**AUT CENTRE FOR
PERSON CENTRED RESEARCH**

The impact of Covid-19 on people experiencing long-term neurological impairment or other age- related neurological decline and their support organisations

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A thematic analysis of qualitative data generated from members and staff

This project
was funded by:

Brain Research
NEW ZEALAND
Rangahau Roro Aotearoa

Project Team

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Project development

Through consultation with 5 NGOs who collaborate with Brain Research New Zealand (BRNZ), this project was developed with the intention of accessing a snapshot of the NGO management and experience of the 2020 Covid-19 response in Aotearoa New Zealand. These NGOs are:

Age Concern, Parkinson's NZ, Huntington's Disease Association Auckland, Alzheimers NZ, and the Stroke Foundation.

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Report Summary

Five NGOs collaborating with Brain Research New Zealand (BRNZ) participated in this research project to understand the impacts of Covid-19 (and the Aotearoa New Zealand (A/NZ) Government response) on their membership and the organisations.

These organisations have an ongoing commitment to delivering excellent and tailored support of people with neurological conditions, age related neurological decline, and/or the elderly. This research project was developed in consultation between these NGOs and the Centre for Person Centred Research at Auckland University of Technology to help further enhance the ongoing Covid-19 response by the NGOs.

Research Questions

1. Explore the experiences of Covid-19 and the associated pandemic response from the perspective of people and whānau living with age-related neurological impairment and the organisations that support them.
2. Make visible the current and future impact of Covid-19 on people and whānau living with age-related neurological impairment and the organisations that support them.

Interviews with key informants (KI) among the NGO staff, and online surveys with the NGO membership were thematically analysed to offer insight into the impacts of the pandemic and response on these groups. Five themes were produced from this analysis that are explored in detail in the extended findings section of this report. These themes were:

Who's the pandemic response for anyway?

Although information and communication from government sources was considered to be clear, robust, and appropriate, navigating the new normal was a drain on energy for NGO membership. The pandemic response was often framed by participants as designed for the majority of the population, with members often feeling marginalised or located as 'vulnerable.'

Rethinking business as usual in the new normal:

The Covid-19 restrictions and the pandemic itself, gave opportunity to rethink and reflect on what was meaningful and valuable. This theme reflects on the ways the NGOs and the members themselves saw this period as a time to do things differently, or at least clarify what was working well for them in a novel, high pressure situation.

The pandemic amplified individual, social, system level gaps and problems:

There was a wider acceptance among all participants that the pandemic and the response led to an amplification of existing problems across multiple spheres. This meant that those already on the margins or vulnerable due to reliance on support systems and structures were more likely to struggle under the restrictions.

Elbow grease and the smell of an oily rag: Offering care during the pandemic response

The work of the NGOs was critical as was their deep sense of commitment to this work. Irrespective of the NGO strategy, this work was essential and often involved supporting the most vulnerable.

A whole new world of technological support:

A turn to technological solutions became paramount for the NGOs to engage with their membership. For many members, their experience of the pandemic was shaped by their access to and familiarity with these technologies. A wider focus on reducing digital poverty was viewed as central to improving the experience of future lockdowns.

A number of impact statements and recommendations for the NGOs have been drawn from the evidence within these themes, and will make up the next sections of this report. These take into consideration the shift from the original Alert Levels to the new Covid Protection Framework.

Impact statements

In this section, we will explore some of the specific impacts of Covid-19 and the government response on the NGOs and their memberships. Using the thematic narratives as an organising framework, we have identified a number of salient features of the NGO response that are worth considering in present activities and into the future.

Who's the pandemic response for anyway?

- The government response, while robust and clear, needed significant tailoring by the NGOs for their memberships.
- Tailoring in most cases involved the development of an information infrastructure.
- The ongoing psychosocial impacts of navigating the pandemic and response by members continues to be a significant feature of NGO support of membership.
- Members of the groups often felt marginalised by the *general* guidance of the pandemic response, and the inherent assumptions embedded within that guidance.
- The shifts between various Alert Levels were complex for members.
- The discourse of vulnerability did not give tools to navigate risk, and instead increased fear among various members.

Rethinking business as usual in the new normal:

- The importance of taking stock and reassessing life trajectory is common in crisis moments – this was evident in the members' data.
- When 'business as usual' could not be maintained, this provided opportunities for to rethink the status quo. This contributed to service improvements.
- The lockdown periods and the return to lower Alert Levels (1 and 2), often gave time to understand what was working for members.
- As the response continued, emphasis started to shift toward wellbeing of NGO staff rather than maintaining workloads
- Business-as-usual funding does not account for increased demands on the NGO workforce.
- Business-as-usual funding does not account for constraints placed on some funding sources and the competition orientated funding environment.
- A by-product of the response was enhanced organisational digital literacy and information systems.

The pandemic amplified individual, social, system level gaps and problems:

- There was a general sense that existing cracks in systems and gaps in care were made evident or amplified by the pandemic and the response.
- In many cases these gaps would ordinarily be filled by people's hard work and willingness to go above and beyond.
- Appropriate social support of the most vulnerable is an essential service that did not receive the same level of access or capacity as clinical support.
- The vulnerability and potential for burnout among formal and informal carers was emphasised by key informants and members.
- Those members who were already vulnerable had this vulnerability intensified by the pandemic across a number of metrics.
- The impacts of major life events (e.g., loss of a family member) and transitions (e.g., relational breakdown) were amplified by the pandemic, making those events much more complicated.
- Increased surveillance by the wider population meant older people and those with neurological conditions often felt stigmatised or marginalised.

Elbow grease and the smell of an oily rag: Offering care during the pandemic response

- The data evidenced the *critical* and *essential* nature of the work performed by the NGOs over the pandemic period.
- New systems and programmes developed in response to the Alert Level environment were innovative and supportive of memberships.
- The relationships between NGOs and their memberships enabled an in depth understanding of the needs of these populations and where those needs were unmet.
- This support was readily verified by members and those that support members (i.e., whānau, informal carers).
- Navigating the new intensities of the pandemic response is a form of invisible labour that is both draining and under recognised.
- Changes to the funding environment involved navigation, adaptability, and prioritisation.
- Bolstering of existing work or recognition of labour rendered invisible were not areas where funding was readily available.

A whole new world of technological support:

- An increased reliance on digital infrastructure defined the experience of individuals and organisations in 2020 and 2021.
- Digital literacy (and lack thereof) had the potential to undermine the safety and wellbeing of many NGO members.
- Wide ranging support for enhancing the digital literacy of individuals and increasing organisational digital literacy was not a feature of the pandemic response for many services.
- Often individualised orientations to expectations of increased digital literacy meant many people (and their needs) became invisible in the pandemic response.
- NGOs increased the sophistication of their own organisational digital literacy, but became increasingly aware of a need for supportive infrastructure for their members.

Recommendations for present and future work

Although these recommendations draw directly from data relevant to the Covid-19 response, they are likely to be relevant in the context of any comparable crisis. Indeed, some recommendations are structural things that, if implemented, would more generally support the development of a more resilient sector. This was evidenced in some KI comments that spoke of the Christchurch earthquakes as providing impetus for some organisational changes that proved beneficial for the Covid-19 response.

Design a response that addresses, rather than exacerbates, the cumulative impact of vulnerability including:

- Taking an intersectional approach when designing our crisis response so that equity is built into the response from the outset – see [1] for a useful reflection on intersectionality in the context of the Covid-19 pandemic
- Targeted funding and programmes focused on the *most* vulnerable
- Working with NGOs to develop tailored information that addresses the unique and particular needs of their memberships
- Engaging with essential services (e.g., supermarkets) to aid understanding of the range of diverse experiences and capabilities of people within their communities and develop tools to support them to optimise access to their services in ways that minimise anxieties for diverse populations
- Pre-emptively address public attitudes in nationwide communications
- Developing psychosocial resources that organisations can draw on to help manage ongoing anxieties and other mental health outcomes.

Recognise and invest in the critical role that NGOs play in supporting high need populations in the absence of other readily available supports including:

- Valuing and drawing on the in-depth knowledge NGO organisations have about the unique and particular needs of their memberships to more adequately respond to system gaps and failures in any future response
- Ensuring there are sources of funding need to be available that account for increased workloads, system gap filling, and broader strategies for change needed under Alert Levels and Covid Protection Framework
- Aligning NGO strategy with new Ministry for Disabled People to ensure that the needs of membership are understood through more than a health lens
- Developing structural supports that recognise the increased need for social as well as health related care in crisis.

Develop structural supports to manage impact on NGOs including:

- Taking the opportunity to consolidate learning so far to inform our future response
- Identifying opportunities for identifying tiered levels of support that can be tailored to different groups within memberships
- Looking for opportunities for greater focus on *inter*dependence among NGOs, despite competition orientation that exists in funding environment e.g., development of a shared information infrastructure, digital literacy programmes, and databases
- Engaging in reviews of best practice for telehealth with people in populations with complex needs and developing tools to support telehealth practice.

Anticipate challenges and complexities that will arise as we transition to the new Covid Protection Framework and beyond including:

- Investing in strategies which support transition when levels change
- Providing resources for making sense of the Covid Protection Framework, given likelihood of similar need for navigation by memberships e.g., a ‘one-stop-shop’ of tailored information for each phase of the Covid Protection Framework could enhance the experience for members (similar to sector-specific advice already being produced)
- Preparing for the likelihood of ongoing and sustained impacts for higher need populations as a direct consequence of both the pandemic response itself, as well as resulting from the inevitable spread of Covid-19 following a strategic shift from elimination to suppression and vaccine-based mitigation of the virus
- Anticipating the financial pressures NGOs are likely to face given the inevitable downstream effects the economic impact will have on their philanthropic funding sources.

Background

The purpose of the research was to explore the experiences of people and whānau living with neurological impairment during the Covid-19 pandemic and the perspectives of the organisations that support them.

Given the lockdown periods were novel and challenging for most people, the research team and NGO collaborators, wanted to discover what impact the Covid-19 lockdowns had on the lives of these populations. The Aotearoa NZ context had relatively unique responses and outcomes in relation to the virus. [2,3] This means reliance on international evidence is not always useful when informing service improvement and membership support.

It was agreed that findings would be analysed and presented in a report for the organisations and subsequently made available to the wider community. One potential outcome of working with stakeholders is the generation of findings which could inform government policy and organisational funding in future [4] and we envisaged that this work could contribute in such a way. Collaboration with community stakeholders, where they are involved with design and implementation, recognises the strengths of different partner organisations and how each perspective can contribute to a project. [5] This project was designed with input from stakeholder groups at each stage of development, including data collection and analysis. This included access to membership, referring members of staff who could best articulate the experience of members and the NGOs, and feedback on preliminary findings.

Involving multiple stakeholder groups in research provides important benefits to the researchers and the organisations involved. There is a potentially strong public endorsement from the outset which aids the recruitment process. Credibility for the research is improved, while also being beneficial to the stakeholder organisations, who can in turn, demonstrate a connection with university researchers. [4] Although expectations and organisation-specific protocols from a group of stakeholders can be diverse and challenging, maintaining feedback and engagement potentially leads to significant insights, which may eventually inform policymaking at a government level. [4]

This project began in discussions with five collaborating non-government organisations (NGOs), all of whom have members with a degree of neurological impairment. There was an explicit intention to investigate and make visible the unique and specific impacts of Covid-19 lockdowns during 2020 on this population. This report will present key themes from the data and make practical recommendations that will support the NGOs reflection and further development of their service provision.

The five organisations are:

Age Concern is a charity dedicated to people over 65 years, their friends and whānau. They promote dignity, wellbeing, equity and respect and provide expert information and support services in response to older people's needs while offering expertise and knowledge of available services for older people as well as social activities.

Source: ageconcern.org.nz

Alzheimers NZ represents people living with dementia, at a national level, by raising awareness of dementia, providing information and resources, advocating for high quality services, and promoting research about prevention, treatment, cure and care. Local Alzheimers NZ organisations provide support, education, information and related services directly to members of their communities who are affected by dementia.

Source: alzheimers.org.nz

The Huntington's Disease Association Auckland is a not-for-profit charity supporting individuals and families affected by Huntington's Disease (HD). The association's aim is to maximise the quality of life of people living with HD by:

- Ensuring those who need it get the right support services and medical attention;
- Enabling others to understand the disease; and
- Furthering research to manage and cure Huntington's Disease.

Source: hdauckland.org

Parkinson's NZ offers education, information and professional support to people living with Parkinson's including their caregivers, friends, and families. Parkinson's nurses work closely with the person with Parkinson's and their carers to deliver individualised care that upholds their health and lifestyle. The nurses liaise with health professionals that treat Parkinson's in the community, including speech-language therapists, occupational therapists, and physiotherapists.

Source: parkinsons.org.nz

The Stroke Foundation is the national charity in New Zealand solely dedicated to the prevention of and recovery from stroke. The organisation actively promotes ways to avoid stroke and dedicates themselves to working closely with stroke survivors, their family/whānau and carers.

Source: stroke.org.nz

Covid-19 and the context of this analysis

The Covid-19 pandemic, and the various responses to it internationally, have highlighted and exacerbated the challenges experienced by some older adults and people with neurological conditions. The highly specific and unusual conditions of the responses have included social distancing mandates and high reliance on technological infrastructures to support this distancing. The need for this rapid shift to social distancing to manage the virus within the community cannot be disputed, however, it has resulted in other effects that have ongoing ramifications. [6]

For instance, the shift to a digital environment has proved problematic for populations who have difficulty using internet technologies and devices. [7,8] People with cognitive limitations are especially vulnerable to reduced capacity to learn or use technology, and may require staff assistance in aged care facilities or carer support to manage. [8] This has created what some authors have referred to as a “double burden of exclusion” – which has implications for NGOs that work specifically with these groups.

Further, research evidence demonstrates that stress related conditions, such as anxiety and depression, which occur at higher rates among people with neurological conditions, are reduced through social interaction. [8,9] Further, exercise and socialisation are considered to be the key features of programmes for people with neurological conditions, aside from medication. There is strong evidence these elements have powerful mitigating impacts on symptoms of neurological conditions. [9,10] Given the constraints created by lockdowns and Alert Level restrictions in Aotearoa NZ, as in other parts of the world, it is highly likely that NGOs working with these populations will see some impact on their memberships.

Methodology and Methods

Design

This project uses a Qualitative Descriptive Methodology to explore the research question. The study incorporated an online survey seeking to capture the perspectives of people and whānau living with neurological impairment, and key informant interviews with purposively sampled representations from collaborating organisations to explore the research question. Reflexive thematic analysis [11,12] was used to analyse interviews, and the survey questions.

Data and participants:

All data were collected between February 2021 and July 2021, marking almost a year following the first lockdown and experience of various Alert Levels in all regions.

Online survey (n=72) Paper survey (n=26)

Survey design:

We created a short, qualitative survey with 6 open-ended questions, administered online via Qualtrics. We also made a paper version of the survey available. After giving their consent to take the survey, participants were first asked a series of demographic questions before the survey questions began.

The survey itself included questions around participants' experience of Covid-19 especially during lockdown periods and the associated pandemic response, the impact on them or their family/whānau, their experience of and access to services over this time, and perceived current and future impact of the pandemic. Participants were able to respond in as much or as little detail as they wanted to.

Participants:

Adults (>18 years) living with age-related neurological impairment and their whānau were eligible to take part in the survey.

Recruitment:

Collaborating organisations shared the survey with their members through their newsletters and social media pages and invited their participation. We also held three community events (in Auckland, Wellington, Dunedin) where people and whānau who were members of the NGOs, were invited to participate. The events provided an opportunity for those who either did not wish to, or did not have capacity to participate in an online survey to take part in an interviewer-administered survey. The events provided space for participants to connect with other people and whānau and were an opportunity to give back to the community.

In Auckland, we worked with the Huntington's Disease Association (HDA) to join them in their annual day out as an opportunity to present the study and surveys, while attendees (HAD and Stroke Foundation members) had the opportunity to listen to a speaker (Prof Sir Richard Faull) and wander around the zoo. In Wellington, we arranged a morning tea at Wellington Museum and invited Parkinson's NZ and Age Concern members to attend. After listening to our speaker for the occasion, Prof Mark Weatherall, attendees were able to wander around the museum. A very similar event was held in Dunedin at Toitū Early Settlers Museum, with afternoon tea and speaker A/Prof Yoram Barak, for the Alzheimers NZ Otago members.

At all these events, opportunity was given for members of the organisations to interact with each other, with the speaker and with the researchers regarding the study.

Key informant interviews (n=10)

Interviews:

Key informant (KI) interviews took place via Zoom as this was most logistically viable. Research evidence suggests that there is little difference between interview data collected from different modalities. [13] In total, we conducted 10 interviews, with 11 participants, across the 5 NGOs. Interview questions followed a semi-structured interview style, but included: What has worked well or not so well? How has the pandemic impacted on your service provision? What stories can you share about the experiences of your members? Interviews were audio recorded and then transcribed.

Participants and sampling:

Participants invited to take part in a semi-structured interview were key informants in their organisation (having been referred as a possible participant by our collaborating partners) with depth and breadth of experience on the organisation's pandemic response. We purposively sampled for one person in each organisation who could speak to the organisational level and sector impacts of Covid-19 and the associated pandemic response, and another person who interfaced with communities who could share their insights on impact at the ground level.

Data Analysis:

We drew on a qualitative approach (that is, a narrative-based approach, as opposed to statistical representation of participant responses), which is common in psychology research and focuses on detailed accounts of people's lived experiences and sense-making. Specifically, our research design was informed by a form of thematic analysis developed by Braun, Clarke, and colleagues [11,12,14] who have proposed the following steps:

1. **Familiarisation with the data:**
   A thorough reading and re-reading of the data, with extensive notes taken of initial impressions.
2. **Coding the data:**
   Generating labels or 'codes' which describe or interpret key ideas in the data
3. **Constructing prototype themes:**
   Clustering codes together that reflect a prototype of a larger idea or potential 'theme' that can then be tested.
4. **Reviewing themes:**
   Checking themes for appropriate representation of the data, and are shaped to describe the data.
5. **Defining and naming themes:**
   Refining each theme and describing it in the context of the overall 'story' of the analysis.
6. **Producing the report:**
   Refining the overall narrative, weaving in extracts to illustrate key points and ideas.

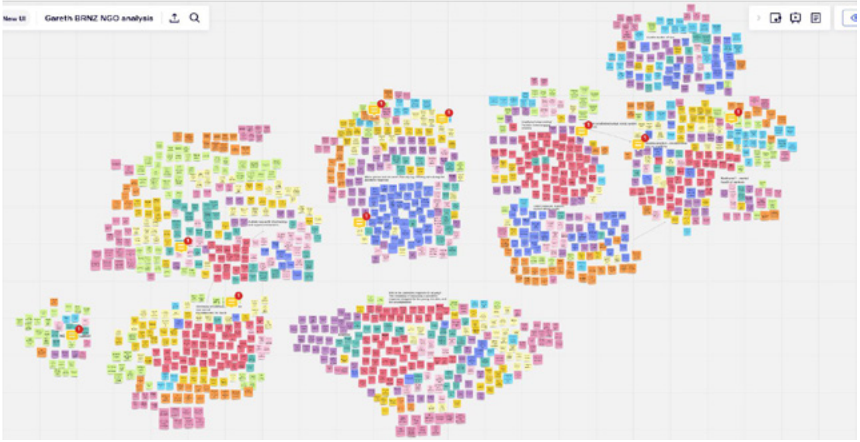
These steps are recursive and iterative and help facilitate engagement and in-depth understanding of the dataset. The result of this analysis is a collection of themes, including interview and survey extracts, and researcher interpretations, which describe the key features of the interviews. Themes are understood as patterned meaning constructed from the data around a central organising concept, and extracts used are representative of these concepts. At points throughout the analysis, preliminary findings and insights were shared with NGO representatives for input and clarification.

Ethics:

This project was developed and conducted in accordance with Auckland University of Technology Ethics Committee (AUTEC) ethical standards and received ethical approval from AUTEC 20/398 dated 26/01/2021. All extracts have had participants' identifying characteristics and names removed.

Extended Findings Narrative

The thematic analysis resulted in 9 candidate themes, which we then reviewed against the whole dataset. After discussion amongst the team, some themes were collapsed or realigned due to overlap and/or a shared central organising concept, leaving 5 final themes. These themes were: 1) who's the pandemic response for anyway? 2) Rethinking business as usual in the new normal; 3) The pandemic as amplifier of individual, social, and system level gaps and problems; 4) Elbow grease and the smell of an oily rag; 5) A whole new world of technological support. We will now give more detail about these themes alongside representative quotes.



Final stages of thematic analysis

Who's the pandemic response for anyway?

The unusual nature of the pandemic (and the corresponding Aotearoa NZ government response) created significant cognitive burden for many people as they found themselves navigating new ways of living and new embodied practices (e.g., mask wearing, social distancing, elbow coughing, digital connection). Certainly, most participants reflecting on the initial outbreak expressed a strong sense of the unknown.

For example:

> We sort of say it all the time now, it's like nobody knew what was gonna happen, you know, would they extend it? Would there be an outbreak in the community? What would that mean? Hospitals flooded and deliriums and or you know just ordinary health things you know it was just really quite a scary time I think (KI5).
>
> Of course, it was new for everyone, it was like goodness me what does (laughing) this mean? And what do we do? And where do we go from here? (KI6).

Although information and communication from government sources was considered to be clear, robust, and appropriate, navigating the new normal was a drain on energy – especially for those with the added complexities of neurological and age-related issues. In many cases, the work of the NGO staff involved repeating government messaging. One KI spoke about being under pressure to return to face-to-face visits by members when Alert Levels did not allow for this:

> You know I can't get to my clients some of them are asking me to, and I'm having to say no, and I have to be um you know kind of strict on that and definitely explain to clients that not at the moment but as soon as we can visit, I'll be in contact, so it was just working through that kind of scenario as well (KI6).

Aside from the specifics of (re)explaining what was possible in terms of services, KIs and members all spoke of the need for messaging to be repeated in order for it to 'sink in.' Hearing the messages from both Government and NGO sources reinforced these messages to some extent, especially when members weren't accessing social media or other internet based information sources. Some KIs spoke of the need to give people frameworks to make decisions for themselves and those they cared for, for instance:

> We started to just say well no we're gonna run our programmes and we believe we're doing it safely and we're gonna tell everybody what we're doing um and what precautions we're gonna put in place and then they can decide whether or not they come and obviously in our case we're talking about their care partners having that decision cos a person with dementia may not be able to make that decision safely but their care partner can um (KI1).

Participants often framed much of the pandemic response as being designed for a particular version of the population, and an understanding of society as primarily made up of younger, abled, uncomplicated individuals. One KI noted:

> So, these people have got a movement disorder they can't stand in queues. I think for essential workers and for over sixty five there was allowances made at New World and Countdown but not for people with neurological disorder the expectation was that they stood in a queue along with the general public and the queues in the height of the Covid was for hours (KI3&4).

Participants would often talk of the marginalising effects of this focus (e.g., feeling like Level changes didn't include advice for them), and the added layers of difficulty understanding what they could do at various points given neurological and age-related impairments. This was most often reflected in talk of members being excluded from even basic tasks (a 'lock up the vulnerable' discourse) like grocery shopping or walking in the neighbourhood. Further, key informants argued the government response sometimes lacked nuance, as it generated assumptions of vulnerability among particular groups:

> You know there would be statements made to them about you know you shouldn't be here so people, to some degree, were doing that um as a matter of caring and concern but it might have come across at times quite harsh to people so all of that I think has played into how older people felt (KI2).

A number of members spoke about the intensity of protections placed around them and struggling with the implications of these for social interaction and connection. This did not deny they were at higher risk because of their condition, but instead highlighted the complex ways that clinical vulnerability increased social vulnerability. For instance, one member commented:

> I found life in lockdown lonely. As I am autoimmune, I stayed at home and even my family stood metres away from me. Felt like a leper. As I live alone, my girls did my grocery shopping for me and I was told I wasn't allowed out. When I turned 80, I lost my license due to Parkinson's and this has hit me really hard as I have had my driver's licence for 65 years and have always been very independent. Oh, to be able to come and go as I please (80F, Pākehā, Aged Concern member).

Navigating risk was made more complex by these assumptions rather than giving members tools to navigate easily. As a consequence, 'hunkering down' (especially during lockdowns) was presented as an understandable response by both members and NGOs. Many members spoke of fear and anxiety in the initial stages of the pandemic, using words like "fear," "isolation", "anxious," and "scared" when describing the first lockdown:

> It was all very surreal. My family and I initially were very frightened about the chance of catching covid-19. Gradually, my and my husband's anxiety reduced as we put into place the strategies recommended by the MoH, e.g., social distancing, hand washing (69F, Pākehā, Parkinson's member).

A number of the members, similar to the one above, referred to increasing confidence as the rules began to make more sense to them. Many of the key informants argued that giving members (especially those considered 'vulnerable') tools to navigate the new environment should have been a priority. Loading them up with judgement for 'failures' only reinforced the sense that their contribution to the pandemic response was simply to stay inside:

> Accepting that older people are allowed to make a decision even if it's a bad one (laughing) and that's okay um because there was just so much conversation and um rhetoric around the community around seeing older people in the supermarket and what were they doing in the supermarket and you know all that kind of stuff and there was this real kind of thing going on around older people judgement of older people making poor decisions (KI1).

Much of the process of navigation without specific guidance for older populations or those considered vulnerable, meant people were often making extremely conservative decisions, even when those decisions harmed them:

> A chap that through fear didn't leave his house for three or four days. So, he'd gone without food (pause), so, he drank excessively to fill his hunger. And he's gluten intolerant and [a neurological condition], so then he went to Countdown and stood in the queue, but he's got a movement disorder so people perceive them as being intoxicated or just looking odd and I think he was in a queue [...] and nobody would hold his queue and he needed to go to the toilet and security wouldn't let him use the toilet cos he had to stay in the queue and he was starving so he urinated against the wall and he was arrested and he was taken to Auckland ED (KI3&4).

Given the necessary immediacy of the government response and the need to provide general guidance for as many people as possible, there would always be risk that people would feel (and be) marginalised. However, ensuring steps to make sure these problems were not perpetuated, was important to the ongoing work of the NGOs, both in advocacy and in development of new ways to meet the needs of their memberships.

Rethinking business as usual in the new normal

For many among the membership, but particularly for the NGOs themselves, the lockdowns and the pandemic itself gave opportunity to rethink and reflect on what was meaningful and valuable. For many of the members, this involved questioning the status of work or other aspects of their lifestyle heading into the future – including the possibility of early retirement. For instance, one member commented:

> The pandemic resulted in a huge drop in workload for the small company I worked for and so I was made redundant. My wife and I decided that at my age and after looking at our financial situation that I could make that redundancy permanent and call it retirement. Retirement has taken a weight from off my shoulders and led to me feeling more relaxed and less stressed. Covid-19 has been a blessing in disguise for me. I am quite comfortable about being at home by myself through the day and I am looking forward to my wife joining me in retirement probably early next year (62M, European ancestry, Parkinson's member).

One KI observed this kind of reassessment in relation to the return to work programmes his membership were involved in, a willingness to reject the terms of these, and move in other directions:

> I think part of it is, you get these life events where it causes you to reflect [on] where you are and it's sort of whether when I'm saying when they've decided not to do it it's usually a case well no I've been doing that for so long I'm gonna do something different, I've you know I've had enough. Whereas previously people would've battled on there's been a lot more you know I've had a wakeup call um there's more important things to life than doing what I was doing (KI8).

This shift in direction was not limited to individuals. For the NGOs, this rethinking often meant finding new ways to bolster or innovate, with opportunities to rethink the status quo and what was core to their work. The first national lockdown provided opportunity to determine what worked and what was superfluous for both NGOs and members. For some, this was straightforward:

> Our response went really smoothly um (pause) we were able to transition really quite well from a face-to-face service into Telehealth and virtual um because our systems and processes that we had in place already existed um we (pause) we basically were able to remain fully operational, but just moved to a virtual environment rather than a face to face so we carried on except we continued to accept referrals we continued to um action those referrals so we had initial assessments we had our follow-up reviews (KI7).

For other organisations, this was much more complex:

> We had varying levels of difficulty nationally and locally around transitioning to work from home so um it we it was a real test of how our IT works in terms of you know moving rapidly to an at home working [...] certainly some learning in terms of what works for IT support [...] and awareness that in various situations, not just a pandemic, we may need to pick it up and work remotely by and large people managed (KI9).

Members noted that bunkering down during the lockdown meant lower levels of stress and increased mindfulness about tasks and life more generally, often using words like "peaceful", "new routines," "rhythms", "slowing down", and "gratitude". One member commented on the Alert Level changes in relation to these ideas:

> Each stage was a little more freedom. It really made you appreciate the freedom that you didn't already have. Watching what was happening on the other side of the world made me grateful. (M, Pākehā, Huntington's Disease Association member)

And another spoke of increased mindfulness around care for others:

> We continue as before, but have a much greater awareness of responsibility (78M, Pākehā, Parkinson's NZ member).

An assessment of the kinds of activities they were engaging in became important to understanding the next stages of their response. One KI noted that their immediate information provision was useful beyond the context of the pandemic:

> Here's some of the things you might wanna write down um in regards to ah cos most of our clients or are carers of a person with dementia so getting them to think about um how they could manage in an emergency with regards to in particular largely if something happened to the carer what what strategies would they put in place to make sure their person with dementia was cared for um which we've now realised we should've been doing that with our clients as sort of a standard practice (KI1).

As part of this, a greater focus on the staff's wellbeing became paramount and was considered essential to their ongoing response. Building up of databases and systems that could help reduce workload became important to this process of rethinking practices. Other NGO participants noted that there was a general acceleration of improvement to systems and increased organisational digital literacy that occurred as a direct consequence of the pandemic (see, *A whole new world of technological support*).

Increasing awareness of overlaps in coverage between the various NGOs meant that prioritisation of key groups could occur - but this could only occur (and certainly could be improved upon) if NGOs were working collaboratively. When this collaborative work and prioritisation was possible, it meant greater emphasis could be placed on adaptive activities that could sustain the business of the NGOs in other lockdowns and the various Alert Levels.

The pandemic amplified individual, social, system level gaps and problems

These was a wider acceptance among all participants that the pandemic and the response led to an amplification of existing problems across multiple spheres. At the system level, this was evidenced in DHBs, care homes, and other health organisations appearing to have reduced capacity for business as usual:

> There was slow information to clarify our position going into the hospital because we attend weekly ward meetings [...] so that was a bit slow in coming, as in, when can we come and how do we come? Do we mask and can attend, or can we not attend? [...] The email to the clinical nurse specialist that we always deal with, she had to go to somebody else, some other department and they went somewhere else and that kind of thing but you know we got there in the end [...] because we are contractors and we're not staff at the hospital that we sit at the side where people are not sure you know, kind of what to do with us really [...] just not knowing with the PPE were we required to gown, would we go so that was unclear for a while (KI7).

Referrals dropped significantly from clinical partners, which had an onflow effect in some NGO's ability to follow up and support people:

> And then obviously we couldn't get referrals through the hospitals like we normally get cos normally most of our referrals come through the hospitals um and so it was a case of working with the hospitals the best way that we could get that in some cases um it was probably a couple of weeks from the initial lockdown before we started to get referrals so once we get the referrals we can make contact with the clients and see what their needs are (KI8).

NGOs and family members were often shut out of care homes, formal care staff were either told they were not essential workers or refused to return to work. The vulnerability of the latter group was highlighted by the pandemic, as these were generally considered low paid but high-risk roles. This loss of access to formal care meant a higher proportion of the care needed to be handled by informal carers such as family members. A lack of respite increased risk of carer burnout, and this remained one of the invisible stories of the pandemic. As one key informant noted:

> When you take away those supports whether they can't come in or you can't provide them or they're not approved [...] the pressure builds on carers and they tip over, during Covid we had six carers pass away [...] just the sheer extra volume of I don't know, work and you know they had to do more themselves [...] they didn't get a break to go and get the supermarket and all that sort of thing, going to the supermarket with somebody dementia in Covid was just hideous (KI5)

It was here that the distinction between clinical care and social care was made most stark – with only clinical care being designated 'essential', despite social support typically operating to fill gaps and failures in systems, even in ordinary circumstances. Those offering this kind of social support to their memberships, sometimes did not tend to have the same levels of access and capacity for emergency service provision as their clinically orientated partners, for example:

> We did our best to um attend to P and P, but personally for me in my role, it was quite difficult for me to get personally get in as well cos even so the staff at the private hospital were quite strict with their who gets in or not I think (inbreath) my colleague in her role as a clinical specialist had more access (KI3&4).

This often meant that those on the margins and already experiencing stigma sometimes did not get the levels of care and support they needed. Consequently, for those who were already vulnerable, the pandemic only increased their levels of vulnerability. This might occur in any number of ways, but certainly intersections of poverty, digital poverty, cognitive and affective difficulties, and physical impairments made accessing essential services or managing major life events (e.g., family members dying, grandchildren being born, family overseas) increasingly difficult. The key informants from the extract above spoke of another case that exemplified this complexity:

> So, in A's household he had a family [...] his daughter who had a partner and they had kids, um so his grandkids, but unfortunately right before Covid hit, his daughter and partner had broken up and they were forced out of their home because it was under the partner [...] so we had to find emergency housing for A who has yeah [a neurological condition] [...] it was quite difficult [...] he went into respite at a home, private hospital and his daughter found a place elsewhere but since then because of Covid his daughter couldn't visit [...] then he was just on his own and this is yeah, after years of spending time with his family so it affected him quite a lot and I guess he's still struggling right now [...] he's basically lost contact (KI3&4).

These were things that already made life hard enough before the pandemic, but were amplified in this new context. This was intensified in cases where individuals either did not understand restrictions or 'stood out' in a context of increased surveillance and general fear within the community. The gaps and issues created by this amplification and the need to rethink their practices (see Rethinking business as usual in the new normal) resulted in the NGOs' having to significantly step up their workloads.

Elbow grease and the smell of an oily rag: Offering care during the pandemic response

The data associated with this theme emphasised the critical nature of the work the NGOs performed over the first months of the pandemic response, and their deep sense of commitment to this work. There was no question that this work was *essential* given a) the novelty of the response to covid-19 and b) the system gaps discussed in the previous theme. The staff of the NGOs were able to identify particular needs, and due to relationships built over time, had a very clear sense of who might fall through the gaps. One informant noted that although many of their NGO's members seemed to be fine for the most part, as the lockdown continued, they became aware of increased need:

> There was quite a bit of trepidation for the first couple of weeks and then they sort of hunkered down and it's like yes, this is what we're dealing with and it's like generally they seemed to cope not too bad. What we started to get probably about 4 or 5 weeks and possibly a little bit later [...] was starting to hear, you know, more psychosocial issues that were coming as far as higher degrees of anxiety and depression (KI8).

For those working directly with vulnerable members in difficult circumstances, there was a tendency to work above and beyond to ease the burden these members experienced, as few others seemed to be meeting the needs of these groups.

> We had a gentleman, very young guy only in his twenties but he needed a wheelchair [...] he'd had numerous falls hence why he heeded the wheelchair [...] and nobody from Kaitaia DHB were able to deliver that wheelchair to him so he was continuing to fall and have head injuries [...] so that took a nurse specialist driving from Auckland to Kaitaia Hospital [...] actually I flew to Kerikeri, hired a car, went to Kaitaia, picked the wheelchair up and took it 500m from Kaitaia Hospital to the client's house (KI3&4)

This tendency was located in more than staff, also including the volunteer base:

> We have amazing volunteers and there were lots of volunteers who went above and beyond during lockdown either actually signing up to help with new services um that emerged during lockdown or just doing the extra bit for their usual visiting service, client dropping in, shopping, dropping in food, um you know picking up ah a bill to post, or um you know just doing things that were needed um and going the extra mile so very grateful for our fantastic pool of volunteers (KI9).

This meant that for many of the NGOs, the lockdown and Alert Levels following were initially experienced as periods of intense work and stress – often compounding individual anxiety related to the pandemic. This workload was increased in situations where access was constrained to a very small number of NGO workers or where there were small teams. One informant noted the various responses of their staff to the pandemic, and how that influenced their own workload:

> Some yeah ah two or three of them it rocked them um and I possibly personally wasn't um as understanding as I could've been or should've been ah cos I just I went to work everyday um seven days a week right through for twelve weeks um so it cos I just kept myself busy and my wife and son were at home doing ah working from home one upstairs one downstairs so I thought I was just a spare wheel so um I just hooked into work many of them did the same thing ah and some just couldn't focus at all um and were almost ah resentful that I'd given them work to do (KI5).

On the other side of the coin, due to an initial drop in referrals, or assessments, some NGO staff had an initial lighter period, followed by a significant influx of activity and workload when the Alert levels shifted and the country (and DHB services opened up). Others spoke of members deferring virtual appointments in the hope of a face to face interaction, and the burden this placed on staff later in the year:

> So, that was kind of an unintended consequence of the virtual was (pause) maybe not explaining to our clients as well as we could've that this is your opportunity to be seen and if you choose not to be seen in that forum you know we can just see you again in six months or a year, but we can't stack everyone up (pause) so that when we come out of you know lockdown in June we now have all of April May and June's people who want to be seen face to face which we can't do so (inbreath) you know a bit of a backlog (KI7).

Increased workloads also came about at a time when funding was at increased risk and there were wider concerns about viability of staff retention – especially in an already under-resourced sector. The Government's wage subsidy gave most NGOs a degree of security and ability to retain capacity to manage the NGO response to the new normal.

More broadly, a flurry of contact and information provision activity defined the first lockdown. Production of new materials and tailoring of information for the membership populations was considered central to support, as was advocacy at government levels. Some of this extra work was recognised by government and new forms of funding were made available, but often these were framed in terms of new initiatives, rather than bolstering what was already being done well. One key area that all NGOs had to respond to, was the new digital landscape.

A whole new world of technological support

With significantly reduced access to face-to-face interaction, fundamental to much of the NGO core work, a turn to technological solutions became paramount to engaging with their membership. New technologies (such as zoom and internet-based services) and existing technologies (such as phone or email correspondence) all involve levels of literacy. Essential services such as banks and grocery shopping also relied heavily on digital infrastructure that many people had avoided through face-to-face mechanisms. During the pandemic it became especially important to offer specific support those who experience digital poverty as these people were often more isolated and struggled to gain access to essentials.

> I think it's the struggle [...] of a single elderly woman [...] all alone in a family house, no internet, probably has a landline, all of her face-to-face social support has gone instantly, what do you do to help that person and I don't know what that resource is [...] that's the person that concerns me (KI10)

Tying to the first theme (see, Who's the pandemic response for anyway?), much of the response involved relying on digital infrastructure, which assumed a particular sub-group of the population who were able to manage comfortably online. This assumption was most evident in the lack of added support for online access, which often left NGOs supporting and helping their members to navigate the online environment. This support was often highlighted as a sitting at the intersection of *access* and *ability*, with either resulting in increased disconnection, and both compounding this:

> It was the scenarios of having no device to poor connection to 'I don't even want to go there, it's just too much to think about' and then some of the physical aspects for people you know, hand use or vision, that they um didn't feel that was something easy enough to do (KI6).

Among the NGOs, a wider recognition that there is a need to shift from a model of individual digital literacy to one of organisational digital literacy became apparent. One informant commented on this:

> We definitely see more people now virtually than we ever did beforehand and our client group got a bit more comfortable with the idea that some things can be done via Zoom, our networking occurs much more frequently via Zoom so that was a benefit (KI8).

This meant that not only did staff need to become familiar, comfortable, and ideally skilled in their own use of technologies, but also in the ability to support member experience and skill acquisition. For many members, their experience of the pandemic was shaped by their access to these technologies and familiarity with their use.

> We did a bit with Zoom with our clients, with the clients that it worked for, um and at the time we thought oh we could probably do a little bit more of this but it actually hasn't worked out that way [...] we're still probably more likely to do it over the phone [...] it also takes a bit of prep time and [...] that doesn't always work for someone caring with a person with dementia um to be able to schedule a time that they're going to log on to the computer and you know do that, it's actually just easier to pick up the phone (KI1).

Not only did this allow connection with the NGOs, but also more broadly to family and friends in ways that reduced the impact of isolation. Almost all members surveyed, and all NGO participants, noted the wider focus on reducing digital poverty as central to improving the experience of future lockdowns. In a number of cases, digital access could not alleviate the impacts of lockdowns, and so other mechanisms of support and information provision needed to be explored.

Conclusion

In this report, we have highlighted the significant implications of the Covid-19 pandemic and the Aotearoa NZ Government response on a small group of NGOs that provide services for older people and people with neurological conditions. This report emphasises the intensity of the 2020 period for the staff and members of these organisations and the need for adaptability and increased capacities that were required. The themes presented here, constructed from interview and survey data, are a strong indication of the value the NGOs provided and continue to provide their members during this complex time. Continuing to build on this work into the new Covid Protection Framework is important for increasing and enhancing crisis resilience in the NGOs and the members they serve.

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