



## ***Spirituality on the Blog – Interpretation of the Narrative of a SMA Patient***

### ABSTRACT

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**RESEARCH OBJECTIVE:** The main goal of this article is to try to recognize the importance of spirituality in the process of dealing with SMA described on the patient's blog.

**PROBLEM AND RESEARCH METHODS:** We searched for answers to questions about the importance of spirituality in the context of struggling with the disease, religious coping strategies, and the way of growing in faith shown on the blog. A research approach was used, embedded in an interpretative paradigm, aimed at understanding and discovering the meanings given by the author of the narrative. Blog entries have been interpreted hermeneutically and phenomenologically.

**THE PROCESS OF ARGUMENTATION:** The introduction contains a description of the SMA, characterizes the blog as a research source and outlines the subject of the text. In the next section, the categories of spirituality and religious strategies for coping with disease are characterized, and research on the relationship between spirituality and health is reviewed. The presentation describes the methods used and the results of own research. In conclusion, an attempt was made to define the meaning of spirituality in the patient's life in the context of his life with the disease. The implications for pedagogical practice include reflections on the role of accompaniment in illness in the context of spiritual growth.

**RESEARCH RESULTS:** Spirituality is an important part of the author's life – he searched for answers regarding the meaning of suffering. He most often used a religious coping strategy through positive reevaluation (Harrison et al., 2001). The main motive for writing about transcendence seems to be the need to give a testimony. The blog is an illustration of the process of growing in faith.

**CONCLUSIONS, INNOVATIONS, RECOMMENDATIONS:** The blog is a source of knowledge about patients' experiences, helpful for specialists. Accompanying the sick person and listening to their history can be of educational value for both parties.

→ **KEYWORDS:** **PEDAGOGY OF RELIGION, DISABILITY, DISEASE, COPING, EDUCATIONAL SCIENCES**

## STRESZCZENIE

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**CEL NAUKOWY:** Głównym celem artykułu jest próba rozpoznania znaczenia duchowości w procesie radzenia sobie z SMA opisanym na blogu chorego.

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**PROBLEM I METODY BADAWCZE:** W trakcie badań poszukiwano odpowiedzi na pytania o znaczenie duchowości w kontekście zmagania z chorobą, stosowane strategie religijne radzenia sobie, drogę wzrastania w wierze ukazaną na blogu. Zastosowano podejście badawcze osadzone w paradygmacie interpretatywnym ukierunkowanym na rozumienie i odkrywanie znaczeń nadawanych przez autora narracji. Wpisy na blogu chorego na SMA poddano interpretacji hermeneutyczno-fenomenologicznej.

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**PROCES WYWODU:** We wstępie zawarto opis SMA, scharakteryzowano blog jako źródło badawcze oraz nakreślono tematykę tekstu. W kolejnym podrozdziale scharakteryzowano kategorie duchowości, religijności i religijne strategie zmagania się z chorobą oraz dokonano przeglądu badań na temat powiązań duchowości i zdrowia. Następnie opisano zastosowane metody i wyniki badań własnych. W podsumowaniu podjęto próbę określenia znaczenia duchowości w życiu chorego w kontekście jego życia z chorobą, stosowanych strategii religijnych radzenia sobie z nią. Implikacje dla praktyki pedagogicznej obejmują refleksje na temat roli towarzyszenia w chorobie w kontekście duchowego wzrostu.

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**WYNIKI ANALIZY NAUKOWEJ:** Duchowość jest ważną częścią życia autora bloga – w niej szukał odpowiedzi dotyczących sensu życia. Chory najczęściej stosował strategię religijnego radzenia sobie przez pozytywne przewartościowanie (Harrison i in., 2001). Głównym motywem pisania o transcendencji wydaje się dla niego potrzeba dania świadectwa wiary. Blog stanowi ilustrację procesu wzrastania w wierze.

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**WNIOSKI, INNOWACJE, REKOMENDACJE:** Blog jest źródłem wiedzy o doświadczeniach pacjentów, pomocnym dla specjalistów. Towarzyszenie choremu i słuchanie jego historii może mieć wartość edukacyjną dla obu stron.

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→ **SŁOWA KLUCZOWE:** PEDAGOGIKA RELIGII, NIEPEŁNOSPRAWNOŚĆ, CHOROBA, RADZENIE SOBIE, PEDAGOGIKA

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## Introduction

Spinal muscular atrophy (SMA) is a rare chronic disease of genetic origin, which until recently was considered incurable ([www.fsma.pl](http://www.fsma.pl)). Gradual muscle wasting is caused by the degeneration of motor neurons in the spinal cord (Iłżecka, 2021). It affects almost every area of patients' lives, gradually taking away their independence: "some patients may require special speech, chewing and swallowing therapy" (Iłżecka, 2021, s. 278).

Currently, about a thousand people with SMA live in Poland. About seven hundred of them are under treatment that gives a chance to stop or slow down the progress of the disease ([www.fsma.pl](http://www.fsma.pl)). There are few studies on living with SMA in the world literature.

Research shows the “need for novel, disease-specific assessments of quality of life in SMA” (Thimm et al., 2022).

In this article, I would like to focus on the spiritual dimension of living with the disease described in the SMA blog. I looked at the questions such as the importance of spirituality in the process of coping with the disease, the process of maturing in faith and the author’s message to readers.

Blogs are websites with a specific structure (Gumkowska & Maryl, 2009). For patients, the blog can become a place where they can tell their stories, share difficult experiences and gain understanding (Siuda & Pluta, 2020). Some researchers pay attention to the emancipatory dimension of the Internet for people with disabilities (Żuchowska-Skiba, 2015). Blogs are a source of information about an individual’s experiences. In pedagogical research, they can be analyzed as a form of narrative, although few researchers still use them (Ocloń, 2003).

## Relation of spirituality and health in research

The term “spirituality” is derived from latin verb spirare – “to breathe,” which is interpreted as a breath of the spirit (Różycka & Skrzypińska, 2011). With time, it gained new meanings – related to the sense of the meaning of life (Różycka & Skrzypińska, 2011). In the psychological sense, they can be understood as a kind of form of self-realization or a relationship with Higher Power (Heszen-Niejodek & Gruszczyńska, 2004, p. 22). In the psychology of religion, it is sometimes interpreted as a feeling of union with the Absolute (Krok, 2009, p. 129). Spirituality can also be seen in terms of activity aimed at discovering the meaning of life (Woods & Ironson, 1999). In Christianity, it is defined as a form of relationship with a personal God (Ostrowski, 2010).

Currently, in mainstream pedagogy, there is a tendency to negate the spiritual dimension of man (Ablewicz, 2007; Sztaba, 2015).

In the context of health pedagogy, the spiritual dimension is the subject of research on, inter alia, coping with illness, searching for the meaning of life, quality of life (Emmons, 2001; Heszen-Niejodek, 2006).

Religion, understood as a category related to spirituality – concerning rather religious practices – is treated as one of the strategies for dealing with difficult situations in many questionnaires: COPE – Coping Orientation of Problem Experience (Carver et al., 1989), WCQ – Ways of Coping Questionnaire (Folkmann & Lazarus, 1988), CSQ – Pain coping Strategies Questionnaire (Rosenstiel & Keefe, 1983). It is treated as a form of positive reevaluation, seeking support and coping with pain. Many studies confirm the positive relationship between religiosity and health (Pawlikowski & Marczewski, 2008).

Harrison et al. (2001) cite many ways of how one can deal with the illness with help of religion – from redefining it as Satan’s work or punishment for sins to treating it as a test from God or an opportunity for conversion. The sick person may also seek communication with other people through religion, or share his testimony with others. One can

look for hope in God. Prayer can be a distraction from a stressful situation. The danger broached by the above-mentioned authors is escaping from responsibility for the healing process and passive “relying on God.”

## Methodology of research

My aim was to reconstruct the patient’s experiences and find answers to the following research questions: What importance did the author of the blog assign to spirituality in the context of coping with the disease? What was the way of growing in faith described in the blog? What did the author want to convey to his readers about faith?

The source of the interpretation were the blog posts of a 26-year-old man with SMA, published over the course of 9 years (<https://kambloger.blogspot.com/>). I only selected the notes that referred to spirituality.

In my research embedded in an interpretative paradigm, I assumed that there are no naked facts that speak for themselves. It is the knowing subject that transforms data into facts, giving them a specific meaning in the light of the adopted, preliminary assumptions, concepts that define their nature and content (Olejnik, 2000, p. 118). My goal was to seek to understand and interpret the subjective human experience by discovering the meanings given through language (Gadamer, 2004).

The combination of hermeneutic and phenomenological methods helped me to understand the individual experiences and experiences of an individual (Ablewicz, 1994). At this point, I would like to quote selected blog entries along with my interpretation of the patient’s words. They concern the following categories: spirituality, religion in the context of coping with the disease. Chronological quoting of the entries will help me to show the process of author’s faith growth.

## Results of interpretation

Over the course of nine years, the author had published over a dozen entries on his blog relating to spirituality. Initially, he wrote on that matter only during the pre-Christmas preparations. The nature of the entries changed with the passage of time and the progress of the disease. I would like to present blog entries to show the changes which took place in the author of the narrative. The first post on spirituality was published just before Christmas, about a year after starting the blog. The author was 17 years old then.

I composed a poem. [...] Don’t let vodka do the singing. Let a man tire himself a little soberly. [...] Let us open our eyes to see the light. And let him no longer make us drown out our consciences! I do not know how I end up teaching God... (Cierniak, 2011).

The content of the post makes a lot of sense, even though it is kept in a playful tone. The commercialization of Christmas is a topic that strongly touched the author of the

blog – since he wrote about it for three years in a row just before Christmas Eve. He noticed the spiritual emptiness of people describing themselves as believers, who focused on external rituals.

It is only in 2014 that the author began to write about religion and spirituality in other contexts. He described a situational anecdote related to the visit of Jehovah's witnesses.

When they knocked on the door, they said that if someone had questions like why God allows suffering, etc., they would be happy to provide some answers. [...] I started talking to them in order to beat them (that means – to convert them) (Cierniak, 2014b).

In his entry, the young man shows himself as an active defender of the faith. It is clear that he had vast religious knowledge and was willing to debate with people with other views.

The next entry is about the meaning of life, faith, and values. It has a philosophical character.

People can be divided into those who see Meaning in Man's life and those who do not. I believe in Meaning. Even apart from Faith... (Cierniak, 2014a).

This statement is also an expression of self-identification. The author writes: "I believe in meaning" – as if he wanted to emphasize his position. It is a confession of faith in transcendence, without identifying it with a specific religious denomination. It can be assumed that the spiritual life allowed him to adopt a different perspective of assessing current events. Instead of focusing on the limitations of his illness, he tried to look for the meaning of life. In Harrison's terms, the entry combines several strategies of coping through religion – including "spiritual cleansing" (catharsis) and "spiritual connection" (connection with a higher force).

The next entry does not refer directly to spirituality but shows the power of the message of author's entries.

One of the priests [...] told me that he had created the Way of the Cross based on my various entries. At first, I have to admit, it made me feel good. But after some time I realized that something didn't work out well. [...] After all, I usually try to make it somewhat humorous [...] (Cierniak, 2015).

The author of the blog tried to keep his entries in an ironic tone, but also presented the difficulties he struggled with on a daily basis. It was not his intention to arouse compassion in the readers. The theme of the disease was so deeply connected with the author's identity that he did not notice his heroism in the ongoing struggle. However, he was pleased with the power of his narrative's impact on readers. He tried to bear witness to his suffering without feeling sorry for himself. Perhaps he treated his illness as a kind of God's mission. One of the coping strategies described by Harrison et al. is "religious helping," which can be understood as giving spiritual support to others (2001). The author has repeatedly emphasized the importance of faith in the context of sickness and death.

“Maybe I will repeat myself, but in the context of death, Faith is a really useful thing” (Cierniak, 2017b). In his entries, he referred to the perspective of eternal life.

Regardless of Faith, the prospect of death somehow determines us, but probably to a different degree. [...] We think about making better use of the time here, but we also bear in mind what will happen next (Cierniak, 2017b).

The author of the blog did not treat his illness as a punishment for sins or acts of Satan, but he tried to adopt a divine perspective on it. Tried to see it as an inexplicable but not meaningless experience. It is a strategy of positively reevaluating the meaning of difficult experiences and turning to transcendence (Harrison et al., 2001).

Next, the author reflects on the nature of suffering. His enthusiasm on scientific subjects and tendency of being rational appeared in it, but on the other hand, he clearly emphasized the importance of the spiritual sphere.

Some people ask themselves why they have some kind of misfortune. [...] Many diseases are simply the result of genetic errors. These, in turn, are a kind of “price” for evolution. [...] And that evolution chose me? Well... [...] Evolution and statistics can therefore explain evil, many diseases, accidents... The problem is that it does not comfort you. [...] Only faith can help here (Cierniak, 2017a).

He described his suffering as a natural part of life. He was partially able to understand his fate by science, but this did not give him spiritual comfort. He sought it in faith. In his entries, he never directly wrote about his illness as being marked by God, being chosen to proclaim his word. It can be assumed, however, that he tried to turn his experiences into something good – to make them meaningful by supporting other people in their spiritual development. For him, the experience of sickness was a test of faith. With his penultimate post he wrote about the examination of conscience:

It feels strange to be aware that in a moment you can go to the “Land of the Eternal Hunt.” You make a quick examination of your conscience and you see nothing special. The determination to improve is much stronger than usual, all thoughts are more intense. And then somehow you come out of it and the whole “catharsis” thing goes to hell [...] (Cierniak, 2020a).

The author has experienced a state of near-death many times in his life. He described it as a moment of strong spiritual awakening and was saddened by the fact that it always happened to be temporary. His assessment seems too harsh. It is natural that peak experiences occur in the face of death (Harrison et al., 2001).

In his last entry, he referred to the prevailing coronavirus pandemic. It seems that the entry contained some kind of educational rebuke. He wrote:

[...] for all those affected by the epidemic, for all those martyrs-hostages. You can do it! [...] ‘Maybe life is so hard because we constantly strive to make it easy for us?’ (Cierniak, 2020b).

In the face of death, the author wanted to sensitize his readers to the fact that perhaps they are losing a broader assessment of the events of their lives by focusing on passing difficulties.

I noticed that the author used two main strategies of coping with the disease through spirituality: mechanisms of positive reevaluation and seeking support through religion and spirituality (Harrison et al., 2001). The first way is to try to interpret one's fate through the prism of faith. The second is to offer help to other people. The author tried to see God's will in his life. Perhaps seeing his disability as a testimony of faith helped the author to cope with the difficulties.

## Summary

The statement that spirituality was for the author one of the strategies of coping with the disease is not enough. In faith, a man searched for answers to questions about the meaning of life and suffering. As in the research of other authors, mechanisms of positive reevaluation and seeking support through religion and spirituality can be discerned in the narrative. He did not seem to believe blindly, but also did not ignore God's interventions. His attitude was closer to the collaborative style (Harrison et al., 2001).

The blog illustrates the process of the author's faith growth. Initial reflections on the Christmas turned into serious entries about the essence of life and death. The sick person wrote about conscience and the acceptance of God's will.

By mentioning the topic of spirituality so often, the author proved that it was an important part of his life. On his blog, he tried to bear witness to faith. His reflections were a gift to the readers. It became an inspiration for me, for a priest who wrote considerations of the Way of the Cross, and for many other readers.

In his entries, he referred to priests who accompanied him on trips and retreats. From the pedagogical point of view, it can be assumed that his process of spiritual formation was strengthened by the support of significant people.

## Conclusion and recommendation

Regarding the implications for pedagogical practice, I have two main reflections on the spiritual sphere – they are focused on accompanying the patient in suffering. It is important to support the patient, to give him your time and attention. On the other hand, witnessing suffering in the course of voluntary work may have an educational significance. This ministry, "especially to the sick, is not just one-way giving. It is not that only healthy people give the sick time, attention, good words" (Wojtkun, 2017, p. 47). The cited author writes: "Spending time with a sick person is an opportunity to become his eyes, thanks to which the sick can see better, and the healthy one sharpens his spiritual gaze" (Wojtkun 2017). Accompaniment in suffering is a kind of gift that can serve

the spiritual formation of the patient and his companion. I believe this has a deep pedagogical significance.

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