



URSZULA BARTNIKOWSKA,
KATARZYNA ĆWIRYNKAŁO

University of Warmia and Mazury in Olsztyn, Poland

The resources of adults taking care of their elderly parents at home – a research report

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Considering the increased demographic aging and system changes in the welfare system in Poland, home care became one of the most important forms of taking care of disabled or elderly persons. Although the country is rooted in the idea of a nanny state, based on large institutions and providing minimum income, for a long time now family has been considered as the basic provider of informal care to the elderly. The aim of the present study is to give some insight into the resources of adult children providing care to their elderly, disabled parents. In order to acquire a comprehensive perception of the phenomenon, the authors chose an interpretivist paradigm and applied a phenomenographic method. 21 participants, aged 41–65, who were caregivers of their parents, took part in semi-structured interviews. Two main research problems were formulated: (1) How do the participants perceive their resources as caregivers of their elderly, disabled parents? (2) What kind of support related to the care of their parents do they consider essential? Results: The participants distinguish two main kinds of resources: internal (e.g. values, passions, feelings for parents, economic situation) and external (e.g. parents, family, friends, professionals, medical equipment and centers they have access to). The narratives of the participants also indicate a number of needs they experience. Implications for practice are discussed.

KEY WORDS: home care, elderly parents, caregivers, resources, needs

Introduction

The increased demographic aging is the phenomenon that can be observed around the world, including Poland.¹ Generally, there are three sectors implementing social policy in Poland: 1) public entities implementing social policy, 2) a market sector operating on a commercial basis (there is a possibility for these organizations to obtain public resources), 3) a non-government, non-profit sector, whose aim is the implementation of various social goals.²

An overview of aged care support and services shows that there are both institutional (day, temporary or permanent stay) and family forms of caring for the elderly in Poland:

- 1) Daily support facilities: 1) daily support houses (places of daily support for the aged, conducted by public or non-public entities: associations, church organizations, social cooperatives). Seniors spend 8 hours a day on weekdays there. In 2013 there were 226 such facilities and this number is steadily growing (in 2017, when the Senior+ government program was launched, it started supporting the foundation of such institutions), 2) multifunctional social service centers – there are not many of them in Poland, although they show that support for older people can be comprehensive, 3) Daytime Homes and Clubs ‘WIGOR / Senior +’.
- 2) Residential aged care facilities: 1) Social Support Houses – permanent residence for the elderly in a large institution, 2) Family Support Houses – smaller facilities for 3–8 elderly persons (less common than social support houses), 3) long-

¹ H. Wang, Y. He, Y. Li, F. Wang, *Study on the Home Health Caregiver Scheduling Problem under a Resource Sharing Mode considering Differences in Working Time and Customer Satisfaction*, “Discrete Dynamics in Nature & Society”, 2020, 5/11, pp. 1–11.

² B. Szatur-Jaworska, *System wsparcia społecznego osób starszych w Polsce*, [w:] *System wsparcia osób starszych w środowisku zamieszkania przegląd sytuacji propozycja modelu. Raport Rzecznika Praw Obywatelskich*, red. B. Szatur-Jaworska, P. Błędowski, Warszawa 2016, <https://www.rpo.gov.pl/sites/default/files/System%20wsparcia%20os%C3%B3b%20starszych.pdf>, 9.07.2018.

- term care institutions – care and nursing facilities created at health care institutions, 4) hospices – for terminally ill people.
- 3) Family support: 1) supported and assisted living (Social Welfare Act allows to offer this type of services to certain groups of people (e.g. children who lived at orphanages, the disabled, the aged). They need support in independent functioning, but do not need 24-hour care, 2) support for seniors in their place of residence.

Poland is rooted in the idea of a nanny state, based on large institutions and providing minimum income.³ Actually, the percentage of GDP used for social expenditure that comprises cash benefits, direct in-kind provision of goods and services, and tax breaks with social purposes, is still relatively high, thanks to which the country can be considered a nanny state.⁴ The number of people in social support houses is actually still growing and using other forms of support (e.g. supported living) is very rare. For example, in 2015 there were 815 of such houses and 86,502 persons lived there. Overall, one in 450 people lived in a social support house and one in 15,000 used supported living services.⁵ Nonetheless, family is considered to be the basic provider of informal care to the elderly.⁶

As far as the home care for seniors is concerned, there are several forms of support available in Poland:

³ C. Aspalter, K. Jinsoo, P. Sojeung, *Analysing the welfare state in Poland, the Czech Republic, Hungary and Slovenia: An ideal-typical perspective*, "Social Policy and Administration" 2009, t. 43, nr 2, pp. 170-185; M. Ciczkowska-Giedziun, M. Zmysłowska, *The family and child welfare system in Poland: Family assistantship as a new solution in social work with families*, "Child Care in Practice" 2017, t. 24, nr 1, pp. 29-42.

⁴ J. Sawulski, *Czy Polska jest państwem opiekuńczym?*, 2017, <https://ibs.org.pl/publications/czy-polska-jest-panstwem-opiekunczym/>, 18.07.2020.

⁵ A. Bodnar, *Apel Rzecznika Praw Obywatelskich w sprawie deinstytucjonalizacji systemu wsparcia dla osób z niepełnosprawnościami i osób starszych*, 2016, <https://www.rpo.gov.pl/sites/default/files/Apel%20do%20Prezes%20Rady%20Ministr%C3%B3w%20w%20sprawie%20deinstytucjonalizacji%2011.2017.pdf>, 11.07.2018.

⁶ M. Sierakowska, H. Doroszkiewicz, H. Markowska, J. Lewko, E. Krajewska-Kulak, *Factors determining satisfaction of elderly people's caregivers with the home care they provide*, "Progress in Health Sciences" 2014, t. 4, nr 2, pp. 82-86; M. Szweda-Lewandowska, *Opieka nad osobami starszymi. Wspierający i wspierani*, UŁ, Łódź 2017.

- financial support for the family and a dependent person (care payments and care allowances) – unfortunately, they are very low (much lower, for example, than care payments for people who acquired disability before the age of 25),
- environmental care minder's support after submitting an application to a local support centre – available for people who cannot afford to pay for private care (usually 2 hours a day, the scope and frequency of support is defined by support centres),
- nurse's support for people with chronic diseases (treatments that bring relief to suffering, e.g. pressure ulcer care, injections),
- home hospice: doctor's visits (once a week), nurse's visits (2-3 times a week), other specialists and volunteers' visits (depending on the needs),
- payments offered specifically to the aged community: age pensions (for men – from the age of 65, for women – 60), rent assistance/ disability payments,
- free equipment rental, e.g. an anti-bedsore mattress, a wheelchair, free medicines for people over the age of 75.⁷

Although home care for the elderly became one of the most important forms of taking of elderly or disabled individuals, there seems to be lack of Polish literature on the subject, especially concerning the situation of family caregivers. In this article we attempt to fill this gap, paying attention to the resources of the caregivers. In the current research we will refer to Conservation of Resources Theory by Stevan E. Hobfoll. Hobfoll distinguishes two kinds of resources: internal (available directly, e.g. optimism, self-confidence,

⁷ K. Klukowska, *Opieka nad osobami starszymi. Co robić, gdy nie da się jej pogodzić z pracą zawodową?* „Gazeta Wyborcza”, 27.07.2017. <http://wyborcza.pl/7,97654,22153742,opieka-nad-osobami-starszymi-co-robic-gdy-nie-da-sie-jej.html>, 11.07.2018; M. Topolewska, *Podwyżka zasiłku pielęgnacyjnego: Od kiedy opiekunowie dostaną więcej pieniędzy?* „Gazeta Wyborcza”, 17.05.2018. <http://praca.gazetaprawna.pl/artykuly/1124373,podwyzka-zasilku-pielegnacyjnego-od-kiedy-opiekunowie-dostana-wiecej-pieniedzy.html>, 11.07.2018.

competences) and external (social support, employment, socioeconomic status). The author also divides resources into: (1) material (e.g. a house, a car, valuable possessions), (2) personal (skills, personality features), (3) resources of state (structures or situations which enable access to resources, e.g. health, employment, marriage), (4) resources of energy, which can be exchanged into other resources (e.g. money, knowledge, time).⁸

Design

The results presented in this paper are a part of a larger research project designed by Beata Antoszevska, Urszula Bartnikowska and Katarzyna Cwirynkało and conducted from 2016 to 2018. The project explored the situation of adult children who take care of their elderly parents. For the purpose of this paper, two main research problems were formulated: (1) How do the participants perceive their resources as caregivers of their elderly, disabled parents? (2) What kind of support related to the care of their parents can be considered essential?

Method

In order to help to understand the perception of resources and needs of the caregivers in all their complexity and variability, the study reported in this paper is of qualitative character based on an interpretivist paradigm⁹ and a phenomenographic method.¹⁰ Based

⁸ S.E. Hobfoll, *Stres, kultura i spoleczność. Psychologia i filozofia stresu*, GWP, Gdańsk 2006, pp. 70-76.

⁹ E. Husserl, *Nastawienie nauk przyrodniczych i humanistycznych. Naturalizm, dualizm i psychologia psychofizyczna*, [w:] *Fenomenologia i socjologia*, red. Z. Krasnodębski, PWN, Warszawa 1989, pp. 53-74.

¹⁰ R.G. Paulston, *Pedagogika porównawcza jako pole nakreślenia konceptualnych map teorii paradygmatów*, [w:] *Spory o edukację. Dylematy i kontrowersje we współczesnych pedagogiach*, red. Z. Kwieciński, L. Witkowski, IBE, Edytor, Warszawa-Toruń 1993, pp. 25-50.

on the assumptions of phenomenography, the authors focus was on second-order perspective and different ways that individuals can experience the same phenomenon.¹¹ Individual interviews were used as a method for data collection, which allowed the authors to gather participants' thoughts, beliefs and experiences.¹² The interviews were semi-structured (consisted of open questions and followed a guide created by the authors) and were conducted in a number of towns and villages in north-eastern Poland between 2016 and 2017. Each interview was previously arranged and lasted approximately from one to three hours and took place either at participants' or researchers' homes. A total of thirty two hours of recording was collected and transcribed verbatim. All participants gave written consents to record, transcribe the interviews, code and store the data and use it for scientific purposes.¹³ Afterwards, interview transcripts were encrypted, encoded and anonymized. The data analysis was conducted using the guidelines for coding and categorization proposed by Flick¹⁴, Kvale¹⁵ and Gibbs.¹⁶ In this process the following steps can be distinguished: (1) coding words generated from verbatim data, (2) categorization – grouping generated codes from verbatim data into broader textual categories, (3) comparing categories and examining their relation to the research problems, (4) categorization – segmentation the verbatim data from transcripts according to research questions, (5) presenting the results in a diagram and text.¹⁷

¹¹ F. Marton, *Phenomenography – describing conceptions of the world around us*, “Instructional Science” 1981, t. 10, pp. 177–200; A. Assarroudi, A. Heydari, *Phenomenography: A Missed Method in Medical Research*, “Acta Facultatis Medicae Naissensis” 2016, t. 33, nr 3, pp. 217–225.

¹² H.F. Hsieh, S.E. Shannon, *Three approaches to qualitative content analysis*, “Qualitative Health Research” 2005, 15, pp. 1277–1288.

¹³ T. Rapley, *Analiza konwersacji, dyskursu i dokumentów*, PWN, Warszawa 2010.

¹⁴ U. Flick, *Projektowanie badania jakościowego*, PWN, Warszawa 2010.

¹⁵ S. Kvale, *Prowadzenie wywiadów*, PWN, Warszawa 2010.

¹⁶ G. Gibbs, *Analizowanie danych jakościowych*, PWN, Warszawa 2011.

¹⁷ S. Kvale, *Prowadzenie wywiadów*, PWN, Warszawa 2010.

Participants

The selection of participants of the study was deliberate and took place according to the following criteria: 1) being an adult person, 2) taking care (currently or in the past) of a sick or disabled parent for a period of minimum 6 months, 3) giving written consent to participate in the research. Overall, 21 participants, aged 41–65, who were caregivers of their parents, took part in semi-structured interviews.¹⁸

Results

The analysis of the content of the interviews shows that the participants distinguish two main kinds of resources that help them take care of their sick or disabled parents: internal and external.

1. Internal resources

Four main resources described by the interviewees were classified as internal: their values, passions, economic situation, and physical strength (fitness).

Values

The values were often revealed by the interviewees when they were discussing the motives of taking care of an elderly person. Several subcategories were distinguished: 1) high position of family care in the hierarchy of values of the interviewees, 2) feelings towards the parent, 3) faith in God. They all seem to be connected and interlinked.

The high position of family care in the hierarchy of values often stemmed from the parents' contribution to the upbringing of children and a deliberate transfer of a caring attitude perceived as

¹⁸ H.F. Hsieh, S.E. Shannon, *Three approaches to qualitative content analysis*, "Qualitative Health Research" 2005, 15, pp. 1277–1288.

something desirable and worthwhile. Some of the interviewees also emphasized that it was also important to them that their parents treated them kindly and friendly in their childhood.

In our early childhood, youth [...], our parents told us all sorts of fairy tales and stories. They often referred to situations in which children help parents. (Alicja)

[Mum] brought me up that way. She kept telling me that it should be like that [that children are responsible for their parents when they grow old and need help]. (Ewa)

It must be worked out, maybe a relationship with family, with children, to have that feeling, desire and not even to think about it. (Cecylia)

I like helping people. (Filip)

The system of values along with the position of home care is sometimes strengthened by a social cultural message referring to the obligations of a young generation towards an older one and a commitment to gratitude for the effort of upbringing.

You just felt this duty that you have to help. (Krystyna)

How could I not take care? [...] I was expected to do this. (Leszek)

This is my duty... Well... It's so natural. (Maria)

In many cases, these messages are also accompanied by positive feelings towards a parent, which make it easier to overcome everyday difficulties related to looking after the parent. This element facilitates the empathic understanding of the parent and the inner desire to satisfy his / her needs.

[Mum] is an important person in life. Someone for whom you should do a lot. She nursed me, took care of me, raised me. (Jowita)

The common hierarchy of values with the closest family members also turns out to be important. This is essential in those cases where a sense of duty is accompanied by the need for cooperation / mutual support.

Some of the interviewees emphasized the role of faith in God as an important element of motivating specific care activities.

[Faith] helps in my opinion. It helps because it explains many things.
(Ewa)

As a Christian, I've never thought of being just self-satisfied [...] I just know that having no strength isn't an excuse for God. (Nadia)

Some people emphasized that the duty of caring for parents and for exercising their power derive from religion.

Passions

In several cases passions as internal resources have been emphasized. They mainly referred to traveling. It is possible that this passion, which can be interpreted as the opposite of being on the spot and caring for a person – often immobilized – gave them a sense of freedom and an opportunity for self-realization. In their narratives, those people who liked travelling, emphasized the possibility of pursuing this passion even when they were taking care of a dependent person. It enabled them to regain their strength and balance.

I am a person who likes travelling and exploring, and riding a bike, and exploring the world. (Alicja)

And I like traveling with my daughter, Asia very much. We go for a drive from time to time and often go for walks. (Filip)

For some interviewees, the implementation of this type of 'escape' from everyday life was impossible. In such cases, several caregivers used a symbolic 'escape', e.g. into the world of literature or films. An example of such a person is Maria:

Sometimes I turn myself off, take a book, turn on a movie, close the door and I'm just gone for everyone. (Maria)

Economic situation

Family's financial resources also turned out to be an important factor which helps both in the pursuit of passion and daily care of a sick or disabled parent. For some people reality in Poland is not optimistic. Families taking care of an elderly, dependent person often face economic hardship. On the other hand, families who have a stable financial situation and good sources of income, mention these elements in their statements:

We could afford to spend a lot of money on hygiene measures so that she wouldn't suffer. (Alicja)

When I was building a house, I always dreamed about having a multi-generational home [...] It was very important for me so that there was one floor only and there was no need to climb the stairs. (Hanna)

Having more material and economic resources is an important resource that enables more effective care for an elderly person, gives greater comfort both to the dependent person and his or her caregiver.

Physical strength

Taking care of an elderly, dependent person requires commitment on many levels. The interviewees emphasized the special importance of physical strength that helped them do certain tasks:

Most difficult? The nightly getting up, I think, and also raising grandma, because it was hard... there were both of us [the interviewee and her husband] and we hardly managed to get along. (Krystyna)

When my mother was already a person who really needed help – such huge physical support, then, if my husband was not there, then there was my brother who lives next door. He always helped me here, always. (Alicja)

The physical strength of these people was essential to take care. It was often a resource that was shared with other family members.

On the one hand, it was important to have your own resources of fitness and physical endurance, on the other hand, the possibility of getting physical help from others (in the cases from this study – other family members) was sometimes also necessary.

2. External resources

External resources can be divided into two subcategories: personal and non-personal resources. The first group includes: family, friends, professionals and parents themselves, the other consists of places (e.g. health service facilities) and equipment that supports the functioning and rehabilitation of a sick or disabled person.

Parents

The analysis of the interviews shows that the physical and mental state of the parent could be perceived by some research participants as a resource. The better an older parent functions, the greater the resource understood as the strength of the elderly person. Moreover, the interviewees valued the words of gratitude expressed by their parents:

Once she kissed my hand and said with tears in her eyes, 'thank you'. Maybe even several times. I did not want that, I just kept saying, 'Stop it, you know I love you'. (Jowita)

Emotional attachment, feelings expressed by a parent, words or gestures expressing gratitude were important elements facilitating the process of providing care by the interviewees.

Family and friends

In most cases that we studied, the caretakers of an older person were children or sons-in-law and daughters-in-law of this person. People supporting the main caregiver were usually their family members (in order of frequency: husband / wife of the caregiver, his / her children, siblings of the guardian, siblings of the depend-

ent person. Among non-family members (apart from professionals) there were: friends, acquaintances and neighbours.

The interviewees, apart from defining the group of people involved in care, also gave examples of situations in which they could count on them as well as described the activities that they performed.

My husband did everything around his mother [...] he even changed the nappies. (Barbara)

I cannot always take her to the doctor, then this family help is very important. (Alicja)

I really, really enjoyed talking to my friend. It helped me a lot. [...] when I really felt so tired of all this, I talked and talked and in a way get rid of this burden. I charged my batteries and could continue working. (Ewa)

The involvement of friends and family included providing various types of support. Sometimes it was a physical relief in the form of taking temporary care of a dependent person, in other situations it could be material or financial support as well as mental or spiritual support. Family members and friends provide informal support, which is an important resource for dealing with the hardships of care.

Professionals and access to facilities

The interviewees indicated that from time to time their parents received some support from such institutions as: hospitals, hospices, home hospices, associations (e.g. Association for Quality of Medical Care). Access to facilities / institutions involves access to various types of professionals: doctors, nurses, family assistants, hospice employees, but also MOPS/GOPS (city or council centres of support) employees, social activists from associations and charities (e.g. Caritas). In their narratives, however, they did not appear frequently, because the families were determined to have an aging

family member at home. Therefore, contact with professionals was limited to incidents of hospital stays and very limited opportunities to receive their support in the family home. Unfortunately, there are hardly any good solutions in this area in Poland. The interviews show a great need to change and improve the system of professional institutional support for older people. A few examples of positive experiences include only help from associations and charities. Beneath we present the examples of these statements:

Caritas helped us a little when she broke her leg [...] the girls from Caritas are cool. (Łucja)

There is a group of nurses in this Association for Quality of Medical Care and they also called me to ask how they could help me. And, for example, there was Marysia who taught us how to wash my Mum [...] It turns out that nurses have their own methods, they have their own ways how to wash a disabled, elderly person without too much strength. (Alicja)

Equipment

Nowadays two aims of using technical equipment can be distinguished: 1) to improve the functioning of dependent people by facilitating them doing certain activities, 2) to support the activities of caregivers. The interviewees talked about the equipment, but only in the context of improving the functioning of the elderly. To give an example, there were references to wheelchairs and other orthopedic equipment, hearing aids, devices such as a glucometer or a blood pressure meter. The analysis of the interviews shows that there are still no devices in the living space of these families that would facilitate the process of care of a dependent person (e.g. lifts).

Only one person describes the adaptation of her home space to the needs of a person losing her fitness:

The bathroom is adapted so that there were a lot of handles to make her feel safe. Antiskid in the bathtub and next to it as well. (Hanna)

Sometimes, as the interviewees convinced, technical equipment they bought or received turned out to be useless or unsuccessful. For example, one of the participants received a glucometer, although her mother did not have a diabetes, another one bought a hearing aid which the parent refused to use. In other cases, a participant received a wheelchair which was broken and another interviewee got a corset (for her mother) which was so heavy that she did not manage to wear it.

Discussion and conclusions

The analysis of the narratives show that adult children who take care of their elderly parents distinguish two types of resources which help them perform this task: internal and external. They are presented in Diagram 1.

According to the interviewees certain internal resources (system of values, faith in God, passions, good economic situation) and

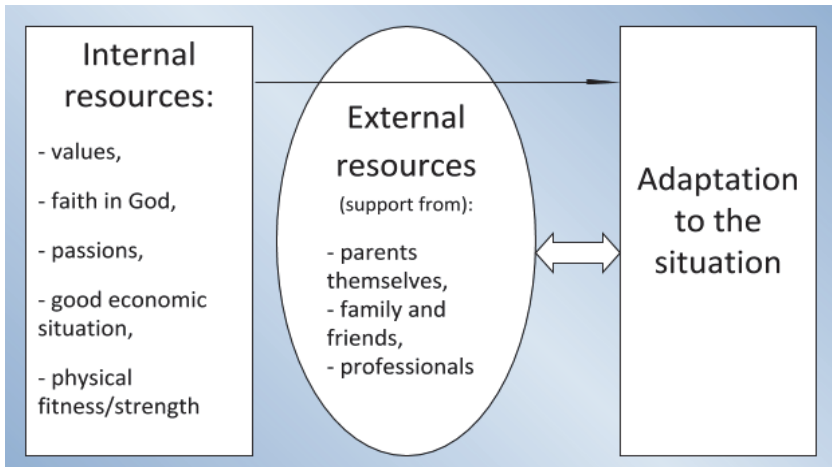


Diagram 1. Meanings given to resources of adult children taking care of their elderly parents

external resources (support received from others) help them cope with the process of taking care of an elderly, dependent parent, which means it leads to the adaptation to the difficult situation. What is also worth noting, is that in each of the areas in which interviewees indicated the existence of resources, there are also huge needs, which may suggest implications for practice. Clearly, as other authors (Li et al., 2017) suggest, due to a greater longevity and changes in family structure, the need for formal care has also been increasing. The needs are particularly noticeable in case of professional (medical, palliative) support that would help the family members who decided to take care of an elderly, dependent person. We believe that there is a huge demand for the state to provide support and assistance to carers of the elderly, both in the form of support payments (carer payments or carer allowances, which should be more adequate to the needs and available also for family members who are employed) and support services (e.g. funding for home help, health promotion programs, dementia support programs, rehabilitation and medical equipment rental, carer respite centres and carer resource centres).

Limitations

Clearly, several limitations to this study should be taken into consideration. First, general limitations of research referring to opinions might be emphasised, particularly when subjects like values, feelings, needs and difficulties are concerned. It is possible that interviewees wanted to report socially correct responses (connected, for example, with the position of family care in the hierarchy of values, feelings towards parents) and their nonverbal attitudes remain unknown. Observations of children taking care of their parents as additional research methods could fill this gap. Second, the qualitative character of the study does not allow any generalisations. The interviewees who took part in this study constitute a relatively small (21 persons) group of adult carers of elderly parents in

north-eastern Poland. It is plausible that the results of the research conducted among people taking care of parents in other communities, regions and countries could be different.

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