Focused Ethnography on *Disability* and *Home-based Care* in Scotland in Opinions of Polish Migrants Employed as Caregivers: A Preliminary Research Report

Beata Borowska-Beszta * Piotr Krakowiak ** Urszula Bartnikowska *
Katarzyna Ćwirynkało ****[1 2]**

[1] * Principal Investigator (PI) Associate Professor, PhD, Head of Chair of Disability Studies, Nicolaus Copernicus University, 1 Lwowska Street 1, 87-100 Toruń, Poland e-mail borbesz@umk.pl, borbesz@gmail.pl
** Associate Professor, PhD, Head of Chair of Social Work, Nicolaus Copernicus University, 1 Lwowska Street, 87-100 Toruń, Poland, e-mail: pkrakow@umk.pl
***Associate Professor, PhD, University of Warmia and Mazury, 14 Żołnierska Street, 11-041 Olsztyn, Poland, e-mail: u.bartnikowska@uwm.edu.pl
**** Assistant Professor, PhD, University of Warmia and Mazury, 14 Żołnierska Street, 11-041 Olsztyn, Poland e-mail: k.cwirynkalo@uwm.edu.pl
[2] The preliminary focus group research and the ethnographic project was designed and then performed from April 2017-April 2018 under Scientific Consortium agreement involving Nicolaus Copernicus University in Torun, Poland (leader) and University of Warmia and Mazury in Olsztyn, Poland (partner). The research was performed under official agreement and financial support of Faculty of Education Sciences of Nicolaus Copernicus University and Faculty of Social Sciences of University of Warmia and Mazury.

Abstract

Preliminary report on ethnographic research conducted by a team of 4 researchers from Poland in Scotland with the participation of group of economic, migrants from Poland in, employed legally in home-based care in Edinburgh & Livingston. The project was developed and undertaken from April 2017 to April 2018. The main research question was: What kind of disability and care concepts held migrants from Poland employed in home-based care? The collected data from focus groups and individual interviews allowed to generate basic codes and categories of disability and care concepts in the opinions of migrants from Poland. Among them are: the concept of disability and care and detailed subcategories of care, such as: care tasks & duties, care norms & rules, care & taboo, care burdens & difficulties, care values for caregivers, caregivers and artifacts related to home-based care. The research allowed for the development of 3 main themes related to: femininity issues and care for elderly females, concepts of implemented independent living and features of support system.

Keywords: social sciences, education, social work, ethnographic research, focused ethnography, economic migrants, disability, elderly people, home-based care, Scotland.

Introduction

The economic and legally employed migrants from Poland have found since more that decade own and satisfying place for living in Scotland. The following project aimed to explore the concept of *disability* and *home-based care* held by migrants from Poland, employed for at least 1 year in home-based care in Scotland. The research project performed as focused ethnography was constructed and implemented from April 2017 to April 2018 and conducted by 4 experienced researchers from two Polish universities and faculties: the Faculty of Education Sciences of Nicolaus Copernicus in Torun and the Faculty of Social Sciences of the University of Warmia and Mazury in Olsztyn. The research was conducted as focus groups interviews with Polish migrants and semi-structured FTF interviews with specialists.

Review of the literature

Żyta (2011), Borowska-Beszta et al. (2016a) point out the lack of social research on generational families living with adult members with various disabilities. Furthermore, there is lack of the qualitative research undertaken among Polish migrants employed legally as caregivers in various types of employment abroad in: Europe, Asia, Australia, Africa, North and South America. Besides, there is lack of Polish interdisciplinary ethnographic research led on caregiving offered by Polish economic migrants including the perspective of social model of disability and disability studies described by Barnes, (1992), Barnes & Mercer (2001, 2008); Brown (2002), Goodley, (2011), Berger, (2013) concerning the functioning of families with disabled people in long-term care (Wade et al. 2007). The recent survey led by Leszniewski, Krakowiak, Biernat (2017) on lives of Polish migrants in Scotland, have stressed that Polish people form actually the biggest foreign economic migration group in Scotland, working often in home care for disabled and elderly people. The authors indicate the need to undertake the scientific studies on generational families in the cycle of lifelong support for members with disabilities and elderly people at home.

The trends in decentralization of care concept in Europe describe Saltman et al. (2007). Home-based care for disabled people received much attention since the last decade in Europe. International European comparison between institutional and home care analyze

Burau et al. (2007). The conclusion indicate the advantages of home-based care in safe environment. Home care for the elderly people and those at the end of their lives has been long promoted by hospice and palliative care (Krakowiak 2012; Janowicz, Krakowiak, Stolarczyk, 2015), being recently one of the strategies of NHS in Great Britain and Scotland (NHS, 2015). The differences between informal and formal care in Europe analyzes Viitanen (2007) depicting characteristics of both. Buczkowska (2007) indicates that long-term care generally includes: care, therapeutic and care activities that are provided long-term for disabled and limited in their lives as a result of illness, disability or age.

Kędziora-Kornatowska et al. (2010) indicate the conditions of qualification for home-based care for the person as having chronic incapacity for independent living, an impairment of the organism's ability to meet without the assistance of other persons essential life need as: self-service, mobility and communication; with physical or intellectual disability, who have had to use long-term help and support from others in their daily lives; Disabled because of age. Literature analysis indicates gives regularities in the European home-based care system leading to: (a) reduction the costs of caring and transfer them to caregivers and family members (Genet, et al. 2012; Kozierkiewicz & Szczerbińska, 2007), (b) the variety of caregivers in home-based care and their limitations (Palczewska, 2010; Krakowiak et al., 2011; Kuźmicz, 2013; Kułagowska & Kosińska, 2014).

Kuźmicz (2013) points to the different conditions in family related to care secured by family members. These conditions are grounded in: value systems, socioeconomic status, life experiences related to disability and the opportunity to take care of loved ones. (c) Another regularity is the decrease in the capacity and the chances of family members to provide good quality of care (Kułagowska & Kosińska, 2014). In addition, (d) the increase in the number of chronically ill people with disabilities (also in working age) indicates the need for comprehensive care in long-term care (Kułagowska & Kosińska, 2014).

Advantages of patient-center palliative care should be included in home care for disabled and elderly people (Krakowiak, 2012), in Scotland often assisted by Polish migrant workers. Brief analysis raise the question about the challenges of the home-based care offering by Polish economic migrants. The main interest is focused on particular educational content of formal and informal learning that was/is needed by Polish migrants who became caregivers of disabled and elderly people receiving home care assistance in Scotland. The general conclusion after the initial review indicates the need of comprehensive ethnographic research on the content of the learned cultural norms, values, rules, artifacts related to home-based care for disabled and elderly people.

Method

Focused ethnography

Focused ethnography chosen for the research is broadly analyzed and described by Wall (2015). The author indicate after Mayan (2009) that focused ethnography grounded in assumption that "we no longer need to travel to far-away places to study culture; nor is culture defined only along ethnic or geographical lines" (Mayan, 2009, p.37). The author suggests that thank to focused ethnography researchers may explore “cultures and subcultures are everywhere and may be relatively unbounded” (Mayan, 2009: after Wall 2015 p. 3).

Wall (2015 states, that a “focused ethnography usually deals with a distinct problem in a specific context and is conducted within a sub-cultural group rather than with a cultural group that differs completely from that of the researcher (Wall, 2015). The author after

Knoblauch (2005) add, that “focused ethnography is especially relevant when conducting applied social research in highly fragmented and specialized fields of study” (Wall, 2015). The other feature indicated by Wall (2015) is that “participants may not even know each other but the researcher focuses on their common behaviors and shared experiences and works from the assumption that the participants share a cultural perspective” (Wall, 2015).

Theoretical frame and research design

- Rooted in cultural anthropology (Knoblauch, 2005)
- Interpretivist approach - research was embedded in the interpretivist paradigm

(Jemielniak 2012a, 2012b), methodological concepts by, Woods (1986), Hammersley & Atkinson (2000), Brewer (2000), Pole and Morrison (2003), Hymes (2004), Whitehead (2005), Agar (2006), Borowska-Beszta (2005, 2013, 2016a, 2016b). Flick (2010, 2011), Gibbs (2011), Denzin & Lincoln (2009a, 2009b), Creswell, (2009), Rapley (2010), Wall (2015).

- Sociolingustic ethnography (Spradley 1979, 2016)
- Data-driven research developmental research (Wolcott, 1992)
- Focused ethnography involved emic and etic perspective Spradley (1979, 2016), Wolcott (1992), Angrosino (2010).

The objective of ethnographic research project undertaken since April 2017 until April 2018 was understanding of concepts of *disability* and *care* among Polish economic migrants working legally as caregivers of the disabled and elderly people in Scotland. Preliminary research report is based on assumptions:

- Focused ethnographic research was carried out as fieldwork including 3 focus groups interviews additionally supported by 5 individual FTF interviews with Scottish specialists from the field in the field of caregiving
- Place of the research: Scotland, Edinburgh & Livingston

The main research question was formulated as:

- What concepts of *disability* and *home-based care* held Polish migrants employed as caregivers of the disabled people in Scotland?

Tasks and responsibilities of the research team members and timeline of the project

- Theoretical framework and research design – (PI) Beata Borowska-Beszta
- Fieldwork management, rapport and sampling – Piotr Krakowiak
- Data collection and transcriptions - Beata Borowska-Beszta, Urszula Bartnikowska, Katarzyna Ćwirynkało and partially Piotr Krakowiak.
- Data analysis - Beata Borowska-Beszta, Urszula Bartnikowska, Katarzyna Ćwirynkało
- April 2017 – October 2017: Development of concept, preparation and framework design
- October 2017: 1 week of intensive fieldwork in Scotland in two cities: Livingston & Edinburgh
- October 2017 – February 2018: Data transcriptions
- February 2018 – April 2018: Data analysis

Data collection

The data was collected during the fieldwork in October 2017. All collected data raised from 17 informants and additionally 5 specialists in the field of Scottish home-based care and disability. Previously, the data collection plans assumed the implementation of 5 focus groups of about 6-12 participants to give data from a purposive sample of 50 participants, but the reality of the fieldwork and data collection, its specificity, challenges related to logistics and research organization in foreign country, building relationships turned out to be much more complicated. As a result, after three intense efforts it was possible to conduct 3 focus groups among Polish economic migrants legally employed in Scotland. The team performed also 5 FTF interviews with Scottish specialists in area of home-based care, elderly care and social work. The total amount of participating informants was 23.

Access and recruitment of purposive sample

Polish migrants were recruited by researcher Piotr Krakowiak, who managed all issues in the fieldwork which concerned the meetings and purposive sample. Participants were recruited while meetings in various Polish cultural centers in Livingston and Edinburgh. Informants in mentioned 3 focus groups research were 17 adults (12 females and 5 males) employed (over 1 year) as caregivers at homes of disabled and elderly people. The informants stayed legally and lived in Scotland more than 5 years up to 12 or more years. The purposive sample was recruited by using snow ball strategy (Maxwell, 1997) that formed heterogeneous (Patton, 1990) group of informants.

The research team performed in preliminary analysis:

- 3 Focus groups interviews lead in: Edinburgh and Livingston with caregivers.
- 5 Individual interviews FTF lead in Edinburgh and Livingston with specialists in the Scottish ground of social work and care giving.
- Totally in preliminary focused ethnography were interviewed 17 participants - Polish migrants (12 females and 5 males) and 5 professionals, what gives 23 persons.

Purposive sample detailed characteristics

- Polish legally employed economic migrants, working more than 1 year in home-based care in Scotland with disabled and elderly people
- Informants in 3 Focus groups FTF (each 4-7 participants)
- Total number of participants in focus groups interviews 17

Additionally

- 5 individual interviews FTF with Scottish professionals in social work (2 males and 3 females)

Ethics of data collection:

- Verbal data: oral informed consent for focus groups (Green & Bloome 1997), and agreement of 17 informants.
- Storage of transcribed data as well as assent to confidentiality and anonymity was assured for informants (Flick, 2011; Angrosino, 2011; Spradley 2016).
- The personal data was encoded and after agreement in consent each participant was named in the written report only after her/his real first name. The names of people mentioned in transcriptions were encoded on letter "E".

Characteristics of collected data and trustworthiness

Research practice during data collection has shown some difficulties. The problems concerned the recruitment of a purposive sample among Polish economic migrants who, although initially declared willingness to take part in focus groups, in practice it turned out that some did not show up for meetings. Researchers completed 3 full, long focus meetings. Difficulties in recruiting the target group may be connected with that in addition to encouragement in the person of the gate-keeper, key informant, books imported from Poland, the team did not take into account other incentives to participate in the research.

The second type of problems concerned the collection of data by the team and some problems within the group related to non-compliance in the concept of focus interviews themselves and their conduct.

Focus groups interviews FTF (4-7 persons)

- 1 focus (47min: 45 sec.) 4 participants; (2 males and 2 females) transcription: 38 536 characters
- 2 focus (47min:21 sec.) 7 participants; (3 males and 4 females) transcription: 43 905 characters
- 3 focus (2h 54min:17 sec. (!) 6 participants: (6 females) transcription: 169 138 characters

Trustworthiness was assured by triangulation and member check (Flick, 2011; Angrosino, 2010; Rapley, 2010).

- Triangulation of data sources, team of researchers, meeting the criteria and standards of qualitative research. Member check.

Data analysis

- Verbal data analyses - coding and categorization procedures (Gibbs, 2011; Kvale, 2011; Flick 2010, 2011), analysis of cultural themes (Spradley 1979, 2016; Borowska-Beszta 2013, 2016b).

Results

The following research results, due to the extensive data collected during field work, have been narrowed to the presentation of the main *disability concepts* and much broadest is discussed the *home-based care concepts categories* generated and held by participants of the research - economic migrants from Poland in Livingston and Edinburgh. The research also indicated the shape of three cultural themes related to independent living concept implemented successfully since years in Scotland. Speaking on concepts of disability – the data basically indicated understanding it as the level of independence or dependence of the client, and was based on the social model of disability. The second way of conceptualizing disability has indicated the understanding it in the perspective of the medical model of disability. No informant has indicated that she/he conceptualized the disability of clients in the perspective of the theoretical model of personal tragedy.

Concepts of disability

“Mrs. Emer - pearl at eight in the morning”

- Disability as level of independence
- Disability as medical condition

Anita: *These people are mostly independent, the person I deal with is relatively independent, has its own flat, lives there alone. She has care for 24 hours a day, and someone stays there for the night. She is so independent that she simply moves, but she must be assisted by such "personal care".*

Anita: *I had previous experience with a person who had a personality disorder, who had been in the hospital for 8 years and just after leaving the hospital, she could not function normally in society.*
Agnieszka: *my first Mrs. Emer - the pearl at eight in the morning. Hairstyle – "Little Queen", she was cool, she was, yes…a nice impression. Well, the other man, it was Edan - after the stroke, probably, a strong, tall man, well built and I had to deal for the first time with real old age.*
Iwona: *At the moment I deal with elderly people. They are people who want not be taken to nursing home, but they do not manage 100% themselves at home. So they need such light support, encouragement and with this our work they are able to function independently. These are, of course, those who have physical abilities, who must cope in the toilet, especially must be independent during the night.*
Ewa: *[...] has advanced MS (multiple sclerosis). Who does not walk, who for a minute is unable to stop, because she is shaking all the time.*
Iwona: *It is difficult for such people, when this independence is taken away from them, when it comes to such a moment that this person sits and is unable to do anything. It's just a total breakdown for her ... This is the worst thing that can be.*
Alice: *Well, grandma with dementia, she did not know what she was doing, every move in her direction she took it as if it was an attack. She could spit or fight, hit me.*
Ewa2: *Because they are people with dementia, they are difficult people, but in turn, if you undertake this work, then you need to know what to expect.*
Iwona: *They were people. Most of them are already permanently in beds. Some of them - a small part, were people who could still walk, but with dementia, so that they...lost memory already ... this sclerosis, on pampers already at all, etc. Also such an advanced level of care.*

In addition to the clear division of conceptualization of disability in the social model (dependence or independence) or medical perspective - detailed analyzes 2 above indicated additional disability concepts as the sub-structure and sub-categories, such as:

- Differentiation of the disability concept depending on:

The level of dependence: the internal sense of dependence, the external assessment of the degree of dependence, events indicating the degree of dependence, the needs of a disabled person
Social-cultural: generational dissimilarity, cultural determinants of behavior, dependence on life history

- Search for places or solutions:

Search for a place or solutions - a category that bridges the diversity of disability and solution concepts.

- Solutions

Human: scope of interference
Beyond human: technical, financial and organizational support.

Concepts of care - "…but some part of his body he did not let me touch…"

Disability concepts generated from verbal data are closely related to the concept of care analyzed in more detail below.

- Concept of care
- Care tasks & duties
- Care norms & rules
- Care & taboo
- Care burdens & difficulties
- Care values for caregivers
- Caregiver
- Artifacts

Concept of care

- Care as walking & visiting
- Centered persons care

- Care as supporting independence of client
- Care as taming
- Caregiver as being closest person

Alicja: *the first time I went to care, it was just walking around the houses and helping people. A kind of caregiver walking around the houses.*
Ewa: *[the client is always in the first place and his ... his voice. What he/she expects and requires, regardless of whether he/she has cognitive problems or not. Every time we have to ask. Valued care. This is called centered person care.*
Anita: *but we rather try to stand aside, and she rather decides what she wants to do, where to go, sets the menu and things like that, no?*
Iwona: *Our task is not to do everything for someone, to take away all his/her independence and only to make him/her feel needed all the time, that he/she is at home, this is his/her home and we are just there to help him/her a little so that he/she would still feel ... just so useful. Not that he's/she's sitting like a plant, and we're doing everything around him/her.*
Iwona: *And this is a form of independence too. What he wants, he buys it, does not ask anyone - "Son, I ran out of bread or something." This is where independence is.*
Honorata: *In contrast, we do not do it for less than an hour...*Honorata: *[It does not make sense. At the end we must even make tea, give water, put laundry or just talk...*
Honorata: *Yes. One must feel after our visit, that everything is done, that she/he do not have to do anything, that there is a visit completed.*
Agnieszka: *Both ... and they ask me what is good? Well, what will be good for them, what now will I do now? or what can I offer them yet? And just like Honorata says, with every visit, every week, they just open up...*
Ewa: *[(loud) maybe there is no rehabilitation as such ...*
Honorata: *[for example, with this gentleman, I had 5 visits to him ... and only for two visits he let me touch him ...*
Iwona: *Sometimes we are [caregivers] those closest to them, and of course they ask, "What's up? Did you have a weekend off? And daughter? And remember… remember.*

Care tasks & duties (excerpt)

- Help in self-service activities - partial or total support in washing, dressing, toilet, transport to the bathtub, toilets, away from home
- Help in housework (inserting laundry, cleaning, serving a meal, bringing laundry to or from the laundry)
- Distributing drugs and collect them from the pharmacy
- Transporting clients („grandmas, grandpas") outside the home for socializing
- Service and care last for not less than 1 hour
- Assistance and conversation - providing nice company and conversation
- Giving information and feedback from the world

Anita: *You have to help her with the money, to shop. She has her own car so I drive her everywhere - she has problems with walking. Uses such a "walker". In addition, she has problems with eczema on her legs, so that we must have to take care of the same "medication". Do her shopping, bring her everywhere to her…*
Iwona: *To do a little cleaning, a little ... They are elderly people, who, for example ... she/he knows how to turn on the laundry, but she/he cannot carry a basket with these things, right? So she/he segregates things herself, and so on, and I, for example ... My task, for example ... I'll just take and carry to the laundry, turn on and bring her/him dry and clean clothes later, and this lady/gentleman will take care of the cupboard.*
Iwona: *We only support these people. And now we do, we help in personal hygiene and of course in dressing ... in all such things that ... during the day that is done at home. Of course, plus medical care and medicines. Well, we do everything properly. Two meals are also issued for those who are sponsored by the Council - so that these people would have valuable food, of course. Well, what else?*
Ewa: *[and the client in whose case it was possible, for the risk account to be made - risk assessment - that the client must have two caregivers. Because such risk assessment is done on the basis of the worst case scenario. And if he/she does it - because here he/she is the one who is called - occupational therapist - who comes and makes such a risk scenario. This scenario is based on the darkest event that can happen. So - this person will have an accident, if there is only one person, there is a chance that this will happen. But in 9 cases out of 10 this person has no problem that he/she would be with 1 caregiver.*

Agnieszka: - *"tomorrow you go to the clients" - I used to say that ... after the first meeting, after the first training, first my Mrs. Emer - pearl at eight in the morning. Hairstyle – "Little Queen", she was cool, she was, yes… a nice impression. Well, the second man, it was Edan - you, after the stroke, probably, a huge, tall man, well built and I was dealing for the first time with real old age, where you had to: help, wash, dress, and ... the pressure jumped high! I was not afraid of old age, as well but I remember that after this training - can I manage? Are you sure?*
Ewa: *Eee ... and in fact her care consisted of ... everything on: help in eating, on ... help ... for example in ... going somewhere ... for... to study, to assist her.*
Honorata: *[desserts ...* Gosia: *[and it is really high quality. It's not that bad!*
Honorata: *[it's not that we have to cook ourselves. We usually prepare something that is cooked already*
Agnieszka: *we take it out of the freezer and the microwave ... 10 minutes and we have dinner...*
Ewa: *[to the oven ...*
Honorata: *[we must clean up afterwards. It works…*
Ewa: *For some of these people we are just the only people who come and ... For such a care a lawyer is looking after the person's property, when the person does not have a close family or if for some reasons this family does not have contact or this person does not maintain contact with his/her family, so then the lawyer organizes care for such a male/female.*
Ewa: *From the beginning to the end, that is from purely physical care, from washing, clothes, assisting in changing the dressings…*
Ewa: *Eee ... assisting in the catheterization - during catheterization, doing the cleaning of the bladder, for example. Different things. With such care yyyy ....maybe not psychological but supporting these people anyway. Riding with them on trips, speaking, giving them support. E the whole day is a work 1 to 1.*
Ewa: *Some of these people were fed parenterally - PG. So giving this extracorporeal food. In addition, feeding such people with problems in swallowing, with choking ... So that all this, among other things, belonged to my duties, and completing documents: risk assessments. Filling the care plan, accepting new people, because every new person who came had to be saved to the system, information had to be entered, if nothing had changed since the previous visit. What are the new diseases? What's new?*
Gosia: *Well, as Ewa said they are...they are...how we say it - clients - patients. There are people who need it. Really (*louder with emphasis*) I had such an impression that they need our company and preparation...and sitting, talking. Spend this moment together. Make coffee, tea, something to eat. I… know we devote attention to these people more than any real medical care does.*
Izabela: *I come because I want to, because I like it. They can like it too, they may not, but usually it's such an idea that we do not make friends with them because we cannot do it, but this relationship should be so positive, right? And bringing something good (...) Sometimes it is an hour of conversation or being with someone at all, sometimes it is just sitting with someone and looking at the sky, at the stars, watching birds together, a small, quick walk is enough.*
Gosia: *From washing, dressing, through medicines through serving a meal. Basics.*
Honorata: - *Ummmm ... what we do is actually care and help people who are in their homes at home and ... feel good about it. As there are such worse states, they simply go to other centers. Our job is to help these people. Watch them because they forget about drugs, sometimes you have to ... clean up ... prepare food, dress up to wash, help with washing. Transport. Some of our actions require just such hoys to carry, transfer to another room, to the bathtub.*
Honorata: *These are the basic things we do not do anything extraordinary. We do not have the right to change dressings. Actually, we do not even have the right to pick up a person who is lying on the floor. Its internal corporate arrangements. So there are other people from that, they come. We are only supposed to take care of these people so that they will not lack anything. That they be in good condition, which they have something to eat, that they have care. Mainly it's also about talking to them. They really need such information from the world because they are trapped in these homes. They rarely leave so they are curious about everything.*
Agnieszka: *I think what else I can add...Well, everyone is different, everyone has their own routine, everyone has own habits. Well... and how are people who are very resourceful... but for example, the family feels safe when someone visits the mother. There are people - what makes me smile at work, I work for a year and a half and I have been doing the same for breakfast for a year and a half. Well, just...(silent laughter in the background) Well ... for a year and a half now, all days are the same ...!*
Ewa: *[This ... is rooted in this culture ... It's not even an individual matter, it's only a cultural matter. They are prisoners of their own culture.*
Honorata: *[sometimes we only visit once a day because this person lives with the family. This is just help with bathing, at the toilet. Everything else is done by the family members. They simply cannot cope with such things as: washing, changing. And only that. So these visits are not that frequent. Just 1 a week, every day or every 2 days.*

Ewa: *but we have, for example, clients who have the service much more often. They have 5 times a day. They have 24-hour care. So then we change. For example, caregivers come, for example, for a few hours. Then another caregiver comes for a few hours. Later again. And there is someone else for the whole night. Someone is all the time. Well it is depending on the needs, depending on what is happening and, for example, there are clients who started from 1 hour a day and finally had a 24-hour care service. Until the end. Either to the death of the client or to transfer to a nursing home.*
Ewa: *[In addition, we are still trying to facilitate the administration of these drugs to minimize the risk of incorrect administration of medicines. The pharmacy prepares a blister pack - that is, medicines are - every day is uploaded through the door of a client - and every time in which medicines should be taken - it is sent by the pharmacy…*
Honorata: *[right dose, hours ...*
Agnieszka: *[this ... this is great for example, and this blister pack is for the whole week. And here the pharmacies, through the door, just throw in the letterbox ...*
Honorata: *[and sometimes you have to pick up ...*
Agnieszka: *[and sometimes you have to pick up. But generally, the drugs arrive home in advance. Drugs are free and we have very few drugs...*
Honoria: *[he takes them from various places, transports them to one place ... You can order a special taxi, where the company pays for it, because the client has such a service or another, and want to go to church/chapel.*

Care norms & rules

- Befriending as a norm
- Keys of access to client
- Monitoring of daily life activities
- Subtle control of sexual life
- Reports
- Prohibitions in home-based care

Izabela: *I cannot make real friends with them. I cannot. Well, I cannot share my own data with them, just as volunteers cannot share their phone numbers with them, they cannot reveal this information about themselves, such ... personal, so to speak. Especially at the beginning. There are situations such as, for example, when it comes to a mobile phone number. We had such a person but with dementia that went deeper into relationship and exchange the number with female volunteer. This relationship also changed and we had a situation that our volunteer had to change the phone number, because this lady called her at night. She called her several times a night. So these are very practical things.*
Honorata: *[we as people who come...and these people, for example ... are in bed, and do not have to open the door. We have to call the company and ask for the code to enter. And we open the door with such a special key, which is secured there, then we have to reset. In the same way we have different clients, where there are safes with medicines, because these people themselves cannot have access to these drugs, and we have codes for those safes to give them the drugs at the right time. It was not in Poland!*
Anita: *yes, of course. She cannot be left alone. She has a boyfriend, we have to be present always: his support worker and me. We are always both in this presence, but she also takes contraceptives. Beata: that is, the agency is watching over it so that procreation will not occur? Anita: Yes, it's just people who are not able to have sexual contacts, maybe because they are people who can be used that way? Someone else can use them in this way. Because she, for example (this woman) she is obsessed with men, so we control her... She has a graphic when she can meet with particular male and always in the presence of someone.* Beata: *how did it happen that she has such a form of contact with men? Who accepted this plan? Because this is what I would say a little bit progressive plan: one woman and six men?*
Anita: *this is the whole "team" that work on this case, but they're not all at once in meeting, it's a graphic designer. She was allowed once a month with one such man to meet. But this is the type that we go to bingo together, or he is invited home and for dinner. This is the meeting.* Beata: *How many sexual partners she has? Anita: no, there are not any, it is (contraceptives) just like something happened, for safety. No, no (laughs) it's gone. No, no, (laughs) that's not the way it works.*
Ewa: *[in addition, we as caregivers are subject to an institution called the Care Commission. We are regularly supervised and checked ... we work according to established legal norms, the breaking of which is a violation of the law.*
Ewa: *[Reports] and...We have to prove that this care is being carried out in the right way. Based on the reports, based on what we have reported from the caregivers and caregivers are responsible for their actions...That's why all they write and report is the protection of themselves. Because these people - and the company - are*

responsible for what's going on at the moment. These reports and all documentation are documentation that can later be used in court if there is a lawsuit. We've never had such a situation but…!
Agnieszka: *[very often there are people, children of our clients who invent a problem where it is not. They can also be so hotheaded that...where it would seem that the service is done as best as possible ... but it is always but! We are dealing with people simply. Some are, others are so...*
Ewa: *[and the client in whose case it was possible for the risk account to be made - risk assessment - that the client must have two caregivers. Because such risk assessment is done on the basis of the worst case scenario. And if he does it - because here he is the one who is called - occupational therapist - who comes and makes such a risk scenario. This scenario is based on the darkest event that can happen. So - this person will have an accident, if there is only one person, there is a chance that this will happen. But in 9 cases out of 10 this person has no problem that she would be with 1 guardian.*
Ewa: *[Yes. And only then ... And only then, because it is based on experience. Qualifications, these are professional qualifications, i.e. the person who performs the profession must actively work in it. Otherwise, he/she is not able to do these qualifications.*
Agnieszka: *[... I will not mention the hairdresser and grandmothers! We do not wash their heads in life. They have hairdressers for it. I never washed my grandma!*
Agnieszka: *[listen - all grandmothers have hairdressers! (*merrily*)...*
Honorata: *[ladies for changing dressings, nurses, have a manicure service ... pedicure ...*
Agnieszka: *[for manicure!*
Honorata: *[and ... you are really going to the next visit and immediately – And your client has scarred fingers, because someone did it badly, and we must…*
Beata: *Was something prohibited different that, for example, something ladies cannot do something?*
Ewa: *[cutting off nails ...*
Iwona: *It's good here too ... there are often falls, right? - With these elderly people, etc., then I am not allowed to raise a person here alone. I cannot use any equipment at all, I cannot use ... - it's the most popular ... There must be two people. So I'm alone at night, I have to ask for help. And there is a telephone for such crisis caregiver - they just come and carry.*
Ewa2: *well, practically everything that a wholesome person does: poking, pushing, just like you said - putting in shame...*
Alicja: *[forcing to eat…*
Ewa2: *or to leave a person on the toilet while you go to the phone and check something and the person is there on the toilet. It threatens safety. It's practically everything that while caring for healthy person, and here even more.*

Care burdens & difficulties

- Sadness caused by the death of the clients - because of more than befriending quality of established bonds between caregivers and clients
- Transferring emotional burdens from work to own families and private lives
- Aggression (verbal, physical) of clients with disabilities (difficult but understood)
- Dilemmas while cultural differences and customs – preparing the „same breakfast for 1 year"; or clients „drink 6-7 coffees a day" (what about nutrition plan?)
- Subtle dilemmas with independent living rules - client decides in all matters no matter of his/her real health condition and consequences (e.g. dementia in progress)
- Too much paper work
- Gossiping a little bit as the way of regular communication of the clients with disabilities with various caregivers. Transferring (and remembering) a lot of the private data of caregiver. How?
- Not regular time of work

Iwona: *it is how someone passes away (dies). You are on a daily basis with these people and they treat you, as you were a family member. Because not all families, not all children are so caring, they visit their parents and are in such close contacts.*
Adrian and Alice: *People also died, with whom Alice got used to. There was also a woman who had a Polish husband, and who with Alice was singing a Polish hymn every day while bathing. And in one moment that person died. Before that she was asking Alice for some small things that: she would like to pee, that this… that…After her death Alice began to cry, she was completely disturbed. I said that the end, give it a rest, because*

the supervisors who were there did not allow her to treat those people as a loved one, like someone with whom one spent every day.
Ewa2: *the worst thing was that when the time was approaching so that he would die, I could not prepare for it.*
Ewa2: *I can just say physically decayed in health, and mentally, you will feel it already, it's because it's really a job that you come, maybe not every day, but very often, it's working with elderly people, you come every day and you see what's happening to them. And it is not that it does not reflect psychologically on you, that you do not see in your psyche how this person walks, how he is looking for something, how he gets undressed, how he does not know what's wrong with him going on, it's so sad.*
Ewa: [death of client] *This is so painful...because I know that this man ... somewhere goes! In Some degree, he leaved. Either I knew someone from the very beginning, where the disease was not advanced and later in time this person got worse, worse, worse...so much so that it is not the same man anymore! It was scary!*
Anita: *And it depends on who has the problem, no?* (laughs) *Because then you stay alone, I had previous experience with a person who had a personality disorder who had been in the hospital for eight years and just after leaving the hospital, she could not function normally in society. And she could be so aggressive that the police did not cope with her. This is the most difficult one. And the most difficult is the hardest. I think the hardest thing is that we cannot touch that person, even if she attacks us, we cannot defend ourselves. We can do it somehow (demonstrates the embrace), but we cannot hit anyway. Or run away, or ... I do not know. This is the biggest problem.*
Ewa: *[but from the one I've done before - you cannot go home without loads. Looking at a young female who is not much older than me, who has advanced MS. Who does not walk, who for a minute is unable to stop, because she is shaking all the time, it's hard to come home, sit down and think like that - it's great!*
Honorata: *we already know that this particular person is...is dangerous to him/herself, to others. Something can happen and we cannot take the risk. We cannot primarily expose the caregivers who come there, if someone is aggressive - no...We cannot expose someone to something that can happen. That this caregiver will be after...maybe beaten, hit. On the other hand, s/he would be exposed to insults. Whether a visit to this person will cause a lot of stress....*
Agnieszka: [*we had, we had such a client ... which, already - the time of our visit ended - she saw that we were gathering - then she was getting nervous and thinking up - "And that's what I need, and that's it" - to endure as long as possible. To stay ... and I do not know ... and not as such malice, but only to last as long as possible. This visit.*
Gosia: *[She beats caregivers and in general - you know who I am talking about - I was terribly afraid... and it lasted for 4 hours. And just the day before that visit I did not sleep anymore. I was afraid that she will push me - from the stairs! - You cannot stand in front of her. Wonders! So what ... she turned out to be such a great person ... really ... great!*
Gosia: [*The lady...whom I did not know. And she also has her regular caregiver... right?! That ... this lady - iii ... And this caregiver just told me - this person needs yyy ... how to say? Yyy ... - the right person! A person who will not be afraid of her. Because if she sees that someone is afraid of her...well then she is aggressive…*
Ewa: *[I also did not have a problem with her until we were driving (saying laughing) and … I just go through the lights and she hit me in the car while I was driving, because she wanted me to turn right!*
Ewa: *[I sprained because we were doing it anyway and she - "Why do not you turn right?" - She has such an advanced Alzheimer's. And also, and so it is that with a given person, with her regular caregiver - she also beats her...*
Gosia: *[the most surprising was the preparation of these strange meals. In the morning, for example - I'm not talking about those ready ones. No, because...these were really cool. Just for example, toast - with butter and a cup of coffee and that's all.*
Agnieszka: *[e.g., what is funny - these people drink 6-7 coffees Ewa: [coffees! a day ... Yeah.*
Honorata: *[they can do whatever they want ... Some people have access to choose what meals they want to get. And the family does not really influence it. They try, of course - because we have such clients from family members who said that - "No, because you have to eat fish once a week ..."*
Gosia: *[or "you cannot chocolate"*
Ewa: *[and ...we have to prove that...that this care is being carried out in the right way. Based on the reports, based on what we have reported from the caregivers and caregivers are responsible for their actions...That's why all they write and report is the protection of themselves. Because these people - and the company - are responsible for what's going on at the moment. These reports and all documentation are documentation that can later be used in court if there is a lawsuit. We've never had such a situation but!...*
Agnieszka: *[very often there are people, children of our clients who invent a problem where it is not. They can also be so hotheaded that ... where it would seem that the service is done as best as possible ...but it is always - but! We are dealing with people simply. Some are so, others are so...*
Ewa: *If we are not able to continue caring for this person - we say - we are sorry, we have such and such time. We are not able to continue our care because the situation has changed. This man, e.g. a family, a client needs 2*

guardians and the family says no! We will not pay for 2 caregivers you have to cope with it as 1. Where is transporting with a lift! There is no such possibility! If something happens, then this family will come and say, - listen - why did this person have an accident?
Magda: *[you know, promotions would be associated with more duties plus probably some more paperwork. But I do not really like the paperwork. Mainly I like contact with children and do needed... papers.*
Ewa: *[but it is also dangerous...it is very dangerous. The point is to maintain a professional relationship between what we tell the client from own backyard, our own life. This is very difficult, very difficult (with emphasis), really, because at some point of gratitude and how this person treats you, you start to open more and more, more and more, only more and more, that this person also transmits this information to own family which do not like it very much!*
Honorata: *[... they pull it out from us! Gossiping somewhere over there... they want...*
Ewa: [sideways, sideways, sideways ... from 1 person they will pull...such a tiny crumb. From the next, another tiny crumbs and the entire puzzle is built. Beata*: [But that will they remember all data? Honorata: [hehehe ... (laughs)*
Anita: *the difficulty is that these are irregular working hours. "The work is set for 3-4 weeks, but there are no regular working hours, it is work from seven to six, or from 10 to 10, this type, no?*

Care & values of caregiving

- Signs of gratitude for everything and articulation – as smile, touch by the hand, nice words: *I missed you so much*, *thank you, child*
- Building relationships and real relationships with disabled and lonely elderly people at homes
- Human life stories and narratives of clients - there is no such thing in the office
- Care at homes gives adrenaline and is addictive
- The work with disabled clients teaches humbleness and distance to one's own life problems

Gosia*: [smile ... how they are holding your hand...they say thank you!, this is...*
Ewa*: [And until ... "Oh ... I missed you so much!"*
Iwona: *This is above all. This gratitude for some smallest..., for any help, for the fact that someone came to them at all, visited that, they ask: "Well, how are you feeling today? How are you? "Do you remember that the daughter visited and," How's everyone at home? "This is a huge thank you," Thank you for coming. Thank you, child. Even sometimes making tea or whatever - sometimes they just need to sit down and talk. Just sit and listen. They are very grateful for ... for everything.*
Agnieszka: *[but these are such relationships ... true, listen to us! We go ... to their home, to their lives, to their routine, to their intimate ... in intimate situations. That everyday life. And we ... we have these relationships - where often children do not have them - well know! Well! Well!*
Anita: *Yes, it is a very satisfying job, because these people are very attached to us and it is certainly a plus that there is no such ... such direct control, no one is standing over us and we can give a lot from each other. Although there is a "care-plan" that we must work according to it, but we can do a lot of it. If we are creative, then we can create different things from each other, if you agree.*
Agnieszka: *[I think it is very interesting. I'm fascinated by all their stories! These are...these relationships, real emotions (with enthusiasm) This is something, it does not translate into an office work. In the office there is no...This is something that!*
Ewa: *[we are on a different basis...we know their secrets - often ...*
Magda: *[building a relationship with them. Smile... go for a walk. Conversation - for them - it means a lot (with emphasis). Small things when for us...*
Ewa: *[it is so ... it is the unpredictability of the situation in which one is entering. This is adrenaline, one that is addictive and it's not like that - I do not know - (laughs) parachuting. This is not an addictive adrenaline - but on the other hand - addictive because helping - even for money - because we do - this is our job - is still addictive.*
Ewa: *They knew everything about us and each time - we came, for example, twice a year - they knew and remembered everything! Absolutely everything! It was unbelievable. One gentleman, for example, was collecting cards - coupons - for Lego for my child.*
Honorata: *[... it is also such interfering in our lives, because they ask - "And how did you spend your holidays?" "And where are your next holidays?" And what are you doing at the weekend? - They want to be on...*
Gosia: *[this work teaches humility above all and such a distance to oneself... And our problems - invented many times - in a collision with such reality – a person whose only world is to sit on a wheelchair and look ahead? Well, we can just re-evaluate some things...*

Magda: *[well, I'm a little bit fresh, because I've been working in this profession for only 2 years. As for today, I love my job and I certainly would not like to change it. I know I can burn out - because it is very hard work and very often I come back with a migraine and totally tired, mainly - this is not physical work for me more is psychological work…*

Care & taboo

- Native language accent of caregiver & Scottish Gaelic accent of client – both complicated issues, are under attention and mainly resolved by managers of home-based care
- Nationality of caregiver – Polish caregivers as not accepted by some elderly couple
- Gender of caregiver – e.g. preferred males for elderly Scottish female: „*males only*"
- Age of caregiver – complicated as adolescent caregivers have nothing to speak about with elderly caretakers
- Beauty of caregiver - to young and to gorgeous Polish female as caregiver for young and disabled Scottish females
- Carnality of client and *intimacy barrier issues* - a long time of adaptation to caregiver including restricted body areas of touching – during regular service – e.g. shower, bath etc. Especially when different gender of caregiver and client. Changes after establishing intimate understanding, safety and dignity.

Honorata: *some clients even reserve and express existing language barriers that "we just do not understand each other" something* ...Ewa: *[accent (with emphasis, loud)* ... Ewa, Honorata: *[...and it works both ways...*
Izabela: *language is a barrier for me. After all. All the time. And this is also what I think is related to such a cultural approach, because you can speak English, but you can ... Well, this is not my language. I know this. I know that it will not be my first language for the rest of my life. I will always think in Polish. We construct sentences, we think in Polish as if. Well, I'm not talking about slang and like that anymore ... Because it's also a thing that it's hard to go through.*
Honorata: *[But I have already noticed that, for example, on the first visit there are such because Do not...hiding - we speak with a slightly different accent, we have a different culture, they too... different...*
Honorata: *[Families] No. They cooperate with us, they even ask for some individual information. There's no taboo there. They are all related to the company. Usually, when a problem comes out somewhere...first you have to write a report...*
Agnieszka: *[Write a report* (loud)...
Honorata: *... and send information to the service company. If it is a wish that it is straight to the family, we call and notify the family, but all these links connect. We cannot simply omit something....*
Agnieszka: *Or if I'm not able to, or something does not play between me or this person, he has the right to just give up his care. He can choose another client (*hesitation)*, so to speak...*
Ewa: *It is that the caregiver n is assigned to this client and this client says "I want another person and the end". We try to make these clients have the best possible service, but also, making the caregivers unhappy does not make any sense, because this site will not play. No way. It's like in life ... we like some people and we do not necessarily feel good with others. It works both ways (loud). The client has the right to say - "I'm sorry, I do not have anything to this person, but I feel better with this one, with this and that one..." Therefore, we always present a few people at the beginning and then some of them stay in the form in which they were moved or changed just the person says - "Can I have this and that person? - and that's enough for me.*
Ewa: *[we had clients who said - "we absolutely do not like Poles". What is not...What is illegal. [...] [They could not but... they said ... But they said (loudly) and there is something that - let's agree - it was not politically correct - but this gentleman and his wife were over 90 years old and generally - well - occurrence to court (laughs: focus group members, Honorata, Ewa)*
Ewa: *[for example, we had a lady who did not become our client who said that "absolutely no woman will touch her" - she only wanted men. Agnieszka [... and grandma - this was in fact "grandma" (loud). - What happened? - We did not have males who would be ready. This lady, cognitively and psychologically, did not met the standards and we knew that there would be a problem with that, so unfortunately we had to refuse this service.*
Honorata: *[yes! ... Ewa: [for a young girl, because, for example, very young people are very often in the care, for example... Gosia: [after school...*
Ewa: *[sixteen-years-old...*
Ewa: *16, 17, 18, 20 years old, which really have no topic to talk about with clients …*

Ewa: *These people (loud, with emphasis) also want to feel...worthily...with this guardian! Also...young people, if a young, shapely, able-bodied girl comes to them and this young female is in a wheelchair and also had such a life, and is not with what is happening in her life at this moment - she will not want that person!*
Beata: *[that is beauty? ...* Honorata: *[yes...*(quietly).
Honorata: *As we have, for example, clients - so far I came to male - but some part of his body he did not let me touch...It is only time (2 sec)... such... such ...sense that he is treated well and that he is not treated so objectively ...only let him. After some time - OK. I'm glad you came - we can start.*
Honorata: *I have the same problems with female, who is after mastectomy and she has not let me so far. I used to come to her for services, but someone else always came from her family and washed her. She never let me wash her and recently she herself asked for it - "Could you take me a bath?" - So it also need a time for them, that they feel so comfortable with you! It takes a while. And it does not matter if you are a trained person or not. They just have to feel that - you will not look at them differently. That you will not subtly concentrate to it what they are ashamed of, what they are ashamed of ... How you treat them, yes, after some time they open themselves. They ask for it themselves...*
Honorata: *[and ....and sometimes it is hard. They are ashamed of what they have and how they do it ... and how they need to be around them...to get to them ... but after a while they are great. They are happy they cannot wait for this visit. And it is so in their eyes - no?! This...*
Honorata: *[sometimes requires. Well, I have not worked in this company for quite a long time. There is no one yet. But I have already noticed that, for example, on the first visit there are such because...Do not...hide, we speak with a slightly different accent, we have a different culture, they also...different...*
Agnieszka: [we have to add families to it. Because they live after them! Because their culture is a bit different and it can be seen with the naked eye! This house is differently decorated (smile). For example, what was fun to me ...They have a lot of photos, from their grandchildren, from their youth...
Ewa: *[Completely! Here (in Scotland) after all, there are no such close relationships. Not in every family. A large percentage of people do not have such close contact with the family as in Poland. That these families were once so multi-generational that the children had the responsibility to look after their parents, grandparents and… that Polish families are so ...- „Are we on the way or not on the way, we have a duty, and we have to look after, because it is our duty ". There is no such thing here. It looks a bit different culturally. Here are these shelter apartments accommodation, these people change in life…*
Ewa: *Here (in Scotland) it is not, here this house, if the family does not look after the person, and there is a need for this person to go to a nursing home - This house is simply sold and this money from this house is transferred to look after that person in residential facility. All these resources that are collected by this person during his/her lifetime are then transferred to look after that person for that final protection. And how lucky she is that she will die earlier - well, then the family may inherit something. But there are also such exceptions that the family very much wants to inherit the house in a good neighborhood and does everything to prevent this person from going to a nursing home. And practically this grandmother, is kept speaking frankly - in the closet - that these funds do not go somewhere to the state. We also had such situations that there was no indication at all that this person was at home. It was not possible. We came. I looked after such a lady, but she is no longer alive. Maybe - good for her. There was absolutely everything there. In this house…*

Caregiver:

- Qualifications
- Learning training
- No criminal record

Ewa: *generally, the profession of caregiver is a profession that was eligible as a profession to all people - after another profession like cleaning, or on a par with cleaning - as so-called - margin. Due to the fact that one day in the care, anyone could come to look after clients! Absolutely everyone! Girls or boys who finished school - at the age of 16 - have no education - everyone could go and work as a caregiver. This situation has changed. At the moment, everyone cannot work in the care. The person who will work in care must be qualified. At this point the caregivers who work...in ...terrain - they must be registered. This is called policy. This is the Regulated Bill that regulates the work of doctors and nurses. Caregivers must all be registered, on October 2nd each year. And everybody has to undergo training every year, in 5 years from the date of registration they have to finish the qualification. Minimum - Scottish Vocational Qualifications. Without this, they will not be able to continue working in the profession at all.*
Ewa: *Internal certifications here that confirm that I do what I do, and I know what I'm doing. And in fact, there are also annual trainings. We were obliged to have an annual series of trainings that were provided by the company and this is a week of training that is very intense.*

Ewa: *[every person who is employed, is checked, has a proven criminal record, full no criminal record in so much detail...*
Honorata: *[5 years back probably?*
Ewa: *[Working with...vulnerable people is generally about checking and ... cannot work if it is somehow - if it is unclean - or we get references that there is nothing - that's why we always ask for references from 2 places. From the employer and from someone who knows this person ... Without reference the same, this person probably will not get a job.*
Ewa: *[no!* (with emphasis) *The employer writes or gives oral references, from which we must make a note, which must be in the documents, because we must have a basis for why this person was not employed. In addition, there is additionally - there are trainings - there is induction - an introduction to work. Later there are changes on which the person follows the work of the other person, and depending on what experience and what kind of education this person has - if it is someone who has never had contact with another person - this shadowing - he will have more. If he worked in the profession, if he has medical education in any degree, then the training is a little less - because this person - we assume that he knows what he is doing! But if there is a need for more of these trainings - these are the trainings.*
Ewa: *[shadowing] means that this person, goes with a given caregiver-experienced and shows what is doing at the client's place, i.e. the routine of that person, the documents are filled out. Because on induction, they are 4 hours in which they say, say, speak and each company has such an introduction to work*
Ewa: *[in addition, we as guardians are subject to an institution called Care Commission. We are regularly supervised and checked and work according to established legal norms, the breaking of which is a violation of the law.*
Ewa: *[Yes. And only then, because it is based on experience. Qualifications, these are professional qualifications, i.e. a person who performs this profession must actively work in it. Otherwise, s/he is not able to do these qualifications.*

Artifacts

- Apartments equipped by the Council
- Hoys
- Cell phones
- Personal care clothes
- Drugs & care supplies supported by the Council

Ewa: *[because then such a procedure looks like this: the person [disabled, dependent] gets a flat. This, of course, is time. But because it is a significant disability and non-resourcefulness of life, this person gets a caregiver and that's enough.... And it depends on which case. For some, it takes a bit longer, because these people decide what flat they want to get, in what neighborhood. It's not just that I'm asking you: "You have a mix somewhere in the middle of some environment and you have nothing to say. And you get on the 4th floor without a lift. „It is not like that. This is an apartment always prepared for this and must be adapted, adapted. If hoys are needed under the ceiling, the ceiling, then the ceiling hoys will be mounted. All things that are needed for such a person to live will be assured. For this care ...*
Ewa: *[Hoy - this is a lift. This is a lift. There is a rail.*
Honorata: *[hoy, just security for such a person... Ewa: [that's the equipment ...*
Agnieszka: [(with emphasis) we must also say aloud that help and these apartments are adapted and this is a huge step.
Ewa: *[uniform, work in uniform above all. Gloves, a plastic apron because we walk from one person to another. Frequent washing of hands. At least I hope that this is happening ... but in the previous work I washed my hands, so that I had enough dermatitis - because my skin broke, and this glove work that I literally had for ... cracked skin. So what else?*
Ewa: *[phone in the car, and iii ... and keys!* (laughter) *and frequent calls from the company: - "Can you take ..." - I make these calls and they either answer or not* (laughs).
Anita: I think: the phone, because it is a phone without a break, we are on the phone, yes, yes, this is the main guess. Keys, keys must always have. What else? Maybe some of these folders are associated with me, because you always have to write these protocols you have to write
Honorata: *[we also have items all of which are helpful to move to another room, to another room ...*
Agnieszka: *[hoy is so much ...*
Ewa2: *[Hoy is a device that lift person, so there are devices ...*
Honorata: *[... and almost every house is different, lift ... It's not like you have the same thing. And it is regulated. If you have a problem with this leg, because something happened suddenly, they are already changing...*

Honorata: *[trolleys and any such help, those on wheels ...mmm...what are moving ... and try to walk on their own.*
Agnieszka: *[bathrooms are adapted ... Everything is...*
Agnieszka: *[Walker. How many here? You have 3 in one room and 2 in the next.*
Agnieszka: *[No... I'm not talking about free pads, inserts, diapers, pampers. Well...well...well then...that's it...these are basics!*
Agnieszka: *[needed drugs come through the door - thrown in. grocery shopping? - ready.*
Ewa: *[And yes, they can order products from the catalog. They receive. I do not know if soups...dishes*
Iwona: *... Well, I do not know?...Well, safety bracelets ...Some wear such a button on their neck. If something happens - such an emergency situation - well, I do not know - chest pain, fall or something, everyone pushes and automatically sends a signal to central and... Sometimes to the Council, but there are other service companies and they call us. It depends who signed the contract. And someone calls us and says, - "Please go check. I have a signal from and from that person."*

Cultural themes

Preliminary results and data analysis indicated the existence of three cultural themes related to the general patterns of the concept of independent living implemented in home-based care in Edinburgh and Livingston and Scottish support system.
They are:

- Respected dignity of femininity of elderly females: Implemented concept of independent living respects dignity and femininity of elderly females

Agnieszka: *[listen - all grandmas have hairdressers!* (cheerfully)... *FG: [laughter of women.*
Honorata: *[ladies for changing dressings - bandages, nurses, have a manicure service ... pedicure ... Agnieszka: [for manicure!"*

- Home-based care as a home-designed isolation: The concept of independent living as a trap

Honorata: „*Mainly it's also about talking to them. They really need such information from the world because they are trapped in these homes. They rarely leave so they are curious about everything."*

- Lack of flexibility in Scottish support system of home-based care: System of support perceived as a prison

Ewa: *[here it is also that a little bit everyone becomes prisoners of the system ... in which they function. Because they (Scottish people) do not make any change. Here with our (Scottish) colleagues is very difficult. If they are already working in some system and he/she is stubborn - there is no chance ...* (quietly, exhale long). *It's just banging your head with concrete.*

Preliminary conclusion

The concept of home-based care illustrated the picture of a complex and rewarding type of paid activity in opinions interviewed migrants, when the majority of participants were females (12). While 5 male informants expressed opinions of care as more temporary form of employment. Mainly female informants expressed their satisfaction with legal employment as home-based caregivers, they felt valued and needed. The situations that were unpleasant and incidental were rarely mentioned. Their understanding disability and home-based care is a construct based on the concept of independent living of people with disabilities and dependent people being implemented broadly in Scotland. Participants of the research sometimes mentioned the chasm and gap which in their opinions exists between the care of home-based care and care in the care home, institutions highly criticized.

The results of the preliminary focused ethnography revealed three main cultural themes related to care concepts in the opinions of migrants from Poland. The first subject indicated as a kind of amazement and admiration concerned:

1. *Respected dignity of femininity of elderly females*, expressed in the practical fulfillment of the needs of a good image, well-being thanks to hairdressers and beauticians employed for women in late adulthood.

The second was related to secondary construction of home isolation at homes:

2. *Home-based care as a home-designed isolation*, which meant that, paradoxically, the concept of independent living of disabled people of different ages, and dependence levels and especially of the elderly is a kind of trap, as some clients, for example, having dementia and other degenerative diseases. Especially elderly clients with dementia who have an unlimited desire and free unlimited choice for particular type of diet, which can unfortunately work to their detriment. The limits and the helplessness of the caregivers' actions in these situations are subtle but discernible. They need to and they respect clients' wishes, even risky for them. The system also has weakened secondarily family ties because a father or mother with dementia do not have to call longer own adult children with the request *"Son, I ran out of bread"* because they can call the caregivers and support system staff. On the one hand, the concept of independent life raised the certain level of autonomy for the disabled people themselves, but, according to the research participants, also subtly weakened secondarily bonds with generational families.

The third indicated some features of established support system rules of home-based care based on the concept of independent living:

3. *Lack of flexibility in Scottish support system of home-based care*, which means that the Scottish home-based care system is based on rigid procedures and rules, and there is no question of changing these procedures or negotiations of its changes, which would be more optimal for individual client, in the opinion of the caregivers. The system becomes somehow a prison for all its participants: clients, caregivers, family and supervisors.

What facilitates the work of home-based caregivers from Poland and is highly by them appreciated is related to three dimensions. First is financial support for the clients and their families assured by Edinburgh City Council and the Scottish authorities. Support includes also paid equipment that caregivers have at work as: hoy lifts and other necessary supplies that provides the system of supporting for independent living in Scotland. The second dimension is related to satisfying salaries for the caregivers for their work and satisfying career opportunities.

Much of the recognition of the research and focus groups informants was concerned also with planned transitions of clients, supported by Edinburgh City Council, related to the allocation of apartments to young or elderly adults with disabilities. Besides, equipping them with wheelchairs, walkers, and all needed prosthetics and supplies to provide other daily assistance in support programs. The third dimension is related to organization of work and not extensive work time in home-based care, which allows women's caregivers to lead an active professional life with a satisfactory payment, raise children, lead own family life and participate in local communities' cultural events. The only moment of confusion, sometime a bit silenced by informants, may be the fact that diplomas, even university degrees diplomas from Poland, are not honored in Scotland, it is impossible to nostrify them and, therefore, having in Poland proper level of nursing specialized education - like, among others, Honorata - an educated and experienced in Warsaw hospital cardiology nurse - works in Scotland below her qualifications as a home-based caregiver.

References

Agar, M., (2006). An Ethnography By Any Other Name, *Forum: Qualitative Social Research,* Volume 7 (4)

http://www.qualitativeresearch.net/index.php/fqs/article/view/177 (Accessed: 4/4/2018).

Angrosino, M., (2010). *Badania etnograficzne i obserwacyjne. Niezbędnik badacza. Metodologia*. Warszawa: PWN.

Atkinson, P., Hammersley, M., (2007) *Ethnography: Principles in Practice* 3rd Ed. Abingdon: Taylor & Francis e-Library.

Atkinson, P., Coffey, A., Delamont, S., Lofland, J., & Lofland, L., (2001). *Handbook of ethnography*. Thousand Oaks, CA: Sage.

Barnes, C., (1992*). Disabling Imagery and the Media. An Exploration of the Principles for Media Representations of Disabled People*. z: http://disability studies.leeds.ac.uk/files/library/Barnes-disabling-imagery.pdf (Accessed: 7/4/2017).

Barnes, C., Mercer G., (2001). Disability Culture: Assimilation or Inclusion? In: G. L Albrecht K. Seelman M. Bury (eds.), *Handbook of Disability Studies*. London.

Barnes, C., Mercer G., (2008). *Niepełnosprawność*. Warszawa: PWN.

Berger, R., J., (2013) *Introducing Disability Studies*. London: SAGE.

Borowska-Beszta, B., (2005). *Etnografia dla terapeutów (pedagogów specjalnych) – szkice metodologiczne*. Kraków: Impuls.

Borowska-Beszta, B., (2012). *Niepełnosprawność w kontekstach kulturowych i teoretycznych*. Kraków: Impuls.

Borowska-Beszta, B., (2013). *Etnografia stylu życia kultury dorosłych torunian z zaburzeniami rozwoju*. Toruń: Wyd. Naukowe UMK.

Borowska-Beszta, B., (2016a). *Oswajanie odmienności psychosomatycznej. 11 Raportów z polskich jakościowych badań pedagogicznych i andragogicznych*. Saarbrucken: OmniScriptum.

Borowska-Beszta, B., (2016b). Analiza antropologiczna jako transformacja: Problemy I techniki generowania tematów kulturowych, *Problemy edukacji rehabilitacji socjalizacji osób niepełnosprawnych. Wybrane zagadnienia metodologii I metodyki badań w obszarze niepełnosprawności i codzienności osób z niepełnosprawnością*, 23 (2), pp. 23-50.

Brewer, J., (2000) *Ethnography.* Buckingham: Open University Press.

Brown, S., E., (2002). What Is Disability Culture? *Disability Studies Quarterly* Spring, Volume 22, No. 2, www.dsq-sds.org Society for Disability Studies, pp. 34-50.

Buczkowska, E., (2007). Rola pielęgniarki w opiece długoterminowej nad niesprawnym seniorem w środowisku, [w:] Senior w domu, (red.)Twardowska-Rajewska J., Poznań: Wyd. Nauk. UAM.

Burau, V., Theobald H., Blank R., (2007). *Governing home care: a cross national comparison*. Cheltenham: Edward Elgar Publishing.

Creswell, J., (2009). *Qualitative inquiry and research design: Choosing among five traditions* (2nd Ed), Thousand Oaks, CA: Sage.

Denzin, N., Lincoln, Y., (2009a). *Metody badań jakościowych*. T. 1. Warszawa: PWN.

Denzin, N., Lincoln, Y., (2009b). *Metody badań jakościowych*. T. 2. Warszawa: PWN.

Flick, U., (2010). *Projektowanie badania jakościowego*. Niezbędnik badacza. Metodologia. Warszawa: PWN.

Flick, U., (2011). *Jakość w badaniach jakościowych*. Niezbędnik badacza. Metodologia. Warszawa: PWN.

Genet, N., Boerma, W., Kroneman, M., Hutchinson, A.,Saltman, R., B., (2012) (Eds.) *Home Care across Europe. Current structure and future challenges.* WHO http://www.euro.who.int/__data/assets/pdf_file/0008/181799/e96757.pdf (Accessed 4/4/2018).

Gibbs, G., (2011). *Analizowanie danych jakościowych*. Warszawa: PWN.

Goodley, P., (2011). *Disability Studies. An Interdisciplinary Introduction.* London: SAGE.

Green, J. & Bloome, D.,(1997). Ethnography and ethnographers of and in education: A situated perspective. In Flood, J., Heath, S. B., & Lapp, D. (Eds.), *Handbook of research on teaching literacy through the communicative and visual arts*. New York: Macmillan Publishers, pp. 181-20.

Hymes, D., H., (2004) *"In vain I tried to tell you": Essays in Native American Ethnopoetics.* Lincoln: University of Nebraska Press.

Janowicz, A., Krakowiak, P., Stolarczyk, A., (2015). *Solidarni. Opieka paliatywno-hospicyjna w Polsce*, Gdańsk: Wydawnictwo Fundacji Hospicyjnej.

Jemielniak D., (2012a). *Badania jakościowe. Podejścia i teorie*. Warszawa: PWN

Jemielniak, D., (2012b). *Badania jakościowe. Metody i narzędzia*. Warszawa: PWN

Kędziora-Kornatowska, K., Muszalik, M., Skolmowska E., (2010) *Pielęgniarstwo w opiece długoterminowej: podręcznik dla studiów medycznych,* Warszawa: Wydaw. Lek. PZWL.

Knoblauch, H., (2005). Focused ethnography. Forum: Qualitative Social Research, 6(3), Art. 44, http://nbn-resolving.de/urn:nbn:de:0114-fqs0503440 (Accessed: 4/4/2018).

Kozierkiewicz A., Szczerbińska K (2007) *Opieka długoterminowa w Polsce, ocena stanu obecnego oraz rozwiązania na przyszłość*, Kraków: Wydawnictwo Wspólny Rynek Medyczny.

Krakowiak, P., Krzyżanowski, D., Modlińska, A., (2011). *Przewlekle chory w domu*, Gdańsk: Fundacja Lubię Pomagać.

Krakowiak, P., (2012). *Wolontariat w opiece u kresu życia: geneza, rozwój, funkcjonowanie, możliwości optymalizacji i integracji: ku syntezie socjopedagogicznej*. Toruń: Wyd. Naukowe UMK.

Kułagowska, E., Kosińska M., (2014). *Opieka długoterminowa w Polsce – potrzeby, organizacja, bezpieczeństwo, jakość*, Sosnowiec: Instytut Medycyny Pracy i Zdrowia Środowiskowego.

Kuźmicz, I., (2013). Rodzina w sytuacji terminalnej choroby bliskiej osoby (w:) Matejek J. Zdebska E. (red), *Senior w rodzinie i instytucji społecznej*, Kraków: IRIS Studio, s. 28-54.

Kvale, S., (2011). *Prowadzenie wywiadów*. Warszawa: PWN.

Leszniewski T., Krakowiak P., Biernat T., (2017). Problemy współczesnych migracji na przykładzie doświadczeń Polaków w Szkocji. *Kult. Eduk.*, 3(117) pp. 11-28.

Mayan, M., (2009). *Essentials of qualitative inquiry*. Walnut Creek, CA: Left Coast Press.

Maxwell, J., A., (2009). Designing a Qualitative Study, In. *The SAGE Handbook of Applied Social Research Methods,* Eds. Bickman, L., & Rog, D., J., Thousand Oaks: SAGE.

NHS(2015).https://www.nhs.uk/Planners/end-of-life-care/Pages/care-at-home.aspx (Accessed: 15/1/ 2017).

Palczewska, A., (2010). System opieki długoterminowej a zapotrzebowanie na ten rodzaj świadczeń (in) *Nursing Topics* 2010; 18 (2): pp. 198–206.

Patton, M.Q. (1990). *Qualitative evaluation and research methods*, 2nd Ed. Newbury Park, CA: Sage.

Pole, C. J., Morrison, M., (2003). *Ethnography for education*. Maidenhead: Open. University Press.

Rapley, T. (2010). *Analiza konwersacji, dyskursu i dokumentów*, Warszawa: PWN.

Saltman, R.,B., Bankauskaite, V., Vrangbaek, K., eds. (2007). *Decentralization in health care: strategies and outcomes. Maidenhead,* Open University Press (European Observatory on Health Systems and Policies series).

Spradley, J., (1979). *The Ethnographic Interview*, New York: Holt, Rinehart and Winston.

Spradley, J., (2016). *Participant Observation*, Long Grove: Waveland Press, Incorporated.

Wade, C., Mildon, R., Matthews, J., (2007). Service delivery to parents with an intellectual disability: Family-centered or professionally centered? *Journal of Applied Research in Intellectual Disabilities*, 20(2), pp. 87–98.

Wall, S., (2015). Focused Ethnography: A Methodological Adaptation for Social Research in Emerging Contexts, *Forum: Qualitative Social Research*, Volume 16, (1), http://www.qualitative-research.net/index.php/fqs/article/view/2182 (Accessed: 4/4 2018).

Whitehead, T.,L., (2005). Basic Classical Ethnographic Research Methods Secondary Data Analysis, Fieldwork, Observation/Participant Observation, and Informal and Semi-structured Interviewing; *Ethnographically Informed Community and Cultural Assessment Research Systems (Eiccars) Working Paper Series*. http://www.cusag.umd.edu/documents/workingpapers/classicalethnomethods.pdf (Accessed 31/03/2017).

Wolcott, H., (1992). Posturing in qualitative research. In M. LeCompte, W. Millroy &, J. Preissle (Eds.), *The handbook of qualitative research in education* (pp. 3-44). San Diego, CA: Academic Press. Woods, P. (1986). *Inside Schools*. London: Routledge.

Viitanen, T., (2007). *Informal and formal care in Europe*. Sheffield: University of Sheffield and IZA (Discussion paper No. 2648).

Żyta, A., (2011). *Życie z zespołem Downa. Narracje biograficzne rodziców, rodzeństwa i dorosłych osób z zespołem Downa*. Kraków: Impuls.