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'I will never be old': adults with Down syndrome and their parents talk about ageing-related challenges

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(Accepted 13 February 2019)

Abstract

The life expectancy of people with Down syndrome (DS) has increased significantly over the last few decades. Consequently, they and their families face new ageing-related challenges, the first signs of which appear in people with DS around the age of 30. The goal of this study was to explore the perceptions of adults with DS regarding their own and their parents' ageing and end of life, and to examine the views and concerns of the parents regarding the ageing of their children with DS. The unique approach used in our study was to convene not only the ageing people with DS but also their parents, to discuss the subject together. A total of 33 people with DS participated in the study. Most of them were interviewed with one or two parents. Participants with DS found it difficult to talk about their own old age and addressed the issue mainly through the decline in the functioning of an older person they knew. The parents emphasised the changes needed in terms of the official regulations, so as to ensure that their children with DS age with dignity and quality of life. Our study identifies the increasingly pressing need to prepare adults with DS for their own and their parents' ageing and end of life in a timely manner.

Keywords: Down syndrome; ageing; parents; qualitative; end of life

Background

Down syndrome (DS) is the most frequently occurring chromosomal abnormality in humans (Malt *et al.*, 2013). A worldwide and highly significant change in the survival of people with DS has occurred over the last two generations, with life expectancy estimates increasing from nine years in 1929 to nearly 60 years of age (Bittles *et al.*, 2007). This dramatic increase in life expectancy has presented people with DS and their families with new challenges related to the ageing process – the first signs of which appear in people with DS around their late thirties. However, the issues involved in parenting ageing people with DS have hardly been studied

(see McEvoy *et al.*, 2017), mainly because this is a relatively new phenomenon. Likewise, only few studies have dealt with the experiences of older people with intellectual disability (ID) (see Patti *et al.*, 2010).

The aim of the study was twofold: (a) to understand better the ways in which adults with DS (*i.e.* over the age of 30) perceive their own ageing and their parents' ageing; and (b) to learn about the ways in which the parents of adults with DS perceive their children's ageing process, especially in light of their own ageing. Often, children with DS are born to parents who are approaching or have passed the age of 40 (advanced maternal age is the only certain risk factor for the great majority of DS pregnancies; see Coppedè, 2016). Therefore, by the time these children reach their late thirties, their parents are either in their seventh or eighth decade of life. To the best of our knowledge, the perceptions of each generation regarding the other's ageing process have yet to be investigated, hence the importance of the current study.

Only in 1979 did authorities in Israel begin to keep records of the births and deaths of people diagnosed with DS at birth. It was estimated in 2012 that there were 6,900 people in Israel with DS (Tenenbaum *et al.*, 2012). In 1999 a committee in Israel that dealt with the ageing of people with intellectual and developmental disabilities determined 45 as the transition age of people with DS to old age (Ben-Noon *et al.*, 2008). A comprehensive study of older people with ID (*i.e.* over 40 years of age) conducted in Israel between 2004 and 2007 (Ben-Noon *et al.*, 2008) suggested that increased need of close medical attention is the reason that, as they age, people with DS – more than any other population with ID – move into residential care centres. As Kählin *et al.* (2016: 8) noted, 'Ageing with a lifelong disability is a complex phenomenon that has been neglected both [*sic*] within disability and ageing studies'. Given that people with DS are considered to be part of the population with ID, and both conditions constitute 'a lifelong disability', pre-existing studies pertaining to both population groups are reviewed herein.

The ageing experience of people with DS and ID

Ageing is usually defined in terms of the person's years of life. However, the definition of 'old age' in people with DS is more complicated, for many reasons. First, they appear to age more quickly than others. Age-related changes in the health and functioning can sometimes be identified when they are in their thirties and forties (Rice and Robb, 2004). Disability-related conditions are more frequently present among ageing people with DS than they are among the general ageing population (Malt *et al.*, 2013). For example, the prevalence of type 1 diabetes was found to be over four times higher among persons with DS than in the general population (Bergholdt *et al.*, 2006). By the time they are in their forties, virtually all adults with DS present with symptoms of Alzheimer's disease and at least 70 per cent develop dementia by the age of 55–60 (Hartley *et al.*, 2015). The second reason that it is difficult to define old age in this population is that chronological ageing seems meaningless to them: they remember important events in their lives, such as birthdays or family events, but their precise age is less relevant to them (Haveman *et al.*, 2009).

The physical changes associated with ageing do not appear to be a major concern for older people with ID (Thompson, 2002); rather, it is the combination of the biological, psychological and social features of old age that has the greatest effect on their functional abilities (Walsh, 2002). When they experience difficulties walking, seeing, hearing, eating and/or talking, they may start to feel old. They are able to relate to the decline of self-help skills and the anxiety of becoming physically ill (Haveman, 2004). Other changes – only some of which are related to ageing – are also of concern to older people with DS, such as loss of family, residential moves and changes in the availability of services (Thompson, 2002). Nevertheless, people with ID are rarely informed or aware of how their lives may change as they age. Given the limited work opportunities for adults with ID and the fact that the majority are employed in sheltered work conditions, retirement has a different meaning for this population than it does for the general population, yet it is rarely discussed with adults with ID (Heller *et al.*, 2000).

Typically the social network of adults with ID is limited and this also has an impact on their quality of life at an older age. Often, they have neither a partner nor children. Few of them are property owners who have saved for retirement, and most depend on formal or informal support to help with daily tasks. Most of them live in supported housing, and those who still live in their parents' home inevitably will need to move to a supported residence due to parental death or ageing-related deterioration (Bigby, 2002).

Many individuals with ID have developed coping skills based on life experiences and many have come to terms with the nature of their disability. However, as their age increases, disabilities may become compounded or even worsened and, as a result, it is likely that their existing coping tools and mechanisms will no longer be sufficient (Kessel *et al.*, 2003). Also, as they are typically affiliated with a special system that oversees their work activity, housing and leisure, they are often dependent on the help of others. This, too, has an effect in terms of their functioning when they reach old age (Haveman *et al.*, 2009).

Todd (2003) noted that given that people with DS live longer, there is a higher probability that they will experience significant loss due to the death of someone they love. This claim was further supported by recent research which demonstrated that adults with ID had poorer understanding of death, knew less about end-of-life planning, and were more anxious about death and the dying process, as compared to the general population (Stancliffe *et al.*, 2016). Many were also found to lack an understanding of the lifecycle and to hold rather fatalistic views as to the causes of death, viewpoints which may indicate minimal biological understanding of how the body works (McEvoy *et al.*, 2012). Being unaware of the meaning or significance of death, people with ID forgo the opportunity to say goodbye to their loved ones or to express their wishes about the distribution of their possessions or their preferences for end-of-life care (Wiese *et al.*, 2015).

The challenges of parenting older children with ID and DS

As a result of the longevity of people with DS, there is an emerging group of ageing parents who at the time of their own ageing continue to provide care and assistance to their elderly children, who likewise have aged (Seltzer *et al.*, 2004; Walker and

Hutchinson, *in press*). When the child with ID nears the age of 30, often their parents feel torn between the need to remain active care-givers even during the child's adult years and the desire to allow their child to experience – as much as possible – the independence associated with adulthood (Foley, 2013).

Piazza *et al.* (2014) suggested that the ability of ageing parents (mean age of 65 years) of an adult child with ID to cope effectively with the challenges of the child's ageing is most likely related to the extent to which they continue to be directly responsible for the care of their adult child. Garnham *et al.* (2019) pointed out that without a clear pre-planned pathway to alternative residential and other care-related arrangements, families typically face a crisis when the death or incapacity of an older parental care-giver prohibits the further provision of primary care within the home. Cumella and Heslam (2014) showed that almost all family members who acted as care-givers to people with ID (who were 26 years of age or older) continued to provide support to them after their care recipients had transitioned into a supported living arrangement. The families' support was most extensive in dealing with more complex tasks, such as financial management, responding to crises and managing an illness. By contrast, the tasks of the staff at the supported living facility concerned mainly the routine activities of daily living. Heller *et al.* (2000) found that most interventions that were intended to support adults with ID and their families in the process of later-life planning had only limited success in helping families make actual plans. The projects which were intended for families of people with ID tended to neglect training the person with ID, whereas the projects that focused on training the adults with ID tended to neglect the issues related to long-term future planning, which resulted in greater reliance on family input.

Lastly, based on interviews with four parents of children with ID, McMaugh *et al.* (2017: 292) found that parents played an important role in helping their children with ID 'learn about, emotionally respond to, and develop an understanding of dying and death. Parents not only discussed dying and death with their children, but also involved them in activities associated with dying and death'. The authors noted that the parents' precise role in helping the child with ID develop an understanding of end-of-life issues is unknown, as there is no current research on this topic, which further underscores the importance of the current research.

Methodology

A qualitative method was selected for the current study. Previous studies (Thompson, 2002; LeRoy *et al.*, 2004; Dew *et al.*, 2006; David *et al.*, 2015; Kählin *et al.*, 2015) found qualitative methods appropriate and effective for investigating and shedding light on the personal experiences of people with ID from their point of view.

Participants

Our study involved 33 people with DS, 19 women (average age 35 years) and 14 men (average age 39 years). A total of 27 people with DS were interviewed (together with a family member or in the case of two women with a workplace supervisor),

and six additional participants (four men and two women with the average age of 38) took part in a focus group (a detailed description is provided later in this section). The oldest male participant was 54 years old and the oldest female participant was 50 years old. Eleven participants were living in their parents' home (or in one case in the brother's home) and the rest were living in community residential settings or in designated facilities – all located either in the central or southern region of Israel. Most (30) of the participants were employed.

After the research was formally approved by the Ministry of Social Affairs and we received the appropriate ethical approvals (detailed below), we obtained lists of potential study participants from the Clinic for Children with Chronic Diseases at Hadassah Medical Center in Jerusalem, as well as from staff members working in designated residential or workplace facilities. We asked to recruit people with DS over the age of 30 who are verbal, willing to be interviewed about their life, and whose parents or other close family member are also willing to be interviewed.

The times and locations of the interviews were determined in co-ordination with the parents and their adult children with DS. Usually the parents were more flexible and emphasised the importance of letting their children adhere to their normal routines by setting a time that suited the children's schedules. Interviews were usually either in the place of residence or the workplace of participants with DS. One interview was held at the interviewer's house (this was done at the request of the interviewee with DS and her mother). Two other interviews were held at the clinic from which the interviewees were recruited.

We debated whether to interview the parents separately or together with the participants with DS. Interviewing young adults with ID has rarely been attempted in research, due to the challenges related to the limited communication abilities and comprehension difficulties of this population (Lloyd *et al.*, 2006). Our first concern was the welfare of the participants with DS. We had feared that they would feel uncomfortable in the company of an interviewer whom they had never met before, and that speaking into a tape recorder would be a source of stress. The Helsinki Committee, which approved the study, raised a similar concern, so we finally decided that the parents would be present (unless participants with DS specifically asked for a different setting). However, this decision was fraught with uncertainty. We were particularly concerned that the parents might patronise their children and speak on their behalf. In the end, we decided that the presence of the parents was likely to help the participants with DS feel comfortable and safe. We also hoped that parents' presence would help us to understand better the responses of the participants with DS, given that the parents would be very familiar with their children's particular ways of self-expression. Fortunately, our concerns about the joint interviews were dispelled. The parents gave their adult children adequate time and space to express themselves comfortably during the interview and we were privileged to witness some interesting dialogues and instructive insights related to the research questions. After the interviews, the parents received the contact details of the interviewer and were able to add in writing or orally things that they might have wished to comment on separately.

It should be noted that although most of our interviewees with DS were independent, there were great differences among them in terms of their functioning abilities. For example, the oldest of our interviewees was using a walker and had

a permanent catheter attached. He was illiterate and lived with his elderly mother, who was also in a state of health that required nursing care. Another interviewee was employed in a large government institution and consequently had daily interactions with people without DS. A third interviewee spoke two languages and had travelled abroad a few years earlier to attend a summer camp for people with DS.

Focus group

Towards the end of the field work we decided to convene a focus group of six participants with DS, all of whom had been living in the same community setting for many years. Focus groups are particularly useful when working with marginalised groups, such as people with disabilities (Teitelman and Copolillo, 2005). The purpose of the focus group was to gain an additional perspective on the views of participants with DS when they are with their peers and without their parents. However, a supervisor with whom the participants with DS were very familiar was present during the focus group discussion, to make them feel comfortable and safe.

Interviews

The fieldwork was conducted between November 2013 and February 2015. A total of 26 open-ended interviews were held. Of these, 25 were conducted with individual participants, accompanied by a parent (in two interviews, both parents were present) or, in three cases, by a sibling. One pair of women who were good friends and worked together requested that they be interviewed together at their workplace. A staff member with whom they felt comfortable was also present. We stopped interviewing at the 'saturation point' as is standard in qualitative research, *i.e.* when it became evident that no new information was being presented.

Each interview lasted approximately two hours. All interviews and the one focus group were tape-recorded and transcribed verbatim. In addition, a notebook was used to record the interviewer's observations. At the beginning of the session, the interviewer introduced herself and the purpose of the study. After a short presentation by the researcher and the participant's indication of informed consent (details below), the interviewer opened with a question addressed to the participant with DS, for example, 'Tell me about your life today' or 'What do you like about your life?' We chose to begin with questions that would help the participants with DS feel comfortable, to relieve any potential stress caused by the setting of the recorded interview. We wanted them to feel that we respected them and valued their opinions. In general, only a few leading questions were asked, to keep the conversation focused on the main topics of the research. According to Robson (2002), the use of qualitative research techniques when dealing with sensitive participants, such as people with DS, is what allows both the interviewer and the interviewee to react and adapt as the interview unfolds: the interviewees answer at their own pace, using their own terms; the interviewer maintains a rational progression that flows naturally from the interaction. Throughout the interview, the interviewer often asked the interviewees with DS to provide examples, so as to gain a clear understanding of their experiences and be able to follow their train of thought as much as possible.

The questions intended for the parents were usually addressed in the course of the conversation. A parent who wanted to express an opinion while the child was talking usually respectfully requested the child's permission to do so. Only in a few cases did the participant with DS say, 'Mother/father do not interrupt me', in which case this request was immediately honoured by the parent. This gave the interviewer the opportunity to gain an additional perspective on the special relationship between the parents and their children.

Towards the middle of the interview, we began posing questions about ageing, usually addressing the person with DS first: 'Who is an old person in your eyes?'; 'Will you ever be old?'; 'Do you know old people?'; 'Are your parents old?', *etc.* In some cases, if the interviewer felt that the atmosphere in the interview allowed for it, she posed questions about the end of life. Depending on the response of the participants and especially the participants with DS, the interviewer decided whether and how to continue the conversation on this sensitive issue.

Informed consent

The research obtained the ethical approval of the Helsinki Committee of the Hadassah Medical Center in Jerusalem. Before we scheduled the interviews, we explained the purpose of the study to the parents. The committee demanded that both the parents and their adult children with DS sign an informed consent form. Although informed consent is the basis of research ethics, it is difficult to obtain such consent from people with ID who are candidates for a study (Lloyd *et al.*, 2006). It is possible to ask these participants for oral consent, and try to gauge whether the situation is stressful or embarrassing for them. Oral consent is especially appropriate if the interviewer feels that the interviewee did not really understand what the signing of the form actually means (McCarthy, 1998). In our research, the issue was raised before the interview began, and we emphasised to the candidates that they were in no way obligated to participate and if they did consent, they could still stop the interview or refuse to answer any question. After the consent was expressed orally, we introduced the option of signing a form. All participants, both people with DS and their parents, agreed to sign the form. Although it is virtually impossible to be sure that participants with DS understood the full meaning of their signing, we relied mainly on the parents' sense of their child's comprehension, given the close nature of the relationship between parent and child.

Analysis

All transcripts were analysed using the principles of the phenomenological approach used by Eatough and Smith (2006). Our choice was reinforced by the observations of Fujiura and RRTC Expert Panel on Health Measurement (2012), who noted that although a great deal is yet unknown about the parameters of self-report for individuals with ID, there is some evidence that interviews with them can be meaningful in the phenomenological sense. Kählin *et al.* (2015), who studied the experiences of people with ID, also used the phenomenological approach in their research.

We used the inductive approach of interpretative phenomenological analysis (IPA; Smith, 2004) to construct a detailed picture of the participant's subjective experience, as it was embedded in the individual's narrative of his or her personal lifeworld (Eatough and Smith, 2006). IPA has now been used to examine a wide range of psychological topics, *e.g.* the degree of awareness among patients with Alzheimer's disease (Clare, 2003). IPA provides a set of flexible guidelines which can be adapted by researchers to match their research aims (Smith and Dunworth, 2003). In our study, we treated the interviews and the focus group as a single data-set, because we found that what was said in the focus group was in keeping with the general ideas and feelings expressed in the interviews. The analysis involved several stages. First, the transcripts were read several times in order to feel more 'immersed' in the data and become more responsive to what was being said. Notes were taken of anything that appeared significant and of interest. Also, sentences were considered important if they expressed either a unique idea or an idea that appeared in several other interviews. At this stage, we saw that it was worthwhile analysing the responses of the adults with DS separately from those provided by their parents, despite the fact that these utterances were said in the same context and usually in response to each other. This separation allowed us to focus more precisely on each of the two sets of narratives. The second stage involved a second review of the transcripts in an attempt to identify among the initial notes and ideas more specific themes or phrases. As this step calls for the use of concepts and abstractions, we began to think about how the issues raised by the participants could be conceptualised. However, this conceptualisation implies taking a stance in regard to the data; therefore, caution was exercised, to ensure that our interpretations were methodically grounded in the participants' words. The third stage consisted of finding connections between the preliminary themes and clustering them appropriately. Nuances identified in the participants' accounts were retained and embedded in a framework which defines the phenomenon under study. These clusters were given a title, to convey the conceptual nature of the common theme. Smith and Osborn (2009: 70) suggests that in the selection of titles, researchers should 'imagine a magnet with some of the themes pulling others in and helping to make sense of them'. A brief, illustrative data extract was presented alongside each theme. Finally, we identified higher-order themes and the sub-themes that comprise each one. We produced a brief illustrative data extract alongside each sub-theme and some of the most prominent quotes were added. The key themes to emerge from the interviews are described below and those pertaining to the discourse of the adult children with DS are presented separately from those drawn from the parents' responses. All names have been changed to ensure anonymity.

Findings

'I will never be old': the perceptions of adults with DS about their own and their parents' ageing and about the end of life

During the interviews, the main issue that participants with DS focused on was the 'here and now' in their life. For example, when asked: 'What do you like about your

life?', Kalanit (age 40) said: 'I love working a lot ... it gives me a feeling ... a good atmosphere.' They described in detail and with great pride their daily activities: their work (a waitress in a coffee shop, an assistant in the neighbourhood laundromat, a kitchen worker at a children's institution, *etc.*), their leisure activity (*e.g.* swimming, dancing, playing the piano, participating in a theatre class) and their social activities with friends (*e.g.* going out to movies and shopping). They especially emphasised their independence and efforts to lead a healthy life by maintaining a balanced diet and trying to exercise regularly.

However, the interviewees with DS found it difficult to imagine themselves in the future as 'old' and to talk about their ageing and their end of life. For example, to the question 'Do you know that we will all die some day?', Pinchas (age 30) responded: 'Yes, except me.' This difficulty was despite the fact that some of them already had experienced serious illness and the death of relatives or close friends with DS of the same age. For example, Rami (age 47), one of the older interviewees, already had lost both of his parents. A few years earlier, he had cancer and recovered. Rami's hair is greying; he walks slightly bent. His sister who accompanied him to the interview mentioned that, in recent years, Rami experienced difficulty walking and now she supports him when climbing the stairs to her house.

- Interviewer: Do you feel you're getting old?
 Rami: No, [I] do not think I'm getting old.
 Interviewer: I understand. You do not feel like you're getting old. Can you tell me what you think an old man is like?
 Rami: An old man ... he is a man who has gained wisdom ... But a man, who is beginning to have grey hair, is an old man.
 Interviewer: ...And will you ever be old?
 Rami: I have time until then.

Like Rami, also other participants seemed to recognise that people are ageing or dying. Some of them could recognise the physical difficulties of old age; yet, despite acknowledging their own difficulty in completing daily chores, they found it difficult to speak about themselves in the context of ageing. Some responded with a nod or smiled in what seemed like embarrassment. Here is the continuation of the interview with Rami:

- Interviewer: [Old people] are weaker people?
 Rami: Sometimes ... some are in a wheelchair ... and sometimes they are [with] walkers.
 Interviewer: And ... Have you ever thought you'd be an old man like them?
 Rami: No.
 Interviewer: Have you ever thought about that?
 Rami: I think I'm an independent guy.

Later in the interview, Rami's sister reminded him that lately she had been supporting him as he goes up and down stairs. She asked him about the possibility of using the elevator in the future. Although Rami agreed with her that an elevator could help him, it was not easy for him to accept the idea, because it meant that he would not be as independent as he had been before.

It was also very difficult for the participants with DS to relate to the fact that their parents were getting older and would some day die. Some of them responded emotionally when we raised the subject or when we asked about people they knew who had died. The presence of the parents at these moments was meaningful for both participants, as the following example (part of the interview with Pinchas) demonstrates:

- Interviewer: So you will always be here, but what about Mom and Dad?
 Pinchas: I worry about Mom and Dad.
 Interviewer: God forbid, but one day they will die. Have you ever thought about that?
 Pinchas: First of all, it's hard for me. It's sad and it's a bit difficult.
 Mother: But there are many more years, don't worry. There's plenty of time.

However, in their own way, a few interviewees referred more directly to the issue of death mainly when it came to a close person that died. Yaron (age 45) spoke about how he took care of his father when he was ill, until his death a few years ago: 'I told my sister: "Tell them [his nephews] that I helped both my mother and father ... It was very hard for me to say goodbye to my father."' Yaron also said that he was sorry that his mother was left alone. Later in the interview, when the mother left the room to take a phone call, Yaron signalled to the interviewer that he wanted to stop the conversation about his father's death so as not to upset his mother. When his mother returned, Yaron put his arm around her shoulders and hugged her.

Some shed a tear when we talked about the subject, as in the following example, when one of the participants in the focus group talked about his grandfather who had died recently:

- Participant: My grandfather is now in heaven.
 Interviewer: Oh, he died recently?
 Staff member: Yes. It's still a fresh memory.
 Participant: It hurts all the time, and it's very sad.
 Interviewer: Were you close to him, to your grandfather?
 Participant: It's been a long time. It really hurts. But I'm fine.

'What awaits him in the future is a question that worries us day and night': the perceptions of parents of adults with DS about the ageing of their children

Most of the parents in our study said that so far, they had not discussed the issue of their own ageing or the end of life with their children with DS. During the interviews, several parents noticed the difficulty their children were having when talking about ageing and the end of life. However, no parent asked to stop the discussion or to change the subject. It seemed that the parents actually wanted to hear what their children had to say about the subject and even encouraged them to do so. For example, in the interview with Ada (age 41) she found it difficult to talk about her grandparents, to whom she felt very close and who had passed away a few

years earlier. The mother recognised the difficulty, turned the subject around and spoke about the death of the family dog to which Ada had been emotionally attached. Ada was very happy to recall those memories and later on she could speak a little more about her deceased grandparents.

Two parents and one sibling contacted the interviewer after the interview and said that they were surprised by their children's lack of understanding about ageing and end of life. They said that the meeting helped them recognise that they were facing a new phase in their child's life which required special attention and preparation. They said that raising the subject was very important and significant to them and that it 'opened the door' for them to continue talking about the issue with their relative with DS.

The following are the main issues that were mentioned by the parents or siblings in relation to their ageing relative's present and future.

Independent living in the past and in the future

Most of the parents said that the transition of their children with DS to the community setting or housing setting was a significant step, for the child and for them as well. They noted that back then, they had understood how important it was for their child to live independently with peers. Some of the parents related to their own ageing and said that the decision to move their child to supported community housing was based on their concern about what would happen to the child when the parents were no longer alive. The mother of 30-year-old Ilan said:

First of all, I thought about my daughters, that it would be fun to have him on the weekends, that there would be no burden to worry about, and besides, that he would be in the company of other people, with a [positive] atmosphere, and have a job that suited him ... [This step] was hard for me ... but he adapted well... I saw that it was good for him.

Even after their children had left home and were living in the community, the parents stayed in very close touch with them, knew their daily routines and maintained close contact with the residential staff.

However, the parents expressed great concern about the time that they will no longer be able to take care of their child with DS as they have done so far. For example, Ada's mother worried that after her own passing, when her daughter is older, the authorities would place Ada in a nursing home and there would be no one left to protect her:

I'm very anxious ... I am afraid that [she hesitates] ... she will be transferred into a place like ... [a name of a nursing home], or of its kind ... Yes, the future is very scary.

This comment was made after discussing the signs of ageing, when Ada's mother realised that Ada had recently shown signs of loss of memory.

Most of the parents whose children were still living at home with them (with the exception of one mother) described burnout, fatigue and impatience. They said that they understood how important it was for their child with DS to move to a

community setting. For example, the father of 31-year-old Gila told the interviewer that his daughter preferred to continue living with her parents, and added:

We are realistic. We do not know how long we will be able to take care of her and that is why we are trying to find something for her so that she will have a future when we will not be here ... she will be protected ... to have as much of an independent life as possible.

Some of the parents said that the signs of old age in their children came to them as a surprise. They realised that it was time to find a suitable place before their child would need nursing care and they would no longer be able to take care of them. At the time of the interview, Asher (age 31) was preparing to leave home and move into supported community housing. His mother said:

Already four or five years ago the social worker had started to tell me: 'He is already grown up and you have to get him out of the house.' I told her that I didn't feel he was mature enough to leave.

Now the mother is afraid that it may be too late to move Asher to the community housing because in the last year he had experienced some physical and mental decline, such as urinary incontinence and less involvement in home life routines. 'As the doctor had once told me – Asher has aged.'

Dilemmas in relation to the siblings

The parents are aware that in the future, the siblings will play a major part in taking care of their brother/sister with DS, as the mother of 31-year-old Mazal said: 'I keep warning my children [Mazal's siblings] that ... they must always check and see what is going on [with Mazal]', and she added: 'It's [emotionally] difficult for me ... Will they [the hostel's staff] continue to provide all of the treatments Mazal is currently receiving? ... I think my children will see to it that she visits [them] ... two of them will be her guardians.' All of the parents said that they were entirely confident that the siblings would take care of the sibling with DS. Yet, the parents expressed great discomfort and guilt feelings about the burden of responsibility that they felt they were imposing on their other children, as Ilan's mother said, 'After all, they have a life of their own.'

A few parents talked sadly about the weakening of relations between the siblings over the years. While the siblings grew up and went on with their life, the child with DS remained 'in the previous life', as Yaron's mother said, and they had fewer common subjects to talk about:

he wants to tell about things, and they do not listen to him anymore, because he tells about things from the past, and they have moved on ... They talk about what they are involved in today ... his experiences are very different ... And it is very difficult for him (Yaron nodded in agreement).

Some of the parents spoke about their efforts in the last years to bring the siblings closer. For example, it was important for them to make sure that their child

with DS would take part in all family gatherings. The mother of 36-year-old Eyal said:

I want to bring his brothers to feel closer [to him] ... I talked to them already and I told them I want to know that they will be available for him when we will not.

Three participants with DS were accompanied by their siblings. The conversations were very moving. All siblings mentioned how important it is for them to keep in touch with and take care of their brother or sister with DS. For example, Rami has four siblings. He lives in an apartment with other individuals with ID and there is a counsellor with them around the clock. The apartment is located two blocks from the home of one of his sisters. Every weekend he visits one of his siblings for a meal and sometimes stays overnight.

Ran's brother talked about his concern regarding Ran's ageing. Ran (age 47) was living with his mother, who herself needs full-time nursing care. Ran's physical and mental health condition had deteriorated in recent years. In the last few years the brother was Ran's guardian. The brother said:

Throughout the years Ran has lived with my parents. In the last few years, we have started talking about moving Ran to a hostel. However, because Ran's health condition has recently taken a turn for the worse, no hostel is willing to accept him in his current condition.

The brother wondered what would happen to Ran in the future, when the mother would no longer be alive. Who would take care of Ran and where would he live? During this part of the conversation Ran hardly spoke. He looked at his brother with tears in his eyes. At one moment, the two brothers held hands and the brother said to Ran: 'You know I love you and I will never leave you.'

Perspectives about ageing

A few parents whose children with DS were around the age of 40 said that they recently had noticed that their child with DS had begun to have mental, cognitive and health problems, such as diabetes or memory loss. They said that at first they did not think it had to do with their child's age. However, ever since they had scheduled the date for the interview, they had started to think about the possibility that the problems were part of their child's early ageing. The difficulty in grasping the gap between the chronological age and the biological age was addressed, for example, by Mazal's mother, who said that recently Mazal's health problems had worsened, especially issues with her eyesight, but until the interview she did not relate it to Mazal's age: 'She looks small, and I cannot see that she's getting older.' Eyal's mother said that lately he looked depressed to her, so she sent him to a special psychologist. Following our talk she wondered whether it might be age-related. After the interview, she contacted the interviewer and requested her assistance in finding an expert in geriatric medicine for adults with DS. She wanted to find out if some other health problems her son was experiencing were age-related. Also Ran's brother found it difficult to find physicians that would

agree to treat Ran's dental and dermatological issues. The brother described ignorance and reluctance on the part of the medical staff:

Because of the problems with his teeth, he has difficulty eating, and many times he chokes ... They [the physicians] are afraid to anaesthetise him ... We were with him when he was hospitalised because of skin problems, but no one came up to him ... as if it were an alien body, you see?

Mazal's mother also raised the issue of doctors' lack of knowledge about ageing adults with DS and said: 'I have to teach the doctors.'

Concerns about the future

In general, the parents were satisfied with the work of the staff at the hostels. Nonetheless, some voiced concerns about the staff's knowledge and their ability to address the future needs of their ageing children. Kalanit's father said:

For many years her [physical] condition was the same. But if it goes downhill ... it will require more manpower to take care of her needs, and the existing system in the hostel is not prepared for this.

The parents whose children were around the age of 40 were especially concerned about the future of their children in the hostels as they aged. When Kalanit was young, her father was an activist who – along with other parents – had struggled for the rights and needs of children with DS and their families. Now, about 30 years later, he described his and other parents' great concerns about the future of their ageing children with DS:

I just hope that these independent living facilities [hostels], which we worked so hard to establish, will continue to care for them [*i.e.* people with DS] even when their health deteriorates and they are in need of nursing care. This is our hope and ambition, that no one will move them from their permanent place.

He said that one of the hostels that was built was intended to serve people with DS over the age of 45, but

Unfortunately, the Welfare Ministry does not recognise this group of adults [with DS], and therefore does not budget it accordingly ... and therefore ... I say it even here to the microphone: 'you cannot trick us parents into believing that our children will receive equal care [when they grow old]'.

The father of Ariela (age 31) decided to join forces with another family that has a son with DS. Together, they drafted a legal agreement giving the two families joint custody of both adult children with DS, so that 'the children would have a network of protection for the time that we [the parents] are not available, for one reason or another', for example, in case of travel, or death. He recommended that all families with children with DS find a similar solution:

I appealed to the court and asked to add ... [the mother of the other family that had a son with DS] as an additional guardian for Ariela ... so if her father [speaking about himself and turning to face Ariela] travels or Ariela needs something urgent, a signed permission or something else, there is a guardian available and she will not dependent on the graces of ... the so-called *agents of the state*.

Sagi's (age 41) parents were part of the group of parents who were activists in the 1980s. They proudly described the high expectations they had for Sagi when he was young and their pride in his accomplishments. However, it appears that every two weeks, the residents with DS go to their parents' home to spend the weekend with them. This is not decided by either the children or their parents, but rather dictated by the routine established for all community housing. The parents noted that the perception behind this practice is that the parents' home is the primary home for their child with DS, whereas the hostel is temporary. This is despite the fact that the move to the hostel years ago actually signalled a shift towards independence. With regard to our conversation about Sagi's future as he grows old, the parents pointed to a fundamental difficulty with the hostels in this regard. The interview took place in the nursing home where the parents had been residing for the last few years. Their apartment is very small and is suitable for the needs of an elderly couple. The mother said the following:

When we brought Sagi to the hostel they [the staff] were very proud to tell us: 'This is a home for life...' ... For life??? Every second Saturday he is at our home ... and we are getting older, and the house ... well, it's not a house at all, is it? But it's still every second Saturday at home.

It was important to the parents to emphasise how happy they were when Sagi came to visit. However, they found it difficult to host him for the entire weekend. Furthermore, the father had recently needed repeated hospitalisations and Sagi and his mother had stayed with him in the hospital over the weekends.

Like Sagi's parents and Kalanit's activist father, the other parents too pointed out that a permanent solution that would suit the needs of their ageing children with DS needed to be found. Sagi's mother summed it up:

What awaits him in the future is a question that worries us day and night ... You have to think of the future. What happens to those residents whose parents are no longer so functional? ... [Must they] start relying on the siblings, and send him each weekend to a different brother or sister? ... It's not proper planning.

Discussion

The ageing of people with DS, and the social and emotional implications, have been the subject of an ever-increasing amount of research (Walker and Hutchinson, in press). The unique approach used in our study was to convene not only the ageing people with DS, but also their ageing parents, to discuss the subject together. Davies and Morgan (2010) showed the added value of research that brings parents and children with DS together. Our findings too demonstrate that the increased life

expectancy of people with DS entails a range of personal and family challenges, as well as bureaucratic and legal implications, with which adults with DS and their ageing parents must contend.

Based on our interviews with people with DS, it became evident that they do not fully realise that they are entering a new period of life. They seemed unaware of the physical and cognitive changes which had already begun to appear, and they did not associate those changes with the ageing process. These findings are consistent with those of Haveman *et al.* (2009) and of Fender *et al.* (2007), who noted that often adults with DS do not have a sufficient grasp of the physical changes that occur with ageing or of their consequences. It is possible that these difficulties are related to their ID, which makes it impossible to imagine future consequences or developments, particularly regarding an abstract issue such as death (Snell, 2007). The study of McEvoy *et al.* (2017) demonstrates that equipping adults with ID with the relevant knowledge about the functioning of the human body can have a positive effect on their understanding of the need to support end-of-life planning.

It is now widely accepted that although adults with ID have an incomplete understanding of death, it is not necessarily a barrier to experiencing grief (Gray and Abendroth, 2016; McEvoy *et al.*, 2002). Furthermore, people with ID are at increased risk of emotional and behavioural problems following bereavement. The main reason for this is the difficulty they experience in expressing and understanding the emotional aspects of death (Kessel *et al.*, 2003). Indeed, most of our participants with DS expressed aversion and even fear when asked about ageing and the end of life, despite having experienced ageing and death in their near vicinity. In their descriptions of old age, they mostly referred to specific individuals in their close surroundings, as was noted also in the study of Kählin *et al.* (2015). In addition, they stressed their independence, as if to contradict any suspicion that they too might be ageing. Such statements suggest that at least some of our participants had internalised the ageist approach that exists in Western society about old age as a 'dead' time in life, marked by a decline in activity; consequently, they had negative associations regarding the prospect of ageing (McHugh, 2003; Reed *et al.*, 2006).

As for the parents of the interviewees with DS, they gave the impression that the ageing of their children caught them quite unprepared. It appears that the interview was not the first time that they had thought about the future of their children with DS in light of their own ageing. Yet they had not broached the issue with them and said that the interview was an opportunity for them to do so. For most of them, the dialogue provoked an emotional reaction and they were surprised to see their children's difficulties in addressing the topic during the interview. They noted the importance of having access to professional guidance on how to address this new stage in their children's life, so as to prepare for it accordingly with their other children.

As indicated by Seltzer *et al.* (2004), ageing parents are primary sources of support and care-giving for children with DS, a role that continues throughout their children's lives, even after the children leave the home and move to a supported living residence. This type of reliance was noticeable also in our study. As their children were approaching the fourth or fifth decade of life, the parents came to a deeper realisation of the fact that their children still needed close supervision and that this state of affairs was never going to change. Consistent with the observation made by Heller *et al.* (2000), the parents in our study were usually a source of

decision-making support for their children with DS and were continually monitoring their activities, even when the children were no longer living at home.

In the past, some of the interviewed parents were among those who had paved the way for children with DS to be able to live independently. However, the hope and motivation that characterised their activities in the past were now replaced by weariness. Now that they were ageing, they realised that they ought to engage in a new struggle, to ensure that their children continue to maintain a decent quality of life in old age, but they found it difficult to do so.

Our research calls attention to the changes that need to be implemented in policy and regulations to ensure that people with DS maintain their wellbeing and dignity as they grow old. Although this was already identified about 25 years ago by Hand *et al.* (1994), and there are indications of decision makers' more recent efforts (see e.g. Ben-Noon *et al.*, 2008), our research shows that not enough is being done to address the concerns of the parents and families of people with DS. We suggest that all parties, including the parents, the adults with DS and their family members, should be involved in the efforts to design creative solutions that will affect their children's lives, even in the later stages of life.

Our study identifies the increasing need to prepare adults with DS for their own and their parents' ageing and end of life, in a timely manner, as noted by Todd (2003). Also the needs of the siblings of people with DS should be taken into account, in light of the challenge of having to care simultaneously for their ageing parents and their ageing sibling with DS. We recommend that future research investigates the differences we found between the parents' perceptions of the way their other children feel about caring for the sibling with DS and the siblings' actual statements. According to our observations, the parents' guilt about burdening their other children may be baseless, as it did not accurately reflect the quality of the sibling relationships demonstrated by our participants.


Sterns *et al.* (2000) found that later-life training programmes were able to address the lack of awareness of people with DS about making choices regarding later-life issues, including work and retirement, health and wellness, residential living arrangements and leisure. This finding was supported by Kessel *et al.* (2003) and Blackman (2003) who also concluded that the employers of service providers to individuals with ID should make sure that employees receive special training and support, so that they can help people with ID deal with ageing and death, and thus prevent serious emotional problems in this population.

Strengths and limitations

Our study gave individuals with DS the opportunity to express themselves and their attitudes. Nevertheless, our research raises some questions about whether the open interview is the best way to gather data. Following McEvoy *et al.* (2002), we recommend that further studies use additional methods (e.g. the use of images) to review the topics that emerged in our research. Another issue to consider is the reliance on physicians, social workers, employers and others for recruitment purposes. This approach may have created a certain bias. We suggest that future research be directed to participants online, thus enabling potential interviewees to respond to the call on their own. Third, although our focus group did not raise new issues

compared to the interviews, it is our impression that this group format allowed a very special and liberated atmosphere among the participants with DS. Following Teitelman and Copolillo (2005), we think that in future studies it would be worthwhile using this format more regularly. Similarly, a separate focus group of parents of adults with DS could be convened to discuss issues of ageing and end of life.

Our research did not directly address the issue of the hostel staff's knowledge and readiness for the ageing of their residents. Findings presented by Kählin *et al.* (2016) indicated that group home staff members described the process of ageing among people with ID in a manner that appeared to be rooted in the medical paradigm of disability. However, the staff did suggest the need to raise issues related to ageing and ID in national disability policy documents. Our research supports this conclusion. Proper staff training can address some of the issues that worried the interviewed parents. Also, it seems important to improve communication channels and co-operation between the residential staff, the parents and other family members, for the welfare of the ageing people with DS.

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Acknowledgements. The authors are very grateful to the individuals who participated in the present study and the many staff members who helped us reach the participants. We would like to thank the Shalem Foundation for the research grant.

Author contributions. We declare that all named authors made a substantial contribution to the conception, design, analysis and interpretation of data. All read the draft of the article and approved the version to be published.

Financial support. This work was supported by the Shalem Fund for development of services for people with intellectual disabilities in the local councils (research grant number 120).

Conflict of interest. The authors declare no conflicts of interest.

Ethical standards. The study was approved by the Helsinki Committee of Hadassah Medical Center, Jerusalem, Israel (number 0622-11-HMO).

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Cite this article: Finkelstein A, Tenenbaum A, Bachner YG (2019). 'I will never be old': adults with Down syndrome and their parents talk about ageing-related challenges. *Ageing & Society* 1–20. <https://doi.org/10.1017/S0144686X19000266>