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The role of religious beliefs and spirituality on the quality of life of rare diseases patients

Salomea POPOVICIU[1], Delia BIRLE[2], Serban OLAH[3], Ioan POPOVICIU[4]

Abstract

This study explored the relationship between religious beliefs and spiritual beliefs and the quality of life of Romanian rare disease patients. Specifically, the study, firstly, analyzed the correlations between self-reported life satisfaction and participants' beliefs in heaven, afterlife and God. Secondly, correlations between self-reported optimism and participants' belief in the role of spirituality and life meaning were studied. Thirdly, the relationship between self-reported health and church attendance, importance of church and importance God for Romanian rare disease patients were examined. Implications for social workers, counselors and health providers were also discussed.

Keywords: religious beliefs, spirituality, quality of life, rare disease patients.

Introduction

Rare diseases are usually chronic and often life threatening, and thus, their impact on the quality of life of those affected and their family is significant (Wästfelt, Fadeel & Henter, 2006). By definition, a rare disease has a prevalence of less than five in every 10,000 people from European Union, or less than 200,000 individuals from the USA (Hughes, Tunnage & Yeo, 2005). Therefore, rare diseases are really not that rare. Some studies estimated that 25 million North

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Americans and 30 million Europeans were, in 2006, affected by one of the 5,000–6,000 types of rare diseases identified since then, most of which were of a genetic origin (Haffner, Whitley & Moses, 2002; Haffner, 2006). Moreover, due to an increase in understanding of the underlying pathological and physiological mechanisms and the separation of large categories into smaller entities, hundreds of new rare diseases are identified each year (Wästfelt, Fadeel & Henter, 2006: 2). Even if no official statistics exist, the National Plan for Rare Diseases in Romania (NPRDR) (2010-2014) reports that the prevalence of Romanians affected by rare diseases is approximately 6-8% of the entire population, meaning that around 1,300,000 people suffer of a rare disease. Also, the data given by NPRDR suggest that around 1,250,000 Romanians do not yet have a correct diagnosis or adequate treatment and care. Considering the total number of affected individuals, there is an urgent need for research devoted to specific areas of interest related to rare disease patients. One area of interest is how a person who has been affected by a chronic illness adapts and adjusts (Sidell, 1997).

Many studies examined the influence of spirituality, religion and/or religiousness on coping with challenging situations such as health problems (Conway, 1985-1986; Gordon, et al. 2002; Holt & Dellmann-Jenkins, 1992; Koening, George, & Siegler, 1988; Rosen, 1982). Although, some research has focused on the role of spirituality, religion and/or religiousness on serious or chronic illness (Carver, et al. 1993; Pergament & Hahn, 1986), to the authors' knowledge no study has looked at the relationship between rare disease patients' coping skills and quality of life and their religious or spiritual beliefs. This study, using a quantitative research design in the form of a social survey, explored how religious and spiritual beliefs could be used to improve the quality of life of affected persons.

The healthcare and religious context of rare disease patients in Romania

Healthcare for Romanian rare disease patients

The collapse of Ceausescu's regime in Romania has been perceived by the people as a great liberating event. However, more than two decades later, Romania lags behind most other Central and Eastern European countries, struggling to reduce corruption, control black market and mass emigration, and convince European Union officials that the commitment to social and political reform is genuine (Romocea, 2011: 243). Nonetheless, since the turn of the twenty-first century, positive transformations have slowly begun to take place, offering hope for a more stable society. For example, joining the European Union in January 2007 was a significant achievement, but it also presented Romanian society with

the challenge of implementing effective changes at all social-economic levels. One of those challenges remains healthcare reform. In Romania, the healthcare system has as central authority The Ministry of Public Health, who is responsible for setting public health priorities. Healthcare is mostly founded through mandatory social insurance, while private health insurance remains underdeveloped. Due to low funding of healthcare, informal "out of pocket" payments are a very common way of insuring a slightly better treatment than the decreased healthcare standard that is one of the longstanding legacies of the Ceausescu regime.

In this context, the first steps taken to address the unique challenges met by rare disease patients were taken in 2003, when the Romanian Prader Willi Association (RPWA), a patient-parent advocacy group, was founded. RPWA was initiated by the parents of an affected child, and became one of the key players in providing a patient perspective on rare diseases. RPWA is also a leader in fostering rare disease research, promoting education and establishing partnerships between patients, families, doctors, researchers and authorities. Another important moment in Romanian rare disease history was in 2005, when the Centre of Information for Genetic Rare Diseases (CIGRD)—the first such centre in Romania—was opened. The main objective of CIGRD is to increase the awareness of rare diseases by informing patients, their families, specialists and researchers about the diagnosis and management of rare diseases. At the end of 2007, RPWA—who acts as a centre of information not only for Prader Willi but also for all other rare diseases—with the Romanian National Alliance for Rare Diseases (RNARD) concluded a partnership agreement with the Ministry of Public Health. As a result, the first National Plan for Rare Diseases in Romania (NPRDR) was created and as a consequence, the coverage of orphan drugs was improved, rare disease registries have been initiated and genetic counseling is on its way of becoming a reality for Romanian rare disease patients.

Future perspectives of NPRDR include providing a platform where academia, pharmaceutical companies, public authorities, policy makers and patient organizations can work towards the common goal of improving the diagnosis and treatment of rare diseases. Also, NPRDR aims to increase awareness and access to orphan treatment for all these conditions (Planul National de Boli Rare din Romania, 2010-2014).

The Romanian religious background

In Romania, after the events on December 1989, the presence of the Orthodox Church at the establishment of the first interim political leadership indicated to the people that churches would play a positive and active role in the transition from an authoritarian regime to democracy (Romocea, 2011: 244). One image that remained in the memory of Romanians is that of religious leaders and clergy leading public prayers with the protesters in the markets and streets of various

cities during Revolution days. While countries like France or USA promote separation between church and state, in Romania, after the fall of the Ceausescu regime, state support for religion was not questioned, but enthusiastically welcomed by most. After many decades of institutionalized atheism, the turn towards religiousness "was radical but somewhat expected" (Sandor & Popescu, 2008: 172). Therefore, in Romania, religion is supported by the state, meaning that central or local governments pay for church personnel, religion is part of the school curricula, Orthodox churches are built from public money (and sometimes with the help of private donations) and public displays of religious symbols are present in many state institutions (Sandor & Popescu, 2008).

Understandably, not all are content with the *status quo*. For example, the claim that the Orthodox Church is the "national church" is somewhat of a national dispute, often leading to confrontations between the majority church and minorities. For example, non-orthodox Romanians, generally reject the position of the "national church" on both legal and cultural grounds. Thus, while some argue that a "national church" is against the Constitution, others feel that a symbiosis between church, nation and culture feeds into the rise of nationalism and marginalizes Romania. The Orthodox theologian, Ion Bria (1999: 163-164) notes: "While the Evangelical Protestant movement denies the Christian character of the Romanian people and history (their quasi-mentor, Mihai Ralea, a Marxist sociologist, describes the "Romanian phenomenon" as secular and religions as irrelevant to people), the Catholic movement protests the political implications of the "national church" title. Romanian Orthodox, they say, found it very difficult to distance themselves from the communist regime, and thus, compliantly collaborated with them. The Reformation churches, Reformed (ethnic Hungarians) and Lutheran (ethnic German) for whom *cuius region eius religio* is still a positive principle, have reacted strongly against the proposed phrase as an exclusion of all other forms of Christian communities in the country and of confessional plurality". In defense the Orthodox Church argues, more or less convincingly, that being a "national church" does not equal discrimination against the rights of religious minorities. The religious freedom of all denominations is, in fact, protected by the Constitution and the state insists that it assures the freedom and justice of any recognized religious groups in Romania.

Another notable reaction came in 2006, when a debate was initiated regarding the public display of religious symbols (CNCD Decision 323/2006), which was seen as an attempt to prevent discriminatory attitudes towards other religious groups, some of whom made efforts to receive a similar treatment from the state. However, the initiative was short lived, as in June 11, 2008 the High Court of Cassation and Justice ruled that the presence of religious symbols in public institutions is in fact legal. In consequence, the CNCD's ruling for "respect of the secular character of the state and autonomy of religion" was overruled. The Romanian nation and culture remain deeply rooted in the Orthodox tradition, with

Romania being the "only Christian nation in European history whose identity is a synthesis between Eastern tradition and Latin culture and language" (Bria, 1999: 164). According to a recent Public Opinion Barometer (POB) (2005), religious and spiritual indicators in Romania remain relatively high. This report examined different religious and spiritual beliefs and religious practices in Romania such as: the importance of religion to Romanians, attendance of religious services, spirituality and the meaning of life and the importance of religion in addressing social problems. POB noted that in 2005, 91% of Romanians thought of themselves as religious people, 96% stated that they believed in God and 66% declared that God played an important role in their lives. Only 6% declared that they are not religious people and less than 1% reported that they are atheists. Regarding spiritual practices, 93% noted that they engaged in activities such as meditation or prayer and 64% contemplated, at least sometimes, the meaning of life. Participants, also, believed that the church offers solutions to people's spiritual questions (81%), moral needs (71%), everyday family problems (62%), and to a lesser extent, social problems (39%).

It is well known that the religiosity of Western Europe is somewhat different from the religiosity of Eastern Europe, particularly in Romania. The reasons are, of course, multiple. On the one hand, according to Remond (2003, cited by Voicu, 2007), predominantly Orthodox countries from the East witnessed a delay in secularization partly due to the long Ottoman Empire domination. On the other hand the majority of these states, excepting Greece, had been for at least half a century under atheist Communist regimes that placed restrictions on religious faith (Cojocaru, Cojocaru & Sandu, 2011). Therefore, secularization in the East has been influenced, not only by local religious traditions, but also by the atheist policy promoted by Communism (Voicu, 2007: 17). A more controversial explanation of Romanian religiousness can be offered by appealing to Iannaccone's theory of religious economy (Iannacone, 1998, Blasi, 2009). Iannaccone, who was a former student of Gary Becker (the renowned economist from University of Chicago), proposed that the difference between the high and relatively constant religious participation in the United Stated and the lower religious participation in Western Europe can be explained by using a conceptual economical model. Thus, if in Sweden (Iannaconne's chosen example), with its Lutheran majority religion, the clergy are generously paid by the state, in the United States, with its competitive market, religious leaders are encouraged to creatively meet the religious and spiritual needs of a wide range of people. Under these conditions, the diverse religious market may lead to a rise in religious participation. However, the theory of religious economy does not adequately explain Romanian, or Eastern European, religiosity, a fact acknowledged by Iannaccone. In Romania, the Orthodox Church is similar, in its privileged position, to the Swedish Lutheran Church: the clergy are paid by the state, and there is a high religious services attendance both on

Sundays and in holidays. In Romania, some of the most celebrated religious holidays are: Christmas, Easter, Flowers' Sunday and St. Mary's.

Another way to look at differences in religiousness (or lack thereof) between societies is to appeal to variances between social-economic standards. Inglehart (1990, 2003, 2004 cited by Voicu, 2007:17) noted that in intensely industrialized countries religiousness is, generally, lower than in less developed countries. The main argument is that people who have been socialized and live in an insecure social environment are subject to multiple risks such as poverty, disease or unemployment, and thus welcome the predictability and security given by religious beliefs (Cojocaru & Sandu, 2011). In Romania, as everywhere the individual with a rare disease must find strategies to reduce the impact of his or her illness. Thus, the individual's subjective psychological outlook in the presence of chronic illness determines his perceived quality of life (Burckhardt & Anderson, 2003). In the context of illness, quality of life (QOL) is a multidimensional, dynamic and subjective view of health relating satisfaction. Research shows, that this health-related satisfaction is connected to spiritual and religious well-being (Bishop, 2005; Koening, George & Siegler, 1988; Mickley, Carson & Soekn, 1995; Sawatzky et al., 2005), which in turn can be shaped by the individual's social culture. Therefore, the results of the present paper should be understood and interpreted in light of the healthcare and religious context of the participants.

Method

The current study was part of a larger research funded by The Norwegian-Romanian Partnership for Progress in Rare Diseases that involved an extensive survey on the quality of life of rare disease patients in Romania. The current paper reports only on the religious and spiritual dimension of the QOL of rare disease patients in Romania. Considerable debate has revolved around the differences and similarities between concepts such as spirituality, religion and religiousness (Zinnbauer et al., 1997). For the purpose of this paper, religiousness will be seen as both intrinsic - the commitment and importance an individual assigns to religion (Allport & Ross, 1967; Kelley, 1995) - and extrinsic - the comfort and social connections people find in their religious practices (Mickley, Carson, & Soeken, 1995). Religion will be used in the sense Zinnbauer et al. (1997) suggested: as belief systems and practices of a church or any other organized religious institutions. In contrast, spirituality, while it can be expressed in religion, is quite different from religion, in that it may also encompass other areas, such as a person's culture or philosophy of life (Tanyi, 2002). Due to the fact that a number of individuals may not identify themselves with a particular religious tradition or ideation, it is important to examine spirituality as distinct from religion (Peterman,

et al, 2002). As such, "spirituality is not a homogenous practice, but reflects individual expressions of being" (Adegbola, 2006: 44).

The religiousness and spirituality of Romanian rare diseases patients were measured by answers given to survey questions such as: "Do you believe in God?", "How important is God in your life?", "How important is church in your life?", "How often do you attend religious services?", "Do you believe in heaven or life after death?", "Does spirituality help you cope with your illness?", "Do you believe your life has meaning?" and "Does spirituality help you better understand suffering?"

A religiosity scale was created to examine respondents' belief in God, afterlife and heaven. This variable had 5 items, asking respondents if they believed in God, heaven, hell, sin and life after death. Internal consistency was high, with a Cronbach's alpha coefficient of .718 (N of valid responses=564, N of items=5). Another scale was created to examine respondents' spirituality. For this variable, 4 items were created asking participants if adhere to statements such as: "spirituality helps me better understand suffering", "spirituality helps me find the strength to cope with my illness", "my life has meaning", "spirituality helps me understand the purpose of life". Internal consistency was high with a Cronbach's alpha coefficient of .836 (N of valid responses=580, N of items=4).

This study also included three evaluations that were then correlated with religiosity and spirituality: self-reported of life-satisfaction (answers were given on a 5 point Likert scale where 1=high level, and 5=low level), self-reported of optimism (answers were given on a 5 point Likert scale where 1=high level, and 5=low level) and self-assessment of health (answers were given on a five point Likert scale, where 1=excellent and 5 poor).

A number of 645 rare disease patients took part in the study on a voluntary basis. A snowball sampling method was used. Access to patients was obtained through RPWA, and although not all persons suffering of rare diseases were members of RPWA, it is the only such organization in Romania, and we felt that a large number of patients could be reached through it. E-mails were sent to county representatives of the National Alliance for Rare Diseases (NARD) who identified patients and their families. These patients and their families were asked to forward it to other patients suffering from a rare disease. Surveys were collected in 2010-2011, and an electronic database was set up to collect and summarize the information obtained. The surveys were examined using the database's sort capabilities, and analyses on each research question were generated. Condentiality and anonymity were assured, and all study procedures were approved by the Emanuel University of Oradea's Ethical Board.

Participants

Participants in this survey were 645 rare disease patients from all 44 Romanian counties (including Bucharest and Ilfov). After the data collection procedure, data from 46 respondents were eliminated because of large number of missing responses, which gave us a final sample 599 participants who reported suffering from a total of 41 rare diseases (see table 1).

Table 1. *Respondents' rare disease diagnosis*

Rare disease	Frequency	%	Rare disease	Frequency	%
Acute Promyelocytic Leukemia	6	1.2	Thalassemia major	1	.2
Aortic Insufficiency	1	.2	Williams syndrome	1	.2
Atrial septal defects	4	.7	Von Recklinghausen's disease	2	.3
Autism	2	.3	Osteogenesis imperfecta	7	1.2
Congenital Dislocation	2	.3	Spastic tetraparesis	2	.3
Congenital heart malformation	2	.3	Plasma thromboplastin antecedent deficiency	1	.2
Coxarthrosis	22	3.6	Prader Willi Syndrome	14	2.3
Epidermolysis bullosa	16	2.7	Pulmonary arterial hypertension	1	.2
Fenilcetonuria	21	3.5	Amyotrophic lateral sclerosis	1	.2
Friedrich ataxia	1	.2	Parkinson's Disease	4	.7
Gaucher Disease	1	.2	Angelman syndrome	2	.4
Hemophilia	150	25.1	Down syndrome	32	5.4
Hepatitis B	1	.2	Rett syndrome	66	11
Hereditary angioedema	9	1.5	Neurofibromatosis	65	10.9
Hipomelanoza Ito	1	.2	Werdnig Hoffman Disease	1	.2
Hodgkin's Lymphoma	1	.2	Tetralogy of Fallot	1	.2
Kugelberg Welander Syndrome	1	.2	Narcolepsy with cataplexy	2	.4
Muscular dystrophy	3	.5	Congenital Sclerosis	1	.2
Myasthenia gravis	23	3.8	Multiple sclerosis	121	20.2
Progressive Myoclonus Epilepsy	3	.5	Negative rheumatoid factor polyarthritis	1	.2
Von Willebrand disease	1	.2	**Total**	**599**	**100.0**

The respondents were aged between 14 and 81 years old (m=34.00; s.d.= 12.96); 285 were male and 314 female. Their academic attainment was: 74.1% graduated high-school, 15.6% had a university degree and 10.3% had post-university studies. Also, out of a total of 599 participants, 480 noted that they were Orthodox (80.1%), 49 Evangelical Protestants (8.2%), 26 Roman-Catholic (4.3%), 16 (2.7%) Greek-Catholic, and 23 (3.8%) reported that they have a different religion. In our sample no subject declared himself an atheist.

Results

Overview of statistical analyses

Firstly, analyses were carried out to verify the correspondence between participants' self-reported life satisfaction and each of the following: (1) participants' belief in heaven; (2) participants' belief in an afterlife; and (3) participants' belief in God.

Secondly, analysis were carried out to verify the correspondence between participants' self-reported optimism and each of the following: (1) participants' belief that spirituality helps them better understand suffering; (2) participants' belief that their life has a meaning; and (3) participants' belief that spirituality helps them better cope with illness.

Thirdly, analysis were carried out to verify the correspondence between participants' subjective assessment of their health and each of the following: (1) the importance of God in their lives; (2) participants' church attending rate; and (3) participants' assessment of the importance of church in their life.

Differences between participants' self-reported life satisfaction, optimism and health assessment

Table 2. *Participants' self-reported life satisfaction, optimism and health*

Item*		1	2	3	4	5	**Total****
Self-assessment of health	f	4	13	88	250	241	**596 (3 missing)**
	%	.7	2.2	14.8	41.9	40.4	**100**
Self-reported life satisfaction	f	22	182	154	142	87	**587 (12 missing)**
	%	3.7	31	26.2	24.2	14.8	**100**
Self-reported optimism	F	71	131	168	194	20	**584 (15 missing)**
	%	12.2	22.4	28.8	33.2	3.4	**100**

*A five point Likert scale was created for each item. 1=excellent/totally agree; 2=very good/agree; 3= good, moderate; 4= satisfactory/slightly agree; 5=poor/disagree.

**The total number does not add to 599 due to missing answers

Table 2 displays the frequencies and percentile for participants' self-reported life satisfaction, optimism and health. Results show that most participants assessed their health as poor, and were generally not very optimistic about their future. However, most respondents noted that their satisfaction with life is good enough.

Correlations between self-reported life satisfaction and participants' beliefs in heaven, afterlife and God

Table 3. *Life satisfaction and belief in heaven*

		Belief in heaven		**Total***
		Yes	no	
Self-reported life satisfaction	Very high	18	4	**22**
	High	172	7	**179**
	Moderate	145	6	**151**
	Low	124	13	**137**
	Very low	68	16	**84**
Total		**527**	**46**	**573**

*The total number does not add to 599 due to missing answers

Table 3 shows the correlations between life satisfaction and participants' belief in heaven. Contingency coefficient was computed with a value of .208 ($p<.01$). This coefficient was chosen as the variable "belief in heaven" and was considered on a nominal scale. The association between life satisfaction and belief in heaven is statistically significant as results show a higher frequency for low life satisfaction and unbelief in heaven. The higher frequencies indicate an association between higher life satisfaction and belief in heaven (N=172).

Table 4. Life satisfaction and belief in an afterlife

		Belief in afterlife		**Total***
		Yes	No	
Self-reported life satisfaction	Very high	18	4	**22**
	High	165	14	**179**
	Moderate	139	12	**151**
	Low	108	23	**131**
	Very low	63	20	**83**
Total		**493**	**73**	**566**

*The total number does not add to 599 due to missing answers

Table 4 displays the correspondence between participants' self-reported life satisfaction and belief in an afterlife. The contingency coefficient' value is .184 ($p<.01$). The number of respondents that reported not believing in an afterlife is twice as high as the number of respondents that reported not believing in heaven. This difference might be explained by the more abstract concept of "afterlife", compared to the commonly used (and thus better understood) concept of "heaven". Associations are found between higher life satisfaction and belief in life after death.

Table 5. *Life satisfaction and belief in God*

		Belief in God		**Total***
		Yes	No	
Self-reported life satisfaction	Very high	20	2	**22**
	High	179	2	**181**
	Moderate	153	1	**154**
	Low	135	1	**136**
	Very low	83	1	**84**
Total		**570**	**7**	**577**

*The total number does not add to 599 due to missing answers

Table 5 displays the correspondence between self-reported life satisfaction and belief in God. A significant coefficient was found between the association of the two variables, with a contingency coefficient of .145, $p<.05$. This association is not as high as the ones found between life-satisfaction and belief in heaven or an afterlife, due to lower negative frequencies for belief in God. A very high percentage of respondents reported believing in God, and thus, it is difficult to estimate the direction of the association between this belief and life-satisfaction.

Correspondence between self-reported optimism and participants' beliefs that spirituality helps them better understand suffering, their lives have meaning and spirituality helps them better cope with illness

Table 6. *Optimism and the role of spirituality in understanding suffering*

		Role of spirituality in understanding suffering				
		Very high	High	Moderate	Low	**Total***
Self-reported optimism	Very high	37	17	7	4	**65**
	High	38	58	21	8	**125**
	Moderate	36	73	46	7	**162**
	Low	11	73	87	8	**179**
	Very low	5	5	7	1	**18**
Total		**127**	**226**	**168**	**28**	**549**

*The total number does not add to 599 due to missing answers

Table 6 shows the correspondence between participants' self-reported optimism and their beliefs that spirituality helps them better understand suffering. A significant association was found between the two variables, with a Somers' d coefficient of .285, $p<.01$. Somers' d coefficient was chosen for the measure of the association between the two ordinal variable. The direction of the association

suggests that respondents who reported a higher role of spirituality in understanding suffering also noted higher levels of optimism.

Table 7. *Optimism and meaningful life*

		Meaningful life					
		Very high	High	Moderate	Low	Very low	**Total***
Self-reported optimism	Very high	39	26	1	1	1	**68**
	High	45	62	19	0	1	**127**
	Moderate	22	81	48	10	0	**161**
	Low	11	61	97	10	2	**181**
	Very low	2	7	5	5	1	**20**
Total		**119**	**237**	**170**	**26**	**5**	**557**

*The total number does not add to 599 due to missing answers

Table 7 shows the association between self-reported optimism and participants' belief that their lives have meaning. The association between the two variables is significant, with the value of Somers' d coefficient of .421, at a significance level $p<.01$. Respondents that noted a lower meaning of life also showed less optimism toward their future.

Table 8. *Optimism and spirituality as a coping strategy in illness*

		Spirituality as coping strategy in illness					
		Very high	High	Moderate	Low	Very low	**Total***
Self-reported optimism	Very high	36	24	4	2	3	**69**
	High	43	52	23	5	3	**126**
	Moderate	40	74	43	7	1	**165**
	Low	18	67	87	10	3	**185**
	Very low	5	7	4	2	2	**20**
Total		**142**	**224**	**161**	**26**	**12**	**565**

*The total number does not add to 599 due to missing answers

Table 8 displays the correlation between self-reported optimism and the belief that spirituality can help in coping with the illness. The value of Somers' d coefficient is .279, and the level of significance $p<.01$. Results indicate that a strong belief in spirituality as a coping strategy in illness correlate with a high level of optimism. Results also suggest that low levels of optimism correlate with lower beliefs in spirituality as a coping strategy.

Correspondence between subjective assessment of health and participants' beliefs in the importance of God, church and church attendance

Table 9. *Health assessment and importance of God*

		Importance of God					
		Very high	High	Moderate	Low	Very low	**Total***
Health assessment	Excellent	0	0	0	0	4	**4**
	Very good	0	0	0	3	8	**11**
	Good	2	2	7	14	59	**84**
	Satisfactory	6	1	24	49	163	**243**
	Poor	4	2	15	39	172	**232**
Total		**12**	**5**	**46**	**105**	**406**	**574**

*The total number does not add to 599 due to missing answers

Table 9 shows the association between self-assessment of health and participants' report on the importance of God in their lives. Due to a large number of null cells, the analysis can only describe the frequencies repartition. In this study, none of the participants reported that God is of no importance to them, and also, quite understandably, none of the participants assessed their heath as "excellent" or "very good".

Table 10. *Health assessment and church attendance*

		Church attendance				
		At least once a year	At least once a month	At least once a week	More then once a week	**Total***
Heath assessment	Excellent	1	2	0	1	**4**
	Very good	4	6	3	0	**13**
	Good	18	34	20	8	**80**
	Satisfactory	70	87	48	9	**214**
	Poor	80	81	41	5	**207**
Total		**173**	**210**	**112**	**23**	**518**

*The total number does not add to 599 due to missing answers

Table 10 displays the correspondence between health assessment and church attendance. Most respondents declared that they attended church services at least once every month. They also reported lower levels of heath. Due to the presence of null cells, we can, again, only analyse observed frequencies.

Table 11. *Health assessment and importance of church*

		Importance of church					
		No importance	Low importance	Moderate	Important	Very important	**Total***
Health assessment	Excellent	0	0	1	0	3	**4**
	Very good	1	2	3	2	5	**13**
	Good	4	8	6	14	48	**80**
	Satisfactory	6	14	40	47	107	**214**
	Poor	6	9	38	33	120	**206**
Total		**17**	**33**	**88**	**96**	**283**	**517**

*The total number does not add to 599 due to missing answers

Table 11 displays the correspondence between health assessment and the importance of church for participants. Results indicate that for the majority of respondents church is very important. On the one hand, this result correlates with a lower health. On the other hand, none of the participants indicated "excellent" health or church as of "no importance" or "low importance". The association of frequencies shows that respondents with poorer heath seem to think of church as "important" or "very important".

Discussion

The results of this study suggest that rare disease patients in Romania are deeply religious people. The majority reported belonging to the national Orthodox Church, and no respondent identified himself as atheist or „without religion". While it is evident that factors other than religious beliefs are important in the QOL of people with rare diseases, our results show that religion and spirituality can be an important dimension in the QOL of people diagnosed with a rare disease. While, social workers and counselors should not assume, even in a „Christian nation" such as Romania, that all are indeed Christians, they need to be willing to address issues related to religion and spirituality (Spitznagel, 1997). Providers of healthcare have, at times, tried to avoid religious and spiritual issues, categorizing them as personal beliefs with little therapeutic value (Koenig & Larson, 2001), but a careful assessment of the cultural variables that affect rare disease patients, could lead to the development of appropriate goals that incorporate clients' religious and spiritual beliefs (or lack thereof) into intervention plans. Also, social workers and counselors should strive to convey their ability to listen carefully, and without judgment, to the religious and spiritual beliefs that clients may wish to disclose (Sermabeikian, 1994; Rodriguez & Walls, 2000; Cojocaru, 2005). The results of this study indicate that rare disease patients who perceived lower health levels were more willing to attend religious services. It is possible that participation to religious services could provide them with needed peer support and create a context for significant interactions with others. These interactions have potential to enrich life and provide a sense of new meaning in the face of suffering (Sermabeikian, 1994). Some research suggest that actively belonging to a religious group may offer a spiritual basis for life meaning and a place for receiving support from others; factors known to potentially reduce and protect against depression (McCullough & Larson, 1999).

Results also show that higher levels of spirituality and meaningful life positively correlate with optimism. Facing an illness that points to the fragility of existence can lead people to question the purpose of life. Spirituality and the sense that life has meaning can provide rare disease patients with the opportunity to develop a personal symbolic visualization of a higher power. This manifestation

of spirituality has the potential to aid them to look beyond their immediate circumstances and find optimism and courage in dealing with the painful emotions that often accompany illness (Bormann et al., 2006; Gordon et al. 2002). Sometimes, spirituality needs to be examined alone, in order not to exclude those who do not subscribe to denominational religious beliefs, but who yet have spiritual beliefs and practices (Peterman at al., 2002).

Results show that belief in God, heaven or an afterlife can lead to greater life satisfaction. While some people suffering from rare diseases may have angry feelings toward God, or may view their illness as a form of punishment (Weaver et al., 2006), others may find hope and strength in their religious beliefs. For example, Koening and Larson (2001) found that religious beliefs centering on compassion, caring, hope, forgiveness and transcendent meaning, can provide an optimistic worldview and a better perception of well-being in the midst of illness symptoms. Thus, when the religious views of clients begin to hinder their ability to cope with rare diseases and lower their QOL, social workers and counselors might need to challenge or redirect their clients' reasoning. Other times, social workers and counselors may need to collaborate with religious and spiritual leaders in order to find ways to enhance spiritual balance and improve QOL (Adegbola, 2006).

This study is not without limitations. Firstly, due to the homogeneous nature of the population studied, the results cannot be generalized. Secondly, in this paper, only the role of religious beliefs and spirituality in the QOL of rare disease patients were examined, but other factors not studied here could have played a critical part. However, the results of this study suggest that it would be in the benefit of rare disease patients to have the option of a sensitive and non-indoctrinating spiritual or religious assessment by healthcare providers. This assessment may have the potential of improving the QOL of people diagnosed with rare diseases.

Conclusions

This study explored the connection between religious and spiritual beliefs and the QOL of Romanian rare disease patients. Firstly, results showed positive correlations between life satisfaction and participants' belief in heaven, afterlife and God. Secondly, participants who believed that spirituality can provide them with a better understanding of illness reported more optimism towards the future. Thirdly, participants that showed an increase in spirituality and life meaning, also had a more optimistic and hopeful outlook in life. Lastly, results indicate that actively belonging to a religious group and viewing church as important to one's life might create a valuable time where religious rare disease patients can receive support and significantly interact with other people. More research is needed to

investigate if patients who are less religious may find that same benefit in support groups, or other meaningful connections with peers.

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