

Palliative care for people living with cardiac disease

Consensus document of the Expert Group of the Polish Cardiac Society

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KEY WORDS

cardiac implantable electronic devices, communication, grown-up congenital heart disease, heart failure, palliative care

ABSTRACT

Many cardiovascular diseases lead to heart failure, which is a progressive syndrome causing significant distress and limiting the quality of life, despite optimal cardiologic treatment. It is estimated that about 26 000 people in Poland suffer from advanced heart failure, and this number is growing. That is why palliative care (PC) dedicated to people living with end-stage cardiac diseases should be urgently implemented in Poland. Well-organized PC may not only relieve symptoms and improve quality of life in people living with cardiac diseases not responding to treatment but also support patients and their families during the dying process. Palliative care in patients with cardiac diseases should be continued during the end-of-life period. It should be implemented regardless of prognosis, and adjusted to patients' needs. Two approaches to PC are presented in this expert opinion. The first one (generic) is provided by all medical professionals incorporating PC principles into the usual patient care. The second approach, namely, specialized PC, is ensured by a multiprofessional team or at least a PC specialist who received appropriate training in PC. The model of needs-based (not prognosis-based) implementation of PC is discussed in this paper. Symptom control, support in decision-making, and sensitive, open communication are considered integral elements of PC interventions. Medical professionals developing PC in Poland should think about groups of patients with special needs like those with valvular heart disease, grown-up congenital heart disease, and pulmonary arterial hypertension, as well as elderly people. This consensus document presents main recommendations for future PC organization in Poland. Among others, we suggest changing the Polish National Health Fund reimbursement rules regarding PC and improving cardiologist education on PC.

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Introduction and basic definitions Palliative care (PC) was conceptualized as a holistic approach to the care of people at the end stage of malignant diseases and has been expanded

to address the needs of noncancer patients, including those with cardiac disease.^{1,2} The European Association for Palliative Care (EAPC) and the World Health Organization define PC as

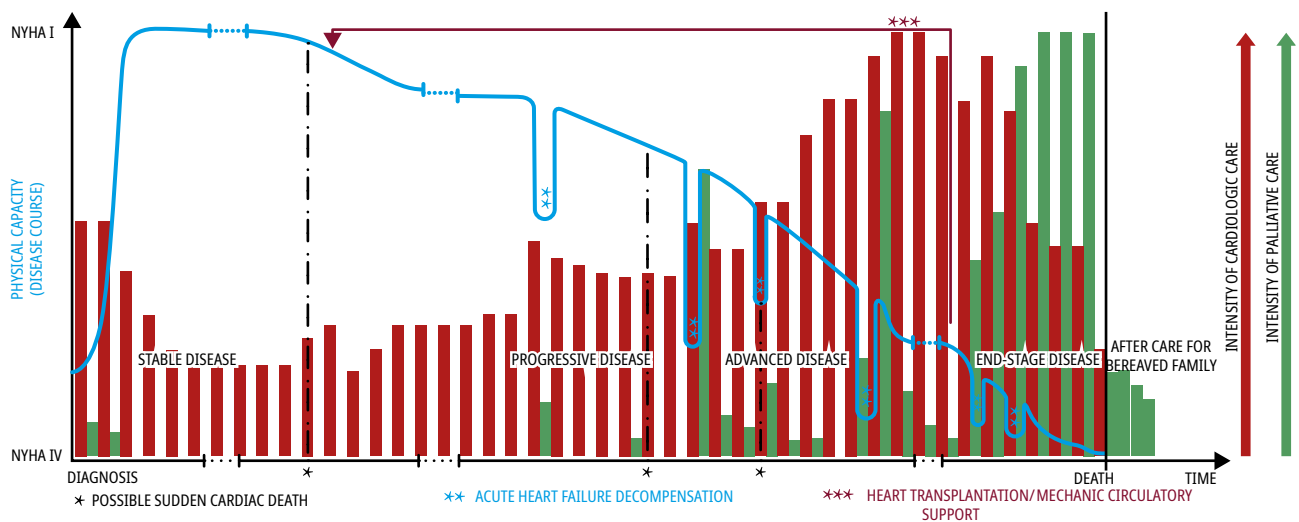


FIGURE 1 The clinical course of heart failure with associated types and intensities of available therapies. Adapted from Sobanski¹⁰¹ (figure in press)

Abbreviations: NYHA, New York Heart Association

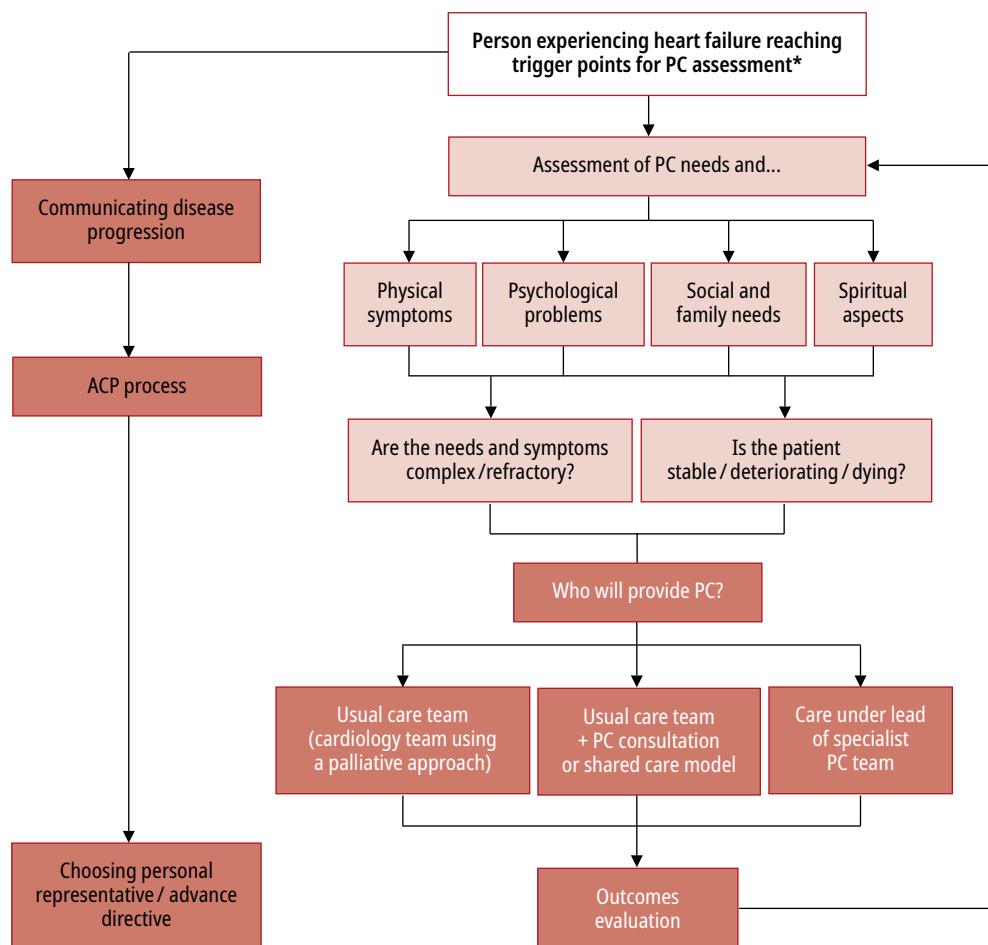
the active, total care of a person whose disease is not responsive to treatment.^{3,4} Of note, the unresponsiveness to treatment does not refer to a situation in which “nothing more can be done.” What it actually means is that therapy has insufficient efficacy and does not satisfactorily alleviate symptoms nor does it limit the disease burden. With the current definition of PC, EAPC promotes a new perspective on healthcare. It advocates extending the scope of healthcare beyond prolonging life and suggests a meticulous care of all components of patient’s quality of life (QoL) to enable them to live a full life to the greatest extent possible. Currently, PC is considered appropriate during the whole life span of a patient with cardiac disease, unrelated to expected prognosis, and should be provided according to the existing needs (FIGURE 1).

Palliative care is an interdisciplinary approach focused on the ill person and his or her relatives, addressing patients’ needs wherever they are, whether at home or in any healthcare institution.³ Palliative care services can be defined as generic (known as the PC approach) or specialized. Generic PC is provided by all healthcare professionals who apply PC principles to the usual clinical practice. Specialized PC services are delivered by a multiprofessional team, or at least a PC specialist, who received appropriate training in PC. Palliative care approach can help the majority of people living with heart failure (HF) meet their needs. A small group of patients, who have complex needs or problems persisting despite receiving generic PC, need specialized PC.^{5,6}

Triggers for palliative care in patients with cardiac disease When to start PC is one of the most relevant issues defining the cooperation between cardiologists and PC specialists.

The majority of validated tools aimed to identify patients who should receive PC, like Supportive and Palliative Care Indicators Tool (SPICT) or “surprise question,” unfortunately indicate only those at risk of deterioration or death.^{7,8} However, as mentioned above, the rationale of PC nowadays should not be helping only patients at risk of deterioration or death but recognizing unaddressed needs, which are independent from these risks.^{1,3} The Needs Assessment Tool: Progressive Disease—Heart Failure (NAT: PD-HF) is a validated tool, which supports healthcare professionals in the evaluation of PC needs in patients with cardiac disease and corresponds with the current perspective on PC.⁹⁻¹¹ It evaluates the needs of patients and caregivers, including their wellbeing and ability to care for patients. Confirmed disease progression and expanding treatment, particularly if the disease is burdensome or associated with high deterioration risk, should trigger the evaluation of PC needs and initiate the delivery of PC services if appropriate.² The possible triggers initiating the evaluation of PC needs and the flow-chart showing how to evaluate patients’ need for PC are presented in FIGURE 2.

Symptom evaluation After symptoms or problems were identified, they have to be assessed and appropriately treated by the providers of PC, that is, either the core team (applying the PC approach) or a PC specialist or team (applying the specialized PC).² Optimally, the assessment should be performed using validated tools. The most frequently used tools for symptom evaluation are the Edmonton Symptom Assessment System (ESAS), which determines the intensity of 9 symptoms most frequently seen in PC patients and 1 self-defined



*Triggers for PC assessment

I. Significant change in heart failure trajectory:

- New HF (incidental HF) with refractory, severe symptoms before discharge
- Before ICD / CIED implantation or replacement
- Qualification for heart transplantation or mechanic circulatory support
- Consideration of high risk or high burden intervention or treatment
- After resuscitated sudden cardiac death
- Signs or symptoms of advanced HF: especially with risk markers or fulfilling criteria for referral to tertiary cardiac centres e.g., NYHA class III / IV, appetite / weight loss, physical wasting, initiation of intravenous inotropes, more than one unplanned hospitalization or visit due to decompensated HF within 12 months.

II. Periodic HF follow up or significant changes in health status:

- Periodic HF visit (in stable condition at least yearly check up)
- Essential changes in health status (new significant comorbidity)

III. Patient / family related factors:

- Desire for additional communication
- Request for excessive medical interventions
- Request by or excessive burden of relatives / informal caregivers
- Patient declining / dying with difficulties in acknowledging it
- Request to hasten death / suicidal statements
- Request of family or team caring for patient
- Substantial change in next of kin circumstances (like new illness or death of spouse, or caregiver)
- Declining ability to provide self-care

FIGURE 2 Patient's needs assessment—flowchart. Reprinted with permission from the Oxford University Press²

Abbreviations: ACP, advance care planning; CIED, cardiac implantable electronic device; HF, heart failure; ICD, implantable cardioverter-defibrillator; NYHA, New York Heart Association; PC, palliative care

symptom,^{12,13} and the Distress Thermometer, which aims to assess psychosocial and spiritual problems.¹⁴ The Hospital Anxiety and Depression Scale (HADS)^{15,16} and the Functional Assessment of Chronic Illness Therapy-Spiritual Wellbeing (FACIT-Sp) are further assessment tools, which are frequently used in medical practice.¹⁷ Before or at least in parallel with starting symptomatic treatment or palliative care interventions, every effort should be made to optimize cardiac treatment. Palliative care interventions, on top of this, reinforce the meticulous efforts to prolong life with the best quality possible.¹⁸ Unfortunately, the outdated view that the disease-specific treatment has to be exhausted, stopped, or limited before starting PC is still considered valid by laymen and non-PC professionals. The currently advocated coexistence of both approaches in the treatment of patients with cardiac disease is depicted in **FIGURE 1**.

Elements of palliative care interventions

The key elements of PC include symptom management, support in decision making including advance care planning (ACP), social support, spiritual care, and care of the dying patient, as well as bereavement counselling for families.^{1,19} The components of PC that may actually be applied should be tailored to the existing needs and can differ substantially at particular stages of disease progression. Many patients with advanced cardiac disease suffer from pain, dyspnea, depression, and other symptoms surprisingly similar to those reported by patients receiving PC due to other progressive diseases, including cancer.^{13,20-23} Growing data show that timely implemented PC successfully alleviates symptoms and improves QoL in people with HF, without shortening their lives.^{18,24-27} What is more, effective pain management has been recently shown to prolong life in patients with cardiovascular diseases.²⁸⁻³⁰ The need for psychosocial support and physical therapy are generally well-recognized and accepted indications for PC. Addressing patients' spiritual needs usually escapes attention of healthcare professionals but should be a standard element of patient-centered care.³¹

Palliative care and the trajectory of living with heart failure and dying of this disease

Heart failure is a progressive syndrome and an end stage of numerous cardiovascular diseases. At first presentation, patients usually have severe symptoms on slight exertion or at rest (New York Heart Association class III or IV). In the minority of cases, patients' condition deteriorates quickly and they die shortly after the first HF-related hospitalization. However, the majority of patients show improvement during the index hospitalization and reach a sort of plateau, usually disrupted by acute decompensations, and, after months or years, develop end-stage

HF and ultimately die (**FIGURE 1**). Not every person living with HF dies of it, as some patients die of other diseases, with HF being a concomitant disease. The proportion of noncardiac or non-HF-related deaths differs according to age and HF severity and form (HF with preserved, midrange, or reduced ejection fraction). Patients with HF with preserved ejection fraction frequently die of a concomitant noncardiovascular disease (mainly malignant).³² In other patients, cardiovascular deaths are reported, which can be specified as, among others, sudden cardiac death (affecting a significant proportion of people living with HF, including those with less advanced stages of HF), HF-related deaths, acute myocardial infarction-related death, and acute cerebrovascular death. The specific HF-related deaths can be further classified as end-stage HF with or without secondary end-organ failure (kidney or liver failure).³³

Palliative care and symptom management

Symptom management is an integral part of PC in patients with HF. Symptoms occurring in this population can be related to HF (congestion and limited organ perfusion due to decreased cardiac output, resulting in limited exercise capacity and/or dyspnea), secondary to HF (fatigue, anxiety), caused by a concomitant disease (pain), or have complex etiology (cognitive impairment, cachexia). Dyspnea at rest or on slight exertion is an almost universal symptom of advanced HF, and, surprisingly, pain is very common in patients with HF. The principles of symptom management in PC of patients with HF are summarized in the recent EAPC position statement.²

Management of patients with cardiac implantable electronic devices

A growing number of people live with cardiac implantable electronic devices (CIEDs). The umbrella term CIED encompasses different devices, and each of them delivers specific treatment: 1) pacemakers, which deliver antibradycardia pacing and thus prevent symptoms of bradycardia or cessation of heartbeat; 2) cardiac resynchronization therapy (CRT) devices, which stimulate and synchronize the contractility of the left ventricle and may significantly improve its function; 3) implantable cardioverter-defibrillators (ICDs), which have several functions to cease tachyarrhythmia (additionally, they can deliver antibradycardia pacing); 4) a combination of 2) and 3), that is, CRT devices with defibrillator (CRT-D); to distinguish CRT-D from devices that deliver resynchronization pacing only, the name CRT-P is used.

Some functions of CIEDs, normally perceived as life-saving, can negatively influence the quality of the dying process. That is why selected CIED functions should be considered for deactivation if patient's death is inevitable. Appropriate

modification of CIED activity should be performed when patient's death is predictable, but this needs to be communicated much earlier—optimally, even before implantation. Decision making regarding the modification of CIEDs should be an integral part of ACP. Despite these recommendations, the appropriate communication and timely modification of CIEDs are not common. According to a European survey, only 6% of patients reported that they discussed the modification of CIED activity at the end of life (EoL) with their doctors in detail, and 12% of respondents remembered that this topic was covered only briefly.³⁴ As a result, most patients approaching predictable death have their ICDs fully active, even those who have a do-not-resuscitate order.^{35,36} In 35% of patients with ICDs, ventricular tachyarrhythmia (including electrical storm) was recorded during the last hours of life, and 31% received potentially painful high-voltage therapy in the last 24 hours of life.³⁵

Pacemakers deliver cardiac pacing, which is unnoticeable for patients. After ceasing this stimulation, patients lose protection against the symptoms of temporary (ie, dizziness, dyspnea, and syncope) or chronic bradycardia (ie, anginal pain or aggravation of HF symptoms). The continuation of antibradycardia pacing neither causes suffering nor prolongs the dying process (besides very exceptional situations like irreversible brain injury), and, apart from that, its cessation can precipitate the above mentioned symptoms. That is why discontinuing pacing cannot be considered a PC intervention in a dying person.³⁷⁻⁴⁰

In patients responding to CRT and showing improvement of HF symptoms, even an accidental loss of effective stimulation leads to the abrupt deterioration of cardiac function and may precipitate fulminant, acute HF symptoms like dyspnea or acute pulmonary edema. Device reprogramming, which stops resynchronizing stimulation, would evoke similar acute HF symptoms. Therefore, it should be strongly discouraged and cannot be regarded as a PC intervention.³⁸⁻⁴⁰

Implantable cardioverter-defibrillators and CRT-D devices deliver low-voltage therapies (antitachycardia pacing [ATP]) unnoticeable for patients or usually painful high-voltage interventions, ie, cardioversion and defibrillation. The modification of antitachyarrhythmia therapy in patients approaching death, in whom the underlying diseases cannot be successfully treated, aims to avoid suffering precipitated by the CIED interventions or to prevent prolongation of the dying process (futile therapy). Abandoning high-voltage interventions is sufficient to avoid patients' suffering, and ceasing all antitachycardia therapies should be considered appropriate to prevent prolongation of the dying process. If the patient prefers not to lose any of

the device activities but wants to avoid suffering, leaving only ATP active, prolonging detection time or limiting the maximal number of high-voltage interventions can be an option. If ATP is left active, the risk of accelerating tachycardia should be considered. In the case of CRT-D, antibradycardia pacing and, even more importantly, resynchronization therapy should be left fully active, as discussed above.

In the context of EoL and PC, 4 scenarios regarding the modification of CIED function can be considered:^{40,41} 1) deactivating the shocking function or all antitachycardia functions of ICD / CRT-D devices; 2) suspending antitachycardia therapies emergently using a magnet; in patients imminently dying unless the preferred electronic deactivation can be performed; 3) abandoning ICD replacement after battery depletion; 4) deactivating antibradycardia pacing or stopping CRT (this can be considered only exceptionally as a PC intervention).

Considering the modification of CIED activity, local medical, ethical, medico-legal, spiritual, and religious issues need to be respected. The Polish law permits modification of (selected) ICD functions. Specifically, the Act on Patient Rights and the Act on the Patient Rights Ombudsman emphasize patients' right to die in peace and dignity.

Communicating with people living with heart failure

Sensitive and open communication is considered an integral part of PC interventions; in particular, discussing prognosis, disease progression, and, if necessary, the risk and pattern of health deterioration and dying. Disease management options are usually well discussed with patients by the Heart Team, but the risk of deterioration and dying is hardly explained. Nevertheless, these issues are relevant and should be covered.⁴²⁻⁴⁴ Discussing realistic prognosis allows ill people to make plans and to maintain realistic hope. The physician should initiate a conversation about patient's future condition, especially EoL, in advance, before patient's condition deteriorates, making his or her active participation difficult.⁴⁵⁻⁴⁷ The communication process is often challenging for both the patient and the physician. To make sure that the quality of communication is high and to facilitate the active involvement of patients in the decision-making process, healthcare professionals working in cardiology should receive training in communication skills. This will help them to feel more comfortable, especially in challenging situations.⁴⁸ Personal beliefs and values may influence the ability of healthcare professionals to communicate with patients at the EoL and care for them. Concerns about death and dying may be a reason for avoiding these topics or making the discussion unclear. It is important to acknowledge this fact and

involve other healthcare professionals if needed. Of note, showing emotions is not a sign of unprofessional behavior or weakness.^{47,49-51} Elements that should be included in the communication with patients living with HF are presented in TABLE 1.

Setting up communication

1 Build a collaborative team. The team is responsible for delivering care, which should consider patients' individual values and preferences.⁵² Tasks and responsibilities need to be appropriately split among professionals of various specialties, taking into account different fields of patients' needs.⁵³ The communication pathways between caregivers and team members should be established.⁵⁴

2 Evaluate the situation. Components crucial for decision making should be reviewed and discussed if needed. They include patient's condition and values related to healthcare, aims and preferences, concerns about QoL, and the contextual issues.^{49,51}

3 Prepare structured discussion and consider the following issues:

Who? Who should be present during the conversation? Ask the patient who he or she wants to assist him or her.

What? Be aware of patient's personal goals before starting the conversation. Get ready for new issues that can appear during the conversation and affect the discussion.

When? Take your time and complete the planned discussion calmly. Sit during the conversation, showing the patient that you have time needed to discuss all issues. Good communication is time-consuming and a single session takes 20 to 30 minutes on average.⁵⁵

Where? Talk with the patient in a quiet room; if the conversation has to be held at the bedside, ensure that the place is as quiet and intimate as possible.

How? Prepare a plan for discussion. Write down conversation goals and pay attention to the reactions of your interlocutor. Be flexible, as patient's needs may change during the conversation.^{45,50,53,56,57}

TABLE 1 Communication with patients living with heart failure^{48,49,99,100}

1. What patients and caregivers need to know:

- Diagnosis and disease stage
- Anticipated disease progression and related problems

2. Challenging issues associated with heart failure:

- Uncertain prognosis
- Progression of heart failure and health deterioration are inevitable but cardiac treatment can usually alleviate symptoms, slowing patient's decline and improving survival.
- The risk of cardiac arrest/sudden cardiac death; patient's preferences regarding resuscitation need to be discussed (the likelihood of successful resuscitation should be addressed).

End of life in people living with heart failure

The concept of EoL refers to the period of progressive disease deterioration, which precedes imminent death and cannot be stopped by adjusting disease-specific treatment. Contrary to common belief, the EoL lasts weeks or even months and is characterized by progressive decline and physical wasting. In contrast, the phase of active dying is much shorter, limited to the last days or hours of patient's life, and is characterized by signs and symptoms of imminent death.⁵⁸ This last phase is a dynamic process when consciousness and symptoms fluctuate, previously observed symptoms disappear, and usually the new ones occur. The timely recognition of the EoL and dying is of utmost importance, as treatment and care need to be properly adjusted, and the observation should be communicated to the patient and his or her loved ones openly and in a compassionate way. Critical re-evaluation of treatment goals, adjusting the ongoing treatment, and starting new management focused on symptom control are needed.^{59,60} The modification of CIEDs should be performed at this time at the latest, based on conclusions from previous conversations.^{38,61} In the dying phase, frequent (at least every 4 hours), careful monitoring of symptoms, suffering, and need for PC interventions is recommended. Basic bereavement counselling for both the dying person and the family may be needed.

Palliative care in selected patient populations

Patients with valvular heart disease In economically developed countries, valvular heart disease is often diagnosed for the first time at advanced age.^{62,63} Aortic stenosis, the most common primary valvular disease, requires surgical or catheter-based treatment if it has a severe course.⁶³ The Heart Team should discuss the best suitable treatment option for a given person. For those who are too ill, too frail, who do not consent to valve repair or replacement, applying symptomatic treatment, including PC if needed, can be the optimal solution. For this reason, the members of a PC team, or at least a PC specialist, should be included in the core Heart Team.⁶⁴ In such cases, PC can include assistance in the decision-making process, communicating alternative, noninterventional treatment options, ACP, or delivering care for the dying in the case of serious complications.^{64,65} Further studies are needed to assess the impact, efficacy, and safety of specific PC interventions in the population of patients with valvular heart disease.

Elderly patients with heart failure Heart failure is regarded as a disease of the elderly and, in most cases, it is associated with concomitant diseases such as coronary artery disease, valvular heart disease, chronic obstructive pulmonary disease, renal failure, diabetes, or anemia.⁶⁶⁻⁶⁸ It

is sometimes difficult to differentiate symptoms of HF from those related to other diseases or ageing. At advanced age, the prevalence of frailty syndrome and other geriatric syndromes, such as depression, dementia, chronic pain, incontinence, limitations in mobility, and difficulty performing basic self-care activities, increases.⁶⁹⁻⁷¹ Moreover, the social network is frequently impaired, and the informal caregivers do not manage to provide sufficient care. Multimorbidity is inseparably associated with polypharmacy and the fragmentation of medical care provided by different specialists. Of note, it is frequently difficult to indicate the doctor responsible for patient's care and to make decision about deprescribing unnecessary drugs. Discussing issues around the QoL and EoL preferences with elderly patients is significantly hindered by their cognitive disorders, lower mood and worsened functional status, symptoms of other diseases, and lack of social support.⁷²

Finally, the choice, dosage, and administration of analgesics should be modified in elderly patients with HF.⁷³⁻⁷⁵

Patients with grown-up congenital heart disease

Congenital heart disease occurs in approximately 0.8% of live births. Successful surgical and percutaneous interventions at young age resulted in a growing population of young adults who require lifelong both cardiac and noncardiac care,^{76,77} including PC in more complex situations.⁷⁸⁻⁸⁰ The access to optimal, comprehensive care for people living with grown-up congenital heart disease (GUCH) should be regarded as a standard element of medical care and social responsibility.

In Poland, there are approximately 80 000 to 100 000 patients with GUCH. An annual increase of approximately 2240 cases can be anticipated, assuming that 80% of the currently born neonates with congenital heart disease survive to adulthood. According to international data, 20% to 25% of the whole population of patients with GUCH has complex problems and requires lifelong expert care in dedicated centers, whereas 35% to 40% of this population needs expert consultations. Other patients with simple or cured heart defects need specialist consultations only rarely.

Patients with functionally univentricular heart, who underwent the Fontan procedure, have to deal with the most complex problems. This intervention allows the affected patients to survive, however, with multiorgan damage leading to significant morbidity and mortality in long-term follow-up.^{81,82} In many cases, the management of late complications is possible but the final deterioration inevitable. Heart transplantation can be considered an ultimate therapeutic option, but it is accessible only for the minority of patients. Patients with the Fontan circulation who experience late complications could benefit from PC delivered in parallel with cardiac treatment and care.⁸²

In most cases, life expectancy in patients with GUCH is still shorter than in the general population. One-third of deaths occur suddenly, whereas the majority of patients die after progressive health deterioration over a few months, mainly of chronic HF.⁸⁰ Such patients could benefit from incorporating PC into cardiac care.⁸³⁻⁸⁶ The models of PC provision in this population still need to be established, respecting local traditions and international experiences. Palliative care should probably be provided as an element of comprehensive care and delivered by the team who used to take care of a given person and whom the patient trusts. For this reason, healthcare professionals with essential PC skills should be a part of the core team in the GUCH centers or closely cooperate with them.

As presented above, discussing EoL-related issues in advance helps to deliver care in line with person's individual goals and values and to improve the QoL and dying.^{83,84,86} Many patients with GUCH prefer to be involved in EoL decision making at an early stage of the disease course, and a majority of them even expect such discussions.^{83,84}

Patients with pulmonary arterial hypertension

The currently available treatment of pulmonary arterial hypertension (PAH) has markedly improved patients' survival. Nevertheless, PAH remains an incurable disease, which significantly impairs patients' QoL. People living with PAH and their families experience emotional, physical, social, and spiritual distress. In this population, PC should focus on symptomatic patients with functional New York Heart Association class III or IV despite maximal medical therapy. Usually, they are frequently hospitalized due to worsening of PAH-related symptoms. In Poland, the number of patients newly diagnosed with PAH can be estimated as 100 cases per year. The usual care for this group includes home oxygen therapy, use of parenteral diuretics to alleviate symptoms of right ventricular HF, and surveillance over the use of parenteral prostanoids. The most common goals for PC in this population are the amelioration of dyspnea, treatment of depression and anxiety, multidirectional support for the family including communicating disease progression and the expected pattern of health deterioration in addition to discussing disease-specific treatment options. Social and spiritual needs of patients and their relatives should be addressed as well. According to the current guidelines on the management of PAH, a PC specialist should be the core member of an interdisciplinary team taking care of the patient, together with a home nurse, a social worker, and a spiritual care specialist.⁸⁷

Palliative care resources in Poland In Poland, the principles of PC were introduced at the end of the 20th century. The Polish Society for Palliative Medicine (Polish: Polskie Towarzystwo

Medycyny Paliatywnej [PTMP]) was established in 2002. Since 2003, palliative medicine has been a medical specialty, and since 2006 also a nursing specialty. In total, nearly 500 physicians and 900 nurses are specialized in palliative medicine. In Poland, PC is reimbursed by the Polish National Health Fund (Polish: Narodowy Fundusz Zdrowia [NFZ]). According to NFZ, palliative services were reimbursed in 2017 by 142 outpatient clinics, 486 home hospices, 67 home hospices for children, and 180 stationary hospices. Some of them operate as nongovernmental institutions and their services are not reimbursed by the general health insurance. According to the Polish Ministry of Health, 788 PC units and hospices were registered in Poland in 2017. Based on the *International Classification of Diseases and Related Health Problems, Tenth Revision [ICD-10]*, NFZ specified disease entities, for which PC is reimbursed, and, unfortunately, HF has not been included. Cardiomyopathy is the only *ICD-10* entity related to cardiac disease that is considered eligible for reimbursement.

Need for palliative care for people living with heart failure in Poland

According to recent data, the number of people living with diagnosed HF in Poland is estimated as 744 500 cases in 2017, whereas 133 900 new cases are diagnosed and reported to the NFZ database every year.⁸⁷ More than 80% of patients with newly diagnosed HF are over the age of 65 years.⁸⁹ According to NFZ, 194 039 people diagnosed with HF were hospitalized in 2017. The total number of HF-related hospitalizations is continuously growing, approximately with a 1.1% increase per year, and reached 227 483 hospitalizations in 2017.⁸⁷ The estimated incidence of advanced HF in different studies and populations ranged from 2% to 5% of all patients with diagnosed HF.⁸⁹⁻⁹² Based on these data, it can be assumed that about 26 000 people in Poland suffer from advanced HF. The number of people living with end-stage HF in Poland can be expected to reach 28 000 cases in 2025 if the treatment of HF in everyday practice does not change significantly.

Proposed structures of care for people living with cardiac disease who have palliative care needs

High-quality PC should be delivered in any place where patients receive care: at home, in long-term care facilities, or in any inpatient unit including general, cardiology, or intensive care units. Care can be provided, depending on patient's needs and place of care, by general practitioners, internists, geriatric specialists, cardiologists, or PC specialists, closely cooperating with other disciplines if needed.² Primarily, integrating PC in the patient care, and not transferring patients to the PC units, is the current paradigm of providing PC in patients with cardiac disease.^{57,93-95} The optimal

model of care, including PC, for patients with cardiac disease and their families has not been defined so far. However, patient care delivered by a cardiologist and/or Heart Team consulting PC specialists seems to be the most appropriate solution, preferred by patients. In this model of care, patients receive comprehensive care from the team they trust, which is in line with their existing needs. A cardiologist and/or Heart Team continues to provide optimized cardiac care, whereas a PC specialist or PC team focuses on symptom management, provides psychosocial and spiritual support, and helps with shared decision making (including ACP), and finally takes care of the dying person if appropriate. In the last phase of patient's life, PC providers can take the lead in care.^{55,96,97} This kind of care is appropriate in both in- and out-patient settings. If the PC team has been involved during patient's hospital stay, PC can be continued after discharge if needed, based on PC outpatient clinics, in addition to usual cardiac care.

Cardiac centers should cooperate with specialized PC units or, at least, a PC specialist should be a member of the core Heart Team. The American authorities (Medicare and Joint Commission) require a PC specialist to be a member of a team responsible for mechanical circulatory support being an element of target therapy programs.⁹⁸ In the primary care settings, care can be delivered by general practitioners, who should apply the principles of generic PC and receive support from a cardiologist and a PC specialist (or a PC team) according to the existing needs. This model is particularly applicable in patients who require care of several specialists and/or cannot use services delivered by outpatient clinics. In several countries, general practitioners and family nurses play a key role in the care of patients with advanced cardiac disease. Optimally, nurses should have experience in both cardiology and PC. For some patients, particularly those with relevant comorbidities or slowly progressing cardiovascular diseases and a prolonged EoL period, hospices with home-like inpatient units or home care can be the most appropriate model of care. In such models, close cooperation with cardiology specialists is mandatory.

Main recommendations for Poland

- There is an urgent need to change the rules of reimbursement of PC services by NFZ in Poland and the list of diseases should include other *ICD-10* codes related to cardiac disease, heart failure (I50) in particular.
- Medical personnel in the existing hospices, which signed contracts with NFZ, should be trained in delivering care to patients with cardiac disease.
- Palliative care should be included in the curriculum of cardiology specialist training and postgraduate education.

SUPPLEMENTARY MATERIAL

The Polish version of the paper is available at www.mp.pl/kardiologiapolska.

ARTICLE INFORMATION

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