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Experiences of ageing and aged care in Australia of older survivors of genocide

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ABSTRACT
This qualitative study investigated the ageing and aged care experiences in Australia of two cohorts of older survivors of genocide: Jewish Holocaust survivors and older Cambodian genocide survivors. It was carried out in response to an identified need to better train aged care workers who are in contact with these groups. In-depth interviews were conducted with 21 community-dwelling survivors aged 65 and over. Credibility was ensured by methodological triangulation and peer debriefing. The study highlighted the importance of understanding older survivors' ageing and aged care experiences in the context of their entire lifecourse and in terms of both vulnerability and resilience. It showed that trauma history can heighten older survivors' sensitivity to many aspects of the social and physical environments in residential, community and home-based aged care settings. The study also uncovered the potential for aged care services to help older survivors cope with the psycho-social and emotional effects of resurfacing post-traumatic stress symptoms. The implications of the study findings for care practice include the importance of recognising older survivors of genocide as a distinct group of clients and the need to distinguish staff training for caring for this client group from general cultural awareness training.

KEY WORDS – genocide, mass trauma, Holocaust survivors, Cambodian genocide survivors, residential aged care, home and community aged care services.

Background

This article focuses on the ageing and aged care experiences in Australia of older migrants (aged 65 years and over) who are survivors of genocide (hereafter 'older survivors'). It is based on the findings from a qualitative study that was part of the Australian Caring for Older Survivors of Genocide and Mass Trauma project. The project was initiated by Jewish Care Inc. (Victoria), in response to a perceived need to improve the quality of care provided for Holocaust survivors by various organisations and in recognition

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of the relevance of this research for other refugee groups in Australia. Aged care in Australia is defined as the personal care and/or nursing care provided to frail older people and their carers to facilitate independence, good health and wellbeing. Aged care is delivered through two main government-funded programme: residential aged care and Home and Community Care (HACC). Planned Activity Groups (PAGs) are provided through the HACC programme. PAG activities are aimed at enhancing the skills required for daily living and providing physical, intellectual, emotional and social stimulation. They also provide respite opportunities for carers (Australian Government Productivity Commission 2011: 4–6). An aged care worker is a person employed to provide aged care services. Home support workers provide these community services in older peoples' homes.

As older people in Australia live longer, community and residential aged care staff will be caring for many more people who experienced traumatic life events than they did in the past. Genocide is probably the most extreme and catastrophic form of trauma. This study focused on Jewish Holocaust survivors and older survivors of the Cambodian genocide. These two groups of older adults experienced genocide as young people. Subsequently, they left their countries of origin in their early or middle adult years and have experienced the process of ageing in Australia. Clearly, the histories of these two catastrophes are different. The events leading up to trauma, the aims of the perpetrators and the methods of extermination were different. Nevertheless, there are similarities between the survivors in these two groups which relate to a 'universal human response to overwhelming trauma' (Savin and Robinson 2002).

The term Holocaust refers to the extermination of six million Jews during the Nazi era (1933–45). Nazi policy was to erase the Jewish race systematically and meticulously. A Holocaust survivor is defined as any Jew who lived in a country under a Nazi or Nazi collaborator regime or under Nazi occupation, as well as any Jew who fled owing to a Nazi regime or occupation (Shmotkin, Blumstein and Modan 2003). After World War II, about 35,000 survivors of the Holocaust arrived in Australia and settled mainly in Melbourne and Sydney. Australia has the highest number of Holocaust survivors per capita outside Israel (Rutland 2005).

The Cambodian Genocide (1975–78) was an attempt by Khmer Rouge leader Pol Pot to reconstruct Cambodia into a communist peasant farming society. The population was forced to work as labourers in one huge federation of collective farms. All political and civil rights were abolished. An estimated two million Cambodians died from starvation and overwork or by execution. Between April 1975 and June 1986, the number of Cambodians who came to Australia under the Refugee and Special Humanitarian Program was 12,813; approximately 3,500 resettled in Australia under the family migration stream in the 1990s. The number of Cambodian-born people in Victoria in 2001 was 9,022 (Australian Bureau of Statistics 2006).

Literature on Holocaust survivors and Cambodian genocide survivors shows that extreme and prolonged traumatisation can have a profound and sustained impact on the ways in which individuals respond to, and cope with, the numerous and often cumulative challenges that arise during the final decades of life (Hinton *et al.* 2005; Shmotkin, Blumstein and Modan 2003). Bartolomei, Hugman and Pittaway (2003) found that few care providers in Australia recognise the needs of older people from refugee backgrounds as distinct from the needs of the general migrant population. A lack of awareness by care providers of the potential impacts of prior trauma on aged care clients has implications for practice and for client outcomes.

The main purpose of this research was to develop an evidence-base to inform training aimed at enhancing the preparedness of aged care workers' for caring for older survivors. The importance of sharing the lessons from this study is highlighted by the horrific reality of persistent wars and additional genocides. Rosenbloom, in her discussion of what can be learnt from the Holocaust stated, 'The lessons of the Holocaust are vital and universal, timely, and timeless' (1985: 181). The findings of this study may contribute to raising awareness of the ageing and aged care experiences of the more than 675,000 displaced people, refugees and humanitarian programme entrants who have arrived in Australia from war-torn countries since end of World War II (Forum of Australian Services for Survivors of Torture and Trauma 2006).

Literature on older Cambodian refugees

Cambodian refugees are characterised as having experienced more traumatic events than most other refugees (Kinzie 2001). A key strand of the literature on Cambodian refugees is the long-term effects of trauma on their physical and mental health. This literature shows high levels of post-traumatic stress symptomology and increased levels of physical illness both in psychiatric populations (Hinton *et al.* 2005) and in general population samples of Cambodian refugees (Boehnlein 1987; Carlson and Rosser-Hogan 1993; Uehara *et al.* 2001).

In the last ten years, research on Cambodian refugees has incorporated ageing and examined how older Cambodians have adapted to life in Western countries. Studies have described the process of ageing in the United States of America as complex for this group due to issues such as loss of role as respected elder, fear of living separately from children, feeling devalued by children, self-blame for intergenerational gaps, exacerbation of post-traumatic stress symptoms, and under-utilisation of available health care and support services (Lewis 2009; Strumpf *et al.* 2001). Many of these issues have also been identified among older Cambodian people in Australia (Gifford, Atwell and Correa-Velez 2007; New South Wales Refugee Health Service 2006).

Literature on ageing Holocaust survivors

The evolution of the literature on Holocaust survivors can be aligned to their developmental lifecourse (David 2008). At the end of World War II the average age of the majority of Holocaust survivors was 18–30 years old and for the next few decades survivors were establishing themselves in adopted countries and raising new families. Most of the research in this period was based on concentration camp survivors who were receiving psychiatric treatment (Kellermann 2010; Niederland 1981). By the 1970s the cohort was entering middle age and retirement, and researchers were beginning to identify methodological problems with earlier studies (Ornstein 1981). In the 1980s literature on Holocaust survivors incorporated ageing, and complex Post-Traumatic Stress Disorder (PTSD) was defined to accommodate extreme circumstances of trauma such as the Holocaust (Herman 1997; Sadavoy 1997).

In the 1990s many people in this cohort began experiencing major age-related challenges (including retirement, widowhood, and increasing frailty) while simultaneously more survivor narratives emerged. Research began considering late-life stressors and the re-emergence of post-traumatic stress symptoms among ageing Holocaust survivors and other groups of trauma survivors. The literature suggested that ageing Holocaust survivors were vulnerable to poor mental health outcomes because they were simultaneously facing aged-related life transitions, such as declining health and widowhood, and worsening of past traumatic memories (Amir and Lev-Wiesel 2003; Brodaty *et al.* 2004; Danieli 1997; Trappler *et al.* 2002).

Studies with community samples found higher rates of mental and physical health problems among ageing Holocaust survivors than in their peers. For example, in comparison with other older Israelis, those who were Holocaust survivors reported higher rates of cardiovascular problems, chronic skeletal pain, mobility problems, sleep disorders, and feelings of loneliness, expressed more negative attitudes towards their own health, and required higher intensity of home care (Brodsky *et al.* 2010). An Australian study of community-dwelling Holocaust survivors found that while their social and daily functioning was normal 55 years after the end of World War II, they functioned worse on a range of psychological measures than two control groups of older Jewish people who were not in Europe during the war (Joffe *et al.* 2003).

During the last decade research has included more qualitative studies and incorporated adaptation and resilience perspectives. This approach reflects the view that too much emphasis had been placed on the negative psychological effects of trauma, and not enough on health-promoting factors such as growth, adaptability and resourcefulness. In this respect, Lomranz (2000) has spoken of the 'skewed image of the Holocaust survivor'. Similarly, Shmotkin, Blumstein and Modan (2003) suggested that the sequelae of extreme trauma should be understood in terms of both vulnerability and resilience, emphasising variability between individuals rather than uniformity in their capacity to cope. More recently, two Canadian studies of the life trajectories of ageing Holocaust survivors living in long-term care facilities (LTCFs) have identified indicators of resilience that were characterised by hope, trust, 'facilitative beliefs' and pragmatism (Hirst, LeNavenec and Aldiabat 2011; Pirner 2006).

Older survivors of genocide and aged care

The literature on the aged care experiences of older survivors of genocide and mass trauma is sparse. There is a complete gap in the literature in relation to the Cambodian experience of aged care in Western countries and the literature on Holocaust survivors in aged care is methodologically limited. The early literature, which was based on the experiences of clinicians working in nursing home and acute hospital settings, suggested that Holocaust survivors can experience relocation to institutional care as profoundly disturbing due to its potential to induce feelings of helplessness and reactivate traumatic memories (Adams *et al.* 1994; Carstairs 2004; David and Pelly 2003; Ehrlich 2004; Hirschfeld 1977; Levine 2001; Zilberfein and Eskin 1992). However, empirical studies have found less evidence of this effect. Shour (1990) found that Holocaust survivors living in a nursing home in Canada were similar in their behaviour, psycho-social needs and physical needs to the other residents. They tended, however, to use a greater number of medications and to access fewer medical services and they were more likely than other residents to be described as being aggressive. Letzter-Pouw and Werner (2003) found no differences between Holocaust survivors (N = 94) and a comparison group (N = 74) on their willingness to enter a nursing home. However, within the Holocaust survivor group, those who tried to avoid memories of the Holocaust were less willing to enter a nursing home than those who made less of an effort to avoid such memories. Lomranz, an expert on the long-term effects of the Holocaust, asserted that while entry to residential care and hospitalisation can be perceived as 'gateways to psychopathology' (2005: 257), Holocaust survivors usually do not react adversely to these situations. Further limitations of this strand of literature include the lack of research concerning older survivors' experiences of community-based aged care services, and the absence of older survivors' own accounts of their aged care experiences.

Methodology

The social constructionist paradigm of qualitative research (Creswell 2007) was used to examine older genocide survivors' views on their own ageing and aged care experiences within the social, cultural and historical context of their entire lifecourse. The ageing and lifecourse perspective, which seeks to account for outcomes later in the lifecourse on the basis of earlier life experience (Dannefer 2011), provided a theoretical framework for interpreting the study findings. While in-depth interviews focused mainly on ageing and aged care, we also touched on interviewees' war-time experiences, their migration and resettlement stories, and their thoughts about the impacts of those events in their ageing years. This information enabled the researchers to examine the interviewees' ageing and aged care experiences in the contexts of their individual life stories and their cultural norms.

Participants

Purposive sampling was used to recruit study participants in 2009. The inclusion criteria for the study were: (a) being a survivor of the Cambodian genocide or a Jewish survivor of the Holocaust, (b) being aged 65 years or over, and (c) being a current user of home support services or participating in government-funded planned activity groups, or residing in a LTCF. Older survivors were invited to participate in the study by aged care service managers from Cambodian welfare organisations in Melbourne and Sydney and Jewish Care in Melbourne. They were told that the researchers would like to ask them about their experiences of ageing and using aged care services in Australia and that the findings would be used to inform future aged care staff training. Informed consent was given by all participants. For the Cambodian participants, the process of obtaining written consent and the interviews were conducted in Khmer. For most Holocaust survivors, this process employed English, but for those from the former Soviet Union it was conducted in Russian. The project had ethics clearance from the La Trobe University Human Ethics Committee.

Twenty-one community-dwelling older survivors (18 women, three men) were interviewed: 12 Holocaust survivors and nine older Cambodian survivors. Nine interviews were conducted in English and 11 through qualified interpreters (three Russian and eight Khmer). In-depth interviews were digitally recorded, transcribed by a professional service, and analysed with the assistance of NVivo software.

Data collection and inductive thematic analysis occurred interactively. The analysis began with open coding. The data were examined and sorted to produce initial codes that reflected the processes (ageing and aged care) being explored. These codes were clustered into categories of major themes to gradually extract the meaning of the texts. Finally, the researchers sorted for ways the themes might make parts of an overall story (Braun and Clarke 2006; Creswell 2007; Strauss 1990).

Credibility was ensured by methodological triangulation: the process of using multiple sources of data to expand on, provide additional context, and verify identified themes. Two additional sources of respondents were available for triangulation of the older survivors' statements, eight interviews with family carers, ten focus group interviews held with a total of 90 aged care workers recruited from a range of aged care service types, including home support services, LTCFs and community centres, and 14 in-depth interviews with aged care, health and welfare professionals. These data collections assisted the researchers in understanding the meaning of what survivors said about their aged care experiences and what they may have omitted to say. A second method for establishing credibility was peer debriefing provided by a panel of five expert advisors from a range of relevant backgrounds (*see* the Acknowledgements) who met regularly with the researchers to test the thematic analysis.

The researchers

The researchers are academics in the field of gerontology. The main researcher's parents arrived in Australia as Jewish child refugees shortly before the outbreak of World War II. In this study she interpreted the study participants' stories through the lens of her professional discipline with an awareness that this lens was filtered by her family and cultural history. The co-researcher is a psychologist and her research focuses on aged care services.

Findings

The major theme relating to older survivors' experiences of ageing that resulted from the thematic analysis was: living with trauma and loss. In relation to aged care experiences, three major themes emerged: reluctance to take up formal care, the potential for emotional and social support, and the potential for evoking past trauma.

Living with trauma and loss

Interviewees in both groups had typically endured extreme and prolonged brutality as well as years of living with fear and the daily threat of death. They had suffered multiple losses, multiple relocations, as well as deprivation of food, shelter and medical care. For many, the process of resettlement in Australia, mostly in their early to middle adult years, had also been accompanied by enormous hardship. Despite this suffering and hardship, the participants had in general succeeded in rebuilding their lives, bringing up families, and establishing themselves financially or assisting their children to become established. Some had also made important contributions to their communities. For example, the daughter of an older Cambodian survivor explained: 'My mum used to be a very active member in the community. She had a very responsible role at the temple.'

Most participants felt that 'getting on with their lives' had helped them to cope with the trauma and losses they had experienced prior to their resettlement. However, in considering their ageing years, the predominant view was that increasing frailty and slowing down from previously busy lives had led to growing social isolation, precipitated more frequent and intense feelings of grief and loss, and resulted in worsening of sleep disturbances. A Cambodian older survivor explained that her husband still dreams about being arrested: 'They want to send him to the killing fields . . . They attempt to kill him but now he [still] wakes up shaking.' Similarly, Holocaust survivors spoke about being affected by traumatic memories at night time:

> Sometimes at night time, you can't sleep, you think about [the Holocaust] . . . a lot of things, they come back to you at night.

Holocaust survivors tended to have acknowledged their feelings about the past and to have considered how those feelings had evolved over time, as illustrated by two quotes from Holocaust survivors below:

> It's just there. For as long as I live, I know people that I love live in my heart. They are always with me . . . the past is with me. This is not something that you can sort of forget. It's with you even subconsciously, all the time. And I don't want to forget.

> I think the anger passed away and maybe I am not strong enough to be angry. It's definitely sadness. The thing that varies is the degree of sadness. Some days are very, very sad.

Cambodian interviewees in general disclosed very little about the past trauma to the researchers. Those who did mention it spoke of being 'trapped in feelings and unable to express them', being able to talk about the past with their peers but not with their children, and trying unsuccessfully to suppress traumatic memories of the past: 'I want to try to forget but how can you . . . the stories seem to follow me.' The image of being 'chased' by traumatic memories was a commonly expressed metaphor. Many interviewees felt that as the pace of their lives had slowed down, these memories had 'caught up' with them. This was eloquently described by one of the Holocaust survivor interviewees:

> The trauma comes back, the older you get the more you think about it, you can't help that. When you're young and you're busy raising children and meeting friends and making a home and finding a job but when you get older all this trauma comes back you can't help it . . . It's [the past trauma] always there . . . more now than it was before. Because you lost your sense of purpose . . . you were married, you have your children, your children have children, to a certain degree it has been accomplished and you feel you're just fading away a bit, you're just taking it easy but you can't take it easy because when you take it easy you get absolutely overwhelmed with what happened to you.

Themes relating to aged care experiences

Theme 1: Reluctance to take up formal care. In both groups there was widespread reluctance to accept aged care services in the home which interviewees largely attributed to their expectation for filial care. However, accessing social support services through ethno-specific, government-funded PAGs was socially acceptable and widely taken up by older survivors in both groups. Older survivors generally avoided assistance in the home by being supported by their spouse and/or adult children. Family members had often persevered with the care of their extremely frail or cognitively impaired loved one without formal or family assistance until the situation had become unmanageable or they reached a crisis point.

Some Cambodian survivors had sponsored, or were attempting to sponsor, a young relative to come from Cambodian when family support was unavailable in Australia. In some cases, these clients had been convinced by Cambodian care workers to accept government-funded in-home respite or home support services. Similarly, case managers spoke of the struggles they had faced trying to get services into some Holocaust survivors' homes. In a few cases, even after home help had been arranged, Holocaust survivor clients had refused to let the home support workers into their house.

Older survivors expressed a range of concerns about home support services including: the perceived high cost of services, suspicion (and in some cases fear) of strangers, and a desire not to be a burden. Language was a barrier to accessing services for most of the Cambodian interviewees and for the three Holocaust survivors who migrated to Australia from the former Soviet Union in the 1990s.

In both groups, there was also a tendency to deny needing assistance. One older woman whose husband had dementia stated that she was quite able to look after him despite the fact that his behaviour usually kept her awake for most the night. When asked what she would do if she could no longer cope, she replied that she would: 'Cross that bridge when she got to it.' She explained that her husband had been tortured by both the Khmer Rouge and guards in a Thai refugee camp more than 30 years ago and he still suffered from his injuries. For this reason, she said they would not accept help from any aged care service in their home. She explained:

> His injury is still there and his scalp is dented in . . . we prefer not to have anyone come to the house . . . even now he likes to sit by himself . . . he just want to do things by himself.

Among the Holocaust survivors, the tendency to deny needing assistance was attributed to a fear of the consequences of showing physical weakness or illness. A case manager had learned that:

> You've got to be very open to hearing more than they say. Sometimes they'll tell you a lot but they're not telling you significant stuff like the care they actually need or that they're not managing at home [I think that is] because the ones who were sick and frail then [during the Holocaust] were immediately killed.

The predominant attitude towards relocation to LTCFs in both groups was that such a move would be an absolutely last resort. This attitude is common among older people regardless of cultural background (Hutchinson *et al.* 2011); however, our data suggest that earlier trauma compounds what is already a stressful life transition. We learned that older Cambodians were concerned that living in a LTCF would lead to premature death by 'starvation' which was an unwelcome reminder of the deprivation suffered during the Pol Pot years. They also perceived LTCFs to be places where Cambodian people would be socially isolated and lonely. For Holocaust survivors, the transition to residential care was considered to be stressful because of its potential to evoke earlier life experiences of forced displacement, loss of possessions and multiple relocations.

Theme 2: The potential for social and emotional support. Older survivors' stories revealed that socialisation and other activities provided by community aged care services can have positive effects on older survivors' emotional wellbeing and assist them to some extent to cope with resurfacing, or worsening post-traumatic stress symptoms.

Many Holocaust survivor interviewees had developed meaningful relationships with the care workers who came to their homes to provide support. They felt that these relationships had helped reduce their feelings of sadness, loneliness and social isolation. A Holocaust survivor participant said:

> The [Holocaust] survivors were all damaged and if the carer is gentle and understanding that is a great help. I can see the difference, not just coming and

> cleaning, that's not enough, it's cleaning my pain and my soul is more important. I'm much more appreciative of a carer who comes and sits down and has a cup of tea with me and says, 'How are you?' and gives me a hug and gives me a kiss much more than when she will clean my house – and I love to have the house cleaned.

Holocaust survivors tended to describe positive relationships with care workers as those that involved friendship and 'mutual caring'. Aged care professionals pointed out that because of the time it can take to establish trust with older survivors, frequent turnover of care staff can be a major problem for these clients. In contrast, Cambodian interviewees in general had little expectation of developing close relationships with care workers.

The evidence showed that ethno-specific PAGs were particularly important for older survivor clients. These groups were valued because they provided staff who understood the clients' backgrounds and connected them with other aged care services, opportunities for older survivors to spend time with people they could relate to, and a 'safe' environment to occasionally 'contemplate the past'. A Holocaust survivor felt that the PAG staff understood her groups' emotional needs and worked to help them stay connected to others and engaged in life. She recited a Russian poem called 'The Autumn of Life' to sum up how she felt about the painful past:

> 'Thousands of pains and memories that come flooding back . . . Some hair going grey and the rain falling and all those questions that remain unanswered'. That is pretty much what the Autumn of Life is about, but these people [PAG staff] . . . pretty much try to cheer us up and they say to us, 'Well don't close down, don't shut out, just go out to the world, look at things, try to be interested in things.'

Similarly, an older Cambodian survivor said that prior to joining the Cambodian activity group, he had not wanted to be involved with a crowd and enjoy life because he had been through so much suffering in the past. He said:

> Since I have been involved [in the group] I see the amazing and important things that have changed my life. I can't wait to join this group every week, I look forward to it. I want to be part of this group – it is a new life for me. I am nearly 70 years old, but now I feel 50 years old. The group makes me feel young. I feel that there is a bright future for me now; I won't get bored with my life.

One Cambodian participant valued being able to talk openly with friends about the past, without fear of retribution:

> Sometimes we do talk about it here. . . . Because in the Pol Pot time, we can't even sit in a pair to talk to one another. . . . [In Australia] we discuss our fears, what we went through, and we happy that now we got each other here to talk about it. Here you're free to talk about it . . . and we don't worry about who is recording us!

Older survivors also made it clear that while involvement in the PAG provided a welcome distraction from painful thoughts about earlier-life suffering and losses, those thoughts were indelibly etched in their memories. This experience was exemplified by an older Cambodian survivor who said:

> When I go [to the PAG] and see my friends I feel happy, but when night comes it makes me feel sad again because I think too much and cannot sleep.

Theme 3: The potential for evoking past trauma. The researchers questioned whether study participants had experienced situations in either residential or non-residential care settings that they found distressing due to resonances with earlier life traumatic experiences. This question was prompted by evidence in the literature suggesting that residential care and hospital settings can lead to re-traumatisation among older survivors (David and Pelly 2003; Hirschfeld 1977; Joffe, Joffe and Brodaty 1996).

Older survivors, family carers and professional carers identified a range of situations, in LTCFs, clients' homes, hospitals and PAGs, that had led to some older survivor clients experiencing extreme feelings of distress, fear, anxiety and humiliation. In some cases these situations had led to clients becoming verbally or physically aggressive towards care workers.

As none of the older survivor interviewees were living in a LTCF at the time of the study, information about older survivors' experiences of living in residential care was derived from what community-dwelling older survivors reported about their friends' and spouses' experiences and from interviews with care workers and family carers. Interviewees confirmed that certain design aspects of the built environment in LTCFs can potentially trigger traumatic memories for older survivors. These included: enclosed spaces, long corridors, and locked windows and doors. A Jewish family carer said: 'The fact that we can't open windows . . . It's like a jail'.

Aspects of the physical environment were also found to trigger trauma responses in community care settings. An older Cambodian survivor mentioned being uncomfortable going on social outings to forested areas because they raised thoughts about the murders that were perpetrated by Khmer Rouge. A Cambodian respite care manager had assisted the home nursing service that was unable to get into the home of an older Cambodian woman who required care after she was discharged from hospital. The care manager explained that the client had become terrified by her neighbour's car headlights shining into her window at night and had gone into 'survival mode':

> The headlights had triggered memories of Khmer Rouge night patrols when bright lights were shone in people's houses and family members were taken away and killed.

A PAG worker described the response of a Holocaust survivor when two staff members coincidentally came to work one day dressed in similar dark skirts and blouses.

> She [the Holocaust survivor] ran to the gates and they were locked. She was screaming for help from passers-by, because she thought that she was in the camp and that we were wearing uniforms . . . She was screaming, she was so desperate to run away.

In LTCFs, aspects of the social environment that were thought to be potentially distressing for older survivors included: lack of privacy, communal dining, and having one's daily routines dictated by rosters and processes. A family carer felt that those Holocaust survivors who were in concentration camps and witnessed their relatives or friends dying would not easily tolerate overhearing the suffering of others in a long-term care facility.

Some Holocaust survivor interviewees acknowledged that they were very sensitive about the way they were treated by staff. They attributed this sensitivity to their earlier life experiences of brutality and violence and they stressed the importance of aged care staff being aware of their past history. In contrast, most older Cambodian interviewees did not think that care workers required knowledge about the genocide to provide good quality care. Only one Cambodian survivor offered an alternate view:

> I strongly believe the people who come to work for us should be aware of what we went through because all of the issues are there with us. Most of us from day to day are quite different. Even in one day, we can be happy in the morning and not happy in the afternoon. People who don't have any knowledge of our background will feel it hard to cope with our mood swings.

Care processes that older survivors, family carers and care workers identified as potentially problematic in both residential and community care settings were aged care assessment, personal care, medical procedures, food provision and planned activities. Aged care assessments may raise questions about the availability of family support. These questions can be painful reminders for older survivors who lost close family members during the genocide. Assessments also have the potential to revive old memories of interrogation. Many care professionals felt it was important to avoid completing official paperwork in front of older survivors. However, when asked about aged care assessment, the older survivor interviewees did not identify particular fears regarding paperwork.

Interviews with PAG staff revealed that a range of activities including health promotion, religious and cultural celebrations, art, music and life-writing sessions can bring up frightening or painful memories from the past. A Holocaust survivor became distressed by the use of gold stars in an art session. His reaction was likely to have been related to the Nazi policy during World War II of forcing Jews to wear yellow star-of-David shaped badges.

While some older survivors (in both groups) had found writing their life stories helpful in facing their past trauma, others were unable to contemplate this activity. Special celebrations such as religious festivals were described as simultaneously joyous and sad occasions, forever shadowed by longings for, and memories of, loved ones who did not survive.

Sensitivities around nudity and touch are intimately associated with personal care. David and Pelly (2003) described how concentration camp survivors' experiences of invasions of personal boundaries, having no privacy, and few or no opportunities for maintaining personal hygiene, can result in long-lasting feelings of humiliation, degradation and shame. Our study confirmed that for Holocaust survivors, more than 60 years after the trauma was experienced, those feelings can be re-evoked by insensitive handling of personal care. Several Holocaust survivors described distressing personal care situations that reminded them of humiliating experiences during the Holocaust years:

> [One time in hospital] after the shower the nurse told me to go out without the towel. I was sitting for about 15 minutes naked and shivering, waiting to get dry. No help and no understanding. So this was the worst experience I had in the hospital which reminded me of [the camp]. I had something like that experienced only in Auschwitz.

Interviewees were aware that some older female survivors became particularly agitated when personal care was provided by a male. A Holocaust survivor explained that it was important for her to be assisted in the toilet by a female carer because during the war she and her fellow concentration camp inmates had suffered the daily humiliation of having to go to the toilet out in the open in full view of men:

> [In hospital] I asked for a woman to help me in the toilet because I really feel humiliated when a man comes. So most of the time a woman came. But very often the men came. And they keep telling me, 'you hate men do you?' And I said to them I didn't hate men but that I need some privacy … I didn't explain this to them that in the camp … we didn't have a toilet in the barracks. We went out in the open and on the other side of the barbed wire were men living. So it is most embarrassing for me. It wasn't a matter of hate. I didn't mind men for anything else but not in the toilet.

For survivors who experienced torture and beating earlier in their lives, having to accept the close proximity imposed on them by personal care could be distressing. The intense feelings of terror experienced by concentration camp survivors when being showered by care workers was described by a number of family carers. This fear relates to the mass murder of Jews in gas chambers during the Holocaust. A daughter-in-law said:

> [My parents-in-law] never had a shower in all the years [since the war]. They always took baths … For years we never realised. … They used their shower recess like storage and then it twigged on us. When my mother-in law went to residential care she didn't want to shower. She kept saying, 'I'm clean, I don't need a shower' … and it was always difficult to get her into the shower. Apparently, she screamed through it.

The issue of personal care was not raised by Cambodian interviewees possibly because they had not experienced having their personal care needs attended to by a non-family member or because they were unwilling to discuss such situations with the interviewers.

Holocaust survivors were concerned that care workers who had not experienced extreme hunger may not understand their anxiety about food. An interviewee was angered by her friend's experience in a LTCF. When the friend asked for extra food she was told to wait until the next meal. The interviewee felt that the nursing staff should have understood that someone who has experienced starvation should not be forced to wait for food. Food-related issues and behaviours among Holocaust survivors have been previously reported in the literature (Sinder, Wellman and Stier 2004).

Medical and dental procedures can evoke intense feelings of helplessness and anxiety among older people who experienced brutality earlier in their lives (Downs, Bernstein and Marchese 1997; Ehrlich 2004). A PAG participant was extremely upset by the provision of information about dental services. His response was due to his personal experience at the hands of a dentist in the Auschwitz concentration camp. A Holocaust survivor explained that blood tests were terrifying for her because they took her back to a time when she was tattooed with a number on arrival at a concentration camp:

> I have very bad veins and to take blood still brings back the memories of the tattoo. [In hospital] I was frightened [of the medical staff], apart from one girl . . . she was the only one who knew how to talk to me. She said, 'Don't worry it won't hurt.' Just a simple sentence like that. Like to a child. I was so happy when [she] was on duty.

Discussion

This study used ageing and lifecourse theory (Dannefer 2011) to gain a better understand of the ageing and aged care experiences of older survivors of genocide within the social, cultural and historical contexts of their individual lives. Similarities in the ways in which Holocaust survivors and older Cambodian survivors experienced ageing and aged care were revealed. After decades of post-war resilience in the face of unimaginable trauma and loss, many older survivors were now simultaneously experiencing losses related to life transitions and intensified grief related to the reactivation of traumatic memories. These findings support previous research on trauma and ageing (Amir and Lev-Wiesel 2003; Brodaty *et al.* 2004; Danieli 1997; Trappler *et al.* 2002) and the view that sequelae of extreme trauma should be understood in terms of both vulnerability and resilience (Shmotkin, Blumstein and Modan 2003).

The aged care journeys of older survivors in the two groups were characterised by the underrating of their own need for support, reluctance to take up home-based services, and willingness to participate in community-based activities provided by HACC PAGs. Some of the barriers that older survivors faced in taking up aged care services and the difficulties that they encountered while receiving these services were heightened by their trauma history.

Once they had overcome the barriers to taking up care services, most interviewees reported being satisfied with the type and the quality of care they were receiving. The study uncovered the potential benefits of community-based care services for the psycho-social wellbeing of older survivors. By nourishing the five psychological needs outlined by Kitwood (*i.e.* attachment, comfort, inclusion, occupation and identity; 1997), PAG participation, in particular, enhanced older survivor participants' feelings of belonging and helped many counter the late-life emotional impacts of earlier life trauma.

Previous literature has discussed ageing survivors' sensitivities to aspects of the physical and social environments in institutional care settings. This study showed that receiving care in community and home-based settings can also evoke distressing memories of earlier life losses and intensify trauma-related feelings such as grief, fear, anxiety and humiliation. Care processes that required care workers to show enormous sensitivity and understanding about past trauma included personal care, assessment, medical procedures and food provision.

Differences between the two groups in their experiences of ageing and aged care may be explained partly by cultural, language and religious differences. The differences could also be a reflection of the ages of the two groups. Holocaust survivor interviewees were all aged over 80 years and some were coping with end-of-life issues. By contrast, the Cambodian survivor interviewees were mostly aged in their sixties and seventies and for them, transitions such as retirement and no longer being needed to bring up grandchildren were more salient. Furthermore, the two groups may have been at different stages in the process of trauma recovery with the Holocaust survivors having experienced the genocide 30 years earlier than the Cambodian group.

There are limitations to this study. Interviewees were asked about war-time trauma, migration and resettlement; however, the researchers did not persist with this line of questioning if participants were reluctant to discuss these events. As a result, gaps in the life stories of interviewees were apparent. Another limitation is that interviews were conducted in English for those who were fluent and through an interpreter for those who were not. Not speaking in their mother-tongue, or speaking through an interpreter, may have affected the content of the interviews or the rapport with the interviewers.

The research also possessed several strengths. Unlike prior studies which presented the views of paid carers, this research focused on the perspectives of the older survivors. Additional data from interviews with family carers and care workers from varied cultural backgrounds contributed to the researchers' understanding of the older survivors' life stories.

Conclusion

While most of the older survivors who participated in this study had succeeded in rebuilding their lives in the years following the genocide, the passing of time had done little to diminish the intensity of traumatic memories in their later years. They faced a range of barriers to accessing aged care services including language, cultural expectations in relation to filial care and distrust of strangers. Those who had experienced aged care situations in which they felt that they had little control over their care were likely to have had poor care outcomes. The data suggested that the main barriers to ensuring positive aged care experiences for older survivors were a lack of understanding of the trauma process on the part of some care providers and failures to accommodate for the possible impacts of trauma in care planning and care provision. The study has implications for aged care practice, staff training and further research. Care providers need to recognise older survivors of genocide as a distinct group of aged care clients and distinguish staff training for caring for this client group from general cultural competency training. This specialised training needs to involve providing care workers with the knowledge and skills required for interacting and communicating effectively with older survivors. The literature suggests that the quality of care for older survivor clients can be improved by increasing carers' knowledge of the long-term effects of extreme trauma and improving their skills for dealing with these effects. However, further research is needed to widen our understanding of how: relationships between staff and older survivors can be improved; care workers can enhance older survivors' feelings of safety, choice and control over their care; how compassion in staff can be strengthened; and how compassion fatigue can be avoided. Our research has highlighted the heightened awareness and specialised skills that caring for older survivors demands.

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