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Challenges of community-based care for chronically ill people and their families in Central and Eastern European countries The case of Slovakia, Hungary and Poland

ABSTRACT: This article attempts to analyze the social as well as relational needs and problems of people suffering from chronic oncological diseases. At the same time, we would like to present the possible available ranges of social support that oncologically ill people can get under the existing support systems in Poland, Hungary and Slovakia. This article will also present the results of the first findings based on the pilot studies which were the expert interviews aimed at discerning environmental, institutional and non-institutional forms of support. This research project undertaken by researcher from Poland (University of Silesia in Katowice), Hungary (Reformed Theological Academy of Sárospatak) and Slovakia (Trnava University) is to answer the question of the types of community psychosocial support available to cancer patients, their families and carers.

KEY WORDS: community-based care – chronically ill persons – Central European countries.

Introduction

In recent decades, the issue of cancer has increasingly featured in the literature on the sociology of health and illness, especially the sociology of

the experience of illness. The reasons for conducting research in this area are related to several social phenomena. Demographic trends associated with an ageing population have created a need to prepare health infrastructure and support services for the increasing cancer incidence. In addition, approximately 70 per cent of cancer cases are in women and men over 60. With declining rates of care, the question arises about the capacity and effectiveness of support systems in caring for people with chronic diseases, including cancer. The battle against cancer is most often fought in the family environment. This is due, among other things, to the Europe-wide trend towards shorter hospital stays. The cancer illness of a family member becomes the 'illness' of the whole family. It creates a myriad of problems, both of a medical nature and, above all, of a psychosocial nature (Frank, 2002; Charmaz, 1983). It becomes a 'biographical disorder' for the patient (Bury, 1982) and a 'biographical challenge' for their loved ones (Chamberlayne, King, 1997, pp. 601–621).

The special situation of older people is characterised by their limited network of contacts. The number of supportive contacts decreases with age. The most difficult situation is that of the single, or widowed elderly, although research shows that the age homogeneity of the relationship decreases and the emotional resilience increases with age. The burden of illness therefore needs to be managed by fewer people living in closer contact with older people (Dávid, 2016) (Gyarmati, 2009) (Albert – Dávid, 2021). The caregiver support¹ ratio is also decreasing significantly in the countries studied, in 2020 it was 6.04 in Hungary, 5.66 in Poland and 8.24 in Slovakia. These are projected to fall to 3.11 in Hungary, 2.47 in Poland and 3.09 in Slovakia by 2050 (Riberio et al, 2022).

The analysed Eastern European countries have high cancer incidence rates and outstanding mortality rates. Hungary has the second highest mortality rate in the European Union, Poland the 11th and Slovakia the 13th. Unfortunately, in Eastern Europe, Hungary leads in both male mortality (colorectal) and female mortality (breast) (GLOBOCAN, 2023). In Poland, patients are the last to know their diagnosis and have less access to information in the health system, while in Hungary, patients have access to more information about the disease, faster diagnosis protocol, but still higher mortality rates. Overall, people in CEE countries have too late cancer diagnose (Sagan et al, 2022) and have to wait longer for treatment than in other EU countries (Ramavic et al, 2020).

¹ Rate of – 45 – 64 year old population in relation to 80+

Because of its specificity, primarily due to the life-threatening acute phases of cancer and the cumbersome treatment process, it is considered an illness that requires an extraordinary mobilisation of social support (De Leeuw, 2000). To overcome the crisis triggered by a cancer diagnosis, it is necessary to fully mobilise the strengths and resources available to the person suffering from the disease and their immediate social environment (Kacperczyk, 2006). The multiplicity and complexity of the tasks that the disease imposes on the shoulders of the patient and the family results from the need to ‘work on the disease’, ‘work on everyday life’ and ‘work on symptoms’ (Kacperczyk, 2006) its symptoms, “work on everyday life” – performing everyday tasks and duties, and “work on the biography” – which undergoes sudden, often unacceptable changes in the face of illness (Strauss, Corbin, 1985). In the flurry of problems associated with chronic illness and the process of managing it, it can be easy for all elements of support for the patient and their family to collapse if they do not receive adequate help (Pawlas-Czyż, 2018).

Globally, a growing body of research focuses on carers of people with cancer (Romito et al., 2013, p. 2164). These are studies of informal carers or family carers. From their review, suggestions emerge that are important for researchers and policymakers. Considering the number of carers, their increased effort and time spent on caring, and their health, social and financial costs, informal carers are a group that should be considered in terms of hidden fees to the state. Eurocarers White Paper (2017) stresses the importance of accepting, emphasising and supporting the role of family carers in the disease process. It highlights the role of flexible employment, pension and health entitlements, and crucial caregiver social and mental support. Research among family caregivers shows that the support of a family caregiver reduces stress for cancer patients and improves their quality of life (Johnston et al., 2022).

Unfortunately, there is a conspicuous lack of research on people with cancer and their carers in Central and Eastern European countries.

Family carers of people with cancer often have an empowering experience caring for them. However, if they are exposed to excessive and persistent burdens, they have a lower health-related quality of life. A significant proportion of them have comorbidities: depression, anxiety disorders, insomnia, migraines, and headaches. The deterioration of health is sometimes reflected in significantly higher medical care consumption compared to those who do not care for the patient (Goren, Gilloteau, Less, da Costa DiBonaventura, 2014, pp. 1637–1646). Cancer patients and their family caregivers react to their illness similar to a dynamic system of interconnected vessels. Caregivers often experience emotional distress, anxiety and depression to a similar degree as

patients (Northouse, Katapodi, Song et al., 2010, pp. 317–339). The advanced stage of the disease is a tough time for them. Numerous empirical studies confirm that there is an even more significant increase in depressive symptoms in caregivers than in the patients themselves (Braun, Mikulincer, Rydall, Walsh, Rodin, 2007). Despite the high emotional burden, carers rarely seek mental health support, which may increase the risk of persistence and chronicity of health problems (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005) (Gee et al., 2016) (Given – Sherwood, 2006) (Haley, 2003).

Researchers working on the macroeconomic impact of disease point out that cancer affects close relatives of patients, i.e. informal carers, to a much greater extent than others. They point out that in addition to the time spent caring, they also experience behavioural and physiological burdens that can negatively affect physical and mental health (Weitzner et al., 2000). This can harm the economy. They affect the professional sphere, where they increase absenteeism and presenteeism (i.e. inefficient work). The indirect costs of cancer in Poland have not yet been subject to economic analysis. However, the first comprehensive analysis of the indirect costs of cancer in Europe was carried out in our country. The data confirm the significant economic importance of this problem. Indirect costs related to absenteeism due to care of relatives with cancer amounted to approximately PLN 732 million in the Polish people in 2009. Much higher are the costs of presenteeism, which amount to PLN 2, 877 billion (Macioch, Hermanowski, 2013, p. 204). Analyses of the situation of carers of dependent persons in Poland indicate a significant risk of their multi-faceted social exclusion. This risk can take the form of social exclusion, exclusion from support, exclusion from the labour market, health exclusion and social exclusion (Anioł, Bakalarczyk, Frysztacki, 2015).

Research work on the relationship between the quality of life of oncology patients and the support received shows that people with cancer need a lot of it in particular and that its role is positive (Courstens, Stevens, Crebolder, Philipsen, 1996; (De Graeff, de Leeuw, Ros, Hordijk, Blijham, Winnubst, 2000). The support received influences the adaptation to the illness situation and the permanent changes it causes (Grassi, Rostti, Lasalvia, Marangolo, 1993). Its long-term consequences have also been observed: the provision of emotional support in the peri-diagnostic period is found to be a significant predictor of better health eight years later (Schroevers, Helgeson, Sanderman, 2010). The effect of social support on depressive symptoms in cancer patients has also been well studied. The available support ensured that sufferers experienced less severity of these symptoms in the future (De Leeuw, De Graeff, Ros, Hordijk, Blijham, Winnubst, 2000).

The social support system in many European countries faces the challenge of building a high-quality approach to help patients and their families cope with the psychosocial aspects of oncological illness. One element of this can be oncological social work. This one, to meet the needs of the 21st century, should involve the help of individuals and families from the peri-diagnostic period, through the different stages of treatment, at the time of its completion, in remission, during relapse, re-treatment, transition to a chronic state, at the end of life and during the experience of bereavement after the loss of a loved one (Zebrack, Jones, Smolinski, 2015, pp. 34–35). The primary spectrum of activity of oncology social workers is to undertake interventions targeting the psychosocial aspects of coping with cancer. In providing professional services to patients and their relatives, social workers respond to the social, psychological, and social difficulties individuals face with cancer, as well as to problems arising from the medical treatment of the disease (Fleishman, Messner, 2015). The social work activities undertaken in this area aim to help patients and their relatives function as well as possible in their social roles. In their work, they refer to knowledge, methodology and experiences from the social work field and from the knowledge about cancer and its treatment process (ibid.: 3–8).

Description of the forms and scope of support for peoples suffering oncological diseases in Slovakia

Introduction

Oncological diseases still hold the first places in patient mortality, along with cardiovascular diseases in Slovakia.

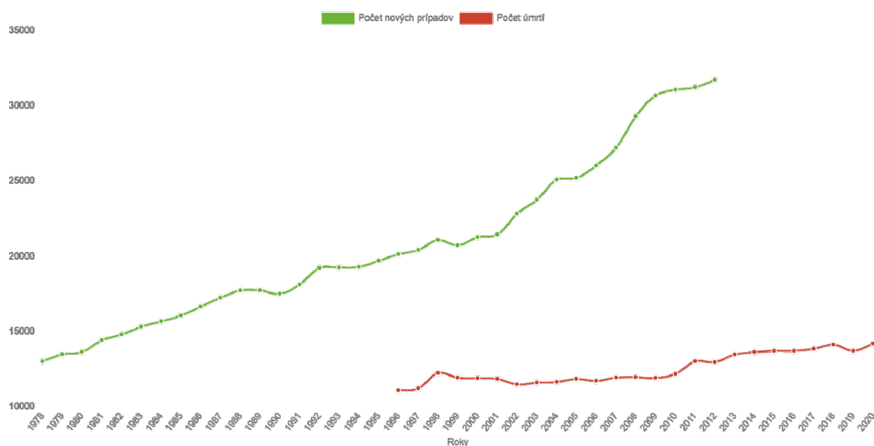
Table 1. The rate of mortality in Slovakia

Cause of death (ICD-10 classification)	1996	2000	2005	2010*	2013	2014	2019
Communicable diseases							
All infections and parasitic diseases (A00-B99)	187	155	223	366	487	505	
Non-communicable diseases							
Malignant neoplasms (C00-C97)	11 049	11 871	11 794	12 072	13 183	13 278	13 722
Endocrine, nutritional and metabolic diseases (E00-E89)	647	794	759	714	766	721	
Mental and behavioural disorders (F00-F99)	21	12	10		11	128	
Diseases of the nervous system (G00-G98)	213	468	651	694	723	786	
Circulatory diseases (I00-I99)	27 898	28 967	29 111	28 519	26 173	25 198	
Diseases of the respiratory system (J00-J98)	3 785	2 904	3 106	3 300	3 455	3 279	
Diseases of the digestive system (K12-K98)	2 155	2 622	2 782	2 844	2 588	2 636	

Diseases of the genitourinary system (N00-N80)	753	668	687	754	679	739	
External causes							
Transport accidents (V01-V99)	841	839	754	511	369	427	
Suicide (X60-X84)	668	726	677	628	513	546	
Total number of deaths	51 236	52 724	53 475	53 445	52 089	51 346	

Source: National Oncological Institute of Slovakia

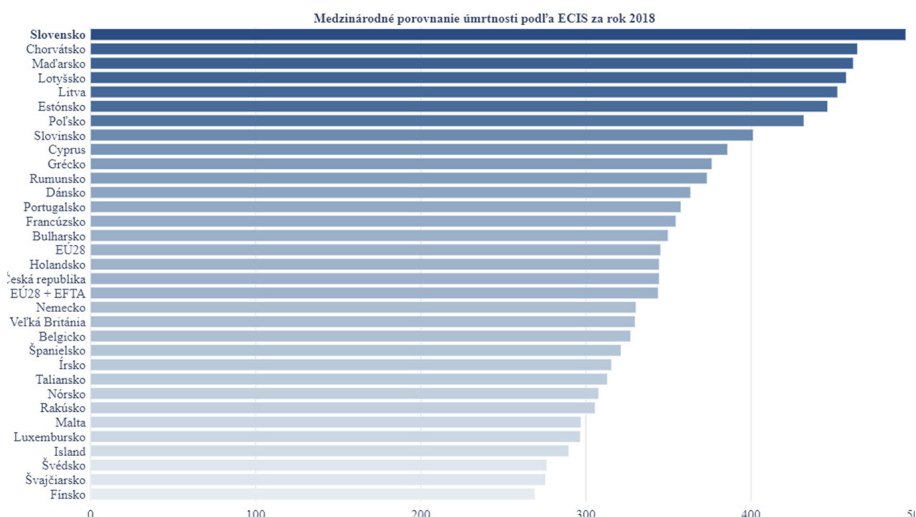
Numbers of oncological illnesses is continuously increasing (National Oncological Institute)



Graph 1. Numbers of oncological illnesses in Slovakia

Source: National Oncological Institute of Slovakia

Based on the absolute number of patients by age group, a slight decrease in the number and share of patients aged 45–64 (from 42.6% in 2011 to 36.2% in 2020) and an increasing share of older patients 65–74-year-olds (from 21.1% in 2011 to 29.3% in 2020) and 75-year-olds and older (17.7%) (Public Health Authority of SR). Due to continuous ageing of population, we can assume that this trend will increase also in the future. One of the most worrying facts is that Slovakia has the highest death rate from malignant tumors, based on European Cancer Information System – ECIS.



Graph 2. The death rate in European countries
Source: European Cancer Information System – ECIS.

Institutional support during oncological illness in Slovakia

The situation in the field of long-term social and health care is currently alarming, due to the long-term postponement of complex solutions to problems, partial solutions caused by departmentalism. This fact has been known for a long time to all those involved. One of the major reasons is that the social care system and the health care system evolved separately, leading to different organizations and sources of funding, even though many of the services they provide are practically identical. This may pose a barrier to effective solutions in the provision of long-term social care and health care (Smatana, 2016).

As mentioned also in Strategy of long-term care in Slovak republic (Stratégia dlhodobej starostlivosti v SR, 2021), long-term support of dependent persons is carried out partly within the sectoral competence of the Ministry of Health, partly within the sectoral competence of the Ministry of Labour, Social Affairs and Family, but without the necessary systemic and integrated approach in the effective use of public funds, technical and human resources for the necessary interventions for the benefit of the individual. Also, for this reason, one of the most important topics is currently the need to connect in the field of providing social services and health care, especially in the field of nursing care and medical (medical) rehabilitation. The only option for solving

the need for a coordinated approach in the field of support for these persons is a system of long-term social and health care, which is absent in the Slovak Republic. This fact was strongly stressed in all the collected interviews.

Table 2. Institutional support during oncological illness in Slovakia

Health care system	Social care system
Outpatient care	Social services
Home care nursing agencies	Community care
Ambulatory care	Social consulting and social rehabilitation
Day care	Supported living homes
Inpatient care	Home nursing care
LTC departments	Facilities for nursing care
Sanatoriums	Day centres
Homes for nursing care	Respite services
	Institutional care
	Retirement homes (facilities for elderly)
	Social services homes
	Special care homes
	Social compensation of disability
	Financial compensation to informal carers

Source: Smatana, M., et al. (2016). Slovakia: Health system review. *Health Systems in Transition*, 18(6):1–210.

Current framework of support in the process of treatment and rehabilitation of oncology patients

There are two major subsystems of support of long-term care for oncological ill people: Health care and social care.

Social Care in context of Slovak system consists of two subsystems: Informal and formal care.

Informal care, provided mainly in the home environment, is supported in the form of a monetary allowance for caregiving and a monetary allowance for personal assistance (Act No. 447/2008 Coll. on monetary allowances for compensation of severe disabilities).

In 2020, an average of 61, 734 individuals taking care of individuals with a severe disability were provided monthly care allowance in the total amount of EUR 285 010 833. The average monthly number of recipients of the cash allowance for personal assistance was 11 117, and funds in the total amount of 78 330 715 euros were spent on its provision.

Offices of Labor, social affairs and family are responsible for deciding on entitlement to individual benefits, but they do not supervise the scope of care and do not focus on supporting informal carers at all. The physical and mental burden of caregivers is high. Long-term caregiving of a loved one is

a significant stressor that affects the quality of life of both the cared-for and the caregiver and creates a prerequisite for the possible emergence of psychological disorders. This is also why it is extremely necessary to develop a system of not only financial support for informal caregivers as part of the long-term care system, as relying only on family solidarity is risky. Although the legislation guarantees the possibility for persons cared for to use outpatient facilities of social services within the framework of the care allowance and the provision of respite (relief) services to caregivers, by providing social services for the cared-for 30 days a year, in 2019 only 259 caregivers used the respite service. Only 611 cared for were provided with outpatient services concurrently with care by family caregivers (Stratégia dlhodobej starostlivosti v SR, 2021).

Formal care in the system of social services is provided mainly through social services provided in facilities (ambulatory form or weekly or year-round residential form) or using home nursing services. The main goal of social services is the prevention, solution, and mitigation of the unfavorable life situation of a person, family or community, the preservation, restoration or development of the physical person's ability to lead an independent life and the support of his inclusion in society. Social services are provided by public and non-public providers.

In 2019, home care services were provided to 16, 000 people, which represents a slight increase compared to the previous year, mainly thanks to the National Project Support for the Development and Availability of Field Care Service. But we have to stress that the financing of this service from the funds of the European Union is not a systemic solution and could lead to repeated problems in the continuous provision of these services. The number of recipients of care services at public providers has a decreasing trend and is around 13 thousand recipients in 2020, while in 2009 their number was 17, 050. At non-public providers, it decreased from 4, 276 in 2015 to 2, 799 in 2019 (decrease by 35%), while it is clear from the monitored data that the changes in the number of cared for are mainly influenced by the financing of the care service from EU structural funds (Stratégia dlhodobej starostlivosti v SR, 2021).

Health Care

The health care system in Slovakia is based on universal coverage and health care, with exceptions, is provided to insured free at the point of delivery through benefits-in-kind (paid by a third party). After fulfilling certain explicit criteria, there are no barriers to entry to health care provision and health

insurance markets. Health care providers are owned by different stakeholders. The state owns and operates the largest health care providers, including four university hospitals, eight faculty hospitals, highly specialized institutions and almost all psychiatric hospitals and sanatoria. Most of them have the legal status of so-called contributory budgetary organizations. Furthermore, there are more than 50 privately run hospitals in Slovakia and several mixed forms of ownership. Almost all outpatient facilities are in private hands and patients are often faced with waiting times.

Primary care services are provided by physicians predominantly working in private practices. Inpatient care is provided in general and specialized hospitals, which are owned and managed by a range of actors, including ministries, regions, municipalities, private entities and NGOs (Smatana, 2016).

Long-term care is provided on an outpatient basis through home nursing care agencies (ADOS); specialized ambulatory care (mobile hospices, geriatric clinics); in the form of institutional health care (long-term sick wards, geriatric and palliative wards in hospitals) and in specialized medical facilities – (psychiatric hospitals), and above all in hospitals for long-term patients, nursing homes (hereinafter referred to as DOS), hospices, and in social assistance facilities (in facilities for the elderly, care service facilities, specialized facilities, social service homes and facilities for the social and legal protection of children and social curates) (Stratégia dlhodobej starostlivosti v SR, 2021).

As shown in interviews analysis as well as statements of professionals, the main shortcoming is the underestimation of nursing care in the social sector and the underestimation of social care in the health sector.

Institutional support during oncological illness in Poland

The report of the National Cancer Register published in January 2022 shows that in Poland we record over 171, 000 new cancer cases annually and over 100,000 deaths due to them. In Poland, malignant neoplasms are the second cause of death, accounting for 25.7% of deaths in men and 23.2% of deaths in women, respectively. They are a significant health problem primarily in young and middle-aged people (25–64 years). This phenomenon is particularly relevant to the female population, because for several years it is among them that cancer has been the most common cause of death before the age of 65. They account for 31.7% of deaths in young women and 46.8% in middle-aged women, respectively. The “Health at a Glance” report (<https://health.ec.europa.eu/state-health-eu/health-glance-europe>) published in 2021 shows that although the cancer incidence rate in Poland is relatively

low (267 cases per 100, 000 inhabitants, for most OECD countries, the average is 294), while the cancer mortality rate in our country is one of the highest (228 deaths per 100, 000 inhabitants, with the OECD average 191 deaths per 100, 000 population). In mortality statistics, we rank fourth, just behind Hungary, Slovakia and Latvia. (<https://www.szpitalnaklinach.pl/blog/rak-globalne-wywanie-xxii-swiatowy-dzien-walki-z-rakiem-2022-world-cancer-day/> accessed 21.03.2023)

Assuming that as important as medical procedures for a full (possibly optimal) return to physical, mental and social well-being is the process of rehabilitation of oncology patients in the broadest sense. In this view, we consider rehabilitation as “a complex process involving therapeutic, social, occupational, pedagogical interactions aimed at restoring fitness and enabling independent life in society for a person who did not have such opportunities or, due to an injury or disease, lost them.” (Encyclopedic... 1996, p. 263).

The forgotten heritage of good practices in rehabilitation in Poland

It is understood that the foundations of medical rehabilitation in the broad sense were laid by the first centers of comprehensive rehabilitation, which were established in Poland under the direction of Professor Wiktor Dega at the Orthopedic Clinic in Poznan, and in the USA at Bellevue Hospital in New York headed by Professor Howard Rusk. In Dega's conception, rehabilitation is supposed to encroach on primary treatment and be an integral part of it, and in this spirit he established rehabilitation and orthopedic centers from the early 1950s. Until the 1970s, rehabilitation centers were the only facilities for comprehensive therapeutic improvement. Then, in 1973–1975, the then Ministry of Health and Welfare established the organizational structure of medical rehabilitation in the country and rehabilitation based on the current model was introduced by law as an integral part of primary treatment. Rehabilitation was developed on the premise that it was to be universally accessible, early initiated, comprehensive and continuous – the essence of the Polish model of medical rehabilitation.

Medical rehabilitation according to Dega's model was characterized by four features: universality, early initiation, comprehensiveness and continuity. Where universality, understood as accessibility to all patients, also refers to the concept of interdisciplinarity – rehabilitation must include all fields of medicine and related fields. Early initiation – understood as improving the patient both before scheduled surgery and immediately after surgery in the form of a wide range of exercises and other rehabilitation activities while still “on the hospital

bed.” When an injury or illness completely changes the patient’s life situation, comprehensive rehabilitation conducted by a rehabilitation team (team) should be introduced. According to Dega, comprehensive rehabilitation consisted of kinesitherapy, physical therapy, speech therapy, orthopedic supplies, psychological assistance, social assistance, ergotherapy, schooling in the case of children and adolescents, and the assistance of a vocational instructor. Continuity, on the other hand, implied that rehabilitation is to be uninterrupted, and medical, vocational, social rehabilitation is to be carried out at the same time. The notion of continuity of rehabilitation also means the continuation of these activities after leaving the treatment center, i.e. community rehabilitation.

Dega also defined the principles of rehabilitation teams, which included specialists in various fields both medical and non-medical. The essence was that a rehabilitation specialist became the coordinator of the rehabilitation team and subordinated to him: rehabilitation specialists and physiotherapy technicians; orthopedic supply engineers and technicians; a clinical psychologist; an ergotherapist and a social worker. Officially, the Polish model of medical rehabilitation was accepted at a meeting of the WHO European Office in 1970 (more on Lubecki, 2011).

Current framework of support in the process of treatment and rehabilitation of oncology patients

In Poland, a person diagnosed with cancer has the opportunity to obtain various forms of support at the stage of treatment as well as convalescence or rehabilitation. It should be noted, however, that the level and forms of this support, as well as the entities that provide it, varies greatly at all stages of the disease, the treatment process or rehabilitation in the broadest sense.

In January 2015, regulations came into force introducing the so-called oncology package, a group of regulations aimed at improving the diagnosis and treatment of cancer in Poland. According to the Health Ministry, these regulations were intended to, among other things, improve the service of oncology patients by medical facilities, enable the detection of diseases at an early stage thanks to the expansion of the diagnostic powers of POZ (Primary Health Care), and ensure that everyone has access to reliable information on where to get the needed health services the fastest. Within the framework of these regulations, the so-called rapid oncology therapy was developed, dedicated to patients in whom doctors suspect or find a malignant tumor and patients undergoing oncological treatment. (<https://pacjent.gov.pl/system-opieki-zdrowotnej/pakiet-onkologiczny> accessed 12.02.2023)

Among other things, the so-called “DiLO Green Card” was introduced – Card for Cancer Diagnosis and Treatment, which in its assumptions was intended to be a priority referral of a person with suspected cancer. The premise was that a patient with a DiLO card bypasses the usual queues and is entitled to faster oncological diagnosis and anti-cancer treatment. Promotion of the so-called interdisciplinary oncological treatment, which consists, among other things, in the fact that within two weeks of the patient’s notification to the doctor should take a Consilium, that is, a team of doctors of various specialties, which will develop a detailed plan for the patient’s treatment. The patient has the right to participate in the Consilium’s deliberations when it decides how the treatment should proceed. The oncology package also introduced the function of a Treatment Coordinator acting as a kind of assistant to the patient. Once the Consilium has determined the treatment pathway for a given patient, it will appoint a Coordinator, whose tasks are to supervise the treatment process, keep an eye on the set deadlines, provide informational, administrative and organizational support to the patient, as well as help in communication with doctors (more widely www.pakietonkologiczny.gov.pl accessed 13.02.2023).

Despite the measures taken, the situation of patients suffering from oncological diseases has not changed dramatically, as indicated, among other things, by the report of the Supreme Audit Office. It reads that “the organizational changes introduced in 2015 by the oncology package reduced waiting times for patients with an oncology diagnosis and treatment card. However, the oncology package did not significantly improve the situation of patients with a suspicion or diagnosis of cancer, as the DiLO card was obtained by only a fraction of patients who were eligible for it due to their diagnosis. The uncoordinated and chaotic diagnostic process, finances and the issue of too late detection of the disease remained a significant problem. The effectiveness of the treatment provided was also a concern” (<https://www.nik.gov.pl/aktualnosci/pakiet-onkologiczny.html> accessed 13.02.2023). Although the National Health Fund has expanded the possibilities to use the services within the oncology package, some centers still prefer to treat patients without the Oncology Diagnosis and Treatment card. These are most often children’s hospitals and hemato-oncology departments, where DiLO cards are even avoided due to the need for instant treatment and the desire to skip time-consuming procedures. Although, according to experts, there are still too few patients with cards, patients still have to wait in lines.

Surveys of those who are employed as coordinators and those who serve as coordinators also indicate that this arrangement has limited effectiveness in

supporting cancer patients. In their conclusions, the study's authors point out that currently the coordinator's formal positioning in the "patient pathway" begins from the time of the consilium until the end of treatment. Which means that coordinators are basically not involved in the earlier stages of diagnosis (screening, suspected cancer, initial and in-depth diagnosis) when the patient "collides" with the traumatic situation of diagnosis. The ineffectiveness of the current patient coordination system may be precisely due to the lack of patient support at the time of cancer suspicion and at the first stage of diagnosis. Coordinators are also not involved in the stage of the patient's extensive rehabilitation (physical, social, occupational) and in the organization of post-treatment follow-up (both after the patient is cured and in the case of disease progression/recurrence). Most of the people to whom they perform the role of coordinator as are administrative staff or medical secretaries and perform the duties of coordinator as an additional job. The motivation for such selection for the role of coordinators in cancer hospitals may be the large number of administrative and billing duties associated with the implementation of the oncology package, which is why the function of coordinators is given to people experienced in administrative work. Unfortunately, these individuals very often do not have the experience or preparation to enter and maintain a meaningful therapy relationship with the patient. Among coordinators who have this kind of experience, the vast majority are those employed as nurses, but they too perform the tasks of a coordinator as part of their additional duties, and they have to organize the work themselves and often do not have enough time for patients (Osowiecka, Rucińska, Andrzejczak, Żarłok, Chrostek, Nawrocki, 2020, pp. 8–10).

Further steps, widely publicized by the Ministry of Health, related to the support of oncology patients consisted of the creation of Cancer Units – that is, facilities where patients with a specific type of cancer would be provided with diagnosis, treatment, rehabilitation and psychological support.

In 2019, the first Breast Cancer Units, or facilities where breast cancer patients are provided with diagnosis, treatment, rehabilitation and psychological support, began to be launched. The BCUs will be staffed by doctors from a variety of specialties, including oncologists, cancer surgeons, chemotherapy and radiation therapy specialists, clinical psychologists, and rehabilitation specialists. Announcements by policymakers suggested that a patient, upon arriving at a BCU reference center, would receive comprehensive care – from diagnosis, treatment and rehabilitation, to monitoring the effectiveness of treatment once the therapeutic process is completed. Similarly, in April 2021, the introduction of the model of comprehensive oncological care in colorectal cancer was initiated (<https://www.gov.pl/web/zdrowie> accessed 11.02.2023).

Also specialists are quite critical about the current possibilities of conducting effective and multifaceted rehabilitation of oncology patients in Poland. According to Professor Piotr Majcher², “Currently, we do not have an adequate number of specialists and facilities in Poland that can conduct rehabilitation of people after oncological treatment. Such facilities can function at hospitals, oncology centers, anywhere, but the point is that specialists who know the specifics of the cancers treated there and the rehabilitation standards associated with them should be concentrated there. It is also important to maintain continuity in the rehabilitation process. Rehabilitation is a continuous process, which we start even before the start of treatment, preparing the patient for surgery, for example. Then, in some patients, we conduct it in parallel with primary therapy. Let’s not forget that nowadays oncology patients live many years and, in addition to the disease, they also struggle with the extended adverse effects of cancer therapy, and this should also be the scope of rehabilitation activities. So they need to find a facility where they can continue rehabilitation after they finish treatment and return home. The expert also points out that the vast majority of support for the broader rehabilitation of cancer patients is currently provided by the non-governmental sector. I appreciate the tremendous work that oncology patient organizations are doing in the field of oncology rehabilitation, thus filling the huge shortage in comprehensive cancer care. However, they are unable, for financial and organizational reasons, to surround patients with comprehensive rehabilitation, lacking the ability to coordinate activities. Oncological rehabilitation should be handled by the state in a systemic way. In Poland, about 20 billion zlotys a year are spent from the budget on people with disabilities and rehabilitation. If these funds were well invested, the effects would be much greater. Currently, several ministries and state institutions dispose of them, starting with the National Health Fund, Social Insurance Institution (ZUS), Social Insurance Fund (KRUS), and PFRON, and ending with the Ministries of Health, Sport, Education, Family or Defense. There is no coordination between them. It has been calculated that one zloty spent on rehabilitation pays back at least three times. This is another profitable investment for the state in the health of its citizens.” (<https://glospacjenta.pl/rehabilitacja/fizjoterapia/279>, [rehabilitacja-onkologiczna-powinno-sie-w-sposob-systemowy-zajac-panstwo](#) accessed 13.02.2023).

² Professor Piotr Majcher, MD, Head of the Rehabilitation Department of the 1st Military Clinical Hospital with Polyclinic in Lublin. Chairman of the Oncological Rehabilitation Section of the Polish Rehabilitation Society.

A resolution of the Council of Ministers in 2019 adopted the National Cancer Strategy (NSO) for 2020–2030 (subsequently approved by the Act of April 26, 2019 on the National Cancer Strategy, Journal of Laws of 2019, item 969). The NSO is a so-called cancer plan, or comprehensive program to fight cancer. The NSO guides the development of the healthcare system in the field of oncology, pointing to 5 strategic areas that are key to improving the effectiveness of cancer therapies and adapting system solutions to the needs of cancer patients. These areas are to be: Investment in the medical workforce; Investment in lifestyle education; Investment in the patient (increasing accessibility, improving the quality of implementation and introduction of new screening tests, increasing the involvement of primary care and occupational health teams in improving screening reporting); Investment in science and innovation (support for scientific research in oncology, greater participation of oncology patients in clinical trials, access to innovative therapies, increasing the number of reimbursed drugs); Investments in the oncology care system (implementation of the National Oncology Network, creation of entities specialized in the diagnosis and treatment of selected cancers, ensuring the highest quality standards of diagnosis and treatment for all oncology patients, increasing access to modern medical equipment, development of rehabilitation, palliative and hospice care, improving the quality of life of oncology patients, the right to live without pain for all oncology patients, launch of the National Oncology Portal) (see: <https://www.gov.pl/web/health/national-oncology-strategy> accessed 10.02.2023)

Of course, it is difficult to assess what will be the effects of the proposed activities in terms of broadly defined support for oncology patients, given the short duration of the strategy, but the inclusion of direct provisions for broadly defined rehabilitation and activities to improve multidimensional quality of life, one can assume that its effective implementation may bring many positive changes in this matter.

Institutional social support

In addition to the support that people with oncology can receive as part of the broader process of treatment and rehabilitation, there is also the possibility of applying for support of a social nature implemented mainly within the social welfare system. According to the information that can be found on the website of the Ministry of Family Labor and Social Policy, one of the basic forms of monetary assistance that can be obtained from the Social Assistance Center (OPS) is permanent benefit. It applies to people who have

no income or whose income does not exceed the so-called income criteria, which currently are, respectively: for a single person – PLN 776 and for a person in a family – PLN 600.

The permanent benefit is granted to: 1) a person who is a single farmer, incapable of working due to age or totally incapable of working, if his income is lower than the income criterion for a single farmer; 2) an adult person remaining in a family, incapable of working due to age or totally incapable of working, if his income, as well as the income per person in the family, is lower than the income criterion per person in the family.

A person with a moderate degree of disability or a Social Security Administration ruling of total inability to work is considered totally incapacitated. Unfortunately, there are situations when a person, even with such a Social Security certificate, does not meet all the conditions to receive a pension. Then it remains to apply for a permanent benefit to the Social Assistance Center (OPS) competent for the place of residence. The Social Assistance Center also pays the health insurance premium for persons receiving permanent benefit from social assistance who are not subject to the obligation of health insurance on other grounds.

Periodic allowance is granted in particular due to long-term illness, disability, unemployment, the possibility of maintaining or acquiring entitlements to benefits from other social security systems: 1) a single person whose income is lower than the income criterion of a single person; 2) a family whose income is lower than the income criterion of a family.

Target benefit is an optional benefit granted to meet an essential living need, and in particular to cover part or all of the costs of purchasing food, medicine and medical treatment, heating, including fuel, clothing, necessary household items, minor repairs and renovations in the home, as well as funeral expenses.

Among the non-monetary services that oncologically ill people can also apply for, the first to be mentioned are care services or specialized care services. Such services are granted to a single person who, due to age, illness or other reasons, requires the assistance of others and is deprived of it. They may also be granted to a person who requires the assistance of other persons, and the family, as well as a cohabiting spouse, ascendants, descendants cannot provide such assistance. **Care services** include assistance in meeting daily living needs, hygienic care, care prescribed by a doctor and, as far as possible, providing contact with the environment. **Specialized care services**, on the other hand, are tailored to special needs resulting from the type of illness or disability, provided by persons with specialized professional training. When granting care

services, the social welfare center determines their scope, period and place of provision. In particularly justified cases, in particular, when there has been a sudden deterioration of health or when the coverage of persons with care services or specialized care services is due to the need to provide such persons with adequate care, these services may be granted on an urgent basis.

Non-pecuniary forms of support also include **specialized counseling**, particularly legal, psychological and family counseling, which is provided to individuals and families who have difficulties or show a need for support in solving their life problems, regardless of their income. Legal counseling is carried out by providing information on the applicable legislation in the field of family and guardianship law, social security, protection of tenants' rights. Psychological counseling is realized through the processes of diagnosis, prevention and therapy. Family counseling includes problems of family functioning, including problems of caring for a disabled person, as well as family therapy. (See: <https://www.gov.pl/web/rodzina/uslugi-opiekuncze-i-specjalistyczne-uslugi-opiekuncze> accessed 12.02.2023)

Helping a family with a cancer problem is part of the repertoire of tasks posed by social work, which aims to respond to both personal and macro-social difficulties and sudden and unexpected situations, including crises. Oncological illness is an example of one of the more difficult crisis events. Social work with families in the face of a problem caused by an oncological illness of a family member appears to be a little-developed area in Poland (Pawlas-Czyż, 2018). It is more often concerned with those families about which the emergence of problems related to the situation of poverty, multiple children, single-parent family, having a single breadwinner, incapacity, old age of family members, as well as where pathological phenomena such as alcoholism, violence, crime or demoralization of minors have appeared (Wódz, 1996). In Poland, there is a clear need to spread the use of professional social work solutions, specialized in assisting families with an oncological disease of one of its members. Oncological social work can play such a role (Pawlas-Czyż, 2018). The primary spectrum of activity of oncological social workers is to undertake interventions targeting the psychosocial aspects of coping with cancer. In providing professional services to patients and their relatives, social workers respond to the social and psychological difficulties faced by individuals about the onset of cancer, as well as to problems resulting from the medical treatment of the disease (Fleishman, Messner, 2015). The social work activities undertaken in this area aim to help patients and their relatives function as well as possible in their social roles in the face of illness. The direct tasks of social workers include one/ assessment and monitoring

of the psychosocial functioning of patients and their relatives, 2/ assistance in adapting to the illness, 3/ emotional support and counselling, 4/ service planning, 5/ advocacy (Zebrack, Jones, Smolinski, 2015, p. 38). In their work, they refer to knowledge, methodology and experience from the field of social work and a lot of knowledge about cancer and its treatment process.

The Ministry's "**respite care**" program is dedicated to family members of people who have become dependent due to oncological illness. It is aimed at family members or caregivers who require support in the form of an ad hoc, temporary break from direct care of children with a disability certificate, as well as those with severe disabilities, and to improve their skills and knowledge in this area. The respite care is designed to relieve the burden on family members or caregivers of people with disabilities by supporting them in their daily duties or providing temporary replacements. With this support, those involved in daily care will have time to devote to rest and recuperation, as well as to run necessary errands. The respite care service can also serve to periodically provide for the needs of a disabled person when caregivers are unable to perform their duties for various reasons. The program is financed by the State Target Fund – Solidarity Fund. The main objective of the MRiPS Program is to support family members or caregivers providing direct care for: 1) children with a disability certificate; 2) persons with severe disabilities and equivalent certificates, through the possibility of obtaining ad hoc, temporary assistance in the form of respite care services. The program is also intended to provide: strengthening of the existing support system through the provision of respite care services for family members or caregivers providing direct care for children with certified disabilities or persons with severe disabilities/equivalent certificates, financial support for municipalities/counties in the implementation of respite care services, temporary relief from the daily duties associated with caregiving, provision of time for rest and recuperation as well as the completion of necessary errands (for more details: <https://mops.wodzislaw-slaski.pl/> accessed 11.02.2023).

Treatment and care for cancer patients in Hungary

The number of the mortality rate of cancer disease is still very high, the highest beside the cardiovascular diseases.

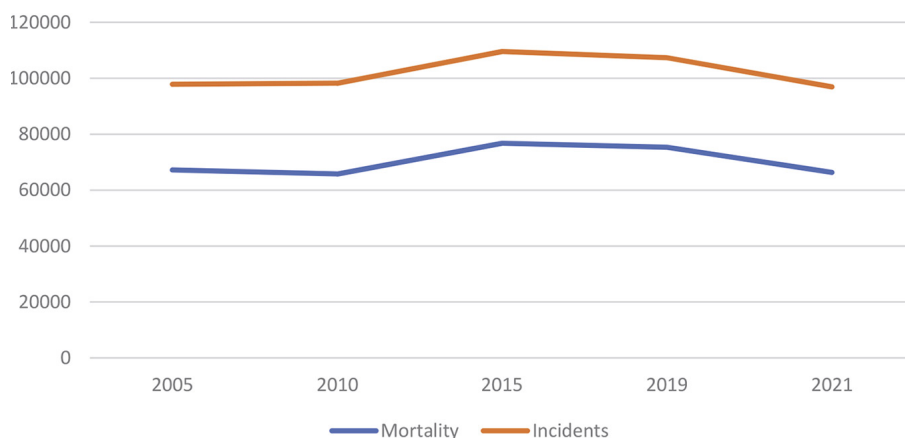
The fundamental starting point for the treatment, care and rehabilitation of Hungarian cancer patients is the shift towards outpatient care in oncology. This brought many challenges. For example, the patient's responsibility for accessing elements of the system is increased, as well as the importance of

family support. The effectiveness of systems of diagnosis, therapy, care and follow-up can be measured in terms of the rates of morbidity and successful survival, not least in terms of the mortality rates from cancer. The success of the programme is based on the coordinated functioning of health and social protection systems, on the one hand, and on care and rehabilitation methods adapted to the disease and the patient, on the other. One of the keys to quality care, as in other countries, would be to eliminate the division between health and social sectors, but this has not yet been achieved. The purely medical focus on illness has long discouraged the strengthening of psychosocial support (Csikai – Patyán 2008). In the past, such support was available to patients mainly through patient organisations. Patient care with a psychosocial perspective is typically represented by those working at the interface of medicine, psychology and psychiatry (Rohánszky, 2014), but the field is still identified as a “new, emerging discipline” (Prezenszki et al, 2015). So, another obstacle to helping patients, in addition to the fragmentation of sectors, seems to be the lack of an interdisciplinary approach. The Hungarian National Cancer Programme sets out the priorities and tasks for the area until 2030. The programme does not contain references to support for family members in care, the tasks of social professionals or the promotion of social inclusion. The priorities of the programme include prevention, improvement of treatment, research and development of rehabilitation and training of volunteers and professionals (MNREP, 2018).

Table 3. The mortality rate in Hungary

	1996	2000	2005	2010	2015	2019	2021
Cancer	33.475	33.280	30.615	32.460	32.792	32.012	30.593
Acute heart failure	14.087	11.312	10.247	7.481	6.026	5.699	6.059
Cardiovascular	17.259	18.487	26.646	26.361	26.979	25.971	25.917
Stroke	20.158	18.939	15.557	14.001	12.500	11.488	10.734
Respiratory	4.380	3.732	4.849	4.589	6.266	6.262	4.783
COVID-19	–	–	–	–	–	8.981	24.838
Accidents	1.427	1.292	1.269	793	734	720	645
Suicide	3.438	3.269	2.621	2.492	1.870	1.550	1.561

Source: Hungarian Statistical Office. 2023 https://www.ksh.hu/stadat_files/nep/hu/nep0010.html



Graph 3. Cancer incidence and mortality rates in Hungary

Source: Hungarian Statistical Office. 2023 https://www.ksh.hu/stadat_files/nep/hu/nep0010.html

Hungarian research experience shows that patients are diagnosed more quickly, but the rates of morbidity and mortality are high compared to other CEE countries. Among the many reasons for this, the importance of prevention, access to appropriate care, efficiency of care or rehabilitation should be highlighted. In any case, it can be seen that the effective functioning of some elements and the less effective functioning of others do not contribute to the overall prevention of disease and the effectiveness of treatment and care (Romavic et al, 2020). The focus of treatment has therefore shifted to the integration of service elements (Csanádi et al, 2022).

Service integration programmes have been mainly funded by the EU and their results focus on the development of integrated services in CEE countries. One project focused on the development of palliative consultation services. Its results highlight the need for integrated consultation services at home (Zemplényi et al, 2020).

Table 4. The availability of services for cancer patients related to 100.000 inhabitants

	Western European Countries	CEE	Hungary
Home care TEAM	0, 4	0, 21	0, 69
Impatient palliative care	0, 35	0, 14	0, 13
Consult services	0, 3	0, 08	0, 03

Source: Zemplényi et al. BMC Palliative Care 2020. pp 2.

In the case of older people, other characteristics should also be taken into account, such as the possible impact of age on treatment protocols, the age-related narrowing of the network of relationships, and the way and culture of living with the disease by the patient and family. Older cancer patients, for example, may experience of hidden forms of age-related discrimination – for which there is no evidence in the absence of scientific research³ – or discrepancies in the information provided to patients. Research has shown that older Hungarian cancer patients are often not informed of their exact diagnosis, partly because of the doctor’s judgement and partly because of requests from family members, making it difficult for the patient to cope and challenging for the social carers involved (Csikai – Patyán 2021). They may suffered significant difficulties in using health care facilities especially under the COVID-19 pandemic (Bekele et al, 2022).

Support for cancer patients

It is difficult to describe the rather fragmented system of support for cancer patients, as many benefits are only available under specific conditions. In many cases, there are no special services for cancer patients. Social benefits, income replacement services are generally linked to the care of chronic patients. In addition, the system of health, health insurance and social assistance are separated.

Table 5. Formal care forms in Hungary

Health care system	Social system
Screening programmes	Hospital hospice social work services
Home care nursing agencies including Hospice and palliative care	Home care (social care)
Ambulatory care	Retirement homes (facilities for elderly)
Inpatient care,	Social compensation of disability
Nursing unit	Care allowance to informal carers
Mobile palliative teams	Crisis support
Transportation services	

Health care services

The health insurance system does not treat cancer as a separate category; in general, some of the costs associated with the disease are covered by health insurance. Certain health services are fully or partly financed by the Hungarian

³ <https://168.hu/itthon/diszkriminalo-egeszsegugy-75-felett-nem-jar-gyogyulas-11344> (Discriminative health care. No right for threatment after 75?).

Health Insurance system. In the case of special treatment needs, the National Health Insurance Fund (NEAK) may exercise individual equity and subsidise treatment. Beside of the treatment there are two significant health service that support cancer patients in their home. Home specialist care and home hospice and palliative care are covered by insurance (14–56 visits). Treatments are prescribed by a general practitioner or specialist, with a fixed number of visits also covered. A physiotherapy service is also available as part of the treatment. The situation is similar for medication. Certain aspects of treatment are covered by health insurance. In cases of social need, the cost of treatment may be subsidised (public health care). Patients can reduce the cost of their treatment by subsidising the purchase of medical equipment and reducing the cost of public transport for them and their companions, if necessary. This must be claimed through the social system and is available to those in social need.

Under Hungarian law, a doctor cannot accept money from a patient in public health units. Due to the problems (waiting times) in recent years, some patients are turning to private health services.

Patient transport is free of charge within certain limits and is provided by patient transportation services. If someone has to use another service instead of the designated treatment place, they have to pay for the transport. Some service providers also provide free transport in such cases. Psychosocial oncology services are only available in certain institutions, typically in the capital.

Social benefits

It is also true for the social care system that there are no specific services for cancer patients, but the loss of working capacity, the loss of income and the increase in medical costs, the situation of family carers induce certain social services and benefits. Income replacement services such as sickness benefit are often not available to older patients because they are already receiving a pension. In cases of financial hardship, the state subsidises the cost of medicines and assistive devices. The situation is similar for subsidising the costs of going to treatment. These allowances must be applied for at the government office. Ad hoc, crisis grants may be awarded by the municipal council. Under certain conditions (severe disability), the patient may also qualify for tax relief.

Social services

Cancer patients can first meet a social worker in the oncology department of the hospital. The specialist is responsible for developing a discharge plan and liaising with local services. The specialist can provide information to the patient and their relatives. During outpatient care, the patient can contact the

social worker at his/her request. If the hospital has a psycho-oncology team, the patient can ask for their help. Health services standards require social workers to be employed in both institutional and home hospice services. These professionals help patients access care and social benefits.

Long term care services usually do not equip for nursing care for cancer patients. Indeed, patients have to use another inpatient hospital care. According to the latest change in the Social Welfare Act (01.01.2023), elderly people requiring specialised care are placed in so-called specialised care institutions for the duration of the care. It is expected that older patients with a serious condition and patients requiring intensive care will be placed in these schemes in the future.

Support for informal carers

Support for family carers needs significant improvement in Hungary. Traditionally, a relative can take two years unpaid leave to care for a relative with cancer, but most of carers do not afford to do this. Only a family member of working age can receive a care allowance if the cared-for person has been classified as severely disabled. The level of support is far below the minimum wage. No other financial compensation is available to older cancer patients, or older caregivers as it is linked to active age. Indirectly, it is possible to use the services of home help and day care in the care of elderly cancer patients, although cancer patients tend to be excluded from the latter.

Patient organisations

There are about 32 NGOs helping cancer patients in Hungary, many of them national-wide organisations. They provide a wide range of services and work with many volunteers. Patients can get in touch with them and they can provide a lot of practical advice and information to help patients and their families (daganatok.hu).

Overall, there is no social service system in Hungary specifically designed to help cancer patients and their families. Patients contact professionals and services through the hospital and community social care system. The services are not integrated and coordinated, so access to appropriate information and services plays an important role. Support for family carers is typically a white spot in the system. The hardest hit are the less well-off patients who cannot afford private health care, especially if they are unable to access family support. Pilot interview experience also shows that older patients living in rural areas face a number of challenges in accessing appropriate treatment. Recent efforts have focused on early detection and treatment of cancer through targeted and

free screening programmes, with a strong emphasis on developing palliative and hospice care. This has led to the specific situation whereby patients can meet a social worker during their hospital stay as well as during palliative care at home.

Analysis of empirical material – pilot interviews

Description of the research idea and methodology

The “Research on the needs and possible scope of community support for elderly people suffering from chronic/oncologic diseases) based on activities in the field of the social economy” – nechron-secon, project is carried out by international research team composed of employees of the Institute of Sociology, Faculty of Social Sciences, University of Silesia; University of Trnava and a Theological Academy of Sárospatak. The main objective of the project is to investigate the situation of oncologically ill people and answer the following questions: what are the needs of cancer patients to be met throughout the course of the disease? What are the sources of support at the various stages of treatment and recovery of the cancer patients? What are the most common obstacles in the use of social services by cancer patients?

Both qualitative and quantitative research activities are planned in the project. At present, expert interviews, [with: professional care givers in a field of social work; experts in social policy and health (academics, people involved in policy making processes etc.; privilege observers (members of social support groups for the cancer patients and its families, ect.) psychologists who are working in a field of support cancer patients and representatives of the medical system] are being carried out as a pilot study, on the basis of which the quantitative tool aimed at oncologically ill people will be developed.

The results presented below are the result of analysis of the first expert interviews, which were conducted in all partner countries. However, it should be noted that they represent only a sample of the empirical material that is currently being collected. Our goal is to want to present these very preliminary and limited, but in our opinion interesting results.

Poland

Support at different stages of the disease and treatment process

Representatives of the foundation supporting oncologically ill people “Eye to Eye with Cancer”, who themselves have experienced cancer – breast cancer, point out that oncologically ill people, especially single ones face many problems of not only physical but also mental or emotional nature requiring

support at various stages of the disease. A particularly important moment is the stage of diagnosis.

R1. [...] In general, the diagnosis is a shock to her, a big shock and now: what next? If there is no one to turn to, well it's really hard to go through it, to find out at all what the treatment is about, because the doctor does not inform exactly, it's not like that yet in our country, maybe there are exceptionally some doctors who inform how it all looks like. It is described, because there are cards of information, but now the question is how much strength a woman has to go through it all, because many times ladies of this age are not even able to read it all – this is certainly also a great difficulty already.

The respondents, referring to their own experiences of struggling with oncological disease, treatment and hormonal therapies, say that the patient can count on certain forms of support within the medical system only until the active treatment process. Later, when his treatment enters a phase of long-term hormone therapy after surgeries and operations, radiation therapy and chemotherapy, he is left to fend for himself.

A colleague (R2) is four, I am five years (after the end of active treatment), and we are all the time on hormone therapy and check-ups, but actually no one is interested in us anymore.

Interviewer researcher: So, once a patient is past the main treatment, he falls into such a state of non-existence?

R1: He falls into the non-existence of hormone therapy, endless hormone therapy, because it's not known when it will end – well, he's left alone.

R2: You could say that it's as if you put him somewhere out there on the road in a foreign city and tell him "go."

In addition, the health care system at some point sort of stops noticing patients, limiting their check-ups and medical care to a very limited range, which results in either high out-of-pocket costs for patients, or the discontinuation of check-ups and thus possible prevention or response at an early stage of recurrence.

R1: Research is already very thin, very poor and limited to a minimum.

R2: The kind of tests we have, it's actually frankly without ultrasound, it's mammography, it's blood tests.

R1: I don't even get that anymore, I only get blood tests anymore.

R2: And that's where the topic ends, so in fact a person would still have to have a second wallet to get himself tested.

This, perceived, lack of interest in the health care system, with a low level of self-advocacy in the role of the patient, often leads to neglect of diagnostic and control measures and even in the maintenance of systematics and self-discipline in the use of hormone therapy, which can often lead to the uncontrolled development of further or new health problems.

R1: If someone has, such sensitivity just for himself, he has to observe and control himself, because no one does. Unfortunately, many people do not have this sensitivity and simply later forget about this hormone therapy at all, even about the pill he is supposed to take every day. He just can't figure it out for himself, he no longer has the care he used to have, as he felt he had, and so it all falls apart a little bit for him sometimes, too. And how he is so out of touch (incompetent in self-treatment), and still how he doesn't know his body, how he hasn't learned that sensitivity of himself to observe himself, often leads to further problems. We are told everywhere that just because we get sick, it doesn't mean that we won't get cancer already, and that we won't be sick with something else at all, and whether we won't get some more accompanying diseases because of it. So all the time you have to be vigilant and attentive simply, and this attentiveness, patients already left behind afterwards, it falls apart for them.

Lack of readiness to accept support

It is pointed out that the need for support will very often not be externalized at all by those who are ill. For various reasons, people affected by oncological disease not only do not seek help, but in some cases do not even want to inform those around them about their illness. Particularly often, according to our respondents, such a situation applies to middle-aged and elderly women, which, if it involves single people, compounds the negative emotional consequences associated with struggling with the disease alone.

R2: [...] in fact, post-mastectomy women in this late middle, older age feel so very unnecessary. These are the people who lock themselves in such a shell, they need help, but they won't ask for it because they are ashamed, because they are afraid, they don't involve the family. For example, the family really wants this woman to go, to ask for this help, because they see that she needs it, but this woman doesn't do it. She's just so stereotypical, that no, it's not allowed to ask for help, not for psychological help at all anymore, or under this particular direction. So this group of women, it seems to me, is the most withdrawn here. Although this woman is not alone, she is alone because she is on her own and does not want to let herself be helped.

Very often cancer patients do not want to burden family members additionally with their disease. In many cases, the reason for this is the desire to save the family the trouble – so that an illness that will pass does not burden other family members. Another issue is also the problem of constantly facing sympathy from others, which in social relations does not allow to forget about the disease. This situation causes all relations with relatives, acquaintances, friends to be reduced to having to confront the sadness of others who want to comfort us by showing sympathy. Sometimes sick people are forced to comfort relatives who cannot cope with the sadness of their illness, which creates a situation in which the sick person who needs support becomes the one who supports, without receiving support himself.

R2: There are situations when, for example, you walk in somewhere and someone just starts lamenting so much that you, as a sick person, comfort that person, because such situations also happen very often. It's not that they comfort us – no. It happened very often that I had to comfort someone.

R1: They can't handle the situation.

R2: In my circle it was very often the case that people would go somewhere very far away, then somewhere after two years they would come, sit down and say that they just can't cope, that's why they went away, because for them it was just a better way. That's the way it is, unfortunately. The elderly are also sometimes lonely, because these very friends, acquaintances also move away for this reason.

In some cases, this inability, the inability to cope with the illness of loved ones, friends or acquaintances, causes healthy people to limit or completely suspend contact with sick people in order not to have to confront their illness.

Social stigma affecting a person with oncological disease

There are voices talking about the social stigma associated with oncological disease, which causes some people not to admit their illness. Some respondents, referring to their experience, point out that in small rural communities this stigma is sometimes very pronounced. And although, of course, this social awareness is changing, it is still a rather slow process.

R1: In the countryside it's terrible. There are some villages that I even had a conversation with a girl who had a friend like that, who they didn't even let out to the children so she wouldn't get infected, so really.

At the same time, in many cases, it's important to talk about self-stigmatization, which is the feeling that everyone knows about my disease and sees me only through its context.

R2: The other thing is still this nonetheless low awareness, because in small towns, for example, it's the case that if someone has cancer and has chemotherapy, they're going to die. In fact, with the moment of diagnosis, the spread of this information, a person already feels like they have this hourglass stuck on the door, because that's how it is, unfortunately.

Hungary

Work and treatment

Being away from the world of work causes difficulties. In many cases, therapy is prolonged and patients are unable to work continuously. An important and missing element of rehabilitation is some form of compensation for the time off work. Today, this is entirely up to the employer and in many cases is not good for the patient.

Employers do not understand that chemo affects everyone individually. It takes someone off work for a week while others can work alongside them. Although going for treatments can also cause problems at work. Just when you really need financial security.

Social security system failures

The social care system is not coordinated and benefits are difficult to access. There are many small discretionary benefits in both social and health care, but most patients are unaware of them and they are difficult to access. The tax benefits that patients can claim negatively affect those who are out of work and those in retirement.

You know, I work in Budapest for a big service provider. My patients in the countryside suffer a lot. The last time I called the local government in my client's place of residence to help him. He was the breadwinner, now they have no income. They got back to me, finally a man told me that they don't have social assistance for such a case. You understand? According to the law, there should be at least a municipal allowance.

Same with patient transport. If the patient needs special treatment and is not taken to the district hospital they already charge a fee. I've tracked down an organisation that does this for free.

Conclusions – challenges in long-term care for chronically ill people

Main challenges and problems in the field of long-term care in Slovakia

Based on the above, we can conclude that the main challenges in the area of concern for long-term sick oncology patients, identified during the analysis of interviews with experts, fully coincide with the challenges listed in the Strategy of long-term care in Slovak republic (2021):

1. Absence of functional connection of social and health care and vertical fragmentation of competences.
2. Non-uniform and non-systematic assessment of disability and the need for long-term care.
3. Lack of long-term, follow-up and palliative care services, especially community-type services.
4. Inefficient method of financing.
5. Dysfunctional system of supervision of social care, including care in the home environment.
6. Absence of readiness of social service facilities for patient/client isolation needs.
7. Inadequate level of application and implementation of telemedicine and telenursing.
8. Absence of legal regulation of the institute of previous wishes, including the area of long-term care.
9. Absence of the patient's journey and management after the end of hospitalization in acute beds, in the case of the need to provide long-term care, based on a comprehensive health-social assessment and the needs of persons dependent on health-social care.

Main challenges and problems in the field of long-term care in Poland

1. Not adequate number of specialists and facilities that can conduct medical, psychological and social rehabilitation of people after oncological treatment.
2. Wide understood rehabilitation is a continuous process, which should start even before the start of treatment, preparing the patient for surgery, or other therapies. In Poland the support (if it appears from the institutional side) is limited to period of medical treatment.
3. Oncological patients have very limited access to professionals and facilities in the scope of psychological support and rehabilitation after finishing treatment and return home. This kind of support on local level is almost not existing in institutional system.

4. The vast majority of support for the broader rehabilitation of cancer patients is provided by the non-governmental sector. It is very significant help, based on huge engagement of peoples who in general also were (are) affected by oncological problems, but for financial and organizational reasons, this organizations are often unable, to surround patients with comprehensive rehabilitation and socio-psychological support.
5. Lack of systemic, state solutions of oncological rehabilitation and socio-psychological support.
6. Absence of adequate educational and informational support and supervision procedures for professionals employed in social aid and medical institutions, who are responsible for direct support of oncologically patients.

Challenges with care system in Hungary

1. The care system is not specialised in the care of elderly cancer patients, nor in providing specific financial support for them.
2. The care and rehabilitation of cancer patients is still more of a health issue in Hungary, despite efforts to promote psychosocial counselling.
3. Rehabilitation does not cover vocational rehabilitation and social inclusion.
4. Strategies lack social care and social work with patients and their families.
5. Home care focuses mainly on palliative nursing care. This care is more accessible, while counselling services are not accessible to patients, despite the needs assessed.
6. Support for families, including family carers, is not provided in Hungary. Special attention and support is needed for older cancer patients whose carers are also older.
7. Patient organisations can provide important support to patients and their relatives, and their support is needed.

Many of mentioned challenges and problems are defined by professionals in social aid and medical systems in Slovakia, Poland and Hungary seems to be very similar. This similarities are especially seen in areas like: lack of systemic, state, long-term solutions of oncological rehabilitation and socio-psychological support; fragmentation of competencies and lack of cooperation inside of institutional system; lack of money or not sufficient management and distribution of financial resources between institutions; absence of sufficient management and coordination of professionals work and very limited or

absolute absence of management on patient long-term medical, psychological and social rehabilitation and support.

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