



Review paper

Practice of providing Voluntary home care to Elderly and Disabled people: model project in Debrecen

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Abstract

The present study built on HELPS “Housing and home care solutions for elderly and persons with disabilities and local partnership strategies in Central European cities” project. HELPS is realized within the framework of the Central-European Transnational Program of Regional Cooperation Programs with the support of European Regional Development Fund. Human society faces many challenges as a result of population boom, longer life span and the globally emerging information age. While in developing countries we see that population grows at a high rate, developed countries experience decreasing population. At the same time, the number of elderly grows both in relative and absolute terms in every region. In our study we present practical knowledge required by informal caregivers for giving care to elderly people and people with disability.

Keywords: Practice model field home, care, elderly, disabled, people.

Introduction

By 2060 the number of people above 65 will have been doubled in the European Union while the number of those above 80 years of age will grow even more, by nearly threefold. Challenges associated with old age are often coupled with factors that make elderly people more vulnerable, such as disability and social exclusion. Looking at the services provided to elderly and other people in vulnerable positions, it becomes clear that the logic of centralization still has deep roots, especially in Central Europe.

In this environment HELPS international project wishes to promote innovative forms of housing and home care. The project is realized as part of the Central Europe program with the co-financing of Hungary and the European Union. The project, HELPS – Housing and home care solutions for elderly and persons with disabilities and local partnership strategies in Central European cities, seeks answer for six challenges through an integrated approach: i. Accessibility of information regarding services that facilitate an active and independent life for elderly and people with disabilities. ii. Accessibility of places of everyday life in urban areas through innovative urban design that supports independence and social integration. iii. Development of human resources of the personnel engaged in the areas of health care that are in a difficult situation due to an increasing demand. iv. Building neighborhood level social networks that are based on reciprocity and solidarity in activities of integration and help. v. Applying ICT solutions that facilitate independence. vi. Sustainability and efficiency of distribution.

The objective of the pilot project of the Municipality of Debrecen is to train informal caregivers in order to ensure that elderly people and people with a disability may stay in their home environment in the long term and to improve the quality of life of these people in the broad sense. This study presents the main practical knowledge for informal caregivers how to work with elderly people and people with disability in their home¹.

Natural ageing

The World Health Organization distinguishes three stages of human life: progressive, productive and regressive stage. The regressive stage may be divided into three parts: 60-74 years: ageing person, 75-89 years: elderly person, above 90 years: old person. This division is appears important especially if we consider that according to KSH data in Hungary life expectancy was 70.93 for men and 78.93 for women in 2011. It is important to state that ageing is not a one way road that only has negative aspects. On the contrary, it is not deformation, it is a change with multiple directions that takes place in individual ways. Physical-mental changes along with changes in social relations and on the level of spirituality together have a complex impact on the life of an ageing person.

In general, we may say that the ageing body is characterized by loss of weight, absolute and relative loss of water content and increasing number of connective tissues. We may encounter differing views on mental state and psyche of the elderly person. It is primarily the mental outlook of the person that determines the psychological impact of ageing. Phenomena may become

more pronounced, but behavior does not change fundamentally. In certain cases we may observe that personality becomes „blunt” compared with that it was at younger age, adaptability is weaker or it disappears. A bodily illness may distort the personality. The ageing person finds herself in a difficult position in the third phase of her life. By becoming pensioner, her life changes significantly both materially and in terms of daily routine too. There is a need for creating new opportunities in a situation when vitality is reduced; ability to adapt to and resist change decreases and backup energy is at the minimum. Social status of elderly persons may be assessed according to the following criteria: marital status and position within family, financial condition and biological condition. It is important to note that we do not know of illnesses that exclusively occur at old age since all illnesses may occur at all stages of life. However, the way they manifest themselves and their frequency is different from what we experience at younger age. Therefore, we may distinguish illness at old age from illness in general. Clinical course and symptoms are contingent upon individual health condition, ability to adapt and resist and the decrease of reserve energies of the body also influence it significantly².

Practical knowledge for informal caregivers

In this section we present the main practical knowledge required by informal caregivers for giving care to elderly and disabled people involving external support workers on the following topics: i. the laboratory of empathy, ii. the basics of a supportive relations, iii. communication, iv. physical care, v. mental condition, vi. the framework of helping activity.

The laboratory of empathy: Empathy is an important precondition of keeping and deepening our human relationships. A long-term friendship, a harmonious marriage, a balanced parent-child relationship, a fruitful teacher-student relationship or even a collegial cooperation is unimaginable without it. A supporting connection presumes a unilateral empathy from the supporter's side.

People who want to develop their facility for empathy should first practice how to pay less attention to themselves but more to their partners with whom they are in relation. If one in a relationship constantly pays attention to what the other person thinks about him, how the other person relates to him, how much the other person appreciates him or what he can get etc, he will hardly be able to develop his facility for empathy. First stop on the path of progress in this field is an important change in attitude: do not use your partner as a mirror through which we can get information about ourselves, but a surface to explore which we would like to get know and understand better.

Personal experiences about elderly and disabled people: What kind of experience does the caregiver have about elderly and disabled people in family, at school, at workplace, in the residential surrounding? What is the caregiver going to be like when he/she grow old? Charting of motivation: Why does

she/he wants to help others? Why is it important for the caregiver to help other people?

The basics of a supportive relation: Care giving relationship is a regulated relation between the caregiver and the recipient of care. Intervention takes place through methods of communication, physical and mental care in the interest and with the consent of the person in need of help in order to achieve a common goal. In all forms of care giving relationship one person listens to and helps the other that needs the time, attention and service of another human being.

The systemic approach of care giving relationship sees issues and possible solution within the social system of the individual, family, group and community. Human beings are social beings that are in interaction with persons that belong to other systems. For example relatives, family, department, firm, society are different levels of the system that are integrated. Larger ones include smaller ones that create issues and that need to be solved. Thinking in terms of system allows us to see beyond individual opportunities and also considers the multi-layered interaction between the individual and its environment. A person belonging to the system acts, feels and thinks depending on members of the system. It is an essential method in recognizing problems since it enables caregiver to understand the needs of the person that asks for help and provide effective help.

Role of external factors in shaping care giving relationship: Cultural elements: Nation: that we belong to, that determines our attitude, eating habits, hygienic habits and even our self-perception. Location: the place where we live may also be an important factor in all areas of life. A person from the Great Planes lives and acts differently from one from the mountains and there are important differences between lives of a person from the arctic and one from the tropical zone. We live differently in a metropolis and in a village. The family that we belong to has its own customs, traditions and world view, beliefs, legends and moral principles etc.

Institutional framework and background: here we mean the institution, form and type of service that provides room for the care giving relationship. It directly determines the framework of the relationship. An example for that is the system of home care.

Communication: The two-way conversational situation and the act of communication (one person transmitting a signal to another) viewed as a unit in the general theoretical model of communication has always been deeply embedded in the system of social communication. The situation, the relationship between the conversing parties determined by societal rules, and the full context of the message are equally significant in all communications.

In general we can define *problem* as being aware of a desired goal but not knowing the way to get there. Defining the problem

is always unique (subjective) and relative, the same situation may or may not present a problem for different individuals. The difference between *task* and problem-solving is that in case of the former we are aware of both the goal and the way to get there. A problem will always trigger a thought process. The role of cognition in discovering the world and ourselves is to enable us to discover things inaccessible through our senses and direct perception. One function of cognition is problem-solving, whereby situations that would require a set of actions can be solved purely in the realm of intellect. When we intellectually design and solve a problem, it becomes a task. This is the basic theory of the problem-solving model.

Phases of problem-solving counseling: i. Recognizing the problem. ii. Defining the essence and specifics of the problem. iii. Working out options for possible solutions. iv. Picking the optimal and most implementable of all alternatives. v. Designing and implementing the solution. vi. Evaluation of results.

Physical care: Each time we meet an elderly or a disabled person placed under our care it is always required to monitor the given person's physical and mental condition. It is possible that a person receiving care will not yet notice the symptoms when his or her condition worsens, but an outside observer will. The care giver does not look upon the person who is to receive care as a doctor; nevertheless it is important that the care giver is aware of the aspects he or she needs to take into consideration.

The co-operating patient accepts assistance and tries to co-operate in accordance with his or her condition. The resisting patient is reserved, in many cases does not complain and is rather indifferent. This attitude can later turn into co-operation. Resistance and distrustfulness can have a number of reasons: the patient sees it as a failure that he or she needs somebody else's help, or his or her previous bad experiences lead to distrust.

It is not an easy task to judge whether pain exists or not and if it does how strong it is. The subjective signs of pain depend on individual sensitivity. It is a well-known fact that people react differently to a pain caused by the same disease. One person would describe a feeling as great pain; another might not even mention it. It is also possible that someone complains about continuous pain but no disease can be detected. Sometimes external symptoms help to notice the existence of pain. Tired or worried look, wide pupils and uneasiness point to serious pain. When in great pain the patient cannot sit or lie calmly.

Keeping the body neat is not only a good feeling for the individual, but is also expected of him or her by the environment and by fellow human beings. For that very reason the cleanliness of the body cannot be an exclusively personal issue for anyone. There are different ways of continuously and regularly getting ourselves clean. In case of a sick person cleanliness can have a psychological and physiological meaning. A person's cleanliness reflects his or her condition and

its improvement or deterioration. It can always be interpreted as a good sign if the patient "cares for his or her reputation" regarding both clothing and neatness, cares about his or her appearance and does not neglect himself or herself. Keeping the body clean is an essential condition of the patient's recovery.

Mental condition: Maintaining activity, or in other words keeping the patients occupied, is a very important nursing task, especially in case of elderly or disabled people. By keeping them occupied we do not only achieve that they spend their time by engaging in a useful activity in a good general state of health and in a good mood, but we also maintain the level of their existing abilities and develop these abilities. By doing so isolation, idleness, the abnormal thought of being old and sick and also the thought of being useless can be brought to an end. We cannot neglect the role active programs play in forming a community either, therefore we need to convince the elderly or disabled person living in his or her home to spend as much time in a community as possible, provided that the conditions permit this. Even if we satisfy their physical needs, it is not enough to pay attention to their physical condition.

There are certain rules of maintaining activity, or that is to say, keeping someone occupied, which are required to be kept. The first of these rules is the voluntary principle. Taking part in the activities can never be obligatory for the elderly people. By persuasion or by applying small tricks every elderly person can be initiated in active free time activities. Expedience is a very important rule. If the activity does not have a "tangible" purpose, it can even have a harmful effect on the person receiving care. If we discuss it together what the purpose of our activity is, they will take part in creative activities a lot more willingly. By involving them in these tasks we do not only make them to participate collectively and happily, but we also maintain and perhaps even develop their mental alertness, existing abilities and skills. The next very important rule is continuity. When organizing activities, continuity should not be confused with monotony. Continuity means that the active programs should take place on specific days and at specific times. If we break this continuity, it will lose its purpose and the attended people will also feel that this program "is not so important". It needs to be explained why certain occasions were cancelled and if we are unable to attend, we always need to find a way so that elderly people would still take part in some kind of active occupation. The main purpose of keeping someone intellectually, culturally occupied is the maintenance of mental alertness and the prevention of mental decline and alienation, keeping contact with the outside world, raising one's cultural level and the acquisition of knowledge. The following fall under this category: recitation, reading out aloud, organizing different programs, going to the cinema or a museum, attending a theatre performance, taking part in various cultural events, reading, listening to the radio, watching TV. All these can be done both individually and in a group. Keeping someone entertained cannot be markedly separated from intellectual and cultural

activities, since both can offer means of entertainment for individuals and groups alike³.

The planning and organization of the occupations need to be done together with the people receiving care. In order to do so, however, it is necessary to know every participants' walk of life, physical, health and mental condition, all personal data concerning the occupations (qualification, interests, hobbies, etc.) and all the related nursing problems and tasks that need to be solved. These details will only be available for us if we prepare a care plan which has to include an occupational plan as well.

The individual development plan includes: the description of the condition of the person receiving care, the description of the changes of his or her condition and also his or her individual development, the individually required special services and pedagogical, mental and other tasks regarding assistance; also the schedule of these tasks and the participation in the occasions, preparing people for the use a new service or for a new way of nursing patients when it is required, measures to be taken in order to restore or substitute missing or restrictedly available personal functions.

The framework of helping activity: The volunteer can only carry out voluntary activity if he or she complies with the laws defined by the act concerning volunteers.

The informal care giver can have the following tasks: talking, letter writing, reading out aloud, helping to walk others, supervision, cleaning, cooking, managing official affairs, shopping, feeding, drinking, etc., keeping patients occupied.

Feeling safe belongs to the primary needs of man. Defense, effective protection against harmful environmental factors, stability, discipline, orderliness, observing the rules of coexistence and getting rid of fear, distress and disturbing situations form the basis of feeling safe. Physical comfort is similarly important, especially for elderly, disabled and sick people.

To assess the problems deriving from environmental injuries affecting patients, visitors and staff alike, the nurse needs to examine two things: Are there any factors which may decrease the patient's ability of self-defense? Are there any environmental factors which may be potentially dangerous?

To conclude the examination the care giver needs to know the patient's age, the condition of his or her sense organs, the clarity of his or her consciousness, possible limitation of motion and general medical condition. The care giver needs to know for what purposes the patient requires assistance (feeding, moving etc.). The care giver also needs to know the nature of the disease and the results of the treatment, provided that the patient receives any. The care giver needs to be aware of how much all these decrease the patient's ability of self-defense because most

patients feel distressed in a hospital. The care giver needs to recognize the signs and degree of distress. For the sake of prevention the care giver needs to know the security regulations which can be associated with attendance. All those furnishings need to be removed from the patient's environment which may be a source of danger to him or her.

Ethical frame of voluntary personal care givers

In the process of carrying out their activities voluntary personal care givers fulfill their tasks to maintain, restore and realize the values and human dignity of the people receiving care. Voluntary activity can only be carried out to provide personal help, if it is based on ethical norms. The voluntary care giver's responsibility is to observe these norms without within the boundaries of the competency assigned to the care giver. The voluntary personal care giver has respect for the values, rights, aims and intentions of his or her clients. The voluntary personal care giver carries out his or her duties without discriminating the clients⁴.

The voluntary personal care giver does not take an advantage of the client's defenseless position. The voluntary personal care giver protects the client's interests, but observes other people's interests as well. The host organizations need to ensure that their members meet the ethical requirements. The relationship between the client and the voluntary personal care giver is based on trust.

After due professional consideration and/or in case of incompatibility the voluntary personal care giver can discontinue the relationship by reporting this to coordinator of the host organization, who will take care about the further attendance of the client. The voluntary personal care giver respects the views of his or her colleagues and respects their qualification and obligations. It is the responsibility of the voluntary personal care giver and the institution or organization employing him or her that the care giver only gets in the immediate vicinity of the client in such a condition which enable the care giver to carry out his or her tasks. If the informal personal care giver learns about any grievance or insult suffered by the client, or that anyone has taken an unfair advantage of the client's defenseless situation, the care giver has to report it to the host organization⁵.

Conclusion

The systemic approach of care giving relationship sees issues and possible solution within the social system of the individual, family, group and community. Human beings are social beings that are in interaction with persons that belong to other systems. For example relatives, family, department, firm, society are different levels of the system that are integrated. Larger ones include smaller ones that create issues and that need to be solved. Thinking in terms of system allows us to see beyond individual opportunities and also considers the multi-layered

interaction between the individual and its environment. A person belonging to the system acts, feels and thinks depending on members of the system. It is an essential method in recognizing problems since it enables caregiver to understand the needs of the person that asks for help and provide effective help. Partners of the care giving relationship in the narrow sense: 1) client, who for help and with who we make contract; 2) care giver, who is competent in care giving. In our study we demonstrated the complexity of home care work for elderly people and persons with disabilities.

We often hear the wisdom that we should teach our fellow human beings in need how to catch fish i.e. help them to find solution on their own, instead of providing them with fish so that they will be able to feed themselves. This principle is correct, but what happens if a person in need is not able to learn fishing and depends on others for the rest of her life. It is very important to recognize needs and place them to different levels that are in a certain order of importance.

References

1. Czibere I., RÁCZ A. (eds.), *Theory and Practice of Providing Home Care to Elderly People and Persons with Disabilities - A Handbook for Informal Caregivers*, Debrecen: Department of Sociology and Social Policy, University of Debrecen (2014)
2. Felszeghy M., *The basics of Gerontology*, pp. 9-42. In: Czibere, I., RÁCZ, A. (eds.) *Theory and Practice of Providing Home Care to Elderly People and Persons with Disabilities - A Handbook for Informal Caregivers*, Debrecen: Department of Sociology and Social Policy, University of Debrecen (2014)
3. Nouwen H.J.M. and Gaffney W.J. *Aging: The Fulfilment of Life*, New York: Bantam Doubleday Dell (1976)
4. Naylor C., Mundle C., Weeks L. and Buck D., *Volunteering in health and care - Securing a sustainable future* London: The King's Fund (2013)
5. Robison W. and Cherrey Reeser L., *Ethical Decision-Making in Social Work* Boston: Allyn and Bacon (2002)