

Why are middle-aged people with intellectual disabilities still lonely in the community in Korea?

- Kyung Mee KIm (Soongsil University)and Eun Woo Joo(Chung Ang University)

Method

- Research question: understand the experiences of aging people with intellectual disabilities who have lived with disabilities for a prolonged time
- Recritment participants: service agency such as group Home, sheltered workshops, centers for independent living and community social welfare centers

Method

- 24 people with intellectual disabilities
 - 13 males and 11 females.
 - 1 participant had first-degree intellectual disability, 10 had second-degree, 13 had third-degree
 - 20 were single, 2 were divorced, and 2 were married.
 - 15 were in their 40s and 9 were in their 50s.
 - 11 elementary school dropouts or graduates, 3 middle school dropouts or graduates, and 10 were high school graduates.
 - 13 living in group homes and 11 were living in houses or apartments with their families.
 - 17 working at sheltered workshops while 7 were not working.

Method

- Interviews were conducted from February to April 2016
- Semi-structured interview questions were and interview questions was revised, supplemented, and finalized after pre-interviewing 2 people
- The interviews were conducted using simple and clear language.
- The interviews lasted approximately 30-40 minutes
- The interviewees were ensured confidentiality and anonymity and the interviews were conducted after obtaining consent forms from the participants.

Method

- The interviews were recorded under consent to keep accurate record of study participants??expressions
- The interviews were conducted at the study participants' group home, sheltered workshops, community welfare centers with consent from their families or organizations.
- Before beginning the interview, the interviewer and respondent spent some time drinking tea or beverages to establish friendliness and rapport with the respondent.
- Follow-up interviews were conducted only to a few cases if data was insufficient or needed to be supplemented.

Analysis

- The data collected through interviews were transcribed.
- Transcripts of the interviews were read several times and line-by-line analysis that focuses on the meaning units was conducted.
- Similar ideas were grouped together and categorized by theme.
- The actual language used by people with intellectual disabilities were reflected as much as possible.

Results

- Continued weakening of social relationships.
- Analysis revealed that the poor relationship experience in people with intellectual disability was due to
 - changes in familial roles and weakened relationships
 - narrower social relationships and low social involvement
 - fear of death, and aging
 - depression and loneliness from economic dependence

Changes in familial roles and weakened relationship

- changes in their role as they grew older: the economic caregivers and emotional support to their parents: the shift in roles occurred only in the cases that lived with their parents.
- For study participants who lived with family members other than their parents, the family members did not have much interest in each other and were emotionally distant.
 - "We all live separately" and indicated that the family members have lived together without communication for an extended period of time.
- For study participants who had siblings that did not live together said they rarely met their siblings since they moved out and started to live independently (Participant 12)
- In this case, the study participants showed low levels of interaction between family members and they did not show a sense of intimacy with those family members.

Changes in familial roles and weakened relationship

- The study participants' aging process is closely related to the family life cycle. The death of their parents, aging of their parents, marriage of their siblings, etc.
 - Participants whose mothers passed away experienced psychological shock and loss.
 - Participant 2 stated that after their mother passed away they had changed to a more passive person such as becoming drastically quieter.
 - Some said they woke up in the middle of the night and walked around or even showed self-injurious behaviors.
 - However, there rarely were cases in which they received counseling on what death means, how to cope with loss, and how to deal with psychological difficulty due to loss.

Narrower social relationships and low social involvement

- What makes a difference is their employment status, money spent for personal use, and opportunities accumulated from self-decision making that gives confidence
- Most of the study participants said they do not have friends. They all said they are alone.
 - Participant 14 said their days are always spent left alone at home, eating alone, watching TV, and sleeping.
 - They said they are left alone at home since each of their family members needed to go to work.
 - Only personal assistants made home visits, which meant there was nearly no one they could meet in reality. ??All I meet is the personal assistants. No one comes to visit.

Narrower social relationships and low social involvement

- People with intellectual disabilities who went to the welfare centers or sheltered workshops had weak social networks but they still existed.
- Most of those who experienced effects of aging to a lesser degree were working at sheltered workshops. The participants showed great affinity to their work.
 - One participant said they feel the most happiness when they said to their colleagues at work.
 - They 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 from the income earned by working at the workshops.

Narrower social relationships and low social involvement

- The pride they gained from working made them feel they mattered and gave them a social role that allowed them to experience a positive aging process.
- Work was the most important driving force of their lives.
- Furthermore, study participants responded that working at the workshop was fun while staying at home is stifling and said that their depression worsens when not working.
- The participant said he would like to work until he grows old and becomes a grandfather who cannot go out.

Narrower social relationships and low social involvement

- The life domains for most people with intellectual disability were very simple: the sheltered workshops, rehabilitation centers, homes, and churches.
- The participants said they found vitality through daily activities because their life domains were simple.
 - These statements indicated that the participants' lives were vitalized and energized by participating in daily activities.

Limits on Economic Self-determination and Psychological Atrophy

- Parents or siblings of the participants managed their income made from going to sheltered workshops
- the people with intellectual disabilities received allowances that would take care of daily necessities such as transportation fees.
- Although the individuals 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 to do.
- 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 for their commute.
- The lack of feeling they mattered causes depression and alienation.

Fear of death, and aging

- People with intellectual disabilities assigned different meanings to what aging is.
- The first meaning they assigned to aging was that their siblings got married and had children. However, because the participants were not married, they conceived aging as reaching an age that was appropriate for marriage.
 - Marriage was an important experience to this participant in understanding aging.
- The second meaning they attributed to aging was that they change into a self they do not wish to be.
 - I feel like I changed to a homeless person, my body is a bit weird.

Fear of death, and aging

- The third meaning associated with aging was that they could not live with their parents.
 - To not live with their parents meant changing residence; however, this becomes a factor for more anxiety when they do not have any plans on future residence.
 - Participant 24, who associated aging as going to a nursing home.
 - Participant 10 associated aging and their own funeral after their death and said they were already worried .

Fear of death, and aging

- Participant 22, who connected aging to their mother' death, expressed that they did not have any place to go if their mother passed away.
- Not having permanency planning.: I worry a lot about going to heaven when I get old. When someone dies they have funerals and stuff.
- Aging, for the participants, was expressed as a psychological feeling rather than a physical change and they assigned meanings to it.
- The study participants showed that they have negative thoughts on aging. Aging meant an uncertain fear about not being able to live with their parents anymore.

Implications

- With the death of their parents, people with intellectual disabilities lose their most actively social network of support.
- The study showed that this affected them as a severe loss or depression.
- Their siblings became busy living their own lives as they grew older which further weakens the support system coming from the family.

Implications

- Could the family relationship be replaced?
 - Constructing a community network that allows a continuous relationship between the community members and people with intellectual disabilities is the solution.
 - It is necessary to provide ways to expand the social networks for people with intellectual disabilities and maintain continuous networks with professionals who can provide the support.
 - Community organizations need to develop and provide day activity services and programs that meet the age and characteristics of older people with intellectual disabilities.
 - 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.

Implications

- Work and activity stops aging in people with disabilities. Work makes their lives full of vitality, maintains social relationships, and maintains physical and mental activity through tension necessary in life.
 - It is extremely difficult to find a new job in the middle age.
 - Activity also helps maintain their youths.
 - As simple as doing and seeing something on a daily basis within their life domains helps to postpone aging.

Implications

- Education on the aging process and teaching what positive and active aging is to people with intellectual disabilities is needed.
 - Aging from growing older is a natural process and it is necessary to understand it as a transitioning process of life.
- Furthermore, not only do people with intellectual disabilities need to learn about the physical and psychological changes that occur with aging.