

The Influence of Spirituality and Religiosity in Palliative Care

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Abstract

In recent years there has been talk of "Palliative care", an interdisciplinary approach of care, which focuses on supporting and relieving patients and their family environment in progressive and life-threatening illnesses. Its aim is to provide optimal comfort and quality of life, maintain hope and family cohesion despite the possibility of death and generally support patients and their families in the stages of pain, illness and mourning. The theological approach of palliative care, with the opening of new horizons of view of pain and illness and their management with the help of faith, are challenges for the age of human omnipotence. The factors "spirituality" and "religiosity" have begun in recent years to be taken into account in the multitude of biological, psychological and spiritual factors that affect the body's psychosomatic response to illness and treatment. In the present study, we are trying to explore the influence of religious faith in the management of physical, psychological, and mental problems, that arise in the parents of children with cancer. The research was conducted on a sample of 133 families facing childhood cancer and the collected data were analyzed using open source software. Purpose of the study is to explore whether belief in God in the general frame of palliative care, can play a decisive role during the childhood illness, managing emotions such as anxiety and fear, and maintaining the parent's psychological balance.

Keywords: Palliative Care, Spirituality, Religiosity, Pastoral Care and Counselling for Sickness, Suffering and Pain, Childhood Cancer

Introduction

According to the definition of the World Health Organization (WHO), Palliative care (PC) is an *"approach aimed at improving the quality of life of patients who face problems associated with life-threatening diseases, as well as their families, through the prevention and relief of suffering, thanks to the early recognition and correct assessment and treatment of pain and other physical, psychological, social and spiritual problems"* (WHO, 2020).

PC aims to relieve pain and other distressing symptoms of illness, by taking into account and integrating the psychological and spiritual aspects of caring, but also by helping family to adapt to the new situation and manage its difficulty and its own bereavement in loss (Connor, 2020). The ultimate goal is to improve the quality of life and contribute in the positive influence of the disease and that's why PC is recommended to get started from the onset of a disease, alongside clinical treatments aimed at prolonging life.

PC proposal includes a holistic and interdisciplinary care provision which, at each stage of the course of the disease and based on the needs of the patient and the social environment, collaborates with many and varied specialties. Doctors, nurses, occupational therapists, physical therapists, social workers, psychologists and clergy, as well as a multitude of similar scientific subjects, deposit their knowledge in a round bank of cooperation and establish a common line of support for the patient. Teamwork is seen as central to palliative care, with the composition of subspecialty teams varying based on many factors, such as the nature of the disease, the stage of the disease and the extent of care (Radbruch et al., 2009).

This holistic therapeutic approach is an umbrella under which a multitude of concepts, actions and purposes is included. Hospice care, Terminal care, Continuing care, Care of the dying, Palliative care, End-of-life care, Supportive care, are some indicative examples from the relevant terminology, which reflect the multidimensional course and action of PC. It is even worth mentioning that there are indications confirming that teamwork and interdisciplinary approach in PC units, work beneficially for the patient. Specific research on the efficiency of specialized palliative care teams in the treatment of cancer, proved that the teams in PC increase patient satisfaction and manage to focus more on the needs of families, compared to conventional treatments (Hearn et al., 1998). Another relevant study supports that the expansion of the group and the flexibility of movements at each stage of the disease, increase the results at the level of pain relief and treatment of symptoms (Higginson et al., 2003).

Palliative care is divided into basic, general and specialized and is provided at all levels of the health system (National Commission for the Development and Implementation of the Strategy for Palliative Care in Greece, 2019). Basic PC intends for all patients, offered by trained in the basic principles of PC health scientists and

includes information, education and support of the patient and his family. General PC concerns patient populations in need and is undertaken by scientists involved in the treatment and care of patients with life-threatening diseases, including symptom assessment and management, end-of-life care, communication with the patient and his family in a general frame of specialized PC services.

The theological approach of palliative care intends to prove that far away from prejudices and blinders, the dialogue brings only positive results for the care and support of patients. The collaboration of the sciences of Psychology and Theology opens up new horizons of considering pain and illness and their management with the help of the Christian faith.

The factors "spirituality" and "religiosity" have begun to be taken into account in recent years among the multitude of biological, psychological and spiritual factors that influence the body's psychosomatic response to illness and treatment. Spirituality is defined as the way in which a person tries to give meaning and purpose to his life, as well as to his experience of contact with himself, others, nature and supernatural forces (Puchalski et al., 2009). Religiosity refers to the acceptance of certain rituals and beliefs within an organized religion and can be seen as a means of expressing spirituality (Hill et al., 2003).

Spirituality essentially refers to the spiritual needs that every person has, regardless of whether they believe or not and is a broader concept than religiosity, which is related to specific beliefs, participation in worship, cultural and social norms of a religion. Studies of the last decades have shown that both factors significantly affect the quality of life and patient satisfaction, as well as the quality of care (Nixon et al., 2013) (Phelps et al., 2009) (Rego et al., 2020) (Gijssberts et al., 2019).

In addition, there are studies that focus on the needs of patients receiving PC themselves about taking care of their spiritual needs. A related study reports a rate of 87.4% of the participating patients who evaluate themselves as a spiritual person (Grant et al., 2010), while in a combined result of 4 American studies, the percentage of patients who are interested in their spiritual needs, ranges from 40 to 94% (Post et al., 2000).

At the liminal moments of a person's life, at that point where the possibility of death greatly increases the odds of becoming a certainty, regardless of the outcome of the disease, the patient is confronted with himself, called upon to manage these thin boundaries between the present and the after-death unknown experience. The opportunity for this spiritual review can be offered by contemporary pastoral counseling as a therapeutic process, with the aim of re-searching for lost hope and bringing it back to the fore.

The pastoral contribution to PC of the sick person and especially the sick child, lies in the true contact, the free communication, the unconditional and selfless participation in pain and the fraternal and sincere "embrace" of the other.

We have to emphasize at this point, that the patient listening and silent presence next to the patient mentioned above, is the most responsible attitude that can be held by anyone who participates in PC. Contributing to dealing with loneliness does not necessarily require a degree, education or expertise. In their related book on pain, Paul Brand and Philip Yancey characteristically write that "when I ask, '*Who helped you the most?*', patients usually describe a calm, humble person: someone who was there when needed, who listened a lot and spoke little, who did not constantly look at the clock, who hugged and caressed and cried" (Brand et al., 1993). We often see this perception admitted by the medical world, where according to the testimonies of the doctors themselves, sympathy and practical attitude next to the patient constitute a form of treatment, with calming effects both for the sufferer and his family. The same is advocated by the pastoral care of illness and suffering, with the cornerstones of its selfless action, love for fellow human beings and the resurrection perspective.

In this announcement, research results are presented (Nizamis, 2022) (Nizamis et al., 2022), in which the influence of faith in the management of physical, psychosocial, practical and spiritual problems in parents of children with neoplasia is investigated multivariately. With the study of these parents, the results of which showed high levels of fatigue and physical difficulties, anxiety and fear, social disorders and spiritual searches (Nizamis, 2022), we try to explore how spirituality and religiosity can contribute to the management of all the aforementioned problems in the context of an organized PC.

Methodology

The research was conducted on a sample of 133 families of children with cancer and the results were displayed after statistical processing and data analysis with R statistical software. In Greece we have about 250-300 cases of childhood cancer every year. It is therefore easily understood that the research covered more than 1/3 of the total annual population of childhood cancer that exists in the country.

The research was conducted in the 4 largest pediatric oncology departments of Greek hospitals. More specifically, we studied 64 cases from the Pediatric Oncology Department of the Hippocrate's General Hospital of Thessaloniki, 26 from the University Pediatric Clinic of A.P.Th. in the AHEPA General University Hospital of Thessaloniki, 25 from the Oncology Department of the "Panagiotti & Aglaia Kyriakou" Children's Hospital and 18 from the Department of Pediatric Hematology-Oncology (TAO) of "Agia Sophia" Children's Hospital.

The aim of the empirical research was to gather questionnaires within 1 full calendar year, in order to collect a sample based on the total cases of childhood cancer that we

have in our country. Despite the difficulty of the Covid pandemic, we accomplished to collect the data in a frame of 12 months of research, so the result characterized by high representativeness.

Participation in the research was carried out through the completion of a closed questionnaire, which processed statistically in order to provide findings and results. For the compilation of the questionnaire, researches of other universities and research centers were taken into account on issues of management of childhood illness and specifically of neoplasia by parents and relatives. In addition, questionnaires regarding the concepts of religiosity and spirituality were studied. Furthermore, a systematic review of research tools for PC issues was conducted¹. This was also followed by meetings with researchers specializing in PC, in order to provide information and relevant training on the subject, as well as the relevant conditions that prevail in our country.

In the main part of the questionnaire, a series of statements regarding the period of the child's health issue are listed, in which each participant notes the extent to which each statement applies to him, expressing his agreement on a 7-point Likert scale. In addition, there are some questions in the form of multiple choices. The questionnaire consists of 3 parts, with the first focusing on psychosocial and physical issues as well as practical and everyday issues, the second on spiritual issues of faith and contact with the divine element and the third on PC. At a further level from the PhD thesis, a conjoint analysis was conducted between responses regarding the occurrence of psychosocial problems such as fear, anxiety, depression, etc. to parents during their child's illness and corresponding outcomes regarding belief in God, perception of the afterlife, occurrence of anger toward God, and the possible effect of the child's illness on all the above. Statistical processing of the data was carried out by multivariate analysis, using methods of multiple correspondence analysis in a 0-1 table and automatic hierarchical classification. These methods were chosen as they allow the phenomenon to be examined as a whole, without assumptions and models (Koutsoupas et al., 2019) (Koutsoupas, 2018).

1 Indicatively, research tools – questionnaires, which were studied before the creation of the research questionnaire are mentioned: Edmonton Symptom Assessment System (ESAS), Caregiver Priorities & Child Health Index of Life with Disabilities (CPCHILD), Hospital Anxiety and Depression Scale (HADS), Memorial Symptom Assessment Scale (MSAS).

Results

After the onset of my child's illness:

Table 1.

The concept of faith affects my life most.

	Frequency	Percent
1	19	14.3 %
2	6	4.5 %
3	4	3.0 %
4	15	11.3 %
5	17	12.8 %
6	21	15.8 %
7	51	38.3 %

Graph 1.

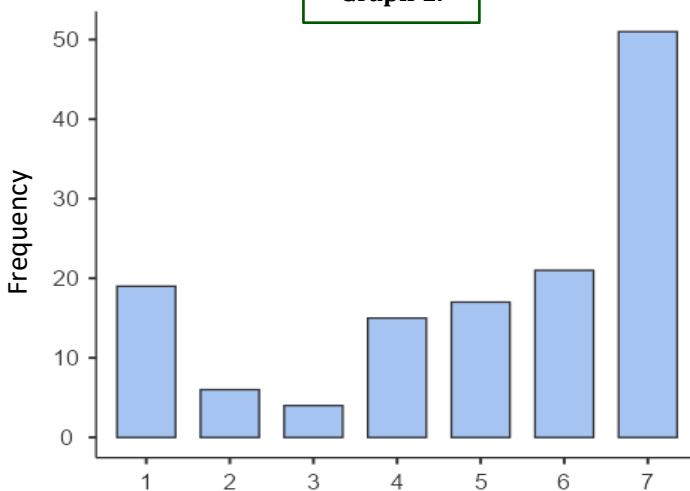


Table 2.		
I felt anger towards God several times.		
	Frequency	Percent
1	72	54.1 %
2	14	10.5 %
3	13	9.8 %
4	8	6.0 %
5	14	10.5 %
6	5	3.8 %
7	7	5.3 %

Graph 2.

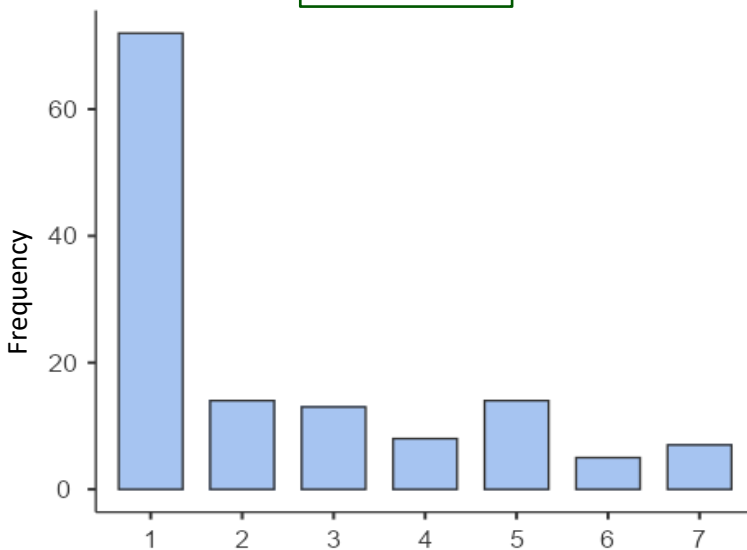


Table 3.

I felt the need to communicate with God through prayer.

	Frequency	Percent
1	7	5.3 %
2	3	2.3 %
3	2	1.5 %
4	5	3.8 %
5	13	9.8 %
6	10	7.5 %
7	93	69.9 %

Graph 3.

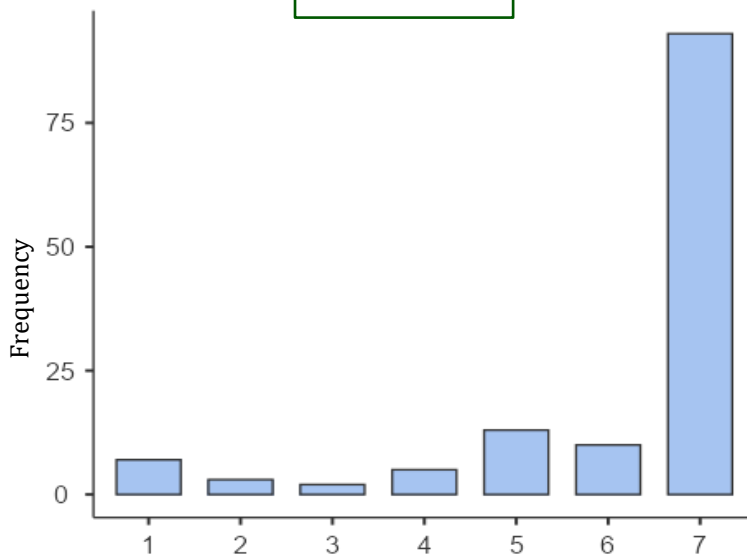


Table 4.		
I consider myself to be:		
	Frequency	Percent
Just as faithful as before	47	35.3 %
Less faithful than before	2	1.5 %
More faithful than before	84	63.2 %

Graph 4.

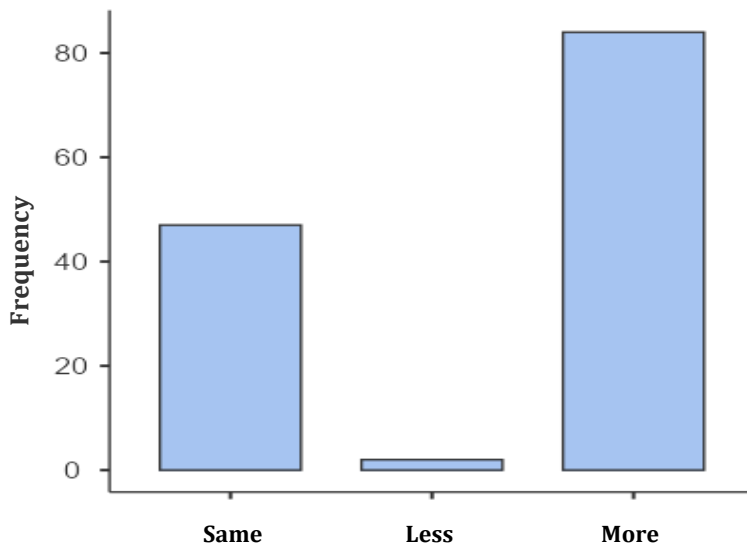


Table 5.		
Further support on the Psychological level would help.		
	Frequency	Percent
1	21	15.8 %
2	6	4.5 %
3	7	5.3 %
4	19	14.3 %
5	21	15.8 %
6	23	17.3 %
7	36	27.1 %

Graph 5.

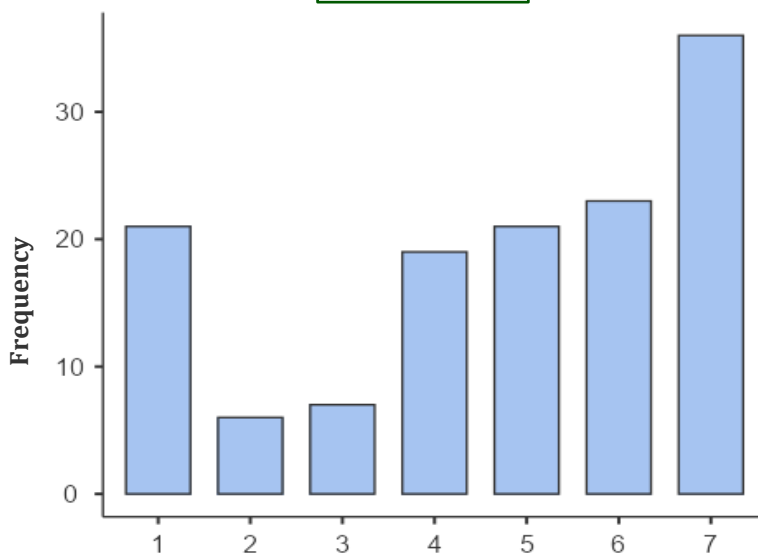
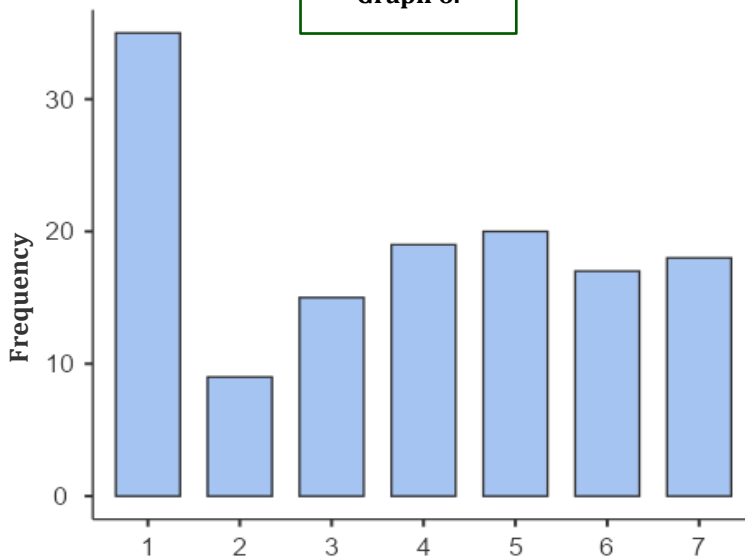
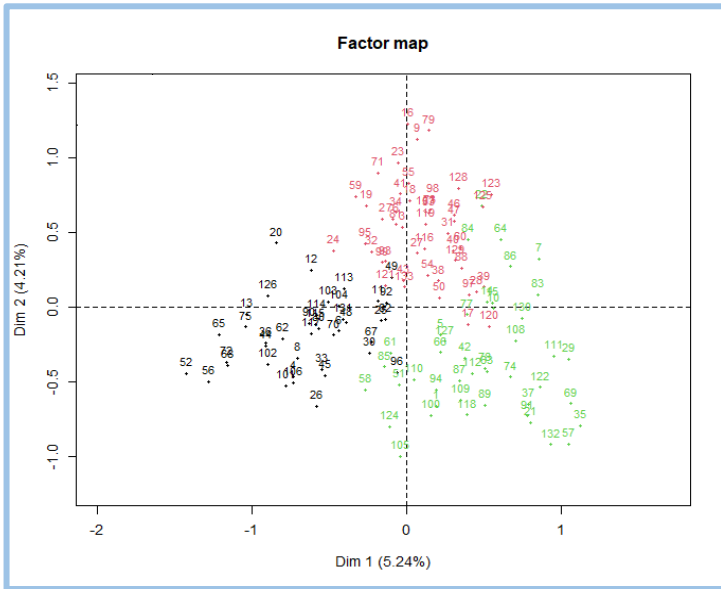


Table 6.		
Further support on the Spiritual level would help		
	Frequency	Percent
1	35	26.3 %
2	9	6.8 %
3	15	11.3 %
4	19	14.3 %
5	20	15.0 %
6	17	12.8 %
7	18	13.5 %

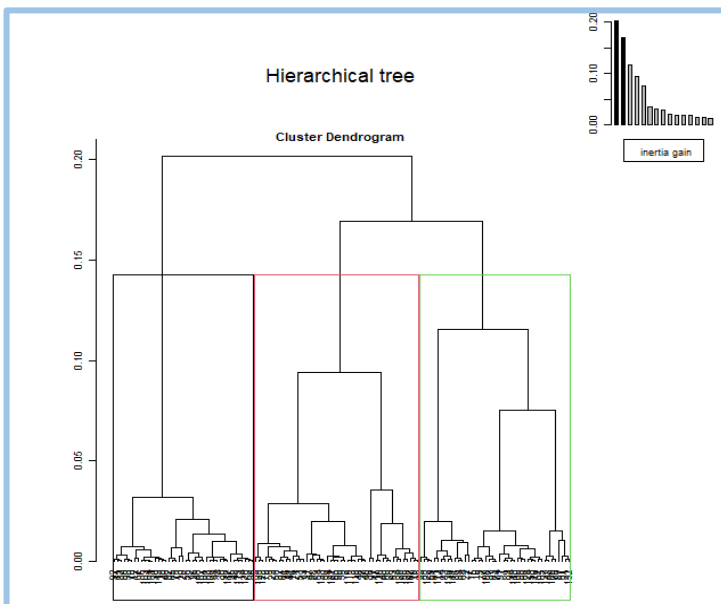
Graph 6.



Graph 7. The first factorial level



Graph 8. The classification dendrogram



Discussion

The results of the research show that belief in God gathers large percentages with a significant impact in people's daily lives. In the question whether after the appearance of the child's illness, faith affects the parent's life more, the total number that answers positively is 66.9%¹. This reinforces the view that spirituality and religiosity should be taken seriously account in the factors that regulate the course of a disease. This result, if combined with the next question about the development of anger towards God after the presentation of the childhood disease, which corresponds to a total percentage of 74.4% answering negatively², leads to the conclusion that in man's consciousness God holds a decisive role in his life. The data shows that human nature may be shaken at the onset of illness, but it does not displace God from the moment of this trial by placing the responsibility on Him, as some atheistic views maintain.

This view is reinforced by the results of the next question, which focuses on prayer as a need and a form of communication with God during the illness and care of the child with cancer. The prayer gathers a cumulative percentage of 87.2% in the three highest levels on the Likert scale, which represents 116 people of a total of 1333. The data from the question whether after the illness the respondent considers himself less, more or the same faithful as before, reveal that 63.2% answer more, 35.3% the same and only 1.5 % less⁴.

The following results essentially convey parents' requests for further support during their child's illness. In specific 60.2% chose the three highest levels regarding the need for psychological support⁵, with the corresponding percentage regarding support, on an intellectual level, being 41.3%⁶.

In the results of the present exploratory study, in order to get an overall picture of any latent groups in the sample data, we used methods of Data Analysis and in particular we used Hierarchical Classification after Multiple Correspondence Analysis through the language R. We notice in the results that 3 groups were formed with common between-person characteristics, where the color gradation (based on the listed contribution value) represents the category's degree of participation in the group's characterization⁷.

More specifically, the 1st group (green color) includes 43 people who are characterized by little expression of emotions such as fear, anxiety, loneliness,

1 Table 1 & Graph 1.

2 Table 2 & Graph 2.

3 Table 3 & Graph 3.

4 Table 4 & Graph 4.

5 Table 5 & Graph 5.

6 Table 6 & Graph 6.

7 Table 7 & Graph 8.

without experiencing fluctuations in their mood or any premonition that something bad about the outcome of their child's illness was going to happen. People with these characteristics do not seem to be affected in spiritual matters from the appearance of their child's illness onwards. More specifically, they note the lowest answers (number 1 on the 7-point Likert scale) to the questions whether after the onset of their child's illness, their belief or opinion about the afterlife affects their life more. In addition, these people answer negatively to the question about anger towards God because of their child's illness.

In the 2nd group (red color) we observe a parallel increase in the indicators in the answers of psychosocial and spiritual questions. In this group, which is the most populated with 52 of a total of 133, individuals are characterized by relatively high feelings of fear and despair, often experiencing loss of temper and inability to make decisions when adapting and responding to the new needs that arise. At the same time, a partial increase in positive answers in questions of faith, such as the existence of God and the change in parents' perception of the existence of life after death due to the appearance of childhood cancer, is observed in these individuals.

The 3rd group (black color) includes 38 people, who choose particularly high answers to the psychological issues under study. In particular, they choose the highest ranks (numbers 6 and 7 on the 7-point Likert scale) to the questions about loneliness, anxiety, fear, despair, depression, psychological trauma, expressing at the same time that they often experienced losing their temper and disturbing their psychological balance. These people state that after the appearance of their child's illness, the concept of faith affects their lives more.

Essentially, it could be said that an escalation is observed between the 3 groups, which seems to link the questions under study. The people who belong in the 1st group, do not show psychosocial difficulties and they also seem to be indifferent to spiritual issues. Subsequently, the partial increase in positive responses regarding psychological or social issues in the 2nd group, is accompanied by a corresponding partial increase in the levels of positive responses to faith issues. This escalation peaks in the 3rd group, where parents with high levels of expression of psychological difficulties, declare a greater influence of faith in their lives after the appearance of their child's illness.

Based on the above data we can argue that the experience of intense emotions and psychosocial problems may be related to the development of spirituality and religiosity. We see in our data that belief in God gathers large percentages in cases of parents with a high expression of psychological issues during their child's illness. However, it should be noted that the limitations of the research include the use of existing measurement tools based on the literature and for the specific point in time only. It is worth pointing out that the research field regarding the connection of spirituality or religiosity with childhood cancer and chronic illness, quality of life and

psychosocial empowerment of parents, is still unclear. It has not been determined with certainty whether and how spirituality and religiosity are related to the patients and their environment. A significant portion of the sources supports their positive correlation and the catalytic role of spirituality and religiosity, as sources of spiritual empowerment, hope and social well-being (McCoubrie et al., 2006) (Tarakeshwar et al., 2006).

Taking into account the exploratory results of the present research, spirituality and religiosity are suggested to be taken seriously among the factors that regulate the course of a disease. However, this is a first phase of exploratory research in Greece. In the context of palliative care, a concept that has been increasingly discussed in recent years, the contribution of Pastoral Counseling and Psychology, as a result of collaboration between Medicine, Psychology and Theology, can become decisive.

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