The role of technology and the internet greatly assisted participants in communicating with family and friends and provided access to leisure activities. Platforms such as WhatsApp, FaceTime and Zoom proved to be invaluable communication tools and played a strong role in mitigating social isolation. Online shopping, Netflix and video games were noted as excellent leisure activities. While older people in Ireland lagged behind their European counterparts in using the internet, this research, and statistics from the CSO and Eurostat, show that older people are closing the digital divide. Technological supports should be embedded in the new statutory home care scheme to continue to close this divide.

In conclusion, older people and people with disabilities and underlying conditions were forced to cocoon and faced an extraordinary burden throughout the pandemic. Social isolation, loss of physical mobility, closure of support services and fear of Covid-19 placed a significant strain on participants mental and physical wellbeing. The robust safety and infection control measures implemented by carers and providers assuaged participants fears and ensured that Covid-19 cases remained low across the sector. Participants embrace of technology proved crucial in lessening the impact of social isolation. It is important to note that the pandemic is ongoing, and its long-term impacts are not known. Future research may build on this study to explore the long-term effects that Covid-19 has had on home care client's mental and physical wellbeing.

6. Summary Recommendations

6.1. Coming Out of Covid-19:

As society reopens, older people and people with disabilities will face significant challenges. This research has shown that participants have faced social isolation, reduced physical mobility and suspended medical and care services. There are several short-term measures that can address this and instil confidence in vulnerable people to fully re-emerge from the pandemic:

1. All home care clients should receive a full medical check-up to establish if any medical conditions have been undiagnosed or untreated.
2. Funding should be ring fenced to ensure older people and people with disabilities have improved access to care and support services, including physical rehabilitation, to combat the prolonged period of reduced mobility.
3. Social and community programmes should be implemented to combat social isolation and loneliness.
4. Begin an engagement campaign to encourage clients to re-emerge from public health restrictions.
5. Conduct future research on the long-term effects of Covid-19 on home care clients.

6.2. Using Technology in Home Care

Technology and the internet have proven to be an invaluable tool for people cocooning during the pandemic. Likewise, telehealth has emerged as an important tool. These advances in client's digital literacy should be exploited, with new measures put in place to improve quality of life and standards of care through technology:

1. Providers, the Department of Health and the HSE should work together in developing home care technology that supports better care and quality of life. These supports should include sensors to monitor falls, activity and movement and voice-controlled alarms, lights and heating.
2. Further develop remote patient monitoring and virtual medical appointments.
3. Include a new technology framework within the Statutory Home Care Scheme.
4. Promote the benefits that technology and the internet can bring for vulnerable users.
5. Implement programmes to further improve digital literacy and access to the internet for older people and people with disabilities.

6.3. The Future of Care

Covid-19 has made it necessary to reimagine the future of care. With home care proving to be the safest method of care and a clear preference among people to remain living at home, implementation of the Statutory Home Care Scheme should

be expedited, and the lessons learned from Covid-19 should be incorporated into the Scheme and the wider care sector:

1. Educate doctors and GPs that home care is the safest method of care.
2. Consolidate enhanced infection prevention and control measures into training and health and safety policy.
3. Continue the close cooperation between HCCI, providers and the HSE on Covid-19 issues and expand the co-operation to cover all areas of home care.
4. Implement the Statutory Home Care Scheme as a priority and ensure that older peoples default place of care is their home.
5. Introduce a client-centric model of holistic care that takes account of clients wishes, gives clients a choice in their care and gives providers autonomy to make decisions on a client care plan.
6. Expand the role of carers to include medical and social functions.
7. Acknowledge the benefits of providing home care to people with family support when making care assessments and stop penalising those who have a family carer.
8. Include older people, people with disabilities and providers in public health discussions.

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APPENDIX I: INFORMATION LEAFLET



AN INQUIRY INTO THE LIVED EXPERIENCE OF COVID-19 IN THE HOME CARE SECTOR IN IRELAND: CLIENTS' EXPERIENCES

Thank you for considering your involvement in this study. Your participation is on a voluntary basis. Please do not hesitate to contact me for further information:

Dr Tina Bedenik
Research and Policy Officer, HCCI

What is this research about?

This research is part of a wider project that explores the health, social and economic impact of covid-19 pandemic on the home care sector in Ireland, including provider organisations, home care workers and their clients. This particular study will focus on clients' experiences of home care services during covid-19 pandemic, which includes people aged 65 and above who availed of the services before and/or during the pandemic.

The study will explore how were the clients cared for during the pandemic, how has their physical, mental and emotional well-being been affected and, looking forward, what are their needs to facilitate a general sense of wellness. The study will also elucidate why some clients cancelled home care services, how were they cared for during that time, and why they chose to restart their care.

Who can take part in this research?

The participants for the study include people aged 65 and above, who received home care services by HCCI member organisations prior to and/or during the pandemic. This study will unfortunately have to exclude persons with language difficulties, as well as persons with mental and intellectual impairments.

What happens if you take part in this study?

If you decide to take part in the study, you will be contacted by the researcher to arrange an interview. The interview will take about 30-45 minutes and it will be conducted over the phone or a different communication platform (e.g. Skype) at a time that suits you. The researcher will firstly read you the Consent Form to ensure that you are fully informed about the research and that you consent to participate. The interview itself will resemble a conversation during which you will be asked to tell the researcher about yourself and your experience of home care during the pandemic. The interview will be audio recorded to enable the researcher to conduct the analysis afterwards.

How is the audio recording used?

The audio recording will enable the researcher to make an interview transcript and to subsequently conduct the analysis. This material will be safely stored on the password-protected laptop of the researcher. The audio recording may be shared with colleagues at HCCI in order to assist with transcribing the interviews. However, the audio recordings and the transcripts will not be shared with anyone outside the HCCI. Following the completion of the research all the data will be destroyed and audio recordings will be erased.

How is your privacy protected?

All the necessary procedures are in place in order to ensure your anonymity. Instead of using your real name, the researcher will assign you a pseudonym. Any names and locations mentioned during the interview will be removed when the interviews are being transcribed. That way the interview transcripts will contain no identifiable information. A list of names and contact details of those participating in this research will be stored separately to the transcripts. This list will not be shared with anyone outside the HCCI.

What are the benefits of taking part in this study?

Your involvement in this research will help elucidate home care provision during the pandemic – what worked well and what could be improved. This information will inform the work of HCCI, HSE and the Department of Health, with the potential to translate this information into interventions to improve home care and health care services.

Are there any risks of taking part in this study?

There are no anticipated risks for participants.

Can you change your mind and withdraw from the study?

Your participation in this study is voluntary. This means that you can withdraw from the study at any time, up until the commencement of the data analysis. Your decision will be dealt with confidentiality and respect.

APPENDIX II: CONSENT FORM



AN INQUIRY INTO THE LIVED EXPERIENCE OF COVID-19 IN THE HOME CARE SECTOR IN IRELAND: CLIENTS' EXPERIENCES

This research is conducted by Tina Bedenik from Home and Community Care Ireland to collect information about your experience of home care during the pandemic.

Your participation is anonymous and confidential. You will not be identified by your name in the final report.

Your participation is voluntary. You can decline to answer any question, and you may withdraw from the study at any time.

The interview will be audio recorded and a transcript of the conversation will be made. You can request to receive the transcript.

You have had all the questions answered to your satisfaction, and you agree to partake in the study.

APPENDIX III: Research Design

This project employs a qualitative and phenomenological approach in exploring participants lived experiences of home care during the Covid-19 pandemic in Ireland. Both the qualitative research lens and the phenomenological approach have been chosen for their propensity to place the individual's experience at the centre of inquiry, and to obtain detailed information about a lived experience of a particular phenomenon. Qualitative research (Creswell 2007, Neuman 2007, Mertens 2009) is typically investigative and open-ended in nature, and it is suitable for generating initial but also in-depth knowledge and insights about a particular subject matter. It is epistemologically open and more tolerant to non-linear research cycles, which makes it the most suitable method for this exploratory study. Phenomenology (Creswell 2007) on the other hand is concerned with seeking a thorough understanding of several individual's experiences of a particular phenomenon, and what ties, and potentially separates, those people in their respective experiences. Phenomenological research relies on semi-structured and in-depth interviewing technique in order to obtain a detailed insight into participants' worlds.

Interviews were conducted over the phone and lasted between 30 minutes and one hour.

Participants

Using purposive sampling, nine clients of HCCI providers participated in this study. Participants were either older people or people with disabilities. Their ages ranged from 49 to 89, with a mean age of 71. Four participants were female and the remaining five were male. Six participants lived alone, with the remaining three living with their spouse or children. All identified as White Irish. All participants lived in urban areas. Seven participants reported a disability or significant health issue that requires home care. Most participants received care daily. Participants have been receiving care for between six months and ten years, with a mean average of just under three years. To aid recruitment and to facilitate in-depth research, participants who were known to be open and chatty were recruited.

Data Analysis

All the interviews were conducted over the phone and recorded with Automatic Call Recorder and Audacity. Recordings and transcripts were stored on a password protected laptop. The interviews were transcribed verbatim in full, at which stage the process of anonymisation began. Specifically, all the identifying markers such as names, locations and other potentially identifying data about the clients or their carers had been removed. Instead of real names, a code was assigned to each transcript, e.g. F66, M72 etc. with F and M denoting the gender of the participant followed by their age. All other names mentioned during interviews had been replaced with pseudonyms, and all locations had been altered on a 'like-for-like' basis including cities and counties within Ireland.

Once the transcripts have had been fully anonymised, a thematic analysis was utilised to investigate the data. The analysis followed an inductive or bottom-up

approach, which means that inferences were drawn only after carefully engaging with individual transcripts and seeking patterns, overlaps and regularities between them. Individual transcripts were read several times and subsequently coded line-by-line by hand. Following the coding of all transcripts, initial themes started to unfold. These have been identified, recorded and later classified as overarching, major and minor themes. A master list of themes was drafted adhering to the three research questions – and thus overarching themes – and it encompassed all the themes emerging from the data. This list was then reviewed and amended accordingly throughout the process of data analysis, which meant that some themes were merged, and others were removed.

Finally, the master list of themes was translated into a coherent narrative. In this process some minor changes were implemented in order to enhance readability. This means that minor hesitations such as ‘Like...’, ‘You know...’ or ‘Hmm...’ were often removed, and certain expressions have been converted into standard English (i.e. ‘meself’ to ‘myself’) largely for the purpose of concealing participants’ identity. If participants talked about one subject and then digressed, this was then indicated with dotted lines in round brackets. Any additional information deemed necessary to provide a context to what was being said was indicated in squared brackets.

Ethical Considerations

Working with HCCI providers, a robust set of procedures were put in place to protect participants’ privacy and safeguard their wellbeing. Providers assisted in recruiting participants and explaining the background and objectives of this research.

Before each interview, the participant was briefed about the research and their involvement by having the Consent Form read out to them. They were informed that their participation is anonymous, confidential, and voluntary. They were made aware that they can decline to answer any question and have the right to withdraw from the study at any stage. At no stage did any participant decline to answer a question, and many participants stated that they would be happy to do follow-up calls if required.

Limitations

The limitations of this research are primarily linked to sample size and composition. In order to complete this project ten interviews were conducted, nine of which were included in the analysis. The small sample is consistent with the nature of qualitative and specifically phenomenological research for the aim is not to generalise the findings onto the entire population, but rather to enable a detailed insight into the lived experiences of a chosen few.

The small sample size reflects the challenges encountered in the process of participant recruitment. It could be hypothesised that these challenges were a result of the ongoing pandemic, and the pressure and demands placed on the home care providers, who might not have had the time and capacity to assist with the recruitment as they otherwise would have. Another limitation of this research is the unforeseen exclusion of rural participants. Given the challenges of recruiting suitable participants, it was not possible to diversify the study



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