# Home hospice care in rural areas.
# Model and recommendations

Fundacja Hospicjum
Proroka Eliasza
*z szacunku dla życia*

# TO GIVE WHAT IS REALLY NEEDED

A model of professional home care for dependent, terminally and chronically ill people and support for their carers in rural areas tested under the partnership project "Dać to, czego naprawdę potrzeba – To give what is really needed"

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# I. Introduction

**“Dać to, czego naprawdę potrzeba” - “To give what is really needed”**
*An innovative model of professional home care for dependent, terminally and chronically ill people and support for their carers in rural areas*

In Poland, approximately 40% of its citizens live in rural areas, which constitute over 93% of the country's area[1]. Despite statistics indicating that 500,000 people arrive and settle in rural areas every ten years, we are observing the aging and depopulation of these rural areas. Poverty also affects people in rural areas more strongly. The report of the Supreme Audit Office (NIK) shows the inefficiency of social care provided to older people in their place of residence[2]. Old, terminally and chronically ill people, dying people, living in rural areas, full-fledged citizens of Poland and the EU, are people who, for obvious reasons, cannot fight for their rights. People living in rural areas with a low or very low level of socio-economic development, inhabiting poor, sparsely populated and remote from larger centers areas are even more helpless. During thirteen years of operation, we have experienced that the system offering specialized hospice care[3] and long-term care in rural areas is inefficient. It is difficult to talk about "comprehensive and holistic care", as hospice care is defined, when such important aspects as "alleviating mental, spiritual and social suffering" are not sufficiently guaranteed within the public health service.

We were asked for help and support for dependent people not only by family doctors, but also by municipal social welfare centers, the State Fund for Rehabilitation of Disabled Persons (PFRON), parish priests and village heads from nearby villages, who know their people's needs well. Sometimes there were neighbors concerned about the health of the neighbor living behind the fence. Good cooperation with all of them (with really small human resources in our sparsely populated areas) is one of the most important keys to success. We decided to implement and test an innovation in our organization that could propose a new model of care for chronically and terminally ill people, effective in rural areas.

By joining the innovation, we became the voice of approximately 50% of the inhabitants of our region and approximately 40% (40.1%) of the population of Poland[4]. In the near future, the problems of old and chronically ill people will strongly affect other EU countries, where rural areas constitute approximately 77% of the countries' area and are inhabited by half of the population of the European Union (2013). For each society, an old, sick, suffering and dying person has been a challenge. The measure of civilizational progress is not only the development of technology, but also the way in which society faces this challenge and how it treats its weakest citizens.

Why did the project leader, Prophet Elijah Hospice, decide to test innovative solutions? The foundation has been operating for the thirteenth year in the rural areas of eastern Podlaskie. As a

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[1] Source: Polish National Census https://spis.gov.pl/

[2] “Care services provided to older people in their place of residence. Information on audit results”, NIK, No. of Evid., 31/2018/P/17/043/KPS

[3] The concepts of hospice, palliative and palliative-hospice care are defined differently in different EU countries. When writing about hospice care, we understand it in its original, broad meaning - providing care for terminally, chronically ill, dying and dependent people - requiring professional support. The closer to the end of life, the greater the emphasis is placed on improving its quality, even at the expense of abandoning procedures that are burdensome in this period of life and carry the risk of complications.

[4] Source: Central Statistical Office, Rural areas in Poland in 2016

non-governmental organization, we are constantly improving and changing, trying to respond to the needs of those who we support the best way possible.

We operate in areas with low and very low levels of socio-economic development[5], depopulating and aging ones. The recipients of our activities are people from several groups - chronically and terminally ill, dependent people, their carers, but also recipients of our educational activities.

When we decided to implement the project, we had experience of caring for over 1,000 people - terminally ill and dependent people in their homes, their caregivers and family members. In practice, this means many hours of observations, meetings and conversations about the needs, difficulties and challenges faced by chronically and terminally ill people and their loved ones. We had more and more experience and we were increasingly able to see and identify the needs and pain points of our beneficiaries. Being close, we have learned to look at them from the perspective of sick people and their loved ones living in rural areas of our country.

In the case of institutions such as ours, operating in rural areas, far from large urban centers, especially those operating in large areas with insufficient medical and transport infrastructure, the decision not to admit a patient who needs home hospice care, but does not meet the formal criteria is particularly important and dramatic, because it means condemning the patient to - often lonely - suffering at home, for lack of a real alternative. Less than half of our patients meet the criteria for state-reimbursed hospice care. For the rest, we try to “tailor make” help, which unfortunately is not reimbursed from the public funds.

What motivations, what mechanism underpinned our willingness to engage in the innovation? From its beginnings, the hospice movement has been a grassroots movement, resulting from the deep need of people who are sensitive, not indifferent to human poverty, compassionate to misfortune, weakness and loneliness of their neighbors. Even when it was included in an institutional framework, its goal was never only to implement norms, procedures or rigid adherence to the rules. It was created and led by charismatic people who deeply felt the meaning of their actions, able to attract others and infect them with their commitment and devotion to sick and suffering people. These people responded to the real needs of their clients and were not afraid to propose changes or, as we would call them today "innovations" - from the deacons and devout widows of the first centuries of Christianity, from Basil the Great, who built the first hospitals for the dying, to Dame Cicelly Saunders and Hanna Chrzanowska. The latter (a lady from a good home, the daughter of a professor), in the times of deep communism, dared, with her feet firmly on the ground, to nurse and care for the dying in their homes and create the foundations of modern community nursing. She was also not afraid to talk about the spiritual needs of dying patients[6]. Similarly, we - when seeing possible solutions and ways of helping our clients more effectively - practice them and want to share our proven solutions with others.

Care for terminally ill and dying people is changing, evolving and must constantly grow and adapt to the new, ever-changing reality. We see this and feel responsible for the chronically and incurably ill people entrusted to us. We change their difficult reality for the better (and we want to

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[5] Report "Monitoring the development of rural areas. Stage I", 2014, EFRWP, IRWIR PAN, source: https://bs.net.pl/aktualnosci-zrzeszen/monitoring-rozwoju-obszarow-wiejskich

[6] Florkowska M.: The joy of giving. Hanna Chrzanowska in memories, letters, anecdotes. Saint Stanislav Publishing House, Krakow, 2017.

do it better and more effectively) by offering comprehensive, professional help to sick people and those who care for them in their homes.

Within 36 months, we have prepared and then implemented activities related to testing innovations. The leader, with the support of the Regional Center for Social Policy (ROPS), defined and created a network from local resources of health and social welfare institutions and other institutions invited to operate within the network. The beneficiaries of the project were people who did not meet the requirements for hospice care financed from the public funds (NFZ), but were seriously ill, terminally ill, disabled and with various degrees of dependence - they required such care and support at home. Due to the ineffectiveness of other methods of support in rural areas, without our involvement they would not receive help adequate to their needs. Creating a "new", expanded hospice team is another task. Based on the existing home hospice team, which works well in cities but is ineffective in rural areas - we have expanded the team with additional professionals - caregivers, dietician, and we will provide them with support (as well as other members of the network) thanks to the recruitment of a Dependent Person's Care Coordinator (KOOZ). We had previously prepared the scope of KOOZ responsibilities in cooperation with the project partners.

Part of the task was a scientific study to monitor the effect of the innovation implemented for over 2.5 years. So far, we have drawn conclusions about improving the quality of life and dying only from conversations with the beneficiaries - i.e. sick people and their relatives. In order to reliably investigate improvements in these aspects of functioning, research was needed to be conducted. It was constructed and carried out by researchers from the Institute of Rural Development and Agriculture of the Polish Academy of Sciences (IRWIR PAN). The research and course of innovation were substantively supported by the Regional Center for Social Policy (ROPS). Experts organized meetings and training on networking, as well as meetings where we presented the conclusions from the innovation to those deciding on the development of social policy. The project partners met several times to jointly assess the progress of innovation testing and get acquainted with the results of innovation research. The project was administered by specialists from the NGO's Support Center - they were responsible for reporting and settling the project. Having these tasks carried out by this unit, innovators and researchers were able to focus on the task at hand, delegating this part of the project work to an experienced partner.

What goals did we want to achieve with our project? We were convinced that our proposed method of providing care for terminally ill, dependent and dying people in rural areas would significantly improve the availability, quality of care and quality of life of chronically and terminally ill people and their caregivers, as well as the quality of life at its end and the quality of dying in the countryside[7]. Our goal was to provide effective respite support for home carers, often also elderly and sick people. We also wanted to create jobs that bring measurable benefits to our employees and give team members joy, satisfaction and a sense of meaning in the work they do, the possibility of professional development, expanding and deepening competences, as well as fair remuneration for the work performed. These are factors that have an anti-burnout effect, to which they are particularly vulnerable in this type of work.

By acting locally, we wanted to have a global impact. This is a slogan known from our previous initiatives, but it seems particularly appropriate here. We want to share the experience

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[7] The concepts of Quality of Life (QoL) and Quality of Dying and Death (QoDD) have been known in medicine since the 1960s and 1970s

of this innovation. We talk about it in the media, on our website and in social media, as well as during scientific conferences and meetings to which we are invited or that we organize ourselves. We are convinced that we have created a model that is lasting, effective, replicable, and networking (scarce in rural areas) resources of helpers at many levels - from neighbor help and informal groups, to public sector organizations and NGOs.

The provision of long-term, palliative and hospice care was intertwined, changing and adapting to the times and needs that these times brought. Hence, we, as the successors of this tradition, dare to claim that even today, the ways of institutionally providing support to chronically and incurably ill people are not a finally and forever shaped reality. They can and should change and realistically respond to the needs of terminally ill, dependent and dying people.

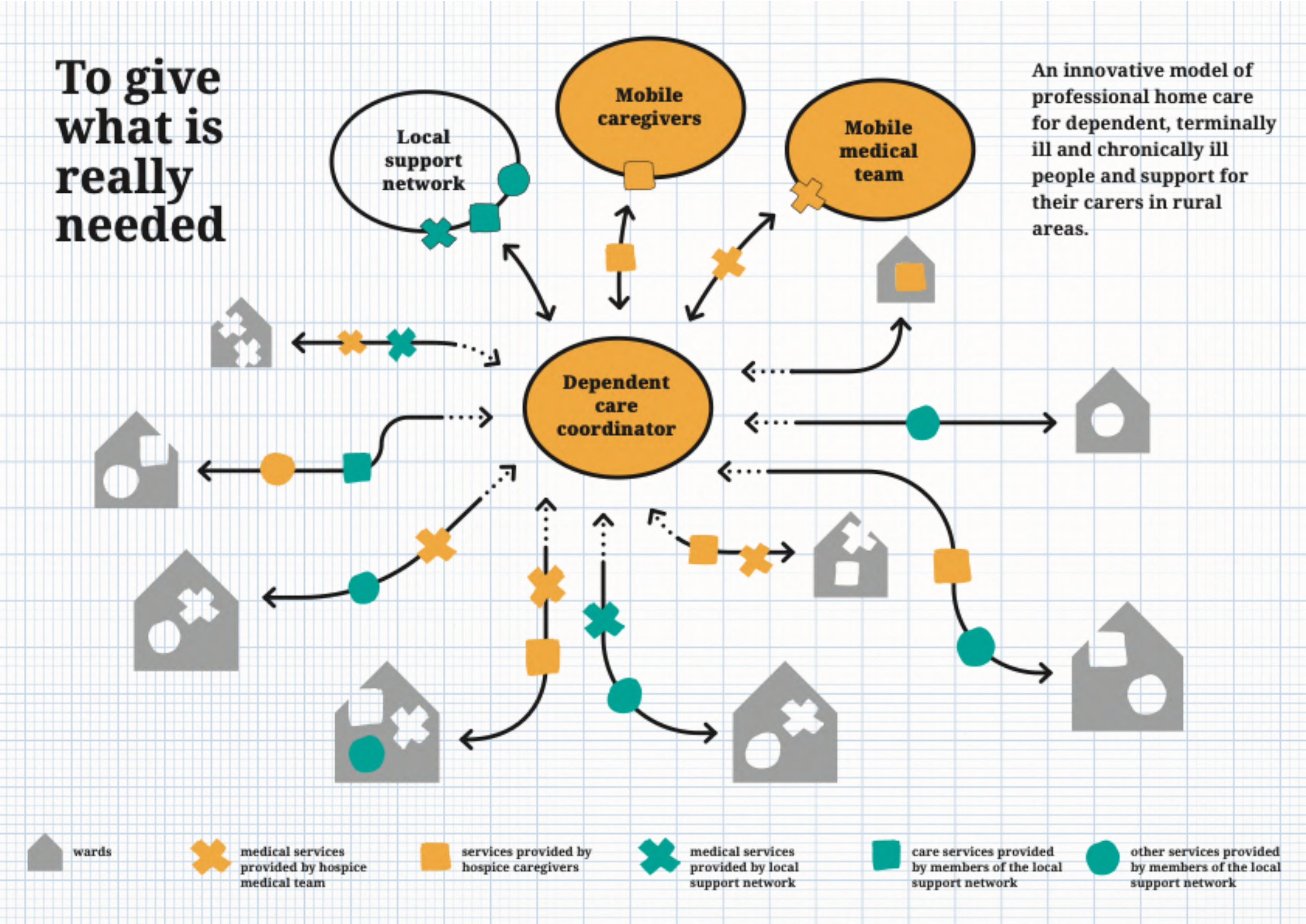
In addition to consenting to the existence of public institutions and units in which the possibilities of action are regulated and somehow limited by rigid regulations, we must also allow those hospices to operate that still cultivate the tradition of helping old and dependent people, regardless of whether the code of the disease entity qualifies them for care financed from the public funds. Institutions operating in places where these people will not receive any other help - due to the inefficient system, the fragility of specialist staff, long distances, or the poverty of people in need of help. After initially having tested our innovation, we will want to share its effect with others, like a recipe. Maybe this is not the only way, not the only cure for the problems of people from the group we care for. We know that our method will not work if used alone, taken out of the social context, without the involvement of institutions and local communities. Together with a group of innovation Partners, we provided the necessary research so that they would want to engage in these activities with full conviction.

There are several arguments for implementing testing of such a model of functioning of a rural hospice. We are convinced that:

1. It will meet the real health needs of this group of rural residents.
2. It gives you the opportunity to respond flexibly to the needs of the clients.
3. It offers a professional, high-quality "service" tailored to the needs of the beneficiaries.
4. It rationalizes (reduces) the costs of care.
5. It shows the real effectiveness of the care provided.
6. It allows you to avoid artificial contracts that satisfy only institutions and officials and function only "on paper".
7. It can be multiplied and duplicated and in the future it may serve other units operating in rural areas with similar health needs.

This model is an implementation of an approach that should form the basis of the philosophy of joint action of social care and health care. It combines these two areas, enabling a holistic approach to patients and residents. At the same time, it implements the principle of supporting dependent people in their local community and avoiding, as long as possible, placing them in social welfare homes or inpatient hospices.

The result of the task are the recommendations presented in this publication on how to provide care for chronically and terminally ill people - residents of rural areas - in their homes.



An innovative model of professional home care for dependent, terminally ill and chronically ill people and support for their carers in rural areas.

Source: Prophet Elijah Hospice Foundation

# II. Old age, illness and dying in the countryside. Conclusions from four years of field work

## 1. About the problem and the proposed solution

Demographic changes, taking place in the European Union, indicate that the aging of its inhabitants has been a constant trend for a long time. This is due to many factors: a later age of starting a family than before, fewer children being born, and medical progress allowing for a longer life. Some regions of the EU are aging faster than others, also because of the outflow of young inhabitants and related to this extremely low birth rate. In these places, we can often observe the disappearance of services, commercial ones, due to their decreasing profitability and public ones due to low tax revenues (Bem, Ucieklak -Jeż, Prędkiewicz 2013, 2014, 2015; Bennett, Probst, Vyavaharkar, Glover 2012; Casey, Thiede Call, Klingner, 2001; Frączkiewicz-Wronka, 2004; Goins, Williams, Carter, Spencer, Solovieva, 2005; Guagliardo, 2004; Krawczyk-Sołtys, 2014, Łuków et al. 2021). In the face of such changes, the situation of seniors remaining in areas where the processes described above take place seems to be particularly difficult (Roksandrić, Sikoronja 2021; Watts et al. 1999). They are deprived of access to services that may determine their health or quality of life. This problem is becoming so urgent that the need to implement ways of dealing with the effects of the described processes has become the focus of the European Commission's attention. By announcing the *Call for proposals on social innovation and national reforms - long-term care,* the initiatives were looked for that could become model solutions as the most promising answer to existing needs. The call announced in 2019 received several dozen initiatives - innovations, of which seven were selected for testing. Among them was one from Poland - the innovation *"To give what is really needed"* implemented by a consortium of 4 partners.

According to the National Population Census (2021), approximately 60% of the population of the Republic of Poland currently lives in the cities, and 40% in rural areas. According to demographic forecasts, by 2050 the population of cities will decrease by as much as 17.4%, while the population of rural areas will decrease by only 1.8%, which is due to a higher fertility rate in rural areas than in the cities and migration from the cities to suburban areas statistically classified as the villages. However, not everywhere the data regarding rural areas are so optimistic. In terms of districts (poviats), the population will increase in districts surrounding provincial capitals and decrease in cities and districts distant from them, which will be mainly related to migration from the cities and peripheral areas to suburban areas and the sprawling of the cities themselves. What does the readiness of rural areas to welcome new residents look like from a health care perspective? According to the Central Statistical Office (GUS) report "Rural areas in Poland in 2020", there were 4.6 thousand clinics in rural areas in 2020, which accounted for 21.5% of all facilities in Poland. Since 2010, 440 of them have been opened. In turn, in the cities, in 2020, there were almost 16.9 thousand (16,866) clinics, and over 10 years their number increased by 4,448, i.e. more than ten times compared to rural facilities. This means that per 10 thousand people, there are 3 health care facilities for the inhabitants of rural areas, and in the cities this ratio is almost 6.5. Therefore, access to basic medical services is not equal (see also Ucieklak-Jeż, Bem 2017). When it comes to highly specialized hospital care, it is understandable that it would be irrational to disperse resources, equipment and a few specialists (see, among others, Siedlecki Bem, Ucieklak-Jeż, Prędkiewicz 2017) and it is better to manage only a few, but highly specialized centers. However, it is very important that access to them is possible for everyone. It is worth looking at the data on primary health care provided in clinics, which should be located close to where we live. Residents of small towns should be able to easily reach these facilities, both for help and for referrals to further treatment by specialist physicians.

A special type of medical care is that provided to people at the end of life. Nowadays, the prevailing opinion is that the best solution - both from the perspective of the senior's satisfaction, but also from the perspective of reducing the costs of care - is for an elderly person to function at home for as long as possible, and not in a care and treatment facility. The Polish government also announced such assumptions in 2021, postulating a shift from care in large institutions to providing support in the local environment, at the place of residence - this is the main assumption of the "Strategy for the development of social services"[1]. At the same time, in rural communes, a long-term home nursing care is less frequently available, which is important from the perspective of chronically ill and dependent patients, under which the patient receives help at home[2]. The reason is that many rural clinics lack a sufficient number of employees who could provide this type of services. This is due, among other things, to the fact that the Act, when regulating the issue of employee remuneration, does not provide for the need to travel to the patient by one's own means of transport, and also to the fact that this transport takes much longer in rural areas due to the scattered housing. Employee remuneration does not take into account travel time for the service provided, which means that the employee may make fewer visits or (contrary to the regulations) shorten them, including the time spent on travel in the duration of the service. The system of financing medical or care services does not take into account specific conditions sometimes occurring in rural areas. For similar reasons, patients living in rural areas have difficult access to home hospice care. The results of research from 2012 (Dziechciaż et al. 2012) suggest the need to increase seniors' access to long-term care and comprehensive geriatric care aimed at the various needs of older people and their caregivers.

Rural areas struggle with many problems resulting from their disparity situation. This situation is the result of many years of neglect, combined with demographic processes: aging of the population, migration of young people to the city, single-generation families, singularization of old age. The aging population is associated with an increase in the incidence of incurable diseases that limit the fitness and independence of seniors. The approach to health and treatment in agricultural communities (compare: Szpak 2016) and the degradation during the crisis of the 1980s and the post-communist transformation of the system of health care facilities in rural areas built in Poland after World War II (Jarosz, Kosiński 1995; Jastrzębowski 1994) make that the health care conditions of rural residents are not satisfactory. The crisis situation is deepened by the disappearance of public services, the high costs of private services and their centralization in the cities. The lack of convenient public transport, especially in peripheral areas, deepens the crisis (Ciechański 2021; Wolański et al. 2016).

The aim of the activities undertaken in the innovation *To give what is really needed* was to test an innovative approach to providing long-term care for elderly and dependent people, chronically and terminally ill in rural areas, affected by depopulation and rapid aging of inhabitants. In this publication, we present selected results of scientific research carried out during the implementation of the innovation and during actions taken to ensure that the proposed innovation becomes an element of social policy at the national level. Extended results and analyzes were presented to the Consortium members in partial working reports prepared during the work and were included in a publication summarizing the completed research.

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[1] https://isap.sejm.gov.pl/isap.nsf/DocDetails.xsp?id=WMP20220000767

[2] Regulation of the Minister of Health of November 22, 2013, on guaranteed benefits in the field of nursing and care services within long-term care (Journal of Laws of 2015, item 1658, as amended)

The proposed innovation consisted in the development and implementation of a network care system and was intended to be a response to the specific problems of rural areas and the communities inhabiting them, described above. A team of employees of the Prophet Elijah Hospice Foundation faced them in their daily work, operating in five communes of eastern Podlaskie. It was this institution that became the leader of the Consortium implementing the innovation. The key stage of innovation was the construction from scratch of a multi-level, lasting partnership model of local institutions, the so-called network. "Networking" covered state and non-governmental institutions providing care and providing professional medical and social support. In addition, the position of a local Dependent Care Coordinator (KOOZ) was created. The purpose of its creation was to coordinate activities leading to improvement of the possibilities and quality of cooperation and the availability of services addressed to elderly and dependent people and people who take care of them on a daily basis.

Photo: A. Dowgier - Home hospice team of the Prophet Elijah Hospice Foundation

In rural areas, it is much more difficult to obtain access to specialist support. Therefore, an additional benefit of the implemented model was to strengthen the available resources of professionals who should provide the most adequate support possible, responding to the real and well-diagnosed needs of the innovation beneficiaries. As a final result of the task implementation, recommendations were developed together with provincial and national entities and authorities, containing assumptions regarding the necessary systemic reforms, the construction of the long-term care system and care for terminally ill and dependent people and their caregivers - in their homes and in the countryside. The innovation was implemented in an area where the processes taking place throughout Poland are particularly advanced - aging of the population, depopulation of rural areas and disappearance of services. If forecasts, regarding demographic changes, in the coming years are confirmed, these processes will also progress over time in other regions of Poland and the European Union. The solutions developed in the Podlaskie region can therefore be treated as an attempt to prepare for what is coming in the "laboratory" conditions, where changes and processes are already at a much more advanced stage.

## 2. About research

The subject of research in the project entitled "To give what is really needed" was the method and context of implementing the innovation, as well as its effectiveness and validity. The research procedure was planned in such a way as to enable the analysis of activities undertaken by members of the team responsible for implementing the innovation within its three main components, i.e.

**A.** Creating an interdisciplinary team within hospice home care consisting of doctors, nurses, physiotherapists, caregivers, a dietician and a psychologist,

**B.** Building a cooperation network of local formal and informal institutions/organizations providing services to the elderly, terminally ill and dependent people,

**C.** Creating the position of a Dependent Person's Care Coordinator (KOOZ).

When designing scientific research, a reference was made to the principles of the comparative method. This method involves searching, describing and explaining similarities and/or differences between two entities. In our case, these are two institutions: the one that implements the innovation - the Prophet Elijah Hospice Foundation - and the one that does not implement it and operates in a standard way. In this project, the role of the second institution - the control/comparison institution - was played by NZOZ "Nadzieja" (the full name of the facility in Polish is Niepubliczny Zakład Opieki Zdrowotnej "Nadzieja" which means Non-public Health Care Institution "Hope"), that operates in the Podkarpackie Voivodeship. The study covered employees of this institution and local authorities from selected communes in which it operates. Research on the control unit and its institutional environment made it possible to compare the satisfaction of employees of both institutions in various work-related aspects, to learn about their expectations and workload, and finally to check what other forms of support the residents of both institutions can use in their place of residence.

The research was also dynamic. Some of them were repeated periodically in order to analyze changes occurring during the implementation of the innovation. At the FHPE hospice, the employee survey was conducted four times (2021, 2022, April 2023, September 2023) to capture changes in the opinions and needs of the FHPE employees at the beginning of the implementation of the innovation, during it and at the end of this process. However, in NZOZ "Nadzieja" (i.e. "Hope" facility), the survey among employees was carried out twice - in 2022 and 2023, using the employees' availability and their consent to participate in the survey.

Our research was based on a combination of elements of *Participatory Action Research*, which recommends techniques such as (1) describing/documenting reality and (2) its contextualization, and *Social Innovation Biography*, recommending, among others, the network analysis, interviews/surveys with various actors. Our analyzes used the triangulation of research techniques to analyze and then describe individual elements of the implemented innovation as comprehensively as possible.

Table 1. Research methods and techniques used

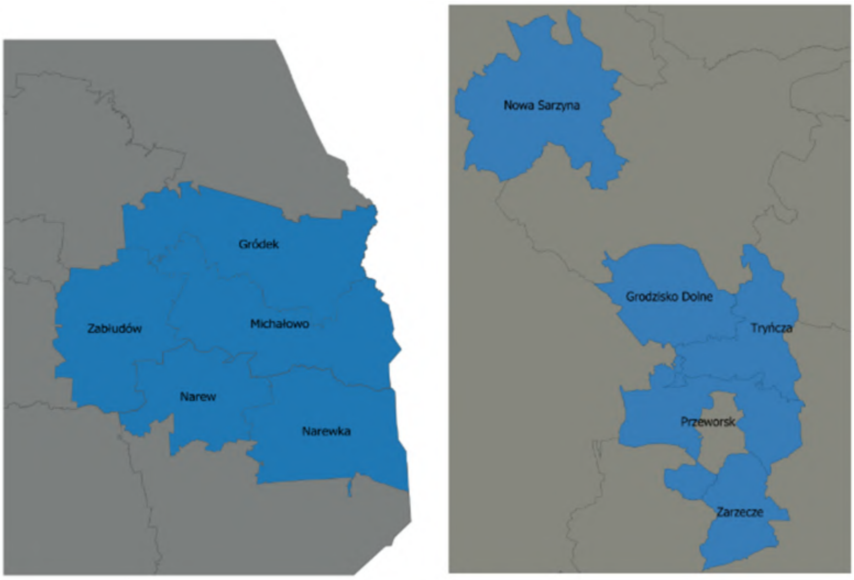
| | |
|---|---|
| **A.** Creating an interdisciplinary team as part of hospice home care, consisting of doctors, nurses, physiotherapists, caregivers, a dietician and a psychologist. | ● Desk research,<br>● Research on hospice employees,<br>● Individual in-depth interviews with hospice employees,<br>● Individual interviews with health care and social policy experts,<br>● Participant observation |
| **B.** Building a cooperation network of local formal and informal institutions/organizations providing services to the elderly, terminally ill and dependent people. | ● Desk research,<br>● Individual interviews with local leaders,<br>● Research on hospice employees,<br>● Individual interviews with health care and social policy experts,<br>● Sociometry,<br>● Participant observation |
| **C.** Creation of the position of a Dependent Person's Care Coordinator (KOOZ) | ● Desk research,<br>● Research on hospice employees,<br>● Interviews with a person in the position of KOOZ,<br>● Individual interviews with health care and social policy experts,<br>● Participant observation |

*Source: own study*

The specific context of the implemented innovation is determined by the units in which the Prophet Elijah Hospice Foundation operates. These are five communes located in the Podlaskie Voivodeship: Michałowo (urban-rural commune, Bialostocki poviat), Zabłudów (urban-rural commune, Bialostocki poviat), Gródek (rural commune, Bialostocki poviat), Narew (rural commune, Hajnowski poviat) and Narewka (rural commune, Hajnowski poviat).

Fig. 1. Communes where the research was carried out

*Source: own study*



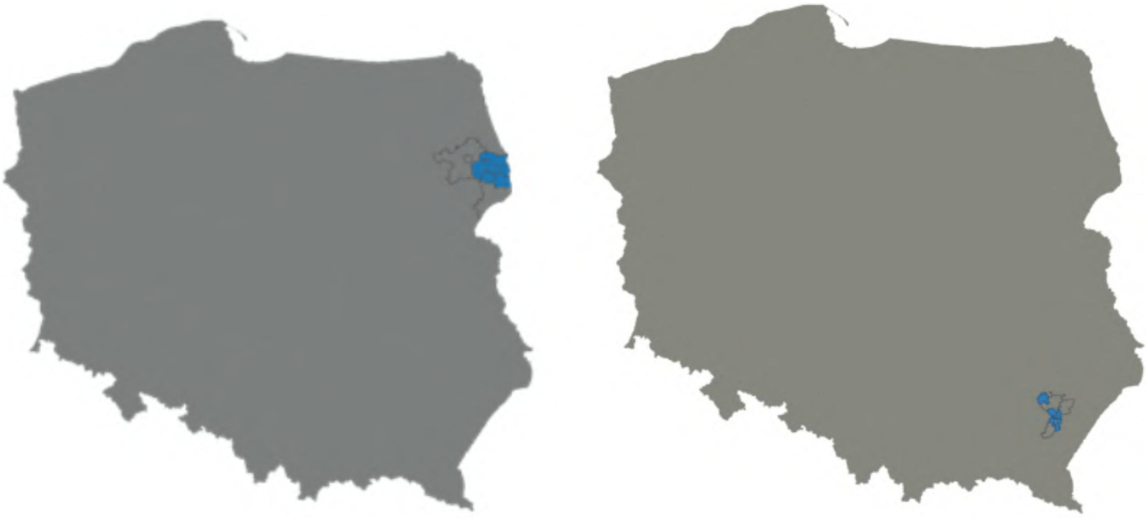


Fig. 2. Communes where the research was carried out, marked on the map of Poland

*Source: own study*

However, the comparative institution - NZOZ "Nadzieja" (i.e. "Hope" facility) - operates in a more extensive area than the FHPE hospice and provides care to more people. It was impossible to cover all of them, so five communes were selected, where the facility's patients are numerous. Efforts were made to ensure that the communes selected for analysis were similar to the types (urban-rural and rural) of communes in which the FHPE hospice implementing the innovation operates, which ensured greater comparability of the contexts of operation of the two facilities. Ultimately, the research covered the following communes: Nowa Sarzyna (urban-rural commune, Leżajski poviat), Grodzisko Dolne (rural commune, Leżajski poviat), Przeworsk (rural commune, Przeworski poviat), Tryńcza (rural commune, Przeworski poviat) and Zarzecze (rural commune, Przeworski poviat).

The research covered the team of the institution implementing the innovation (Prophet Elijah Hospice Foundation (FHPE)), a psychologist working with the Foundation's team, the Dependent Person's Care Coordinator appointed as part of the innovation, local institutions that have created a cooperation network, local leaders in the communes in the area where the innovation has been implemented. In addition, the patients of the institution implementing the innovation were also indirectly surveyed, regarding their needs and expectations. The indirect way of examining them resulted from the specificity of this group - most of them were dying and/or seriously ill people. Therefore, when obtaining information to describe their condition, as well as how the implemented innovation affects them, we used data collected for the needs of other entities - primarily for the needs of the Dependent Person's Care Coordinator.

## 3. The most important research results

The research description has been adapted to the main elements of the new model of professional home care for dependent, terminally and chronically ill people and support for their caregivers in rural areas, implemented as part of the innovation. It consisted of the three elements already mentioned.

**A.** Creating an interdisciplinary team as part of hospice home care, consisting of doctors, nurses, physiotherapists, caregivers, a dietician and a psychologist.

- The analyzes indicate market deficits in medical professions in both surveyed locations, but in the Podlaskie Voivodeship the situation is clearly more difficult.

Table 2. Relationship between available employees and employers' needs (2022)

| | **Podlaskie Voivodeship** | **Bialostocki district** | **Hajnowski district** | **Podkarpackie Voivodeship** | **Leżajski district** | **Przeworski district** |
|---|---|---|---|---|---|---|
| Physiotherapists | balance | deficit | deficit | deficit | deficit | deficit |
| Doctors | deficit | deficit | deficit | deficit | balance | balance |
| Carers of an elderly or disabled person | deficit | deficit | deficit | balance | balance | balance |
| Nurses and midwives | deficit | deficit | deficit | deficit | deficit | deficit |
| Psychologists and psychotherapists | balance | balance | deficit | balance | balance | balance |

*Source: own study based on the "Occupation Barometer" data*

The situation on the labor market means that FHPE has seen a higher rotation of employees who were looking for better-paid and less burdensome work. For many of them, FHPE is not the only place of work. For the Prophet Elijah Hospice Foundation, this means the need to look for employees in a larger area, which in turn generates higher operating costs.

- The average monthly cost of FHPE care per patient - in the various analyzed variants and using real FHPE rates and reference rates specified by the National Health Fund - is from one third to one fifth lower. However, the conducted research shows that the rates of specialists in hospices operating under the National Health Fund contracts are higher than the minimum rates indicated by the National Health Fund. Tailor-made, more flexible care provided to FHPE patients was cheaper. They were often suffering from diseases other than those on the National Health Fund's list, which could reduce some of their needs. However, flexible care in the wider context of staff shortages can lead to the risk of insufficient care, when there is a lack of appropriate control and management.

- The employee labor market causes various types of irregularities to appear in professions where there is a shortage of specialists. For example, employing the same person at FHPE and another facility resulted in him or her giving priority to providing care within the institution where he or she could receive higher remuneration.

- The element of the innovation, which was planned to take care of their mental well-being, was of little interest to employees. This can be explained in various ways. On the one hand, there are cultural conditions in Poland - still found in the countryside, even in the environment related to care or medicine, such as reluctance to use the help of a psychologist (or psychotherapist or psychiatrist) as a sign of weakness. On the other hand, during the implementation of the innovation in the FHPE team, results in the burnout test improved and the risk of burnout decreased. Perhaps, psychological support was not really needed in this particular group after all.

**B.** Building a cooperation network of local formal and informal institutions/organizations providing services to the elderly, terminally ill and dependent people.

- The network of local institutions created as part of the innovation is in practice five networks operating in each commune. This arrangement results from the specific nature of the administrative division and the tasks assigned to local government bodies. This was supported by the fact that FHPE operates in a wide area, and the attempt to maintain close contact between network members and contact between institutions and the Dependent Person's Care Coordinator (KOOZ) using the network's resources determined the arrangement of these networks, i.e. 1 commune - 1 network.
- The most active actors in the networks were those under the authority of the local government, and it was more difficult to mobilise other actors.
- Building the network was hampered by external factors - activists' involvement in other issues (COVID-19 pandemic, crisis on the Polish-Belarusian border, Russia's attack on Ukraine).
- The value noted during participant observation that emerged during the construction of the network is establishing relationships, improving communication, and building trust between people involved in cyclical meetings organized by KOOZ. The process of creating the network has begun, but it will be long-lasting. Its durability may be hampered by the rotation in the positions in entities involved in the network.

**C.** Creation of the position of a Dependent Care Coordinator (KOOZ).

- The tasks carried out by KOOZ were very diverse - they included administrative, legal, logistic, orderly and care matters. An important responsibility of KOOZ was monthly visits to patients, which built a sense of security, allowed monitoring their needs and facilitated communication with the FHPE team.
- Recruiting for the KOOZ position a person who is familiar with local conditions proved to be an effective solution.
- KOOZ's activities covered a relatively small number of people - they concerned mainly those under their care who did not have sufficient care in their place of residence and reported many different needs. In this case, KOOZ repeatedly replaced the family or employees of existing institutions in carrying out tasks.
- Research shows that the main task of the dependent person's care coordinator in the future should be to manage available services at the local level (commune, district). These services should cover the widest possible scope, i.e. social, welfare, medical and rehabilitation services.
- Failure to embed the coordinator within existing institutions may adversely impact on his/her ability to act. Placing the position of KOOZ within the structures of existing institutions: municipalities, health care or social policy, may increase the effectiveness of his/her activities,

especially in dealing with different actors operating within a strictly defined regulatory framework.

## 4. Conclusions and reflections from the research

- The innovation provides care for chronically ill and dependent people and their carers through a new model of hospice care in rural areas in the event of failure of the health and social care system resulting from the changes taking place in rural areas.

- The innovation combines activities subject to the provisions of two orders: social policy and health care. Trying to connect them at a micro level for this innovation was difficult. Social policy has institutional representation at the commune level and the solutions available in the social welfare system are managed at the local level. The situation in the health service is more complicated because at the commune level there are no entities having a real impact on changes in the healthcare system, and responsibility for providing medical services is dispersed. When services are no longer available, it is difficult to identify those responsible for these shortcomings.

- The care provided as part of the innovation allows for a flexible approach to various life situations of the patients. For example, during winter trips to family, medical and care services at home are suspended, but the patient may receive Christmas packages provided by donors. This is beneficial from the perspective of the beneficiaries, but from the point of view of the current health services contracting system, it is difficult to introduce as a standard practice.

- Where the social welfare system works well, KOOZ is less involved in aid activities (example of the Zabłudów commune). The need for such a position did not appear in the expectations of the employees of the control institution.

- Even though in Zabłudów the problems of seniors are not priorities in strategic documents and in the opinions of local authorities, there are factors that make the situation of dependent people better than in other communes. Apart from objective factors (such as location and accessibility to Białystok), the presence of one institution that notices problems and actively works for dependent people (MOPS i.e. Municipal Social Welfare Centre) turned out to be important. This means that the support system for dependent people is more efficient than in other communes. According to research, what is crucial in this case is a competent manager who actively obtains funds and organizes help. The quality of the institution's operation should not depend on the competences of individuals, but should be built into the system.

- The consequences of the dispersion of causality in health care were evident in the work on translating the innovation into national policy. Work in the area of social policy was more efficient than in matters related to health care.

- It turned out to be problematic to expand the medical team to include a psychologist whose task was to ensure the mental well-being of FHPE employees. Few employees were interested in the offer of psychological support. This may result from the work ethos prevailing in Poland, which values heavy workload. If employees wanted to reduce the number of hours worked, many patients could be left without care (thanks to employment in many facilities and in many jobs, patients receive help, at the expense of overloading employees).

- Introducing sustainable, innovative solutions is difficult without ensuring stable, reliable sources of financing.

- Project financing interrupts institutional continuity (even at the level of the name of the implemented activities). In practice, apparent changes are often introduced in activities in order to obtain funds in new, subsequent calls for proposals. Instead of building lasting, predictable solutions, a pool of short-term, dispersed and duplicative actions is created.

- Building a lasting, institutional-based change that interferes with two orders: health care and social policy, is not possible from the grassroots level. Without confronting the crises in health care and social policy (in which the first actions have already been taken for dependent people and seniors), this will not be possible at all.

- The health care system operates on the basis of financial and staff deficits and assumes consent for individuals to work in the public and/or private care system. Depending on the patient's financial capabilities, help can be obtained in the public system (slower, free of charge) or private system (faster, for a fee). In the case of end-of-life care in rural areas, obtaining help in both systems may be difficult or impossible.

- Existing deficits are exploited by individuals who benefit from it because they have built their life strategies into an inefficient system and defend existing solutions and resist change.

- There is a risk that activities implemented as part of the innovation will be used as a replacement for other facilities that should operate in the area of health and social care.

- At the micro level, at the grassroots level, the innovation is needed and works well where there are clear deficits in the functioning of the existing national social and health care systems. Innovation activities can temporarily solve emerging problems, but including them in a system that causes deficiencies would require a policy/system reform. This requires actions at the macro level that will be long-term and will take into account those elements of the innovation that have proven to be effective and efficient in a crisis situation.

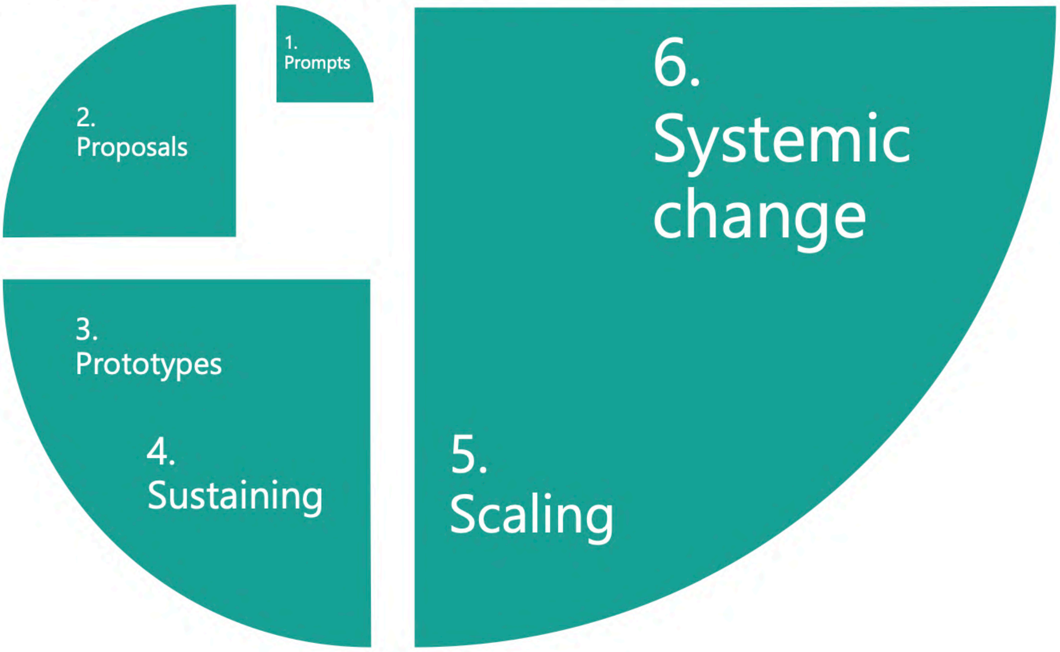


Fig. 3. Innovation as a process: "innovation spiral"

*Source: Komorowska, Wygnański (2010); adapted from Murray, Caulier-Grice, Mulgary (2010)*

- Referring to the above model presented by Murray, Caulier-Grice, Mulgary (2010), elements 1 - 3 of the innovation can be implemented at the micro level, in a *bottom-up* approach. However, ensuring the durability of activities (point 4, ensuring sustainability), in the opinion of the respondents, requires certain sources of financing, and the competition system is not considered as such. According to research, points 4 and 6 require a change in the system and policy at the country level. In turn, point 5 (scaling), as shown by FHPE's previous experience, can be implemented gradually, promoting innovative solutions, without nationwide support. However, in this method of operation, scaling institutions obtain funds for innovative activities through the competition system.

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# III. Proposal of recommendations developed on the basis of the tested care model

## PROPOSAL OF RECOMMENDATIONS DEVELOPED ON THE BASIS OF THE TESTED MODEL

**Addressed to:**

Ministry of Health

Agency for Health Technology Assessment and Tarification

National Health Fund

Patients Ombudsman

Ministry of Family and Social Policy

Ministry of Funds and Regional Policy

Department of the European Social Fund

Ministry of Agriculture and Rural Development

Ministry of Education and Science

Ombudsman

Photo: P. Mojsak

# 1. Introduction

People with incurable and chronic diseases staying in their homes, including those in rural areas, have the right, among others, to benefit from:

- primary health care and coordination of health care services provided by a primary care physician, in cooperation with a primary care nurse and a primary care midwife[2],
- therapeutic rehabilitation at home[3],
- coordinated therapeutic services and educational and consultation support for his/her family within the Mental Health Centers[4],

and

- nursing home long-term care[5], and/or
- palliative and hospice care[6].

In addition, they are entitled to:

- using social assistance benefits and social services: care, specialized care services[7], support of a personal assistant for people with disabilities[8],
- and from January 1, 2024, people over 75 years of age after initial geriatric assessment will be able to use health care services specified in the Act on special geriatric care[9].

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[2] Act of October 27, 2017, on primary health care.

[3] Regulation of the Minister of Health of November 6, 2013, on guaranteed benefits in the field of therapeutic rehabilitation.

[4] Regulation of the Minister of Health of June 9, 2023, amending the regulation on the pilot program in mental health centers.

[5] Regulation of the Minister of Health of November 22, 2013, on guaranteed benefits in the field of nursing and care services within long-term care.

[6] Regulation of the Minister of Health of October 29, 2013, on guaranteed benefits in the field of palliative and hospice care. From: "Healthy Future. Strategic Framework for the Development of the Health Care System for 2021–2027, with a perspective until 2030, Annex No. 1 Deinstitutionalization strategy: Health care for the elderly, p. 26 (Appendix to Resolution No. 196/2021 of the Council of Ministers of December 27, 2021): Services guaranteed under palliative and hospice care are provided at home as part of a home hospice or home palliative care teams.

[7] Act of March 4, 2004, on social assistance.

[8] As part of the implementation of departmental programs of the Ministry of Family and Social Policy

[9] Act of August 17, 2023, on special geriatric care.

Families and home carers[10] of people with incurable and chronic diseases have the right, among others, to:

- psychological, informational, instrumental support,
- social assistance and health care services (including telemedicine),
- respite care, support in the form of a temporary stay of a sick person in a hostel, social welfare home, or other entity.

However, the possibility of obtaining support depends on its availability in the place of residence and meeting the conditions for receiving medical care or social assistance.

Unfortunately, despite a number of provisions in the above-mentioned legal acts regarding the right to use health care and social assistance services, as well as the coordination of these services:

- sick people and their home carers do not have full information about the services they are entitled to that provide support in everyday functioning,
- there are no places/people to coordinate services in the commune providing information about the services provided in a given area (commune/district),
- disproportions in access to services between rural areas and cities are still large (according to the Central Statistical Office report[11], data from OZPS i.e. Social Welfare Resource Assessment of communes and poviats/districts and experience from testing the model), despite the increase in access to health care in rural areas,
- differences are also visible between voivodeships.

The crisis situation is deepened by the lack of convenient public transport, especially in peripheral areas, which makes it difficult to access specialist doctors who see patients mostly in county towns (i.e. towns in poviats).

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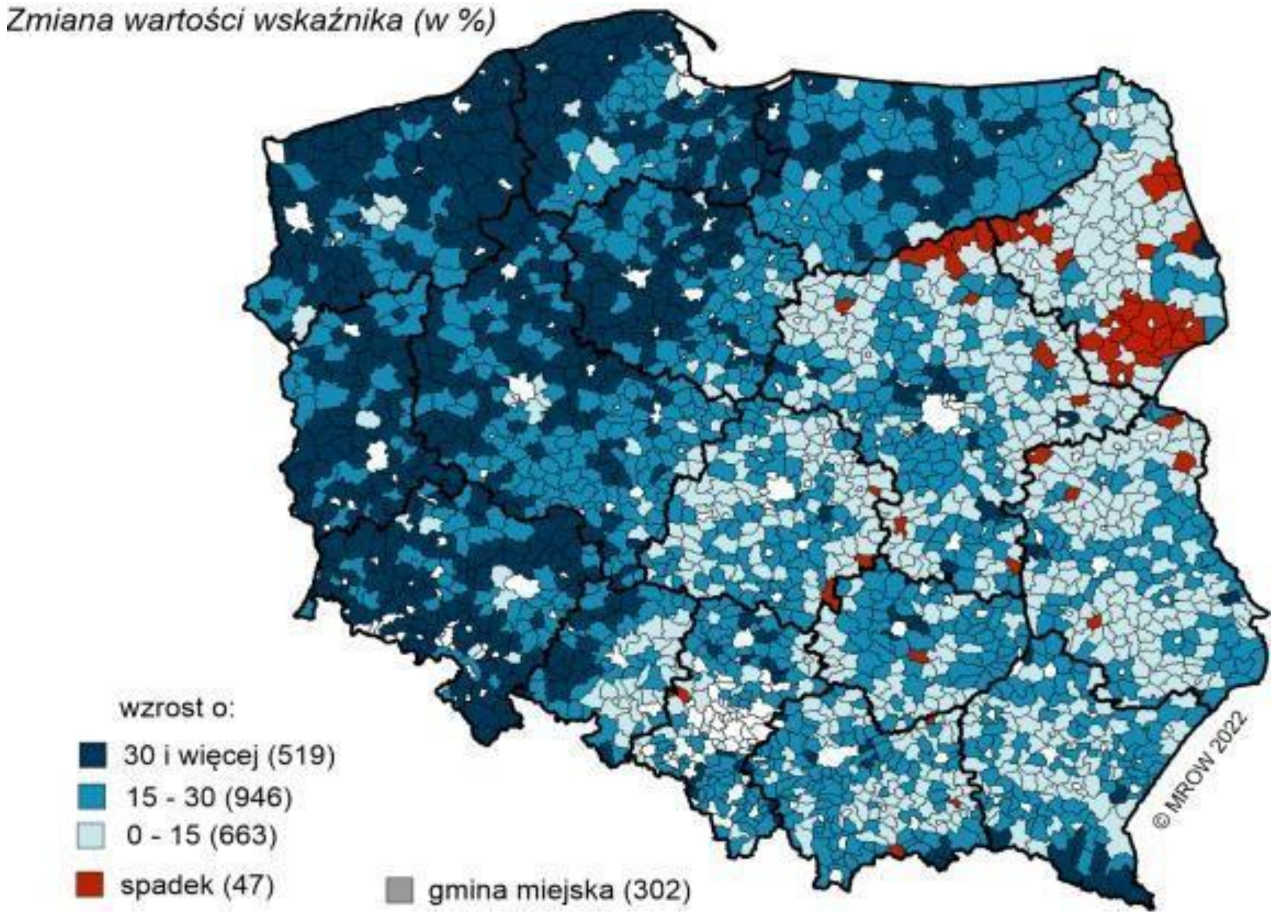
[10] The Model and the developed recommendations assume that a home caregiver (to a narrower extent than an informal caregiver) is an adult who takes care of a dependent person, who is not a professional caregiver and does not receive remuneration for caring for a dependent person, most often a family member. From: Guidelines for the implementation of projects in the area of social inclusion and combating poverty with the use of funds from the European Fund Social and the European Regional Development Fund for 2014-2020, Minister of Investments and Development, Warsaw, July 8, 2019, p. 9. In Guidelines, an informal caregiver is also referred to as an actual caregiver

[11] Central Statistical Office report "Rural areas in Poland in 2020", among others, indicates that in 2020 there were 4.6 thousand clinics, which accounted for 21.5 percent of all such facilities in Poland.

Figure 1. Change in the value of the W21 indicator (percentage of population at post-working age) between the Monitoring of Rural Development 2014 and the Monitoring of Rural Development 2022



Source: Foundation European Fund for the Development of Polish Villages Institute of Rural Development and Agriculture of the Polish Academy of Sciences, Monitoring of Rural Development Stage IV, Warsaw 2023

Residents of rural areas struggle with unfavorable demographic processes: population aging, depopulation, migration of young people to the city, single-generation families and even singularization. Aging is associated with an increase in the incidence of incurable diseases that limit fitness and independence.

The conditions indicated above required the development of a model of flexible, individualized, coordinated home care for people with incurable and chronic diseases and support for their home carers in rural areas.

Among the patients of 528 hospices for adults, only less than 9% of patients received services from entities operating in rural areas.

It was assumed that among older people with incurable diseases, access to medical and assistance services could be increased by expanding the group of home hospice recipients, flexibility of the composition of the hospice care team and introducing coordination of these services.

Home hospice care, financed by the National Health Fund, in practice depends on 4 elements:

1. accessibility of the facility and/or distance to the sick person's place of residence,
2. a disease entity from the catalog of diseases qualifying for the provision of guaranteed benefits in the field of palliative and hospice care,
3. a limit specifying the maximum level of financing by the National Health Fund for services provided by the entity,
4. ensuring appropriate home conditions and trained home caregivers in the field of care and maintenance.

Even if these conditions are met, the currently proposed package of benefits under the National Health Fund is "rigid", sometimes too excessive and uncoordinated.

The preparation of a targeted and holistic package of medical and social services provided in the home environment is part of the ongoing deinstitutionalization process. Implementation of coordination of activities addressed to home hospice patients and terminally and chronically ill people outside home hospice, as well as their families, dissemination of access to information on medical and social services and securing their implementation by a competent care coordinator affects the satisfaction of real needs and improvement of the quality of care for dependent persons.

Photo: P. Mojsak

## 2. Tested model and its elements

The model of professional home care for people with incurable and chronic diseases and support for their home carers in rural areas was tested by the Prophet Elijah Hospice Foundation in Michałowo (FHPE).

During 30 months of testing the Model, admission to home hospices and the coordinated, flexible provision of services tailored to individual needs were decided by a doctor together with the home hospice care team, after recognizing the situation of the dependent person and his or her family/home carers.

During this period, 60% of patients supported were people from outside the 8 disease groups from the National Health Fund catalog. 95% of those under our care were people from rural areas, and access to them was provided within a distance of approximately 40 km from the Foundation's headquarters. Each person and their home carer were covered by an individual, coordinated support plan developed by the Dependent Care Coordinator (KOOZ).

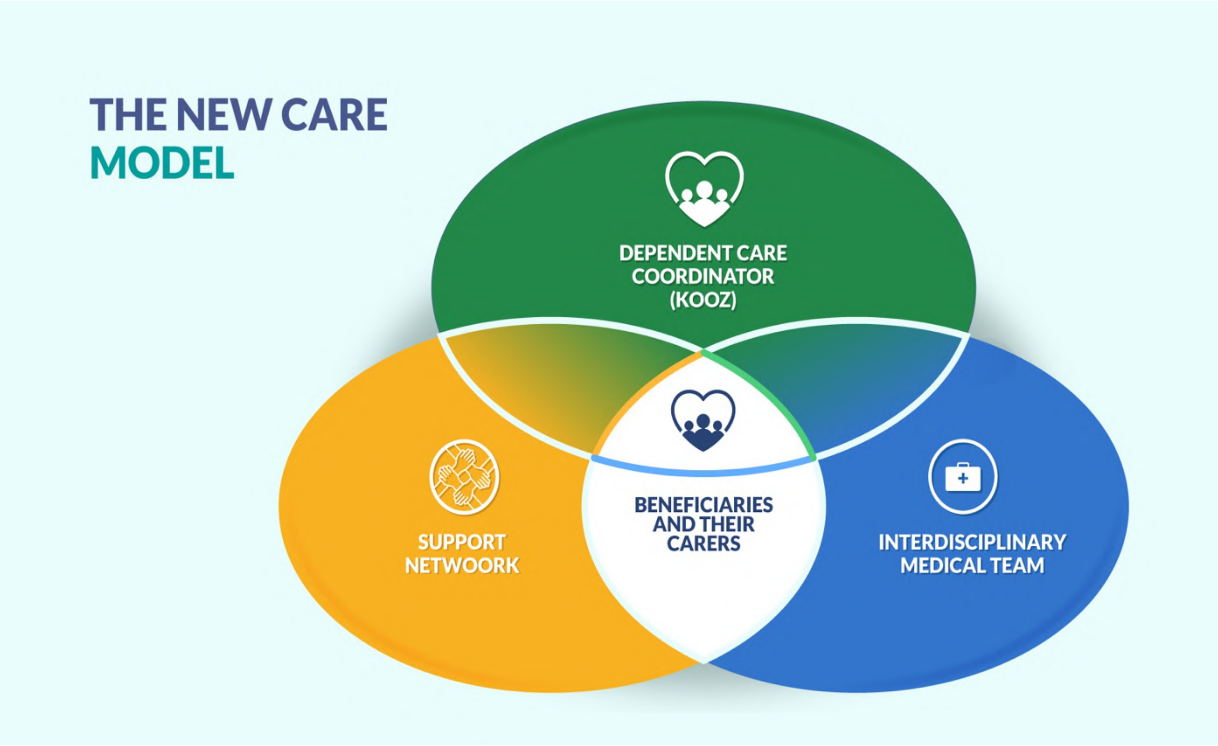


Figure 2. Elements of the new hospice care model at home according to FHPE

Source: Prophet Elijah Hospice Foundation, Michałowo/Makówka

The home care service tested by FHPE foundation introduced four elements:

1. Expanding the group of patients and providing support to their home carers: people admitted to hospice care, by the decision of the medical team, had disease entities "on" and "outside" the National Health Fund list, but according to the doctor and the home hospice team, they qualified for home hospice care, and their home carers for various forms of social support. The nature, frequency and length of activities undertaken were decided by the team, not by a specific limit of services per patient[8]. As a result, more people with incurable diseases were supported by hospice care at home. Hospice services that met their needs resulted in fewer people in the local community requiring systematic care provided by primary care and social welfare centers. The support was also provided to home carers while caring for a dependent person and during the mourning period.

2. The hospice care team in the home environment has been expanded to include a medical caregiver, a dietitian and a KOOZ[9] The team held coordination meetings once a month. Individual team members have contacted each other on an ongoing basis, as needed.

3. Dependent Care Coordinator (KOOZ) – a person in the hospice care team responsible for coordinating social services, building and using a social network, providing support for those under care, among others: social, material (including medical and rehabilitation equipment), renovation and identification and satisfaction of other necessary needs for everyday functioning. Moreover, an important task of KOOZ was to organize for home carers, among others: information and educational support or providing respite care.

4. The network of local entities acting for the benefit of dependent persons and their guardians consisted of public and non-public institutions, non-governmental organizations, informal groups, parishes, local leaders and other residents involved in assistance, organized and coordinated by KOOZ as part of systematic meetings (at least once a quarter) in each of the five communes. After the information meetings, each of these entities submitted a declaration of joining the support network.

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[8] Regulation of the Minister of Health of November 22, 2013, on guaranteed benefits in the field of nursing and care services within long-term care.

[9] Individualized needs were also reported, e.g. a speech therapist or psychiatrist.

The aim of the undertaken activities was to test an innovative model of hospice care at home for people with incurable and chronic diseases and support for their home carers in rural areas in 5 communes, in the range of 25-40 patients a month.

The addressees of the activities are mainly people from rural areas from the communes of Michałowo (urban-rural commune), Gródek (rural commune), Zabłudów (urban-rural commune), Narew (rural commune) and Narewka (rural commune). About 9 out of 10 people receiving benefits under the model were people living in rural areas. Some of the patients were diagnosed with a disease from the list of eight disease entities defined by the National Health Fund and qualifying for home hospice care. The remaining people suffered from diseases that would not qualify them for treatment in a home hospice operating on the basis of the principles set out by the National Health Fund. These people include, for example, a person after a stroke, a person with severe dementia and aphasia, or a person after a limb amputation.

The communes where the model was tested differed in terms of the actual use of medical and social services. However, in all communes there is no access to long-term nursing care. Another problem for residents who need support is the lack of specialist doctors in rural areas. There are also few entities providing commercial medical services, and access to rehabilitation equipment rentals and pharmacies is limited.

In the five communes surveyed, the needs of the residents were different and the offer which they could make use of within the existing healthcare system differed. Where the system worked efficiently and was supported by other institutions, the demand for innovation services was lower. The greater demand for services as part of innovation is related to many factors: low involvement in the care of people with dependencies by local authorities, shortages on the labor market, weakness of the system offer (e.g. long waits for visits to doctors or physiotherapists, inability to use existing forms of assistance due to communication and infrastructure difficulties, etc.), few non-governmental organizations.


Photo: A. Dowgier

The analysis of data from the testing of innovation allows us to conclude that it improves the quality of services by:

- increasing the number of network entities/intensifying social contacts in institutions providing social and medical assistance,
- strengthening and supporting home carers of dependent people,
- coordinating and increasing access to hospice care in rural areas and
- reducing the costs of care for terminally and chronically ill people, with a more flexible approach to care, not subject to the rigors of the National Health Fund.

The innovation model is consistent with the assumptions of the documents: "Healthy Future. Strategic Framework for the Development of the Health Care System for 2021-2027, with a perspective until 2030", especially with the annex "Deinstitutionalization Strategy: Health care for the elderly" and the Act of August 17, 2023, on special geriatric care.

The main goal of the implemented solutions - in the field of care for the elderly - is to improve the quality of life and health of seniors and their carers through the development of human resources, development of forms of day care, home care and innovative forms of care. The support for home/informal carers and coordination of community care are expected.

We believe that the tested model and its four elements can be conducted as part of “redefined” hospice care at home by home hospices, as well as other medical and social entities operating in rural environments[10]. **The extended care model, as part of the new hospice care service at home according to the FHPE model, makes it possible to provide care to a larger number of patients, thereby increasing the availability of home care.**

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[10] Compare R. Bakalarczyk, Long-term and hospice care in Poland, Old problems, new challenges, Report for Caritas, May 31, 2023 (Recommendations in the area of hospice and palliative care, Recommendations on the reform of the care system outside the medical area, Recommendations on support for families and informal caregivers, pp. 66-73).

# 3. General recommendations

Providing comprehensive, in response to the environmental needs, home care for people with incurable and chronic diseases and support for their home carers in the system of medical services and social assistance requires:

1. Coordinated, flexible, tailored to individual needs hospice care at home with the support of home carers implemented by medical entities, contracted by the National Health Fund.

2. Coordinated in the commune, flexible, tailored to the needs of home care for other sick people, with the support of their home carers, implemented by medical and social entities, financed from national funds.

3. During the transition period, i.e. for the duration of the development and implementation of systemic changes: legal, organizational and educational (presented in detailed recommendations), the following is proposed: coordinated, flexible, tailored to individual needs care at home with the support of home carers. This service may complement services contracted by home hospices under the National Health Fund and concern selected elements of the FHPE Model[11]. It can also be implemented according to the FHPE Model by medical and non-medical entities from national funds or co-financed by the ESF.

Photo: P. Mojsak

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[11] New definition formulated during model testing.

# 4. Detailed recommendations

| Condition | No. | NAME OF RECOMMENDATION |
|---|---|---|
| | | GROUP OF PATIENTS AND SUPPORT FOR THEIR HOME CARERS |
| Necessary | 1 | INTRODUCTION OF A NEW DEFINITION AND IMPLEMENTATION OF "HOSPICE CARE AT HOME" ACCORDING TO THE FHPE MODEL<br>Changes are suggested in legal regulations, in publications and work standards of the home hospice team, and in the way care itself and support for home carers is provided.<br>Appendix No. 1. "Template of a questionnaire about the needs of the patient and his/her home caregiver." Popularization of definitions and permissions.<br>Change in the Regulation of the Minister of Health of October 29, 2013, on guaranteed services in the field of palliative and hospice care - based on the definition of WHO (World Health Organization) and the recommendations of AOTMiT (Agency for Health Technology Assessment and Tarification). |
| | 2 | ESTABLISHING A NEW CRITERIA FOR ADMISSION TO HOSPICE CARE AS: "SYMPTOMS AND CLINICAL INDICATIONS DIAGNOSED BY A DOCTOR"<br>Hospice care at home should be AVAILABLE to every patient in the end-stage of their disease and should include symptomatic treatment of patients suffering from incurable, progressive, life-threatening diseases that cannot be treated causally. Development of accreditation standards for hospice care by the Center for Monitoring Quality in Health Care (which will create conditions for accrediting entities providing health services).<br>Change in the Regulation of the Minister of Health of October 29, 2013, on guaranteed services in the field of palliative and hospice care - based on the definition of WHO (World Health Organization) and the recommendations of AOTMiT (Agency for Health Technology Assessment and Tarification). |
| | 3 | INTRODUCING EASIER ACCESS FOR PATIENTS TO STRONG PAINKILLERS AND OTHER MEDICINES<br>NECESSARY FOR SICK PEOPLE STAYING AT HOME THROUGH A NEW DELIVERY PATHWAY<br>Procedure: a specific pharmacy point imports/orders a medicine dedicated to a specific patient and the pharmacist dispenses it based on the patient's electronic prescription.<br>Changes in the Act of September 6, 2001, Pharmaceutical Law. |

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|  | 4 | INTRODUCING A NEW DEFINITION/OR SUPPLEMENTING THE FUNCTIONING DEFINITIONS OF CARE PROVIDED IN HOME<br>ENVIRONMENT BY ELEMENTS SUCH AS: SUPPORT FOR HOME CAREERS AND COORDINATION OF SERVICES<br>Legal regulations, publications and standards should include descriptions of support and coordination of services provided by the hospice team, as well as methods of providing care: community, specialist, long-term, geriatric and other, and keeping records of patients and their home caregivers.<br>Changes in the Act of March 12, 2004, on social assistance, provisions of the Act of July 19, 2019, on the implementation of social services by social service centers, changes in the Regulation of the Minister of Health of November 22, 2013, on guaranteed benefits in the field of care and nursing services within long-term care and in the implementation of departmental programs of the Ministry of Family and Social Policy.<br>Implementation of provisions in the announced terms and conditions of calls for proposals financed from ESF – Managing Authorities and programmes. |
| Optional |  | DISSEMINATION OF THE RESPITE CARE PROGRAMME AND THE PROVISION OF RESPITE SUPPORT TO HOME CARERS<br>AND FORMS OF DAY AND SHORT-TERM STAYS IN RESIDENTIAL HOMES (DPS)<br>Expanding the provisions in subsidy programs and calls for proposals to include availability in each commune, including the "Respite Care" programme. Stability and continuity of support should be ensured, e.g. through changes to the Act of March 12, 2004, on social assistance, guaranteeing receipt of financial and organizational support in the implementation of this type of activities. The program organized by the Ministry of Labor and Social Policy should promote the service in rural areas and include travel to people in rural areas in the cost of the service by increasing the rate. |
| **HOME HOSPICE CARE TEAM** |  |  |
| Necessary | 5 | FLEXIBLE CONTRACTING BY THE NHF (NFZ) OF THE HOSPICE CARE TEAM IN HOME CONDITIONS<br>It is proposed to abolish the rigidity of the team composition. The minimum required composition of the home hospice care team is suggested for negotiations with the National Health Fund: doctor, nurse, **medical guardian,** physiotherapist, psychologist, **KOOZ**_and possibly people for the extended team: dietician, speech therapist, psychiatrist, etc. according to the discretion and local needs. Joining the home hospice team of medical caregivers **(with their now extended competences) will enable the smooth functioning of many hospices presently struggling with shortages of nursing staff).**<br>Introduction by the Minister of Health of an amendment to the Regulation of the Minister of Health of October 29, 2013, on guaranteed benefits in the field of palliative and hospice care, Annex II - a provision on contracting for medical services in the field of hospice and palliative care of medical caregivers in the work of home hospice for adults. |

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| | 6 | INTRODUCTION OF REFERENCE LEVELS FOR HOSPICE CARE TEAMS<br>We propose differentiating the requirements for primary palliative care teams compared to units with higher degrees of reference (as is the case in other medical specialties).<br>Proposed: head of the primary palliative care unit: doctor with specialization in palliative medicine. Others: with a specialist course in the field of palliative medicine, with no limits on the percentage of doctors with specialization or course. Similarly - in the case of nurses.<br>The course program should be consistent with the requirements of the regulation of the Minister of Health on guaranteed services in the field of palliative and hospice medicine contracted by the National Health Fund. |
| | 7 | ENTERING THE COSTS OF TRAVEL TO THE PATIENT AND THE RULES FOR UPDATING THIS RATE IN THE TARIFICATION PLAN BY THE AGENCY FOR HEALTH TECHNOLOGY ASSESSMENT AND TARIFICATION (AOTMiT)<br>Entering the costs of travel into the tarification plan by the Agency for Health Technology Assessment and Tarification (AOTMiT) based on detailed data obtained from healthcare providers and entering the rules for updating this rate.<br>This applies not only to the commuting costs of the home hospice team staff, but also includes the commuting costs of long-term care nurses, home physiotherapists and other specialists. The team at AOTMiT agency should consider different financial scenarios (maximum, minimum, average) in different types of areas (with particular emphasis on peripheral areas). |

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| | 8 | DETERMINING THE WORK STANDARD OF THE HOSPICE CARE TEAM IN HOME CONDITIONS WHILE MAINTAINING THE FLEXIBILITY OF SERVICES<br>“Tailor-made” care, i.e. tailored to the individual needs of the patient, means that the scope of services provided by a nurse and medical caregiver, etc. is decided by the patient's doctor and his/her team, after assessing the patient's condition, always reacting to changes in the patient's health. This ensures the quality of services and their availability, and enables building a service network close to patients and their families. Adapting the type and frequency of services to the individual needs of the patient means reducing the costs of care. At the same time, it will be necessary to introduce mechanisms that will prevent "generating savings" at the expense of providing insufficient care for the patient.<br>**We propose setting the service efficiency limit at the level: one team can provide services at an optimal distance of 40 km from the place/registered office of the entity. One KOOZ (full-time employee) supports a maximum of 30 patients.**<br>This recommendation still requires extensive consultations among hospice teams. |

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|  | 9 | FAMILY DOCTORS' COMMITMENT TO COOPERATE WITH THE HOSPICE CARE TEAM IN HOME CONDITIONS/KOOZ (THE LEVEL OF THE CAPITATION RATE)<br>The obligation to cooperate is one of the conditions for concluding a contract for primary health care services.[12] We propose that the cost of cooperation with the home hospice team should be included in the pricing of this service and the concluded contract, perhaps increasing it accordingly (cooperation with the care coordinator, participation in meetings of the hospice care team, e.g. once a month).<br>Introduction of changes to the Act of October 27, 2017, on primary health care. |
| CARE COORDINATION |  |  |
| necessary | 10 | CREATION OF THE POSITION OF DEPENDENT PERSON'S CARE COORDINATOR WITH SPECIFIC STANDARDS<br>EMPLOYMENT OF KOOZ COORDINATOR AS PART OF THE HOSPICE CARE TEAM IN HOME CONDITIONS<br>Hospice care at home should be coordinated (taking into account medical and social resources available in the patient's local environment). The tasks of KOOZ include building an individual/personalized basket of services addressed to people with chronic and terminal diseases and their home caregivers:<br>• Support for patients and their families (organizational, informational, educational, emotional, material support, and implementation of respite care).<br>• Support for the team and social network entities, taking into account the individual needs of patients and their home caregivers.<br>• Participation in building a network, using resources to increase the effectiveness of help for sick people and their caregivers.<br>Introduction in the Regulation of the Minister of Health of October 29, 2013, on guaranteed benefits in the field of palliative and hospice care in Annex II indicating the requirements for staff in home hospice for adults, point 5) as follows: dependent person's care coordinator - equivalent of 1/2 full-time employment to 15 beneficiaries.<br>KOOZ: at least secondary education, in social studies, experience in environmental/community activities, organization of local communities and cooperation with NGOs. |

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|  | 11 | EDUCATIONAL/METHODOLOGICAL/TRAINING PREPARATION - PROVIDING COOPERATION TOOLS for nurses, primary care caregivers/primary care doctors, care coordinators for dependent persons operating at home hospices or other health care units providing assistance at home, social welfare center's caregivers, employees of other entities. It is suggested to implement the methodology, tools of the Collaboration Models implemented by ROPS (i.e. Regional Centers for Social Policy) in Poland as part of POWER programme funds, and networking experience within the tested FHPE care model. |

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[12] Art. 4 and Art. 5.1 of the Act on primary health care

| NETWORKING OF LOCAL ENTITIES | | |
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| necessary | 12 | INCLUSION OF LOCAL ENVIRONMENT ENTITIES IN ASSISTANCE ACTIVITIES ADDRESSED TO PATIENTS AND THEIR CARERS<br>Creating a network of involved entities in the local environment may be the task of the KOOZ in the commune or the entity providing hospice care at home. Signing declarations or agreements (in accordance with the Cooperation Models methodology) allows to:<br>• make better use of the medical and care and support services available on site,<br>• create an opportunity for quick, effective, flexible and tailored help, provided at the patient's home, which will extend the period of his/her fitness,<br>• and it is a preventive, effective and cheaper action compared to institutional assistance, including hospital assistance. |
| | 13 | BUILDING AND UPDATING SOCIAL SERVICES BASKETS BY KOOZ ONCE EVERY ½ YEAR<br>The social services basket is a list of services available in the commune/district in the area of care for dependent people, terminally ill people and their home caregivers. The task of KOOZ would be to collect information about services, prepare and update a service basket (at least once every six months), and then disseminate it to the community and use it for support and planning of further activities. The basket concerns the commune/district, and the services include health care services, including hospice care at home. Once created, the list of services should be published on the websites of municipalities and poviats. In the hospice service model, meetings to coordinate service lists are the first stage of networking.<br>The list of social services (including access to hospice services) developed by the commune and district specifies social services in the scope referred to in Art. 2 section 1 point 114 of the Act of 19 July, 2019, on the implementation of social services by social service centers and public tasks referred to in Art. 4 section 1 of the Act of April 24, 2003, on public benefit activities and volunteering (Journal of Laws of 2023, item 571), commissioned in the modes referred to in this Act. |
| | 14 | ASSIGNMENT OF COOPERATION IN THE SCOPE OF TASKS IN THE AREA OF HEALTH, INCLUDING HOSPICE CARE AT HOME CONDITIONS WITH POVIAT AND PROVINCE LOCAL GOVERNMENTS, VOIVODES<br>We suggest that the district should be responsible for analyzing needs together with municipalities and for providing hospice care services at home together with health care entities in its area (suggested use of COOPERATION MODELS methodology and tools).<br>The voivodeship government would have the following tasks: participation in creating the document and reporting social needs, the care area to the Health Needs Map and the Health Area Transformation Plan together with the Voivode, preparation and training of KOOZ, organization of training according to the needs reported by teams, supplementary training of medical caregivers, dissemination of support programs, respite care and other social campaigns. It is also proposed to establish a nurse position |

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|  |  | within the ROPS team (in Regional Center for Social Policy), due to the need to organize and supervise training, including the medical caregivers.<br>Voivode - provincial health consultants - for reporting and determining, together with ROPS, the needs in the field of Health Needs Maps, including home care and hospice care at home in communes and poviats (analyses and plans for 3 years), training medical entities, primary care in the field of new hospice care at home and new care at home.<br>Such cooperation would be the first step in combining the areas of health and social policy. |
|  | 15 | CONDUCTING EDUCATION OF VOLUNTEERS, GROUPS AND LOCAL COMMUNITIES IN THE FIELD OF KNOWLEDGE AND SKILLS TO HELP ELDERLY PEOPLE WITH CHRONIC AND INCURABLE DISEASES AND THEIR HOME CARERS (direct or online)<br>Entities providing care or hospice care at home should organize training for home caregivers, neighbors, communities and groups regarding, among others, support for people with dementia, first aid, motivating them to use psychological help, disseminating knowledge about the rights of sick people and their household members. As part of the care teams, KOOZ could coordinate these activities and conduct online consultations. |

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| optional | DISSEMINATION AND EDUCATION ABOUT ALTERNATIVE FORMS OF SUPPORT, SUCH AS NEIGHBOR SERVICES OR<br>TELECARE (campaigns, materials, reports, publications on social media).<br>Changes introduced in the Act on social assistance of July 29, 2023, include definitions and rules of payment for neighbor help, care and other services necessary to organize assistance and support for dependent persons and their caregivers using hospice services. Medical and social entities and KOOZ associated with the home hospice team can apply to the commune for such services or help organize them as part of cooperation in the network.<br>PROMOTING AND REWARDING HOSPICE VOLUNTEERING/HOME HOSPICE CARE<br>Introduction of provisions in the regional cooperation program with NGOs. Introduction of a support system, including: free training for hospice volunteers, financing travel costs to home hospice patients. |

# 5. National recommendations, affecting the development of coordinated, flexible care

1. Introduction of a newly defined service: hospice care at home, an update of:
   - Regulations of the Ministry of Health on guaranteed benefits in the field of palliative and hospice care;
   - Healthy Future Strategy in the area of palliative and hospice care by the Ministry of Health.
2. Introduction of a cyclical analysis of the effects of limiting hospice care services - National Health Fund on the initiative of the Ministry of Health, e.g. an attempt to calculate the burden on the system of additional costs due to the need to provide patients who are not covered by hospice care with services that do not always meet their needs and are more costly (e.g. extended hospital stay) - in this activity, the National Health Fund and the Ministry of Health may be supported by the Patients Ombudsman and the national and provincial consultants for the palliative medicine.
3. Initiating a dialogue between the Ministry of Health and the Ministry of Family and Social Policy in order to determine the directions of development of palliative and hospice care and the target model of functioning of this care - the entity initiating this dialogue may be the Patients Ombudsman. Preparing the health care system and the social policy to coordinate long-term care with hospice care at home as part of the dialogue between the Ministry of Health, the Ministry of Family and Social Policy and the Patients Ombudsman.
4. Developing a research methodology to assess the needs, the scope and the direction of development of services in the area of home care and hospice care at home. Indications and recommendations should include, among others, the number of: people in need of social and medical services, hospice care teams at home (voivodeship/district/municipal level).
5. Cyclical analyzes of the employment level and qualifications of nurses and medical caregivers, taking into account the actual needs of patients in various areas of Poland, conducted by the Health Departments of Provincial Offices.
6. Increasing the number of residency places for doctors specializing in palliative medicine - in 2022, there were 19 of them, and the change requires a regulation of the Minister of Health, a justification: palliative medicine has been indicated as one of the priority fields of medicine (Regulation of the Minister of Health, December 2022, an example just like anesthesiology, but in the case of which the number of residents was 248 people in 2022 - 13 times more than in the case of palliative medicine, in geriatrics the number of residency places was 34, almost twice as many as in the case of palliative medicine).
7. Establishing a scholarship fund/program for students in medical fields (e.g. medicine, nursing, physiotherapy or future medical caregivers) encouraging them to work in rural areas[13].

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[13] Good practice - A scholarship program for students of nursing and midwifery, addressed to students from the Hajnówka district obliging them to work in a hospital in Hajnówka afterwards (2 communes from the Hajnówka district took part in testing of the Model).

Considering the introduction of a system of motivation to take up work in areas with staff shortages (company accommodation, salary supplements, faster promotion path, preferences/priority when choosing specialization).

Organizing a nationwide competition for the best initiative to support dependent persons by the Ministries to which these recommendations are addressed.

8. Promoting good practices in networking of social services (Ministry of Family and Social Policy and ROPS) and health services (Ministry of Health, Health Departments of the Marshal's Offices).
9. Social campaigns and increasing the prestige of medical and social professions - Ministry of Family and Social Policy, Ministry of Health.

Photo: A. Dowgier

# 6. Dictionary of terms and definitions

## CONCEPTS CURRENTLY IN FORCE (STATUTORY)

**Palliative and hospice care** is a comprehensive, holistic care that includes symptomatic treatment of people suffering from incurable, progressive, life-threatening and life-limiting diseases that cannot be treated causally. This care is aimed at improving the quality of life, is aimed at preventing and alleviating pain and other somatic symptoms, and soothing mental, spiritual and social suffering[14]. According to the World Health Organization, palliative care is an approach that improves the quality of life of patients suffering from a life-threatening illness as well as their families by alleviating suffering, treating pain and reducing other physical, psychosocial and spiritual problems. It should be implemented when a life-threatening disease is diagnosed and then increased as needed[15].

**Long-term care** means the organization and provision of a wide range of medical, care and nursing services as well as assistance to people whose ability to live independently is limited in the long term due to age, health condition or functional disability. According to the definition of WHO and OECD, long-term care is defined as the range of services provided to people with limited physical, mental or cognitive ability to function, as a result of which these people become dependent on assistance for a long time in basic activities of everyday life. This care can be treated as a whole range of medical and social activities consisting in the provision of a long-term nursing care, rehabilitation, therapeutic services and nursing and care services as well as a continuation of pharmacological and dietary treatment to people who are chronically ill and require support in everyday functioning, but who do not require hospitalization in a hospital ward. This care may be provided by formal caregivers (medical staff and social welfare workers) or informal caregivers (family, loved ones, volunteers).[16]

**Catalog of qualifying diseases** providing guaranteed services in the field of palliative and hospice care. Palliative and hospice care is a service guaranteed, however, Annex No. 1 to Regulation of the Minister of Health of October 29, 2013, on guaranteed benefits in the field of palliative and hospice care and the **Announcement of the Minister of Health of December 17, 2021.** (List of incurable, progressive, life-limiting cancer and non-cancer diseases) contains a limited catalog of diseases qualifying for treatment in this area.

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[14] Regulation of the Minister of Health of October 29, 2013, on guaranteed benefits in the field of palliative and hospice care, § 3. 1., Journal of Laws of 2013, item 1347.

[15] From: Recommendation No. 16/2019 of April 3, 2019, of the President of the Agency for Health Technology Assessment and Tarification on changing medical technology in the definition of palliative and hospice care and in the scope of indications constituting the basis for qualification for palliative and hospice care.

[16] "Healthy Future. Strategic Framework for the Development of the Health Care System for 2021–2027, with a perspective until 2030, Annex to Resolution No. 196/2021 of the Council of Ministers of December 27, 2021, p. 52.

A list of ICD-10 adult disease entities eligible to benefit from home hospice support:

- B20-B24 disease caused by human immunodeficiency virus (HIV)
- C00-D48 cancers
- G09 consequences of inflammatory diseases of the central nervous system
- G10-G13 systemic primary atrophy affecting the central nervous system
- G35 multiple sclerosis
- I42-I43 cardiomyopathy
- J96 respiratory failure, not elsewhere classified
- L89 pressure ulcers.

**Special geriatric care** is addressed to people over 75 years of age and is aimed at: maintaining the greatest possible functional capacity and independence of eligible persons; ensuring, those specified in the Act[17], health care services; planning and coordinating health care for patients of the 75+ health center, in particular by ensuring a comprehensive geriatric assessment and developing and implementing an individual therapeutic plan, hereinafter referred to as the "individual plan"; ensuring drug conciliation for the center's patients; ensuring preventive and health promotion activities tailored to the needs of eligible persons, including those aimed at preventing their disability and dependence; providing health education to the center's patients and their caregivers; providing psychological support to patients of the 75+ health center.

## CONCEPTS USED IN THE MODEL AND RECOMMENDATIONS

**Dependent Person's Care Coordinator (KOOZ)** - a person whose tasks include systematic direct contacts with people with dependencies, as well as with their home caregivers in order to identify medical and non-medical needs, which are registered on the visit card and held in the documentation of the person under care (needs assessment questionnaire and support plan of the beneficiary of the FHPE); staying in close and regular contact with members of the hospice care team at home and with members of the so-called social support network to provide assistance adequate to the needs of residents and their home caregivers. KOOZ coordinator has knowledge and uses the potential of resources available locally for aid activities, and can also conduct activities for the social support network, e.g. of an integrating and educational nature. The tasks of KOOZ are aimed at creating, strengthening, and expanding aid resources.

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[17] Act of August 17, 2023, on special geriatric care.

**Interdisciplinary home hospice care team**[18] ensures the provision of health and psychological care services at home and the satisfaction of hygiene, nursing, and care needs, as well as the social support. The team includes personnel who meet the conditions specified in Annex No. 2:

Conditions for the provision of guaranteed services in the field of palliative and hospice care: doctor, nurse, physiotherapist, psychologist[19] and a medical caregiver, dietitian, and KOOZ.

**Hospice care at home** means coordinated, flexible hospice care tailored to the individual needs of the patient and targeted support from an informal caregiver (during care and during mourning).

These tasks are carried out by an extended interdisciplinary medical team (doctor, nurse, physiotherapist, medical caregiver, dietitian), supported by a psychologist, Dependent Care Coordinator (KOOZ) and local entities acting for dependent persons and their home caregivers. Hospice care at home is available to every patient in the final phase of their disease, and includes symptomatic treatment of patients with incurable, progressive, life-threatening diseases that cannot be treated causally. Admission to hospice care at home is determined by symptoms and clinical indications, i.e. the patient's somatic, psychosocial, and spiritual disorders and sufferings, and not by a specific disease entity.

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[18] In accordance with the provisions of the Regulation of the Minister of Health of October 29, 2013, on guaranteed benefits in the field of palliative and hospice care, Journal Laws of 2013, item 1347.

[19] Regulation of the Minister of Health of October 29, 2013, on guaranteed benefits in the field of palliative and hospice care, Journal Laws of 2013, item 1347.

# 7. Appendix 1

## NEEDS SURVEY QUESTIONNAIRE AND SUPPORT PLAN FOR THE PATIENT OF THE FOUNDATION

## PART I

## PERSONAL DATA OF THE BENEFICIARY

Main Book No.

1. Data of the sick
First name………………………………………………………………………………………………………………………..
Last name ………………………………………………………………………………………………………………………..
Place of residence …………………………………………………………………………………………………………..
PESEL no.: ………………………………………………………………………………………………………………………..
Date of admission to hospice care at home ……………………………………………………………………….

2. The health situation of the patient (from hospice or nursing interview)

Chronic diseases
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Past injuries and their consequences
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Other diseases and their consequences
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Orientation in time, place and personal situation (correct, partial, lack of orientation)
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Hygiene
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Maintenance status of the person (well-kept, dirty, etc.)

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The person is under the care of:
Family doctor (data, address, contact telephone number)

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Specialists (data, address, contact telephone number)

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3. Description of place of residence (from information from hospice or social worker or from information gathered in the community)

Heading ...
Heating ...........................................................................................................................................
Warm water, cold water ...............................................................................................................
Other media ......................................................................................................................................
Bathroom, toilet ..............................................................................................................................
Other amenities (telephone, Internet, washing machine, stove, fridge, own room, own bed, other)

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Facilities for disabled people (equipment, medical products, bed, anti-decubitus mattress, other)

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Maintenance status of the place of residence

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4. Details of the person's guardian

Name ...............................................................................................................................................
Surname .........................................................................................................................................
Date of birth ...................................................................................................................................
Degree of relationship with the care recipient

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Whether the person lives together

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Health condition of the caregiver (physical, emotional) ......................................................

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Functioning of the caregiver (efficiency, independence, mobility, activity, etc.)

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Access to basic services (shop, transport, health center, pharmacy, etc. distance and how it is managed)

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5. Description of the family situation

Information about the person's family members

| Lp. | First name and last name | Place of residence (whether cohabitates?) | Is he/she in touch and provides support? | Contact |
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Other people living together/cohabitating (name and surname, contact telephone number)

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Relationships among people living together (good sides, conflicts in the family - from information from hospice or social worker or from information gathered in the community)

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Domestic violence, addictions (from information from hospice or social worker or from information gathered in the community)

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Other information that the person completing the survey deems appropriate to provide:
Monthly income for the household, fixed costs, where do they get material support, and how much?

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Other types of material support – what kind, how often, is it enough?

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6. Support in the community (hospice, neighbor help, informal groups, institutions)

| The dependent person | | | | |
|---|---|---|---|---|
| Lp. | Name and surname/institution | Type of support | Support frequency | Contact |
| | | | | |
| | | | | |
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| The dependent person | | | | |
|---|---|---|---|---|
| Lp. | Name and surname/institution | Type of support | Support frequency | Contact |
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# PART II

## PLANNING OF SUPPORT

The expectations and needs of dependent person, reported by him/her or the carer on behalf of the person

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The expectations and needs of the carer, reported by him or her or co-residents

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The needs of the sick (dependent person) and his/her home carer, reported, for example, by: FHPE doctor taking care of the patient, FHPE nurse, FHPE psychologist, FHPE caregiver, other members of the FHPE team

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to be collected, e.g. during a medical-care team meeting or an individual conversation with the sick or his/her home carer

The needs of the beneficiary and his/her home carer, reported by other members of the network (Municipal Social Welfare Center/GOPS, clergy, family doctor, community nurse, others)
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**SUPPORT PLAN DATE** ……………………………………….

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|---|---|---|---|---|---|
| Beneficiary | | | | | |
| Lp. | First name and last name/institution | Type of support | Support frequency | Contact | Implementation, comments |
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| Home carer | | | | | |
| Lp. | Name and surname/institution | Type of support | Support frequency | Contact | Implementation, comments |
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