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The terms supportive and palliative care — analysis of their prevalence and use: quasi-systematic review

Abstract

Introduction The terms supportive and palliative care — analysis of their prevalence and use: quasi-systematic review.

Methods. The authors conducted a quasi-systematic review of literature obtained from MEDLINE and Google Scholar, with the use of the following terms: palliative care, supportive care, palliative and supportive care. The article was supplemented with manually added information sources and the use of Google Trends. The authors also analysed the frequency with which the term 'supportive care' was used in literature compared to the term 'palliative care'.

Results. It was demonstrated that the term 'palliative care' is more frequently used in scientific literature, and the median of the ratio of the use of the terms supportive care/palliative care in the analysed texts is 0.51. The term 'palliative care' is also more often searched in Google than the term supportive 'care' (74:4). Differences in the prevalence of both terms also depend on the country from which users searched a given phrase. The term 'palliative care' evokes more negative emotions and is less preferred by medical staff and patients' families than the term 'supportive care', which has more positive connotations. Supportive care is most often viewed as an element of oncologic care, while palliative care is believed to be a stand-alone field of medicine that can treat patients from all of is areas.

Conclusions. Despite being more positively perceived by patients, the term 'supportive care' is still used less frequently. Even though the terms 'supportive care' and 'palliative care' are precisely defined, many authors use them relatively freely. Knowledge should be systematized, nomenclature — clarified and the term 'supportive care' as an alternative to the term 'palliative care' should be popularized.

Palliat Med Pract 2021; 15, 3: 248–253

Key words: palliative medicine, cancer, palliative care, supportive care

Introduction

Even though both health care professionals and healthcare providers tend to use the terms, supportive

care' (SC) and ,palliative care' (PC) interchangeably [1, 2], the frequency with which both these terms appear in literature and on the Internet differs, and they are often attributed different meanings, depending

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Palliative Medicine in Practice 2021; 15, 3, 248–253 Copyright © Via Medica, ISSN 2545–0425, e-ISSN: 2545-1359 DOI: 10.5603/PMPI.2021.0014

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on the field or context [3]. In addition, studies suggest that the perception of each term generates a different emotional charge, which may have an impact on the decision of medical staff or family regarding the course of the treatment process [4]. The problem concerns approx. 40 million people each year, of whom only 14% are currently receiving adequate help in the field of SC/PC. In accordance with the latest definition of the WHO (World Health Organization), PC constitutes an approach aimed at improving the quality of life of patients and their families by alleviating suffering through early identification, diagnosis, treatment of pain and elimination of associated discomforts [5]. In addition, to cite the content of the document adopted at the 67th World Assembly WHA67.19, PC constitutes an ethical responsibility of healthcare systems, regardless of the patient's condition, and end-of-life care is among the key elements of PC [6]. European Association for Palliative Care (EAPC) indicates that uniformization of nomenclature concerning palliative care is a prerequisite for increasing its effectiveness [7]. Due to reports indicating that the perception of the term SC in the context of the above definitions is more positive, and the increasing social demand for medical services and PC/SC [8-15], the authors of the article also compared the prevalence of the terms SC and PC and analysed their use.

Methods

In order to extract the sources necessary for the analysis of the terms SC/PC, the authors conducted a quasi-systematic review of literature. The following phrases were used to search such databases as ME-DLINE and Google Scholar: palliative care, supportive care, palliative and supportive care. The authors applied a time limitation for the articles, including only papers published within the period from 30 January 2011 to 30 January 2021. First, the articles were selected based on the title and abstract, which was followed by the analysis of whole manuscripts that were independently evaluated by two researchers before being included in the analysis. In addition, the authors manually added information from the website of the WHO. To objectify and measure the preferences of the authors of articles regarding the use of the terms SC and PC in 28 manuscripts, the absolute number of the occurrences of each term was compared, and the mutual relationship of one to the other was evaluated. Subsequently, the criterion of normal distribution in data set was assessed using STATISTICA 13.3 (StatSoft Inc., Tulsa, OK, USA) and the Kolmogorov-Smirnov test. When consistency with normal distribution was observed, data were expressed as

a mean and a standard deviation, and in the case of inconsistency - as a median with interquartile range. The authors also used Google Trends to illustrate the interest in the terms SC/PC, and compared the frequency with which both terms were searched. Google Trends was also used for geographical assessment of the preferences related to the use of each term.

Systematic reviews are characterized by a rigorous methodology as well as defined inclusion and exclusion criteria for the analysed articles, in accordance with a predefined protocol [16]. Even though the study meets most criteria for a systematic review, the protocol was developed not before but during the analysis, based on the occurring data. Therefore, the authors decided that the review would be referred to as quasi-systematic.

Results

Comparison of the prevalence of the terms 'supportive care' and 'palliative care'

To objectively assess which term is more prevalent in specialist literature, 26 [17–42] papers in which the terms SC/PC were used in the basic text of the manuscript were extracted from the analysed articles. Analysis of these data revealed that the median of the ratio of absolute use of the term SC to the term PC was 0.51, with an interquartile range of 2.34.

The number of occurrences of each term in every analysed article was counted and compared (Fig. 1).

Using Google Trends, the authors also compared the frequency with which the terms were searched in Google. The analysis showed that the mean for the relative frequency with which the term PC was searched was 74, and for SC — 4. Figure 2 presents data from the years 2011–2021 with the trend light highlighted.

Using Google Trends, the authors juxtaposed both terms and analysed the interest therein in the years 2011-2021. The mean for PC is 74, and for SC — 4.

Google Trends was also used for the assessment of the relative frequency of the use of both terms in relation to the geographic location. The term ,palliative care' was most often used in Australia (100), Ireland (95), Uganda (75), Canada (60), New Zealand (57), Great Britain (50), Kenya (36) and the United States (34). The term SC, on the other hand, was most often used in Australia (100), Canada (95), the United States (57), Austria (56), Great Britain (55) and Germany (27). Countries with an index below 27 were omitted.

The authors compared the interest in the terms PC and SC in relation to countries (Fig. 3). Greater intensity of colour corresponds to a greater interest in the subject.

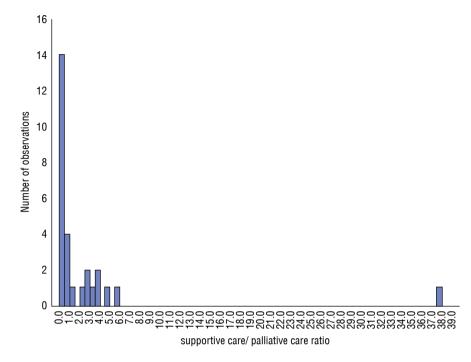


Figure 1. Absolute ratio of SC/PC in the analysed articles

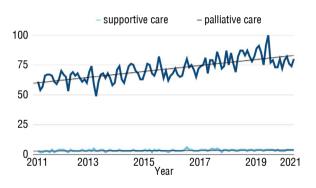


Figure 2. Comparison of interest in the terms PC and SC in Google. Data source: Google Trends

The terms 'supportive care' and 'palliative care' — an attempt at a comparison

The conducted analysis revealed that the definition of the terms PC and SC is still insufficiently clear in the literature on supportive and palliative care [3]. The European Association for Palliative Care (EAPC) indicates that the terms have been so far used interchangeably. Compared to the definition of PC proposed by the WHO [5], EAPC suggests a more complex one, which emphasizes that PC is an active and holistic action and extends the area of its impact to patients' families and carers. According to EAPC it does not depend on whether the patient is staying at home or at a hospital. It is worth mentioning that in its definition, EAPC also draws attention to the fact that dying should be regarded as a completely normal

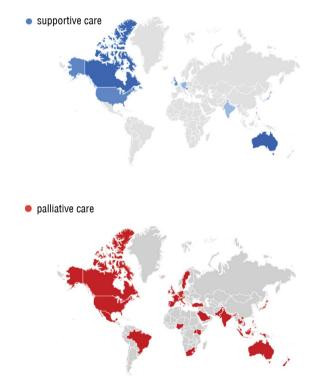


Figure 3. Interest in terms PC and SC in relation to countries. Source: Google Trends

process in PC and its results should not accelerate or delay death [7]. The term PC, however, evokes more negative emotions and, unlike SC, is less preferred by staff and patients' families [8].

By definition, SC is aimed at optimizing comfort, ensuring that patients are as physically fit and active as possible and providing social support to patients, including cancer patients, and their families at all stages of the disease [4]. It is worth emphasizing that SC also concerns patients that can possibly be treated, while the definitions of PC do not specify this criterion. The Multinational Association of Supportive Care in Cancer (MASCC) defines SC as prevention of the negative effects of cancer as well as complications occurring during and after the completion of the treatment. The said definition also emphasizes that intensified rehabilitation, prevention of subsequent cancers as well as end-of-life care constitute integral elements of SC [11]. It is worth emphasizing that the above definitions of SC in the context of PC refer to the field of oncology. In addition, in its definition of PC, EAPC also focuses on preventing the potential side effects accompanying cancer and its treatment. At the same time, attention is drawn to the fact that SC should not be treated as an equivalent of PC, because SC is part of oncological care while PC is a stand-alone field of medicine that treats patients from all areas thereof [7].

Nevertheless, in literature, the term SC is also used in oncology-related fields as well as other medical specialities. Qureshi et al. use the term SC in haematology, in the context of multiple myeloma treatment, and define it as actions aimed at eliminating the negative impact of complications on health-related guality of life (HRQOL) [12]. Davison uses the term with regard to chronic kidney disease (CKD), referring to care that is aimed at improving the quality of life of CKD patient throughout the disease and comprises the treatment process, prognosis, progressive planning of care, conservative treatment as well as emotional, social, spiritual and end-of-life care [13]. In another publication, concerning nephrology, the same author et al. broadens the definition of SC by adding the information that it is focused on both providing a high quality of life and dignified death, regardless of the patient's life expectancy [14]. Davies et al. use the term SC in the context of actions supporting the patient during the first psychotic episode, emphasizing that such support should constitute a complementary part of a patient-oriented treatment process that currently constitutes the basis of psychiatric care [15].

Discussion

It seems that the term SC is better perceived by medical personnel, patients and their families [8, 9]. However, it is worth emphasizing that the use thereof is still limited. The analysis of publications from recent years revealed that the term PC is used 18.5 times more often in scientific literature than the term SC. Similarly, population-wise, the term PC is searched more often in Google, which suggests that it is much more ingrained in social consciousness. In addition, the trend associated with the use of the term PC has been increasing in the last 10 years, while the use of the term SC oscillates around the same level.

The algorithm of Google designates a number that determines the popularity of a term in relation to the most frequently searched term and per number of searches in a given country. Despite the fact that the tool is not perfect, its extensive database makes it one of the most objective criteria for the assessment of the interests of a society and the popularity of a given term, and in the case of the terms PC and SC - in total as well as in individual countries. The frequency with which both terms were searched was similar in Australia, while the term SC was more often searched in Canada (95 vs. 60), the United States (57vs. 35), Austria (56vs. 0), Great Britain (55vs. 50) and Germany (27vs. 0). The term PC, on the other hand, dominated in Ireland (95 vs. 0), Uganda (75 vs. 0), New Zealand (57 vs. 0) and Kenya (36 vs. 0). If the search frequency index was equal to 0 or a country was not listed among the ones provided above, it means that the interest in one or both of the analysed terms was under-expressed, hence they could not be compared using the algorithm. It is worth emphasizing that the analysis was conducted for the English language only. In the case of other languages, the frequency may be different. In addition, the reception of particular terms and their emotional content can also vary depending on the language, which requires further analysis.

A public opinion survey conducted by the Centre to Advance Palliative Care revealed that the term PC is only slightly or not at all correctly understood by respondents, many of whom identify it with end-of-life care which is intrinsically associated with death [9]; therefore, we believe that it is very important to promote the term SC as an alternative. SC indicates a more holistic aspect of palliative care, namely supporting patients and providing them with comfort during their illness and death. Importantly, patients' approach to the term is better and more optimistic. It turns out that the term PC has negative connotations. It's uncertain, however, whether its perception would not change with the popularization of the term SC in the context of PC, with SC taking on the negative connotations associated with PC.

It would also be legitimate to systematize the definitions and meanings of the terms PC and SC so that their interpretation is not completely free as it fosters disinformation and decreases the objectivity of the terminology used in scientific papers and, as a consequence, in a broader range of publications, or in the public discourse in general. The effects of multiplicity and opposites in definitions were observed in the results in which the articles and guidelines identifying the term SC exclusively with oncological care were highlighted [7]; in some manuscripts the term was used much more broadly or in the context of completely different fields of medicine [12].

The fact that the review included only data in the English and Polish language constitutes a limitation to the study. When defining terms, it would be advisable to prepare a larger number of papers that describe the phenomena at the level of the local languages spoken by authors. The lack of an objective methodology for the comparison of the terms SC and PC constitutes an additional limitation of the study. While the paper offers the authors' own perspective, the applied methodology must be investigated in further studies. In our view, a new perspective at the presented problem is much needed.

Declaration of conflict of interests

The authors declare that there is no conflict of interest.

Funding

None declared.

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