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HOME HOSPICE – UNDERSTANDING THE ISSUE, POLES' ATTITUDES TOWARDS IT AND THE STATE OF DISCOURSE IN MEDIA. RESEARCH RESULTS.

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Abstract

The paper presents results of research related to familiarity and understanding of home hospice term and shows how the social media discourse of palliative care looks like. Answers and conclusions are crucial for palliative care organisations as their existence depends on donors financial support which engagement is strongly related to communication activities performed by those organisations.

In the paper there has been presented opinions about public discussion about terminally ill children and its potential need for being treated as a taboo. The data whether futile medical care should be performed whatever the cost is also shown in the paper. Researchers asked also who should be responsible for executing management of hospices in Poland. The main conclusions focus on the necessity to intensify communication activities, especially by the professionals.

Keywords: Children's home hospice, taboo, communication, social media, palliative care, internet discourse

Introduction

Among many topics, which are related to painful, unpleasant, irreversible events and tough life experiences, which may be difficult to discuss, there are issues strongly linked with social aspects of human life. In the European culture such issues are perceived as a kind of taboos, e.g. sexuality, death, some life-threatening illness. Other topics, regularly overlooked or purposefully omitted, are issues related to national and ethnic minorities, transsexualism, attitude to someone else's religious believes or the matter of palliative treatment for terminally ill children. Anna Dabrowska, an author, mentions another examples of so-called taboos like rape, death and the dying process, cannibalism, body and

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nudity, some diseases, cloning, in-vitro or the process of talking about sex with own kids (Dabrowska 2008).

The terms “hospice” and “home hospice” have their official meaning – medical “Home hospice - provides home care for terminally ill children and young adults; the principles of medical care result from palliative medicine”. Organization of both hospice care and home hospice care in Poland are described in the Regulation of the Ministry of Health (Dziennik Ustaw 2018) but in colloquial understanding, hospice as an institution is widely perceived as “death room”. Even the way people usually call the process of transferring ill people to hospice is strongly pejorative. When patients are informed about negative prognosis, untreatable diseases, they commonly say “hospice means the end”, “everything only not hospice”, “there is only hospice left” (Kwiecinska https://psycheon.pl). It seems fear related to term of hospice and the rest forms of palliative care can enhance its taboo connotations.

Most probably that may be the reason why discourse in the internet, especially in the social media, is relatively small and limits only to few minor issues (it requires more research). As some suppose, one of the main factor responsible for that may be insufficient knowledge about hospices and children’s home hospices, issues that family needs to struggle in face of incurable disease of their own child. In other words, it seems these problems are left to solve only by those “who are related to them”.

In fact efficient functioning of children’s home hospice strongly depends on understanding, acceptance and social support and only those factors in combine with appropriate knowledge for palliative care can result in financial support.

Palliative care – forms and specificity

According to WHO’s definition (www.who.int/news-room/fact-sheets/detail/palliative-care), palliative care is an approach that aims to improve the quality of life of patients who suffer from life-threating illness. That special type of care also includes care for families of patients as they also face various problems associated to health condition of their loved ones.

The palliative care helps to relieve the pain and give a helping hand both when the patient’s medical condition is getting worst, when he is passed away and after all, while the family is in mourning. The palliative care includes physical, emotional, social and spiritual aspects (de Walden Gałuszko 2006).

The children’s palliative care was firstly created in the Great Britain at the beginning of 80s. In Poland, that type of palliative care appeared for the first time in 1994, at Institute of Mother and Child in Warsaw, where the first children’s hospice dedicated to young patients was initiated. Children’s hospices in many aspects (e.g. type of care) are similar to the typical hospice, however they have their own specificity, due to it there are pointed some significant differences. Today these attributes positively boost national network of children’s home hospices over the whole country so Poland has probably one of the most developed pediatric palliative care services with range that covers most of the country area (Dangel 2011). That increased demand for palliative care was confirmed in 1999 as palliative medicine was created as a new academic specialty.

Regarding the most often used definition and main idea of palliative medicine, those for whom the hospice care is constituted are people who suffer from though illnesses that inevitably leads them to death and the modern medicine cannot find efficient treatment for them.

Malignant tumor at incurable stage or cerebral palsy are usually type of illnesses that indicate the need for palliative care for children. Appendix 1 of Ministry of Health decree dated at the 29th of August 2009 contains full list of illnesses which qualify young patients for palliative and hospice care. Among those medical condition are listed contagious diseases and their implications, malignant tumors, metabolic and neuromuscular diseases, paralysis, cerebral palsy, liver, kidney, lungs or cardiac insufficiency, in-born defects, chromosome abnormality, results of poisoning or injuries of nervous system.

One of the key factor commonly considered while young patients are selected to go to children's hospice is the possibility to provide them with highly specialised care in home condition, inability to maintain the care by parents without professional support or disqualification for causative treatment.

In the hospice movement there are three main forms of palliative care for terminally ill children and they are as follows: children's hospice at home, perinatal hospice and standard stationary children's hospice. These forms can exist as autonomous unites or offer service both for young and older patients (Szmyd and others 2017).

Nowadays in Poland there exist about 60 children's home hospices, which means that in each voivodship there should be more or less a few of such places funded by the national health system. Contrary to traditional stationary hospices children's home hospices can offers palliative care and medical services at patient's home. According to the regulations, each young patient is visited by nurse or other medical staff at least twice a week. Every two weeks there is another visit by doctor specialised in palliative medicine or certified in field that allows him to work in the hospice. If it is needed, medical staff is available all-night. Regarding the patient's needs hospices provided them with the psychological and physical therapist support.

Most of hospices offers also a kind of an organizational help in order to assist family in dealing with legal issues, especially in contacts with national institutions (supporting ill people and patients in poor financial condition) or to organise some help for them. Another forms of support includes: help in buying and servicing medical equipment, help in adaptation room for palliative care, help in applying for refund for medicines or social welfare benefits, help in organising ceremonies, help for siblings and families in mourning.

The role of the media in providing information on health topics

One of the motives and types of satisfaction obtained through the media is obtaining information and advice as well as learning about the society and world (Mc Quail 1994). Media are the most important source of acquiring knowledge about health. 80% of respondents points them in research (Szymczuk i in. 2011). Among Internet media, Facebook is certainly the most important source. As many as 84% of all Polish Internet users used Facebook at least once a week at the end of 2016 (Gackowski, Brylska i in. 2018).

Therefore, it can be assumed that information, opinions and messages appearing in the media, especially Internet ones, have an overwhelming impact on the state of public awareness.

In addition to these impacts, the media function referred to as "granting status" is of great importance to the issues discussed here. The phenomenon is that "the media focuses the attention of societies on events, people and organizations that they consider important. They give them the status of authority. This is because from the beginning of the emergence of mass media on a global scale, all the topics seen as important appear there. Due to this phenomenon, everyone who appears in the media, any matter, event, initiative and information that will be broadcast in mass media, is treated as something important and the appearance itself gives and legitimizes the status of something or someone important enough to appeared in the mass media. (...) By the very appearance in mass media you can get status of "valid" (B.Kicior 2018).

Thus, the discourse we deal with in the media about hospices in general, and home hospices in particular, undoubtedly shapes knowledge and attitudes towards this form of care. The nature of this discourse has a clear impact on the image of terminal care facilities. This, in turn, translates into a willingness to use help but also financial and material support, volunteering and in general favoring hospices as forms of care.

Research subject

Research scientists were particularly interested in what Polish people know about home hospices and how the internet discourse associated to this topic looks like. It was also extremely interesting whether it is seemed as a kind of a taboo or if Polish people find public discussion is highly demanded and they do not feel any resistance to talk about the issue. Please note that consideration about hospices is commonly linked with taboos like dying or death. Worth studying was also what Polish people think about the form of running the hospices and whether the model in force, dominated by non-government organisations, is perceived as a solution that suits best? Another aspect, strictly related to children's palliative care, was futile medical care and attitude of Polish people to it. Researches were also incredibly curious whether most of them would decide to sustain life at all costs, especially while almost 90% of them is declared Catholics. Finally, how did discussion in the social media looks like and which topics were discussed most frequently?

Research method

The researchers used two ways of data collection: quantitative and qualitative research. The quantitative research was conducted in the last decade of February 2018, using CAWI method, with proportional sample of Polish society with 1048 interviewees. The interviews were conducted by SW Reasearch company from Warsaw on behalf of "Hospicjum dla Dzieci Dolnego Śląska" (children's home hospice in Lower Silesia, Poland).

The qualitative research took place in March 2018 and had a form of internet content analysis. Data came from social media content, posted between February 2017 and January 2018, which included such phrases like "hospice", "home hospice", "children's home hospice". The monitoring of the internet was conducted by Newspoint research company from Warsaw on behalf of "Hospicjum dla Dzieci Dolnego Śląska". Among 50 000 posts with these phrases, there has been 224 posts randomly selected and analysed. The structure of respondents in terms of demographic features is shown in fig. 1.

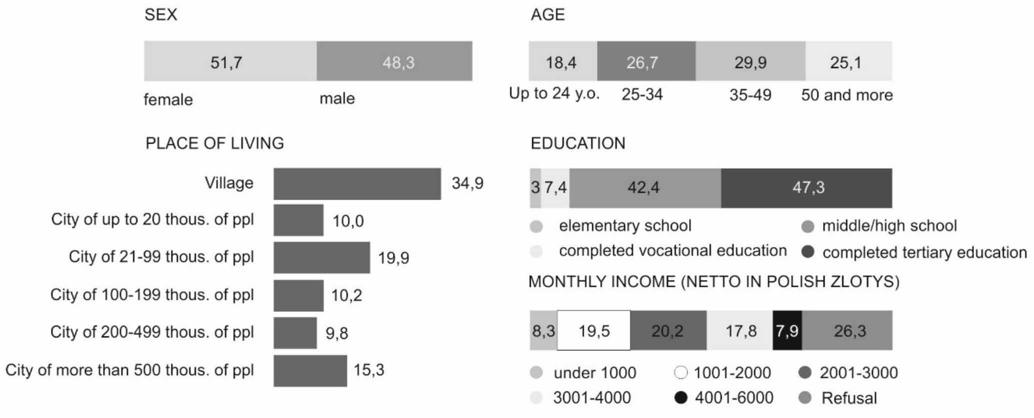

Fig. 1. Structure of the population. CAWI method research. N=1041.

Source: SW Research commissioned by authors.

In the selected time in social media there has been 50 000 posts that included "hospice" phrase, 23% out of them was related to "home hospice", 11% to "home hospice" and 5% to "children's home hospice" (fig. 2)

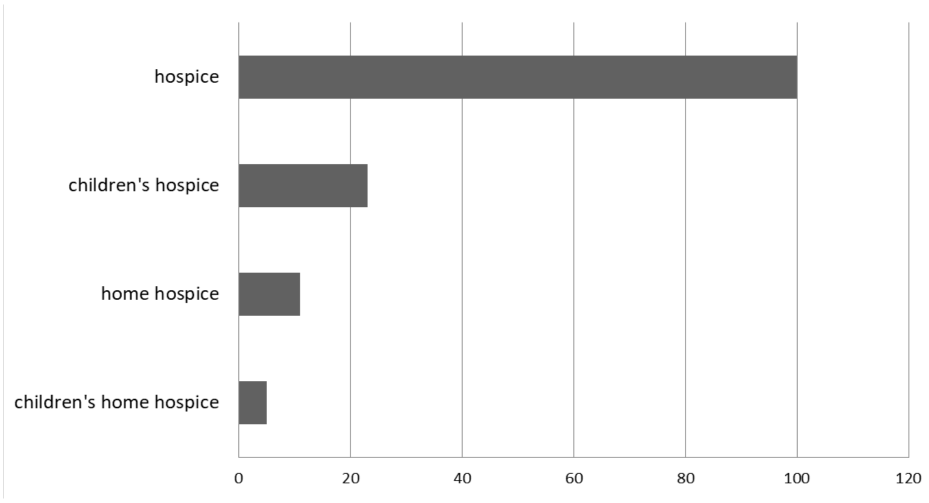

Fig. 2. Amount of phrases including "hospice" phrase. N=244.
Source: Newspoint, commissioned by authors.

Results

The more popular social media website is, the more frequently phrases related to hospice topic appear. As it was expected, the bigger amount of key words was identified on Facebook. Unexpectedly the second website was Twitter, whose vast majority of users are journalists, editors, CEOs, students and freelancers (PBI/Gemius, 2015). Supposingly those groups may be, in some way, interested in palliative care. The distribution of topics in individual social media is shown in fig. 3.

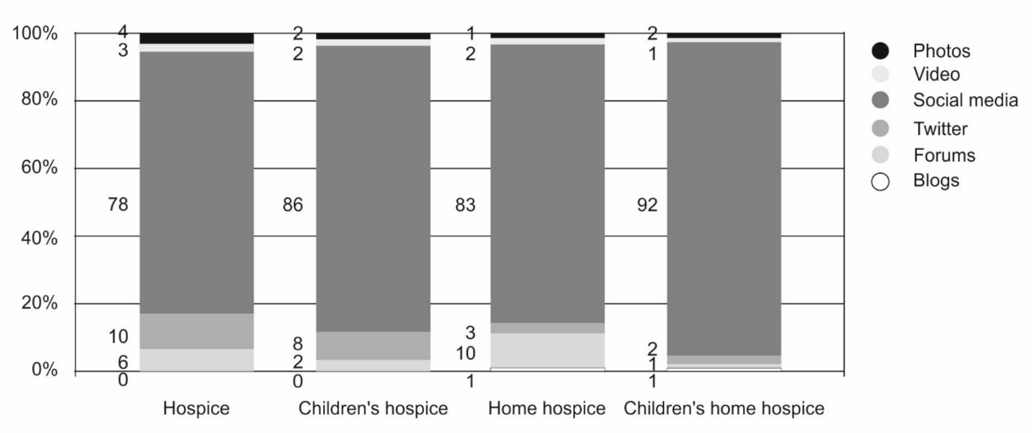

Fig. 3. Hospice topic in the social media (%). N=224.
Source: Newspoint, commissioned by authors.

One of the most realistic explanation why CEOs post about the hospice topic may be charitable activities proceeded by some brands.

The involvement of journalist in the topic requires more research, as this group is significantly responsible for direction of the discussion in media.

Another key factor that has strong impact on the hospice discourse in the internet is level of knowledge and familiarity with hospice topic among Polish people. Value of opinions and scope of the occurrence strongly depend on that familiarity. On the other hand, misunderstanding or limited understanding of what home hospices are will lead to relatively low interest of this topic. The results show almost ¾ of interviewed Polish people admit they have no exact idea what home hospice is and would not be able to describe its definition.

The rest of interviewees (27,4%) declares they know what home hospice is, however when asked to clarify the concept they present various explanations and some of them indicate they might not understand the idea of home hospice. Fig. 4 presents the distribution of respondents who declare they know the “home hospice” term. One out of five asked the question declares he understands the term and explains home hospice is “the place of care away from home”, 3% thinks it is “the place of home character” and more than 5% of interviewees when asked to explain admit that have no sufficient knowledge to do so. In fact that means that more ten 77% of Polish society do not know what home hospice is at all.

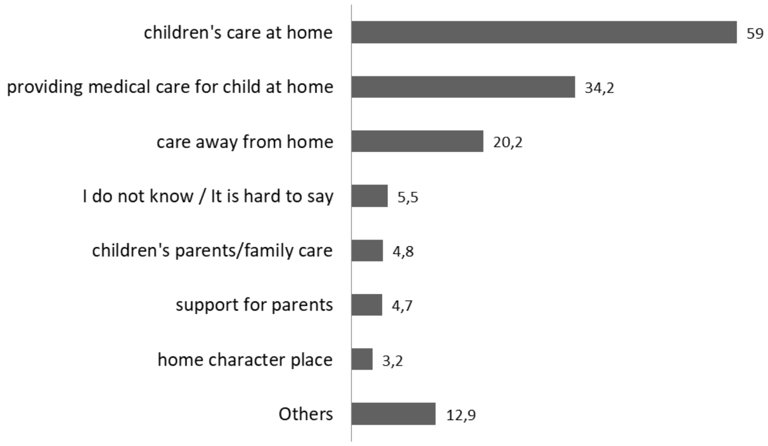

Fig. 4. The understanding of “home hospice” term by those who declares the familiarity. Due to the possibility to choose more than one option the amount of answers does not sum to 100%. N=285.

Source: Newspoint, commissioned by authors.

The current state of affairs implicates several of conclusions about difficulties that lead to complication with creating relationship between the society and home hospice or palliative care organisation. When both sides do not know and do not understand each other it is much more difficult to create the relationship and at the same time some issues with credibility in communication may occur.

While preparing the communication content it must be taken into consideration that the low awareness of term of “home hospice” among the society cause the need to create a set of information that can capture people’s attention in order to build the awareness of the phenomena.

When most of the addressees does not know who the sender is, the persuasive communication (that aims to gain finance support or any other type of help) can be unsuccessful. And that is why one of the most crucial aspect for home hospice organisation seems to be to intensify communication activities in order to arouse public interest in understanding what palliative care actually is.

In order to learn more about potential sources for information interviewees were asked where they have met the hospice topic recently. It should not astonish that ¼ of them declares internet as a source of information. However it should also be pointed that very similar group of people finds they learn about home hospice in traditional media like press, radio and TV.

Even if conclusion seems to sound a little bit trivial, still it shows both channels have their own clients and both channels should be used in order to build the awareness of the phenomena. The conclusion is worth formulating especially as there is a tendency to transfer all the communication activity to the internet. On account of the results, they prove that resignation of using traditional media is inappropriate and seems to be performed “too early” as many people still use them.

Due to limited financial possibilities of palliative care organisations and huge amount of information in public sphere that “attacks” addressees every day, it seems impressive that more than 13% of Polish people declare they have seen social campaign associated to home hospices and it was the only source of information for them.

The fact that hospice topic is able to overcome recognition threshold (as fig. 5 shows, over 13% of interviewees declare they have met the social campaigns) means that information has enough "power" to capture someone's attention and some specific results (when using outdoor activity, TV and radio spots, ads in the internet as a part of typical social campaigns) can be expected.

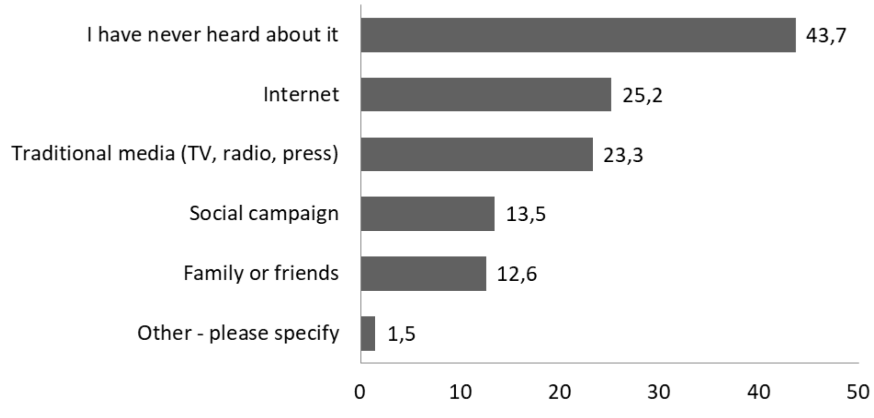

Fig. 5. Medium or situation that allowed interviewees to learn about home hospice. Due to the possibility to choose more than one option the amount of answers does not sum to 100%. N=1041.

Source: SW Research commissioned by authors.

For a group of 12,6% Polish people, the main source of information related to home hospices is discussion with family or friends. It can be assumed that the topic may be a subject of normal and common talks, not inspired by anybody, interesting and not perceived as a taboo.

However it should be pointed the major group of interviewees (43,7%) declares they have not met the topic yet. That percentage presents the scale of challenges that face home hospices and palliative care organisations when they try to build the awareness and create positive relationship. Creation of basic information about existence of palliative care organisations is needed as only then it will be possible to interest and encourage the rest of public opinion to offer them help.

The authors were also interested what topics related to "children's hospices" are discussed in the internet, what is mainly presented by those who decided to post about the topic, what they perceive as an important thing to mention? The most of the posts treats of: attractions prepared for children for the purpose of the described event (22% of all the posts), different cases of people under palliative care (16%), creation or opening of a new hospice (13%) and stories about terminally ill children (10%).

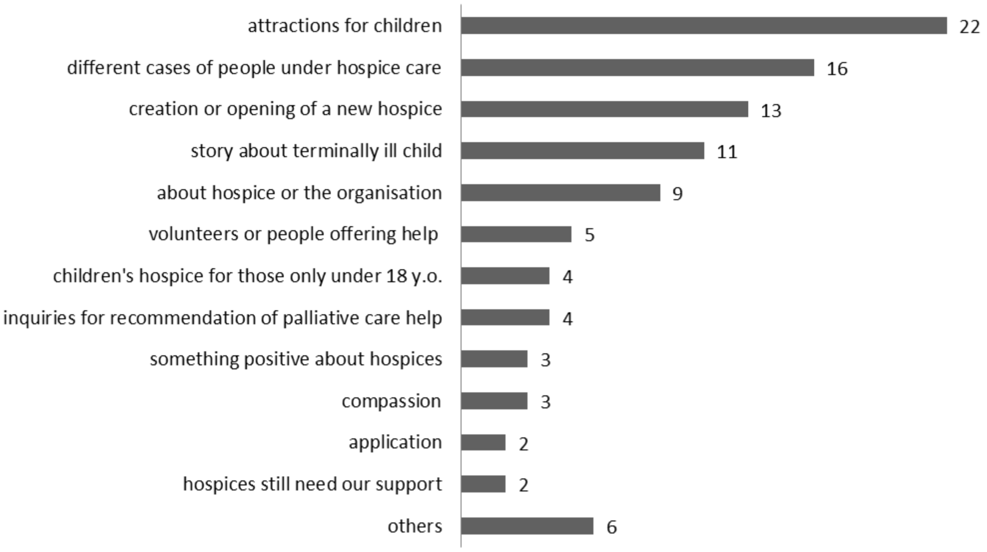

Fig. 6. Topics discussed in social media posts related to children's hospice. N=224.

Source: Newspoint, commissioned by authors.

Among the posts there appears also information about organisations responsible for running hospices (9%) and less often about volunteers offering help (5%) or inquiries for recommendation of palliative care help. Subject matter seems to be diversified, however, it can easily be noticed that vast majority of all the posts comes from corporate that organises their own events as a part of CSR (corporate social responsibility) strategies. Nowadays that activity is quite common, due to that fact it can mislead some users and in results some important issues related to palliative care at home can be misunderstood. The distribution of topics discussed in the media is illustrated in fig. 6.

As it has been already mentioned in the introduction, topics related to death and sufferance is perceived as a taboo. It may noticeably cause low awareness of the phenomena of palliative care, enhance myths and limit the topic's presence in public discourse. Despite palliative care organisations' engagement and professionalism if the thesis were true, it would be extremely tough to change the tendency and to encourage people to discuss about the topic.

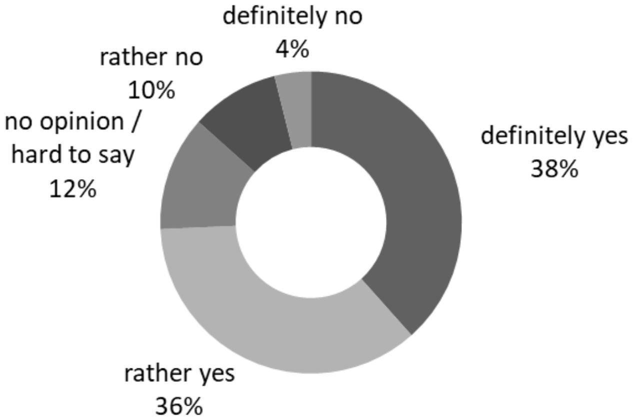

Fig. 7. Do you think that palliative care for terminally ill children is a public discussion topic? N=1041.

Source: SW Research commissioned by authors.

However the significant percentage of interviewees declares openness for the topic of terminally ill children. Almost ¾ of them finds it should be publicly discussed, and what is more, 38% out of them thinks it should "definitely" be a subject of discussion. Different beliefs express 13,4% of interviewees and similar amount of them (12,3%) has no opinion about the topic. To conclude it seems there is 75% of people who are ready to discuss about though topic of terminally ill children and the rest finds it as an unappropriated subject or has no judgment.

Whether it is taboo (and that is why it should not be publicly discussed) or the real reasons are different (e.g. no confidence that any public discuss can positively influence the palliative care system) is worthy of further examination.

Undoubtedly the people's attitude to futile medical care has significant impact on the discourse, tendency to challenge the topic and openness to publicly present their own opinion.

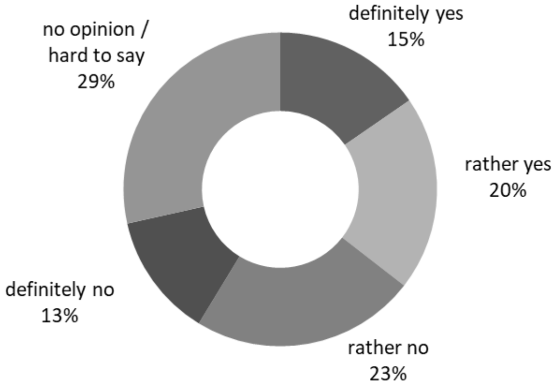

Fig. 8. Do you think that futile medical care is justified even if child is terminally ill and there are no chances to recovery? N=1041.

Source: SW Research commissioned by authors.

As it can be seen the opinions among interviewees about the futile medical care are divided – 35% of them finds it should be performed whatever the cost (15% says "definitely" and 20% says "rather yes") and at the same time there is 36% of interviewees who think differently.

This lack of unanimity of opinions is also confirmed by the fact that quite a lot of Polish people (28,5%) has no own judgement. It only proves there is a need for open public discussion about the topic and its implication or for sharing arguments.

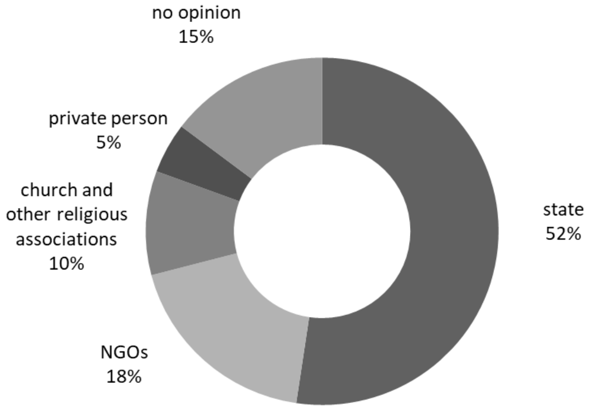

Fig.9. Polish people's opinion who should be responsible for running children's home hospices? N=1041.

Source: SW Research commissioned by authors.

Nowadays home hospices are ran mainly by non-government organisations, foundations or charitable associations. When the interviewees were asked if the status quo is acceptable or rather some changes should be made, most of them (52%) answered that expected and adequate executive management body is state organisation. Supposably it does not mean NGOs manages poorly – it is rather sentimental yearning for former type of system, when the state was responsible for solving problems and paying costs of it.

More than 18% of the Polish people find present solution as optimal and think NGOs can efficiently organise palliative care. What may be interesting, 10% of interviewees pointed that church and other religious associations are the best option. Explanation for the judgement can be the fact that for some Polish people values like compassion, empathy and spiritual aspects, which are strongly linked with palliative care, are also linked with religious associations. On the other hand, complexity of the issue is proven also by the fact that 15% of interviewees have problems with recommending the adequate type of organisation to take care of palliative care.

Summary and conclusions

The fact that most of Polish society does not know what home hospices are has repercussion to the whole research results. It clearly signalize the main barrier which is communication about the topic with permanent lack of information, proper data or basic knowledge about palliative care that allows to initiate wider public discussion.

In fact if the society does not catch the topic, results of the discussion have to be limited and contorted. Therefore anyone who wants to communicate to society on behalf of hospice have to take into consideration that vast majority of addressees does not plainly understand what the information is all about. It means firstly there is a need to inform and explain what home hospices are and what type of help they offer, then secondly the rest of information.

When it comes to the source of information related to home hospices, efficiency of traditional media channels is very similar to the internet, due to that fact preparing communication campaign or initiating of the discussion have to include traditional press, radio, TV and internet channels as well. The specific type of those mass media allows achieving better control over content and precision of the information. It is important especially when the communication is to present, explain or familiarise the hospice topic to society.

Polish society perceive state or state organisation as the most adequate type of executive management body to be chosen in order to increase importance of hospice. It is widely expected that state (or local government) will be activate in order to create and execute different forms of palliative care. It is worth mentioning, after the state, Polish people choose NGOs to do so as well.

The hospice topic is not a taboo and what is more Polish people finds palliative care as a topic for public debate and they declare they are opened and ready to discuss about it. That creates favourable condition for communication activities of hospices.

In the internet the subject related to hospices is dominated by information treating of events and attractions for children – which are mostly part of CSR campaigns. That shows deficit of other arguments in the discussion. Still, however, it gives possibility to present different information associated to hospices topic and due to the diversity of arguments it allows to capture discourse participants' attention and boost their encouragement.

Worth noticing is relatively large percentage of interviewees who admit no awareness of home hospice term and quiet large group of those who has no need for discussion or own opinion about the subject or topic of futile medical care.

It only shows importance and necessity to take professionals, planned communication activities and to initiate public discourse. Otherwise efficiency of hospice activities, possibility to raise financial support, to recruit volunteers or qualified employees strongly dependent on general acceptance and understanding of the phenomena.

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