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Psychosocial experiences of the ageing of middle-aged people with intellectual disabilities in South Korea

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This study aims to explore the psychosocial experiences of the ageing of middle-aged people with intellectual disabilities in Korea. Data were collected through 28 face-to-face interviews with Korean individuals with intellectual disabilities, aged between 40 and 50. This study identified several key factors faced by middle-aged people with intellectual disabilities. First, they experience financial constraints due to a lack of economic self-determination. Second, they have a very narrow range of social connections. Typically, they have small and weak networks consisting of only a few social workers, personal assistants, or group home workers, or their peers at group home or workshops. This is often due to a lack of information, money, and age-appropriate services. Third, those who have jobs in middle age have positive opportunities acquired through work. Fourth, study participants experienced considerable unspecified anxiety about ageing, as well as fear of death and uncertainty regarding the future. Recommendations are made to improve active ageing in an appropriate setting for middle-aged people with intellectual disabilities. Improved training and education about economic self-determination are needed for these individuals and their families, as well as improved information about community services. Moreover, enhanced community services for them must be developed. These individuals would benefit from improved employment opportunities as well. Workshops regarding active ageing and death should be developed. Finally, future plans for living placement must be in place.

KEYWORDS: Community services, provision for ageing, active ageing, intellectual disabilities, middle age, ageing

Introduction

The life expectancy of people with intellectual disabilities (ID) has improved considerably in recent years, as better social and health services have helped more of these individuals survive beyond adulthood into older age (Walker 2015; David et al. 2015). Recent studies in the UK suggest that older people with ID represent the fastest growing group of the disabled population (Emerson and Hatton 2011; Ward 2012). Despite growing attention to older people with ID in recent decades, past studies have predominantly focused on the biomedical ageing process of people with ID (e.g. WHO 2012a); there remain few scientifically rigorous investigations of psychosocial issues of concern to adults ageing with ID. For instance, studies conducted in Western countries report that as they age, the majority of people with ID experience additional psychosocial and mental health issues, including cognitive decline and the presence of dementia (e.g. McCarron et al. 2013; Haveman

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et al. 2010); the lack of ability to communicate feelings, react to stressors, or tolerate changes to routines; and increased risk of depression (Hermans and Evenhuis 2013). In addition, the ageing process in people with ID has often been affected by long periods of institutionalization, as well as by the effects of long-term use of psychotropic medications (WHO 2000). As a result, the Western literature has identified several important psychosocial issues such as unmet needs and concerns regarding ageing (Bigby et al. 2008; McCausland et al. 2010), uncertainty and fear regarding the future, and the concerns of older carers (Clark, 2007; Weeks et al. 2009).

Moreover, older people with ID are often placed out of their homes into community living homes or group homes. But in these cases, social interaction and participation often decreases significantly due to difficulties of access resulting from a variety of existing obstacles, changes of residence, and the loss of loving ties (Alcedo *et al.* 2017, p. 39). Studies conducted in Ireland (McCausland *et al.* 2018) and the USA (Mihaila

et al. 2017) have also found that day care options and educational, social, and recreational activities are limited for this population; they access fewer community-based support programs and have limited social networks to support them in coping with ageing.

Nevertheless, past studies have failed to fully consider the psychosocial experiences of older people with ID, which may be determined by their socioeconomic status, cultural norms and practices, and the availability of social support. In this study, we draw on the biopsychosocial model of disability, which argues that disability arises from the complex interaction of individual, social, and environmental factors (WHO 2001). In accordance with this model, psychosocial challenges are defined as impairments, activity limitations, and participation restrictions. To that end, this study explored how social, cultural, environmental, and developmental factors impact the age-related changes in older people with ID.

Importantly, different definitions are used to categorize 'older age', with advanced chronological age as the key indication in policy and services (Walker and Ward 2013, p. 113). The biological ageing process of people with ID creates unique experiences (WHO, 2012a). Some international studies argue that ageing for people with ID differs from that among people in the general population who are of similar ages, which indicates a combination of impairment and age-related changes (e.g. Bigby 2008; Lin *et al.* 2016). However, other studies argue that the ageing process affects people with ID, especially people with mild/moderate ID, in the same way as it affects the general population (e.g. Holland 2000).

Importantly, the empirical literature in Western countries (Bigby 2012; Head et al. 2012) strongly argues that the ageing process commences sooner in people with ID, at \sim 40–50 years. Nevertheless, the literature has generally focused on people with ID aged over 65; relatively little attention has been given to the phenomenon of ageing in this population, particularly in middle age, at the beginning of the critical ageing process. Therefore, there is a need to understand what it means to be old for this population. Internationally, one of the key determinants of healthy and active ageing identified by the WHO (2012b) is how people perceive themselves as they grow older. While the field has predominately focused on the challenges older people with ID face (Lin et al. 2016), only a limited number of studies have examined the perception of ageing among people with ID, especially middle-aged people with ID. To remedy that gap in the literature, this study focused on that population.

South Korea (hereinafter Korea) has rapidly become an aging society, with more than 13.8% of the entire population over 65 as of 2017 (Korean National Statistical Office 2017); moreover, the fertility rate has

been dramatically decreasing, to just 1.07% in 2017 (Korean National Statistical office 2017). The Korean Ministry of Health and Social Welfare (2017) reports that 34.4% of the total registered individuals with intellectual disabilities (195,000) were over the age of 40; of these, 16% were aged 40-49, 12.2% were aged 50-59 and 5.2% were aged 60 or above. However, there are no official statistics on the average life expectancy of people with ID in Korea. Under the traditional family-oriented, collectivist culture, older people have been cared for by their families (Lee et al. 2007). Recently, though, a combination of factors has altered this dynamic: Korea's rapidly increasing elderly population and changing social values, influenced by urbanization and globalization, have changed family structure and attitudes towards care for older people. The role of family obligation ('filial piety') associated with caregiving for older parents or grandparents has been weakened (Jeon and Kwon 2017). These social and cultural changes have compelled the Korean government to set new policies and create additional public supports for the elderly population. For instance, long-term care insurance and basic old age pensions were introduced in 2008. However, most older people with ID have received little support from the statutory service sector over their lifetime; they are living, or are expected to live, with family carers, usually their parents; there are age limits on services for people with ID such as in group homes, sheltered workshops, or social services at community centers (Nam and Park 2017). This becomes increasingly impractical as people with ID near middle age, as their parents are growing elderly themselves. Nonetheless, complicating factors remain. The majority of ageing family carers have supported their adult son or daughter with ID from birth through older age. Because of this lifelong caring relationship, the lives of people with ID and their family carers are completely emotionally, financially, and practically interdependent. Nevertheless, their issues are not specifically heard when developing policies or services for the elderly in Korea. There also remains a lack of scientifically rigorous investigation of the lives of middle-aged people with ID that could help elucidate the specific needs of this challenged population. Therefore, the purpose of this study is to explore the age-related changes to the daily lives of middle-aged people with ID in Korea.

Method

This study aims to investigate and better understand the experiences of ageing people with intellectual disabilities who have lived with those disabilities for a prolonged time. In order to achieve this goal, the participants for this study were selected based on the following criteria: first, participants were limited to Korean people with intellectual disabilities in their 40s and 50s whose disability onset is congenital or occurred

Table 1. Sociodemographic characteristics of participants.

	Frequency
Gender	
Male	15
Female	13
Age	
40–49	18
Above 50	10
Education level	
No formal education	3
Attended or completed elementary school	12
Attended or graduated from middle school	3
Attended or graduated from high school	10
Marital status	
Married	3
Never married	25
Employment status	
Having job	17
No job	11
Living arrangement	
Group home	13
Living with family	15

in infancy or childhood; second, the participants had to be capable of communicating verbally; third, included participants had never lived in residential facilities and were currently living in their local communities with their biological families or at group homes for disabled people; last, in order to understand the different experiences of main segments of this population – those who work and those who do not – participants' engagement with sheltered workshops for people with disabilities was included in the criteria.

In order to recruit participants meeting these criteria, we contacted a range of venues: a Group Home Supporting Centre, city/district sheltered workshops for people with disabilities, centers for independent living, and community social welfare centers in Seoul, Gyeonggi-do, and Busan, South Korea. Ultimately, 28 people with intellectual disabilities were recruited and selected for participation (see Table 1).

Semi-structured interviews with each participant were conducted from February 2016 to April 2016. The interview questions were developed based on existing research studies related to disability and ageing. The questions were revised, supplemented, and finalized after conducting a pilot study with two people with intellectual disabilities and consulting professionals in the field. The interview questions were as follows: What were the big differences or challenges that you experienced with increased age? What kinds of activities do you do during the day now? What are your favorite things to do now? How are your relationships with friends and family? All the participants were interviewed by one of two interviewers. These interviewers (the first and second authors) developed the research questions, interview questions, and the interview guides together. Then, each interviewer conducted their first interviews, listened to each interview, and arrived at consensus regarding what to do with the interviews. Ethics approval was provided by the Dongguk University Ethics Committee.

The interviews were conducted using simple and clear language. The interviews lasted ~30-40 min in order to be considerate of participants' comfort. The interviewees were assured of confidentiality and anonymity and the interviews were conducted after obtaining consent forms from the participants. Individuals were provided with easily understandable explanations regarding what their participation consent entailed. Five participants who had family members supporting them during the interviews consented with the help of those family members. The interviews were audio-recorded under consent to keep an accurate record of participants' expressions. The participants were assured that the collected interview data would not be used for other purposes beyond research. The interviews were conducted at the places each participant preferred (e.g. group home, sheltered workshop, or community welfare centers' counseling offices or lounges with consent from their families or organizations). Before beginning the interview, the interviewer and each participant spent some time drinking tea or other beverages to establish rapport. During interviews, the researcher observed participants' nonverbal behaviors or expressions.

Analysis

Data gathered from interviews were analyzed thematically. Similar themes were grouped together and categorized. The actual language used by participants was reflected as much as possible. The analysis was conducted to derive themes In order to best reflect and analyze the phenomenon of ageing in people with intellectual disabilities, the researchers of this study continuously exchanged ideas on themes and categories derived from the data and organized them together.

Transcripts were audio recorded and were transcribed verbatim. The transcripts were first read and were descriptively and openly coded by the lead researcher and the second author. The codes were compared and discussed until consensus was reached. The second stage analysis involved discussions within the research team to refine the themes and to develop higher level themes into meaningful conceptual categories. This allowed for the drawing of the final themes concerning the psychological aspects involved in the ageing phenomenon experienced by people with intellectual disabilities.

The reliability and validity of this study was demonstrated using four methods. First, we kept detailed field notes about the interviews that were included in this analysis. Second, the development of a coding system from an *a priori* list of codes was based on the existing literature and interview questions. Third, debriefing was conducted with five staff members of the sheltered workshop or at the group homes regarding the data

interpretation. Fourth, triangulation was used to synthesize the multiple perspectives of the three researchers.

Findings

This study aims to explore the psychosocial experiences of middle-aged people with intellectual disabilities in Korea related to ageing. Data were collected through 28 face-to-face interviews with Korean people with intellectual disabilities, aged between 40 and 50.

This study made several key findings. First, middle-aged people with ID in Korea experience financial difficulties due to a lack of economic self-determination. Moreover, their social connections become smaller and weaker as they age. Individuals who have jobs in middle age gain positive opportunities via work. Middle-aged people with ID experience unspecified anxiety about ageing, as well as a fear of death and uncertainty regarding the future.

Restricted personal financial autonomy

The participants reported experiencing changes in their role and relationships with their parents as they got older. Until now, participants had been receivers of care; now, they needed to change their roles to become the economic caregivers to their parents as their parents also aged.

Interviewer: What does your mother like?
Participant 7: Make money and give it to her. My
mom likes money, so she is happy when I make money.

Although participants were economically active, they said they could not practice their economic self-determination rights in purchasing what they wanted and spending money to do what they wished. Only two of the 17 working participants managed their own bank deposits. The parents or siblings of the other 15 working participants managed their income, which was made from going to sheltered workshops; the people with ID received allowances that would take care of daily necessities such as transportation fees. They seemed more depressed and daunted because they could not realize economic self-determination. It is difficult for them to participate in social activities because they do not receive money other than transportation fees to cover their commute.

Interviewer: Who takes care of your salary?

Participant 25: My mom had my bank account and she used my money for making a living. My father gave me one dollar for every day.

This pattern is likely related to Korean cultural norms regarding people with intellectual disabilities. Even though they are able to make money, parents do not think their children with ID can manage that money appropriately, including using bank accounts. The issues involving financial constraints represent a

continuation of the status quo from across an individual's lifespan. However, they experienced more stress and found it harder to endure this situation due to their restricted financial autonomy as they got older.

Narrower social connections

Even participants who lived with family members, including their parents, experienced a paucity of social connections. According to participants, family members do not have much interest in each other and are emotionally distant, particularly as their family relationships have radically changed in the progression from youth to middle age. Participant 19 stated that he lived with his family, but that they did not communicate for an extended period of time. This state of affairs, the participant said, meant that in effect, 'We all live separately'. Participants who had siblings that did not live with the family said they rarely saw their siblings since those siblings had moved out and started to live independently. For instance, Participant 12 showed low levels of interaction between family members and did not show a sense of intimacy with family members.

Older sister, younger sibling. Well, we don't see each other because they are busy making their livings. (Participant 12)

Most of the participants said they do not have many friends, nor do they participate in many social activities. Regarding social networks and community involvement, participants who do not have jobs have much weaker connections compared to participants who have jobs. The daily activities of most participants were home-based or passive activities such as watching TV; some roam the community by themselves without talking to others. For instance, Participant 14 said, 'I am always left alone at home, eating alone, watching TV, and sleeping'. Participant 22, who said she did not have friends, described her daily life as spending her days alone. Most participants said they were always alone, and it seemed they were used to being alone. Participant 21 said that only personal assistants made home visits, which meant there was nearly no one that participant could meet in regular life.

All I meet is the personal assistants. No one comes to visit. (Participant 21)

They wanted to meet new people, but they experienced rejection from others.

I want to be nice to the other person and be friends, but the other person refuses me. (Participant 27)

The narrow social connections were also related to the participants' body deterioration. Seventeen out of 28 participants experienced physical deterioration such as frequent falling, body pain, complications, chronic disease, and body weakness. Due to physical weakness, they became less independent and found it harder to move around. Earlier retirement or moving from one sheltered workshop or one department to another with lower income based on their physical deterioration made it harder for them to make friends and maintain their previous relationships.

The reasons behind this lack of community involvement seem to be that people with intellectual disabilities have less information about community activities and less money to participate in such activities, and experience a lack of services developed for them. There is a notable gap between people's needs and the availability of services for middle-aged and older individuals with intellectual disabilities in Korea, particularly as most services for people with ID have an age limit. In addition, they did not have information about the diverse activities taking place in the community since their parents were getting older and could not take them for community activities; therefore, their social connections became narrower and narrower.

Positive opportunities through work

The participants who went to welfare centers or sheltered workshops had weak but steady social networks. Most of those who experienced the effects of ageing to a lesser degree were working at sheltered workshops. These participants showed a great affinity for their work. They stated that they were happiest when working and they were happy to be able to make an income. One participant said, 'I feel the most happiness when I said "hi" to my colleagues at work'. The participants expressed pleasure in working because it enabled them to give pocket money to their parents, give gifts to their teachers on teacher's day, and purchase things they wanted thanks to the income they earned at the workshops. Perhaps just as importantly, the pride they gained from working made them feel they mattered and gave them a social role that allowed them to experience a positive ageing process. Work was the most important driving force in their lives.

Ah...I am the happiest when I work. Because I make a lot of money. (Participant 22)

I spend money... and sometimes teachers... parent's day, no... on teacher's day I can give gifts. (Participant 15)

Study participants indicated that working at the workshop was fun, whereas 'staying at home is stifling', and said that their depression worsens when not working. Participant 10 stated that 'It's difficult for people like us to stay home' and said it was 'great' to be able to work as people with disabilities. The participant said he would like to work until he grows old and becomes a grandfather who cannot go out.

It's suffocating to stay at home. I feel my depression gets worse. (Participant 6)

I like working. Playing... idly spending time is hard work. (Participant 23)

I can't go out when I grow old to be a grandfather. So I want to work until then. (Participant 10)

I can't even come here to the workshop if I get older. (Participant 11)

As these responses imply, participants compared their working and non-working selves and expressed great pleasure in working for themselves. Moreover, participants who were vitalized and energized by participating in daily activities were willing to join in community-based activities. For instance, Participant 11 discussed their experience volunteering at a welfare center and showed pride in learning Chinese characters and English and attending singing classes. Volunteer activities also provided joy. For instance, Participant 18 said, 'I serve food ... I scoop hot rice without wearing gloves and bring it to people'. Participant 16 said they really enjoy bowling and going to church on the weekends. These statements indicated that the participants' lives were more active than those of their non-working peers.

I do activities with my teacher, like watch movies together. I travel and there's freedom here... That's what I like most. (Participant 20)

Some developed coping skills related to community engagement:

I play soccer when I feel down with a group of friends. (Participant 12)

As this implies, some participants actively took part in leisure or physical activities with other disabled people despite growing older. The participants' lives were filled with energy and vitality from participating in normal daily routines and leisure activities. However, their social networks only appeared to extend to within the disabled community, not the broader community.

Unknown anxiety: Something has changed, but what?

From participants' perspectives, the meaning of ageing is that they change into a self they do not wish to be. Participant 18, for instance, described ageing as 'my body changes like a homeless person, my body is a bit weird'. It meant that the person noticed her body's change even though she did not say exactly what 'the homeless person' meant to her. The participant added, 'I do not like my body as I get old'.

As the participants get older, they seem to show additional depression and anxiety for unspecified reasons. Participant 8, for instance, showed severe symptoms of depression, saying 'I eat well but now I just eat not to

die'. Participant 11 said, 'I am having heart aches without reason'. These participants said they did not know the reason, but they experienced suffocating feelings in their chests as they aged. This is most likely an emotional issue. Some participants expressed the psychological changes they experienced as they aged as 'depressed and sad'. Even though they could not express the reasons behind these emotions clearly, they were aware of the changes in their feelings.

I feel anxious and I'm anxious when I go somewhere and stuff. (Participant 8)

My feelings keep sinking. (Participant 15)

I feel suffocation in my chest. So I don't like getting old. I feel stuffy and stuck. (Participant 2)

Participant 7 specified her actual age and said, 'I've grown old before I knew it'; expressing her feelings on the matter, she said, 'I hate growing old'. Ageing, for the participants, was expressed as a psychological feeling rather than a physical change and they assigned meanings to this.

However, some participants were indifferent to the phenomenon of ageing, having no special feeling or perception on the matter. For instance, Participant 11 said, 'I do not feel it', about ageing. Some participants expressed a vague emotion, saying, 'Feelings, they just change.' Participants experience their ageing process as fear, depression, and anxiety. As they are uncertain about their living situation after their parents' death, they feel depressed. In addition, because they do not have financial control, their anxiety about the future is increased.

Fear of death and uncertainty regarding the future

Parental ageing and death, siblings' marriages, and other life events cause changes in family relationships that dramatically affect the later years of people with intellectual disabilities. Participants whose mothers passed away experienced psychological shock and loss. For instance, Participant 2 stated, 'Mom isn't here. She went to heaven'. Participant 27 said that after their mother passed away, they become a more passive person, including becoming dramatically quieter; their outgoing personality changed to a more depressed one.

I get very depressed, I don't talk very well, I get worse on my own, I beat other people when I gets worse. (Participant 27).

Experiencing the death of their parents as the study participants aged induced psychological shock along with drastic behavior changes. Some said they woke up in the middle of the night and walked around or even showed self-injurious behaviors. However, they rarely received counseling on what death means, how to cope

with loss, or how to deal with psychological difficulty due to loss.

In the case of participants who live with their parents, this becomes a factor inducing even more anxiety, particularly when they do not have any plans regarding a future residence. For instance, Participant 22 expressed that she did not have any place to go if her mother passed away. Participant 24 said that he disliked the idea of going to a nursing home when he gets old: 'I could not stay at a nursing home'. Participant 10 was already worried because his funeral might be expensive, saying, 'I worry a lot about going to heaven when I get old. When someone dies, they have funerals and stuff'. As seen in these responses, the participants interpreted ageing as uncertainty and fear regarding the fact that they might have to change their place of residence and did not have measures in place to deal with this issue.

Discussion

In this study, we interviewed 28 people with ID between the ages of 40 and 50 to investigate how social, cultural, environmental, and developmental factors may affect their experience of ageing. This study found several common issues experienced by this population. First, middle-aged people with ID often experience financial constraints due to a lack of economic self-determination. Second, they have a very narrow range of social connections. Typically, they have small and weak networks consisting of only a few social workers, personal assistants, or group home workers, or their peers at group home or workshops. This constraint is frequently due to a lack of information, money, and age-appropriate services that might help develop more robust networks. Third, individuals with ID who have jobs in middle age often gain more positive opportunities and outlooks through work. Fourth, individuals with ID experience unspecified anxiety about ageing, as well as a fear of death and uncertainty regarding the future.

A lack of the economic self-determination rights regarding spending money leads to increased depression and frustration for middle-aged people with ID. This economic exclusion can cause feelings of depression and alienation, and as they get older, this affects them more seriously. As most parents seem to think of their children with ID as 'forever children' even into adult-hood, they never taught their children how to manage money. Unfortunately, this lack of economic autonomy or self-sufficiency leads to a painful irony as these middle-aged people with ID become the breadwinners of their family as their parents get old and retire from their jobs.

Second, particularly upon the death of their parents, people with intellectual disabilities lose their most active social network of support (Alcedo *et al.* 2017).

The study showed that this affects them in the form of a severe loss or depression. Their siblings became busy living their own lives as they grow older, which further weakens the familial support. People with ID are already used to being alone and often have weak social relationships, but this worsens as they age (McCausland et al. 2018). In addition, older parents and family members seem to lack knowledge of available support services for people with ID. Moreover, there is an overall lack of services targeted to middle-aged people with ID (Bigby et al. 2008; McCausland et al. 2010), which enhances the sociological effects of ageing in this population. Sociological aging is an especially serious issue for middle-aged people with ID who do not go to social welfare centers or sheltered workshops. Sociological aging will accelerate their physical ageing and lead to additional problems in later life.

Notably, the ageing experiences of the participants of this study showed that middle-aged people with ID who work at sheltered workshops or go to welfare centers, in addition to participating in more social activities such as volunteer work, church, physical exercise, going to the movies, and so on, have improved outlooks over those who are more isolated. They had healthier and more active lives and demonstrated significantly fewer premature ageing symptoms compared to those who stayed at home without engaging in special activities.

Fourth, the study participants each gave their own meaning to psychosocial aspects of ageing, and while they could not specifically express their feelings through language, they expressed their vague feelings, wishes, difficulties, dislikes, and fears (Hermans and Evenhuis 2013). These psychological feelings expressed by middle-aged people with ID can be seen as a natural part of ageing for many of us in the normative population; however, to them, ageing and death are understood in terms of fear, anxiety, and resistance. As they grow older, it is very likely they will experience depression and other mental health issues that are related to the ageing process even though they cannot explain it.

Fifth, participants who associated psychosocial aspects of ageing with death showed a notable fear of ageing. They exhibited depression and anxiety over the fact that they will not have a caregiver when their parents pass away. Moreover, if these individuals do not have a concrete plan for the future, this anxious uncertainty grows as time passes (Hall *et al.* 2013).

Based on the findings above, this study suggests several implications for supporting positive ageing in middle-aged people with ID.

First, enhancing economic self-determination is important, as it gives more freedom for people with ID to use money, which also relates to their life satisfaction. In Korea, parents and family members need to be educated on how economic self-determination is crucial

for people with ID. Moreover, people with ID need to be trained on money management from an early age so they can exercise enhanced economic self-determination as they grow older.

Second, it is crucial to provide ways to expand the social networks of people with ID, and to create and maintain robust networks of professionals who can provide support for these social networks (Mihaila et al. 2017; McCausland et al. 2018). A social network for people with ID is an important resource that supports their lives in all respects. It is necessary to make efforts on the social level to ease the effects of weakening social networks as people with ID grow older and to expand their social networks. Community organizations need to develop and provide day activity services and programs for all ages of people with ID, including older individuals and those with unique characteristics. More specifically, it is important to provide opportunities and conditions that enable the formation of social networks through participation in various activities such as lifelong education, volunteer activities, religious activities, and community mentoring.

Third, work and productive activity slow the detrimental effects of ageing in people with ID. Work enhances their sense of self-esteem and allows them to feel like productive members of their family and community; they become full of vitality, maintain social relationships, and demonstrate enhanced physical and mental activity through this standard facet of life. However, it is extremely difficult to find a new job in middle age – yet for people with ID, work has a more important function than for people without disabilities. Activity also helps maintain their youth and vigor. Something as simple as doing regular activities and seeing the same people on a daily basis within their life domains helps postpone ageing in people with ID.

Fourth, improved education on the ageing process, including teaching those with ID what positive and active ageing involved, is necessary. It is natural to grow older, and it is necessary for people with ID to understand this transitional life process as a normal function. Furthermore, not only do people with ID need to learn about the physical and psychological changes that occur with ageing, but practitioners and staff who provide caregiving services and family members also need to be provided with education on the multiple symptoms and changes that may occur with ageing. Multilateral levels of education on ageing can prevent premature ageing and chronic diseases and will positively affect support for healthy and active ageing amongst people with ID.

Finally, the ageing experience for people with ID could involve planned 'aging in place'. People with ID in Korea traditionally live with their parents. When their parents grow old or die, these individuals experience increased depression and anxiety related to

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uncertainty; to minimize these negative effects, they could continue to live in the place they have resided for most of their lives. One study showed that some people with intellectual disabilities are comfortable moving, as long as they can get advice and have choices (Hussain *et al.* 2014) However, when the health conditions of people with ID worsen, they might do better to be cared for in the communities in which they live since there is not enough community support and there are fewer choices as far as choosing a place to live in Korea.

This study has some limitations. The 28 participants were recruited by service providers, and we interviewed all the people who were referred by service providers. Therefore, there is the potential for bias in this sample.

Conclusion

The results of this study demonstrate the importance of the psychosocial aspects of ageing among middle-aged people with ID in Korea. Understanding the psychosocial aspects of ageing is important because this knowledge underpins the policies and services that guide possible improvements in financial autonomy, social connection, meaningful work, awareness of ageing and death, and preparation for ageing that may improve the outlooks, health outcomes, and life experiences of individuals with ID.

Disclosure statement

No potential conflict of interest was reported by the authors.

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