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EDITORIAL

How might ehealth and digital technologies impact on palliative care?

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There have been extraordinary developments in information and communication technologies over the last 50 years which have impacted on health and palliative care. The purpose of this editorial is to consider to what extent ehealth and digital technologies remain out of reach of many people with life-limiting illnesses and how does this impact on palliative care practice, with a focus on three examples: electronic health records, telemedicine, and sensors and wearable devices.

What are ehealth and digital health technologies?

The World Health Organisation defines ehealth as the 'use of information and communication technologies for health' and have adopted an ehealth strategy (World Health Assembly 2005). eHealth is recognised as one of the most rapidly growing areas in health care. According to the European Commission Policy on ehealth: 'digital health and care refers to tools and services that use information and communication technologies (ICTs) to improve prevention, diagnosis, treatment, monitoring and management of health-related issues and to monitor and manage lifestyle-habits that impact health. Digital health and care are innovative and can improve access to care and the quality of that care, as well as to increase the overall efficiency of the health sector.' Moreover since 2019, digitalisation has been a key political priority in the European Union, with access for all citizens considered to be essential. Digital technologies refer to a wide range of functions including electronic health records, telemedicine, smartphone apps, sensors and wearable devices (for diagnosis and monitoring disease, and health optimisation), speech recognition and natural language processing, virtual and augmented reality, artificial intelligence and robotics. The Covid-19 pandemic precipitated a rapid adoption of many forms of ehealth, including in palliative care contexts (Dunleavy et al 2021).

Implications of digital health for palliative care

There are a number of core competences in palliative care including establishing compassionate personal relationships with patients and families, respect for personal values and goals, empathetic listening and communication, enhancing dignity and patient-centredness, therapeutic touch, and psychological, social and spiritual support, which need to be kept in mind when designing digital health

interventions for palliative care (Gamondi et al 2013). For each aspect of care, it is important to carefully consider both the advantages and disadvantages that digital health may bring. For example, according to a systemic review, the use of electronic health records has increased substantially in palliative care since 2014 (Bush et al 2018). This offers advantages for rapid sharing of information across teams and organisations, with clinicians only needing to ask patients for their medical history once, and it enables them to share information with patients if they have access to their own records. However, questions remain about ensuring the accuracy, security and privacy of data when it is shared across health sectors, and importantly about the availability of access to devices and the need to maintain and update electronic systems. Moreover, there is evidence from the USA, that junior doctors (residents) spend up to 50% of their shift time interacting with computers, and only 10% interacting with patients. This has implications in palliative care where direct interaction with patients is regarded as an essential aspect of compassionate communication.

Telemedicine is a healthcare delivery model that has expanded rapidly in the context of the Covid-19 pandemic when patients with advanced disease were highly vulnerable to infection and mostly preferred to remain out of hospital (Tang and Reddy 2022). For patients undertaking consultations online, using smartphone apps or via conventional telephones may have advantages in reducing travel time and expenses in clinic visits, especially for those living in rural and remote areas. Patients may also appreciate the opportunity to be proactively engaged in managing their own disease and treatment. In addition, telemedicine may offer direct access to specialist palliative care providers which in many countries are very few in number. However, this needs to be balanced by recognising that some people such as older people, those with communication challenges (such as non-native language speakers), those with less access to digital devices and connectivity, and less digital literacy, should not be marginalised. The focus on self-reporting of physical symptoms may mean that psychological, social and spiritual concerns may receive less attention (Payne et al 2020). It may also be difficult to establish sufficient rapport to offer complex psychological or spiritual assessment and support using telemedicine alone.

A third area of rapid innovation is in wearable devices and sensors, especially in the context of long-term care for older people (Uddin and Syed-Abdul 2020). In the context of home-based palliative care, these devices make it easier to monitor patient's condition, require less staff-time in making domiciliary visits, and can provide real-time data such as on physiological parameters and mobility or sleep patterns. However, does the focus remain on what can be measured and 'seen' (such as Fitbit steps), rather than holistic assessments. These devices also raise questions about privacy, where remote monitoring may be regarded as invasive. There is the risk of having more information about patient's physiological functions but less knowledge about them as human beings, their values and goals and social situation nearing the end of life.

High-quality palliative care is a responsibility of every clinical team whose role is to provide care to patients with life-limiting illness. Reaching out to include the innovations offered by ehealth and digital technologies requires a careful appraisal of the balance between advantages and reduction of known barriers for each person to ensure that they are utilised appropriately for the people who will benefit most.

Care ar putea fi impactul asistenței medicale online și al tehnologiilor digitale asupra îngrijirii paliative?

Tehnologia informației și comunicațiilor a cunoscut în ultimii 50 de ani o evoluție extraordinară, cu un mare impact asupra domeniului sănătății și al îngrijirii paliative.

Scopul acestui editorial este de a analiza în ce măsură tehnologiile digitale și de asistență medicală online rămân inaccesibile pentru multe persoane cu boli care limitează viața și cum influențează acest lucru practica îngrijirii paliative, cu accent pe trei exemple: dosarele electronice de sănătate, telemedicina, senzorii și dispozitivele purtabile.

Ce sunt tehnologiile digitale utilizate în domeniul sănătății și asistența medicală online?

Organizația Mondială a Sănătății definește asistența medicală online ca fiind „utilizarea tehnologiilor informației și comunicațiilor pentru sănătate” și a adoptat o strategie în acest sens (Adunarea Mondială a Sănătății, 2005). Asistența medicală online este recunoscută ca fiind unul dintre domeniile cu cea mai rapidă creștere în domeniul sănătății. Conform politicii Comisiei Europene privind asistența medicală online: „îngrijirea și asistența medicală digitale se referă la instrumente și servicii care utilizează tehnologia informației și comunicațiilor (TIC) pentru a îmbunătăți prevenirea, diagnosticarea, tratamentul, monitorizarea și gestionarea problemelor legate de sănătate, precum și pentru a monitoriza și gestiona stilul de viață care au impact asupra sănătății. Asistența și îngrijirea medicală digitale sunt inovatoare și pot îmbunătăți accesul la îngrijiri și calitatea acestora, și cresc eficiența generală în domeniul sănătății. În plus, începând din 2019, digitalizarea a fost o prioritate politică cheie în Uniunea Europeană, accesul tuturor cetățenilor fiind considerat esențial.

Tehnologiile digitale se referă la o gamă largă de funcții, inclusiv dosarele electronice de sănătate, telemedicina, aplicațiile pentru smartphone-uri, senzorii și dispozitivele purtabile (pentru diagnosticarea și monitorizarea bolilor și pentru optimizarea stării de sănătate), recunoașterea vorbirii și procesarea limbajului natural, pentru realitatea virtuală și augmentată, pentru inteligența artificială și robotică. Pandemia Covid-19 a precipitat o adoptare rapidă a multor forme de asistență medicală online, inclusiv în contexte de îngrijire paliativă (Dunleavy et al. 2021).

Implicații ale asistenței medicale online pentru îngrijirea paliativă

Există o serie de competențe de bază în îngrijirea paliativă, inclusiv stabilirea unor relații personale pline de compasiune cu pacienții și familiile, respectul pentru valorile și obiectivele personale, ascultarea și comunicarea empatică, creșterea demnității și centrarea pe pacient, atingerea terapeutică și sprijinul psihologic, social și spiritual, care trebuie avute în vedere la conceperea intervențiilor de asistență medicală digitală pentru îngrijirea paliativă (Gamondi et al. 2013). Pentru fiecare aspect al îngrijirii, este important să se analizeze cu atenție atât avantajele, cât și dezavantajele pe care le poate aduce asistența medicală digitală. De exemplu, conform unei analize sistematice, utilizarea dosarelor electronice de sănătate a crescut substanțial în îngrijirea paliativă începând cu 2014 (Bush et al. 2018). Acest lucru oferă avantaje pentru schimbul rapid de informații între echipe și organizații, medicii fiind nevoiți să le ceară pacienților istoricul medical doar o singură dată, și le permite acestora să împărtășească informații cu pacienții, dacă pacienții au acces la propriile dosare. Cu toate acestea, rămân întrebări cu privire la asigurarea acurateții, securității și confidențialității datelor atunci când acestea sunt partajate între sectoarele de sănătate și, ceea ce este important, cu privire la disponibilitatea accesului la dispozitive și la necesitatea de a menține și actualiza sistemele electronice. În plus, există dovezi din SUA, conform cărora medicii începători (rezidenți) petrec până la 50% din timpul turei lor de lucru interacționând cu computerele și doar 10% interacționând cu pacienții. Acest lucru are implicații în domeniul îngrijirii paliative, unde interacțiunea directă cu pacienții este considerată un aspect esențial al comunicării pline de compasiune.

Telemedicina este un model de furnizare a asistenței medicale care s-a extins rapid în contextul pandemiei Covid-19, când pacienții cu boli avansate erau foarte vulnerabili la infecții și preferau, în cea mai mare parte, să rămână în afara spitalului (Tang și Reddy 2022). Pentru pacienții care întreprind consultații online, utilizând aplicații pentru smartphone-uri sau prin intermediul telefoanelor convenționale, consultațiile pot prezenta avantaje în ceea ce privește reducerea timpului de deplasare și a cheltuielilor în cadrul vizitelor la clinică, în special pentru cei care locuiesc în zonele rurale și îndepărtate. De asemenea, pacienții pot aprecia oportunitatea de a se implica în mod proactiv în gestionarea propriei boli și a tratamentului. În plus, telemedicina poate oferi acces direct la furnizorii de îngrijiri paliative de specialitate, care în multe țări sunt foarte puțini la număr. Cu toate acestea, acest lucru trebuie să fie ponderat datorită faptului că unele persoane, cum ar fi persoanele în vârstă, cele cu dificultăți de comunicare (spre

exemplu persoanele care nu sunt vorbitoare de limbă maternă), cele care au mai puțin acces la dispozitive digitale și conexiune la internet, și care au mai puține cunoștințe digitale, nu ar trebui să fie marginalizate. Accentul pus pe autodenunțarea simptomelor fizice poate însemna că preocupările psihologice, sociale și spirituale pot primi mai puțină atenție (Payne et al. 2020). De asemenea, poate fi dificil să se stabilească un raport suficient pentru a oferi evaluare și sprijin psihologic sau spiritual complex folosind doar telemedicina.

Un al treilea domeniu de inovare rapidă este cel al dispozitivelor și al senzorilor portabili, în special în contextul îngrijirii pe termen lung a persoanelor în vârstă (Uddin și Syed-Abdul 2020). În contextul îngrijirii paliative la domiciliu, aceste dispozitive facilitează monitorizarea stării pacientului, necesită mai puțin timp din partea personalului pentru efectuarea vizitelor la domiciliu și pot furniza date în timp real, cum ar fi cele privind parametri fiziologici și mobilitatea sau tiparele de somn. Cu toate acestea, se pune accentul în continuare pe ceea ce poate fi măsurat și „văzut” (cum ar fi pașii Fitbit), mai degrabă decât pe evaluări holistice. Aceste dispozitive ridică, de asemenea, întrebări cu privire la viața privată, în cazul în care monitorizarea de la distanță poate fi considerată invazivă. Există riscul de a avea mai multe informații despre funcțiile fiziologice ale pacienților, dar mai puține cunoștințe despre aceștia ca ființe umane, despre valorile și obiectivele lor, precum și despre situația socială la apropierea sfârșitului vieții.

Îngrijirea paliativă de înaltă calitate este o responsabilitate a fiecărei echipe clinice al cărei rol este de a oferi îngrijire pacienților cu boli care limitează viața. Incluziunea inovațiilor oferite de asistența medicală online și de tehnologiile digitale necesită o evaluare atentă a echilibrului dintre avantajele și reducerea barierelor cunoscute pentru fiecare persoană, pentru a se asigura că acestea sunt utilizate în mod corespunzător, astfel încât persoanele să beneficieze de acestea cât mai mult.

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ORIGINAL PAPERS

Early integration of palliative care in the management plan of cancer patients through initiation and compliance with opioid treatment - the experience of the specialized outpatient clinic of Hospice Casa Speranței Brașov

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Abstract

Objective: The aim of this study was to determine the impact of Hospice Casa Speranței Brașov outpatient palliative care service on opioid treatment compliance of cancer patients.

Material and methods: The research retrospectively analyzes, from 01.01.2022 to 30.06.2022, the observation charts of patients who accessed the outpatient department of Hospice Casa Speranței Brașov to determine the need to initiate and ensure continuity of opioid treatment. Compliance to opioid treatment of oncology patients monitored in this department was also assessed.

Results: The research group consisted of 52 patients, female = 36, male = 16, urban = 36, rural = 16, mostly belonging to the age groups 60 - 69 years = 21 patients. 35 patients had an ECOG performance status = 2, 10 patients had an ECOG = 1. 22 patients had nociceptive pain; 20 patients had neuropathic pain. Patients with moderate pain are 40, 12 patients stated that the pain is severe. 40 patients use minor opioids, 12 patients use major opioids. 26 patients who presented for consultation had opioid analgesic treatment initiated by other healthcare providers, 16 patients returned for continuation of treatment initiated at some point, for 10 patients consulted during this period opioid analgesic treatment was initiated. 33 patients stated that pain was controlled, 18 patients stated that pain was partially controlled. For 1 patient the pain was not controlled.

Conclusions: The study found that the specialized outpatient clinic of Hospice Casa Speranței Brașov has a positive impact by initiating and ensuring continuity of opioid treatment.

Key words: opioids, treatment compliance, outpatient, palliative care

Rezumat

Obiective: Scopul acestui studiu a fost de a determina impactul serviciului de ambulatoriu de îngrijiri paliative al Hospice Casa Speranței Brașov asupra complianței la tratamentul cu opioide a pacienților cu cancer.

Material și metoda: Cercetarea de față urmărește analiza retrospectivă pe perioada 01.01.2022 - 30.06.2022 a foilor de observație ale pacienților care accesează serviciul de ambulatoriu al Hospice Casa Speranței cu scopul de a determina nevoia de inițiere și de asigurare a continuității tratamentului cu opioide, dar și evaluarea complianței la tratamentul cu opioide a pacienților oncologici monitorizați în acest departament.

Rezultate: Lotul de cercetare a fost reprezentat de 52 pacienți, femei = 36, bărbați = 16, din mediul urban = 36, din cel rural = 16, majoritatea aparținând categoriilor de vârstă: 60 – 69 ani = 21 pacienți. 35 de pacienți au avut un status de performanță ECOG = 2, 10 pacienți au avut un ECOG = 1. 22 pacienți au durere nociceptivă, 20 pacienți au durere neuropată. Pacienții cu durere moderată sunt în număr de 40, 12 pacienți au afirmat că durerea este severă. 40 pacienți utilizează opioide minore, 12 pacienți utilizează opioide majore. 26 pacienți care s-au prezentat la consultație aveau tratament cu antialgic opioid inițiat de alți furnizori de servicii medicale, 16 pacienți au revenit pentru continuarea tratamentului inițiat la un moment dat, pentru 10 pacienți consultați în această perioadă a fost inițiat tratament cu antialgic opioid. 33 pacienți au afirmat că durerea a fost controlată, 18 pacienți au afirmat că durerea este parțial controlată. Pentru 1 pacient durerea nu a fost controlată.

Concluzii: În urma studiului efectuat s-a constatat că ambulatoriul de specialitate al Hospice Casa Speranței Brașov are impact pozitiv prin inițierea și asigurarea continuității tratamentului cu opioide.

Cuvinte cheie: opioide, complianță la tratament, ambulatoriu, îngrijire paliativă

Introduction

According to the World Health Organization (WHO) definition, palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with a life-threatening illness through early identification, accurate assessment and appropriate treatment of pain. (1)

Specialized outpatient clinics are a key point of integration, where the patient has timely access to palliative care services. (2) Their aim is to support the patient by providing care throughout the evolution of the chronic disease and by monitoring them in the early stages of the disease. (3)

Hospice Casa Sperantei is a non-profit organization founded in 1992 in Brașov. The integrated outpatient service manages the monitoring of patients from the moment they request services. (4)

One of the most common and unpleasant symptoms affecting patients diagnosed with cancer is pain. Pain is an unpleasant physical and sensory experience associated with actual or potential tissue damage, or described in terms of such damage. Referred to as the "fifth vital sign," pain is "whatever the patient says they experience, being present whenever they say". (5) It involves more than a physical sensation and is considered "a bio psychosocial phenomenon that includes sensory, emotional, cognitive, developmental, behavioral, spiritual and cultural components". (6)

In chronic pain, positive adaptation does not occur, as time goes by, the system becomes more sensitive, hyperactive and capable of producing intense, widespread and continuous pain. The goal of pain management is to reduce this symptom to a level that allows the patient to have an acceptable quality of life for them and it must be well controlled as quickly as possible.

Chronic cancer pain requires a different approach to treatment than other chronic or acute pain. The aim of treatment is to relieve the pain quickly and prevent its recurrence.

The treatment of chronic cancer pain is a component of the multidisciplinary total care plan and cannot be addressed in isolation from the psychosocial and spiritual issues that can influence pain. It needs to be reassessed to monitor the effect of treatment, to match the stage of the patient's disease, to be consistent and to ensure continuity of care. Any unforeseen changes can lead to loss of confidence in the care team. (7)

The analgesia ladder is a strategy developed by the World Health Organization in 1986 with the aim of providing adequate pain relief for cancer patients. Classification is based on pain intensity which can be measured using the analogue-visual scale (VAS), numerical or descriptive. Three stages of pain are described: first stage = mild pain (VAS 1-3), second stage = moderate pain (VAS 4-6), third stage = severe pain (VAS 7-10). (8)

Pain management in cancer should always start with patient assessment. The assessment should be as

comprehensive as possible, consistent with the patient's comfort, including as detailed a history of the disease as possible, physical examination, assessment of psychological circumstances, assessment of pain persistence, pain intensity. Assessment can be performed using measuring instruments and diagnostic procedures. (9)

Despite the availability of opioid analgesic therapy and current guidelines, pain remains one of the most prevalent symptoms of patients diagnosed with cancer. Ineffective management of pain relief therapy may be the result of misconduct on the part of both the patient or caregiver and the healthcare provider. Adequate pain management depends on the patient's condition, willingness and ability to follow medical advice and poor compliance with the analgesic regimen can be an important reason for ineffectively treated pain. (10)

According to Turk and Meichenbaum, "compliance is an active process with voluntary and collaborative involvement of the patient who adheres to the therapeutic means necessary to improve their health". This perspective suggests that patients need to be involved in making choices about how to implement therapeutic interventions (e.g., taking an analgesic drug). (11)

Nurses play a critical role in caring for patients living with pain throughout their lives. They provide important services that strongly influence the quality and effectiveness of a care plan, ensuring that the patient receives, understands, executes and reports the effectiveness of pain treatment. They play an important role in several aspects of pain care, which include assessing/reassessing pain, developing a patient-centered treatment plan, implementing that plan, observing and reporting the impact of that plan, and providing and reinforcing patient education. (12)

The aim of this study was to determine the impact of Hospice Casa Speranței outpatient palliative care service on opioid treatment compliance of cancer patients.

The objectives of the study were to perform retrospective analysis over the period 01.01.2022 - 30.06.2022 of patients accessing the outpatient clinic service of Hospice Casa Speranței, to determine the need to initiate and ensure the continuity of opioid treatment in patients in the outpatient service of Hospice Casa Speranței. Compliance to opioid treatment of oncology patients monitored in this department was also assessed.

Material and methods

This paper is a retrospective, quantitative observational study of adult patients in the outpatient department of Hospice Casa Speranței Brasov. The study group includes 52 patients. During the period 01 January 2022 - 30 June 2022, 420 consultations were carried out in the adult outpatient service.

Data were obtained from patient observation charts and included socio-demographic, clinical characteristics, malignancy location, pain characteristics, treatment and patient response to treatment. The data

obtained were entered into a database and processed using Microsoft Excel 2010.

The patients who were included in the study were adults with oncological disease attended in the polyclinic service of Hospice Casa Speranței Brasov who are on opioid treatment and who signed the Informed Consent Form.

Patients who were not included in the study were those without pain, patients with mild pain receiving treatment with non-opioid analgesics, treatment with Doreta (Tramadolum + Paracetamolom), Ultracod (Paracetamolom + Codeinum), and patients without analgesic treatment.

Results

The analysis shows that there is a difference in the research group in terms of the gender of the patients, the majority, 69.23% (36 patients) of them being represented by the female gender, while the male gender is represented by 30.77% (16 patients).

Majority of the patients, 40.39% (21 patients) belong to the age group 60-69 years, 26.93% (14 patients) of the patients are in the category of 70-79 years, and 23.07% (12 patients) of the patients belong to the age group 50-59 years.

Patients coming from urban areas represent a percentage of 69.23% (36 patients), while patients coming from rural areas represent 30.77% (16 patients).

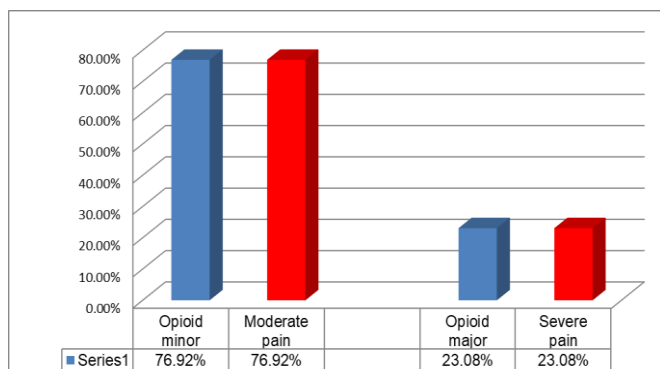
Breast cancer is the most common diagnosis (12 patients) among the patients in the study group.

Holistic assessment of the patient in the palliative care service also involves identifying the psycho-emotional status of the patient. To the question "Do you feel depressed?" 44.23% (23 patients) of patients answered no, 38.46% (20 patients) said they were anxious, 13.46% (7 patients) of patients answered yes, and 3.85% (2 patients) were diagnosed with anxiety-depressive disorder.

In terms of pain mechanism, 42.31% (22 patients) of the patients included in the research group have nociceptive pain, 38.46% (20 patients) of the patients have neuropathic pain and 19.23% (10 patients) of the patients have mixed pain.

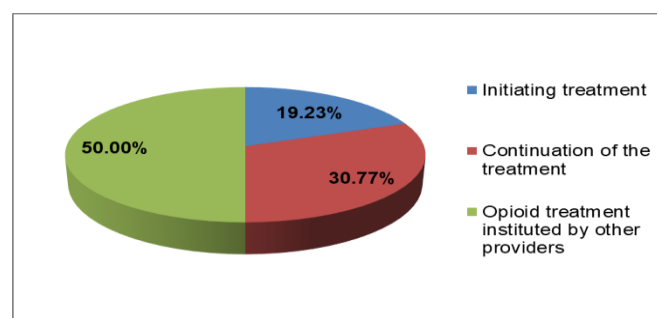
After analyzing the data, it was observed that patients with moderate pain intensity (76.92%) use step II opioid analgesic (76.92%) and patients with severe pain intensity (23.08%) use step III analgesic (23.08%). (Figure 1)

Figure 1 Percentage distribution of pain intensity by category of opioid used



Half (26 patients) of the patients in the study group, at the time of presentation to the palliative care service, had opioid treatment initiated by other healthcare providers (oncology). For 30.77% (16 patients) of the patients the treatment had already been initiated in previous consultations in the palliative care outpatient clinic, and for 19.23% (10 patients) of the patients who presented to the organization's outpatient clinic treatment with opioid medication was instituted. (Figure 2)

Figure 2 Distribution of patients by treatment initiator



More than half of the patients in the study group, 63.46% (33 patients) said that their pain was effectively controlled with the pain medication they were taking. 34.62% (18 patients) of patients stated that pain is partially controlled. For 1.92% (1 patient) of the patients it was found that the pain is not controlled with the pain medication administered. (Figure 3)

Figure 3 Distribution of patients by therapeutic effect

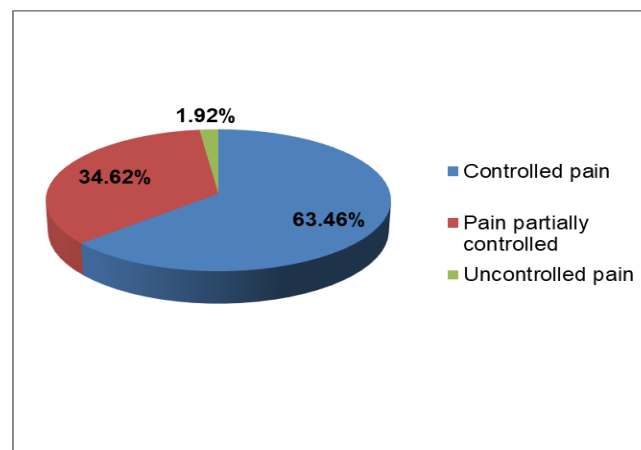


Table 1 shows the factors that influenced compliance of opioid treatment. Of the 18 patients who stated that their pain was partially controlled, 7 patients were not compliant to treatment due to fear of developing dependence to opioid treatment. Low compliance to treatments including oncology was another reason for 4 of the patients. Side effects (constipation) led 1 patient to reduce the dose of pain reliever. 6 of the patients are in the category of patients with difficult to treat pain (neuropathic pain).

Table 1 Factors that influence compliance of opioid treatment

Patient non-compliant with treatment	Fear of developing addiction	7
	Low compliance for any type of treatment	4
	Side effects	1
Pain that is difficult to treat	Neuropathic pain	6
Uncontrolled pain	Patient with schizophrenia who required hospitalization on the adult bed unit	1

Discussion and Conclusions

50.00% (35 patients) of patients have an ECOG of 2, 33.33% (10 patients) of patients have an ECOG equal to 1 and patients with an ECOG of 3 are poorly represented, with 16.67% (7 patients). The results of this study are consistent with studies in the literature that palliative care outpatient clinics should be designed to meet the needs of patients. Patients should be supported throughout the course of chronic illness and by monitoring them from the earliest stages of the disease. (13)

Patients of the integrated outpatient clinic of Hospice Casa Speranței Brașov receive appropriate treatment in terms of pain intensity. According to the World Health Organization, patients who report moderate pain intensity should be prescribed step II (mild opioid) analgesics, and patients who claim to have severe pain intensity should be prescribed step III (strong opioids) analgesics. (5)

For the majority of patients, 90.38% (47 patients), the route of drug administration is oral. 5.77% (3 patients) of patients in the study group use Fentanyl which is applied to the tegument, and 3.85% (2 patients) of patients use the subcutaneous route of administration (Morphine injection).

According to the literature on the principles of analgesic administration in chronic cancer pain it is preferable to choose the oral route of administration whenever possible. (14) For the two patients in whom subcutaneous administration was used, this route of administration was chosen because swallowing the medication was difficult.

Most patients stated that their pain was controlled with the prescribed treatment. However, there were patients whose pain was not effectively controlled. According to the literature, the management of cancer pain can be done incorrectly due to behavioral barriers or based on misconceptions regarding opioid treatment. (15)

Among the reasons given by the patients in the study group was the fear of developing dependence on this type of medication, as well as a decrease in opioid dosage due to adverse effects (constipation).

The literature shows that it is important to take into account the factors that make pain difficult to treat. (10) In the studied group there were such factors that made the therapeutic response partially achieved. In these patients, holistic reassessment is needed to identify the causes of

patient's non-compliance with treatment and to determine the cause of pain (total pain). (9)

The nurse is an important member of the multidisciplinary team. In the integrated palliative care outpatient clinic of Hospice Casa Speranței she has the role of case coordinator for each patient.

From the study it can be seen that the role of the nurse has an impact on the compliance to opioid treatment of oncology outpatients by: monitoring symptoms and prescribed treatment, accurately assessing and educating patients and caregivers about compliance with the treatment regimen. The nurse also ensures access to analgesic treatment by scheduling patients for specialist consultations.

The study also found that the specialist outpatient clinic of Hospice Casa Speranței Brașov has a positive impact by initiating and ensuring continuity of opioid treatment.

For half of the patients who presented, opioid treatment was initiated by other medical services, but they benefited from regular monitoring and evaluation by Hospice Casa Speranței. At the same time, it is encouraging that other healthcare providers are also taking the initiative in opioid treatment.

This study aims to improve the effectiveness of outpatient specialist interventions that have a direct effect on patients' quality of life and stimulate research on this topic to make significant contributions to healthcare in this area.

For a better understanding of the limitations of the study and to obtain additional information, prospective research using questionnaires and/or interviews as research tools is required.

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Evaluation of psychotropic medication use among institutionalized elderly with late-stage dementia

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Abstract

Objective: The aims of the present study were: (1) to describe psychotropic drug consumption patterns in palliative care patients with late-stage dementia; (2) to determine the ratio of potentially inappropriate psychotropic agents prescribed to the above population using two different updated criteria for PIPM: 2019 Beers criteria and v2 STOPP criteria.

Methods: Cross-sectional, observational study of palliative care patients with late-stage dementia. Data on sociodemographic and clinical variables were collected. Psychotropic drugs were classified into four categories: antipsychotics, antidepressants, benzodiazepines and nonbenzodiazepine sedative-hypnotics. To identify the psychotropic drugs to be avoided, a review of treatments received by the patients was performed based on the 2019 Beers criteria and v2 STOPP criteria. Additionally, the patient's medication list was also examined to identify psychotropic polypharmacy.

Results: The study included 107 patients of whom 78.5% were on psychotropic polypharmacy, and 84.1% were prescribed PIPMs according to 2019 Beers criteria and v2 STOPP criteria. Overall, 81.3% of patients were on benzodiazepines, 66.4% on antidepressants, 45.8% on antipsychotics and 37.4% on nonbenzodiazepine sedative-hypnotics. The number of psychotropic medications a person was exposed to range from 1 to 4 with the following prevalence rates: 1 psychotropic drug 21.5%, 2 psychotropic drugs 34.6%, 3 psychotropic drugs 32.7% and 4 psychotropic drugs 11.2%.

Conclusions: Optimization of pharmacotherapy has turned into a global public health problem. A significant number of the elderly received PIPMs based on selected criteria. It is crucial to re-evaluate the relevance and efficiency of these medical prescriptions to improve quality of life for these patients.

Keywords: Psychotropic medications, Polypharmacy, Dementia, Beers criteria, STOPP criteria

Rezumat

Obiective: Scopurile acestui studiu au fost: (1) descrierea tiparelor de prescriere a medicației psihotrope la pacienții cu forme severe de demență dintr-un serviciu de îngrijiri paliative; (2) determinarea prevalenței medicației psihotrope potențial inadecvate prescrise populației mai sus menționate utilizând două instrumente diferite: criteriile Beers 2019 și criteriile STOPP versiunea a 2-a.

Metode: Studiu cross-sectiional, observațional al pacienților cu forme severe de demență dintr-un serviciu de îngrijiri paliative. Au fost colectate date sociodemografice și clinice. Medicația psihotropă a fost împărțită în patru categorii: antipsihotice, antidepressivă, benzodiazepine și nonbenzodiazepine sedativ-hipnotice. Pentru identificarea medicației de evitat, s-au analizat recomandările terapeutice utilizând criteriile Beers 2019 și criteriile STOPP versiunea a 2-a. Totodată, s-au evaluat schemele terapeutice pentru a identifica polipragmazia psihotropă.

Rezultate: Studiul a inclus 107 pacienți, dintre care 78.5% prezentau polipragmazie psihotropă și 84.1% dintre aceștia aveau prescris cel puțin un medicament psihotrop potențial inadecvat, conform instrumentelor mai sus menționate. În total, 81.3% dintre pacienți au primit benzodiazepine, 66.4% antidepressivă, 45.8% antipsihotice și 37.4% nonbenzodiazepine sedativ-hipnotice. Numărul de medicamente psihotrope la care un pacient a fost expus variază de la 1 la 4 cu următoarele prevalențe: 1 medicament psihotrop 21.5%, 2 medicamente psihotrope 34.6%, 3 medicamente psihotrope 32.7% și 4 medicamente psihotrope 11.2%.

Concluzii: Optimizarea farmacoterapiei a devenit o problemă de sănătate publică la nivel global. Un număr semnificativ de pacienți au fost expuși la medicație potențial inadecvată conform criteriilor selectate. Reevaluarea relevanței și eficienței acestor prescrieri medicale este esențială în vederea îmbunătățirii calității vieții acestor pacienți.

Cuvinte cheie: Medicație psihotropă, Polipragmazie, Demență, Criteriile Beers, Criteriile STOPP

1. Introduction

Dementia is a broad term for several diseases that are mostly progressive, altering memory, other cognitive abilities and conduct, and that interfere substantially with a person's ability to preserve the activities of daily living. Alzheimer disease is the most frequent form of dementia and may contribute to 60–70% of cases. Other significant forms include vascular dementia, dementia with Lewy bodies, and a group of diseases that play a part in frontotemporal dementia. The margins between different forms of dementia are indistinct and mixed forms generally coexist. [1]

In 2015, dementia affected 47 million people worldwide (or nearly 5% of the world's elderly population), a figure that is speculated to increase to 75 million in 2030 and 132 million by 2050. Current reviews estimate that worldwide roughly 9.9 million people develop dementia each year; this figure translates into one new case every three seconds. [1]

Dementia is a major cause of disability and dependency among older adults worldwide, having a significant impact not only on individuals but also on their careers, families, communities and societies. Dementia accounts for 11.9% of the years lived with disability due to a noncommunicable disease. [2]

Symptoms of dementia are gradual, persistent and progressive. Alongside the symptoms that affect cognitive functions, there are alterations in personality and behavior, such as agitation, apathy, aggression, psychosis, hallucinations and delusions; their clinical presentation varies greatly among individuals and can cause considerable distress for patients and their caregivers. [3] Behavioral and psychological symptoms of dementia (BPSD) are associated with several negative outcomes, such as faster cognitive decline, functional impairment, reduced independence and inability to complete activities of daily living, with progression to more severe stages of dementia and increasing risk for secondary complications such as falls and fractures, causing higher hospitalization rates and eventually early institutionalization. [4]

Psychotropic medications include antipsychotics, antidepressants and benzodiazepines and these are commonly prescribed to older people in residential settings, particularly those with dementia, to manage BPSD, despite limited evidence of efficacy in this setting and their known potential serious adverse effects. [5, 6] Potentially inappropriate use of psychotropic medications is a particular concern for people living in residential aged care as psychotropic medications have been associated with increased risk of falls, hospitalization, stroke and mortality in this population. [7] Moreover, during ageing, a decline in functional capabilities can increase the risk of toxicities. [8]

To promote effective and safe treatment strategies among elderly, clinicians often rely on tools such as the Beers criteria and STOPP (Screening Tool of Older Persons' Prescriptions) criteria as there is lack of substantive evidence through clinical trials. [9] In January 2019, the American Geriatrics Society published the latest update to the Beers Criteria for Potentially Inappropriate Medication Use in Older Adults. This update includes specific recommendations for a medication or therapeutic class that should not be considered or should be used with caution in older adults. [10] The STOPP and START (Screening Tool to Alert to Right Treatment) criteria were

the first European explicit criteria and are the most used and validated among the European elderly population. After version 1 (84 criteria), version 2 was developed (114 criteria), expanding the explicit criteria as well as incorporating three implicit criteria. [11]

People with dementia are often denied their human rights in both the community and hospitals. In addition, people with dementia are not regularly participating in decision-making procedures and their desires and preferences for care are generally not respected. [1]

The aims of the present study were: (1) to describe psychotropic drug consumption patterns in palliative care patients with late-stage dementia; (2) to determine the ratio of potentially inappropriate psychotropic agents (PIPM) prescribed to the above population using two different updated criteria: 2019 Beers criteria and v2 STOPP criteria.

2. Methods

This was an observational, cross-sectional study, performed in a palliative care facility from Iasi, Romania and included participants with severe forms of dementia. It was conducted from January to June 2022. The sample comprised 107 patients with valid data for all variables. Information on the institutionalized elderly and their treatments were carefully recorded from the medical records and completed with supplementary clinical information. Collection was carried out guaranteeing the anonymity of the patients and the confidentiality of the data.

Demographic characteristics (age and sex) and pathologies (International Classification of Diseases, Tenth Revision, ICD-10) of the residents were registered. Psychotropic drug use was retrieved from medical files. All psychotropic drugs that were prescribed at the date of the study assessment were recorded excluding cognitive-improving drugs. Cognitive-improving drugs, such as acetylcholinesterase inhibitors (donepezil) and NMDA-type glutamate receptor antagonists (memantine) were not included in this study, the main focus being on the potentially inappropriate medications. Only regular prescriptions were recorded, since Pro Re Nata (PRN) prescriptions could not be reliably assessed, as they are hardly traceable or not reliably documented. All treatments were classified according to the World Health Organization (WHO) anatomical therapeutic chemical (ATC) classification system. [12] The medications were further classified in to four groups: antipsychotics, antidepressants, benzodiazepines and nonbenzodiazepine sedative-hypnotics. Medications were ruled as potentially inappropriate if the psychotropic medication was listed in the 2019 Beers criteria and v2 STOPP criteria. Additionally, the patient's medication list was also examined to identify psychotropic polypharmacy. The use of two or more psychotropic medications from the same therapeutic class or two or more psychotropic medications from different therapeutic classes was defined as polypharmacy. Descriptive statistics were used (Microsoft® Office Excel 2007, Microsoft Corporation).

3. Results

A total of 107 residents were included in the present study out of which 60.7% were females and 39.3% were males. **Table 1** summarizes the demographic and clinical characteristics of the participants. 63.6% of the elderly were

aged over 75 years, and the remaining 36.4% were less than 75 years. Mixed dementia was diagnosed in 57.9% of the elderly, 29.0% had Alzheimer's dementia and 13.1% had vascular dementia.

In the studied population, an overall 84.1% of the residents were prescribed PIPMs, and 78.5% were on psychotropic polypharmacy (two or more psychotropic medications for 30 or more consecutive days). As shown in **Table 2**, 81.3% of patients were on benzodiazepines, 66.4% on antidepressants, 45.8% on antipsychotics, 37.4% on nonbenzodiazepine sedative-hypnotics and 78.5% took more than one psychotropic class.

Of the 81.3% of residents on benzodiazepines, 35.5% were on clonazepam. With regard to antidepressants, trazodone was the most frequently used drug (19.6% of residents). In the group of patients on antipsychotics, 18.7% took risperidone. The most commonly prescribed nonbenzodiazepine sedative-hypnotic was zopiclone (25.2%). The number of psychotropic medications a person was exposed to range from 1 to 4 with the following prevalence rates: 1 psychotropic drug 21.5% (N=23), 2 psychotropic drugs 34.6% (N=37), 3 psychotropic drugs 32.7% (N=35) and 4 psychotropic drugs 11.2% (N=12).

According to both tools, 90 patients had been prescribed at least one potentially inappropriate psychotropic drug, which accounted for 84.1% of the sample. The most frequently involved psychotropic class was that of benzodiazepines.

As shown in **Table 3**, in conformity with the 2019 Beers criteria, 54 participants (50.5%) had only one PIPM, 34 (31.8%) received two PIPMs and 2 (1.9%) had three PIPMs. On the other hand, according to v2 STOPP criteria, 38 participants (35.5%) were prescribed only one PIPM, 44 (41.1%) received two PIPMs, 7 (6.5%) had three PIPMs and only 1 (0.9%) had four PIPMs.

Table 1. Demographic and clinical characteristics of residents

Characteristics	Total (N = 107) N (%)
Sex	
Female	65 (60.7)
Male	42 (39.3)
Age (years)	
≤75	39 (36.4)
≥75	68 (63.6)
Primary psychiatric conditions (ICD-10-CM)	
Alzheimer's dementia	31 (29.0)
Vascular dementia	14 (13.1)
Mixed dementia	62 (57.9)
Potentially inappropriate psychotropic medications	
Yes	90 (84.1)
No	17 (15.9)
Psychotropic polypharmacy	
Yes	84 (78.5)
No	23 (21.5)

Table 2. Prevalence of use of the different types of psychotropic medications (N=107)

Medications*	N (%)
Antipsychotics	49 (45.8)
Haloperidol	11 (10.3)
Tiapride	7 (6.5)
Risperidone	20 (18.7)
Quetiapine	11 (10.3)
Antidepressants	71 (66.4)
Escitalopram	11 (10.3)
Sertraline	6 (5.6)
Duloxetine	9 (8.4)
Trazodone	21 (19.6)
Mirtazapine	8 (7.5)
Tianeptine	19 (17.8)
Benzodiazepines	87 (81.3)
Lorazepam	28 (26.2)
Alprazolam	18 (16.8)
Bromazepam	3 (2.8)
Clonazepam	38 (35.5)
Nonbenzodiazepine sedative-hypnotics	40 (37.4)
Zolpidem	13 (12.1)
Zopiclone	27 (25.2)
N° of psychotropic drugs	
1	23 (21.5)
2	37 (34.6)
3	35 (32.7)
4	12 (11.2)

Values are given as number of patients (%).
*The percentage exceeds 100% because some patients consume more than one type of psychotropic medication.

Table 3. Number of patients with PIPM identified by the different criteria	PIPMs per participant	2019 Beers criteria N (%)	v2 STOPP criteria N (%)
0	17 (15.9)	17 (15.9)	
1	54 (50.5)	38 (35.5)	
2	34 (31.8)	44 (41.1)	
3	2 (1.9)	7 (6.5)	
4	0 (0)	1 (0.9)	
≥1	90 (84.1)	90 (84.1)	

PIPm, potentially inappropriate psychotropic medication; STOPP, screening tool of older person's potentially inappropriate prescriptions (v2, version 2);

4. Discussion

The present study revealed a psychotropic polypharmacy prevalence in institutionalized elderly of 78.5%, also most of these residents had at least one PIPM according to 2019 Beers criteria and version 2 STOPP (84.1%). Inappropriate polypharmacy is a global problem in the elderly, as it decreases their quality of life and increases medication costs and healthcare system use. The psychosocial impairment, the concurrence of more than one disease or condition, and patients' functional dependence are some of the aspects which are characteristic of institutionalized patients. These factors can justify the constant use of psychotropic drugs in these patients.

The most common PIPM detected in this study was the regular use of benzodiazepines, which is the most widely used PIM worldwide. [13] Benzodiazepines are frequently prescribed in the elderly for anxiety and insomnia in spite of being one of the pharmacological groups regularly implicated in the incidence of potential drug-drug interactions (DDIs) and adverse reactions (sedation, falls and fractures, mental confusion, cognitive decline, etc.). In persons with cognitive impairment, pharmacotherapy should not lead to further decline of cognition. Nonetheless, it is also essential to treat emotional and behavioral symptoms which cause discomfort for the patient and support system. [14] Important risk of falls has been found with benzodiazepine-like agents such as zolpidem, communally known as nonbenzodiazepine sedative-hypnotics. [15]

In this sample, the second most used psychotropic class was that of antidepressants (66.4%), with trazodone (19.6%) and tianeptine (17.8%) being the most frequently recommended. This result is concerning given the fact that Johnell et al. have reported the increased risk of falls with the use of antidepressants. [16]

Antipsychotics were prescribed in 45.8% of the institutionalized elderly, with risperidone as the most frequently used (18.7%). Antipsychotic use increases among the demented institutionalized elderly, having as potential indication the control of their neuropsychiatric symptoms or delirium episodes. Their use was associated with extrapyramidal, cardiovascular and cerebrovascular events and with an increased risk of mortality derived especially from the use of typical molecules. [17] It is important to mention that even though these drugs have been demonstrated to not only enhance morbidity and mortality, but also involve serious side effects like sedation and cognitive deterioration, are still recommended so often. Although some patients can experience a relieve of burdening symptoms, such as anxiety or restlessness, when treated with antipsychotics, there is a risk in using them as antipsychotic treatment can reduce quality of life. [18] It is critical that prescribers and care providers adhere to guidelines, in so far as possible, by applying non-pharmacological interventions in the first instance and prescribing antipsychotics as a last resort, with proper review and trials of withdrawal. [19]

Recommendations have been made to avoid the use of particular medications in people with dementia, including antipsychotics and benzodiazepines. [10] Nonetheless, people with dementia are very prone to endure behavioral and psychological symptoms of dementia at some point and this can be a serious test for staff in residential care [20]. Recent clinical practice guidelines for people with dementia suggest non-pharmacological interventions should be used as a first line treatment for changed behaviors, such as person-centered care approaches, individual care plans and specific therapies. [21]

This study has some limitations. Firstly, it focused on psychotropic polypharmacy but did not assess drugs used for comorbidities, as they might affect psychotropic prescribing patterns. Another limitation to this study is the relatively low number of patients admitted. Last but not least, PRN drug use was not regarded. PRN drugs could not be accurately estimated, as they were hardly detectable or not meticulously documented in patient charts.

As strengths, this study applied two distinct tools to analyze and determine PIPMs in the elderly, which clearly enhanced this evaluation. Also, direct data collection (data were not obtained from registries or databases) enabled the gathering of accurate information and facilitated full applicability of criteria.

5. Conclusions

Optimization of pharmacotherapy has turned into a global public health problem. Psychotropic polypharmacy is prevalent and frequently shows associations with complications such as falls, hospitalizations, and mortality, regardless of which drugs are involved. This study also revealed a high prevalence of cases on potentially inappropriate psychotropic medication. Benzodiazepines are the most frequently used, followed by antidepressants, antipsychotics and with a lower frequency, nonbenzodiazepine sedative-hypnotics. Patients with late-stage dementia have higher sensitivity to psychotropic drugs owing to their declined brain function and delayed drug elimination due to aging. These aspects make them prone to polypharmacy and drug interactions. Adverse drug events can decrease the patients' quality of life and worsen their prognosis. The utilization of guidelines such as Beers and STOPP criteria recognize high-risk drugs in older adults and are shown to prevent adverse drug effects and overall health care costs. Caution for pharmacotherapy complications will always be necessary. The evidence regarding psychotropic polypharmacy and high-risk medications suggests that our older patients benefit from a persistent, dynamic shift to fewer drugs. Further, prescribers have to recognize that deprescribing is a vital ingredient of successful treatment. Substantial effort should be made to enhance patients' quality of life.

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Assessment of bereavement and how to process loss among students in the General Nursing Program of Transilvania University Brasov

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Abstract

The objectives of the study were to identify the prevalence of grief among the students from the General Nursing Program of Transilvania University Brasov, Faculty of Medicine, to identify the impact that grief had on the education of students and the risk of a possible complicated grief.

Material and method: Out of the total of 460 students who filled out a questionnaire consisting of 14 questions, 117 students lost a close person in the last 3 years, while 123 students did not go through grief. 220 students refused to complete the questionnaire.

Results: The results show that the major impact that mourning had on students was that of decreasing overall performance present in 56.4% of them. Closeness to the deceased was a key factor of mental health and academic difficulties, so the rate of occurrence of possible pathological grief was very low.

Conclusions: This pilot study shows an increased rate of student losses experienced during the Covid pandemic with an impact on school performance and with a very low rate of a possible complicated grief

Keywords: grief, students, education, complicated grief.

Rezumat

Obiectivele studiului au fost acelea de a identifica prevalența doliului în rândul studenților de la Facultatea de Asistență Medicală Generală, Universitatea Transilvania Brașov, impactul pe care l-a avut doliul în educația studenților și riscul de apariție a doliului complicat.

Material și metodă: Lotul de studiu a fost reprezentat de studenții de la Facultatea de Asistență Medicală Generală, Universitatea Transilvania Brașov.

Tipul de studiu este prospectiv observațional, iar instrumentul de studiu s-a bazat pe un chestionar autoadministrat format din 14 întrebări, alcătuit din două părți: prima parte cu întrebări demografice, despre prezența pierderii și modul în care aceasta le-a influențat starea de bine, iar a doua parte a sondajului cu întrebări despre efectele pierderii pentru a identifica un posibil risc de apariție a doliului complicat.

Din totalul de 460 de studenți ai programului AMG, 220 dintre aceștia au refuzat să ia parte la sondaj și un număr de 240 au răspuns.

Rezultate: Rezultatele arată că impactul major pe care l-a avut doliul asupra studenților a fost cel de scădere al performanței generale, prezent la 56,4% dintre aceștia.

Apropiere față de persoana decedată a fost un factor pozitiv cheie al sănătății psihice și al dificultăților academice, astfel încât rata de apariție a unui posibil doliu patologic a fost foarte scăzută.

Concluzii: Acest studiu pilot arată o rată crescută a pierderilor experimentate de studenți pe parcursul pandemiei Covid cu impact asupra performanțelor școlare și cu o rată foarte scăzută de posibil doliu complicat.

Cuvinte cheie: doliu, studenți, educație, doliu complicat.

Introduction

The loss of a loved one or the death of a close family member (child, husband or wife, parent, best friend, etc.) especially through sudden or tragic death, has been identified as the most devastating type of loss and the

strongest stressor in people's lives. However, depending on age, gender, personality characteristics, emotional needs, value system and social support network, and other types of loss can be equally painful.

Research on the prevalence of mourning among students began in 1980, is a little-researched topic, with the areas explored including a limited number of studies on the general prevalence of mourning, the effects that mourning has on students. It is suggested that an average of 30 to 40% of students go through mourning on every university campus. Most of these incidents include the death of a family member or friends, most commonly due to known causes, namely from chronic conditions and accidents.

The effects of mourning highlighted in the research include physical, emotional, cognitive, interpersonal, behavioral and spiritual manifestations.

Since students may have other responsibilities besides student responsibilities, including family or parental, this can make mourning unique in their case. In addition, as the rate of mental illness is increasing in adults, it is also important to explore the prevalence of complicated mourning among students, with the findings of studies being able to provide information about the impact it can have on student education. [1]

The objectives of the study were to identify the prevalence of mourning among all students from the General Nursing Program of Transilvania University Brasov, Faculty of Medicine, the impact that mourning had on the students' learning process and the risk of developing complicated mourning.

Material and method

In order to answer to the research question, a transversal observational study was performed. The data collection instrument was a purposely designed questionnaire build based on elements of complicated grief following the 4 criteria established by Neimeyer's work in 2002. The questionnaire was distributed electronically and was self-administered. The final format consisted of 14 questions: the first part with demographic questions, about the presence of loss and how it influenced their well-being, and the second part of the survey with questions about the effects of loss to identify a possible risk of developing complicated mourning.

The study group was represented by all nursing students from the General Nursing Program, at Transilvania University Brasov enrolled in studies in the academic year 2021-2022.

The study received the approval of the local ethics committee. Descriptive static was used to present the results.

Results

Out of the total of 460 students of the AMG program, 220 of them refused to take part in the survey and a number of 240 responded (RR=52.17%)

The demographic characteristics of the study group are presented in the table

Gen	Feminine 177	Masculin 10	I don't want to answer 53	
Age	18- 19 years 60	20- 21 years 65	22- 23 years 56	over 24 years 59
Religion	Orthodox Christian 182	Catholic 18	Atheist 26	I don't want to answer 14

Table 1. The demographic characteristics of the study group.

In the last 3 years, 117 students have lost one close person, while 123 students have not gone through mourning. For the 123 students who did not go through mourning, the survey ended with this question. Most of the losses suffered by the students surveyed, in terms of the degree of kinship, is represented by those who lost a grandfather or a grandmother, with a percentage of 47%, followed by those who lost their parents with a percentage of 27.4%. Mourning had the main effect on students, the decrease in overall performance of 56.4%. Another effect of mourning was the absence from classes and only 4.3% lost their scholarship due to the decrease in teaching performance.

Regarding the identification of the elements of complicated mourning, most of the students had no problems with remembering the memories of the lost person, only 4 students reported avoiding memories related to the loss, 6 self-reported difficulties in accepting the loss; excessive irritability/anger was experienced by 30 students during the mourning period; experiencing the feeling that life seems to be meaningless was present in 18 students.

The intense longing was experienced by the majority of the bereaved students in number of 85; More than 50% of the grieving students experienced feelings of distrust, insecurity and lack of control during the mourning period, while 49 students did not experience these feelings.

Only 2 bereaved students out of the total of 117 had symptoms that persisted for more than 6 months after the loss of a loved one, which means that they may be at risk of developing pathological grief.

Discussion

In 2013, Varga attempted to determine the incidence of mourning in graduate students in the United States. The focus was on the effects of mourning on the individual, the forms of support provided and the risk of developing pathological mourning. Students (N=1,575) were invited to complete an online survey on mourning experiences. Students who had experienced significant losses (for example, the loss of a parent, family member, or close friend) were also invited to respond to the questionnaire on prolonged mourning disorder. About 25% of participants have suffered the loss of a significant person in the last 24 months. Various effects of mourning have been reported, with the emotional effects proving to be the most significant. In general, the effects were experienced within the first 6 months after the death of a close person [2]. The data of the study from Transilvania University show a higher incidence of mourning among students, but the

study is referring to the experiences of students during the Covid pandemic so the fact can be attributed to this cause.

Walker, Hathcoat, and Noppe (2012) conducted a study to explore the prevalence of mourning among university students. The study also explored the effects of mourning on educational outcomes and psychiatric health in relation to the degree of attachment to the deceased. The results showed that motivation and concentration had a significant negative impact. The results indicated that the closer the students were to the deceased individual, the more academic difficulties they encountered due to changes in motivation and concentration. [3]. Our study also indicates a decrease in school performance as a result of going through loss.

Varga, McClam and Hassane (2015) tried to identify experiences of mourning among American and Arab female students to compare the incidence of mourning, its effects, and the risk of complicated mourning. In total, 471 female students (308 [65.4%] from the United Arab Emirates and 163 [34.6 %] from the United States) completed a survey on their experiences of mourning.

The researchers found that 181 (38.4%) of the 471 students had experienced the loss of a loved one in the last 2 years. There were few differences between countries in terms of the incidence of pathological mourning, the relationship with the deceased person and the cause of death of the person (mainly the disease). Various effects of mourning have been reported; American students experienced effects related to relationships, studies, physical well-being, religion/spirituality, and perspective on life more frequently than Arab students. Arab students suffered sleeplessness, and reported emotional and moody elements of mourning more frequently than American students. The few cases of complicated mourning (n = 10. 5.52%) were mostly among Arab people. The reason for these differences may lie in the relative cultural and religious aspects of life in the two countries, with the related expectations regarding the expression of mourning or not. [1] In this study, the possible complicated grief was identified only in 2 of the 117 cases.

In addition, Eckerd, Barnett, and Jett-Dias (2016) compared the severity of mourning and its predictors into equivalent groups of students who reported experiencing the death of an important person in their lives (n=146) over the past 2 years. The group that experienced a person's death showed higher scores of mourning severity. The closeness to the deceased was by far the strongest predictor of the severity of mourning. [4]

Cupit, Servaty-Seib, Tedrick Parikh, Walker and Martin (2016) conducted a study among undergraduate students in the process of mourning using mixed methods to observe how students handled the process of mourning with the challenging demands of the faculty. The participants in the study were university students who attended one of the two rural public universities in the Midwest, with a total of 950 students at a large regional university and a demanding research institution. The quantitative results showed that closeness to the deceased person is a key positive factor of mental health and academic difficulties, as well as positive associations between changes in relationships with colleagues. Qualitative results showed that closeness to the deceased

was associated with a greater sense of purpose in the university experience after his or her death. [5]

Conclusions

This pilot study shows an increased rate of student casualties experienced during the Covid pandemic with an impact on school performance and with a very low rate of possible complicated grief.

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Self-perceived burden of care among cancer patients with specialized palliative care needs – a cross-sectional study

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Abstract

Aim: To facilitate a better understanding of the SPB (Self Perceived Burden) phenomenon.

Objectives: To identify useful interventions to reduce or remove patients' perception of being a burden and to establish relationships between SPB and physical and/or psychological symptoms.

Material and method: a quantitative, prospective, cross-sectional, observational study, has been conducted between 01.04.2022-05.08.2022 on a group of 55 eligible patients cared in the in-patient unit for adult patients at Hospice „Casa Speranței” Brașov (HCS). Data was collected using: Edmonton Symptom Assessment Scale (ESAS), Mini Mental State Examination (MMSE), ECOG Performance Status and Self Perceived Burden Scale (SPBS).

Results: SPB is common among cancer patients, with 83.64% (n=46) of surveyed patients having SPB, 38.18%(n=21) were being cared by their partner and 27.27%(n=15) by their children.

The proportion of patients with moderate-severe to extreme SPB levels of those with ECOG 4 is 71.43%, of those with ECOG 3 is 65.22%, of those with ECOG 2 is 25% and of those with ECOG 1 is 0. The ESAS assessment revealed that 98% of respondents had pain of various intensities.

Conclusions: Perception of self as a burden to the caregiver is common among cancer patients, with 46(83%) of the 55(100%) participants having experienced SPB. In most cases the primary caregiver is the patient's partner or the children.

The SPB level increases with increasing intensity of sadness, pain, nausea. It is also higher among patients with low functional status.

Coping methods in SPB include: ability to repay the caregiver; caregiver not being part of the patient's family.

Key words: cancer, burden, palliative care, caregiver

Rezumat

Scop: Să faciliteze o mai bună înțelegere a fenomenului SPB (Self Perceived Burden).

Obiective: Identificarea intervențiilor utile pentru a reduce sau elimina percepția pacienților că au devenit o povară și stabilirea relațiilor dintre SPB și simptomele fizice și/sau psihologice.

Material și metodă: Lucrarea de față este un studiu cantitativ, observational, prospectiv, transversal, a fost realizat în perioada 01.04.2022- 05.08.2022 pe un grup de 55 de pacienți eligibili îngrijiți în unitatea de internare pentru pacienți adulți de la Hospice "Casa Speranței" Brașov (HCS). Datele au fost colectate folosind: Edmonton Symptom Assessment Scale (ESAS), Mini Mental State Examination (MMSE), ECOG Performance Status și Self Perceived Burden Scale (SPBS).

Rezultate: SPB este frecventă în rândul pacienților cu cancer, 83,64% (n=46); în rândul pacienților ce aveau SPB, 38,18% (n=21) erau îngrijiți de partenerul lor și 27,27% (n=15) de copiii lor.

Proporția pacienților cu SPB moderat-sever până la extrem și ECOG 4 este de 71,43%, a celor cu ECOG 3 este de 65,22%, a celor cu ECOG 2 este de 25% și a celor cu ECOG 1 este de 0. Evaluarea ESAS a arătat că 98% dintre respondenți au avut dureri de diferite intensități.

Concluzii: SPB este frecventă în rândul pacienților cu cancer, 46(83%) din cei 55(100%) de redpondenți experimentând SPB. În cele mai multe cazuri, principalul îngrijitor este partenerul de viață sau copiii pacientului.

Nivelul SPB crește odată cu creșterea intensității tristeții, a durerii, a senzației de greață. De asemenea, SPB este mai mare în rândul pacienților cu status funcțional scăzut.

Cuvinte cheie: cancer, povară, îngrijire paliativă, îngrijitor

Argument:

The experience as nurses in the HCS in-patient unit for adults has made me aware of the patients wracked with feelings of guilt, some of them blaming themselves for getting sick, for needing help with their daily activities, for being an obstacle instead of a help to their loved ones, concluding that the illness has turned them into a burden to their loved ones. While others were at the opposite pole, feeling entitled to the help they needed to get through the illness.

Patients' contradictory thinking on this topic, and the desire to be able to help them in this regard, trigger our interest and made us want to find out why there are such different ways of thinking about SPB.

The cancer diagnosis and treatment dramatically change the lives of patients and their families. Patients start to rely progressively on the help of family and friends in order to ensure their own functionality, to carry out daily activities, and cope with the psycho-socio-emotional disturbances caused by the disease. Over time, many patients come to see themselves as a burden on their family and loved ones, who support them.[1][2]

Self-perceived burden: definition and implications

Self-Perceived Burden (SPB) is common among seriously ill patients, particularly for those with an oncological diagnosis. It occurs when patients experience physical deterioration or psychosocial, existential problems and is correlated with depression, anxiety, suicidal ideation, hopelessness, and caregiver burden.[1] SPB has a significant influence on the decision-making process related to the disease. To ease the burden on the family, patients may choose to receive palliative care (PC) even though they actually want to continue curative treatment. SPB is known to be a significant predictor of suicidal ideation and actions that hasten death.[3][4][5]

Among patients nearing the end of life, the presence of SPB has been associated with a desire to hasten death.[6]

Christine McPherson defined SPB as: "empathic caring that originates in the impact of illness on others and the need for care that creates feelings of guilt, responsibility, stress and lowered self-esteem for the patient." [7]

Communication is an essential part of care; it is the basis for establishing and strengthening social and professional relationships. It is important both for maintaining trust and for reducing insecurity. [8] Relationships also provide a sense of belonging and security. They contribute to the way people describe their identity. And they are also the pillar of resilience in difficult times, they are one of the most important resources available to people to mitigate the impact of illness or SPB. [9]

Effective communication has been shown to influence wellbeing by identifying and meeting needs and reducing isolation and powerlessness. [8] It is also among the coping mechanisms in SPB. [10]

Recipients of specialized palliative care services and their perception of SPB

Perception of self as a burden is common among patients with advanced cancer disease. In the study of Wilson and colleagues, "*A burden to others, a common source of distress for the terminally ill*", SPB in a mild form was found

in 39% of patients with advanced cancer disease and in 38% of them SPB was moderate to severe.[11]

SPB is intensified when patients: are in pain [12,13]; when they are near death [14]; the primary caregiver is a close person (spouse, parent or child); the patient lives alone with the spouse.[15] SPB also has a negative impact on the patient's quality of life and mental health. [15;16;17]

In the same study "Prevalence of severe depressive symptoms increases as death approaches and is associated with disease burden, tangible social support, and high self-perceived burden to others" it was found that patients with severe SPB are 1.77 times more likely to be depressed than those with low SPB. [18]

According to the study conducted by Su-Ching Kuo, et al. patients with a moderate level of SPB will experience SPB at a higher intensity, as the disease progresses and physical deterioration progresses. In the same study, no association was found between the patient's functional status and SPB level [19].

In the study of Hughes and colleagues, "Experiencing cancer in old age: a qualitative systematic review", several individuals were found to have been able to free themselves from the feeling of being a burden to others by: minimizing the amount of time they spent talking about their illness, planning the funeral and providing emotional support to their family in this regard. These actions were described as a way of restoring the mutuality of the relationship so help is offered by both parties. [20]

Another study reported that the reciprocity of relationships plays an important role in the emergence of self-perceived burden (SPB), as the need for care increases the patients feel they receive a lot and the fact that they cannot offer anything in return makes them feel worthless.[1] Patients with advanced cancer disease use different coping mechanisms to cope and to decrease SPB. How they manage SPB is important for maintaining quality of life and mental health. [7] In the same study, many participants described themselves as strong and independent before their illness. For them, SPB was associated with dependence on others and a need to be cared for, which emerge once the illness progresses. The inability to fulfil their role in society and plans for the future such as getting married or starting a family lowers patients' self-esteem and exacerbates SPB [7; 21].

The study "How palliative care patients' feelings of being a burden to others can motivate a wish to die. Moral challenges in clinics and families" of Heike, et al, showed that often, in terms of patients' desire to benefit from assisted suicide or to hasten their death, SPB was the major reason for not taking this step. Patients felt that the burden on the family would be greater if they hastened their death. [22]

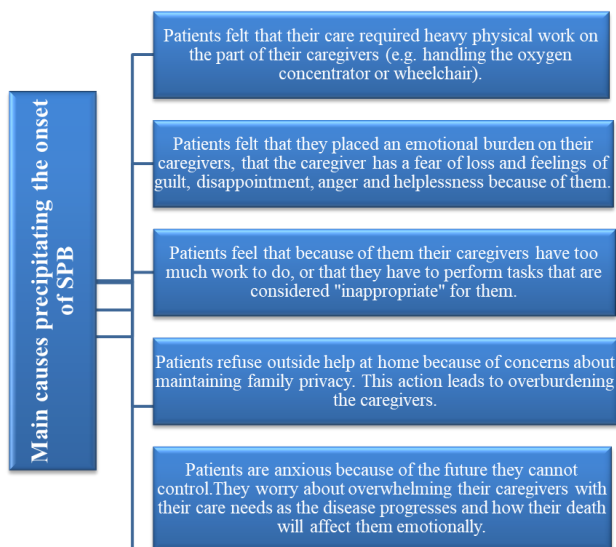


Figure 1 Main causes precipitating the onset of SPB

Aim and objectives:

The research aimed to study SPB of patients who receive specialized PC while admitted, at least once, in the HCS in-patient unit for adults in order to gain understanding over the SPB phenomenon. The objectives of this research have been to identify the reasons patients perceive they are a burden for their caregiver, identifying the interventions considered useful for reducing or removing patients' perception of being a burden and establishing correlations between SPB and physical and/or psychological symptoms. Our research questions were:

"What are the main reasons why patients perceive that they are a burden to their caregivers?"

"What clinical manifestations occur in patients who perceive themselves as a burden for their caregivers?"

"What are the main interventions used to reduce or remove patients' perception of being a burden?"

Material and method:

A quantitative, prospective, cross-sectional, observational study has been conducted between 01.04.2022 and 05.08.2022 on a group of 55 eligible patients admitted in the HCS in-patient unit from Brasov, aiming to facilitate a better understanding of the SPB phenomenon.

The method used for collecting the data was, besides the demographic data, a combination of validated questionnaires: Edmonton Symptom Rating Scale (ESAS), Mini Mental State Examination (MMSE), ECOG performance status and Self perceived burden scale (SPBS).

Inclusion criteria:	Exclusion criteria:
<ul style="list-style-type: none"> • Patients over 18 years of age. • Patients admitted to Hospice "Casa Speranței" Brasov between 01.04.2022-05.08.2022. 	<ul style="list-style-type: none"> • Patients with MMSE score less than 17. • Patient alone, without relatives who does not receive help to care for themselves. • Patients who refuse to participate in the study.

Table 1 Inclusion and exclusion criteria

Results:

SPB is common among cancer patients, with 83.64% (n=46) of patients surveyed presenting SPB.

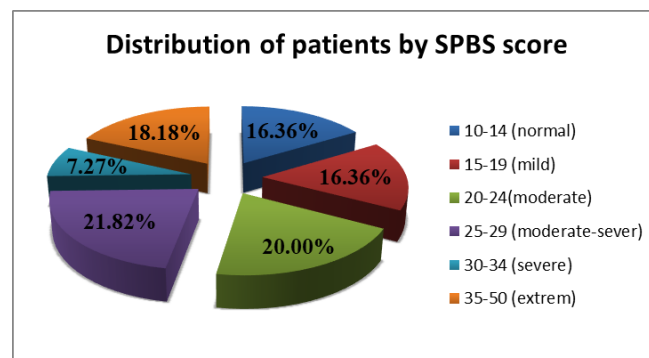


Figure 2 Distribution of patients by SPBS score

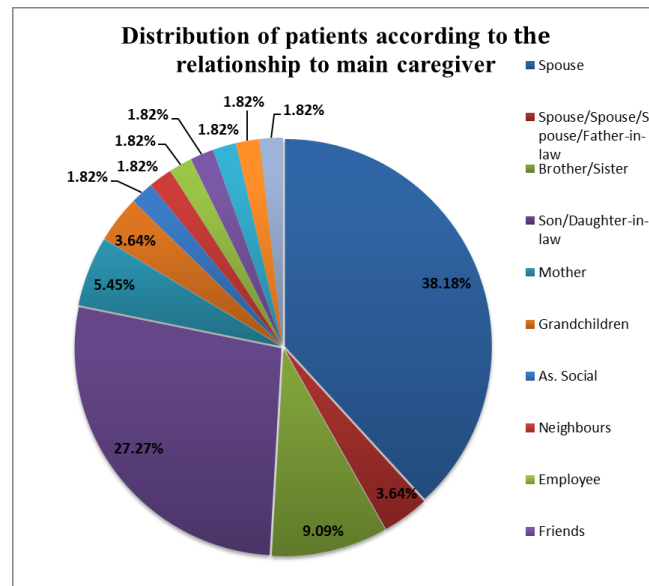


Figure 3 Distribution of patients according to the relationship with the main caregiver

Of the respondents, 38.18%(n=21) were being cared for by their partner and 27.27%(n=15) by their children.

The proportion of patients with moderate-severe to extreme SPB level of those with ECOG 4 is 71.43%, of those with ECOG 3 is 65.22%, of those with ECOG 2 is 25% and of those with ECOG 1 is 0.

The ESAS assessment showed that 98% of respondents had pain of various intensities. One patient among those presenting nausea does not have SPB, the others belong to the group with SPB. Sadness is present in the majority of patients, only 25.45%(n=14) do not have this problem and 10.9%(n=6) of the studied group present sadness without having SPB.

After collecting data from the 55 patients included in the study, it was found that most of the respondents did not answer the question *"What could help you reduce the*

feeling that you are a burden to your caregiver?", i.e., 62.96% (n=34). The others gave the following answers: 11.11% (n=6) "To be healthier/get better"; 5.56% (n=3) "To be able to take care of myself" and "To talk to the caregiver about SPB"; 3.70% (n=2) "Death"; 1.85% (n=1) "To be able to reward my caregivers", "Better public health system", "Hospice admissions", "Caregiver not to be family", "Stop drinking alcohol", "Cry less".

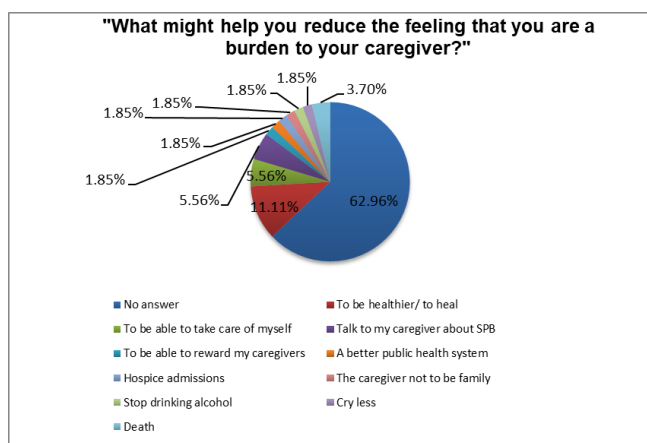


Figure 4 Answers to open question: *What might help you reduce the feeling of being a burden to your caregiver?*

Limitations and future research perspectives:

The data was collected in a limited time, i.e., 4 months, during this time 80 admissions were performed and after applying the inclusion/exclusion criteria, a study group of 55 patients was obtained. Of these, only 8 were admitted more than once during this period so the evolution of SPB over time was impossible to follow. Further studies on this topic are therefore needed, conducted on a larger research group, over a longer period of time, following the changes over time in the relationship with SPB in each individual participant.

In the future, further in-depth research is needed through a longitudinal prospective quantitative study. A small percentage, i.e., 16.67% (n=9) of the patients included in the study, gave relevant answers to the open-ended question included in the questionnaire. It showed the need to conduct parallel qualitative research using the interview to study the patient's perspective in depth.

Conclusions:

The perception of self as a burden to the caregiver is common among cancer patients, with 46(83%) of 55 participants having SPB. In most cases the primary caregiver is the patient's spouse or children.

The SPB level increases along with intensity of sadness, pain, nausea. It is also higher among patients with low functional status.

Coping methods in SPB include: ability to repay the caregiver; caregiver not being part of the patient's family.

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REVIEW

Palliative care in Romania in 2022. Organizational development, education and research

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The 23rd annual conference of the National Palliative Care Association (ANIP) took place in Poiana Brașov between October 20th-22nd 2022, focusing on "Palliative care. Hope, dignity, professionalism" and registered among the international events dedicated to the World Day of Palliative Care 2022.

The opening plenary session of the national ANIP conference presented an update of the situation of palliative care in Romania, covering services development, education programs for the training of professionals in the field, information on various national and international projects aimed at integrating palliative care into the general healthcare system, as well as on research projects.

Current situation of palliative care services

The state of palliative care services was analysed based on the data obtained from the reporting of Romanian service providers for the year 2021. The Order of the Ministry of Health no. 253/2018 stipulates that both public and private palliative care providers should submit an annual report of services provided, with details on the structure and process of care. This regular report can ensure a constant picture of the evolution of services and can be a starting point for the authorities in planning services for areas with poor coverage, as well as for a budget forecasting and allocation as close as possible to real needs. Compared to the previous report¹ analysed for the services in 2019, in 2021 we find a 29.89% lower compliance of suppliers with the obligation of annual reporting, which alters the real picture of the compared data from 2019 and 2022. The lower reporting rate might be due either to palliative care departments having been temporarily converted to COVID units, to reduced number of services delivered due to underfunding, or simply lack of reporting compliance. However, the trends observed in previous years remained similar, namely those of maintaining a high percentage of inpatient service units with designated palliative care beds, compared to the low development of out-of-hospital services in outpatient clinics or in the patients' homes. At

the end of 2021, a number of 80 providers reported functional services, of which 51% in the public system (compared to 49% in 2019), 19% in the private non-profit system (14% in 2019) and 30% in the private for-profit system (37% in 2019).

13 counties still have no palliative care providers yet.

The trend of developing **inpatient palliative care services** continues (77% in 2021, compared to 80% in 2019), with very few outpatient services (8%, compared to 6% in 2019) and home-based services (10%, compared to 8%).

Both in the public and private sector, the number of contracted palliative care beds reimbursed by the health insurance company is about 25% lower than the total number of authorized palliative care beds. This indicates a potential trend to increase in the number of functional beds for palliative care, provided that these service suppliers fulfil the contracting conditions and conclude contracts with the county health insurance companies.

Regarding the admission accessibility to palliative care inpatient units, this is unrestricted in public (60,87%) and private non-profit (11,59%) services and limited in private for-profit ones (27,54%), with the latter charging payment or co-payment.

The actual average cost reported by providers was 761 lei/bed/day of hospitalization, while the rate reimbursed by the health insurance system is 235 lei/day, which represents 30.88% of the real cost. The currently reimbursed rate has not been updated since 2011, although the salary system was radically changed by the Law no. 153/2017 regarding the payment system of clinical staff in public healthcare units. The new salary scales have been significantly influencing the costs of healthcare services, palliative care included.

Home-based palliative care services continue to be delivered exclusively through private providers, mainly charitable organizations (foundations or associations). The 4 existing providers deliver specialized home-based services in 6 counties: 3 providers have services in one

¹ <https://www.ms.ro/wp-content/uploads/2021/08/Raport-furnizori-ingrijiri-paliative-Romania-2019.pdf>

county and 1 provider has palliative care services in 3 counties. Services are generally underfunded both as per visit rate (reimbursement of 102 lei/visit, compared to an average 310 lei/visit actual cost reported by providers), and as a general allocation of funds to community and domiciliary palliative care.

There are only 5 **palliative care outpatient clinics** reported in 2021. The 5 outpatient palliative care services are integrated with hospital units, 2 being in the public system, 3 in private non-profit units and 2 in private units (with patients' payment or co-payment).

Palliative care day centres continue to be underdeveloped, with only 5 services reported by 2 non-governmental organizations that assume, partially or fully, the operating costs to provide free services. The situation is mainly due to the authorities' hesitation in defining the role of these day units with interdisciplinary impact, located on the border between the medical and social fields: from the clinical perspective, medical and nursing interventions are not clearly defined, and from the social one, there are no licensing standards for to palliative day centre services.

Help-line services for patients, reported by a single non-governmental organization, registered 4993 calls throughout the reported year. They suppose a double role in the relation between the patient/family and the professionals: monitoring patients in relatively stable stages of progressive chronic disease (4767 calls) and providing support for patients and families beyond the service working hours (226 calls).

Human resources in palliative services

In 2021, the total number of staff employed in palliative care services in Romania was of 1592 professionals, of which 126 doctors, 589 nurses, 40 social workers, 50 psychologists, 50 physiotherapists, 38 clerics, 489 assistant nurses, as well as and 210 volunteers. Most of the services reported have full-time/part-time staff who provide all components of palliative care, from medical and nursing to social needs or psycho-emotional or spiritual support. Of the total number of employees in different professional categories, approximately half (50.31%) have specialized training in palliative care or are in the process of finalizing their training. Among the various categories of personnel in the interdisciplinary teams, the percentage of doctors with competence in palliative care is the highest, 84% having completed complementary studies in palliative care; 57% of nurses attended specialization training; 65% of social workers, 62% of psychologists and between 40-50% of physiotherapists, clergy and nurses completed multidisciplinary or master's degree courses in palliative care. 20 of the providers (18.7%) report having multidisciplinary teams with 6 out of 8 types of professionals (doctors, nurses, social workers, psychologists, assistant nurses, physiotherapists, priests/spiritual advisors, volunteers), Another 22 (20%) providers do not have the

appropriate rate of palliative care doctors for the number of authorized beds.

Education of professionals

With regard to the education of professionals (doctors, nurses and other professions involved in palliative care), during 2022 a number of 110 doctors completed the competence courses in palliative care, which brings the total number of physicians who obtained the certificate of complementary studies in palliative care. Of these, only 106 (14.68%) are employed (full-time or part-time) in the palliative care services reported in 2021. There are significant disparities between the counties regarding the number of doctors with a palliative care competence certificate, the top being the municipality of Bucharest (105 doctors) and the counties of Iași (70 doctors) and Brașov (65%), and at the opposite pole being the counties of Gorj, Tulcea and Vâlcea with 1 doctor each. The presence of doctors certified in palliative care is mandatory for the authorization of specialized services, therefore the underdevelopment of specialized palliative services in these last counties is obvious. The number of nurses who graduated the palliative care specialization program is 388, of which 338 (87.11%) work full-time or part-time in palliative services.

The multidisciplinary master's courses organized by Transylvania University in Brașov have so far registered 422 participants of all professions in palliative care services.

Development, education and research projects

The most important palliative care project with national impact carried out between 2020-2023 is the PAL-PLAN Project of "Increasing the institutional capacity for the coordinated national development of palliative care and home care". The main purpose of the project is, among others, of setting up a National Palliative Care Program, of legislative harmonization towards the integration of palliative care into the health system, a simplified authorization/accreditation/licensing process of independent or integrated palliative care services, as well as the preparation and piloting of 8 outpatient and home palliative care services in each region of the country (Băilești, Curtea de Argeș, Galați, Ploiești, Târgu Mureș, Timișoara, Turda, Vatra Dornei).

The international leadership program in palliative care EUPCA (European Palliative Care Academy), developed by four partner institutions - Köln University Hospital (Germany), King's College (UK), Copernicus University Torun (Poland) and Hospice Casa Sperantei (Romania), continued with the graduation of the 4th series of professionals from 15 European countries, Bangladesh, New Zealand, Turkey and USA.

The most important international projects with the participation of palliative care providers from Romania aim at clinical services, professional education and research. Among these we mention:



Pal_CYCLES

A project aimed at *Developing and implementing innovative Patient-Centred Care Pathways for cancer patients*. An international project involving consortium of 8 partners, Romania included.

Palliative Care Yields Cancer Wellbeing Support (Pal-Cycles) is a project that aims to find the optimal transition model between the hospital and home, a programme to facilitate patient-centred communication and continuity of care for people with advanced cancer, reducing unplanned hospital admissions and improving quality of life at the end of life. The clinical study will be applied in 14 medical units of 7 European countries, Romania included.



The project "Live well, die well" aims to *Improve quality of care for persons at the end of life*, with the involvement of 20 partners of 13 countries, Romania included.

EU-NAVIGATE

A project aiming at *Implementing a navigation programme to support older people with cancer throughout the trajectory of disease, by profining ongowing supportive care, palliative care and end-of-life care*, and including 8 European countries, Romania included.

PAINLESS

A clinical research project for *Developing and testing an innovative service model addressing the growing need for evidence-based pain relief methods in the treatment and alleviation of cancer pain*. It will enhance the understanding of pain mechanisms and use a true interdisciplinary approach to improve pain management in palliative care programmes across Europe. The project includes 17 partners of 10 countries, Romania included.



The RESPAC (Research for All Palliative Care Clinicians) aims to *Encourage basic research competences in the day-to-day practice of palliative care clinicians*. This will allow clinicians to appreciate the importance of integrating research into their clinical practice, to improve their research abilities and conduct their own research work.



The project will aim to *Improve the quality of higher education in palliative care for nurses*, by:

1. Produce a report on shared basic competences in palliative care at European level
2. Develop innovative educational tools for nursing education in Europe
3. Training of trainers to apply the European basic competences matrix

A project with 4 European universities as partners, amongst which the Transylvania University of Braşov and the European Association of Palliative Care (EAPC)



A project aiming to *Foster palliative care for children and adults with cancer* by leveraging patient reported outcome (PRO) systems through their adaptation to the personal needs of the person with cancer and his/her caregiver(s). A project including 8 partners, Romania included.



"Palliative sedation" is a clinical project focusing on *The use of palliative sedation to alleviate distressing symptoms*. A project covering several European countries, Romania included.

National Conference of ANIP also hosted the elections for a new Board of Directors and for the position of president of the Association. After more than 24 years since its establishment in Braşov, during which the administrative management of the Association was voluntarily provided by representatives of Hospice Casa Speranței, the new Board of Directors was elected on October 22, 2022. Associate Professor. Vladimir Poroch from the Regional Institute of Oncology Iasi was appointed as president of the Association. The new Board of Directors includes: Mălina Dumitrescu (vicepresident). Professor Daniela Moşoiu, MD, PhD (scientific coordinator), Dana Nagy, MD (member, Timișoara), Nicoleta Mitrea, Senior lecturer, APRN, PhD, FAAN (member, Braşov), Psych. Mihaela Dumitrache (member, Bacău), Psych. Marinela Rotariu (member, Oradea), Mircea Şerpe, MD (member, Lugoj), Ariana Roşiu MD (member, Alba), Professor Laurentiu Simion, MD (member, Bucharest), Professor Gema Băcoanu, MD (member, Iași), Senior lecturer Sorina Pop, MD (member, Cluj). Rev. Daniel Diaconu (member, Călimăneşti). The General Assembly of the Association proposed the establishment of 10 working groups organized on topics of interest to the Association, including: the development of palliative care protocols for lung diseases and for paediatrics, access to essential medication for palliative care and its endorsement by national authorities, ethical aspects in palliative care, basic palliative care in primary care, spiritual support in palliative care, the nurse's role in palliative care, palliative care in academic education, palliative care in non-oncological diseases. The XIVth National Conference of ANIP, with the proposed topic "Palliative care - dynamism and innovation" will be held in Iași, between October 26-28, 2023.

Îngrijirea paliativă în România în 2022

Dezvoltare organizațională, educație și cercetare

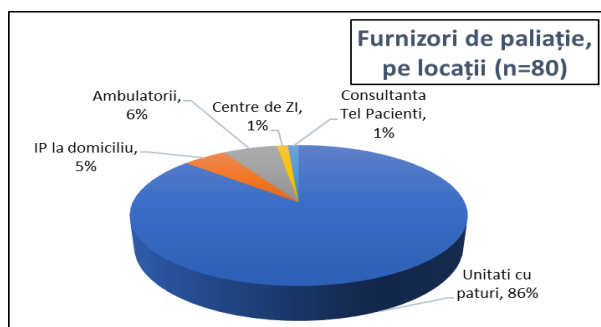
În perioada 20-22 octombrie 2022 a avut loc la Poiana Braşov cea de-a XXIII-a Conferință a Asociației Naționale de Îngrijiri Paliative (ANIP), având ca temă "*Îngrijirea paliativă. Speranță, demnitate, profesionalism*" și înscrisă în cadrul evenimentelor internaționale dedicate Zilei Mondiale a Îngrijirii Paliative 2022.

Ca la fiecare ediție a conferințelor anterioare, plenara de deschidere și-a propus o prezentare actualizată a situației îngrijirilor paliative din România, a serviciilor și a programelor variate de educație pentru pregătirea profesioniștilor din domeniu, a diverselor proiecte naționale și internaționale care vizează integrarea paliativei în sistemul de sănătate, precum și a proiectelor de cercetare în acest domeniu.

Situația curentă a serviciilor de îngrijiri paliative

Situația serviciilor de îngrijiri paliative a fost analizată pe baza datelor obținute din raportarea furnizorilor de servicii pentru anul 2021. Ordinul Ministerului Sănătății nr. 253/2018 prevede raportarea anuală a serviciilor de paliative din sistemul public și privat de sănătate, ceea ce poate asigura o imagine constantă a evoluției serviciilor și poate fi un punct de plecare pentru autorități în planificarea

serviciilor spre zonele cu slabă acoperire, precum și pentru o previzionare și alocare bugetare cât mai apropiată de nevoile reale. Față de raportarea anterioară² analizată pentru serviciile anului 2019, în 2021 constatăm o complianță cu 29,89% mai scăzută a furnizorilor la obligativitatea raportării anuale, ceea ce diminuează imaginea reală a datelor comparate din 2019 și 2022. Rata de răspuns scăzută poate fi datorată realocării unor paturi de paliatie către compartimente, secții COVID, reducerii numărului de servicii datorate subfinanțării, sau netransmiterii raportării. Cu toate acestea, s-au păstrat în general tendințele observate în anii anteriori, respectiv cele de menținere a unui procent ridicat de servicii de internare în unități cu paturi de paliatie, comparativ cu serviciile extra-spitalicești în ambulator sau la domiciliu. La finalul anului 2021 au raportat servicii funcționale un număr de 80 furnizori, dintre care 51% în sistemul public (față de 49% în 2019), 19% în sistemul privat non-profit (14% în 2019) și 30% în regim privat cu profit (37% în 2019).



13 județe nu au niciun furnizor de îngrijiri paliative

Se menține tendința dezvoltării serviciilor de **îngrijiri paliative în regim de internare** (77% în 2021, față de 80% în 2019), cu foarte puține servicii în ambulator (8%, față de 6% în 2019) și la domiciliu (10%, față de 8%).

Atât în mediul public cât și în cel privat, numărul de paturi de îngrijiri paliative contractate este cu 25% mai mic decât al celor autorizate, ceea ce indică un potențial de creștere a numărului de paturi funcționale pentru îngrijirile paliative, în condițiile în care acești furnizori îndeplinesc condițiile de contractare și încheie contracte cu casele de asigurări de sănătate județene.

În privința accesibilității la internare în unități de paliatie, aceasta este neîngrădită în serviciile publice și private

Unități de paliatie, după forma de proprietate		} 48 unități cu acces neîngrădit (73,85%)
> Spitale publice	40 (61,54%)	
> Unități private non-profit	8 (12,31%)	
> Spitale private cu profit	17 (26,15%)	

non-profit și limitată în cele private cu profit, care percep plată sau co-plată.

Costul mediu real raportat de furnizori a fost de 761 lei/zi de spitalizare, tariful rambursat prin sistemul de asigurări de sănătate fiind de 235 lei/zi, ceea ce reprezintă 30,88% din

costul real. Tariful rambursat în prezent nu a fost actualizat din anul 2011, deși sistemul de salarizare a fost modificat radical prin Legea cadru nr.153/2017, privind salarizarea personalului medical din fonduri publice, afectând considerabil costurile serviciilor de sănătate.

Serviciile de **îngrijiri paliative la domiciliu** continuă să fie organizate exclusiv prin furnizori privați caritabili (fundații/asociații), cei 4 furnizori având servicii de domiciliu în 6 județe: 3 furnizori au servicii într-un singur județ și 1 furnizor asigură servicii de îngrijiri paliative la domiciliu în 3 județe. Serviciile sunt subfinanțate atât ca tarif pe vizită (rambursare de 102 lei/vizită, față de 310 lei/vizită cost real raportat de furnizori), cât și ca alocare generală a fondurilor către îngrijirile paliative în comunitate și la domiciliu.

Cei 5 furnizori de servicii **ambulatorii de îngrijiri paliative** au în general servicii integrate unor unități sanitare cu paturi, 2 fiind în sistem public, 3 în unități private non-profit și 2 în regim privat (cu plată sau co-plată).

Centrele de zi de îngrijiri paliative continuă să fie subdezvoltate numeric, fiind raportate doar 5 servicii, în 2 organizații neguvernamentale care își asumă, parțial sau integral, costurile de funcționare pentru a asigura servicii în regim de gratuitate. Situația se datorează în principal ezitărilor de definire a rolului acestor unități de zi cu impact interdisciplinar, aflate la limita dintre domeniile medical și social: din perspectiva medicală nu sunt clar definite intervențiile medicale și de nursing, iar din cea socială nu există standarde de licențiere a serviciilor centrelor de zi de paliatie.

Serviciile de tip help-line pentru pacienți, raportate de o singură organizație neguvernamentală, au fost în număr de 4993 apeluri și au avut un dublu rol: de monitorizare a pacienților în stadii relativ stabile de boală cronică progresivă (4767 apeluri) și de consultanță pentru pacienți și familii în afara orelor de program ale unității de paliatie (226 apeluri).

Resursele umane în serviciile de paliatie

În anul 2021 numărul total al personalului angajat în serviciile de îngrijiri paliative a fost de 1592 de profesioniști, dintre care 126 de medici, 589 de asistenți medicali, 40 asistenți sociali 50 de psihologi, 50 fizioterapeuți, 38 de clerici, 489 de infirmiere, precum și 210 voluntari. Majoritatea serviciilor raportate au personal angajat cu norme complete sau parțiale, care asigură toate componentele îngrijirilor paliative, de la cele medicale și de nursing, la nevoile sociale sau de suport psiho-emoțional. Din totalul angajaților pe diferite categorii profesionale, aproximativ jumătate (50,31%) au pregătire în îngrijiri paliative sau sunt în curs de definitivare a pregătirii. Între diversele categorii de personal din echipele interdisciplinare, procentul medicilor cu competență în îngrijiri paliative este cel mai ridicat, 84% având atestat de studii complementare în îngrijiri paliative finalizate; 57% dintre asistenții medicali au urmat specializarea; 65% din asistenții sociali, 62% din psihologi și între 40-50% din kinetoterapeuți, clerici și infirmiere au urmat cursuri

² <https://www.ms.ro/wp-content/uploads/2021/08/Raport-furnizori-ingrijiri-paliative-Romania-2019.pdf>

multidisciplinare sau masterale pe profil de paliatie. 20 dintre furnizori (18,7%) raportează că asigură multidisciplinaritatea cu 6 din 8 tipuri de profesioniști (medici, asistenți medicali, asistenți sociali, psihologi, infirmiere, kinetoterapeuți, preoți/consilieri spirituali, voluntari). Alți 22 (20%) furnizori nu au suficienți medici de IP la numărul de paturi autorizate.

Educația profesioniștilor

În domeniul educației, a fost prezentată situația principalelor programe de educație derulate în ultima perioadă pentru medici, asistenți medicali și alte profesii implicate în îngrijirile paliative. În cursul anului 2022 un număr de 110 medici au finalizat cursurile de atestat, ceea ce ridică la 722 numărul celor care au obținut atestatul de studii complementare în îngrijiri paliative. Dintre aceștia doar 106 (14,68%) sunt angajați (cu normă întreagă sau parțială) în serviciile de paliatie raportate în anul 2021. Se observă diferențe semnificative între județe, în privința numărului de medici cu atestat, în top fiind municipiul București (105 medici) și județele Iași (70 medici) și Brașov (65%), iar la polul opus județele Gorj, Tulcea și Vâlcea cu câte 1 singur medic. Prezența medicilor cu atestat în îngrijiri paliative fiind obligatorie pentru autorizarea serviciilor specializate, este deci evidentă subdezvoltarea serviciilor specializate de paliatie în aceste ultime județe. Numărul asistenților medicali care au absolvit programul de specializare în îngrijiri paliative este de 388, din care 338 (87,11%) lucrează cu normă întreagă sau fracționată în servicii de paliatie.

Cursurile masterale multidisciplinare organizate de Universitatea Transilvania din Brașov au înregistrat până în



Proiectul are ca scop Dezvoltarea și implementarea de modele de îngrijire centrate pe pacient, pentru pacienții oncologici (traectoria pacientului de-a lungul parcursului bolii). Proiectul internațional se desfășoară în perioada 2022-2027 și este derulat printr-un consorțiu format din 14 parteneri, între care și România.

PaL_CYCLES

Proiectul își propune Dezvoltarea, testarea și implementarea unui program de tranziție între spital și comunitate pentru pacienții cu cancer avansat, ca studiu clinic în 14 unități din 7 țări europene între care și România.



Proiectul "Live well, die well" urmărește Îmbunătățirea calității asistenței persoanelor aflate la final de viață și va avea ca participanți 20 de parteneri din 13 țări, între care și România.

EU-NAVIGATE

Proiectul vizează Implementarea unui model de program de navigare centrat pe pacient și familie (Nav-Care-EU) pentru pacienții vârstnici, de-a lungul îngrijirii suportive continue, îngrijirii paliative, în supraviețuire și la finalul vieții. Proiectul se desfășoară în 8 țări europene, între care și România.

PAINLESS

Acesta este un proiect de cercetare clinică ce vizează Atenuarea durerii în îngrijirea paliativă în cancer, folosind neuromodularea la domiciliu și biomarkeri predictivi. Proiectul include 17 parteneri din 10 țări, între care și România



Proiectul RESPACC (Research for All Palliative Care Clinicians) își propune Introducerea competențelor de cercetare de bază în practica de zi cu zi a clinicienilor din îngrijirea paliativă. Aceasta va permite clinicienilor din toate specialitățile relevante să aprecieze importanța integrării cercetării în practica clinică, să își dezvolte capacitatea de cercetare atât în citirea/evaluarea lucrărilor de cercetare, cât și în efectuarea propriilor cercetări și implicit în îmbunătățirea calității serviciilor oferite pacienților.



Proiectul vizează Îmbunătățirea calității învățământului superior în domeniul educației în îngrijiri paliative pentru asistenții medicali, prin:

4. Elaborarea unui raport privind competențele de bază comune în îngrijirea paliativă europeană
5. Dezvoltarea de „instrumente” educaționale inovatoare pentru educația în domeniul îngrijirilor paliative în țări europene
6. Formarea educatorilor/formatorilor în modul de lucru cu competențele de bază ale matricei europene de îngrijire

Proiectul are ca parteneri 4 universități europene (între care și Universitatea Transilvania din Brașov), precum și EAPC (Asociația Europeană de Îngrijiri Paliative)

prezent 422 de participanți, profesioniști din echipe interdisciplinare de îngrijiri paliative.

Proiecte de dezvoltare, educație și cercetare

Cel mai important proiect de îngrijiri paliative cu impact național aflat în desfășurare în perioada 2020-2023 este Proiectul PAL-PLAN de "Creștere a capacității instituționale pentru dezvoltarea națională coordonată a îngrijirilor paliative și îngrijirilor la domiciliu". Proiectul are ca scop principal, între altele, crearea unui Program Național de Îngrijiri Paliative, armonizarea legislativă în vederea integrării paliatiei în sistemul de sănătate, simplificarea procesului de autorizare/acreditare/licențiere a serviciilor de paliatie independente sau integrate, precum și pregătirea și pilotarea a 8 servicii de îngrijiri paliative în ambulator și la domiciliu în fiecare regiune a țării (Bălești, Curtea de Argeș, Galați, Ploiești, Târgu Mureș, Timișoara, Turda, Vatra Dornei).

Programul internațional de leadership în îngrijirile paliative EUPCA (European Palliative Care Academy), cu parteneri Spitalul Clinic Universitar Koln (Germania), King's College (UK), Universitatea Copernicus Torund (Polonia) și Hospice Casa Sperantei (Romania), a continuat cu absolvirea celei de-a 4-a serii de profesioniști din 15 țări europene, Bangladesh, Noua Zeelandă, Turcia și SUA.

Cele mai importante proiecte internaționale cu participarea unor furnizori de îngrijiri paliative din România vizează aspecte clinice, de educație a profesioniștilor și de cercetare. Dintre acestea amintim:



Proiectul este dedicat Îngrijirii paliative pentru copii și adulți cu cancer, prin crearea unor sisteme tehnice avansate de raportare a rezultatelor de către pacient. Între cei 8 parteneri din proiect se află și România



"Sedarea paliativă" este un proiect clinic ce vizează Utilizarea sedării paliative proporționale pentru ameliorarea simptomelor refractare. Vor fi analizate și revizuite aspectele curente clinice și etice în practicile curente de utilizare a sedării paliative în mai multe țări europene, între care și România

În cadrul Conferinței Naționale a ANIP s-au desfășurat și alegerile pentru un nou Consiliu Director și pentru funcția de președinte al Asociației. După mai bine de 24 de ani de la înființarea sa la Brașov, perioadă în care conducerea administrativă a Asociației a fost asigurată de reprezentanți ai Hospice Casa Speranței, noul Consiliu Director ales la 22 octombrie 2022 a ales în funcția de președinte pe Conf.Dr.Vladimir Poroch de la Institutul Regional de Oncologie Iași. Din noul Consiliu Director fac parte: Mălina Dumitrescu (vicepreședinte), Prof.Univ.Dr.Daniela Moșoiu (coordonator științific), Dr.Dana Nagy (membru, Timișoara), Dr.as.med. Nicoleta Mitrea (membru, Brașov), Psih.Mihaela Dumitrache (membru, Bacău), Psih.Marinela Rotariu (membru, Oradea), Dr.med.Mircea Șerpe (membru, Lugoj), Dr.Ariana Roșiu (membru, Alba), Conf.Dr.Laurențiu Simion (membru, București), Conf. Dr. Gema Băcoanu (membru, Iași), Conf.Dr. Sorina Pop (membru, Cluj). Pr.Daniel Diaconu (membru, Călimănești). Adunarea Generală a Asociației a propus înființarea a 10 grupuri de lucru organizate pe teme de interes ale Asociației, între care: elaborarea de protocoale de îngrijiri paliative pentru bolile pulmonare și pentru pediatrie, accesul la medicația esențială pentru paliative și oficializarea acesteia, aspecte etice în paliative, îngrijirile paliative de bază în medicina primară, suportul spiritual în îngrijirile paliative, rolul asistentului medical în paliative, paliativa în educația academică, îngrijirea paliativă în bolile non-oncologice. Cea de-a XIV-a Conferință Națională a ANIP, având ca temă propusă "*Îngrijirea paliativă – dinamism și inovație*" se va desfășura la Iași, în perioada 26-28 octombrie 2023.

CASE STUDY

Caz clinic și nu numai – o reflecție retrospectivă asupra îngrijirii

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Rezumat

Introducere: Osteosarcomul este o tumoră malignă ce apare predominant la copii și adolescenți. Tratatamentul actual constă în combinația dintre intervenția chirurgicală și chimioterapie. Supraviețuirea pacienților sub 5 ani se datorează gradului înalt de recidivă și metastazare.

Prezentare de caz: Se prezintă cazul unei paciente în vârstă de 19 ani diagnosticată cu osteosarcom din 2015, care se internează în unitatea cu paturi a Fundației Hospice București cu boală în evoluție datorită diseminărilor la distanță prezente în plămâni, os și ganglioni.

Discuții: Nevoia de îngrijiri paliative a pacientei derivă din complexitatea situației pacientei, aceasta prezentând atât suferință fizică reprezentată de durere cronică dificil de tratat, inapetență, constipație, dispnee, anxietate, fatigabilitate, greață sporadic, vomă rară postprandială cât și suferință nonfizică (psihoe emoțională, existențială și socială). Motivația alegerii cazului constă în dramatismul perceput de toții cei implicați (pacienta, mama, personalul medical).

Concluzii: Cazul prezentat a fost unul dificil pentru pacient, aparținător și echipa de îngrijire datorită multiplelor provocări pe planul simptomelor, al managementului farmacologic care a implicat alegerea căii de administrare și al suferinței psihoe emoționale, existențiale și sociale extreme resimțită de pacientă. Preluând o parte din suferința pacientei și a familiei acesteia au fost necesare intervenții de suport pentru personalul implicat. Nevoia de îngrijiri paliative la pacienții cu osteosarcom derivă din agresivitatea bolii care incapacitează persoana din punct de vedere fizic, emoțional, existențial și social.

Abstract

Introduction: Osteosarcoma is a malignant tumor occurring predominantly in children and adolescents. Current treatment consists of a combination of surgery and chemotherapy. Survival of under 5 year for these patients is due to the high degree of recurrence and metastasis.

Case presentation: We present the case of a 19-year-old patient diagnosed with osteosarcoma in 2015, who is admitted to the in-patient unit of Hospice Casa Sperantei Bucharest Foundation with evolving disease due to distant dissemination present in lungs, bone and lymph nodes.

Discussion: The patient's need for palliative care derives from the complexity of the patient's situation, she presents both physical suffering generated by chronic pain difficult to treat, lack of appetite, constipation, dyspnea, anxiety, fatigue, sporadic nausea, rare postprandial vomiting and non-physical suffering (psycho-emotional, existential and social). The motivation for choosing the case lies in the high level of distress perceived by all those involved (patient, mother, clinical staff).

Conclusions: The case presented was a difficult one for the patient, the caregiver and the care team due to the multiple challenges in terms of symptoms, pharmacological management involving the choice of route of administration and the extreme psycho-emotional, existential and social distress felt by the patient. Bearing some of the suffering of the patient and her family required supportive interventions for the staff involved. The need for palliative care in patients with osteosarcoma derives from the aggressiveness of the disease which incapacitates the person physically, emotionally, existentially and socially.

1. Introducere

Osteosarcomul este o tumoră malignă osoasă întâlnită frecvent la copii și adolescenți. În ciuda chimioterapiei asociate tratamentului chirurgical, supraviețuirea pacienților este redusă datorită apariției metastazelor și recurenței bolii (Cersonimo et al, 2020). La aproximativ 50% dintre pacienții cu osteosarcom care în momentul diagnosticului nu prezentau metastaze, boala recidivează local sau la distanță (Whelan et al, 2012). Metastazele apar cel mai frecvent în plamani și cel mai rar în os și ganglionii limfatici. Tratamentul standard constă în chimioterapie neoadjuvantă anterior operației urmată de rezecție chirurgicală a tumorii și a metastazelor rezecabile și de chimioterapie adjuvantă postoperator (Luetke et al, 2014). Pacienții cu osteosarcom datorită vârstei tinere la care descoperă boala pot asocia anxietate și depresie prin prisma îngrijorărilor, fricii și furiei resimțite pe parcursul bolii (American Cancer Society, 2022).

2. Prezentare de caz

Pacientă în vârstă de 19 ani se prezintă la internare, în unitatea cu paturi a Fundației Hospice Casa Speranței București, însoțită de mamă, cu ambulanța. Pacienta este elevă, dar frecventează cursurile mai mult on-line în ultima perioadă. Relațiile sociale cu colegii și prietenii sunt păstrate, dar în ultima perioadă acestea s-au redus la număr. Are un frate de 5 ani, părinții sunt divorțați iar tatăl este în străinătate. Mama a fost îngrijitorul principal pe tot parcursul bolii. Este creștin-ortodoxă, practicantă. Diagnosticul stabilit la internare este: Sarcom pleomorf nediferențiat aripă iliacă stângă, determinări secundare pulmonare, osoase și limfatiche.

Din **istoricul bolii** reținem următoarele: 2015 - debut cu durere lombară stângă, cu iradiere în fesa stângă și membrul inferior stâng. Pentru mai mult de 1 an nu s-a stabilit nici un diagnostic, pacienta primind doar tratament conservator cu antialgice, AINS și miorelaxante sub care durerea a crescut în intensitate și a apărut mersul antalgic. 2016 - stabilire diagnostic după biopsia osoasă, începere chimioterapie neoadjuvantă urmată de intervenție chirurgicală. 2017 - efectuare a 30 ședințe radioterapie cu ușoară ameliorare a durerii. 2017 - urmează o nouă intervenție chirurgicală reprezentată de amputație membru inferior stâng la nivelul coapsei și protezare a membrului inferior stâng apoi o nouă serie de chimioterapie. 2018 apare recidivă locală cu durere intensă, tumefacție la nivelul bontului operator. 2019 - hemipelvectomie. 2020 - o nouă cură de chimioterapie. 2020 - recidivă locală cu invadare oase bazin. 2021 - implantare pompă intratecală pentru tratamentul durerii. 2022 - primește recomandare de îngrijire paliativă, boala este în evoluție, metastazele identificate imagistic pe parcursul ultimilor 3 ani fiind în progresie numerică și dimensională.

Din **anamneză** reiese prezența unei dureri cronice, mixte (somatică, neuropată + durere membru fantomă ("m-am obișnuit să trăiesc cu durerea, e parte din mine, lipsa ei ar fi ciudată") cu intensitate de fond pe scala analog vizuală (SAV) de 2-4/10, cu 8-10 episoade dureroase/24 ore care ating intensitatea de 10/10 pe SAV, durere care se asociază cu inapetență, constipație, dispnee, anxietate, fatigabilitate, greață sporadic, vomă rară postprandială (apare mai ales în contextul în care pacienta se alimentează modest cantitativ și ocazional consumă un volum discret mai mare de hrană ce constituie factorul-trigger) și a altei dureri cauzate de defecație, permițând defecația doar într-o singură poziție.

La examenul obiectiv se constată faptul că pacienta este orientată temporo-spatial, are tegumente palide cu timp de umplere capilară prelungit, status precar respirator și hemodinamic (TA: 100/65 mmHg, AV: 95-115 bpm, Sa O2: 88-92%), cașexie (greutate 28 kg), este imobilizată în decubit ventral, prezintă escare gr. 2 la nivelul spinelor iliace, tumori voluminoase localizate sacrat, crural și parasacrat de 19 cm, 10 cm și 6 cm, mase adenopatiche dure inghinal bilateral, masă tumorală dură, anfractuasă în hemiabdomenul stg/hipogastru, edem membrul inferior drept, sondă urinară permanentă cu schimbare la 3-4 săptămâni, funcțională și cameră implantabilă subclavicular drept.

Pacienta a prezentat la internare următoarea **schemă de tratament**:

- Augmentin 625 mg - 1 tb la 12h, pentru încă 3 zile;
- Nitrofurantoin 50 mg seara, permanent;
- Bisepтол 480 mg - 2 cp luni, marți, miercuri;
- Probiotice pe timpul tratamentului cu Augmentin;
- Morfină 20 mg la nevoie (prn), 1-6 cp/24h;
- Fentanyl 75 mcg pach administrat la 48h;
- Fentanyl 200 mcg prn, 1-4 cp/24h;
- Laxative;
- Gabapentină 100 mg x 3;
- Amitriptilină 25 mg x 2;
- Dexametazonă 4 mg zilnic;
- Pompa (Fentanyl/Ropivacaină/Clonidină), constant + boost prn, rezervă pentru încă 3 zile.

3. Discuții

Premisele inițierii îngrijirii (echipa: pacienta, medicii de îngrijire paliativă, medic ATI, asistenți medicali, infirmieri, psiholog, asistent social, medic voluntar îngrijire paliativă și apartenența clericală, consilier spiritual, preot, mama pacienței):

1. Fentanyl pach inadecvat, doza absorbită necunoscută în condițiile cașexiei.
2. Relatarea pacientei asupra durerii:
 - a. administrarea de Fentanyl oral nu aduce beneficii, a experimentat 3 cp simultan cu reducerea durerii de la 10 la 8 pe SAV, fără efecte secundare,
 - b. efectul analgezic al Fentanyl-ului oral este comparabil cu 20-40 mg de Morfina orală cu eliberare rapidă și 20-30 mg de Morfina injectabilă,
 - c. doza de analgezic on-demand din pompă nu aduce nici o ameliorare,
 - d. de câteva ori platurile cu Fentanyl s-a dezlipit iar pacienta a observat după 1 sau chiar 2 zile în care durerea a fost la fel.
3. Pompa greu de utilizat (lipsa de experiență, accesul la substanțe, soft, dependența de alt profesionist).
4. Suferința complexă:
 - Fizică – durere necontrolată,
 - Psiho-emoțională intensă, refuzul tatălui de a participa la "rămas-bun", vinovăție ("*boala mea a cauzat despărțirea părinților, o ține pe mama departe de frate, sunt o povară pentru toată lumea din jurul meu*"),
 - Socială – dependența de ceilalți, izolare față de colegii de generație și școală.
5. Dorințele și preferințele pacientei:
 - "să se termine odată",
 - "să nu simt durerea, să dorm cât mai mult dar să fiu trează pentru vizitatori – frate, mama, colegi, tată?",

“să dețin control asupra mea”,
 “pe cât posibil fără pastile, mai bine injectabil”,
 “mai stați puțin cu mine”.

Intervențiile echipei de îngrijiri paliative au constat în:

1. Control simptome: durere, dispnee, depresie, anxietate, insomnie.
2. Nursing – poziționare, îngrijire corporală, administrare medicație, asistența nevoilor de bază (hrănire, hidratare, defecație, etc).
3. Montare cateter subcutanat și conectare la seringă automată, stabilire doză antialgic/24 de ore și la nevoie.
4. Intervenție psiholog, asistent social, cleric.
5. Crearea unui cadru de îngrijire lărgit “adopție” (prezența fizică, atingerea, ținutul de mână, povestiri).

Controlul durerii s-a realizat prin medicația de fond și administrarea dozelor la nevoie. S-a decis menținerea pentru moment a platurului de Fentanyl 75 mcg care a fost schimbat la 72h. Morfina s-a administrat subcutanat cu ajutorul unei seringi automate și s-au crescut treptat dozele la 1-2 zile în raport cu intensitatea durerii și numărul episoadelor dureroase relatate de către pacientă, ajungându-se până la 400 mg/24h. Necesarul de medicație la nevoie a fost următorul:

- Ziua 1 (la internare) Morfină - 10 mg administrată subcutanat (sc), 6-8 doze/24h,
- Ziua 3 Morfină - 15 mg sc, 4-5 doze/24h,
- Ziua 5 Morfină - 20 mg, 4-5 doze/24h,
- Ziua 7 Morfină - 30 mg, 3-4 doze/24h,
- Ziua 8 Morfină - 40 mg, 2-3 doze/24h.

Pe parcursul internării s-au asociat următoarele medicamente: Metamizol administrat po fără efect, motiv pentru care s-a retras, Midazolam 2.5 mg prn, laxative de înmuiere/propulsie, Metoprolol, Diazepam 10 mg intrarectal pentru controlul unui episod convulsiv, Metoclopramid 10 mg administrat sc, sporadic, la escaladarea dozelor de Morfină.

Evoluția pacientei s-a manifestat prin deteriorare progresivă. Pacienta a refuzat laxativele deoarece "defecația este un chin". În ziua a 4-a de internare s-a epuizat rezervorul pompei și acesta s-a umplut cu ser fiziologic. Durerea a început să fie bine controlată la 6-7 zile de la internare, în contextul escaladării progresive a dozelor zilnice și la nevoie de Morfina administrată subcutanat. În ziua a 9-a de internare s-a produs abcedarea ambelor tumori dorsale și drenarea spontană a unui lichid sero-sanguinolent, a apărut disfagia, Sa O₂ a pacientei s-a situat între 82-88% motiv pentru care s-a administrat O₂ pe canula 2.5-3 l/min, pacienta a prezentat un episod convulsiv controlat cu Diazepam 10 mg administrat intrarectal și s-a adăugat Clonazepam 0.5mg x 2/zi administrat po în schema de tratament. În ziua a-11-a pacienta a devenit somnolentă, cu disfagie progresivă, a refuzat să se alimenteze și concomitent a început să prezinte incapacitate în administrarea medicație orale motiv pentru care s-a instituit Protocolul de Fază Terminală. În ziua a-12-a pacienta a decedat iar în ziua a-13-a medicul ATI a oprit pompa intratecală pentru a nu intra în regim de alertă sonoră.

Comportamentele observate în cadrul de îngrijire Mama a început să lipsească din ce în ce mai des – distanțare? autoprotecție?

Personalul s-a stratificat spontan în 2 categorii:

- a. evită/preferă să nu interacționeze cu pacienta (evitare, fugă),

- b. preferă să petreacă cât mai mult timp cu pacienta, solicită să fie repartizați în îngrijire (luptă, implicare dincolo de așteptări).

S-au observat profesioniști care au intrat voluntar la pacientă dar nu au putut tolera propriile emoții și au părăsit repede salonul, plângând.

Tatăl a întrerupt orice comunicare cu pacienta/personalul după ce inițial a vorbit telefonic cu psihologul nostru.

După pierdere personalul a procesat cazul săptămâni și luni de zile, menționând-o în context divers.

Transfer/proiecție: “nu mai pot trece iar prin așa ceva” sunt cuvinte rostite când la internare este programat un pacient foarte tânăr.

Emoțiile observate în cadrul de îngrijire, indiferent de calificarea profesionistului au fost de tristețe, furie, revoltă și mânie.

Osteosarcomul este o formă rară de cancer osos care apare mai frecvent la copii și adolescenți (Cersonimo et al, 2020). Tratamentul pacienților cu osteosarcom constă în combinația dintre intervenția chirurgicală și chimioterapie. În ciuda tratamentului chimioterapic agresiv, supraviețuirea pacienților cu stadiu metastatic de boală este sub 5 ani (Zhang et al, 2020).

În cazul pacientei noastre, diagnosticul s-a stabilit târziu iar intervențiile chirurgicale nu au reușit să îndepărteze în totalitate tumorile, ceea ce a dus la progresia bolii și apariția multiplelor determinări secundare. Mai multe consulturi de tip "a doua opinie medicală" cu specialiști din Europa și SUA au concluzionat încă din 2017 că șansele de vindecare sunt minime.

Mama și pacienta au recunoscut pe parcursul internării că "poate ar fi fost mai bine să se oprească din tentativele terapeutice cu mult mai devreme în cursul bolii și poate că astfel ar fi evitat foarte multă durere și suferință". În mod independent pacienta a recunoscut, în absența mamei, că ea s-ar fi oprit mai demult din tratamente dar a continuat pentru a-i aduce alinare și curaj acesteia.

Îngrijirea paliativă a fost accesată târziu în cazul pacientei datorită lipsei de acceptare a evoluției funeste. În scurtul interval de supraviețuire s-a încercat alinarea suferinței adunate în ani de zile.

Cazul a fost ales din cauza dramatismului perceput de către toți cei implicați. Parintele care nu a renunțat la luptă pentru a nu irosi o șansă infimă la stagnare sau vindecare. Parintele care nu a putut accepta că își pierde copilul. Copilul matur care a acceptat suferința, durerea, mutilarea pentru a-i face pe plac mamei și a nu o răni pe aceasta prin renunțare. Copilul care nu poate să își accepte pierderea adolescenței și a viitorului ca ființă adultă. Profesioniștii din domeniul medical care au continuat lupta în ciuda oricăror șanse de succes, pentru a nu se declara neputincioși în fața părintelui și a copilului. Profesionalistul din îngrijirea paliativă care se confruntă cu suferință pe toate planurile, la un nivel impresionant, suferință care se întinde pe parcursul a 7 ani într-o formă sau alta.

4. Concluzii

Cazul prezentat a fost unul dificil pentru pacient, aparținător și echipa de îngrijire datorită multiplelor provocări pe planul simptomelor, al managementului farmacologic care a implicat alegerea căii de administrare și al suferinței psihoemoționale, existențiale și sociale extreme resimțită de pacientă.

Atenția echipei de îngrijiri paliative a fost centrată pe pacientă și pe familia acesteia, echipa îmbinând dorințele cu

nevoile pacientei cu scopul de a ușura suferința. Preluând o parte din suferința pacientei și a familiei acesteia au fost necesare intervenții de suport pentru personalul implicat.

Nevoia de îngrijiri paliative la pacienții cu osteosarcom derivă din agresivitatea bolii care incapacitează persoana din punct de vedere fizic, emoțional, existențial și social.

Clinical case and beyond - a retrospective reflection on care

1. Introduction

Osteosarcoma is a malignant bone tumor commonly found in children and adolescents. Despite chemotherapy coupled with surgical treatment, patient survival is poor due to the occurrence of metastases and disease recurrence (Cersonimo et al, 2020). In approximately 50% of patients with osteosarcoma who at the time of diagnosis do not have metastases, the disease relapses locally or in other sites in the body (Whelan et al, 2012). Metastases occur most commonly in the lungs and most rarely in bone and lymph nodes. Standard treatment consists of neoadjuvant chemotherapy prior to surgery followed by surgical resection of the tumor and resectable metastases and adjuvant chemotherapy postoperatively (Luetke et al, 2014). Patients with osteosarcoma may associate anxiety and depression because of the worry, fear and anger experienced during the course of the disease (American Cancer Society, 2022).

2. Case presentation

A 19-year-old patient is admitted to the in patient unit of Casa Speranței Hospice Foundation in Bucharest, accompanied by her mother. The patient is a student, but attends classes mostly online during the last period. Social relationships with colleagues and friends are maintained, but lately they have been reduced in number. She has a 5-year-old brother, her parents are divorced and her father is abroad. The mother has been the main carer throughout the illness. She is a practicing Orthodox Christian. The medical diagnosis established on admission is: Undifferentiated left iliac wing pleomorphic sarcoma, with pulmonary, bone and lymphatic secondary determinations.

From the history of the disease we note the following: 2015 - onset with left lumbar pain with irradiation in the left buttock and left lower limb. For more than 1 year no diagnosis was established, the patient received only conservative treatment with analgesics, non steroidal anti-inflammatory drugs (NSAIDs) and myorelaxants under which the pain increased in intensity. 2016 - The diagnosis was established after bone biopsy, neoadjuvant chemotherapy was started followed by surgery. 2017 - Completion of 30 radiotherapy sessions with slight pain relief. 2017 – Local disease progression with surgery intervention represented by amputation of left lower limb at thigh level and prosthesis of left lower limb followed by a new series of chemotherapy. 2018 - Local relapse occurs with intense pain, swelling at the operative stump. 2019 - Hemipelvectomy. 2020 - A new course of chemotherapy. 2020 - local relapse with pelvic bone invasion. 2021 - intrathecal pump implantation for pain treatment. 2022 - palliative care referral, disease is evolving, metastases identified with

imaging techniques over the last 3 years are progressing in number and size.

The history shows the presence of chronic, mixed pain (somatic, neuropathic + phantom limb pain ("I am used to living with pain, it is part of me, its absence would be strange") with a background intensity on the visual analogue scale (VAS) of 2-4/10, with 8-10 breakthrough pain episodes/24 hours reaching an intensity of 10/10 on the VAS. Pain is associated with lack of appetite, constipation, dyspnea, anxiety, fatigue, sporadic nausea, rare postprandial vomiting (occurring on occasional consumption of a larger volume of food as trigger) and other pain caused by defecation, allowing defecation in one position only.

On physical examination the patient is found to be temporospatially oriented, with pale tegument with prolonged capillary refill time, poor respiratory and haemodynamic status (BP: 100/65 mmHg, AV: 95-115 bpm, Sa O₂: 88-92%), cachexia (weight 28 kg), immobilised in ventral decubitus, presenting grade two pressure sores at the level of iliac spines. Voluminous tumors located sacral, crural and parasacral of 19 cm, 10 cm and 6 cm were identified, bilateral inguinal hard adenopathic masses, hard, anfractuous tumor mass in left hemiabdomen/hypogastrium, right lower limb edema, permanent urinary catheter with change every 3-4 weeks, functional and right infraclavicular implanted camera.

The patient presented the following treatment plan on admission:

- Augmentin 625 mg - 1 tb at 12h, for another 3 days;
- Nitrofurantoin 50 mg in the evening, permanently;
- Biseptol 480 mg - 2 cp Monday, Tuesday, Wednesday;
- Probiotics during treatment with Augmentin;
- Morphine 20 mg as needed (prn), 1-6 cp/24h;
- Fentanyl 75 mcg patch given every 48h;
- Fentanyl 200 mcg prn, 1-4 cp/24h;
- Laxative;
- Gabapentin 100 mg x 3;
- Amitriptyline 25 mg x 2;
- Dexamethasone 4 mg daily;
- Pump (Fentanyl/Ropivacaine/Clonidine), constant + boost prn, reserve for 3 more days.

3. Discussions

The context for initiating palliative care (with a team comprising alongside the patient, the palliative care doctors, ICU doctor, nurses, nurses, psychologist, social worker, volunteer palliative care doctor and clergy, spiritual counsellor, priest, patient's mother):

1. Fentanyl patch unsuitable, as absorbed dose is unknown in cachexia conditions.
2. Patient's account of pain:
 - a. oral Fentanyl administration has no benefit, after 3 breakthrough doses a very small reduction in pain from 10 to 8 on VAS, with no side effects,
 - b. analgesic effect of oral Fentanyl is comparable to oral rapid release Morphine and injectable Morphine,
 - c. the on-demand analgesic dose from the pump brings no relief,
 - d. a few times the Fentanyl patch came off and the patient noticed after 1 or even 2 days that the pain was the same.
3. Pump difficult to use (lack of experience, access to substances, software, dependence on another professional).

4. Complex pain:
 Physical - uncontrolled pain,
 Intense psycho-emotional pain component,
 father's refusal to participate in "goodbye", guilt
 ("my illness caused parents to separate, keeps
 mother away from brother, I am a burden to
 everyone around me"),
 Social - dependence on others, isolation from
 peers and school.
5. Patient wishes and preferences:
 "I want everything to finish to just get over with it",
 "to feel no pain, to sleep as much as possible but
 be awake for visitors - brother, mother,
 colleagues, father?(with hope)",
 "to be in control of myself",
 "as far as possible no pills, better injectable",
 "stay with me a little longer".

The palliative care team interventions consisted of:

1. Symptom control: pain, dyspnoea, depression, anxiety, insomnia.
2. Nursing - positioning, body care, medication administration, assistance with basic needs (feeding, hydration, defecation, etc).
3. Subcutaneous catheter connected to a syringe driver, setting up pain relief dosage/24 hours and as needed.
4. Intervention psychologist, social worker, clerk.
5. Creation of an extended care "adoption" setting (physical presence, touching, hand holding, storytelling).

Pain control was achieved through regular medication and administration of doses as needed. It was decided to maintain for the time being the 75 mcg/hour fentanyl schedule which was changed at 72h. Morphine was administered subcutaneously using an automatic syringe and doses were gradually increased every 1-2 days in relation to the intensity of pain and the number of painful episodes reported by the patient, reaching up to 400 mg/24h. Medication requirements on demand were as follows:

- Day 1 (on admission) Morphine - 10 mg administered subcutaneously (sc), 6-8 doses/24h,
- Day 3 Morphine - 15 mg sc, 4-5 doses/24h,
- Day 5 Morphine - 20 mg, 4-5 doses/24h,
- Day 7 Morphine - 30 mg, 3-4 doses/24h,
- Day 8 Morphine - 40 mg, 2-3 doses/24h.

During hospitalization the following medications were associated: metamizole administered po without effect, which is why it was withdrawn, Midazolam 2.5 mg prn, laxatives for softening/propulsion, Metoprolol, Diazepam 10 mg intrarectally to control a convulsive episode, Metoclopramide 10 mg administered sc, sporadically, when escalating Morphine doses.

The evolution of the patient was manifested by progressive deterioration. The patient refused laxatives because "defecation is a torment". On the 4th day of hospitalization the pump reservoir was exhausted and filled with saline. Pain started to be well controlled 6-7 days after admission, in the context of progressive escalation of daily doses and as needed Morphine administered subcutaneously. On the 9th day of hospitalization both dorsal tumors abscessed and spontaneous drainage of a serosanguinous fluid occurred, dysphagia appeared, patient's O₂ Sa was between 82-88% reason for which O₂ was administered by cannula 2.5-3 l/min.

The patient presented a convulsive episode controlled with Diazepam 10 mg administered intrarectally. Clonazepam 0.5mg x 2/day administered po in the treatment scheme was added. On day 11 the patient became drowsy, with progressive dysphagia, refused to eat and concomitantly began to show inability to take oral medication for which the Terminal Phase Protocol was instituted. On day 12 the patient died.

Behaviours observed in the care setting

Mother started missing more and more often - distancing? self-protection?

Staff spontaneously stratified into 2 categories:

- a. avoid/prefer not to interact with the patient (avoidance, running away),
- b. prefer to spend as much time with the patient as possible, ask to be assigned to care (struggle, involvement beyond expectations).

Professionals were observed who voluntarily entered the patient but could not tolerate their own emotions and quickly left the ward, crying.

The father stopped all communication with the patient/staff after initially speaking to our psychologist by phone.

After the loss staff processed the case for weeks and months, mentioning it in various contexts.

Transfer/projection: 'I can't go through this again' are words spoken when a very young patient is scheduled for admission.

Emotions observed in the care setting, regardless of the professional's qualifications were of sadness, anger, outrage and grief.

In our patient's case, the diagnosis was established late and surgery failed to completely remove the tumors, leading to disease progression and multiple secondary determinations. Several "second medical opinion" consultations with specialists in Europe and the US concluded as early as 2017 that the chances of cure were minimal.

The mother and patient acknowledged during the hospitalization that "perhaps it would have been better to stop therapeutic attempts much earlier in the course of the disease and perhaps this would have avoided a lot of pain and suffering". Independently the patient admitted, in her mother's absence, that she would have stopped treatments earlier but continued to bring her comfort and courage.

Palliative care was accessed late in the patient's case due to a lack of acceptance of the fatal outcome. In the short time she survived, attempts were made to alleviate the suffering accumulated over the years.

The case was chosen because of the drama perceived by all involved. The parent who did not give up the fight in order not to waste a tiny chance at stagnation or cure. The parent who couldn't accept losing their child. The mature child who accepted suffering, pain, mutilation in order to please the mother and not hurt her by giving up. The child who cannot accept the loss of his adolescence and his future as an adult. The medical professionals who have continued to fight against all odds, not to declare themselves powerless in the face of the parent and child. The palliative care professional who faces grief on all levels at an impressive level, following patients suffering that spans over the last 7 years of her life.

4. Conclusions

The case presented was a difficult one for the patient, carer and care team due to the multiple challenges in terms of symptoms, pharmacological management involving choice of route of administration and the extreme psycho emotional, existential and social distress experienced by the patient.

The focus of the palliative care team was on the patient and her family, with the team matching the patient's wishes with her needs in order to alleviate suffering. Taking on some of the suffering of the patient and her family required supportive interventions for the staff involved.

The need for palliative care in patients with osteosarcoma derives from the aggressiveness of the disease which incapacitates the person physically, emotionally, existentially and socially.

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ESSAY

Ostomies and clothing

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Abstract

Patients with stomas are concerned about their body image and are worried that they will have to change their wardrobe after the operation. This adaptation is not necessary because society considers them normal people, and uncomfortable reactions, when they occur, are mainly due to lack of experience. However, the modesty and alteration of the body image make these patients try to mask the presence of the stoma with clothing. The article aims to review the ways in which the textile industry helps patients with stomas to improve their body image.

Keywords: stoma, clothes, modesty, hide, disability

Rezumat

Pacienții cu stome sunt preocupați de imaginea corporală și sunt îngrijorați că după operație vor trebui să-și schimbe garderoba. Această adaptare nu este necesară pentru că societatea îi consideră persoane normale, iar reacțiile incomode, atunci când apar, se datorează mai ales lipsei de experiență. Totuși, pudorea și alterarea imaginii corporale îi face pe acești pacienți să încerce să mascheze prezența stomei cu vestimentația. Articolul își propune să treacă în revistă modalitățile în care industria textilă vine în ajutorul pacienților cu stome pentru a-și îmbunătăți imaginea corporală.

Cuvinte cheie: stoma, îmbracaminte, pudoare, ascunde, dizabilitate

Introduction

Intolerance towards people with disabilities has historical roots in the culture, economy and justice of different societies, culminating with the infanticide imposed by law for children born with malformations in Sparta (1). Nowadays, according to the World Health Organization, 15% of the world's population has some form of disability (2), but society's perception of disability has changed radically. Even if at the organizational and legislative level the policy to protect people with various deficiencies is very clear, in everyday life there are often situations in which they are discriminated or the discrimination itself produces a decrease in self-esteem in different ways (3).

Globally, the prevalence of stomas reaches 0.12% of the population, the most common being colostomy (0.07%) followed by ileostomy (0.04%) and urostomy (0.002%), more than half (56%) of stomas being permanent (4). In parallel, forecasts for the market value of materials for the protection and care of stoma will reach 4.1 billion euros in 2027 (4), which means, above all, accessibility to stoma bags and care products.

The perception of patients with stomas

The lack of bags and materials for stoma care has led to the stigmatization of stoma patients in society since the

beginning of surgery due to the impossibility of controlling the emissions and inconveniences caused by odors and leaks from stoma. The disappearance of these shortcomings is due primarily to a visionary surgeon with enormous empathy for patients - Dr. Rupert Turnbull and to his ingenious patient with ileostomy Norma Gill, who were the initiators of the first stoma therapy courses and its certification as a nursing specialty (5). On the other hand, since the 1950's, materials for the care of stomas entered the medical market and have changed the lives of stoma patients forever. However, the lack of materials and especially the lack of knowledge for the care of stomas, continued to ostracize patients with stomas. They isolate themselves or are excluded from social life just because of that "but if" the stoma will emit unpleasant odors or there will be leaks when the patient is in the company of other people. It is the role of the stoma therapist nurse to increase self-confidence and eliminate "but if", a legacy of past times when the questionable quality of materials and lack of training put incredible obstacles in the lives of patients with stomas.

The increasing number of people with stomas, the quality of materials used for stoma care, the policies to reduce discrimination and the integration of patients into social life made the sight of a stoma no longer produce discordant reactions, and the people around didn't even look at the ostomy bag for a second time. However, the modesty of

patients with stomas leads them to look for means of camouflage through clothing that they adapt as best as possible to the new situation.

Stoma wardrobe

The stoma does NOT limit the wearing of any clothing, not even the bathing suit. There are, however, some options that can be considered in certain situations. These are not necessary for patients with stomas, but can be useful for improving body image.

Stoma guards are useful when the stoma is at the belt line and requires protection during sports, car travel with a seat belt, or unexpected impact with children or pets (Figure 1).

Other protectors can be attached to the support belt of the trousers or skirt, being extremely discreet, especially when wearing thin, more transparent clothes.



Figure 1. Stoma guards

The ostomy bag holders are designed to support the bags, offering extra safety to patients, especially when they are traveling or in society and do not have the possibility to empty the collection bag in time (Figure 2).



Figure 2. Ostomy bag holder

Ostomy wraps are the

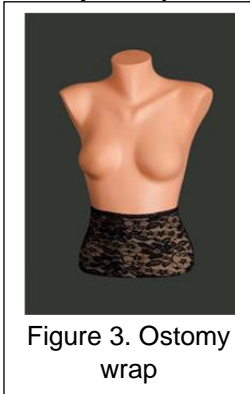


Figure 3. Ostomy wrap

simplest and most effective methods of supporting stoma. They are made of elastic, thin, discreet materials, in different colors and sizes that can be worn as clothing accessories, as a useful post-operative "diaper" or to support the abdomen during pregnancy (Figure 3).

The body line is not modified, on the contrary, the stoma bag flattens, and patients feel comfortable and confident in the image of their silhouette, the stoma being practically hidden, especially when the collection bag is empty. These elastic bands have an inner pocket where the collection bag can be inserted.

The covers for ostomy pouches are used to mask the contents but also to give a signal to the entourage that the patient has perfectly adapted to life with a stoma and is confident in his own body image. The covers are worn mainly during recreational or sports activities and can have a design adapted to the event or the clothing worn by the patient (Figure 4).



Figure 4. Stoma bag cover.

Ostomy protector seatbelt are necessary to protect the stoma from trauma during car rides and from rubbing against the horizontal segment of the belt when it is at the same level as the stoma (Figure 5).



Figure 5. Ostomy protector seatbelt

Clothes have a protective and decorative role and are related to the concepts of identity, belonging and differentiation (6). The production of clothing for patients with stomas supports their social integration

and has the effect of democratizing the textile industry, making it accessible to everyone, without exception. In addition, for people with stomas, clothes must be adapted to their needs and ensure their autonomy (7).

The positive role of models

Studies have shown that despite the improvement in quality of life, body image problems persist for the rest of life, with only a small attenuation over time (8). The influence of mass media is so strong that it leads to adapting the conceptions about the human body imposed by it (9). The result is that perception of features or changes that do not fit the patterns as disagreeable, ugly or shameful. Several patients with stomas have taken on the role of breaking the ice and removing these customs.

"I became a model after my colon was removed" - these are



Figure 6. Gaylyn Henderson

the words of the beautiful Gaylyn Henderson (Figure 6). Due to Crohn's disease, she had to endure numerous operations that ended only after the removal of the entire colon and the creation of an ileostomy (10). The stoma triggered a storm of negative emotions that she only got under control after she started helping and advising other stoma patients to overcome this stigma through the Gutless and Glamorous website she founded (11): "stop thinking of your illness as something that happened to you; try to focus rather on the

strength you showed when you went through those challenges and the strength to be able to continue; learn to love yourself because no other person, no magazine cover, can do that for you - salvation must come from within."

Preconceived ideas about beauty standards were dismantled in parallel with those about the physical performance of patients with stomas. "Life didn't end after the colostomy" says Gill Castle (Figure 7) who went through a traumatic birth

followed by depression and colostomy (12). The recovery from this traumatizing situation was possible because she always tried to test her limits which she had already exceeded: to go skydiving, to compete in triathlons or to swim in



Figure 7. Gill Castle

the cold waters of the English Channel in only a bathing suit and colostomy bag. These two fighting patients and many others like them proved to the community that they do not need to hide their stomas and that they can have a normal life.

Conclusions

Clothes have an important social role and are part of our social identity. They can highlight or hide certain details of the body and are often used by patients to camouflage the stomas.

Although the democratization of the textile industry offers many articles for ostomies, the change in society's conceptions of patients with disabilities makes them useless, but on the other hand, it gives them the opportunity to increase their self-confidence and improve their body image.

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INNOVATIONS AND ACHIEVEMENTS IN PALLIATIVE CARE IN EUROPEA

“Palliative Care Legislation in Greece” – Opening Act

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December 21st, 2022. A day to remember for patients in need of Palliative Care and all other stakeholders in Greece. The Hellenic Parliament voted for the new law on the “Integrated System for the provision of Palliative Care”. This act, could be considered as the finishing line of a long advocacy course, but also as the starting point of a new marathon for the launching of regulatory acts necessary for its implementation.

“Palliative Care has a long history in Greece, yet it has not developed in line with other high-income countries in the European Union”¹.

At present there are only four services delivering Specialized Palliative Care in the country, serving a very small percentage of the 120,000 patients estimated to be in need per year. Three of these services care for adult patients offering care at home, in outpatient setting, Day Center and in one single available, 9-bed Inpatient Unit. The fourth service cares for children and adolescents at home.

All four specialized programs provide their services free of charge within the geographical area of Athens and its surroundings, thus leaving the needs of patients, in the rest of the country unattended. They operate on an unspecified regulatory status of “help at home” and cannot receive compensation from the national health care insurance agency, neither be supported by government funds, thus depending entirely on private and institutional donors. Moreover, they face challenges regarding the availability and prescription of some essential medicines, especially opioids and the lack of sufficient educational programs and accreditation for health care professionals. Nevertheless, for more than a decade, they have found ways to effectively operate, to raise public awareness about Palliative Care and most importantly to alleviate the suffering of their patients and families. At the same time, they have been advocating at a national level for Palliative Care policy development, mainly through lobbying with politicians and other decision makers.

This laborious and long-term effort led to the launching of the “National Committee for the development and implementation of a Palliative Care Strategy in Greece” in 2018

by the Ministry of Health. The Committee was kindly funded by the Stavros Niarchos Foundation with the purpose “to investigate and address the slow progress on Palliative Care development in Greece”¹. The Committee consisted of 15 experts representing all relevant government agencies, the Academia, the palliative care providers and the patient organizations. Specialists from the Worldwide Hospice Palliative Care Alliance and the European Association for Palliative Care offered consultation.

The work of the Committee involved 3 stages. The first was the development of a feasibility study which explored the need for Palliative Care in Greece, assessed the capacity to deliver Palliative Care in the country, and put forward recommendations for overcoming barriers to Palliative Care development. Furthermore, a Palliative Care draft law was prepared for consideration by the Ministry of Health. The second stage elaborated the national strategy for developing Palliative Care in Greece over a 5-year period, while the third stage introduced the operational standards for the future implementation of the national strategy. After two-years of collaborative work, the Committee successfully concluded its tasks in 2020 and submitted the relevant documents to the Ministry of Health. Unfortunately, the proposed plan was bypassed at the beginning of 2020, due to the Covid-19 pandemic and the obvious priorities of the Ministry of Health.

Thus, within the next two years, a series of official letters, personal meetings, telephone calls etc., between many members of the Committee and decision makers or other stakeholders was conducted, to no avail. However, the experience of a big-scale, life-threatening situation as the Covid-19 pandemic put the spotlight on the benefits of Palliative Care and its principles.

Eventually at the very end of 2022, the aforementioned law on “Integrated System for the provision of Palliative Care”, consisting of 16 articles was passed. The law covers the general principles of Palliative Care and sets the stage for further regulatory acts that will be needed in order to enforce service provision. It mentions the definition, basic principle

and aims of Palliative Care, describes the different settings where it can be provided, reimbursement policies and staff training general requirements. Moreover, it determines the development of a patient registry and an advisory board of experts, a National Committee, which will consult the Central Board of Health and the Minister of Health.

The new law is definitely a breakthrough for our country. Nevertheless, there are some concerns, regarding conceptual issues, such as the distinction between General and Specialized Palliative Care and the predominance of doctors and nurses, contrary to other professional, in their representation in the National Committee. In addition, the arduous and time-consuming procedures determined by the law in order for interested stakeholders to be licensed, such as multiple Presidential, Ministerial and Inter-Ministerial decrees raise concerns regarding the time frame of their implementation.

Regardless of our justified concerns, it was delightful and rewarding to watch members of parliament (MPs), from different parties commenting on the indisputable value of Palliative Care and the need to develop such services at a national level. It was after a three-day session, in which MPs and the Palliative Care providers presented their arguments, that the first step towards the vision of accessible Palliative Care services for all patients in need, in Greece, was accomplished. The new law is a reality.

Looking back at all the efforts and the work accomplished, the authors feel that the opening act of "Palliative Care in Greece" has been successfully completed. At the same time a long and challenging route has just begun, for all Palliative Care stakeholders, in their quest for delivering as providers or accepting as patients or families in need, authorized, sustainable, high quality, hopefully free of charge palliative care services, which will alleviate suffering.

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THE PAINLESS project

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Cancer is one of the main causes of morbidity and mortality in the world. Its prevalence is very high: The International Agency of Research on Cancer estimated that in 2020 about 18.1 million cases were diagnosed worldwide, and its incidence is expected to increase in the coming years (<https://gco.iarc.fr/>). Cancer is associated with several physical consequences, of which one of the most distressing for patients is pain.

More than 50% of the oncological patients develop pain at some point before their death (Bruera, 2003; Swarm et al., 2019). It is estimated that 59% of patients under treatment for cancer, 64% of patients with advanced cancer disease and 33% of those cured, suffer from pain (van den Beuken-van Everdingen et al., 2007). However, 20% of these patients with oncological pain show a low response to pharmacological interventions (mostly using opioids) or have serious adverse effects. Thus, there is a need to explore alternative strategies to manage pain in patients with cancer. Although non-pharmacological invasive interventions such as neurosurgical procedures have been tested, they involve high risk for patients and big cost for the society (Bruera, 2003; Steinhauser, 2000). In recent years there has been a growing interest in neuromodulation treatments for the relief of a variety of chronic pain conditions. Among the neuromodulation techniques, transcranial Electrical Stimulation (tES) stands out for its low cost, ease of use and minimal side effects. The most studied tES in the management of pain is transcranial Direct Current Stimulation (tDCS) (Pinto et al., 2018). Transcranial Alternating Current Stimulation (tACS) has been less studied, but its preliminary results on pain relief are also promising (Ahn et al., 2019). Despite the likely benefits of tES in pain management, these techniques have been scarcely studied in cancer patients with pain.

The PAINLESS project was born in response to this reality. **PAINLESS is funded by Horizon Europe** and led by María Teresa Carrillo de la Peña (senior researcher of the University of Santiago de Compostela, Spain). The PAINLESS consortium is composed of **17 partners** from 10 countries, with the representation of medical specialists in oncology and chronic pain, researchers in the field of pain and neuroscience, experts in health economics, as well as patient associations and small-medium enterprises.

The **main goals** of PAINLESS are (1) to develop a tool, based on the assessment of pain perception and modulation mechanisms and clinical variables, to predict the future occurrence of pain in patients with cancer; and (2) to adapt and test a novel, cost-effective, home-based intervention based on

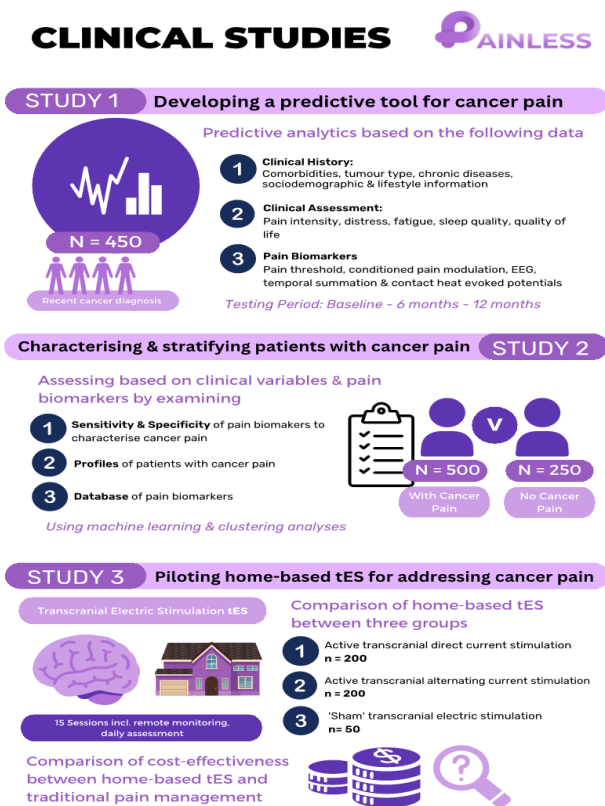
neuromodulation to reduce pain and improve the quality of life of patients with cancer suffering from chronic pain.

For this purpose, in PAINLESS project we designed **3 studies** (see Figure 1). **Study 1** will be a cohort, longitudinal study with 450 patients assessed in the first 6 months after their cancer diagnosis, and 6 and 12 months after this first evaluation. We will perform a comprehensive evaluation of the participants (using validated tests, quantitative sensory assessment and electroencephalographic recordings) and develop artificial intelligence algorithms to predict the occurrence of chronic pain using those biomarkers and clinical variables. **Study 2** will have a cross-sectional design to characterize and stratify oncology patients, from a sample of 500 patients with pain and 250 without chronic pain. We will compare both groups using the same evaluation protocol as in Study 1 to better understand the mechanisms of pain perception and modulation in oncological pain. **Study 3** will be conducted to assess the feasibility and efficacy of at-home delivery of transcranial low intensity electric stimulation treatment (tES) for the palliative care of cancer patients suffering from pain. It is a Randomized Control Trial (RCT) with 450 oncological patients with chronic pain. The PAINLESS proposed treatment will consist of 15 – 20 minute sessions of tDCS or tACS that the patients will administer themselves from home. The researchers in charge will remotely monitor the whole process. To evaluate the effect of the treatment, evaluations will be carried out before and after tES, and at 3 and 6 months of follow-up.

Moreover, to ensure the impact of PAINLESS we will (1) develop a customized web portal to share knowledge on cancer pain and to improve management of the patients; (2) perform techno-economic analyses and Health Technology Assessment of the proposed protocol to assess and manage oncological pain and analyze the possibilities of implementation in different European healthcare systems (after assessment of regulatory barriers).

The PAINLESS project has been running since June 2022 and we are currently finalizing the details to start collecting data for the first study in 4 clinical units across Europe (Spain, Portugal, Denmark, and Romania).

Overall, the three PAINLESS studies will improve our understanding of the mechanisms of oncologic pain and will allow us to assess the effectiveness of a truly interdisciplinary approach to improving pain management in palliative care programs across Europe.



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Figure 1. Infographic of the 3 studies that compose the PAINLESS project.

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