MALES WITH ALZHEIMER'S DISEASE IN THEIR WIVES' NARRATIVES ABOUT HOME-BASED CARE. CASE STUDIES REPORT[1]

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ABSTRACT

The aim of this article is to present the results of qualitative research, 5 case studies of husbands with Alzheimer's disease and the image of daily home-based care for them, provided in family homes by wives. The research question posed in this report was: what is home-based care for a husband with Alzheimer's disease from the wife's perspective? The research results revealed the main category: home-based care characteristics, along with 8 codes, such as: (a) husband's condition, (b) wife's day, (c) husband's day, (d) care, (e) barriers/difficulties of the wife, (f) functioning of the husband, (g) barriers/difficulties of the husband, (h) overcoming problems. The results of the research revealed that husbands with Alzheimer's disease are the most important point of reference and the focus of attention for 24 hours a day in the everyday lives of 5 case studies informants. Husbands, their character, current skills, difficulties, and requirements are constantly present, although their masculine presence is changed by the disease process. The results of the research showed the nature and image of the progressive process of falling ill, the loss of various functions in husbands in the narrative of wives, and illustrated the functioning of males, the involvement in a care of members of the immediate family, and in some cases incoming caregivers and nurses. Additionally, research has shown a picture of home-based care saturated with routines, barriers and hardships, and the burdens of wives assuming more life roles than just taking care of their husbands. Moreover, the results of the research also showed a lot of understanding from the wives' perspective, loyalty, and warm feelings towards seriously ill husbands, manifested in dedication in the constant care, reformulation of one's own life in accordance with the needs of husbands.

Keywords: *Males, Alzheimer's disease, wives' narratives, home-based care, case studies.*

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[1] The article is based partly on excerpts from the M.A. Thesis of the first author of this article.

INTRODUCTION

Alzheimer's disease (AD) is both a socially complex phenomenon and a disease, as it involves groups of people, and a disability that progressively changes the everyday life of the family and relatives associated with the sick person. It is also a difficult phenomenon for the person with Alzheimer's disease, who is sometimes embarrassed by their own limitations (Aupetit 1999), gradually losing cognitive functions and other skills, and experiencing a change in personality. A significant role in supporting a sick person is played by the closest family, whose care, and emotional ties with the member with AD gives the possibility of managing illness at home and not in an institution. The article consists of a theoretical part discussing the key theoretical knowledge and characteristics of Alzheimer's disease and the specificity of home-based care and family support. The empirical part of the article explores the category of home-based care against the background of 5 case studies of caring for husbands having Alzheimer's disease. The research question in this article, was formulated as: what is home-based care for a husband with Alzheimer's disease from the wives' perspective? The article gives additional insight into masculinity issues and changes due to disease progress from perspective of wives, which was an essential aspect of males' functioning highlighting the entire topic of home-based care.

ALZHEIMER'S DISEASE CHARACTERISTICS

Alzheimer's disease, a neurodegenerative disease that is diagnosed in late or middle adulthood, causes progressive acquisition of disability and dependence on the help, support, and care of others. Alzheimer's disease is a degenerative disease of the brain (Aupetit 1999) which consists in ”the accumulation of proteins with a pathological structure in the brain” (Biechowska and Orłowska 2012, p. 70). Currently, 15-21 million people worldwide suffer from Alzheimer's disease (Hausz-Piskorz and Buczkowski 2013). In Poland, 500,000 people have various forms of dementia (Zielińska and Bornikowska 2016). Moreover, about 200,000-250,000 people have Alzheimer's disease (Hess-Wiktor and Opoczyńska 2010; Zielińska and Bornikowska 2016), including 150,000 people without diagnosis, as emphasized by Zielińska and Bornikowska (2016). The deposition of beta-amyloid and tau proteins in the brain (Olejarz and Gomuła 2013) has further consequences regarding progress of the disease. They are ”dysfunction of the neuronal transmission system and degeneration of structural elements of neurons (dendrites, axons, synapses). As a result of these processes, communication between nerve cells is lost and they die” (Nazimek, Błońska and Sąsiadek 2003, p. 75). Hausz-Piskorz and Buczkowski (2013) indicate that Alzheimer's disease has a progressive course and ”lasts 8-20 years” (p. 201). In turn, Gaweł, Potulska-Chromik (2015), are confirming that Alzheimer's disease is characterized by ”a progressive deficit of cognitive functions, especially memory, and behavioural disorders, such as apathy, agitation and psychotic symptoms” (Gaweł, Potulska-Chromik 2015). Grochmal-Bach (2007) adds that Alzheimer's disease is characterized by ” progressive loss of memory, attention, cognitive processes, attention disorders and gradual deterioration in daily activity” (Grochmal-Bach 2007, p. 50). According to Owecki, Michalak and Kozubski (2011), ”the clinical manifestation of Alzheimer's disease covers a wide spectrum of mental disorders, with cognitive impairment as dominating” (p. 162). Moreover, researchers classify Alzheimer's disease as a chronic disease. According to Ziarko (2014), a chronic disease proceeds: ”slowly, its beginnings are difficult to capture (the so-called silent phase of the disease), and the moment of ending is unpredictable in a definable time” (Ziarko 2014, p. 16). Chronic diseases are treated by inhibiting their development: “however, it is impossible to cure them completely. A sick person may function similarly to the pre-disease period, but there is always a risk of the disease coming back. The frequent goal of treating chronic diseases is to enable the patient to function effectively despite the disease, and not to regain full health ”(Ziarko 2014, p. 16). The progress of Alzheimer's disease causes confusion in the person that is ill, but also the symptoms arouse anxiety among members of the closest family as well as fears and concerns related to the development of the disease (Aupetit 1999; Borowska-Beszta and Urban 2014; Wójcicka and Szczuka 2019). Communication and speech disorders are indicated by Cybulski, Krajewska-Kułak and Kowalczuk (2016), who wrote that "a sick person loses the ability to formulate thoughts, forgets how to use words and even gestures. The understanding of symbols is impaired, and with time the understanding of speech is impaired" (p. 56). Szluz (2017) indicates 3 stages of the development of Alzheimer's disease as mild, moderate and profound dementia, while Gaweł and Potulska-Chromik (2015) after Reisberg, Ferris and de Leon (1988) indicate 7 stages of disease progression including the following in the Memory Deterioration Scale: "1. no memory impairment, 2. feeling of difficulty recalling words, 3. deterioration of professional efficiency (up to 7 years), 4. requiring help in complex tasks, e.g. planning a party, filling out bills (up to 2 years), 5. requiring help with selection clothes (up to 2 years), 6 a. requiring help with dressing (up to 3 years), b. requiring help with hygiene, c. urinary incontinence, d. faecal incontinence, 7a. limitation of speech to approx. 6 words, b. comprehensible dictionary made of single words, c. loss of walking ability, d. loss of the ability to sit, e. loss of the ability to smile, f. loss of the ability to keep the head held high "(Reisberg, Ferris and de Leon 1988; in: Gaweł and Potulska-Chromik 2015, p. 471). Grochmal-Bach (2007) emphasizes that the symptoms initiating Alzheimer's disease are difficult to recognize as they may be like symptoms of depression. The author emphasizes that it is mainly the family and close surroundings of the patient who notice the first signs of the disease, and these are changes in: "mood, progressive discouragement towards the activities that have been favourite so far, and apathy" (Grochmal-Bach 2007, p. 44). Mental disorders in dementia and Alzheimer's disease were analysed by Gabryelewicz (2007) and Gaweł and Potulska-Chromik (2015). Gabryelewicz (2007) indicate the following: perceptual disorders (delusions, hallucinations), affective disorders, anxiety, hallucinations, and phobias (p. 92). The author also writes about behavioural disorders that manifest themselves, such as agitation, aggression, dysphoric reactions and wandering (pp. 92-93). Moreover, Gaweł and Potulska-Chromik (2015) describe emerging symptoms and psychiatric disorders (delusions, hallucinations, depression) and additionally indicate neurological (epileptic seizures, smaller range of facial expressions, muscle stiffness) as accompanying the development of Alzheimer's disease. Grochmal-Bach (2007) notes that a patient with Alzheimer's disease may become "erratic, dependent, requires frequent reminders and help" (Grochmal-Bach 2007, p. 45). Additional elements of the progressive process of Alzheimer's disease and its consequences are issues in understanding and having the appropriate sense of time, which becomes incomprehensible, abstract and ceases to be important (Gabryelewicz et al. 1994). Another function that is gradually lost is orientation in space. Grochmal-Bach (2007) notices that it is exceedingly difficult for the patient to find himself/herself in the immediate environment, at home. Moreover, as the disease progresses, the patient is not able to perceive the disorders that are present in his/her behaviour and that he/she experiences.

Home-based care in Poland for family members with Alzheimer's disease

Szluz (2017) after Parnowski (1998) indicates that the family takes care of the person having Alzheimer's disease (92%), and the spouse or child becomes the guardian in such a situation. Lech (2014), after Spisacka and Pluta (2003), also points out that "the results of the analyses conducted on this subject indicate that in Poland from 88% to even 95% of Alzheimer's patients stay under the care of their family members throughout their illness" (Lech 2014 p. 213). Szluz (2017) specifies that "the spouses are the most numerous among caregivers" (50-70%) (p. 149). Moreover, Wójcicka and Szczuka (2019) recommend trying to organize a team of supportive people among extended family members if the caregivers were to deal with care by themselves (p. 94). According to the authors, being a caregiver for a patient with Alzheimer's disease and a spouse has good sides, e.g., retirement and "free" time, but it can be overbearing for an independent caregiver (Wójcicka and Szczuka 2019, p. 140). The steps done building a support team from volunteer students that were undertaken by a husband whose wife fell ill with Alzheimer's disease are indicated in the case study of educational (cognitive) therapy by Borowska-Beszta and Urban (2014). Borowska-Beszta and Urban (2014) indicate that Alzheimer's disease may raise concerns among caregivers and volunteers. The authors mention that finding a suitable volunteer turned out to be a difficult task, because out of 200 emails sent, 1 person replied and stayed for 30 months supporting a female with Alzheimer's disease. Steciwko and Kurpas (2003) confirm that "caring for a patient with dementia is extremely complex and requires the full commitment of all members of the patient's team" (Steciwko and Kurpas 2003, p. 529). The authors indicate that the members are: "family doctor, community nurse, social worker, physical therapist, lawyer, groups supporting the patient and his/her caregivers" (Steciwko and Kurpas 2003, p. 529). One of the themes described during the support and care for the patient (Wójcicka and Szczuka 2019) that is worth mentioning is the phenomenon of burden and overwork of caregivers. Parnowski (1998), Nowicka (2011) and Sadowska (2016) indicate the burdens of everyday care. Sadowska (2016) identifies four basic ones as: mental burdens (associated with progression of the disease and symptoms of overwork and personality changes in a sick person), physical burdens (associated with taking over all household duties, including nursing and self-care tasks performed daily), economic (associated with costs of living, treating, and caring for the patient) and social (related to the social isolation of the caregiver and the patient) (Sadowska 2016, pp. 42-43). The caregiver of a person with Alzheimer's disease plays an important role, which is also difficult for him/her, as Nowicka wrote (2011) and Sadowska (2016). The role of the caregiver is complex, according to Nowicka (2010). In addition, the duties and burdens indicated by Sadowska (2016), involve "new obligations, i.e., obtaining information on the disease and ways of nursing, consulting the health status with specialists, ensuring proper treatment, rehabilitation, care and creating a safety living conditions" (Nowicka 2011, p. 159). Additionally, caregivers of a person with Alzheimer's disease are forced by the progression of the disease to minimize their own interests, needs and dreams in favour of caring for the sick person (Nowicka 2011, p. 159). The difficult and emotionally complex role of the caregiver was indicated by Sadowska (2011). The author writes that the caregiver is obliged to: "accept an unsuccessful diagnosis and the fact that the disease will progress and change his loved ones. He/she cannot expect the patient to cooperate with him/her or express gratitude for what he/she does for him/her" (Sadowska 2011, p. 141). Care in the family home can be supported by educational (cognitive) therapies, as indicated in the case study of 30-month support for a female with Alzheimer's disease by Borowska-Beszta and Urban (2014). Techniques based on learning and cognition can also be used at home and those are among the non-pharmacological support activities (Borowska-Beszta and Urban 2014). Długosz-Mazur, Bojar and Gustaw (2013) recommend 5 forms of support: cognitive therapy (consisting in training of memory and orientation in reality), reminiscence therapy (consisting in evoking memories with the use of materials such as music, photographs, souvenirs), validation therapy (consisting in stimulating correct social behaviour, reducing anxiety and improving well-being), occupational therapy (consisting in consolidating skills, recreating the lost and activating) and environmental therapy, (creating a safe and friendly environment for the sick person)"(p. 459). The authors conclude that these therapies can be used in patients with Alzheimer's disease, however, their effectiveness may be temporary, transient, or may have a slightly frustrating effect on the sick person, however, may improve the behaviour of patients with disease (p. 460).

METHOD

Research Design

The research in the report below was based on the case study method (Creswell 2007; Koładkiewicz and Strumińska-Kutra 2012; Yin 2015) and included the implementation of 5 in-depth case studies on home-based care provided by wives for husbands with Alzheimer's disease. The essence of the case study according to Koładkiewicz and Strumińska-Kutra (2012) is that "a detailed description together with an in-depth analysis should enable the understanding of a given case, as well as formulating conclusions about phenomena or theories of which this case was to be an example" (Koładkiewicz and Strumińska -Kutra 2012, p. 3). Creswell (2007) writes about the case study as follows: "the researcher analyses a limited system (case) or several limited systems (cases), taking into account the time aspect, using detailed and in-depth data collection procedures of various nature, resulting in a case report and many general threads" (Creswell 2007 in: Koładkiewicz and Strumińskia – Kutra 2012, p. 5). The essence of the case against the background of the context is indicated by Yin (2015). The author, who defines the case study as a research method, writes: "the case study is an empirical study that explores the contemporary phenomenon ('case') in the context of reality, especially when the boundaries between the context and the phenomenon are not completely obvious (Yin 2015, p. 48). The report from this study was conducted as multiple case studies, which, according to Koładkiewicz and Strumińska-Kutra (2012), enable the identification of the ‚pattern' and improve the theoretical description of the phenomenon. Data analysis was carried out in accordance with the concept of coding and categorization (Flick 2010, 2011; Kubinowski 2010). The research question formulated in this article is:

- What is home care for a husband with Alzheimer's disease from the wife's perspective?

Purposive sample and data collection

The data for the case studies were collected using the semi-structured interview technique, with the anonymity of the informants' personal data. The participants performing home-based care were coded as: Informant 1, 2, 3, 4, 5 where the number was the order of the case study performed. The characteristics of the purposive sample are presented below. The sample was recruited using the snowball technique (Flick, 2010).

- Informant 1 - age, 72, female, higher education degree, former accountant, pensioner, wife whose husband has Alzheimer's disease, takes care of her sick husband, mother of two children.
- Informant 2 - age 68, female, vocational education level, worked as a manual worker, pensioner, wife whose husband has Alzheimer's disease, takes care of her sick husband, has no children.
- Informant 3 - age 66, female, vocational education level, worked as a manual worker, pensioner, wife whose husband has Alzheimer's disease, takes care of her sick husband.
- Informant 4 - age 71, female, higher education degree, worked in administration, pensioner, and wife whose husband has Alzheimer's disease, takes care of her sick husband.
- Informant 5 - age 70, female, higher education degree, office work, pensioner, wife whose husband has Alzheimer's disease, takes care of her sick husband.

Data was collected and transcribed in 2020 (after the Ministry of Health softened the restrictions related to the Covid-19 quarantine). The collection and processing of data in the case studies lasted 3 months, until August 31, 2020. The informants in 5 cases were 5 wives, females in late adulthood (66-72 years old), whose husbands were already diagnosed. All the wives were already inactive professionally at the time of data collection, as they were retired. Informant 1, Informant 4, Informant 5 are females with higher education degrees, while Informant 2 and Informant 3 are females with vocational education levels. All wives take currently care of their sick husbands at home, with the support of their immediate family, and sometimes nurses and other caregivers. 4 of the Informants have children. Informant 2 is an exception. The data for 5 case studies was collected in accordance with the recommendations of Flick (2010) and Rapley (2010), which involved the signing of formal consent forms for participation by the Informants. The credibility of the research of 5 case studies was ensured by the triangulation of data sources obtained from 5 Informants (Flick 2010, 2011; Koładkiewicz and Strumińska-Kutra 2012; Jemielniak 2012).

Findings

The results of the research provided answers concerning the characteristics of home-based care in wives' perspectives.

Case 1

Category: Characteristics of home-based care. The category indicated includes the detailed codes in the analysed case study, indicated below.

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CODE: The condition of the husband
"At the moment, the husband is diagnosed with the third stage that is advanced" (I1)

CODE: Wife's Day
"It's monotony, I am sure, I get up before my husband in the morning. I know for how long how sleeping pills work". "When I get up, I go to the toilet and perform other personal hygiene activities. I make myself a cup of coffee and have a moment to turn on the TV and watch the news or a rerun of the TV series in the morning. Later the husband gets up. He gets up - in the sense of waking up - because my husband is not walking anymore at this moment. Then I try to talk to him. I ask him how he slept. What was his dream? I will air the room, adjust the pillow. My daughter calls me when she's going to work, so I'll talk to her in the meantime. She will tell me what is up with her family, then I will tell him about my daughter's children. Then I go to make him some breakfast. They are various types of mash - most often they eat semolina in various ways - sweet or salty, I will cool them down and feed my husband. He sometimes eats and spits, but he must eat. When I feed my husband, I give him medication, then change the diaper, lubricate him, because he is always lying down, and bedsores develop. When my husband goes to sleep again, I have time to clean the apartment, wash, iron and cook dinner and sometimes I will do something in the garden. "(I1)

CODE: Husband's day
"Husband's day is monotony. My husband wakes up in the morning, he gets breakfast, I feed him, and I give him medication. I will do hygienic activities and apply cream. He often sleeps. Such monotony until the evening: getting up, feeding, and administering medicines, a drink, and applying cream, changing clothes. "(I1)

CODE: Daily care
"In my opinion, the daily routine of taking care of my husband is difficult, it affects all family members, especially me. From an independent man, a husband, he turned into a very sick man. Medicines cost money, detergents, diapers, bedsore creams, mattresses all cost money, only so much good in the fact that we had a lot of savings and now our pensions. Fees and food are also getting more expensive, and now this pandemic does not make it any easier. Problems with the doctor. Even I can't go do the check up myself and leave my husband alone. Fortunately, we don't need a doctor now, because nothing is happening. But I was worried what would happen if I fell ill with this (Covid-19)? - What about my husband? For him it would mean death, and if I would absent, the whole responsibility would fall on my daughter "(I1)

CODE: Wife's barriers / difficulties
"There are many difficulties. I can't go out and leave my husband, and sometimes I would really want to go for a coffee at my neighbour's, or be in our garden in the evenings, when we used to sit together with my husband, or go out for dinner. The difficulty for me is that I no longer have the strength. This care is exhausting. "(I1)

CODE: Husband's functioning
"He sleeps, eats, and watches and listens to him being spoken to. He tries to answer with his groan, as if he understood, but he probably doesn't understand it anymore, because it's only temporary "(I1)

CODE: Husband's barriers / difficulties
"My husband is not facing anything now. I don't even know if he is aware. He says nothing, except curses, or screams especially when the female caregiver comes and washes him. The husband is in a wheelchair, but he does not move himself, I must push the wheelchair. I still have some strength. One must be careful if he does not get up at night and tries to get out of bed, so I am a light sleeper. "(I1)

CODE: Overcoming difficulties
"I beat the difficulties. I am now the whole institution of marriage. I have the role of a wife, husband, nurse, nanny, cook, and cleaner. Such a low-budget role. I say this as a joke of course. You see, your husband won't help me anymore, he's only lying. I take care of all matters for my husband or with help of our daughter and my son-in-law "(I1)

Data analysis revealed a series of repetitive routines that the wife performs every day (I1) for her husband in the advanced stage of Alzheimer's disease. The husband spends most of his time in bed. Despite the poor communication on the part of her husband, Informant 1 (I1) undertakes activities supporting communication, as well as constant care and hygiene activities, in addition to running the house. Informant 1 indicates the barriers and difficulties that she experiences in the care and daily care, and that the husband experiences. The constant need to be at home is indicated as a nuisance and barrier as well as exhaustion and fatigue regarding care. Data analysis indicates the more pronounced role of finance in home-based care, as well as the difficulties and uncertainty related to the ongoing Covid-19 pandemic. Informant 1 is helped by caregivers for hygienic activities of her husband and is supported by her daughter and son-in-law. Informant 1 emphasizes that the disease caused her to take over various life roles, including complete care for her husband and 24-hour vigilance.

Case 2
Category: Characteristics of home-based care

CODE: The condition of the husband
"To a great extent, I can say that it is the worst. He lies, he is not independent. He is dependent on me and the nurses "(I2)

CODE: Wife's Day
"Seven o'clock, I get up, the caregiver comes. There is washing, dressing, and feeding my husband, then me, myself. I am used to taking a shower every morning. Later I'm washing the dishes, then preparing dinner, going shopping, back it's 2pm. Always 2pm because it's lunchtime and this what my husband is accustomed to. Later, I eat alone. And after lunch, after cleaning up, I have some time for myself, to rest, until 6pm because between 6pm and 7pm I give my husband dinner. Meanwhile, after lunch I give him a banana, yogurt, or some snacks. When I leave the house, and leave him alone for a while, I unplug the electric bed because the TV showed that a patient suffering from Alzheimer's burned himself. There was a short circuit and it caught fire. When I leave home, I always turn off the power to this bed. Nothing will happen for 20 minutes, or even if I go to the cemetery and if I'm away from home for two hours. The nurse tells me to leave the house because she says that I am sick myself, my legs hurt. The nurse says he will be okay. He himself will not get up, he will not fall, and he will lie there. If I raise his head higher, he usually lies on his right side, because even if he choked on something, he would spit it out on the pillow."(I2)

CODE: Husband's day
"Similar to mine, except that I go out and do something and he sleeps all day, rarely opens his eyes. Monotony, that's the name." (I2)
CODE: Daily care
"Very hard, extremely hard, and I don't wish this on anyone else, really. It is ti-

ring not only for me but also for him. He does not know that he is alive, this is a tragedy for him, and an even greater tragedy for me "(I2)

CODE: Wife's barriers / difficulties
"For me, the worst thing is carrying him." (I2)

CODE: Husband's functioning
"His head does not work, if I give him a drink - he may not want to open his mouth. If I put a cracker into his mouth - because you can't put anything bigger - then I give him a drink. He's drinking through a feeding bottle. And I will squeeze the bottle and pour it into his mouth. He can't swallow it. He just can't do it."(I2)
"My husband, if he is in pain and when he feels bad - he only eats blended soups." (I2)
"Some time before he played with toys" (I2)
"The radio and the TV set do not interest him at all. He does not speak; he does not communicate. Nothing ."(I2)

CODE: Husband's barriers / difficulties
"He's not interested in anything anymore. I do not know if he knows that he is alive, what is happening around him. His brain is simply not functioning. He can't go to the toilet alone. "(I2)

CODE: Overcoming difficulties
"Now, I have been overcoming them for a long time. If he were healthy, I would be very well now. Even with such a sick person, there are considerable expenses, two pensions are enough to cover the costs of living, hygiene, food, fees, sleepers, diapers, creams. "(I2)

The analysis of data obtained from Informant 2 (I2) shows that the husband's condition is described as ''lying down and that the husband is completely dependent on his wife and nurse. During the day, the wife carries out care and hygiene activities and can also find some time for herself, when she leaves the house while her husband is asleep. Informant 2 takes care of turning off the electric bed before leaving the house. She also leaves house because of the recommendation of the nurse. The husband of I2 sleeps all day, which the wife describes as 'monotony'. Informant 2 interprets her situation as both her own tragedy and her husband's as well. She points out that it is extremely difficult for her physically to carry her husband. Informant 2 details the complicated feeding process – done with the feeding bottle. In addition, I2 emphasizes the role of finances and larger expenses related to Alzheimer's disease home-based care. Informant 2 has no children and is assisted and supported only by a nurse and a caregiver.

Case 3
Category: Characteristics of home-based care

CODE: The condition of the husband
"In a serious condition. I can say that he is really ill." (I3)

CODE: Wife's Day
"I get up before my husband, get dressed, comb my hair quickly and it all starts... I must help him with clothes and food. When I cook dinner, he calls and calls... When I'm in the toilet, he calls too. Sometimes he will scream. I will go for a walk sometimes, but now it is rare... and it is the same until evening.

CODE: Husband's day
, Breakfast, TV, lunch, dinner, visits. Nothing special. That sort of routine. "(I3)

CODE: Daily care
"Well, I have to help him get dressed, get up, and help him eat, with all physiological activities, with all daily activities... with everything... You know, it's just like with a little child..." (I3)
CODE: Wife's barriers / difficulties
"It's hard for me alone... Barriers? So they are: how to pick him up? How to put him on a wheelchair? Fortunately, my grandson removed these doorsteps between rooms in the house because it was such an obstacle for me that you cannot imagine. A male caregiver also comes to us, so he will pick up my husband. "(I3)

CODE: Husband's functioning
, Like a baby..."

CODE: Husband's barriers / difficulties
"Helpless, as if he wanted to do something but couldn't." (I3)

CODE: Overcoming difficulties
"Prayers, understanding and support of loved ones." (I3)

The analysis of the data revealed specific steps, in terms of nursing and hygiene, which the wife – Informant 3 (I3) takes with her husband with Alzheimer's disease, who tries to communicate verbally, by calling or shouting. Informant 3 described a typical home care day, calling it 'routine'. She points out the analogies of a husband's behaviour to the stage of development of a little child. Informant 3 is supported by a caregiver who helps with lifting and carrying her husband, and with the help of the close family. Informant 3 also overcomes difficulties through prayer.

Case 4
Category: Characteristics of home-based care

CODE: The condition of the husband
"The husband is ill, intermediate level." (I4)

CODE: Wife's Day
"I get up in the morning and prepare food for my husband and myself. My husband must have a proper schedule that I follow. Breakfast, lunch, and dinner are always at the same time. I give him drugs because he would not remember it himself. Several times a week, in the afternoon, my husband's brother comes to us to take care of my husband, then I have time for myself to rest or to go somewhere and arrange our home affairs. I try not to leave my husband alone at home. I had 2 such situations when I had no choice but had to go somewhere. When I got back my husband was not at home because he had gone somewhere, he hadn't even closed the door and he didn't remember how to come back home. Then there is dinner around 8pm, after dinner I watch my husband taking a bath and then we slowly go to bed." (I4)

CODE: Husband's day
"Practically the same day as mine. He does not go out alone, and he has a rehabilitation that lasts an hour." (I4)

CODE: Daily care
"It's hard. It's a life of constant stress and uncertainty. And you still must keep an eye on the other person. Like I said it's like with a child."(I4)

CODE: Wife's barriers / difficulties
"Handling his outbursts of aggression is very hard. It tires me terribly and I also feel very overwhelmed. There is no moment of peace to forget one's worries for a moment and to take care of myself. There is always something to be done with my husband. You must remember something all the time. I am no longer young, and it is not easy for me to keep up with all my responsibilities. The helplessness is also terrible, that the condition of a loved one is constantly deteriorating and that I am aware that I cannot help my husband in any way. I don't know, it's hard to talk about it. As I think about my husband's illness now, everything in such a situation is associated with barriers and difficulties, both physical and mental. "(I4)

CODE: Husband's functioning
"The husband functions in a different world. He just sleeps a lot of the day. He later has trouble falling asleep normally at night. The husband can sit on the couch for several hours in silence, doing absolutely nothing. He often gets extremely nervous and aggressive, for example when he sits by the window, looks, and sees passers-by - our neighbours. Most often, he does not remember who they are at all, and tells some imaginary stories about them. Once he got mad when he couldn't find his wallet at home because he couldn't remember where he put it. He shouted

that our neighbour came and stole the wallet. He shouted that this neighbour escaped from prison and that he had an additional key made for our apartment and that he would sometimes come and take things out of our house. He recently told his brother that I use verbal and psychological violence against him. He said «She has madness in her eyes». My husband thought that everything was mixed up by me, he said that it was impossible to live with me, and he had to start calling the police for help. Fortunately, he can dress, eat, and use the toilet by himself. At night he would be full of energy, and worse, he would leave the house. I had to lock the door and hide. He also forgot that he was eating. He was greedy, he hid food in cupboards as if he was afraid, he would not get enough food. My husband was able to go out on the balcony at 2 am and shout that he has a rocket in his hand. And so, he stood with a mop and a pot on his head, counting down to the launch of the rocket. Maybe it was because my husband was a military man? When he stopped recognizing me, he chased me out of the apartment. Now I have more peace, he no longer screams, he calmed down and mostly lies down, but before - it was very hard. "(I4)

CODE: Husband's barriers / difficulties
"I honestly have no idea. I don't know if he is fully aware of what is happening. I think one of such difficulties may be the feeling of loneliness. First, the husband has very limited contact with other people. He does not recognize many people at all and often also withdraws himself and avoids other people like fire. I and his brother spend the most time with him, but it is difficult to talk about any normal relationship here, since he immediately forgets whether you talked with him and what you said. I think that it must be difficult for him to function in a world in which he has to shut down inside himself and which no one else really understands. "(I4)

CODE: Overcoming difficulties
"It's hard to talk here about our joint overcoming difficulties since, in general, I am on my own and responsible for everything. "(I4)

The data analysis showed that the health condition of the husband of Informant 4 (I4) was defined as the intermediate stage of Alzheimer's disease. The I4 carries out everyday nursing and caring activities supported by her husband's brother (brother-in-law). The husband, a former soldier, can still dress independently and is able to communicate. Informant 4 also pointed out her husband's behavioural disturbances, along with incorrect recognition of reality and presence of delusions. Besides, Informant 4 indicates the husband's aggression, disorientation and gradual loss of memory, recognition, and his social withdrawal. I4's husband has calmed down now, which is felt by Informant 4 as a kind of relief. Informant 4, even though she is regularly supported by her husband's brother, emphasizes the assumption of complete responsibility and roles she has on her and gives a clear signal of the dimensions of the overloads that she endures on a regular basis.

Case 5
Category: Characteristics of home-based care

CODE: The condition of the husband
"He is lying, but it is not such a difficult condition." (I5)

CODE: Wife's Day
"My day begins at night, because my husband is awake, he is to be given medication, so at night I do everything I should do during the day. At night I cook, iron, even watch a movie, but it must be animated cartoon for children, because my husband now likes fairy tales and is happy while watching them. In the morning, my sister comes and takes over care duties, as I say - she's performing a changing of the guard - and I'm going to sleep. I hope that the drugs will help his health, because I can't even go shopping during the day. My husband's brother always brings me groceries and products in the evening and helps me to wash my husband. "(I5)

CODE: Husband's day
"Now my husband is dependent on someone. He needs to be fed, changed, he is already a lying person. He sleeps during the day, but is very active at night. "(I5)

CODE: Daily care
"Care is very strenuous, it is practically 24 hours a day. "(I5)

CODE: Wife's barriers / difficulties
"Constantly making sure that nothing bad will happen to him. Cooking. Because my husband is diabetic, I must be careful not to increase his sugar with food. I must invent meals that can be given to my husband and that they are tasty. The difficulty is in measuring his level of sugar with a device. He takes his hand away, screams when I approach him with it, but I have to do it. "(I5)

CODE: Operation
"At the moment, my husband is lying down, he stops talking, as if he has forgotten his tongue, he needs help with eating and going to the toilet. He does not like washing himself, he starts to eat more liquid things. He is no longer interested in the environment. "(I5)

CODE: Husband's barriers / difficulties
"He is angry about washing, he doesn't like it, especially when I have to wash him. He chased me away. He 'said' only his brother can wash him. He was angry when he forgot at the beginning that he was already eating something, and I was not giving him food. His clothes are causing problems. He doesn't like clothes now and he would constantly undress. His taste changed. He spits food often and doesn't like it when I feed him. "(I5)
CODE: Overcoming difficulties
"Now there are no marital difficulties, we don't even argue because my husband doesn't speak clearly. He does not move. The difficulties with formalities and caring can be overcome, but the organization and solutions of it all is completely on my side. "(I5)

Informant's 5 (I5) day is reversed and adjusted to the husband's functioning. Informant 5 performs all domestic and caring activities during the night. Currently, her husband is diagnosed with the intermediate degree of disease, he is gradually moving into the "lying" phase. Informant 5 indicates that gradually the husband stopped communicating verbally. Anger due to the loss of independence, fitness, and reluctance to wear clothes has recently become barriers and difficulties for a sick male. The husband slept during the day and was active at night. Currently the husband does not allow his wife (I5) to perform hygienic functions but give such approval only to his brother. Informant 5 emphasizes that caring for a sick husband is overbearing and that in the care she is substantially and regularly supported by her own sister and husband's brother. Informant 5 identifies everyday life with a kind of daily 'watch' for her husband.

Conclusion

The research results are based on the comparison of all interviews and 5 cases analysis, which constitute answers to the research question. The main research question: what is home-based care for a husband with Alzheimer's disease from the wife's perspective? As a result of the analysis of the interview data (Informant 1, 2, 3, 4, 5), the research revealed a picture of home-based care and specific conditions of care for a 5 chronically ill males. The findings showed a picture of activities undertaken on a regular basis by the Informants (1, 2, 3, 4, and 5) as home caregivers. Husbands having Alzheimer's disease are in 4 cases males who "lie down" for a longer time. In one case, Informant 5's husband is a recently "lying" male that is active at night. The informants sometimes say about this phase that 'the husband has gone to bed' (Informant 2). The results of the research also indicated a transformation of the narrative about the gender issues and masculinity of males and husbands. All cases indicate, according to classification of Connell and Messerschmidt (2005), that the masculinity of males in wives' narratives was reduced to the category of 'marginalized masculinity' or - what Connell and Messerschmidt (2005) do not mention

– “’lost masculinity’. ‚This is indicated by emphasizing the functioning of their husbands that is like a child. Informant 3 (I3) used the expression that the husband functions ‚like a little child.’ Informant 4 (I4) also emphasized a similar thread: ‘as I said it, like with a child’. Besides, the informant (I2) indicated ‘he is drinking through a feeding bottle. And I will squeeze this bottle and pour it in his mouth.’ The above comments are related to and important for the results obtained as an answer to the research question in this report. The results of the research indicated regular nursing and hygienic activities (Informants 1, 2, 3, 4) and more extended care activities (Informant 5) for their own sick husbands. An important thread of everyday life is the support of caregiving wives (Informants 1, 3, 4, 5) by the immediate family (children, siblings, grandson, husband’s brother, visiting caregivers, male caregiver, nurses). Despite their support, all Informants (1, 2, 3, 4, 5) emphasize in their narrations the image of the physical, mental, and emotional overload that they underwent during the progression of the husband’s illness. This included taking on a variety of additional roles, as the Informants unanimously emphasized, and almost completely giving up their personal lives and time for themselves (1, 2, 3, 4, 5). Each of the Informants (1, 2, 3, 4, 5) indicated difficulties related to financial issues and costs related to everyday life, hygiene supplies and medicine. The Informants (1, 2, 3, 4, 5) agree that in all 5 studied cases, everyday life comes down to providing care and safety to ill husbands. Moreover, the Informants (1, 2, 3, 4, 5) take care of their husbands’ life needs in terms of self-service and hygienic activities. Research has shown that women find it difficult because of the size and weight of their husbands, whom they have to lift, transfer to a wheelchair, and care for while they are in bed, so they rely on the help and support of others. Each of the Informants (1, 2, 3, 4, 5) clearly indicated a high level of care, based on persistent feelings and emotional attachment to sick husbands, manifested devotion, and loyalty to them, despite many hardships of daily home-based care experienced by wives. The pattern of everyday life, both Informants (1, 2, 3, 4, 5) and their husbands, is, in the opinion of the Informants ‚routine’ (I3), ‚monotonous’ (I1; I2), a kind of ‚watch duty’ (I5). In one case (I4), the wife completely adjusted her own daily activity to fit the activity of her husband, who “sleeps during the day, and is very active at night” (I4). In 4 cases, males with Alzheimer’s disease are completely dependent on their wives, their caregivers, and nurses or family members (Informant 1, 2, 3, 4, 5). The Informants (1, 2, 3, 4, 5) face barriers/difficulties in caring for their husband in everyday life as their own weakening physical strength, related to age. Moreover, the Informants (1, 2, 3, 4, 5) face everyday helplessness in the face of the progression of disease, protest, or aggression on the part of husbands and their increasing dependence. The phenomenon of home-based care given by 5 Informants revealed support from family members, i.e., relatives or people on whom the Informants (1, 3, 4, 5) can rely, even though the main burdens related to the husband’s illness were taken over by the wives (Informants 1, 2, 3, 4, 5). An additional factor relieving the Informants were, for example, nurses and visiting caregivers (I2). Additionally, in 5 case studies of home-based care of wives over husbands, the bonds, and feelings in marriage before husbands’ fell ill, turned out to be not without significance. The full research report indicated significant emotional ties between the wives - Informants (1, 2, 3, 4, 5) - and their husbands, even if they mentioned quarrels or conflicts. Before the husbands’ illnesses, satisfaction with the good quality of emotional and marital life was emphasized by I2, and I3. It is worth adding that the Informants, due to their feelings, love, and loyalty to the marriage vows and to a companion of many years of married life, indicated their own understanding of the value of home-based care and its goals. Some of them mention: “we swore love in health or illness, and I think that this help or care should be taken for him, and I cannot live without him, even in the state in which he is now.” (I1). “In health or illness, I am a believer, so I cannot send my husband to an institution.” (I5). They also mention: “you survive together much easier than alone” (I4) and: “all the time just like before the disease. After all, this is my first love, and I still love him very much.”(I4). The Informants (1, 2, 3, 4, 5) did not decide to entrust their husbands to stationary institutions, despite the many difficulties of everyday home care. The Informants (1, 2, 3, 4, 5) decided to accompany their husbands in their illness until death.

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