

SHORT REPORT

‘We have become prisoners of our own age’: from a continuing care retirement community to a total institution in the midst of the COVID-19 outbreak

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Abstract

Background and objectives: during the coronavirus disease 2019 pandemic in Israel, people residing in continuing care retirement communities (CCRC) found themselves under strict instructions to self-isolate, imposed by the CCRC managements before, during and after the nationwide lockdown. The present study explored the personal experiences of CCRC residents during the lockdown.

Research design and methods: in-depth interviews were conducted with 24 CCRC residents from 13 different CCRCs. Authors performed a thematic analysis of interview transcripts, using constant comparisons and contrasts.

Results: three major themes were identified: (i) ‘Us vs. them: Others are worse off’. Older residents engaged in constant attempts to compare their situation to that of others. The overall message behind these downward comparisons was that the situation is not so bad, as others are in a worse predicament; (ii) ‘Us vs. them: Power imbalance’. This comparison emphasised the unbalanced power-relations between older adults and the staff and management in the setting and (iii) ‘We have become prisoners of our own age’. Interviewees described strong emotions of despair, depression and anger, which were intensified when the rest of society returned back to a new routine, whilst they were still under lockdown.

Discussion and implications: the measures imposed on residents by managements of CCRCs during the lockdown, and the emotional responses of distress among some of the residents, revealed that CCRCs have components of total institutions, not normally evident. This underscores the hidden emotional costs of the lockdown among those whose autonomy was compromised.

Keywords: long-term care, trauma, COVID-19, paternalism, autonomy, loneliness, older people

Key points

- During the COVID-19 outbreak, CCRCs have become total institutions.
- Residents experienced the power imbalance and the infringement of their human rights as traumatic.
- Downward comparisons with other worse off groups were ineffective in alleviating residents’ distress.
- A state of complete lockdown and the deprivation of residents’ autonomy and knowledge of the situation should be refrained.

Although the coronavirus pandemic has upended everyday life in most parts of the world, a large percentage of all coronavirus disease 2019 (COVID-19)-associated deaths worldwide have occurred among long-term care (LTC) residents [1]. As of 25th June 2020, there have been 308 confirmed deaths associated with COVID-19 in Israel. Of these, 42.61% are people who lived in LTC settings, but <1% of all COVID-19-associated deaths occurred among continuing care retirement community (CCRC) residents [2]. To put these numbers in perspective, roughly 2% of all older Israelis live in LTC institutions and another 2% live in CCRCs [3].

From a legal perspective, the CCRC is considered a community dwelling rather than a LTC facility. New residents are independent at least upon entering and the CCRC offers varied levels of care, based on people's interest and needs [4,5]. Nevertheless, a recent Israeli study has found that, on average, older residents have the same level of impairment as older Israelis who are legally considered care dependent by the state [6]. Moreover, although older CCRC residents do not share a unit with other residents other than a spouse, CCRC units are usually small with the explicit goal of encouraging social gatherings [7,8]. Hence, despite differences between the traditional LTC institutions and CCRCs, many of the characteristics of CCRCs make their residents quite vulnerable as well [9].

At the outset of the outbreak in Israel, the first group that was instructed to self-isolate was that of older adults over the age of 60 and individuals in LTC settings, including CCRCs. After a period of strict lockdown starting in mid-March, on 19th April, Israel gradually started to reopen and resume a new routine [10]. Most LTC settings and CCRCs, however, continued to restrict any passage of individuals to and from these institutions, for several weeks after the rest of the nation reopened. Following protests of family members, a state document called 'Mothers' and fathers' shield' was issued on 20th April, ordering settings to gradually reopen and allow supervised family visits [11].

In the light of the unique features of the CCRC setting, which has some characteristics of community living that foster independence and autonomy, but also features of LTC settings, including the physical vulnerability of its residents and the structural features of the setting that make physical isolation challenging, the present study set out to bring the experiences of older adults during the lockdown and the slow reopening that followed.

Methods

Recruitment

Following approval by the PI's ethics committee, we recruited 24 participants, who were interviewed between 22nd April and 9th June, corresponding with the transition from a full state of lockdown in the entire country to a partial reopening for most Israeli residents. Our inclusion criteria were CCRC residents who speak Hebrew or English, are willing to be interviewed for the study and able to communicate over the phone.

Table 1. Demographic characteristics of participants

Residents characteristics (N = 24)	Mean (SD)/%
Age	83.75 (5.02)
Gender	
Male	12.50%
Female	87.5
Marital status	
Married	12.50%
Widowed	75%
Divorced	12.50%
Years of education	14.19 (2.43)
Years in the CCRC (SD)	6.43 (5.39)
Referral source	
Personal networks	25%
Israeli CCRC council representative residents	20%
Facebook advertisements	37.50%
CCRC administrators	17.50%
CCRC setting (N = 13)	
Location	
Centre	10
South	1
Jerusalem	2
Socioeconomic status	
High end	6
Middle range	7

Note: Continuous variables are reported as means (standard deviations [SD]). Categorical variables are reported as percentage.

We were interested in the experiences of residents in diverse settings, and we therefore employed varied methods of recruitment. We approached our existing social and professional networks via emails, WhatsApp groups and Facebook advertisements. We also approached the Israeli council of CCRC residents for their collaboration. Recruitment continued to the point of content saturation.

Appendix 1 in the supplementary data (available in *Age and Ageing* online) on the journal website provides detailed information concerning the procedure, analysis, interview guide and trustworthiness of the findings.

The Sample

In total, 24 residents were interviewed. Residents varied in terms of the amount of time in the CCRC, ranging between 1 and 23 years. The age range of residents varied between 75 and 92. Of them, 87.5% were women. Residents came from 13 different settings, from diverse regions of the country. CCRC settings varied in size, with some settings having only 50 and others being quite large, with as many as 500 residents. See Table 1 for details.

Findings

Three major themes emerged through the analysis of interview data. The first theme: 'us vs. them: Others are worse off' concerned older residents' constant attempts to compare their situation to that of others. Specifically, the older persons interviewed in this study compared their situation to others in the community, in their own setting and in the nursing unit, who were seen as being worse off. The overall message

behind these downward comparisons was that the situation is not so bad, as others are in a worse predicament. A second theme, ‘Us vs. them: Power imbalance,’ also involved a comparison, but this time, between the older CCRC residents on the one hand and the staff and management on the other hand. In contrast to the former comparison that empowered and protected older adults from the challenges they faced during the lockdown, the latter comparison emphasised the unbalanced power-relations between older adults and the staff and management in the setting. The third theme, ‘we have become prisoners of our own age,’ concerned the collapse of resources and coping. Interviewees described strong emotions of despair, depression and anger, which were only intensified when the rest of society returned back to a new routine, whereas they were still under lockdown. For a subset of participants who were Holocaust survivors, these emotions were accompanied by vivid memories and experiences from the past, as they unanimously equated their current experiences with their traumatic past. Older CCRC residents vividly described the transformation of the CCRC from a place of pleasure and activity to a prison, even a form of solitary confinement. The three themes are detailed below, accompanied by quotes from the interviews. Table 2 illustrates the themes with direct quotes from the interviews. We use pseudonyms to protect respondents’ anonymity.

Discussion

Although physically safe, most CCRC residents interviewed in this study reported a substantial reduction in their mental wellbeing, including high levels of anxiety, depression, anger and despair. The paternalistic approach, which attempted to protect residents at all costs, allowed for limited autonomy and self-assertion. These features of the CCRC as a total institution have been documented in past research, which has shown that as older adults’ physical abilities decline and health needs increase, their ability to exert their wishes within the CCRC setting declines as well [12]. Our findings provide further support to this. Whereas older adults in the community were allowed to leave their home for a radius of 100 m, and, further, choose whether or not they wish to obey the COVID-19 guidelines (and if they disobey potentially pay the consequences), in CCRCs, most older adults had no place for personal judgement. They were literally forced to stay in quarantine. Based on residents’ reports it appears that the more drastic the measures of the CCRC, the harsher the personal experience of CCRC residents became. Those settings that allowed residents to maintain some level of autonomy, appeared to better support their residents through these stressful times.

While reviewing the findings, it is important to acknowledge the study’s limitations. This is a qualitative study that aims to provide an in-depth understanding of CCRC residents’ experiences, rather than a general picture of the situation in Israel. Nevertheless, the fact that interviewees came from many different settings allows for greater generalizability of the findings. It also is important to note that this study brings a single point of view—that of the

Table 2. Direct quotes from the text to illustrate the three major themes

Who said	Direct quote
‘Us vs. them: Others are worse off’ Ruth, an 89-year-old widow	‘Those who are alone (in the community), my friends who are alone, they are simply jealous of us, because they are saying—“you are in a cage, but a cage of gold, because you are being spoiled.”’
Miriam, a 75, married woman	‘Yes—and we are in a good position because we are two (partnered) and we have a comfortable apartment, but let’s say, 70% of the residents here are lonely’.
‘Us vs. them: Power imbalance’ Ella, a 77-year-old widow	‘Initially, no one spoke (about the effects of the outbreak in the CCRC). They (team) knew that someone died. But, no information in order not to . . . No information on the notification system, nothing’.
Dalia, a 90-year-old widow	‘They (staff) strive to lift up our spirits. They’re so great. They closed the door that leads to the nearby shopping center. They shut that door, they closed off the door that leads in and out, we can’t leave. But we were given a date: the 28th of May, the eve of Shavuot (the Jewish holiday of Pentecost), then we can leave and be with our families. But the families will only be allowed to visit us in the courtyard, 2 meters apart, behind bars’.
‘We have become prisoners of our own age’ Hilla, an 87 year-old widow	‘You felt as if you were being held in prison. Strongly. On the other hand, possibly, because of this, no one here was infected—maybe’.
Rachel, 88, a Holocaust survivors	‘I have been watching myself trying not to let depression in, but it (lockdown) was depressing. From that period, when I was 7–8 years old, all alone, among strangers, in a threatening world. I have learned how to block my feelings when I needed to. So—that girl has become my counselor during lockdown. Even now, the girl is saying: “I am getting over this. I am not thinking about this, I am shutting this out.” I reorganise things’.

residents. We did not interview staff, management or family members for this particular study. Thus, whilst extremely important, it should be kept in mind that the perspective provided in this study is one standpoint. Moreover, our approach to recruitment relied, among other methods, on CCRC managers and thus, might be subject to bias.

Despite these shortcomings, the present findings have important implications for the current management of the outbreak as well as for future waves, or similar pandemics

in the future. Our findings show that the CCRCs were successful in physically protecting older adults at the price of compromising their wellbeing. CCRC residents' defense mechanisms were successful to some extent, but as time went by and the rest of the country returned to a new routine, these mechanisms collapsed and older residents experienced high levels of stress, anxiety, depression, despair and anger. They were forced to acknowledge the important role that management and staff play in their lives and the limited agency that they have to manage their lives during the crisis. From the interviews, it is clear that staff and management can emotionally harm residents, but also calm and ease residents' experiences. Some members of staff were identified as benevolent figures of substantial importance especially at times of distress. Moreover, those settings that allowed greater flexibility and maintained older residents' routine as much as possible helped to protect residents' mental wellbeing. Similarly, the more transparent the measures enforced by the setting were, the more satisfied were the residents. Current efforts should be geared towards maintaining routine and social activities, whilst protecting residents through targeted testing and the constant supply of personal protective equipment. Residents' autonomy and self-assertion should be respected and encouraged as a means for maintaining emotional resilience during these unsettling times.

Supplementary Data: Supplementary data mentioned in the text are available to subscribers in *Age and Ageing* online.

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Declaration of Conflicts of Interest: None.

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