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TELEPHONE AND ONLINE COUNSELING IN THE PRACTICE OF KRAKOW CHILDREN'S HOSPICE

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psychotherapy online

Summary

Objectives: The article is an analysis of the support program for parents who have lost a child, ran by Krakow Children's Hospice. The goal of the study was to determine the reasons why parents after the loss of the child reach for online psychological help, to determine what kind of support they seek and to name the benefits and risks of applying the online communication in providing psychological care.

Methods: The research material consisted of the texts of emails, the texts of forum posts and the telephone help cards, collected during the operation of the program. The author performed a qualitative analysis accordingly to the thematic analysis rules proposed by Braun and Clarke. Results: Four main themes were identified: Reasons for using the program; Circumstances of the first and the further contacts; Needed help: social and specialist support; Needed help: emotional and informational support.

Conclusions: Among the main reasons of using an online psychological support the following were identified easy access to help, possibility to contact a specialist quickly, possibility to contact others in the similar situation and anonymity. Parents are admitted to the program usually up to 6 months after the child's death and further contacts are often linked to the critical events such as anniversary of the child's death, birthdays, holidays. Parents benefit from both, social support and help offered by the specialists. They are looking for an emotional support, but also for the information. The results confirm that online tools are useful in providing psychological support, but also point out how different they are from a classic psychotherapy.

Introduction

Ongoing digitization results in many people performing more and more of their activities on the Internet. E-mail and telephone communication is replacing a lot of traditional face-to-face contacts. It is a trend that also affects professional psychological help. Indirect counselling is often preferred as more convenient, more anonymous and more accessible. The Internet is becoming an increasingly natural environment for all, including people who seek psychological support. In order to meet those needs, Kraków Children's Hospice (Małopolskie Hospicjum dla Dzieci, MHD) has launched a comprehensive support programme for families who have lost a child. Besides traditional psychotherapy and support group meetings, it offers various forms of indirect counselling – online and via telephone.

This article is an attempt to summarize 2 years of functioning of the programme, in particular its indirect counselling component.

Psychological help rendered online and via telephone

Before we start the analysis of the use of technology for the needs of psychological assistance, the great technological and cultural change that has taken place in Poland and in the world over the last dozen years should be pointed out. Everyday contacts with advanced technology have changed the behaviour and the way of thinking of people as well as influenced the way of communicating and gaining information. Devices such a computer with access to the Internet, a smartphone or a tablet are – for most of the people – increasingly convenient tools. Those instruments are widely used for problem solving, gaining information or receiving and providing help, including psychological assistance. Recently, more and more reports confirm the effectiveness of online or telephone psychological help at a level comparable to the effectiveness of traditional forms of contact [1-3]. It seems that psychologists are not yet sure about the consequences of computerization of psychotherapy – or wider – psychological support [4]. Nevertheless, apart from those dilemmas, modern technologies are widely available and are being used for the psychological support needs more and more often.

According to the study of the Central Statistical Office [5], in 2015, 77.9 % of households in Poland had at least one computer. Internet access was available in 75.8 % of households (71.0 % – broadband). At the end of the first quarter of 2015, there were 58,050,000.00 SIM cards in Poland, which was equal to 1.5 card falling on every Polish citizen. The role of the Internet, but also e-mail or telephone communication in solving health problems, including mental health, is significant and seems to grow constantly. The results of the PBI analysis (Polish Internet Research) indicate that 88 % of respondents who seek the information about health, diseases or treatment visit the Internet firstly [6]. As much as 14 % of those health related inquiries refer to mental health. Moreover, an analysis of the daily Internet activity of the American teenagers and young adults conducted in 2010 specifies that 7 % of them almost every day consult discussion groups concerning personal or health problems. 10 % of them look for medical information and 5 % for spiritual and religious tips [7]. Researches confirm the effectiveness of psychological help, especially cognitive-behavioural techniques, provided by the Internet in the treatment of depression and anxiety disorders [8-11], eating disorders [12-16] or in the course of oncological disease [17-20]. Studies show that people look on the Internet not only for psychotherapy but also for emotional support and other forms of non-psychotherapy help. Lagan, Sinclair and Kernohan [21] in their analysis of online behaviours of pregnant women, confirmed that respondents are commonly involved in the online

communities where they receive desirable emotional support. Polish works [22, 23] also confirm that women who are, or plan to become pregnant, commonly use the Internet as a source of information, advice and emotional support.

In their studies, Jagód *et al.* [24] analysed the therapeutic role of the Internet blogs and evidenced that among people with diabetes they are a source of information and emotional support. Other authors emphasize the role of the Internet in gaining support by people struggling with excessive stress [25-28]. In the Internet there are several hundred Polish-language helplines, including general ones as well as specialized, targeted at specific groups, such as AIDS patients, people who care for Alzheimer's patients, potential suicides, victims of violence. There are also several support groups, counselling points and helplines addressed to people in mourning, including parents after the loss of a child. However, literature lacks more systematic works related to online help provided to this group. The subject of psychological help provided to families after the loss of the child is rarely taken into consideration in scientific research. This results in the lack of systematic studies of this topic. The presented article contains an analysis of the psychological help for families in mourning after the death of a child as well as detailed description of the support programme ran by the Kraków Hospice for Children (MHD). It seems that this study can become a valuable supplement to the current knowledge.

The support programme for families after the loss of a child ran by Kraków Children's Hospice

Caring for the family after the child's death naturally fits into the scope of activity of each hospice. From the beginning of its existence the Kraków Hospice for Children provided psychological help for parents and siblings of sick children, also after their death. In November 2014, the Hospice started an open, free-of-charge support programme addressed not only to the families of MHD patients, but also to other people who were never related to the institution. Psychological, legal and spiritual help is available as part of the programme. The pillar of the project is psychological care. People who are beneficiaries of the programme can take advantage of individual and family psychotherapy or support group meetings, as well as online psychological help, e.g. an online forum, a telephone helpline and psychologist's e-mail consultations. In the MHD experience, psychological help via the Internet or telephone is rather a form of crisis intervention than psychotherapy.

Objectives

The aim of the study was to determine the reasons why parents after losing of a child reach for psychological help online, and what kind of support they seek most often. A further objective was to determine the advantages and dangers of using the Internet and telephone in

providing the psychological care for such a group and finally to draw conclusions for further work, both scientific and clinical.

Studied group

The studied group consisted of parents who have used psychological assistance via telephone or the Internet within the programme ran by MHD. Due to the specific nature of the programme (anonymity of consultations), no personal data was collected. The analysis includes contacts with 127 people, of which 125 were women and 2 were men. There is no data on the exact age or place of residence of those people. The analysis showed that the majority of respondents were in the age between 20 and 50 years and were living in the Lesser Poland Voivodeship. At least 6 people were living abroad (2 in Great Britain, 1 in Ireland, 2 in Norway, 1 in the USA). The analysis indicated that over 90 % of those who applied for the programme had personally experienced a loss of a child and the remaining 10 % were close family or friends. More than a half of the people who had received help were women who experienced a miscarriage or perinatal death. Other families have lost their children in a result of a chronic illness or an emergency.

Methods

The channels of the online help offered within the MHD programme were analysed. Those included, an online forum – a tool whose core function is seeking and providing mutual support for people who are experiencing the death of a child; a telephone helpline maintained by a psychologist and e-mail counselling. Data was collected from November 2014 to December 2016. The process of acquiring data included primarily registration of applications to the programme (setting up individual psychological help cards) and keeping a detailed record of each client's participation in the programme. The final forms of the collected data were: the texts of e-mails and forum entries, the telephone call cards and the individual online psychological help cards. The collected data was analyzed using the thematic analysis technique in accordance with the rules developed by Braun and Clarke [29]. The first step was the preliminary analysis of the collected data and their verification. Then the collected data was encoded and separated into initial themes. Finally, 4 main themes and their subcategories have emerged. The themes as well as subcategories they consisted of are presented in Table 1.

Results

The analysis of the collected date allowed the author to distinguish four main themes and 46 subcategories.

Table 1. **Main themes and subcategories with their frequency**

	Main themes	Subcategories which constituted the main theme and their frequency
1.	Reasons for using the programme (indirect help)	A. An easy access to help, no queues (43) – difficulties in getting a classical psychological support (17) – difficult access to help outside the home (5) – other (contact possible at any time, no geographical barriers, no queues) (11) B. the possibility of contact with people in a similar situation (21) C. anonymity (16) D. the feeling that help is directed to a specific group (7) E. free help (4) F. lack of knowledge of the language of the country of residence (1)
2.	Circumstances of applications / contact	A. recent (up to six months) death of a child (115) B. anniversary of the death of a child (107) C. birthday of the deceased child (75) D. planned date of delivery (53) E. Christmas (47) F. a sense of loneliness and despair not directly related to a significant date (38) G. All Saints' Day (28) H. Easter (17) I. Children's Day (13) J. worse parent's day not directly related to a significant date (9) K. Mother's Day (5) L. birthday of a living child (1)
3.	Required help: social and specialist support	A. Social support (455): – telling other parents about the experienced emotions (217) – telling other parents about a deceased child (116) – emphasizing the sharing of common fate (57) – asking other parents for the advice (37) – comparing experiences with other parents (28) B. Specialist support (293): – telling psychologist about the experienced emotions (138) – telling psychologist about a deceased child (96) – asking psychologist for advice (42) – emphasizing the willingness to use the help of a professional (17)

4.	Required help: emotional and informative support	A. Emotional support (828):	
			– talking about a deceased child (248) – talking about despair, sadness, feeling of emptiness (212) – seeking comfort (154) – talking about feeling guilty about the death of a child (93) – attempts to support others (87) – sharing quotes, poems (34)
		B. Informative support – seeking information on: (135)	
			– formal aspects of child death (38) – psychological assistance and psychiatric treatment (34) – doctors, research (especially in the case of miscarriage) (31) – how others deal with the loss (19) – masses, celebration of the day of the lost child (13)

The first extracted theme revolves around ‘the reasons for using the programme’. It refers to such aspects of online support as availability, anonymity or gathering people in the same situation. Those aspects incline parents to decide for this form of help after losing the child. The subcategory with the highest frequency is ‘easy access to help’, understood as no queues, no geographical and time barriers and the possibility of contact without leaving your home. Within this subcategory we can extract: difficulties in obtaining classical psychological support – lack of psychologists in hospitals, long queues to the mental health clinics ("I wanted to see a psychologist, but I was given an appointment to one year from now") and no possibility to get help outside the home, e.g. because of the distance ("I cannot travel to Krakow, I do not even have a driving license".) Another important category of this thread is ‘the possibility of contact with people in a similar situation’. This point is especially valued by people using the forum ("People who have not experienced the death of their own child, will not understand."). In their statements users also emphasized the importance of anonymity, understood as no need of administration of personal data, no face-to-face meetings, and the inability to be identified. For some parents, it is important to feel that the help offered in the programme is addressed to a specific group and therefore the persons who provide it are specialists in this field. Some people use the programme because it is free.

The second specified theme is connected with ‘the circumstances of the application and subsequent contacts’. The great majority of people started participating in the programme up to six months after the death of a child. A lot of contacts are directly related to important dates, such as anniversaries of a child's death, his birthday or, in the case of miscarriage – the planned

date of birth ("Today is Jasiek's 6th birthday, the first without him", "Today my child was meant to be born"). The number of entries on the forum and the number of contacts with the psychologist clearly increase during Christmas, Easter, All Saints Day, as well as Mother's Day and Children's Day. However, many contacts, are not directly related to significant dates. Some of them are associated with a sense of loneliness and despair that accompany mothers ("There are days when pain takes away my mind.", "Today I think only about how much I miss my little daughter.").

Another theme was identified as 'required help: social and specialist support'. It expresses the division into different forms of help needed by the parents. Specialist support, provided by psychologist and social support that can be provided by other people in a similar situation. Some parents first of all need contact with other families ("Girls, thank you for your support, you can understand me like no one else does", "Tell me, how you are doing?"). They want to talk about their experiences – a deceased child – but also seek advice and information. Those parents appreciate the opportunity to empathize and share a common fate with other people who go through the same. Others also use specialist care – e-mail and telephone consultations with the psychologist. They appreciate the opportunity to hear the specialist's point of view and use his knowledge ("I feel that I need to talk to a specialist, because I can't help myself"). Both forms of support complement each other. Their role and tasks differ significantly but both forms coexist in the process of supporting the experience of mourning.

The last theme called 'required help: emotional and informative support' concerned different types of help sought by parents: emotional support, understood by Sęk [30] as a transfer of care, acceptance, solidarity and positive emotions that occur in the relationship and informative support which is an exchange of information that helps in a better understanding of the situation and finding the most effective solution.

Emotional support is a category with a much greater frequency of occurrence. It was divided into 6 subcategories. The analyzed statements were dominated by the desire to talk about the deceased child and about parents' emotions that accompany this death ("My son died.", "He was getting better and then suddenly died.", "I still wonder if I could have done anything in a different way."). The parents sought solace, but also tried to give support to others ("Believe me, in the end it will be better."). Some of them shared quotes and poems.

The category of informative support was divided into 5 subcategories. First of all, parents were looking for information concerning the formal aspects of the death of a child, e.g. the right to burial, benefits ("How do I get it to be done?", "How is it with maternity after a miscarriage?"). They shared knowledge about the psychological help and the psychiatric

treatment and recommended specific specialists ("I recommend Dr. X, she helped me a lot", "I took Trittico, but I did not sleep well anyway"). They were often asking for advice on how to deal with mourning, organization of family life, especially relations with living children. Finally, information about masses and the celebration of the day of the lost child was often looked for.

Conclusions

Among the reasons for using the indirect psychological help, the most commonly named are big range, easy access to help, the possibility of relatively fast contact with a specialist, no time and geographical limitations, anonymity and the possibility of contact with people in a similar situation as well as with specialists with extensive experience in a specific field. Similar motives for reaching for online help are mentioned by King, Bambling, Lloyd, Gomurra, Smith, Reid *et al*. [31].

From the experience of the Kraków Children Hospice, online help is functioning more as a crisis intervention than a long-term psychotherapy. People in an acute crisis are more likely to take part, expecting quick and short intervention. Contacts with parents are rather of short duration and discontinuous. They usually start up to 6 months after the death of a child; later they are clearly related to critical events, such as anniversaries of the child's death, birthdays, holidays, and in the case of miscarriage, the planned date of the delivery.

There is a clear division into the specialist support, provided by a psychologist and social support, provided by people who have found themselves in a similar situation. Both forms complement each other. The conclusion can be drawn that the combination of an online forum where social support is mainly given and e-mail and telephone consultations with psychologist is a complementary entirety.

Parents benefitting from the programme primarily seek emotional but also informative support. They find those both types not only in contacts with specialists, but also in the social contacts on the forum.

Summary

Parents after the loss of a child certainly form a specific group to be researched. Not many studies on psychological support have been devoted to this particular issue so far. The collected results emphasize certain regularities specific to this group and distinguishing it from other groups. First of all, parents after a loss of a child are in a deep emotional crisis. This conditions a very emotional language and diverse, very strong emotions visible at all stages of the contact. The content parents bring to the relations relates almost exclusively to the theme of the child’s death, experiencing mourning and dealing with the situation. In the analysed material

other side-threads haven't been noted. Parents experiencing mourning seek comprehensive support – both emotional and informative, specialist and social. Social support that is obtained from others who are in a similar situation seems to be particularly important for this group. Additionally, the collected results indicate the convergence of looking for help with important dates, such as the anniversary of death or the birthday of a child. The entire activity of parents in the programme is closely related to the stages of experienced mourning.

The collected results indicate the usefulness of psychological help rendered via the Internet and telephone in the care of families after losing a child. At the same time, indirect forms of support differ significantly from the classical ones, based on direct contact and are not always sufficient. The experience of MHD in working with families after the loss of a child indicates the difficulties of conducting psychotherapy or other long-term forms of psychological care basing on online contact. Due to the diagnostic limitations, the different way of building the contact, limitations in the perception of non-verbal stimuli or the risky work with people with suicidal tendencies, the online psychotherapy is not conducted as part of the programme. Parents after losing a child additionally often require traditional meetings, which have not only a supportive but also a curative function. It seems that in the case of patients in need of treatment, online forms work best as a complement to classical forms of contact. Similar conclusions were obtained by other authors [32-34].

The presented analysis also leads to pose several questions. What needs particular concern is the role of online psychological help in supporting families who have experienced a miscarriage, childbirth death or have decided to terminate their pregnancy. Among the people using the programme, this group is more than half of all the patients. This shows the importance of the problem and can indicate the difficulty in accessing a stationary psychological help for this group or about other reasons why women after a miscarriage are eager to use psychological help online. Informal contacts between the families of deceased children, made on the forum or through a psychologist are also worth investigating. It is known that they are an important source of support, but so far no systematic analysis has been undertaken. It perhaps would bring further interesting conclusions about receiving and giving social support.

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