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LONELINESS EXPERIENCED BY INFORMAL CAREGIVERS OF THE CHRONICALLY ILL IN THEIR HOMES. PROPOSED SOLUTIONS AND PRACTICAL RECOMMENDATIONS FOR LOCAL COMMUNITIES

Piotr Krakowiak
Faculty of Educational Sciences UMK, Toruń, Poland

Katarzyna Wasilewska-Ostrowska
Faculty of Educational Sciences UMK, Toruń, Poland

Abstract. *Loneliness experienced by family caregivers of the chronically ill in their homes is described starting with different aspects of solitude in social sciences. Family care as part of informal care should cooperate with formal careers from health and social systems. Welfare institutions and home care in Poland are described in front of growing challenges of ageing societies in Europe. Good practices and practical recommendations for local communities, including better coordination of care, as well as support for family caregivers at risk of loneliness and other difficulties are offered as a conclusion of this report.*
Keywords: *chronically ill, elderly, health care, home care, informal caregivers, integration, loneliness, social care, volunteers.*

Introduction

Modern human being lives in a time of many transformations of globalized world. Diversity, freedom, individualism, hedonism, anonymity are the characteristics that describe a world in which one operates. In today's world the chaos of everyday life, continuous haste and lack of time for loved ones often dominates. In consequence of this, more and more confused people are looking for meaning and purpose in life, experiencing emotional and spiritual emptiness. They often lack answers to basic and important questions of life, such as truth, love, goodness, or value of the family. This latter issue seems to be worthy of special attention and interest in the light of the transformation of the family systems functioning. They are going through a serious crisis, which requires support from the state and various institutions. Last Synod of Bishops of the Roman Catholic Church states that major threat is „rampant individualism, which debased family ties and leads to treating each family member as a lonely island, making domination, in some cases, the idea of an entity which is formed in accordance with their own desires treated as an absolute" (wiara.pl/doc/ Relacja-III-Nadzwyczajnego-Synodu-biskupow).

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In the same place we find other problems affecting the family, such as violence, unemployment, poverty, the disintegration of marriages, neglect of children, disorders of emotional life, or negative attitudes toward the elderly (ibid.). Statistical data obtained from social welfare centers in Poland seem to confirm these facts. One of the problems is the rapidly aging population and the increase in the number of elderly people who require constant care and social support (Baranowska, 2013). The question of who will take responsibility for the sick and dependent people, especially in home care, seems to be significant. We can also ask a more fundamental question of whether the families are important, whether we should be concerned about their future, and how to diagnose their needs, and help to solve their problems. We want to restrict our discussion here to issues related to the difficulties of informal careers of the chronically ill at homes. In our analysis will be primarily describe the social problem of their loneliness in caring process. In the second part we will present proposals for solutions and practical recommendations for local communities in Poland, and other European countries where ageing societies and changing families are the reality of today or tomorrow.

Loneliness experienced by informal caregivers of the chronically ill at home

Loneliness is a phenomenon of our time, which is difficult to define. It is a condition that can be evaluated positively, negatively or ambivalently. Some consider this situation normal, common, and others do not accept it. Loneliness can be an individual experience (being alone with you) or interpersonal one (in our relationships with others), objective or subjective, by choice or by necessity. On the one hand, one escapes from her, on the other needs her. According to Erich Fromm loneliness has always been inextricably linked to human existence, but today in particular individual is exposed to this condition (due to isolation from each other and from nature) (Fromm, 1970). On the other hand, Antoni Kępiński says that solitude is contrary to human nature (Dubas, 2000, 56).

Marco Linnemann with his team made several categories of loneliness:

- interactionist - no contact with other people, there are unmet social needs of individuals,
- systemic-theoretical - warning, crisis situation that requires a solution (in this situation plays a positive role),
- cognitive - due to differences between the expectations of the individual and society, it is necessary to find a compromise,
- psychodynamic - source of loneliness is the personality of the human being and one's difficult experiences in childhood,

- phenomenological - one is focused on social roles, aiming to construct ideal „I” until one loses its real „I” not being able with time to determine ones identity,
- existential - human being is fundamentally alone and has accepted this fact, otherwise one would be miserable,
- sociological - social changes, particularly contemporary family transformations lead to growth of loneliness (source: ibid., 86-87).

According to Elzbieta Dubas, loneliness can be a social and existential phenomenon, it may appear in the family or marriage, in workplace, educational or caring institutions. Loneliness can be related to sex, others or oneself, the homeless, criminals, immigrants, artists, singles, exiles, children, adolescents, adults, seniors, may be the face of history, ideology, globalization, nature, civilization and emergencies, one's own choices, decisions, successes, own death and one of relatives, and in relationship with God (ibid., 118-120). As it is suggested, loneliness can touch every person, regardless of age, gender, or experienced problems. In this text, however, we will focus on the loneliness of the chronically ill, and especially on the solitude of their careers at homes.

Chronic disease is characterized by long-term durability of treatment and gradual deterioration of health, which ultimately could result in death of the individual. Nearly 14 million adult Poles admit to have health problems that last for half a year and more. Healthcare system, established to provide medical assistance, acts in accordance with the guidelines of the Ministry of Health and the National Health Fund, and therefore reacts in life-threatening cases. When the patient's conditions are improving, the homecare is often the option (Szwałkiewicz, 2011, 15). Often comes the dilemma for the family, what do you do with someone who is chronically or seriously ill? To take one's home and take care within the family or refuse and resign from such liability, searching for institutional assistance. If the family accepts seriously disable patient, they must reorganize whole life to date.

Chronically ill patients often require non-stop care and regular assistance from medical experts. Family caregivers must make important decisions about future career prospects, and whole range of financial, house, family and personal issues. They are often forced to dedicate themselves wholly to the patient for many months or years, sacrificing their own needs, dreams, and even their own families. For this new task they have to learn how to care for the sick, and to be present and accompany one physically, emotionally and spiritually.

It happens that the family does not undertake to care for the chronically ill or old patient. This happens for various reasons, such as a need to work abroad or in another city, a lack of housing conditions or poverty. It can occur because of dysfunctional relationship with someone who is sick, and often out of fear that family will not be able to cope with such a task. Then the patient could get

different level of institutional care or is left alone at own home, counting on the support of environmental guardians from health and social care, volunteers, and neighbors.

Regardless of the decision taken by the family, one should not judge, because care of the dependent person is extremely difficult matter. The effort that is associated with this work provide even number of entries on Internet forums, where careers share their experiences and burdens of daily problems. Primarily description of the difficulties is associated with the inability to cope with various emotions, the lack of acceptance of the disease, incomprehensible reactions of ill person and their careers within the family (Care for the elderly). Even more common are requests from families and friends who do not know how to behave in such a dramatic situations, asking advise, criticizing health or social systems, and having also offensive behavior towards others (Oncological forum). Such reactions can occur, however, because of the fear of death, overwhelming sense of powerlessness, or lack of experience and knowledge regarding caring process. „No one who did not come into contact with this terrible disease personally, do not know how to behave in front of the ill person. They are afraid of suffering because of cancer and consequently over time they often distance themselves from people living alone with their pain" (ibid.). Many more complicated issues regards caregivers of dementia patients, whose care may take many years of slow deterioration and lack of contact with the dear ones (opiekanadseniorami.blogspot.co.uk).

Many times family members stop trying to contact with a chronically ill person, leaving them alone in family context. But this loneliness is not helping to recovery from illness or stop deterioration process, but often produces quite contrary effects. As confirmation of these words the results of recent research on people who have had cancer at the age of 30-89 years could serve as adequate example. These longitudinal researches were carried out in Norway for 40 years, with participation of 440 thousand people, and the main variable was their marital status. It turned out that bachelors have died sooner than married men (the difference between two groups was 35%). It was the same with group of women, although the differences there were smaller (Science in Poland). These and other analysis show that the human being in the face of suffering needs support of other people around, requires also a sense of security and fulfillment of other needs, especially psychological and spiritual understanding, respect and acceptance.

But loneliness can also be experienced by family informal caregivers. On one hand, they can experience social exclusion, when they have to take to care for the sick, changing completely their live and personal projects. They are unable to count on the support of individuals and institutions, which is still rare and most of the time not at a sufficient level in home care. They live loneliness

as the limitation of their interpersonal relationships, because they do not have the time, and are forced to give up their interests and passions. So they are isolated socially and often because of constant duties they also alienate themselves from their environment. Another problem is connected with emotional loneliness, which can evolve into sense of abandonment and the awareness that in difficult moments one is relying solely on oneself. This form is most severe and dangerous, because such a caregiver has a lot of unpleasant emotion kept inside, which can cause various forms of self-harm and violence directed at oneself, other people or external objects. One of the escapes of burn-out informal caregiver (especially with long term duties) can also be overuse of stimulants, such as alcohol or drugs, or escape into virtual world with computer, TV-set or mobile phone. Another aspect of this complex issue is called moral loneliness, which can be described as emptiness or lack of purpose and meaning in life. Caregivers do not think about the future, because I do not know how long the caring process will last. They worry instead about what they will do when the dear person will die, and how they will handle the loneliness after long caring process (Krakowiak, 2012).

Although loneliness experienced by family caregivers is a negative phenomenon, it is worth noting that sometimes they could have a need for temporary isolation, rest and stay away from the caring duties, to calm down emotionally and to rest. And in this sense loneliness in caregivers' life could play a positive role, because it allows redefining certain contents of personal and family life. However, caregivers could experience this state only when they have representation, individual or institutional support, which should be made possible in the local community (cf. Krakowiak, 2012). It is a task of social policy makers from every European state to expand existing and launch new forms of support for the informal family caregivers. Among them there are indications to provide better respite care which will be presented among proposal in the next part of this publication.

Suggestions for solutions and recommendations for local communities

Demographic forecasts for the Poland and Europe are not satisfactory. According to the statistical analysis of the population in Poland will fall from 38.3 million in 2010 to 32.8 million in 2060, moreover the number of people over 65 years will significantly increase from 13.5% in 2010 to 36% in 2060 (Baranowska, 2013, 47). Given the fact of growing number of older people it can be assumed that the number of family caregivers in home care settings also will increase. Studies show that now we have about 2 million informal family caregivers in Poland (Janowicz, 2014, 146). Higher demand will also be on institutional assistance for senior citizens and for chronically ill people.

In a situation where an elderly or chronically ill person is alone and cannot count on family support, intervention should be taken by social assistance which is the institutional activities of the state. Social services ought to meet the needs of dependent persons „unable to do so yourself within the existing distribution of wealth services and benefits" (Grabusińska, 2013, 14). Currently, social assistance activities in Poland are regulated by the Act from 12 March 2004. In this piece of legislation we find only the concept of a single person, defined as a person running a household alone, unmarried, not being in any relationship and not having parents and children (Art. 6 of the Act on Social Assistance, 2004). This understanding solitude is significantly different from that adopted in these early concepts of loneliness. It is worth noting, too, that in this document there is no record of loneliness as the difficulties experienced by clients which is often combined with other problems experienced in context of family, such as domestic violence, the problems of suicide or homicide, helplessness in life and homelessness, and various problems related to addictions.

Acts and Regulations issued in Poland indicate that elderly person who is dependent on others can receive financial aid, adequate care services at the residence, including specialized services, protected apartments, day support centers and family care homes and nursing homes. The amount and type of financial support depends on whether the protégé meets certain conditions, especially the income criteria. Care services are granted to a lonely person that requires care and assistance due to age, illness, or disability (Art. 51.1., ibid.). In practice, these records are in the vast majority of cases impossible to meet because of insufficient number of social assistance institutions in local communities and common lack of cooperation with healthcare and other institution in the local environment (cf. Krakowiak, 2012, 208-211).

The fees for care services are established by each municipality (might be paid in full, in part or free of charge). Specialist nursing services in the context of social work are directed to clients with specific needs arising from their illnesses, and caretakers must be properly trained and prepared professionally (Art. 50.4 of the Act on Social Assistance). If there are obstacles hampering the care services the solution becomes a family house social assistance. It is a form of support of a twenty-four hour care and welfare (Art. 52, ibid.). It can be lead by private person or organization in the dedicated apartment or house. Elderly and disabled people can be there temporarily or permanently at the request of the head of the social welfare center. Number of dependents in such institution is not less than 3 and not more than 8 persons (Grabusińska, 2013, 19). This new form of assistance offered to senior citizens in Poland is popular, but obstacles to the creation of further RDPS are strict conditions that must be met in order to start this service. The main institutional form of social assistance for the chronically ill and old are DPS - social welfare homes (Art. 54 of the Act on

social assistance). Their number, however, is far insufficient for the rapidly growing needs, and the quality of the services offered is depends on the wealth of the community and the financial capabilities of customers. In many centers lack of cooperation with the local community, or voluntary services makes those places unwelcoming.

Social welfare institutions fulfill according to the law the role of caring, supporting, educational and social (Art. 55.1, ibid.). There are nursing homes for the elderly, the physically disabled, chronically physically ill, chronically mentally ill, intellectually disabled adults, children and adolescents with intellectual disabilities, people with alcohol dependence (Art. 56, ibid.). The alternative for the elderly, remaining in residence are daily support centers. They are a living form of assistance, and their main goal is prevention of social exclusion of dependant people (Grabusińska, 2013, 21). In Poland, these activities can be distinguished for: daily nursing homes, night shelters, senior citizens clubs, self-help centers, canteens, environmental self-help houses (ibid., 22). These services were underdeveloped for years, and their need in local communities is increasing with the aging population. A number of initiatives in recent years in Poland change the reality of social services in the living environment, and an example of successful ventures shall be support centers created within the national project (senior.gov.pl/ program_senior_wigor).

Services for the local community are usually carried out by social workers and their cooperators. They can provide an important link in the integrated system of aid to the chronically ill and their families (Krakowiak, 2014, 137). The employee should diagnose psychological and social needs of patients, their families and the environment, providing socio-legal advice and support in crisis situations, cooperating with various institutions. Teamwork with specialists dealing with the family and care for mutual communication would help to direct clients to support groups, and to organize support of volunteers as well as work with bereaved families. From a social worker is required primarily to conduct community interviews, and then, in accordance with the possibilities of legal assistance in the form of cash and factual under the Act on social assistance. But the most important task is to organize a family assistance to relieve informal careers or include them in the care system. The social worker should act as a coordinator of care in the local community where all together with family will take care of a dependent at home (ibid., 138-140).

The results obtained in the Kujawsko-Pomorskie in 2014 to 1064 seniors aged over 60 years shows that older people want more frequent contact with family members (at least once a week), and half of the respondents receives adequate support from loved ones. Most of dependent elderly people do not benefit from social assistance (over 80%), assessing their health status as average and waiting for help when shopping, in household duties, preparation of

meals. Over 60% of respondents emphasizes that experiences a chronic disease and disability hindering their normal functioning. However, a small percentage of respondents admit that he would like to use the social services offered by the welfare institutions (Kujawsko-Pomorskie in the context of an aging population, 2014). This involves certainly the stereotype of using this form of assistance mainly by socially excluded people, the unemployed, or dependent. Ashamed prior to use of the social support inhibits individuals under the care of a family from visiting the social welfare center. A common reason is also ignorance about the possible forms of support in a situation of dependence in the family (Krakowiak, Starkel, 2011, 288-322).

In view of the rapid demographic changes there are more and more regional, national and EU programs, which are intended to combat exclusion and social marginalization of older people. The response to the situation described above is the initiative taken jointly by Caritas Toruńska and Social Work Department of UMK in Torun. Preparing and creating Parish Senior Club for 200 Catholic parishes has been the first such initiative in Poland, trying to activate parish communities to integrated care for the elderly and dependents in their homes (cf. Krakowiak & Janowicz, 2015). Another example is the Government Program for Senior Citizens Social Activity for 2014-2020 in Poland. Its aim is to increase educational and cultural integration, the creation of various forms of social activity, increasing the availability of social services in local communities, as well as activities in the area of self-help for elderly (www.mpips.gov.com /seniorzyaktywne-aging/a government-program-asos).

Regardless of the adopted strategy it is worth to promote proposals set out below, which should be included in the state social policy: social assistance for seniors; organization of health care; housing tailored to the needs of the elderly; removal of architectural barriers; educate people about elderly people, their problems and resources; volunteering for older people; training of community nurses and formal caregivers; supporting self-help activities; development of cultural, education for seniors, such as clubs, universities of the third age, circles of interest. One of the crucial elements is connected to support system for informal careers, with flexible forms of employment, and various forms of respite care for family caregivers (Szarota, 2013, 24-29).

Implementation of these measures requires changes in the regulations and integration services through coordination at government and municipal level (Grewiński, 2013, 62-63). One of the dangers of inadequate care is loneliness, which may hinder the experience of life, and consequently contribute to the emergence of many other problems, such as depression, violence, addiction or suicide. That is why they are so important, as well as compensation and intervention in caring process. Social workers should play a leading role in coordinating and integrating the efforts of various stakeholders of care process

in aging population. Need of better coordinated home care and inclusion of health and social professionals with family careers and local environment are recommended as measures which could make more effective existing systems (cf. Krakowiak, 2012, 282). Experiences from hospice-palliative in Poland have been transferred to end-of-life care, especially in home care settings (Krakowiak, Krzyżanowski, Modlinska, 2011. Good practices of teamwork and local communities' involvement from Poland are now available also in English as a free resource for all those who would like to develop the end-of-life care in their communities or countries (Janowicz, Krakowiak, Stolarczyk, 2015).

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