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PALLIATIVE AND HOSPICE CARE IN SOCIAL AWARENESS IN DIFFERENT COUNTRIES

Palliative and hospice care is about improving the quality of life of patients who face a life-threatening illness through pain management, treating other symptoms and providing psychological, social and spiritual support to the patients and their families. Engagement of an interdisciplinary team of specialists provides the opportunity to identify the needs of the patient and his or her family and to implement appropriate interventions to prevent and alleviate suffering. Promoting the idea of palliative and hospice care is important because it increases the chances that people in need of specialist support at the end of life and their loved ones will know what help they can get and where. The aim of this article is to analyze the findings about levels of knowledge and belief of palliative care in different countries (including the United States, Ireland, Italy and Poland), which indicate that there is still much work to be done on building public awareness. An attempt will be also made to answer the question: why do people know so little about palliative care and what can be done to change this situation?

Keywords: palliative care, hospice, social awareness

INTRODUCTION

According to the definition of the World Health Organization, palliative care is "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (WHO 2017). Palliative and hospice care concentrates on patients' relief from pain and other distressing symptoms (for example nausea, vomiting, constipation, drowsiness, anxiety) but, it is worth emphasizing that it also tries to meet other needs of the patients so that they can live a long and satisfactory life. Involvement of an interdisciplinary team (doctors, nurses, medical caregivers, psychologists, social workers, priests) provides the opportunity for holistic care of patients at the end of life and provides necessary help to their families not only during the illness of the patient, but often after death as well. Because all activities in palliative care are designed to improve quality of life, it is worth looking at this construct. Quality of life is a multidimensional construct perceived

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as a subjective, inclusive physical state, emotional and psychological well-being, as well as social interactions (Cellar and Tulsky 1990). Previous studies have shown that patients' health and quality of life are not identical, and the psychological state is rather more important than physical when it comes to evaluating the quality of life (Smith et al. 1999; Papuć 2011). It is known that a hospice can improve the quality of care at the end of life (Kane et al. 1984; Miller et al. 2002; Gozalo et al. 2007). Research indicates that being a hospice patient is relevant to quality of life. In studies involving both hospice patients and their primary caregivers, 50% of patients reported that their quality of life had improved after three weeks of palliative care. According to primary caregivers as well, patients' life quality increased after hospice services were implemented (McMillan and Mahon 1994). Previous studies also indicate that family members are very satisfied with hospice care, especially when compared to the care offered by other institutions (Ringdal et al. 2002; Casarett et al. 2003; Teno et al. 2004). Studies conducted in an Australian hospice showed that there was a relationship between satisfaction with hospice care and quality of life. It is worth pointing out that this relationship was stronger than that between life quality and symptoms (Ryan et al. 1998). Hospice care also alleviate the emotional distress of patients and their significant others. Research results have demonstrated that among hospice patients improved satisfaction was greater than among control patients. Decrease of anxiety and increase of satisfaction with engagement in care among patients' family members was also observed (Kane et al. 1985). Considering the fact that the number of people in need of palliative care is still growing and that hospice care has positive effects both on patients and their families, it seems important to verify what people know about palliative and hospice care. The greater the social awareness of palliative care, the greater the chance that patients and their families will report to an appropriate institution for specialist help and support. What is more, building public awareness of palliative and hospice care can also lead to improved access to hospice services and motivate community members to engage in organization of this type of care. This seems especially important in the context of the fact that the hospice movement was primarily based on volunteering and it is still funded in a large part by communities (Praill 2000).

PUBLIC AWARENESS OF PALLIATIVE AND HOSPICE CARE IN POLAND

Some of the latest data on public awareness of palliative and hospice care in Poland are based on research conducted by the Public Opinion Research Centre (CBOS) in 2009. 1,096 respondents participated in the survey. The aims of the research were to examine levels of knowledge about palliative care, respondents' opinions about hospices, and willingness to take on the role of a volunteer. Some of the respondents were unable to pinpoint for whom hospice care was intended. 17% of participants claimed that hospices were dedicated to sick, lonely and elderly people, 14% of them were convinced that hospice care was limited only to people dying of cancer, and 7% admitted that they did not know exactly for whom hospices exist. To the question of what kind of help hospices provide, over one third of the respondents (37%) answered that hospices offered pain treatment as well as psychological and spiritual support not only to the patient but also to his family, 35% of participants believed that hospice help was dedicated only to patients and there was no support for family members, and 14% claimed that hospice care concentrated on pain relief and disease treatment. Another question in the survey concerned the financing of hospices in Poland. Half of the respondents thought that funds come from the state (through contracts with the National Health Fund – NFZ), 33% believed that the costs of hospice activities were covered by patients and their families, and another 33% of the participants opined that hospices worked thanks to sponsors and private donors. Analyzing the answers to these questions, an aggregate index of knowledge of palliative care was created, which showed that only one in ten Poles had good knowledge about palliative and hospice care. 30% of the respondents had an average level of knowledge, slightly more people (33%) had only basic information, and 24% knew nothing about palliative care. Among the respondents, only 1% had personal experience in volunteering in a hospice, 14% claimed that one of their family or friends was a volunteer in a hospice, but, what is optimistic, 45% of subjects declared a willingness to work in hospice voluntary. On the other hand, the same percentage said that they would not become involved in such help for various reasons.

Interestingly, although many Poles did not know much about palliative and hospice care, they considered the functioning of such institutions necessary, and they spoke of it with appreciation. 96% of respondents (including 71% definitely) supported the existence of stationary hospices and 94% (67% definitely) supported the functioning of home hospices. It is worth noting that despite widespread public support for hospice activities, most respondents (57%) believed that a stationary hospice was a place where dying people should be only in exceptional circumstances, such as when their family was unable to provide specialized care. In other cases, dying people should stay at home. These data allow us to suppose that many people share the view that people should die in their own homes.

Other studies focusing on what Poles know about hospices were conducted in 2009 by PBS DGA on behalf of the Gdansk Hospice Foundation. The results showed that for 51% of respondents hospices were "dying houses", and 27% believed that usually people who do not love their relatives enough decide to entrust them to the care of a hospice. According to 71% of respondents, the goal of hospice staff should be to restore the patients to health (Skura-Madziała 2010; Krakowiak 2012). Although these results confirm that knowledge about hospice care is limited and incomplete in Polish society, it is worth noting that 46 percent of respondents declared that if they had time and a hospice were operating in their town, they would become volunteers. The studies conducted by PBS were repeated in 2010 and some changes could be observed. The percentage of people who thought that hospices were "dying houses" decreased, as did the percentage of respondents who believed that usually people who do not love their relatives enough decide to entrust them to the care of a hospice (Krakowiak 2012).

The latest data on public awareness of palliative and hospice care in Poland focus on children's home hospices (this is, of course, a very specific form of palliative care, but knowledge about it reflects, to some extent, social awareness about the issue of care at the end of life). The research project was carried out in cooperation with Newspoint and SW Research on behalf of the "Formuła Dobra" Lower Silesia Hospice Children's Association. The persons participating in the study were asked: *Could you explain what a home hospice for children is*? Over 72% of respondents were not able to answer this question and even among people who declared that they understood this concept (27.4%) (*home hospice for children*) there were incorrect statements (e.g. it is a place of care outside the home or it is family/parent care). The respondents were also asked where they first heard of the topic of home hospices for children. 43% claimed that they had never heard about it, 25.2% indicated the Internet as the place of first contact, and a similar percentage (23.3%) pointed out traditional media (TV, radio, printed newspapers). The positive information from these studies is that 74.3% of respondents thought that issues related to the form of care for terminally ill children is a topic for public discussion, which may mean that the public's openness to conversations on difficult problems is increasing.

As we can see, Poles do not have good knowledge of palliative and hospice care, which could cause patients at the end of life and their families will not know where and what kind of specialist help is available, or they receive the appropriate help very late. It is also worth emphasizing that the last major research results about social awareness in Poland are from 2010, and since then the situation could have changed somewhat. Ongoing monitoring of attitudes towards death and dying, knowledge of the needs of people at the end of life and the possibilities of caring for them is extremely important, taking into account factors such as increasing life expectancy, which means that more and more people will require professional care in the last period of life. Almost three-quarters of Poles (71%) would like to die in an unexpected way (CBOS 2013), but according to data collected by Eurostat, cancer was a major cause of death across the European Union in 2015, so the number of people who could potentially benefit from palliative and hospice care is very large. However, without adequate public awareness of what palliative care is and where it can be obtained, people who need it are less likely to receive it at the right time.

PUBLIC AWARENESS OF PALLIATIVE AND HOSPICE CARE IN OTHER COUNTRIES

Awareness of palliative and hospice care in the Polish population is not very high but it is worth comparing these data with those from other countries to see if this problem also exists in other societies. Unfortunately, there is still little research on social awareness and perception of palliative care. A study conducted in Italy (Benini et al. 2011) showed that perception of palliative care in the Italian population was also inadequate. 1,897 adult subjects from 18 to 74 years old participated in this study. Concerning the level of knowledge of palliative care, 40.6% of respondents answered that they never heard about it and 10% knew it only by name. 38.7% of Italians believed that the aim of palliative care was to improve life quality of ill people, but at the same time 23.1% claimed that palliative care only reassured the patients, 6.8% were convinced that it could delay death, and 19% did not know (it should be emphasized that it was a closed question and the respondents' task was only to choose one of the given answers). Interestingly, Italians as well as Poles thought that home was a better place for terminally ill patients than a stationary hospice or hospital. Care at home could be provided by family (45.6%) or a specialist team (28.7%). Only 15.2% of respondents was of the opinion that a stationary hospice was a preferred setting and even less (6.1%) considered a hospital as a suitable place.

In 2011 the Center to Advance Palliative Care (CAPC) with support from the American Cancer Society (ACS) and the American Cancer Society Cancer Action Network (ACS CAN) commissioned Public Opinion Strategies in United States to conduct a survey about public opinion on palliative care. 800 adults over 18 years old participated in this nationwide survey. The collected data show that 70% of participants were not at all knowledgeable about palliative care. Considering that to the question "how knowledgeable, if at all, are you about palliative care?" another 8% of respondents answered that they did not know, it seems that almost 80% of American society had no knowledge about palliative care. It is optimistic that when consumers received information about palliative care, they declared that they wanted to have access to this kind of help if they needed it. Over 90% of subjects said that they would consider palliative care for their loved ones if they had a serious illness. As well, more than 90% of consumers claimed that it is very important or somewhat important to make palliative care services available at all hospitals for patients with serious illness, as well as for their family members.

Slightly better levels of social awareness were noted in Scotland, Canada and Japan. The findings of a Scottish survey (Wallace 2003) showed that 49% of respondents had some knowledge about palliative care (vs 32% with no knowledge). Studies conducted in Atlantic Canada indicated that 75.3% of subjects had heard about palliative care before, and almost half of them (48.4%) were able to properly define it (Claxton-Oldfield et al. 2004). 92.3% of those who had heard of palliative care declared that they were interested in palliative care services in a case of a terminal illness in their family. Japanese research concentrated on social perception of the specialized inpatient palliative care service (palliative care units). 38% of the respondents said that their level of knowledge about palliative care units was "considerable" or "moderate", 38% declared that they had some knowledge about it, and 24% had no knowledge (Sanjo et al. 2008). All the results indicate that social awareness about palliative and hospice care around the world is rather low and inadequate. At the same time we can see that many people support the idea of hospice palliative care, especially if they are provided with information on this subject. It is worth considering what causes this lack of public awareness.

POSSIBLE CAUSES OF INCOMPLETE AND INCORRECT SOCIAL KNOWLEDGE OF HOSPICE PALLIATIVE CARE

Researchers point out that "dying" and "death" are taboo in society. People do not want to talk about it, and some of them even believe that talking about death makes other people only feel upset, or that it is connected with wishing it on yourself or others. Talking about death creates fear and discomfort, so most people do not bring up this subject with family members or friends. The fear of talking about death is observed in language as well. The words "death" and "dying" are frequently replaced by "passing away" (Seymour et al. 2010;

Krishbaun et al. 2011). 70% of Scots said that as a community they did not talk enough about death (Wallace 2003). If discussion of death and dying are not present in society, then obviously there is none about care issues at the end of life. What is more, patients and their families noted that even doctors were not comfortable discussing death (Morita et al. 2006), and that they had trouble proposing palliative or hospice care (Kai et al. 1993; Curtis et al. 2000). Another problem is the language used by physicians. Using medical terms and too much jargon in communication with patients makes information incomprehensible, and patients receive a misleading picture of their medical condition (Krishbaun et al. 2011). There are also many myths about hospice palliative care, which makes talking about this subject more difficult. People assume palliative care units and hospices are places where people only wait to die, or even believe that palliative care accelerates death (Sanjo et al. 2008; McIlfatric et al. 2014). In the above-cited studies most respondents who had some knowledge about palliative care admitted that it was based on their personal experience, which means that they had heard before about hospice palliative care because a family member or friend had used hospice services (Wallace 2003; Claxton-Oldfield et al. 2004; CBOS 2009; McIlfatric et al. 2014). It seems that one of the main reasons for rather low social awareness is a lack of generally available information about palliative and hospice care. Those responding to surveys saw a need to educate people from different groups about palliative care. Many people supported the idea of introducing education about death and hospice care to school and universities. It can facilitate assimilation of information and normalize talking about illness and death. It is important to persons to have knowledge about palliative care before a loved one is diagnosed or dying. Social awareness should be increased through TV advertisements, posters, pamphlets, and media campaigns, and by physicians and other medical staff providing reliable information (Claxton-Oldfield et al. 2004; McIlfatric et al. 2014).

CONCLUSION

With the advancement of medicine, we have more opportunities to treat pain and other nagging symptoms. Palliative and hospice services provide comprehensive care for patients at the end of life and their families and can improve their life quality. Unfortunately, social awareness of it is rather low or incomplete and this problem affects not only Poland, but also more developed countries such as Canada and United States. Building public awareness of palliative and hospice care is a great challenge and it will take time, but it can bring many benefits such as empowering patients and increasing access to this type of care. It is worth noting that building positive attitudes towards hospices can also make people more willing to support these institutions, which is very important considering that in Poland many hospices would not be able to function without financial support from the public. As important as financial support is the willingness to become involved in helping a hospice as a volunteer. The hospice movement was first and foremost a voluntary movement and the help of volunteers in hospices is still invaluable. It is also necessary to conduct research that will monitor social awareness of palliative and hospice care and allow assessment of whether actions taken to raise this awareness bring about the expected results.

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OPIEKA PALIATYWNA I HOSPICYJNA W ŚWIADOMOŚCI SPOŁECZNEJ W RÓŻNYCH KRAJACH

Opieka paliatywna i hospicyjna koncentruje się na poprawie jakości życia pacjentów, którzy stają w obliczu choroby zagrażającej ich życiu, przez leczenie bólu i innych objawów oraz udzielanie wsparcia psychologicznego, społecznego i duchowego pacjentom i ich rodzinom. Zaangażowanie interdyscyplinarnego zespołu specjalistów daje możliwość zidentyfikowania potrzeb pacjenta i jego rodziny oraz wdrożenia odpowiednich interwencji w celu zapobiegania cierpieniu i jego łagodzenia. Promowanie idei opieki paliatywnej i hospicyjnej jest ważne, ponieważ zwiększa szanse na to, że ludzie potrzebujący specjalistycznego wsparcia u kresu życia oraz ich bliscy będą mieli wiedzę, gdzie i jaką pomoc mogą uzyskać. Celem tego artykułu jest analiza wniosków płynących z badań dotyczących poziomu wiedzy oraz przekonań o opiece paliatywnej w różnych krajach (w tym w Stanach Zjednoczonych, Irlandii, Włoszech i Polsce), które wskazują, że nadal pozostaje wiele do zrobienia w zakresie budowania świadomości społecznej w tym zakresie. Podjęta zostanie również próba odpowiedzi na pytanie: dlaczego ludzie tak mało wiedzą na temat opieki paliatywnej i co można zrobić, aby zmienić tę sytuację.

Słowa kluczowe: opieka paliatywna, opieka hospicyjna, świadomość społeczna