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# Everyday life and a sense of loneliness in the opinion of elderly persons with disabilities in long-term residential care

**ABSTRACT:** Bernadeta Szczupał, Jolanta Izabela Wiśniewska, *Everyday life and a sense of loneliness in the opinion of elderly persons with disabilities in long-term residential care*. Interdisciplinary Contexts of Special Pedagogy, no. 24, Poznań 2019. Pp. 11-25. Adam Mickiewicz University Press. ISSN 2300-391X. DOI: <https://doi.org/10.14746/ikps.2019.24.01>

The growing number of elderly people, including persons with disabilities, is a major social, economic and political challenge. The article presents the results of a qualitative research concerning the opinions of elderly persons with disabilities in long-term residential care, about their everyday life and the sense of loneliness experienced by them.

**KEY WORDS:** everyday life, loneliness, elderly persons with disabilities, social care homes

## Foreword

In their daily life, elderly persons with disabilities require special help and support. Ageing is a complex process that involves both physical and psychological changes. The ageing process is different in every individual, both in terms of its pace and intensity.

The condition of elderly persons depends on whether they suffer from chronic diseases that lead to the malfunctioning of many organs as well as the process of physiological ageing. An important factor in the dynamics of this process is also the psychological attitude to one's own age<sup>1</sup>. Deteriorating mental efficiency, manifested by problems with attention focus and memory, and loss of previous social functions often cause lower self-esteem, isolation and loneliness<sup>2</sup>. A growing number of elderly persons, including persons with disabilities, is a major challenge for the community. Because of ongoing demographic and cultural changes, more and more families place elderly persons in specialist institutions. One of the biggest problems faced by an elderly person in such situation is living a lonely life without family, friends or acquaintances. Loneliness understood not only as isolation from others, but also a sense of otherness, being left out from the community or living in a strange environment that cannot be changed. Loneliness may lead to marginalization or exclusion of elderly persons. Such persons do not keep in touch with their immediate or more distant circles, which is either their conscious choice or lack of another option<sup>3</sup>. One of the key factors of happy ageing and prevention of loneliness and changing quality of life is maintaining bonds with others and engaging in effective pro-social activities.

## Justification of the research method

The qualitative research whose results are presented in this article was conducted in the years 2016 and 2017. The purpose was to find out what elderly persons with disabilities in residential care

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<sup>1</sup> J.I. Wiśniewska, *Educational activity of seniors as a predictor of successful ageing*, „Interdyscyplinarne Konteksty Pedagogiki Specjalnej” 2018, no. 24, p. 27-46.

<sup>2</sup> B. Szczupał, *Dignity, everyday life, support for seniors with disabilities*, „Interdyscyplinarne Konteksty Pedagogiki Specjalnej” 2018, no. 24, p. 15-26.

<sup>3</sup> K. Ziomek-Michalak, *Znaczenie rodziny w starzeniu się i w starości człowieka*, „Roczniki Teologiczne” 2015, vol. 5, p. 175-194.

think about their daily life and sense of loneliness. The research involved five interviews with four women and one man. They talked about their personal, subjective experiences. In order for a researcher to learn about subjective experiences, he or she must go deep into those phenomena and explore them in their complexity<sup>4</sup>. The research was conducted at the Social Care Home and In-Patient Centre in Mazowieckie region. The respondents of the research were selected on the basis of their age (65-75 years), psychophysical functioning, chronic diseases, acquired or congenital motor, visual or hearing impairment, and time of stay in the social care home or in-patient center (at least three years). Each interview had the same pattern based on the narrative interview methodology<sup>5</sup>. The narrative interview has two subtypes: expert interview and autobiographical-narrative interview. Since the focus of the research was to present everyday situations and changes in the life of the respondents, and positioning those situations in time, the autobiographical-narrative interview method was applied. In this research, respondents may trace certain memories, which makes them reflect on how they evaluate given phenomena and interpret the reality<sup>6</sup>. Talking about one's life is a subjective interpretation of what the respondent experiences, lives through and feels<sup>7</sup>. An analysis of the narrative data was preceded by transcription. The texts of the respective narratives were divided into smaller thematic units and structurally described, in order to identify the processes arising from narratives, e.g. defining the situation of the narrator. Next, the milestones, turning points or critical events in the respective biographies were identified, and elements common for most narratives were identified.

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<sup>4</sup> T. Pilch, T. Bauman, *Zasady badań pedagogicznych. Strategie ilościowe i jakościowe*, Wydawnictwo Akademickie „Żak”, Warszawa 2010, p. 327-330.

<sup>5</sup> E. Kos, *Wywiad narracyjny jako metoda badań empirycznych*, [in:] *Badania jakościowe w pedagogice*, ed. D. Urbaniak-Zajac, E. Kos, PWN, Warszawa 2013, p. 98-104.

<sup>6</sup> T. Pilch, T. Bauman, *Zasady badań pedagogicznych. Strategie ilościowe i jakościowe*, Wydawnictwo Akademickie „Żak”, Warszawa 2010, p. 327-330.

<sup>7</sup> D. Demetrio, *Autobiografia. Terapeutyczny wymiar pisania o sobie*, Oficyna Wydawnicza „Impuls, Kraków 2000, p. 11.

These categories included daily life in the social care home or in-patient center, current health condition, contacts with the family and a sense of loneliness, and the support provided. The interviews revealed the complexity, diversity and ambiguity of these categories<sup>8</sup>.

### **Everyday life and a sense of loneliness in the narratives of the respondents**

Being placed in a social care home or in-patient center means that one has to adapt to the new environment. The daily life that one used to control to a greater or lesser extent has radically changed. Currently the organization of life and the living conditions depend mainly on the institution where a person is placed. Being placed in an institution also means various changed in contacts with the family and social relations.

Seniors with disabilities placed in an institution that offers long-term residential care have very different opinions about their new situation, as is shown by the responses below. They include comments on everyday life, which, in their case is life in an institution, and on social relations.

Ewa (aged 70) said:

*I don't know how many years have passed. I think I've been here since the beginning of this institution, for about five years. Before, I was in a different institution, then in hospital, and later, they moved me here. I think I like it best here. I came here after a stroke and everybody thought I would not make it. For a long time I was bedridden like a vegetable and nobody took much interest in me. I don't know how long it lasted, a year, maybe more. A physical therapist tried to get me out of this. Unfortunately, I will never be quite fit again, I think. Now, I spend most of the time in my room, I don't go out and hardly talk to*

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<sup>8</sup> The article presents the original responses of the elderly persons.

*anyone (...). How do I feel here, in this institution? I got used to it, although obviously I'm not at home here. There was no other option, I had to stay here, because my daughter has other things to do and she could not be with me all the time. I cannot walk on my own, I need full assistance. It's like a hospital here, could be better. I am one of many residents. They do not always see us as a human who has feelings and thoughts, and understands. Elderly persons are not appreciated, they seem to be useless. But one must not allow to be treated badly, one must defend oneself.*

Ewa about her free time:

*I do not like going to activities or workshops. Mostly, I stay in my room. I sometimes go for a walk after dinner, if it's warm. When I have free time, I read a book or do a crossword. I watch the TV.*

Ewa speaks with some hesitation about contacts with her family.

*I don't know... I don't know how I feel. It is hard to say. My daughter comes to visit me. I love her very much. I don't have other children and my husband died 20 years ago. Beata is very good, she helped me a lot before I was placed here, and she comes here frequently. She works in a bank, learns English and often goes on business trips. Last time, she was in Brussels. I brought her up right. She really is a good girl... Whenever she visits me, I am distressed afterwards. I feel sad that I have to stay here. I have here phone number... When I feel very bad, I call her.*

Concerning former relations, Ewa says:

*I prefer to stay in my room and watch the TV. Sometimes, I talk to the nurses. My friends here are as sick as myself. One of them lives with her son by the sea now. He took her after she had fallen from the stairs. I don't know how she is doing now. We stopped seeing each other once I came here.*

Ewa's response suggests that she regards her stay in the institution as a forced situation beyond her control and that she has no other choice. Based on what she says, it may be assumed that she understands and accepts her everyday life, though sometimes, she misses her daughter. She cannot enjoy her life or use the privileges offered by the institution's personnel. Her daily life is limited to spending her time passively in her room. She does not speak negatively about family relations or lack of contacts with the family, but she says her contacts with other people are hindered by her illness. She is rather a loner and does not strive to start or maintain interpersonal relations. Significantly, the woman understands the family who placed her in the institution and approves of the current social relations, even though they are difficult.

Another interlocutor, Seweryn (aged 75), one of the most senior residents in the institution, cannot speak about his situation without tremor in his voice.

*I had a stroke. It happened all of a sudden. I was hospitalized and then I was placed here to get better. At first I felt uncomfortable, because I didn't know anybody here. Now, I have a few friends here, so I have people to talk to. I have been here for about five years now. At first, my son visited me every day, but now he has more duties so he comes less frequently. Sometimes... often, he does not come to see me at all (...). It is hard to say it in one sentence. I feel good, I cannot complain – I have food, drink and care and nothing hurts me, but I keep thinking what it would be like, if my wife was still alive. When I was back at home with my wife, we had a dog. He was like a family member, he even slept with us in bed. My son had to take him when I came here. My son is a chemist, like myself. I think he took it from me, although he always wanted to be an actor. It's good I have him, because he's the only one left.*

Seweryn once again is moved, speaking about his family.

*I love my son very much, and I have beautiful grandchildren. They visit me as often as they can. If I was a little younger, I would go to*

*them myself, but now I am too old for that. I miss them. Especially in the evening, when I go to bed, I think about my family.*

Despite longing for his family, Seweryn does not give up, and he starts contacts with others.

*I have my friends, so I spend most of my time with them. I also look after an elderly man, Kazimierz, I help feed him, because he cannot eat on his own and there is not always someone to help him, even the personnel no longer have time or patience for him. Sometimes, I take him to the day room to spend time with other people or watch the TV. Without that, I would have no contact whatsoever with others, because the family is gone and I am completely alone.*

Seweryn has not come to terms with the changed environment, although he acknowledges that he does not lack any material things and he appreciates the efforts of the personnel. His daily life is filled by meetings with other residents, which is very much in line with the needs of a person. Nonetheless, despite being among people, i.e. lack of physical loneliness, he is very lonely psychologically, which is intensified by his memories of and longing for his late wife. For him, social relations, especially family bonds are very important. Being placed in an institution, he misses his family and feels the need for more frequent contacts. He evidently needs to feel that he is needed and socially accepted. He is very emotional and cries easily, which may be a sign of his emotions associated with being separated from his family.

The next interlocutor, Gertruda (aged 74), said:

*I've been here for long, about three years or maybe more. After I had a stroke, I could not return home. My son and daughter could not look after me. It depends, what it's like here. Now, I have a nice roommate, Zosia, so I feel much better here. Only the time passes so slowly here, every day, I do the same things, I have become useless. I have to feel good here, there is no other option for me. Most of the personnel are nice, cheerful and smiling, and this is a big help. Now, despite being*

*ill, I know there is always someone to help me, and I wouldn't have this at home. I do not lack anything here, but it is not like home.*

About her family, she says:

*They rarely come to see me. I love them very much... but they have no time, they have to work. If they had time, I'm sure they would take me from here. I had a granddaughter, she also comes here, she is a darling. She goes to school, she's very wise, maybe she'll be a medical doctor. I keep waiting for them to come, I count the days, but get lost and don't know how much longer I have to wait for them.*

Gertruda usually rests together with her friend.

*We often go with Zosia to therapeutic activities, where we have a cup of god coffee and talk about things. We do not go out much, we have no power to move around on our own... and we do not like the company of smokers. Every person has their fault and virtues, everybody is different. We are only human, that's right, if you don't like it, do not talk. Do not tell others that she did this or that. I stick with Zosia, we share a room and spend our free time together. We often talk or read newspapers. Of course, in therapy, I talk to everyone... I'm not a loner, but I do not have any complex relations with others and do not feel like meeting new people.*

Gertruda talks about her family.

*I do not care so much about work or friends, but about the family. I remember them the most. I remember my son being born and later my daughter. My husband was happy to have a son first (laughter), but I didn't care, I just wanted them to be healthy. I remember our first holiday, how happy they were! Too bad we cannot go back to those moments if only for a moment. I rarely think about my youth, but I remember sharing one room with all my brothers and sisters... Back then, we were all together. Things are different now. I miss my sister very much, because I had the closest contact with her. She died seven years ago, she was my best friend, I still cannot come to terms with it.*



*When my family finally come to see me, I feel appreciated. I forget my all regrets and feelings and am happy to have them by my side... But when they are gone for some time, I again feel not understood and neglected. I have felt lonely ever since my husband died. My children have their own lives now and he was always with me, and I was with him. I have friends and relatives, but this is not the same. They come and go, and my husband was always by my side. I had someone to talk to, to argue with, to laugh with, and now? I am alone here. I need full time care and assistance. I cannot take care of myself. It should not be like that, couples should die together (...). I don't know what I could do now, I am useless. I have no strength to function independently, so probably, I won't be able to go home, but I would very much like to. If I could live to my daughter's A-level exams, I would be happy to see that she has done well.*

What is characteristic of Gertruda's narrative is that she looks for and provides rational arguments why she has to stay in the institution. Meanwhile, she strives to accept this situation. She is still at the stage where she does not fully approve of her current everyday life. She does not like the daily routine, but she also notices the fact that she has lost her abilities that affect that routine. However, she found space that plays an important part in her current life. These are the therapeutic activities that she likes to attend and is eager to use them. She admits missing psychological proximity. She misses her husband and late sister, with whom she had a very close relationship. Gertruda speaks positively about her family and expresses a need for contacts with them. However, she can justify the fact that they rarely visit her and she dismisses any negative thoughts about her family. She has her roommate to satisfy her need for a close relationship with another person. Her strong desire is to return home.

Zofia (aged 74), whom Gertruda mentioned, said:

*It feels like home here, or almost like home and not always (...). They all take care of me, only the food is poor. When I cooked at home, the food was what it should be. I like attending activities, though usually*

*I do not have the strength for that, I already feel tired in the morning and fall asleep at once. I have been here for more than 3 years, if I count correctly. I had a stroke and that's how it all started. My sons placed me here, because they didn't know how to look after me, but I can take care of myself if only someone sits me in the wheelchair. It is quiet here. The three years have gone by so fast... I had a few roommates, but they moved me to different rooms and now I'm with Gerta and we are OK so far.*

*I have two sons, Piotr and Adam. I like to think about them. I am always curious how they are. They usually visit me once a week or less frequently. Too bad they cannot come more often, but I understand them. The worst thing for me is that my husband cannot visit me. If he were alive, I wouldn't be here, he would take care of me.*

*My eyes are weak, but in my free time, I read newspapers. The caregivers buy me new newspapers every day. I also like books, but I prefer newspapers, because I like to keep myself updated on all gossip. Then, when my friends come, I have things to chat about with them. Every day, Gerta and I go to therapeutic activities and rehabilitation. But I often doze off there, I think I do it in the wheelchair, too, because when I open my eyes, I find myself in a different place – someone must move me sometimes to the room.*

*Nobody bothers me and I think I don't bother anybody, either. I don't have friends here, but in therapy or rehabilitation, we play ball together.*

Zofia remembers the most her youth and love of her husband.

*My husband loved me to pieces. I was lucky, because he was a good man. He had his faults, like we all do, but he was a very good husband. I remember, before I was married, he would come round my place and when he saw a boy leaving my house, he would beat him... he was so jealous. We spent so many years together, and when he died, it was as if someone tore my heart out and stabbed it with a knife. I still cannot come to terms with it. I wish I could be with him.*

Zofia says:

*I used to think I would leave this place, that it was only for a short time, because they all told me that when I got better and was quite fit, they would take me home. I don't know if I will ever be fit again, because I've been here for so long and nothing gets better. I think this will not happen. I would like very much to be home, but I know they wouldn't want to take care of me. I cannot take care of myself.*

Zofia is the kind of person who has a very good judgment of her current living space in the institution. She appreciates the care and activities offered, although she is not uncritical, because she does not like the meals. Her daily life is quiet. She spends time engaging in the activities offered by the institution. She has a passion for reading newspapers and books. Her bond with the family seem to be satisfactory, because her sons visit her regularly, and she has no complaints about these relations. Significantly, however, the same as the other respondents, she misses her late spouse. Having lost her husband, Zofia feels lonely. She is certain that no one and nothing will replace that relationship. However, she does not avoid people and she has a close relationship with her roommate. Despite her very positive opinion about the institution, she wishes to go back home.

Another respondent, Krystyna (aged 67) also has a positive opinion about the institution.

*I feel very good here. They treat me well and respect me here. I have come to like my room and roommate very much. At home, I had a lot of stairs and it was narrow, and all the time, I had to ask neighbors for help. Here, everything is at hand, and there are people to talk to, unlike in an empty apartment.*

Krystyna also speaks positively about her rehabilitation:

*I have suffered from meningomyelocele since childhood. I had my ups and downs, but could always walk on my own. I had a number of sur-*

*geries. Now, I am in rehabilitation, because I have to use the wheelchair. I couldn't live on my own now. I have been here for four years. I have less and less strength for everything. I exercise every day, but it doesn't help. I never married and had no children. My parents died long ago. I had a brother and sister, but they also died. I was the youngest. That's how it is. Now, I am all alone. I only have my friends (...). Sometimes, my neighbors come to see me. When I lived in the apartment building, they would do shopping for me, when I could no longer go out. They always ask me how I am or if I need anything. They really are good people. My friends from work have no way or no strength to come here. I have new friends here, but my old relationships are also very important for me. Contacts with other residents make me feel better. I have my colleagues, but I avoid some of them, because we argued. I trust my roommate, we have our businesses and secrets (...). I no longer remember my past life. Here, every day is the same. I always worked a lot, too much. I spent my best years behind a desk. And what is left of it now? If I had a husband and children, maybe I would be somewhere else now, who knows. I don't even know what to say. It's good that at least I've learned to appreciate what I have in life. In my age, you think about these things. I thank God every day, and I hope he will take me from here soon. Then, I will be happy. I have nothing else left apart from faith in heaven and prayer.*

Krystyna is another person to claim that this place makes her feel safe. She notices many benefits and advantages here. In her own apartment, she felt lonely, and dependent on others, because of her problems with mobility. From what she says, she seems to be pleased with her everyday life. Her living conditions (room) and contacts with other residents are satisfactory. She has a close relationship with her roommate, which could mean that she is satisfied with her contacts with other people. Lack of family causes certain psychological discomfort, but it does not make her feel lonely. She mentions death and seems to have mature feelings about it.

## Conclusions

To sum up, the characteristic feature of most interviews is bringing the past and the present together, missing the family, the need for social contacts, longing for one's youth and activity, and often no perspectives for change. The respondents also feel a strong need for respect, sense of dignity and sense of being useful. They treat their stay in a social care home or in-patient center as a necessity that, due to their physical limitations, is beyond their control and there is nothing they can do to change it. The respondents are also aware that, in the institution, they have a sense of stability, balance and safety and have access to treatment, rehabilitation and therapy.

The daily life of an adult person consists of activities in various areas of life: family, work, local community. A very important determinant of everyday life is the space where one lives, which is usually the family home. Another important factor are social relations. Persons, whose basic element of their life - their family home - changes, experience major changes in the respective other components of their daily life. Not only do their living conditions change, but, more importantly, their relations with the family transform, and their contacts narrow to other persons in the institution. They also become dependent on others. An analysis of the daily life of the group of seniors who responded to the research leads to the following conclusions:

- residents tend to understand why they are in an institution or they try to rationalize the fact. In their case, the main argument is their poor health;
- characteristically, the respondents do not raise the issue of living or material conditions when talking about to their daily life. This suggests that other aspects of life are more important for them;
- the most important factor of everyday life that the residents of the institutions expect are interpersonal contacts with their families, meaning also family bonds and warm feelings from the families. For elderly, sick persons, it is not enough to have

good care, but they also need understanding and contacts with other people;

- a very important, though wishful - in the case of the respondents - element of everyday life is returning to the familiar space of their family homes. It could be assumed then that an elderly person, even despite the best care, will never fully consent to not being at his or her own home.

To sum up, it seems necessary to take actions in order to improve and broaden the care offered to seniors. The planning of such care should provide for statistical data, social situation and living and economic conditions of a senior, and possibilities of non-residential or institutional support<sup>9</sup>. A growing number of elderly persons, including persons with disabilities, is a major challenge for the community. It is necessary to consider the problems of that group as well as explore the phenomenon of the ageing of persons with disabilities and becoming a person with disabilities in old age<sup>10</sup>. In the evening of their lives, elderly persons with disabilities, who worked, raised children and contributed to the development of their societies expect to be treated with dignity in their everyday life. At this stage of life, assistance and support are very important, but the more so is understanding, attention, ability to listen and respect.

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<sup>9</sup> M. Połuszná, *Aktywność rodzinna i społeczna osób starszych*, „Nowiny Lekarskie” 2012, 81, 1, p. 75-79.

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