Insights From The Frontline of COVID-19 in Residential Care Settings for Older People in The Republic of Ireland: A Mixed Methods Study

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Research Article

Keywords: Older people, Residential care settings, COVID-19 – impact and experiences

Posted Date: July 26th, 2021

DOI: <https://doi.org/10.21203/rs.3.rs-645901/v1>

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Abstract

Background

The COVID-19 pandemic had a disproportionate effect among residents, family members and staff in residential care settings for older people in Ireland relative to other health care settings, particularly in wave one of the virus.

The purpose of this study was to explore the COVID-19 pandemic as it was experienced by people on the front line of the virus - residents, family members and staff in residential care settings for older people in the Republic of Ireland (ROI).

Method

A 2-phased mixed methods cross-sectional study was conducted. This consisted of a survey administered anonymously online shortly after the 1st wave of the virus (June - August 2020), via our nursing and health care networks, advocacy organisations for older people and on social media targeting - staff, residents and family members. Family members who took part in the survey were invited to take part in phase 2 - qualitative one-to-one interviews which were conducted shortly after wave 2 of the virus (November - December 2020).

Results

Seventy-six staff members completed the survey as well as 28 family members and 2 residents. Eleven family members took part in the qualitative interviews. Good infection control protocols, good governance/management structures, being prepared and agile responses were important factors in determining better outcomes. Isolation, loss of connectedness (to family, staff members and other residents) as well as a reduction in the level/quality of care provision led to significant adverse impacts for both residents and their families. Staff reported high levels of stress, trauma and burnout. A strong theme emerging from the qualitative element was the important role that family members typically have in supplementing care provision which suddenly and completely ceased during the pandemic. This caused huge distress amongst family members and physical decline and mental anguish amongst residents.

Conclusions

This is the first research study to explore the experiences of residents, family members and staff who were at the front line of the pandemic in residential care settings in ROI when the pandemic struck. This study provides valuable insights which could be used by staff in residential care settings, policy makers/implementers in further waves of the pandemic or in future communicable disease outbreaks. The rights and needs of residents must be carefully balanced with infection control and prevention measures. Strategies to ensure that residents and staff are appropriately supported during future waves of the pandemic should now be implemented.

Background

On 11th March 2020, the World Health Organization (1) characterised COVID-19 as a pandemic. The 1st case of the virus in the ROI was confirmed on the 29th February and the first notification to the Department of Health of a suspected/confirmed outbreak of COVID-19 in a nursing home in Ireland was received on the 13th March (2). In Ireland there are 576 registered nursing homes (440 privately-owned) serving a population of over 30,000 residents (2). By mid-July the pandemic had had a disproportionate impact on residents in care settings for older people with 56% of all deaths (1,748) occurring in this population (3). Other countries across the EU also incurred high mortality rates in this sector during this period - Sweden 49%, Scotland 46% and Switzerland 53% (4). The high death in nursing homes in ROI caused shock and public outcry with much media coverage. During wave one of the virus, visiting rights changed and visiting was only permitted through windows.

In response to the high mortality rates encountered in this population a Special Committee on Covid-19 was established by the Dáil (an arm of government) on 6 May 2020 to consider and take evidence on the State's response to Covid-19. Their report (5) concluded that they were unable to get satisfactory answers as to why 985 residents of nursing homes died after they contracted COVID-19 but pointed to a series of systemic weakness and proposed a series of recommended actions including the need for a public inquiry and a review of the impact of privatisation of Ireland's nursing homes.

A COVID-19 Nursing Home Expert Panel was established by the Minister for Health in May 2020, to examine emerging best practice and recommendations to ensure that all protective COVID-19 public health and other measures to safeguard nursing home residents were planned, and in place over the following 6–18 months. The expert panel consulted with a wide range of stakeholders across the sector and published their report in August 2020 (6). The report highlighted multiple areas for improvement including - public health measures, infection prevention and control, outbreak management, admissions protocols, management, visiting, communication, palliative care, community support, staffing and workforce, education, GP roles, regulations and statutory care supports for older people.

In July, 2020 the Health Information and Quality Authority (HIQA), an independent statutory authority published their report on nursing homes in Ireland (2) detailing the impact of the COVID-19 pandemic on nursing homes. The report details the impact on residents, family members and staff and highlighted the need for reform in the care provision offered to older people in Ireland which included - improved clinical oversight, single occupancy rooms, supplementary or complementary models of care, better governance, staffing numbers and skill mix as well as enhanced infection control and prevention strategies and a focus on person-centered care with a human rights approach.

During wave 2 and 3 of the pandemic in ROI lessons appeared to have been learned and residential care settings did not incur the high death rates seen in the 1st wave. We embarked on our study to explore in more depth and to hear from individuals who were at the frontline of the pandemic when it stuck.

Methods

Aim, design and setting

In this study we set out to explore the COVID-19 pandemic as it was experienced by key stakeholders - staff, residents and family members in the residential care sector in Ireland with an aim to explore the learnings which could be applied in the event of future waves of COVID-19 or new epidemics or pandemics. We used a mixed methods approach, in two phases, as outlined below.

Phase 1

An online anonymous survey was developed and disseminated to

1. Owners/managers and staff of residential care settings for older people.
2. Residents and/or their family members.

No existing survey was available to capture the impact of the pandemic so we developed one specifically for the purposes of the study. Slightly different versions of the survey were used for staff and residents/family members as some of the questions would not have been appropriate for residents/family carers. The online anonymous surveys (see appendices) focused on key questions/areas of exploration including - demographics (geographic location, nature of the setting, private/public/multi-site, number of residents, staffing levels and skills mix) as well as level of institutional preparedness, extent of disease spread, factors contributing to or preventing virus spread, impacts on staff and residents, supports available, level of care during the pandemic, perception of prioritises for future waves of the virus and level of trust in the facility. The survey was circulated by URL link via our networks in nursing and healthcare by email and through social media platforms and was open to respondents in the Republic of Ireland (ROI) only. *Nursing Homes Ireland* and *SAGE*, both advocacy agencies for older people, supported the dissemination of the survey to residents and family members.

Phase 2.

Family members who completed the survey were invited to take part in a one-to-one qualitative interview. Participants who agreed to take part were invited to provide an email address and phone number at the end of the survey, which was not linked to the data. All survey participants who provided contact details were subsequently contacted and eleven family members consented to be interviewed online by zoom, using a semi-structured topic guide developed specifically for the purpose of the study (see appendices). The qualitative data was collected shortly after the second wave of the virus.

Ethics

Research Ethics Approval was obtained from Dublin City University (reference number - DCUREC/2020/158). Consent to take part in the online survey was obtained online. Consent to take part in the qualitative interviews was gathered electronically via signed and returned consent forms. All methods were performed in accordance with the relevant guidelines and regulations

Data analysis

The quantitative data was analyzed by Excel Microsoft. Not all participants answered all questions so percentages for each question were calculated out of the total numbers who answered that specific question, not the survey overall. The qualitative data was recorded on zoom and transcribed by a transcription company. The data was transferred to NVIVO and analyzed by thematic analysis to generate overall themes.

Results

Demographic profile - staff survey

Seventy-six people who work in residential care settings for older people took part in the survey. The profile of the sample was as follows, manager/person in charge (PIC) (n = 22), owners/PIC (n = 5), owner & manager (n = 1), and staff members (n = 49). The profile of the staff members who completed the survey was as follows, nurse managers (n = 12), staff nurses (n = 10), student nurses (n = 2), health care attendants (n = 11), 5 were categorised as other (this included CNS, Intern nurse and clinical advisor), cleaning and catering (n = 2) and administrator (n = 1).

The health care facilities who responded were as follows - HSE facilities (n = 34, 49%) privately owned facilities (n = 30, 43%) and other types of facilities i.e., Sect. 38 and voluntary (n = 5, 7%).

Geographically most of these facilities were based in Dublin (n = 47, 67%), 13 other counties (Cavan, Cork, Donegal, Kerry, Kildare, Laois, Limerick, Louth, Mayo, Meath, Waterford, Westmeath and Wexford) in the Republic of Ireland were also represented. There are 576 facilities in Ireland (meaning we heard from 1 in 7.5 residential settings). Forty-five of the respondents said they worked at a multi-site facility. Almost 70% of staff had worked at their facility for over 2 years.

Residents/family members

Twenty-eight family members completed the online survey (15 daughters, 3 sons, 1 husband, 1 wife, 1 sister, 3 nieces, 2 granddaughters, 2 daughter-in-law). Two residents completed the survey. Five of the family members/residents were from a Health Service Executive (HSE) facility, 20 of them were from a privately owned facility and the remainder said other facilities (such as supported housing, and voluntary facilities). Just over half of the sample was Dublin based (55.5%) with respondents also from the following Counties - Clare, Cork, Donegal, Kildare, Kilkenny, Limerick, Offaly, Westmeath and Wexford. Eight of the respondents had lived at their facility for over 2 years, 11 of them had lived there between 13–24 months, and the other had lived there for between 6–12 months. 56% of the respondents said that COVID-19 had infected residents at their facility.

Qualitative interviews

Eleven one-to-one semi-structured interviews with family members were conducted remotely during December 2020. 8 females and 2 males consented to be interviewed regarding their experience of their family members care in residential facilities during the first wave of the pandemic. One participant was interviewed twice by two different researchers regarding her experience of care at both her mothers and her aunts residential care facilities. There was a mix of HSE and private run residential care facilities reported across the 11 interviews in Dublin and in other parts of the country. Two of the participants identified that their family members had died during the pandemic, one of which was due to COVID-19. No residents took part in the interviews.

Main findings

The main findings emerging from the study were integrated and are presented below.

Being prepared

Being adequately prepared to contend with the effects of the pandemic was regarded as essential by the majority of research participants. This meant good infection prevention and control protocols, sufficient and timely preparation and training, good management and governance structures, isolation and infection control resources, adequate staffing and access to medical expertise and support. One participant said

"I have a few nurses as friends and their friends are in charge of nursing homes – small ones that never got COVID. The only reason it never got COVID was that it was managed well. The same in anything. If something is managed well from the top, it will pass down through every level and the people they employ. They employ people that actually care." (Participant 3)

The percentages of staff who perceived their service as well prepared or ill prepared were roughly equal. Among those who identified a lack of preparedness, many staff and family respondents attributed the lack of COVID – 19 preparation to poor management and leadership, for example not having a pandemic plan/protocols, slow implementation of infection control measures/government guidelines e.g. visitor/staff movement restrictions and Personal Protective Equipment (PPE) training/provision. Fundamental governance issues were raised, for example; lack of communication with staff, lack of teamwork, low staff/patient ratios, high staff turnover, high levels of junior/ inexperienced/agency staff. The main reasons cited by staff as to why their facility was adequately prepared/not adequately prepared for the pandemic are captured in Figs. 1 and 2 below.

Disease spread, mortality and morbidity

Staff identified a higher level of spread and number of clusters occurring in state funded facilities. Some respondents felt that years of under-investment in state facilities had led to residents sharing bedrooms, poorly ventilated common areas which has both facilitated viral spread. Other felt that the transfer of infected patients from the acute hospital sector and movement of staff across different sites had resulted in increased virus spread. A high proportion of staff and family carers believed that the rate of infection could have been reduced by more effective/diligent infection control measures. Family members felt strongly that the residential care homes had not provided clear guidance regarding COVID-19 infection prevention and control protocols to their staff and that staff were not clear on how to use PPE;

"They still hadn't spoken to the staff about a uniform approach to handling people in a close situation, like mask wearing. They were doing it only for people with COVID, but it was the same staff dealing with non-COVID. It was very confusing. I think there were a lot of things that as director and head of nursing both of them should have taken a better hand. I think they were just coping with the fact that they didn't have enough staff and they were trying not to put a lot of pressure on the staff they had remaining." (Participant 7)

Advanced age and poor physical and mental health was cited as increased risk factors for higher morbidity/mortality among residents. Family members believed that residents who did not have family members to advocate for them were at higher risk during the pandemic.

Gaps in the service that are normally managed by visiting family members/ friends were highlighted. For example, my mother, who has limited mobility, spent several weeks in her room in isolation. Requests to be taken out to the gardens were often not met as staff were busy with family Skype calls

Inadequate access to medical support and expertise were also cited as reasons contributing to the spread of the virus at the facility. A third of staff surveyed reported that more could have been done to reduce the number of deaths that occurred. Some respondents felt that low paid healthcare staff living together in their shared accommodation resulted in limited/no opportunity to self-isolate.

Figure 3 below illustrates the main factors cited by staff as contributing to virus spread at their facility.

Comparisons between state and private provision of elder residential care during COVID-19

There was a marked variation in the perceived level of preparedness between state run and private facilities. Staff in private facilities reported higher standards of accommodation (space and single rooms), staff training, infection control practices and governance structures. However, a deficit in medical support and clinical leadership in private care facilities was a limiting factor.

Higher rates of clusters occurred in state facilities compared with privately run facilities, attributed mainly to congregated, unsegregated, poorly ventilated areas, frequent movement of staff and patients through various care units and poor uncoordinated governance in state provided facilities. A family member

described the infrastructure of their family members residential setting;

"The home is a small community hospital. 14 permanent residents and 14 respite care. It is 28. Half of those roughly are standalone wards, single bedded small rooms, and the other half are two person bedrooms...They didn't have a room per se that you could bring people in, visitors, and things like shared toilets. Structural deficits came home to roost during the COVID time and put extra challenges on the establishment. Not having en suite bathrooms, things like that. I don't know how they would have coped in terms of isolation rooms. They maybe had one room." (Participant 1)

However, it was evident that residents had better access to medical care, physiotherapy and occupational therapy/psychosocial supports in state run care than in private facilities.

Our findings showed that there was a perception of higher staffing levels in private facilities but analysis of the staff survey data showed no statistical differences across the numbers of registered nurses or Health Care Attendants (HCAs). Twenty-five of the facilities reported that the state had provided them with additional staff and that this was most welcome.

Impacts on residents

Mental health/social health

Staff reported that at least one third of residents were confined to their own room without company during the first wave of the pandemic. Although psychosocial services (occupational therapy, pastoral/spiritual care) were maintained in some settings, for many residents, these activities were suspended for wave one of the pandemic. Staff observed many adverse psychosocial impacts for residents and families, the most significant issue being that they were unable to see their loved ones during the pandemic. This resulted in loneliness and lack/loss of connection. Staff and family members reported that the majority of residents (98%) could connect remotely with their family members during the pandemic using mobile phones/smartphones for video calls, window visits and brief visitations in the garden or other outside areas of the facility. However, this apparent high level of remote connectedness was deemed to be of poor quality and unreliable by many family participants in the qualitative interviews. Family members placed great emphasis on the need to maintain direct contact with residents and felt that staff had prioritised the public health imperative over the psychological and emotional needs of residents and families and that their relational needs for human connection of residents were not adequately recognised or supported by staff.

"the whole situation is really worrying, it's really unsatisfactory, the social isolation, the lack of movement, the lack of activities. I asked again when I was on with the CEO, "Can we pay more money? Can we give voluntary contributions to try and bring people in to try and get people? Can you please encourage mum to walk? Can you encourage mum to go down to the lounge?" Participant 5

The interviews with families starkly demonstrated the impact of the visiting restrictions on connectedness with family members; not having the opportunity to see loved ones for long periods of time, grandchildren not being able to hold hands, challenges to maintaining meaningful relationships/intimacy. Speaking through Perspex or glass or using technology was identified as less than ideal, especially when residents were trying to communicate their fears of contracting COVID-19 knowing that other residents had died of the virus; anxiety about loneliness and isolation and fears of dying without their loved ones near. The cognitive and expressive abilities of residents were an important determinant of the success of remote visits and hearing and vision also played a role in this regard. The weather was also a deterrent to the quality of the connectedness especially if family members had to be in outside areas of the facility with no shelter. Many staff and family participants observed a decline in residents' mental health and attributed this directly to the visiting restrictions imposed at the time.

"They keep saying, 'She's alright. She's there, she's safe.' I said, 'Absolutely not.' My mother was used to seeing us all, and there is no way, now. Even if it comes back, and we are going to be allowed, whatever it was, one half an hour once a week, I said, 'I am not prepared to accept that.' I will be still up at the door the rest of the week, to talk through a door at her. She needs it." Participant 2.

Physical health

Staff and family members and families reported that the usual care of patients who did not contract COVID-19 was reduced or neglected during the period of the pandemic. It was clear from the interviews with family members that in the majority of cases overall health and wellbeing of residents deteriorated during the COVID-19 restrictions, more that they would have expected over that period in "normal times". While there was an acknowledgement that physical decline was to be expected in residents due to their age and pre-existing morbidity, participants described a marked and acute decline in their loved one's physical health during the COVID-restrictions which some found shocking and distressing. The prevailing description of physical decline related to weight loss, however other issues such as reducing mobility, pressure sores, dehydration, and generally the observation of an unkempt appearance were also described. This impacted on residents' physical and mental health and was very upsetting for family members.

"I could not believe what I saw. My mum had lost a lot of weight in that month; she was grey, drawn, she had weeping eyes, and her lips were all desiccated; very, very dry, dehydration. And I was really taken aback. I was thinking "God, how did she go downhill this quickly?" Participant 7

Some felt the responsibility lay directly with the staff caring for the resident. Staff cited reasons for the deterioration in care provision as resulting from staff shortages and lack of availability of medical interventions. Staff were distressed that they were unable to meet the palliative care needs of patients during the pandemic. Figure 4 below illustrates the impacts on residents as reported in the staff surveys.

Impacts on family members

Family members felt the impact of the pandemic on behalf of residents and themselves. Common emotional responses included fear, distress, anxiety, loneliness, helplessness, frustration and some participants experienced physical challenges such as being outside in all weathers trying to communicate via a window. A strong theme which emerged was the disruption to their customary caregiving role.

"we used to feed her. We would go up with the night time food. We would know what we would give her. She couldn't feed herself that well. You would have to be very patient and stay with her till she finished it. If she was left to eat it by herself, she probably wouldn't do it." Participant 3

The large extent to which family members had hitherto provided direct care, and the importance of this direct care to their loved one became apparent during the pandemic. The majority of families did not perceive themselves to be visitors, but regarded themselves as continuing in their care giver role in the residential environment. Therefore, the visiting restrictions caused huge frustration to family members and their inability to be directly involved in providing care to their loved one during the period of visiting restrictions was described by many as a contributing factor for the physical decline of the resident. This anger and frustration was amplified when families observed the mental and physical deterioration of their loved ones through lack of caring resources, yet, due to public health concerns and government restrictions, they were prevented from intervening and providing this much needed care.

"I don't hold that in any way against any of the staff there. They are doing their utmost. But I do feel, yes, she wasn't... She can't possibly be getting the stimulation that she would have been getting from our family going into her... every night, she had at least two members of the family with her for two or three hours. So, obviously, that all was stopped. Absolutely, she went downhill from there." Participant 2

A family member who completed the survey added the following comments in the open text boxes which supports this theme also

"Gaps in the service that are normally managed by visiting family members/ friends were highlighted. For example, my mother, who has limited mobility, spent several weeks in her room in isolation. Requests to be taken out to the gardens were often not met as staff were busy with family Skype calls or latterly family visits. Seemingly minor issues such as having the batteries in a TV remote control replaced took weeks and several phone calls. While not critical in terms of a global pandemic, being unable to change the channel or adjust the volume of a TV is unnecessary mental hardship. Similarly, it takes several calls to ensure that the radio is not unplugged".

Staffing levels

Multiple issues relating to staffing were highlighted, including low staff-to-patient ratios, due to staff shortages arising from self-isolating, illness, redeployment and not showing up for work. One site reported that there were only two healthcare assistant (HCA) staff to thirty residents some days during the pandemic. A family member at interview noted that

"when you don't have enough staff, people get neglected.... What I would worry about is that they are not even registered as COVID deaths, but they are COVID related in a way because if you don't have the staff, you can't take care of people to the level. I can say just looking, observing mum not as mum but as a body, that was a neglected elderly person." (Participant 7)

Other staffing issues of concern included high turnovers, too few senior staff, staff who lacked the specific skills required, as well as too many agency staff. Family members highlighted the need for a more stable staffing structure which would ensure familiarity with the facility and the resident's individual needs and wishes. These deficits were of major concern to the majority of family members interviewed.

"There was no staff there, which meant the staff from the other floors had to go up. That is how it happened. Staff from other floors had to cover for the floor that was empty. That is how I reckon it spread. It was on every floor." (Participant 3)

Because of the visiting restrictions, many care interventions customarily performed by families/visitors e.g. help with eating, hygiene and mobilising were now reduced or absent. This was a major source of distress to family members.

I don't think they should have shut off families. I don't think the lockdown should have... I think we should have been part of the testing. If the carers can go in and be tested routinely, they could have nominated a family member to do the same. I know it would cost, and all of that, but they shouldn't have let go of the care that the family were giving. We are part of it, instead of shutting us out of it." (Participant 4)

The lack of medical and ancillary/ psychosocial support interventions put additional pressure on staff workloads. However, the state provision of some additional staff during this period was welcomed and staff participants reported that the redeployment of student nurses as HCAs really helped to ease the burden. Many family participants praised the work of the facility staff who they perceived as committed and working to the best of their abilities to keep residents safe in a confusing and stressful context. Staff distress, emotional and physical exhaustion was observed by residents' family members and reported in their interviews. These reports were accompanied by a high level of concern and care for the wellbeing of staff.

"They are doing their utmost... We keep talking about mentally, and I can see it. I can see it, as plain as the nose on my face. I can see that the staff are burnt out. I would be too, if I was in there. They are doing their level best, but they are burnt out." (Participant 2)

Numerous respondents felt that HIQA needed to be more involved and could have helped on the front line. Others felt that additional Allied Health Professional deployment of social workers, occupational therapists, physiotherapists etc to support frontline nursing staff and Health Care Attendants (HCAs) should have taken place.

Impacts on staff

The staff survey showed that staff had many concerns and challenges during the pandemic. The most frequently reported adverse impact was the level of stress and burnout experienced. This was followed by concerns about virus transmission, trauma and fear about death of residents and self. Many alluded to the personal toll it had taken on them. This ranged from information overload, to physical and mental exhaustion, to supporting their peers and covering for colleagues while off sick in addition to managing their own fears. Maintaining work life balance was very difficult for staff. It was evident that the majority of staff had put the needs, fears and concerns of residents above their own needs, fears and concerns. Many staff expressed their distress at witnessing the impact of the virus on vulnerable people who were traumatized, alone and fearful. Others were angry and distressed about the numbers of care staff who contracted the virus and felt unsupported and that their well-being and safety had not been valued or protected. Some staff felt traumatised; perceiving that it would take them years to process and recover from the direct and indirect/occupational impact of COVID-19.

I can see it, as plain as the nose on my face. I can see that the staff are burnt out. I would be too, if I was in there. They are doing their level best, but they are burnt out. Here we go with the second wave.” (Participant 2).

The impacts on staff as captured in the staff survey are illustrated in Fig. 4.

Trust and responsibility/blame

Most staff perceived that the virus itself was responsible for the morbidity and mortality rates among residents and that the age and vulnerability of residents made them more vulnerable. Some expressed anger about what they regarded was the slow governmental response in their sector. Many staff felt that government agencies did not prioritise the health and safety of residents and staff, particularly in wave one and this caused huge anger and distress. Staff placed trust in their own services in which they worked and the majority (89%) said they would trust their facility to provide safe care for residents in the event of future waves. There was no statistical difference between state and private care in the level of trust expressed.

Family members questioned the role of the relevant government agencies and the priority and pace of the response in this sector. Several family members likened the experience of the residents to being ‘prisoners’ with no rights and no freedom. One family member noted; *“that there had been more public disquiet about the closing of pubs than there had been about the fatality rates in nursing homes”*.

Others referred to the limited time that residents have left in their lives and that infection prevention and control measures need to be balanced with quality of life and time remaining to be spent with their loved ones. It was articulated that facilities with good leadership/management/governance prior to the pandemic fared better than with those with obvious poor performances prior to it. Nonetheless, a high percentage of family members said they would trust their facility to provide safe care for residents in the event of future waves of the COVID-19 pandemic. Figure 5 below illustrates where staff felt responsibility for the deaths at their residential centres lies.

Role of the media

While media reports were regarded as important in highlighting the issues in residential care in relation to the rapid viral spread and the need for prompt intervention, some staff and families were distressed at the level of media sensationalization and blaming. These headlines of failures and fatalities caused distress to residents and families and made some staff feel ashamed and embarrassed by where they worked. Significantly, in this context of blame and shame, a small number of participants in our study reported that attempts were made to hide the fact that the virus was in their facility and that it would have been better to have “told the truth” earlier.

Priorities for future waves

Priorities include support in securing PPE, less movement of staff and patients, earlier visiting restrictions, rapid access to testing, more local accountability and better support from government agencies. Some additional responses included the need for a higher profile of the impact of the virus on nursing homes in the media and earlier provision of appropriate accommodation for low paid care staff. In relation to visiting restrictions, and in contrast to the findings of the staff surveys, family members who were interviewed placed much greater emphasis on the need to maintain some direct contact with their loved one.

Discussion

The pandemic had a disproportionate impact on residential care facilities for older people in Ireland and internationally. The experiences and perceptions of those providing and those receiving care are central to informing effective and person centred pandemic strategies and interventions. This research provides novel insights grounded in lived experiences regarding levels of preparedness, factors contributing to the spread of the virus, impacts of COVID-19 and the associated effects on residents, their family members and staff. The study also highlights the governmental and health system response to the pandemic in this sector and informs priorities for future waves/future pandemics.

Our findings are reflected in other studies, for example; ineffective/slow implementation of recognised infection control measures by government and residential service sectoral management (7), lack of/slow implementation of service pandemic plans/protocols (8) excess staff/visitor/patient movement (9), lack of/ineffective staff pandemic training/support (10; 6) and issues with staffing levels and skill mix (11).

Other longstanding governance issues were highlighted, for example; poor management awareness of service characteristics, absence of communication with staff and a lack of teamwork. Wider systemic failures were also identified in relation to infrastructure and interdisciplinary support. Participants identified under-investment in state run accommodation which had facilitated to virus spread in congregated settings. Conversely, privately run facilities appeared to have better estate infrastructure but did not have the interdisciplinary network, medical and training support available to the state run services. Daly’s (7) study of COVID – 19 in nursing homes in the UK points to years of austerity and resource cutting, weak regulation and the de-politicisation of social care with an

accompanying pre-eminence of acute/medically focused state National Health Service (NHS) system. This critique resonates with Ireland where 79% of residential care provision is provided by private care facilities. There were marked differences in the private and public sector in terms of clinical and interdisciplinary expertise and infrastructure. Other studies highlight a lack of recognition/inclusion of the residential home sector in policy making, in particular Kelleher & Twomey (6) identify poor regulation of standards in the Irish private residential home sector. This has resulted in a lack of investment in staff recruitment and training, poor healthcare support and out of date infection control regulation and resources. These authors call for greater regulation and transparency regarding the governance of the sector and call for the residential care home to be integrated into the wider healthcare system so that older people can have their healthcare needs met regardless of their care setting. There have been many anecdotal and some research based observations that the COVID-19 crisis generated improved interdisciplinary relationships and more connected service provision. This was evident in our findings in that participants welcomed the support of the Irish Health Service Executive (HSE) to the private residential sector in the provision of staff and medical support (HSE COVID-19 Response Teams) and has led to wider calls that this level of partnership and cohesion should continue.

The adverse effects of the pandemic on the social functioning being and mental health of a range of populations has been widely reported Brooks *et al* (12). Older people, and particularly those in residential care were further socially isolated and unable to access alternative measures of psychological support due to cocooning guidelines and visitor/contact restrictions in residential care (13). The high levels and detrimental effects of isolation among nursing home residents in COVID-19 has been reported elsewhere (9; 14). Tan & Seetharaman, (8) identify the challenges for people with dementia and communication/behavioural issues in the context of the pandemic and report an increase in restraint use and falls due to imposed isolation. In our study, physical and mental health impairments as well as declining sight, hearing and voice projection seriously hampered successful communication in this socially distanced technological world. Although staff perceived that e-technology and online communication was adequate and effective, family participants countered this staff impression, reporting that this system was dependent on staff availability and the ability of residents/families to use the technology. Similarly, speaking/waving through windows and outside visits during the winter months were regarded as frustrating and potentially damaging to health.

Although it was not possible to interview residents for the study, families and staff identified a range of emotions experienced by these elderly people which are echoed in other contemporary research, for example loneliness and disequilibrium at reduced family contact, fears of contracting the virus, grief and shock at the death of co-residents and fears of dying alone (15). The opportunities to receive comfort, reassurance, presence and human touch were vastly diminished. Parks & Howard (15) emphasise the importance for elderly residents 'to have access to those who love them and view them as special, particular individuals', and that these connections that often hold the identities of the elderly residents in place. Many staff and family participants observed a decline in residents' mental health and attributed this directly to the visiting restrictions imposed at the time. Family members felt that care staff prioritised the public health imperative over the psychological and emotional needs of residents and families and that their relational needs for human connection of residents were not adequately recognised or supported by staff. Initiatives such as limited visiting/appointing a designated visitor with full infection control measures and antigen testing have been suggested and used during the pandemic (16). Timely, honest and consistent communication between staff, residents and families throughout the pandemic experience is essential. Studies also point out that the pandemic has highlighted the need for advance planning with residents/families regarding end of life care (17).

In addition to mental health impacts, the deterioration of residents' physical health was a strong finding from our study with family participants expressing shock and distress at this rapid decline. Some of this deterioration may have been COVID-19 related but in many cases it resulted from the reduction or absence of usual care. Our study highlights the extent to which family members had hitherto provided direct care, and the importance of this to their loved ones. The contribution of families and partners to elder care in residential homes has been highlighted by Philips *et al* (18) who describe family caregivers as the "invisible workforce". (19) and O' Caoimh *et al* (20) claim that the nature of this family caregiving role within residential care home settings is poorly understood, undervalued and under researched. Many families do not perceive themselves to be visitors, but rather regard themselves as continuing in their care giver roles in the residential environment. Davies & Nolan (21) and Fetherstonhaugh *et al* (22) report that families identify as advocates for their vulnerable elderly relatives. In our study, family participants voiced concern that they were not in a position to advocate for their relatives COVID-19 related care. Several family members likened the experience of the residents to being like 'prisoners' with no rights and no freedom.

The loss of the caregiving role was a major source of distress to family members particularly when they observed the mental and physical deterioration of their loved ones which arose from them being prevented from providing care. This is a novel and important finding from our study and supports the recent research by O' Caoimh *et al* (20) who found that COVID-19 visiting restrictions had negative psychological effects on family visitors because of disrupted caregiving roles.

It is important to note that many family participants perceived the staff as committed and working to the best of their abilities to keep residents safe in a confusing, stressful and under-resourced context. Staff distress, emotional and physical exhaustion were observed by family members and reported in their interviews. As in the research by Kelleher and Twomey (6), these reports were accompanied by a high level of concern and care for the wellbeing of staff.

Our findings in relation to staff wellbeing reflect those of Navarro Prados, Jiménez García-Tizón & Meléndez, (11) in that staff experienced information overload, physical and mental exhaustion, as well as fears about personal and patient contagion and death. Staff expressed anxiety at witnessing the impact of the virus on vulnerable people who were traumatized, alone and fearful and distress that they were unable to meet the palliative care needs of patients during the pandemic. The most frequently reported adverse impact was the level of stress and burnout which compromised staff physical and mental wellbeing, a finding also reported by Maben & Bridges, (22) and Tan *et al* (9). Despite the mammoth challenges they faced staff kept going and appeared to put the residents needs and safety considerations ahead of their own. This is echoed in a UK study which reported on the dedication of staff and their commitment to fulfil their duty of care which was described as 'Herculean...the extra work and hours that have been put in to support the NHS (23).

Kitson, Huisman-de Waal & Muntlin (24) highlight that the neglect of frontline nurse worker stress would not be tolerated in other high-stress professions such as the army or police. Nurses in our study and other COVID-19 elder care research cited feelings of abandonment by government and the wider healthcare

sector (25). Delays in attaining quality PPE, infection control equipment and training led them to feeling uncared for and undervalued (10).

In our study staff and families were distressed at the level of media sensationalisation and blaming. Headlines of failures and fatalities caused distress to residents and families and feelings of shame to staff regarding their practice environment their level of competence. The negative and possibly dangerous effects of this stigma and shame is evident in the attempts made not to disclose the fact that the virus was in the facility.

Conclusion

Many of our findings echo the findings of the HIQA report (2) and the Expert panel report (6) about the impact of COVID-19 in this sector which caused much anxiety, grief, fear and isolation for residents, their families, friends and carers and agree broadly with the wide ranging actions that are urgently needed in the sector.

Recommendations

Visiting restrictions should be balanced with the rights and needs of residents.

Facilities should recognize the important supplemental role of family members

All sites should facilitate access to one designated family member who would visit residents on an ongoing basis even in the event of a pandemic, this person would be mandated to avail of basic training in the principles of Infection Prevention and Control so that in the event of future outbreaks they would already be equipped with the skills required.

Mandatory staff skill mix requirements and staff-to-patient ratios should be agreed and implemented at national level for residential care settings

Residential care settings should proactively work on strategies to enhance the retention of their staff and reduce their reliance on agency staff to improve the level of staff familiarity with residents.

Specialist care programmes for those working in residential care settings should be developed and mandatory training for all staff.

Infection control protocols and staff training should be up-to-date at all times and ready to deploy by all staff.

Agreed national principles and minimum standards should be implemented for improving governance and management in residential care settings.

Agreed national principles and minimum standards should be implemented for improving infrastructure /facilities. This should include considerations around single room provision, shared spaces and outdoor spaces with coverage.

Psychological care packages for staff and residents should be developed urgently and offered to staff, residents and family members.

Residential care settings should upgrade their IT infrastructure and upskills staff and if possible residents and family members.

Agreed minimum access to GPs and other allied health professionals

Holistic patient centered and ethical decision making at all times

Abbreviations

Republic of Ireland - ROI

Health Information and Quality Authority - HIQA

Person in charge – PIC

Health Service Executive – HSE

Personal Protective Equipment –PPE

Health Care Attendants - HCAs

Declarations

Ethics approval, consent to participate and consent for publication

Ethical approval for the project was granted from the DCU Research Ethics Committee, including consent to publish the findings.

Participants consented to the data generated being published.

The manuscript does not contain data from any individual person so this is Not applicable

Availability of data and materials

All study materials can be seen at the URLs provided in the appendices below. Raw data and analysis files are available to view on request from the authors.

Competing interests

There are no competing interests to declare

Funding

This study was self-funded by the authors

Authors' contributions

MRS had the original idea for the study, she designed the study, applied for and obtained ethical approval, she designed the materials, administered the survey, and co-analysed and interpreted the data and co-wrote and approved the final manuscript.

AB co-analysed the quantitative data.

CW conducted, analysed and wrote up the qualitative interviews

MV conducted, analysed and wrote up the qualitative interviews

BC contributed to study design and co-wrote the final manuscript

PB supported the set-up of the online survey on qualtrics

AS supported the design of the quantitative survey

All authors approved the final manuscript

Acknowledgements

The authors would like to acknowledge the residents, family members and staff who participated in this mixed-methods study.

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Appendices

Appendix 1 - Staff survey

https://drive.google.com/file/d/1-Q7bRQba6DYbZQt_RV07WwvIki_vvjg0/view?usp=sharing

Appendix 2 - Residents/Family member survey

<https://drive.google.com/file/d/1oUG9n7D6oSOrobUVgJjc6oRbjgWGAPr/view?usp=sharing>

Appendix 3 - Qualitative interviews with family members - interview topic guide

https://drive.google.com/file/d/14TCLvsUvXYKUTeeFpsv0teN2he5nPUp_/view?usp=sharing

Figures

Figure 1

illustrates the reasons cited by staff as the reasons why their facility was adequately prepared for the pandemic.

Figure 2

illustrates the reasons cited by staff as to why their facility was not adequately prepared for the pandemic.

Figure 3

illustrates the factors cited by staff as contributing to virus spread at their facility.

Figure 4

illustrates the main adverse impacts on residents as reported in the staff surveys.

Figure 5

illustrates the main adverse impacts experienced by staff.

Figure 6

illustrates where staff felt responsibility lies for the deaths at their residential centres