How Long-term Dementia Care Facilities in South Africa have coped with the Covid-19 Lockdown

Synthesis report from 2 rounds of a survey

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ltccovid.org
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Key findings

- News from the UK and Europe about the impact on COVID on Long-Term Care Facilities (LTCFs) allowed South African LTCFs to plan in time for the hard lockdown that started in late March 2020. This limited the number of infections and deaths attributed to COVID.
- This report synthesizes findings from a survey of 48 LTCFs. From the time LTCFs went into lockdown until the date of submission of their questionnaires, 16 of the 48 LTCFs (33.0%) surveyed had experienced infections, recoveries and/or deaths amongst residents and/or staff members (last responses dated 2 September 2020).
- Many LTCFs developed their own policies and procedures before receiving these from the government. LTCFs learnt to be flexible and adaptable.
- Training of staff and providing a supportive and accommodating environment facilitated staff commitment and resident well-being, but as the lockdown continued it became difficult to maintain and find replacement staff.
- LTCFs experienced significant financial strain due to unpaid subsidies, an inability to fill vacant rooms from the waiting list and the large unanticipated costs of providing PPE and adapting facilities.
- The impact on people with dementia was significant as many could not understand the need for masks and did not cope with being in isolation in their rooms. Efforts were made in some facilities to find ways to organise the living areas to avoid having to isolate people with dementia in their rooms.
- The lockdown experience raised the profile of older people and LTCFs in South Africa, as it did globally. However, there is no consistent monitoring of infections and deaths within LTCFs specifically. However, in November 2020 the National Department of Social Development initiated a surveillance project on the impact of COVID on older people broadly (i.e. not specifically including LTCFs).
- A recommendation proposed by participants is that the entire long-term care system be reviewed, including LTCFs, home-based care and community-based support. Conversations are needed about the future of retirement villages and care homes, alternative perspectives on ageing, ‘age-friendly’ communities, and appropriate models of care.

1. Introduction

With the outbreak of Covid-19 in South Africa in March 2020, the National Advisory Group (NAG) of the Strengthening Responses to Dementia in Developing countries (STRiDE) research project decided to undertake a survey to ascertain how long-term care facilities (LTCFs) that accommodate people living with dementia were responding to Covid-19 and the resultant lockdown. A Covid-19 Working Group was established to oversee this process. It should be emphasised that this study focused only on LTCFs, and not on home-based or short-term care situations.

Members of the Working Group were requested to circulate a short questionnaire (**Appendix 1**) to their mailing lists, with responses being returned to Alice Ashwell, who was contracted by STRiDE to compile the report. The questionnaire was circulated twice: first in May 2020, during the early stages of the outbreak, and then in July to ascertain how LTCFs were coping as infections peaked.

Initially only an English version of the questionnaire was circulated, but at a meeting of the Working Group in July, it was decided to translate the questionnaire into Afrikaans (**Appendix 2**) and to extend the survey period by a few weeks.

Prior to the production of this report, the results of each the surveys were compiled and shared with members of the STRiDE NAG and Working Group, as well as with the respondents. The report on the first round of the survey was also included in a report on the response of South African LTCFs for the LTC Responses to Covid-19 website (https://ltccovid.org/). Online discussions with Working Group members and respondents about the interim reports informed the Discussion and Conclusions sections of this report.

2. Responses received

This report includes a summary table of statistics from the two rounds of the survey (**Appendix 3**). As stated in the Questionnaire, all responses were kept anonymous. Neither organisations nor individuals are named in this report; instead each case is identified by a number.

- The first round of the survey generated 31 responses (dated 14 May – 5 June 2020), and the second 27 responses (15 June – 2 September 2020).
- Ten organisations responded to both questionnaires, making a total of 48 unique respondents. Of these, 46 were LTCFs, one was the head office of an NGO that manages LTCFs (Cases 24 & 44), and one was an NGO that offers dementia support (Case 19).
- When both questionnaires were combined, all nine provinces were represented as follows: Western Cape (20), Gauteng (12), Mpumalanga (7), Free State (4), KwaZulu-Natal (4), Northern Cape (4), Eastern Cape (2), Limpopo (2) and North-West (2).

3. Covid-19 cases in the LTCFs

From the time LTCFs went into lockdown until the date of submission of their questionnaires, 16 of the 47 LTCFs (34.0%) had experienced infections, recoveries and/or deaths amongst residents and/or staff members (Table 1 & Figure 1).

The following results include both rounds of the survey. Note that Cases 1 & 34, and 8 & 51, are the same two facilities.

Table 1. Numbers of residents and staff who became sick, recovered or died from Covid-19

Case #	Sick		Recovered		Died	Asympto-matic
	Resident	Staff	Resident	Staff	Resident	Resident
[1]					[5]	
34			4	3	3	
8			1	4		
51				4	2	
33		1	7	20	4	
38	6	4	28	37	[11]	
40	7			6	10	
42			8	4	1	
44	8	3	2	2	2	
45			6	10	1	
46			7	4		
48			1	2	1	
49			2	2	1	
50			9	3		
52						1
53			3			
55			1	1	1	
57			1			
TOTAL	**21**	**8**	**80**	**102**	**26 [42]**	**1**

Note: In Cases 1 & 38, the figures in [square brackets] are deaths attributed to natural causes.
Two Totals are given: one (42) includes the deaths due to natural causes; the other (26) discounts these deaths.

First round of the survey: During the early stages of the Covid-19 epidemic, only two of the 31 respondents (Cases 1 & 8) reported infections or deaths:

- Case 1: five residents had died since the beginning of lockdown, none from Covid-19.
- Case 8: five persons (one resident + 4 staff members) who had been infected had recovered.

Second round of the survey: Sixteen of the 27 respondents reported infections or deaths. At the time of submitting their responses:

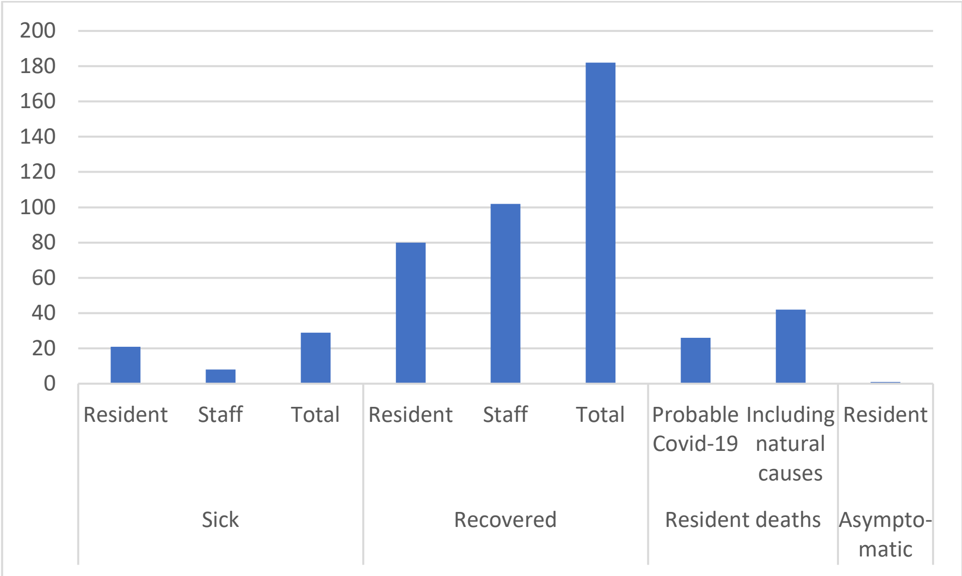
- 21 residents and eight staff members were sick (Total = 29)
- 79 residents and 98 staff members had recovered (Total = 177).
- One resident had tested positive but was asymptomatic. As the Polymerase Chain Reaction (PCR) test generates a high percentage of false positive results, in the absence of symptoms it cannot be concluded that this person actually 'had Covid'.
- 37 residents and no staff members had died. Case 38, however, reported that their 11 deaths could not all "*be attributed directly to COVID-19 as the table [did] not ascertain previous health status, current condition, or co-morbidities. Death certificates received to date all state the cause of death as 'natural causes'*.

During the Covid-19 period, there has been considerable uncertainty as to whether people have died 'from Covid' or 'with Covid' (i.e. from other causes). This report illustrates that confusion. We cannot be

sure about the cause of death in these cases as we do not know if those who died had tested positive for SARS-CoV-2, whether or not these test results were accurate, if patients had shown unique symptoms of Covid-19 (as opposed to the flu), or if a *post-mortem* had confirmed a Covid-19 diagnosis.

Of those respondents who commented on the cause of death, one (Case 40) stated that she "*presumed*" that the ten deaths had been due to Covid-19 but that they had not yet received the test results. As noted above, deaths in Cases 1 and 38 were said to have been due to natural causes. These two numbers are written in square brackets in Table 1. Two totals are given, one (42) that includes all reported deaths, and one (26) that discounts the 16 deaths that may have been due to natural causes.

Figure 1: The number of residents and staff reported sick, recovered or deceased due to Covid-19



The numbers of staff and residents at the LTCFs that submitted two survey forms changed over the course of the lockdown. Thus, the total number staff and residents below are approximate:

- 3,832 residents
- 2,304 staff members (178 management + 1,469 health care staff + 657 support staff)
- Total = 6,136 persons.

Some of the LTCFs did not record the ages of each of the deceased residents. However, of the 16 specific records, one was 74 years old, seven were in their 80s, and eight were in their 90s.

Considering that older persons are especially vulnerable to Covid-19, it is remarkable that so few people (42 residents and no staff members) had died by the time the survey forms were submitted.

4. Discussion of Survey Responses

This section of the report draws together the main points made during both rounds of the survey in response to Survey Questions 1-6 (**Appendix 1**).

The questions covered:

1. Covid-related challenges and frustrations faced by the LTCFs
2. General measures implemented to cope with Covid19 and related challenges
3. Dementia-specific issues and responses
4. Sources of support

5. Unmet needs of the LTCFs
6. Lessons learnt.

4.1. Challenges and frustrations

4.1.1. Inadequate government support:

"V*ery little guidance was given with regard to compliance with prescribed regulations*."

Both public health and social services are provincial rather than national competencies in South Africa. While some respondents were satisfied with the support they had received, most complained that it had been both delayed and inadequate.

During the first round of the survey, a major concern was the delay experienced in receiving adequate guidelines or training on how to respond to Covid-19.

Most LTCFs went into voluntary lockdown at least a week before the official start of lockdown on Thursday 26 March 2020. But, in the Western Cape province for example, it was not until 21 May that the Department of Social Development (DSD) and the Department of Health (DoH) published a comprehensive guideline document specifically for LTCFs: *Practical guidelines for the prevention and management of coronavirus infection in long term care facilities*. Prior to this, LTCFs had had to put a great deal of effort into compiling their own policies and procedures, based on information from international sources (e.g. the World Health Organisation [WHO] and Centres for Disease Control and Prevention [CDC]), and with the assistance of colleagues in the elder care sector.

Despite it being clear that older people were one of the groups most vulnerable to Covid-19, the South African government did not prioritise this sector for support in respect of emergency funding or provision of personal protective equipment (PPE).

Finally, the public health sector was unable to keep up with Covid-19 testing, resulting in delays in receiving test results of up to two weeks around the peak of the epidemic. While some LTCFs were able to create in-house quarantine facilities where people awaiting test results could be isolated, this was not possible in all cases. Testing delays caused a great deal of uncertainty and undermined infection control efforts.

4.1.2. A financial crisis:

"[It was] *so bad that we have to sell our unit – financially we could not cope … I had to retrench 20 staff*."

This lack of emergency funding and in-kind support by government has contributed to a financial crisis in some LTCFs. The lockdown regulations and amendments to the Disaster Management Act exacerbated the situation as, for many months, homes were not allowed to admit new residents, resulting in lost revenue.

Some residents could no longer afford to pay their levies as family members were affected by the economic fallout of the lockdown. Fundraising efforts had to be curtailed, and the failure of many local businesses reduced donations.

At the same time, LTCFs had to prioritise the many costs associated with Covid-19, from creating quarantine facilities and accommodating staff on the premises, to purchasing all the necessary and unbudgeted personal protective equipment (PPE) and cleaning materials.

There was a general feeling that, while government departments had made a number of demands on LTCFs, they had left them to cope with little support.

4.1.3. Infection control challenges:

"Challenges experienced by facilities [were] mainly around protecting residents from infections."

The main challenge for LTCFs throughout the extended lockdown period has been to "*keep the virus at bay*". Initially, a great deal of education was needed in order to convince staff of the need to prevent and control infection, and to train them in the strict protocols that had to be adopted. This has been achieved, and a legacy of Covid-19 will be greater attention to hygiene in LTCFs.

Education of staff and residents was also needed to address high levels of fear and uncertainty associated with this *novel* coronavirus. This was due in large measure to inaccurate epidemiological modelling that greatly overestimated the impact of the virus, and fear mongering by the media.

Fear of infection resulted in some LTCFs undertaking costly and disruptive initiatives. These included having staff members live in for extended periods of time to reduce movement between communities and facilities; and moving residents from their rooms in order to create facilities for isolation and staff accommodation. These measures were only possible in relatively well-resourced facilities, however. Many homes, for example, lacked the space to ensure the physical distance between residents stipulated by the regulations. And in the case of frail elders who require intimate care, it was simply not practical to expect this.

It is a great credit to the sector that, by the time the LTCFs responded to the survey, most (66%) had managed to avoid infections and the great majority (75.6%[1]) of those infected had recovered. However, despite implementing a wide range of infection control protocols, some staff members and residents did fall ill, and some older residents did succumb. It is not clear, however, how many of these deaths could be attributed to SARS-CoV-2.

4.1.4. Management and staff-related issues:

Covid-19 vastly increased the workload of those managers and staff members who remained on duty in the facilities. There was an increase in the burden of administration and policy development, education and training, infection control, family liaison, and nursing care.

Staff on duty had to cope without the involvement of so-called 'non-essential' staff who were sent home; the support normally provided by family members, service providers and volunteers; and personnel shortages caused by the isolation of sick or possibly infected staff members waiting up to two weeks for test results.

Finding replacement staff was challenging as some were unwilling to work in homes where people had been infected because of fear of contracting the virus.

[1] The figure of 75.6% *includes* the 16 people who were reported to have died of natural causes. If these individuals are excluded, 82,0% of infected people had recovered by the time the surveys were completed.

In order to ensure the wellbeing of staff and residents, remaining staff needed to carry out functions that were not normally their responsibilities, such as entertaining residents, providing psycho-social support, and even cutting hair.

Being separated from their own families has been a challenge for staff living in for the duration of their shifts.

In some cases where homes experienced outbreaks of Covid-19, management experienced considerable pressure from the media, families and community members. Similarly, managers have had to deal with the emotional fallout of family members not being allowed to visit and/or have physical contact with their loved ones due to government regulations.

4.1.5. The emotional toll of Covid-19 and lockdown:

"*The greatest challenge is that there have been no visits by family or friends for this long period of isolation*."

Since March 2020, management, staff, residents, family members and others involved with LTCFs have suffered a huge emotional toll due to Covid-19 and the lockdown.

The outbreak of a *novel* coronavirus and the unremitting focus on disease caused many people to experience uncertainty, anxiety and fear. It is well known that fear triggers the 'fight or flight' response, which has a detrimental impact on our ability to think, reason and control our emotions and behaviours. Unsurprisingly, some LTCFs have faced interpersonal conflict and industrial action, and long-term stress has resulted in some staff experiencing burnout.

High levels of stress may have increased the chances of people falling ill from Covid-19 or other causes, as stress depresses the immune system and also increases our susceptibility to chronic, inflammatory diseases.

The lockdown regulations forced on LTCFs have caused a great deal of stress. The most devastating impact of the extended lockdown has been the separation of loved ones, with some families not even being able to visit their loved ones at the end of life. Residents and loved ones have described feelings of confusion, loneliness, sadness, depression, frustration, anger and desperation. Furthermore, lockdown has increased the rate of neurodegeneration in some elders.

The need to focus on infection control resulted in many elders being denied countless everyday rights, freedoms, delights, and opportunities.

The dilemma presented by Covid-19 was summed up in the following statement:

"*The focus has moved to prevention rather than resident care. Personal touch has been restricted and nurses do have to compromise to be able to continue with quality nursing care as well as spiritual and psychological support.*"

4.2. Responses to Covid-19

Having witnessed some of the mistakes made by countries like Italy, the UK and the USA, where many elderly people in nursing homes died of Covid-19, LTCFs in South Africa made great efforts to

keep people safe through early lockdowns, and the development, sharing and implementation of a range of policies, protocols and training programmes. Homes also recognised the need to keep residents physically active, mentally stimulated and socially connected, within the constraints of the lockdown regulations.

4.2.1. Policies and procedures:

Because of delays in receiving official guidelines from government departments, LTCFs did their own research and developed or updated their own policies and procedures to combat Covid-19. LTCFs that were part of larger organisations benefited from the assistance of head office staff in these matters.

As lockdown continued, in response to government proclamations, progression of the epidemic, and developing experience within the LTCFs, some of these policies and procedures were amended.

A number of respondents referred to the establishment of a committee or task team that allowed engagement around the development, implementation and monitoring of these processes. One interesting preparedness initiative was the development of a 'Covid-19 box', which contained all the documents and equipment necessary should a resident need to be quarantined.

4.2.2. Infection control measures:

Most of the respondents listed a very wide range of practical infection control measures implemented in the homes. These included:

- implementing general Covid-19 regulations
- implementing Disaster Management Act regulations governing LTCFs
- stringent hygiene protocols and quarantine strategies
- modifications to the physical environment
- new staffing arrangements and protocols
- restrictions on the rights, relationships and routines of residents.

4.2.3. Health and wellbeing support:

Concerns about the negative impacts of the Covid-19 lockdown on health and wellbeing resulted in a number of LTCFs prioritising measures to improve the physical, mental and emotional health and wellbeing of staff and residents.

Measures to enhance physical health included continuing with exercise programmes, encouraging residents to spend time walking or working in the garden, providing staff and residents with vitamin supplementation, and ensuring that the medical needs of residents were attended to.

Measures to enhance mental health and emotional wellbeing included establishing a team or dedicating a staff member to provide emotional support to staff and residents; encouraging people to discuss their fears and frustrations; ensuring that residents continued to have social contact with one another; continuing with a regular activity programme; celebrating special days; using electronic means of communication to try to compensate for the lack of physical contact with loved ones; and "*[making] every effort to be happy and normal in an abnormal situation*."

As the separation of loved ones has generated the greatest distress during the lockdown, most LTCFs developed strategies to enable relatives and friends to visit residents under strict conditions, and to attend to relatives who were nearing the ends of their lives.

4.2.4. Education, training and communication:

South Africa has not, in living memory, dealt with what was predicted to be a 'deadly pandemic'. The crisis was steeped in uncertainty, and LTCFs made great efforts to inform and educate staff, residents and family members about the virus and to provide training in how to survive it.

Learning opportunities included in-house training, and online webinars presented by governmental and non-governmental organisations. Posters were displayed to remind staff and residents of safety precautions, and in some cases, daily staff briefings took place.

4.3. Dementia-specific issues

"*Surrounding them with love and care really makes the world of difference*."

Residents living with dementia responded to the lockdown in different ways. There was a general sense that those in the early stages of dementia found it more disturbing than those with advanced dementia, as they were more aware of the lack of visits and activities, and unable to understand the changes to their routine.

For most, the loss of physical contact with loved ones has been the most distressing factor. Isolation, confinement, lack of stimulation, distancing, mask-wearing, and hygiene protocols were also mentioned as problems. These changes resulted in feelings of anxiety, confusion, loneliness, depression and irritability, and sometimes in aggressive behaviour, which was difficult for staff to cope with. There were also reports of accelerated cognitive decline and the loss of sensory acuity and communication skills.

Understanding the needs of people living with dementia, some respondents used their discretion and continued providing loving physical contact; wearing face shields rather than masks in the presence of residents; allowing them to move around freely within their section of the home; patiently explaining the situation as often as required; and increasing the level of nursing care to ensure that they were not alone.

4.4. Sources of support

Government departments such as the DoH and DSD were slow to provide LTCFs with adequate guidelines on coping with Covid-19. Facilities therefore took responsibility to search for guidelines on the Internet, and to share policies and procedures with other LTCFs, in order to draw up their own documents.

Support from provincial government departments varied greatly. In general, little financial support was forthcoming, and while some departments did provide materials such as PPE, some LTCFs received no such support. There was one report of a department providing counselling support to elders.

Trustees and head office staff provided valuable support to managers of facilities, including developing policies and procedures, sourcing additional funding and materials, and providing ongoing support through online meetings.

During this crisis, LTCFs valued the support of family and community members who provided encouragement, and gave professional, financial, and in-kind support. Open communication between the facility and its community was important in order to build trust and support.

Many managers gave credit to their staff for their dedicated service, resourcefulness and moral support, commenting on the value of teamwork. Some made a point of dedicating resources to ensure that the emotional, medical and self-care needs of staff were monitored and taken care of.

Respondents also acknowledged the role that their faith in God played during this stressful and uncertain time.

4.5. Unmet needs

By the time the second survey was completed, a number of respondents said that their needs had been met.

A number of respondents did, however, complain about financial constraints, mentioning the lack of financial support from government, the restrictions on admission of new residents, and the prevention of fundraising activities.

There were also concerns about the lack of interest shown by provincial departments in the plight of LTCFs, problems in trying to secure relief staff, inadequate training, and the need for more communication and recognition from management.

4.6. Lessons learnt

During the two rounds of the survey, respondents identified the following lessons learnt from the challenging experience of the Covid-19 lockdown:

- Being prepared for a disaster, with policies and plans in place and staff trained in the necessary protocols, enabled a rapid response to Covid-19.
- In an uncertain and changing situation, flexibility and adaptability are important.
- LTCFs have become proficient in infection control but should not become complacent.
- Educate and train staff to be competent and confident in the face of an emergency.
- Dedicated personnel are vital in an emergency; care for and support one another, especially during stressful times.
- Everyone makes mistakes; respect and support enable people to bounce back.
- Regular, transparent communication builds trust.
- Take personal responsibility for your attitude and responses, and for self-care.

- Many people who care for the elderly are highly motivated and take pride in their work; their dedication needs to be acknowledged.
- During a crisis it is vital to continue offering residents high quality care that supports both physical and emotional health and wellbeing.

5. General Discussion

The discussion that follows is both a reflection on the results of the surveys presented in this report, and a summary of the outcomes of two online meetings at which these results were discussed:

1. 21 October 2020: A webinar with representatives of some of the LTCFs that had responded to the survey; and
2. 23 October 2020: The final meeting of the STRiDE Covid-19 Working Group, which had been set up to oversee the survey project.

5.1. A qualitative rather than quantitative approach

While the questionnaire did require respondents to provide some quantitative data (e.g. numbers of staff members and residents; numbers of people who were sick or had recovered or died from Covid-19), the Covid-19-related figures should not be relied upon or used to draw any firm conclusions. The sample of respondents was relatively small; questionnaires were returned at different stages of the epidemic making it hard to compare the statistics; and deaths could not be conclusively shown to have been due to Covid-19. Furthermore, LTCFs that had experienced Covid-19 related deaths might have been reluctant to participate in the survey, while those that had successfully avoided infections might have been more inclined to share their experiences, thus making it appear that there had been relatively few infections within the sector.

This being said, it was indeed encouraging that only 34% of homes had experienced infections by the time they submitted their questionnaires, and that 71.7% of affected residents and staff members had recovered. These facilities must be acknowledged and congratulated for their efforts.

While the STRiDE survey does not attempt to provide a reliable quantitative picture of the impact of Covid-19 on the LTC sector, the two rounds of the survey have gathered valuable qualitative information about challenges faced by the LTC sector, their responses, issues arising, and the illumination by this crisis of long-term systemic problems. It is hoped that these insights will contribute to ongoing efforts to improve the experience of ageing and the quality of life of older people in South Africa.

5.2. Developments over time

Circulating the questionnaire twice allowed STRiDE to distinguish between two stages of the developing epidemic:

- During the first round, LTCFs were preparing their facilities to cope with Covid-19, and relatively few had experienced infections or deaths.

- By the second round, policies and procedures were in place, and more facilities had experienced infections and deaths. For many, the peak of the epidemic had passed. The LTCFs were learning to live with the extended lockdown and the financial and emotional issues arising from this.

When the two survey responses were compared, the range of responses during the two stages of the epidemic was found to be similar. At both stages, for example, facilities differed in terms of how they balanced the infection control imperative and the need for social contact and stimulation. Some imposed strict regulations, confining residents to their rooms for extended periods to avoid possible infection. Others recognised the importance of social contact, activities and time outdoors to the physical, mental and emotional health and wellbeing of residents, and continued with their activity programmes and having meals together. While some homes tried to avoid physical contact between residents and staff, others recognised that contact was essential, both in order to carry out daily tasks, but also because loving touch is necessary for human wellbeing.

Differences between the two rounds of responses were due mainly to the stage of the epidemic and the level of the lockdown:

- In the first round of responses, there were many more references to the challenges of developing Covid-19 policies and procedures than in the second round, when these were already in place. Concerns included delayed and inadequate guidelines from government departments, which required LTCFs to spend a great deal of time developing their own policies and procedures.
- During the first round, respondents complained about having to wait up to a week to receive Covid-19 test results; by the second round, delays of up to 15 days were being experienced, forcing some facilities to pay high fees to private laboratories to conduct these tests.
- While the same financial issues were mentioned in both rounds of the questionnaire, by the second round, the impacts had become more severe, with retrenchments and the sale of units being reported, and restrictions on fundraising efforts being mentioned.
- During the first round, there were more references to physical alterations being made to the facilities to accommodate staff members living in and residents needing to be quarantined.
- Earlier in the epidemic, there was great uncertainty about the virus, which resulted in facilities proceeding with extreme caution. Numerous infection control measures were introduced, many of which have become normal daily procedure. As the peak of infections passed and the lockdown levels were relaxed, some measures were amended, e.g. allowing limited visitations and relaxing the use of some types of PPE.
- LTCFs were forced to become more flexible in terms of staff schedules during the hard lockdown period, when public transport was limited; this was no longer an issue during the second round.
- Some respondents observed that the attitude of staff to infection control measures had changed over time. Initially some had been uncooperative but, especially after staff or residents had fallen ill, they had come to accept the changes, and some had even started monitoring their colleagues' behaviour.
- By the second round of the survey, respondents observed that people were much more aware of personal hygiene; one stated that they had had no cases of colds of flu during winter.
- Covid-19 revealed gaps in the knowledge and skills of staff members in relation to many aspects of epidemics and infection control. This necessitated ongoing training, the focus of which changed as the epidemic progressed.
- While the emotional impacts of Covid-19 were mentioned in both rounds of the survey, the extended lockdown and staff shortages due to illness and quarantine resulted in an increasing focus on the need for emotional support for both staff and residents in the second round of the survey. There were reports of staff burnout, and residents experienced desperation due to being separated from their loved ones for months on end. Some facilities dedicated a staff member to the pastoral care of residents and colleagues.

- In addition to the emotional devastation of the lockdown, the second round included more references to the cognitive, sensory, and social decline of some residents due to isolation, loneliness and a lack of stimulation.

5.3. General reflections

5.3.1. The LTCF as an ecosystem:

A LTCF is reminiscent of a natural ecosystem, and just as a natural disaster impacts upon an ecosystem, so has Covid-19 impacted on LTCFs. Healthy ecosystems are rich in diversity of role-players and interconnections, and this is what makes them both hospitable and resilient. A devastating crisis affects both the ecosystem as a whole and individuals, who lose their roles and their connections within the system.

The Covid-19 crisis depleted the diversity within LTCF ecosystems, leaving them less hospitable and resilient. Early on during the crisis, in order to protect residents from the virus, so-called ‘non-essential’ staff were sent home; loved ones, volunteers and service providers were refused entry; and involvement of the local community was limited. The system and the individuals concerned suffered from this loss of diversity.

During the webinar on 21 October 2020, for example, participants commented that they had realised how much the homes had relied upon the contribution of ‘non-essential’ workers (e.g. in the laundry), the emotional and in-kind support of family members and friends of the residents, and the services rendered by government departments. In this latter case, fear of catching the virus had prevented the DSD from providing trauma debriefings for the staff of a facility where two residents had died of Covid-19.

It has been hard for the individuals who have lost their roles, agency, and sense of connectedness within the LTCF ecosystem. During the same webinar, an office administrator required to work from home spoke of feeling frustrated because she could not play a hands-on role at work during an outbreak of the virus. Another respondent stated that she believed that some of their residents had died from depression. Many distraught family members, separated from their loved ones for months, decided to remove their older adults from LTCFs, leaving some homes with empty rooms and further threatening their sustainability.

5.3.2. Impacts of the Covid-19 lockdown on people living with dementia

The STRiDE project focuses on improving the care of people living with dementia in developing countries, and this survey sought to investigate how Covid-19 and the lockdown were affecting the lives of people living with dementia in LTCFs in South Africa.

It appears from available data that relatively few people with dementia in LTCFs fell ill or died from Covid-19. In the webinar on 21 October 2020, a participant who worked in a dementia care home reported that residents who had fallen ill from Covid-19 had recovered well. He wondered if the fact that they had been “*less exposed to alarming information*” might have contributed to their recovery. As fear and stress compromise the immune system, their lack of awareness and fear of Covid-19 might have supported their recovery. However, other survey respondents explained that they had tried to convince residents with dementia to adhere to infection-control

and lockdown regulations by frequently reminding them about the pandemic and showing them relevant broadcasts on the television.

In caring for people with dementia, it is fundamentally important to help them feel safe, calm and loved. Yet most of the government's lockdown regulations, while aiming to protect people from the virus, have had the opposite effect. Isolation, confinement, separation from loved ones and other residents, disruption of familiar routines, loss of stimulation, mask-wearing, infection control measures, and many other disruptions have resulted in elders feeling "*confused, lonely, sad, depressed, frustrated, angry and desperate*". While relatively few have died from coronavirus, there have been tragic reports of elders losing the will to live and dying seemingly of depression and loneliness.

Some respondents felt that people in the early stages of dementia, who were more conscious of the changes taking place, may have been more disturbed by lockdown than those in the later stages who were less aware. As stated in the online meeting on 23 October, this is debatable, as communication difficulties in the later stages of dementia may have obscured the effects on those with more advanced dementia.

One infection-control measure that proved problematic in dementia care settings was mask wearing. Many residents were frightened by people wearing masks and some tried to pull them off. Masks also made communication with people with dementia difficult. Being able to see facial expressions is a particularly important aspect of communication, and an open, friendly expression can help a care partner put the person with dementia at ease. Also, as older persons become hard of hearing, they rely more and more on lip reading to understand what others are saying. As a result of these issues, carers in some LTCFs elected to wear face shields rather than masks.

Many residents did not want to wear masks themselves, and in some homes were not required to do so. However, this disturbed some carers, who were afraid of being infected by the residents.

As has been reported previously, some LTCFs attempted to keep life as normal as possible for their residents with dementia, continuing to offer activities, allow free movement, and provide physical affection, while implementing those infection control protocols that protected residents while allowing for social contact, physical activity and mental stimulation.

5.3.3. Dedication within the LTCF sector:

The survey responses and online discussions revealed high levels of dedication amongst the personnel of the LTCFs. Respondents commended their colleagues for their teamwork, with one person observing that they had ignored the constraints of their job descriptions and done whatever was needed in order to provide all services on time.

Staff went the extra mile despite:

- High levels of uncertainty, fear and stress caused by the many unknowns associated with Covid-19;
- Infections and quarantine measures in some homes reducing personnel numbers for weeks, difficulties finding temporary staff, and the extreme workload carried by the remaining staff;

- Many homes suffering a financial crisis, with one webinar participant reporting that unbudgeted expenses had increased by more than three times and it had been difficult to source donations.

Recognising the need for staff members to rest and relax during their long shifts, one of the webinar participants drew attention to the need for better staff facilities in LTCFs.

6. Conclusions and Recommendations:

Covid-19 has placed the LTC sector as a whole in the spotlight, revealing longstanding issues. In the spirit of 'not wasting a disaster', it is hoped that this experience will galvanise the LTC sector, the South African government and the public at large to participate in a new conversation about elder care, and to contribute to the creation of a more integrated and sustainable elder care system in South Africa.

The following recommendations were made by participants in the two online meetings to discuss the draft survey report (21 & 23 October 2020):

6.1. Strengthen networking within the LTC sector:

The Covid-19 crisis brought the LTC community together, with unprecedented levels of information sharing and practical assistance taking place. Networking amongst care homes was critical, especially as guidance from government departments was limited.

These strengthened networks and relationships represent an opportunity going forward, as there appears to be a need for a national body that can lobby and work with government on behalf of the LTC sector. There are, however, many 'silos' within the LTC sector, which tend to resist cooperation. Some inducement may be needed to encourage ongoing cooperation, for example creating an industry body and making subsidies available to members.

6.2. Investigate opportunities to improve government support for elder care:

Around the world during the Covid-19 epidemic, government action has been important in guiding services and protecting vulnerable people. A government that intervenes quickly and acts reasonably is needed. Without government protection, the corporate sector can overrule protective actions and may not always have the rights of people as their main focus. Also, facilities with tight budgets need emergency funding and support during a crisis to help them cope with a loss of income and significant unbudgeted expenses. Emergency funding was especially necessary as banks refused to provide loans to LTCFs (as reported by a participant in one meeting), possibly because of the negative feedback they would receive should they have to repossess assets if the facility defaulted on the loan.

In South Africa, government support for the LTC sector during the Covid-19 crisis was patchy. It became clear that the government did not view the sector as a priority. One strategy going forward may be for the LTC sector to investigate partnering with sectors that are a higher priority for government, such as the Youth, in order to explore mutually beneficial programmes. This might include youth development and employment creation opportunities within the LTC sector.

Independent of the Covid-19 situation, the issue of unregulated LTCFs needs to be investigated and addressed. The government tends to play a punitive rather than supportive role in this regard, being quick to close down unregistered homes and relocate residents. Some homes that do want to register with the DSD find the department's response time slow, resulting in access to subsidies being delayed. The DSD needs to support these facilities to register.

6.3. Work with government to develop regulations that affect LTC:

It is essential that the LTC sector work with government in a cooperative rather than adversarial manner, and that the regulatory environment encourages this. The LTC sector should be involved in the development of regulations that affect it, so that it has a say in terms of its needs, and so that appropriate government regulation dovetails with industry regulations. Government should not dictate in areas in which they can neither implement nor regulate.

Regulations need to be relevant to and appropriate for the South African context, as currently:

- Adhering to conditions of registration within the industry is onerous and increases running costs, making the cost of care less affordable; and
- A feasible system of monitoring regulations is needed, which can be costed.

6.4. Allow for self-regulation of the LTC sector:

South Africa avoided some of the paralysing and fatal errors made by countries with a national health system, like the National Health Service (NHS) in the UK. There, care homes waited for guidance from the NHS and did not act quickly enough in response to Covid-19. Hospitals were instructed to send patients back to care homes without testing them for the virus, causing widespread deaths. Some care homes in the UK could not purchase PPE, as it had been reserved exclusively for NHS use. South African care homes did not wait for the government to declare the lockdown or issue guidelines but went into early lockdown and implemented their own infection control policies and protocols. This may have resulted in many lives being saved. This experience highlights the need for government to allow for self-regulation and flexibility within the LTC sector.

6.5. The need for training:

The Covid-19 crisis made it clear that many carers had not been adequately trained. More investment in staff professional development is needed, especially in the case of carers who carry a huge burden but earn very poorly and receive little recognition. This training must be affordable, as most homes lack the necessary funds.

6.6. Revising the long-term care system:

Due to the separation of loved ones caused by the extended Covid-19 lockdown, a number of families removed their relatives from LTCFs, choosing to care for them at home. Furthermore, some people who had previously planned to move into a LTCF have reconsidered this decision.

In addition, as Africa's wealth increases, the need for retirement villages and care homes is growing but the model is being challenged. While care is needed, this does not necessarily mean 'nursing care', which raises the costs and makes facilities increasingly unaffordable. During the online meetings, there was a call to refrain from 'pathologising ageing' and to de-medicalise elder care.

In this context, the demand for home-based care is increasing, even in retirement villages. The growing need for carers represents an enormous employment opportunity. As mentioned above, this is also an opportunity to link the elder care agenda to other government agendas, such as youth employment.

In the face of these developments, meeting participants proposed that the entire long-term care system be reviewed, including LTCFs, home-based care and community-based support. Conversations were needed about the future of retirement villages and care homes, alternative perspectives on ageing, 'age-friendly' communities, and appropriate models of care.

Some innovations mentioned included:

- broadening how care is framed and provided by making LTCFs places that offered broad-based care, including home-based and respite care
- encouraging residents of LTCFs to take more responsibility, individually and collectively, for their own health and wellbeing
- promoting 'ageing in place', while LTCFs focused on hospice and palliative care
- adapting the 'hospital at home' initiative, which was being discussed by medical aids to treat and monitor patients needing short-term interventions using tele-medicine
- training carers to administer medication, rather than depending on registered nurses.

In summary, reconceptualising the elder care system needed to take into account the economics of elder care, the need for alternatives to the medical model, training and supporting of carers, realistic monitoring systems, and the need to be flexible and responsive.

6.7. Concluding comments:

Thanks are due to the LTC professionals and STRiDE committee members who participated in the two rounds of the survey and provided guidance and comments on the developing report. The opportunity to read and reflect upon the experiences of people working in LTCFs during this unprecedented crisis has been humbling. The dedication, professionalism and deep care of people working in this sector is an inspiration.

The STRiDE Covid-19 Working Group trusts that this report will contribute to a deeper understanding of the needs of LTCFs in South Africa, and to greater support for the sector. It is our hope that the report will help to bring the voices of those who care for elders to the forums that are meeting to discuss the future of elder care in general and dementia care in particular in South Africa. To this end, we invite you to share this report with your networks.

Appendix 1: Survey questionnaire (English)

STRiDE – Strengthening Responses to Dementia in Developing Countries

The Impact of Covid19 on Long-term Dementia Care Facilities

PLEASE RETURN YOUR COMPLETED QUESTIONNAIRE TO
Alice Ashwell – alice@heartofnature.co.za
BY MONDAY 25 MAY 2020

Please TYPE your responses and return your completed questionnaire as a WORD DOCUMENT.

If you would like to respond verbally, please contact Alice on 082 720 7444.

We respect your right to privacy.
No individuals, long-term care homes or organisations will be named in the report.

Today's date						
Name of care home						
Organisation						
Name of respondent	*Dr/Mr/Mrs/Ms*	*First Name*		*Last Name*		
Role in your facility						
Landline number			Mobile number			
Email address						
Street address				Province		
No. of residents	Total		With dementia			
No. of staff	Office-based		Health/Care		Support/Other	

1. What general challenges and frustrations is your facility dealing with in relation to Covid19?
2. What general measures has your facility put in place to cope with Covid19 and related challenges? (e.g. policies, protocols and adaptations relating to staff, residents, loved ones, the physical environment, communication, learning, wellbeing, access to health care and resources, etc.)
3. What dementia-specific issues are you dealing with, and how have you been responding?
4. What and who have helped you cope during this time? (e.g. guidelines, support, resources, information, funding, relief, networks, beliefs, etc.)
5. Which of your facility's needs have not been met during this time?
6. What are the most important lessons your facility has been learning from the Covid 19 pandemic?
7. If you are willing to disclose Covid19-related statistics (which WILL be kept confidential), please report any infections, recoveries or deaths since the pandemic broke out on 1 March 2020.

Case #	A resident or staff member?	Gender	Age	Currently sick	Recovered	Deceased (date)
1						
2						

Add rows if required

8. Would you like to have a follow-up conversation with STRiDE to discuss any of the above?
   YES / NO

Appendix 2: Survey Questionnaire (Afrikaans)

STRiDE – Strengthening Responses to Dementia in Developing Countries

Die Impak van Covid-19 op Langtermyn Demensie Sorgfasiliteite

STUUR ASB U VOLTOOIDE VRAELYSTE AAN
Alice Ashwell – alice@heartofnature.co.za
TEEN MAANDAG 24 AUGUSTUS 2020

TIK asb u antwoorde en stuur die votooide vraelys as 'n WORD DOCUMENT.

Indien u mondelings terugvoer wil verskaf, kontak Alice by 082 720 7444.

Ons respekteer u reg op privaatheid.
Geen individue, langtermyn sorgsentra of organisasies sal in die verslag genoem word nie.

Datum						
Naam van sorgsentrum						
Organisasie						
Naam van respondent	*Dr/Mnr/Mev/Mej*	*Voornaam*		*Van*		
U rol in die sentrum						
Landlynnommer			Selfoonnommer			
Epos-adres						
Straatadres				Provinsie		
Aantal inwoners	Totaal		Persone wat leef met demensie			
Aantal personeellede	Kantoorpersoneel		Versorging		Ondersteuning/Ander	

1. Watter **algemene uitdagings en frustrasies** moet u tydens Covid-19 hanteer?
2. Watter **algemene regulasies** het u fasiliteit in plek gestel om Covid-19 en verwante uitdagings aan te spreek? (bv. beleide, maatreëls en aanpassings met betrekking tot personeel, inwoners, familielede, die fisiese omgewing, kommunikasie, opleiding, welsyn en toegang tot gesondheidsorg en hulpbronne ens.)
3. Watter **demensie-spesifieke uitdagings** moet u hanteer en hoe reageer u daarop?
4. Hoe en wie het u gehelp **om die situasie te hanteer** gedurende hierdie tyd? (bv. riglyne, ondersteuning, hulpbronne, inligting, befondsing, verligting, netwerke, geloof, ens.)
5. Watter **behoeftes** van u fasiliteit is nie gedurende hierdie tyd aangespreek nie?
6. Wat is die **belangrikste lesse** wat u fasiliteit geleer het vanuit die Covid-19 pandemie?
7. Rapporteer asb enige infeksies, herstelsyfers en sterftes sedert die aanvang van die pandemie op 1 Maart 2020.

Geval-nommer	Inwoner of personeellid	Geslag	Ouderdom	Huidige infeksies	Herstel	Oorlede (datum)
1						
2						

Voeg rye by indien nodig

8. Sou u belangstel in 'n opvolggesprek met STRiDE om enige van die bogenoemde aspekte te bespreek?
   JA / NEE

Appendix 3 - Combined Summary of statistics: Rounds 1 (1-31) & 2 (32-58)

Key:

[] = square brackets indicate that a facility completed two survey forms; the other case number is given in brackets

* = deaths reported to have been of natural causes

LTCF #	Residents			Staff members			By Date	Cases	Resi-dents	Staff	M/F	Age	Sick	Recov-ered	Died (date)
	Total	PLWD	%LWD	Office	Health	Support									
*1 [34]	35	24	68.6	4	34	21	14/05	5	5	0			0	0	[5] [natural causes]
2	20	10	50	2	26	2	15/05	0					0	0	0
3 [33]	20	18	90	1	4	30	15/05	0					0	0	0
4	180	11	6.1	2	20	13	17/05	0					0	0	0
5	148	13	8.8	5	31	7	18/05	0					0	0	0
6	39	11	28.2	2	16	14	18/05	0					0	0	0
7	77	77	100	4	49	22	18/05	0					0	0	0
8 [51]	110	40	36.4	5	65	4	18/05	5	1	4	2+3	30-80	0	5	0
9	66	7	10.6	3	24	11	19/05	0					0	0	0
10 [52]	70	31	44.3	3	37	22	19/05	0					0	0	0
11	76	18	23.7	4	35	26	19/05	0					0	0	0
12	86	41	47.7	4	25/ shift	20	19/05	0					0	0	0
13	54	2	3.7	4	14	19	20/05	0					0	0	0
14	42	22	52.4	3	16	9	20/05	0					0	0	0
15	63	25	39.7	2	29	22	20/05	0					0	0	0
16 [53]	229	?	?	?	?	?	20/05	0					0	0	0

LTCF #	Residents			Staff members			By Date	Cases	Resi-dents	Staff	M/F	Age	Sick	Recov-ered	Died (date)
	Total	PLWD	%LWD	Office	Health	Support									
17	69	21	?	10	89	59	20/05	0					0	0	0
18 [40]	69	21	30.4	4	19	22	18/05	0					0	0	0
19	-	-	-	3	-	-	20/05	0					0	0	0
20	24	?	?	6	?	?	18/05	0					0	0	0
21	137	36	26.3	4	43	contract	22/05	0					0	0	0
22 [46]	60	26	43.33	2	44	21	25/5	0					0	0	0
23	189	9	4.76	4	22	25	25/5	0					0	0	0
24 [44]	-	-	-	-	-	-	25/5	0					0	0	0
25 [35]	46	15	32.61	3	21	19	25/5	0					0	0	0
26	64	40	62.5	4	18	8	25/5	0					0	0	0
27 [36]	37	7	18.92	1	20	-	25/5	0					0	0	0
28	167	29	17.37	6	35	-	21/5	0					0	0	0
29	91	58	63.74	2	19	27	25/5	0					0	0	0
30	133	45	33.83	6	41	8	27/5	0					0	0	0
31	28	28	100.00	3	11	15	05/06	0					0	0	0
32	54	2	3.7	4	14	19	16 July	0					0	0	0
33 [3]	23	20		1	20	20	16 July	32	11	21			1	27	4
34 [1]	35	24	68.6	4	34	21	16 July	10	6	4	9+1	28-94	0	7	3
35 [25]	48	18	37.5	3	22	18	17 Aug	0					0	0	0

LTCF #	Residents			Staff members			By Date	Cases	Resi-dents	Staff	M/F	Age	Sick	Recov-ered	Died (date)
	Total	PLWD	%LWD	Office	Health	Support									
36 [27]	37	7	18.9	1	20		16 July	0					0	0	0
37	48	13	27.1	1	24	1	17 July	0					0	0	0
*38	450	27	6.0	4	58	9	15 June	86	45	41			10 6R+4S	65 28R+37S	[11] [natural causes]
39	9	4	44.4		18		24 July	0					0		0
40 [18]	57	10	17.5		18		27 July	23	17	6	?		7	6	10
41	34	33	97.1	2	24	6	27 July	0					0	0	0
42	23	23	100.0	10	50	30	28 July	13	9	4	7M+6F	21-96	0	12	1
43	25	7	28.0	2	18	8	28 July	0	0	0			0	0	0
44 [24]			?				28 July	17	12	5	?	?	11	4	2
45	69	20	29.0	24	24	2	30 July	17	7	10	1M+16 F		0	16	1
46 [22]	60	26	43.3	2	44	21	3 August	11	7	4	3M+8F	30-95	0	11	0
47	73	15	20.5	2	22	22	3 August	0	0	0			0	0	0
48	121	32	26.4	4	55	33	3 August	4	2	2	1M+2F	21-80	0	3	1
49	96	43	44.8	2	35	13	3 August	5	3	2	1M+2F	42-86	0	4	1
50	57	19	33.3	3	27	16	5 August	12	9	3	2M+10 F	39-87	0	12	0
51 [8]	110	38	34.5	5	44	24	6 August	6	2	4	1M+5F	30-75+	0	4	2
52 [10]	69	30	44.0	4	34	17	13 Aug	1	1	0	1F	?	asymp	0	0
53 [16]	236	10	4.2	48	30	0	19 Aug	3	3	0	1M+2F	83-86	0	3	0

LTCF #	Residents			Staff members			By Date	Cases	Resi-dents	Staff	M/F	Age	Sick	Recov-ered	Died (date)
	Total	PLWD	%LWD	Office	Health	Support									
54	46	15	32.6	1	19	1	24 Aug	0	0	0			0	0	0
55	85	10	11.8	3	27	2	26 Aug	3	2	1	1M+2F	50-90	0	2	1
56	42	nil	0	3	26	13	28 Aug	0	0	0			0	0	0
57	139	26	18.7	5	160	3	28 Aug	1	1	0	1M	91	0	1	0
58	78	30	38.5	5	36	33	2 Sept	0	0	0			0	0	0