ANTICANCER RESEARCH 25: 1449-1456 (2005)

Search for Meaningful Support and the Meaning of Illness in German Cancer Patients

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Abstract. *Background: Spiritual needs are an essential component of holistic health care. Several studies have shown that religious involvement and spirituality are associated with better health outcome, coping skills and health-related quality of life. Patients and Methods: Using the newly developed SpREUK inventory, we examined how German cancer patients (n=115) by themselves view the impact of spirituality and religiosity (SpR) on their health and how they cope with illness. Results: Cancer patients with both a religious and spiritual attitude had significantly higher values in the search for meaningful support and in addressing the stabilizing effects of SpR than patients without such attitudes. Patients with non-spiritual religious attitudes had a lower perception of the beneficial effects of their SpR and significantly lower needs for meaningful support. Female cancer patients were convinced that finding access to a spiritual source has a positive influence on their illness, that illness has meaning, regard illness as a chance for their own development and as a hint to change life. Conclusion: Knowledge of a patient's spirituality can help service providers predict aspects of psychosocial needs and to respond sensitively and appropriately. The SpREUK questionnaire is a useful tool to define patients who are more in need of spiritual support than others.*

Spirituality has become a subject of growing interest in health care. The World Health Organization suggests that spiritual needs are an essential component of holistic health care assessment (1,2). Several scientific papers discuss the connection between religiosity, spirituality and health, and the potential to prevent, heal or cope with diseases (for review see 3-13). Levine and Targ (14) found significant correlations of spirituality and spiritual well-being with functional well-being rather than physical well-being, but items pertaining to meaning and peace tended to correlate significantly with physical well-being. Spirituality also correlated significantly with several coping styles. Spiritual well-being offers some protection against hopelessness and despair in terminally ill patients (15-18). Moreover, there is less doubt that values and goals are important contributors to life satisfaction, physical and psychological health, and that goals are what gives meaning and purpose to people's lives (19, 20).

However, in face of a life-threatening disease, do patients find meaning and purpose in their life? There is, as yet, only limited understanding of how patients themselves view the impact of spirituality on their health and well-being, and whether they are convinced that spirituality may offer some beneficial effects. Only a few empirical studies have explored the patients' views (16, 21, 22).

Since search for coping strategies, meaning, purpose and stability in life are relevant aspects of spirituality, we conducted a survey to analyze the basic attitudes of cancer patients towards these distinct topics of spirituality/religiosity, with regard to their illness. Survey data collected among patients in a German hospital were analyzed using the newly developed SpREUK questionnaire (23-26). This questionnaire focuses on whether patients by themselves regard spirituality and religiosity (SpR) as helpful in their life, whether they are in search of a spiritual source, and whether they are convinced that their illness has meaning ("message of disease").

Patients and Methods

Patients. Patients were informed of the purpose of the study and were assured of confidentiality. All patients gave informed consent to participate. The patients were recruited consecutively in the cancer service, and in the internal medical unit of the Communal Hospital in Herdecke (Germany). They completed the questionnaire by themselves.

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Key Words: Questionnaires, religion and medicine, spirituality and religion, cancer patients.

Table I. *Demographic data and SpREUK scores of 115 cancer patients.*

	%	sub-scale 1 (54.5±24.3)	sub-scale 2 (73.4±19.5)	sub-scale 3 (74.2±24.1)	sub-scale 4 (63.1±21.8)	sub-scale 5 (63.2±22.9)
Sex		**	**		*	(*)
female	73	59.3±24.4	76.6±19.2	75.8±23.4	65.8±21.6	65.5±22.7
male	27	41.5±18.5	64.6±17.8	69.8±25.9	55.8±20.9	57.0±22.8
Age		(*)				
30-49 years	24	61.6±22.1	80.2±15.4	70.4±23.2	66.4±18.7	65.5±19.3
50-69 years	62	52.8±25.6	72.3±19.2	74.8±25.1	62.2±21.2	63.3±23.0
> 70 years	14	50.0±20.2	66.0±24.3	78.1±21.9	61.8±29.2	58.9±28.8
Marital status		*			*	
married	72	50.3±23.9	71.3±20.0	72.9±24.7	59.2±22.4	62.3±23.3
living with partner	8	68.5±11.6	79.4±11.9	64.4±21.2	66.7±10.7	68.5±15.5
divorced	8	60.2±32.0	79.6±21.8	79.2±25.6	71.4±21.8	71.3±29.5
alone	8	73.1±21.2	81.9±17.8	84.3±21.0	80.0±17.2	73.1±16.6
widowed	4	19.2±3.5	64.3±11.0	82.7±18.8	70.5±15.1	48.3±19.9
Education[1]		*	**			
level 1	29	43 2±22.5	60.1±18.3	76.6±25.7	58.2±21.5	59.4±22.3
level 2	25	52.7±28.8	82.0±15.6	84.8±16.3	61.3±23.5	63.7±25.7
level 3	34	64.0±20.9	76.0±16.0	77.6±15.0	69.2±14.9	65.4±16.3
other	13	78.0±18.1	82.1±17.7	78.6±19.8	73.9±18.8	77.4±18.4
Duration of disease						
< 0.5 years	18	61.3±21.5	79.2±15.0	78.8±13.8	65.8±19.1	65.8±21.3
0.5-1 years	22	53.2±23.9	66.9±19.0	68.6±26.5	57.7±20.0	58.0±25.4
1-3 years	32	53.6±25.7	74.6±19.0	69.8±26.3	62.5±22.2	62.3±21.4
3-5 years	8	54.2±25.6	68.5±15.2	84.7±19.2	69.5±19.1	58.3±23.6
> 5 years	20	50.9±25.6	74.4±24.5	76.5±26.4	62.6±26.9	67.0±22.6
Religion				**	**	
Christian	84	55.9±23.3	73.4±19.9	78.5±19.7	65.8±20.4	63.8±22.8
Others	4	61.7±22.5	67.5±19.3	82.5±19.2	65.0±19.2	78.3±18.3
None	11	44.2±29.3	73.6±17.4	37.8±25.6	71.9±23.4	52.6±23.7
Spiritual attitude		**		**	**	**
R+S+	35	71.4±19.5	79.4±15.9	86.9±13.4	75.6±14.5	72.7±17.7
R+S-	37	46.5±20.9	70.1±18.3	84.7±13.6	63.9±17.6	63.4±20.7
R-S+	12	64.0±12.9	73.6±25.5	49.1±12.1	60.4±20.6	69.6±19.8
R-S-	13	26.9±15.7	71.5±18.4	37.5±24.3	35.7±19.7	40.0±20.5

[1]Increasing educational level: 1 = secondary education (Hauptschule), 2 = secondary education (junior high; Realschule), 3 = high school education (Gymnasium).
Scores are significantly different (** p<0.01; * p<0.05; (*) 0.05<p<0.10; Kruskal-Wallis test for asymptomatic significance).
Deviations of >15% from the mean were highlighted.

Demographic information of 115 patients (mean age: 57.5±10.6 years) is provided in Table I. Patients with breast cancer were the predominant population (44%), colorectal carcinomas were observed in 17%, prostate cancer in 12%, lymphoma and leukemia in 5%, lung carcinoma in 3%, and other tumors such as melanoma, sarcoma, kidney or liver carcinoma *etc.* < 2% each. Patients in the final stages of their disease were not enrolled.

Questionnaire. The SpREUK inventory (SpREUK is an acronym of the German translation of "Spiritual and Religious Attitudes in Dealing with Illness") was designed in order to examine attitudes of patients with life-threatening and chronic diseases towards spirituality/religiosity (23-26). Its main scales deal with the most common definition of spirituality: to find meaning, purpose and value in life (2). The items were generated from patients' opinions

Table II. *Mean values and standard deviation of items with significant gender-specific differences.*

		Women	Men	*p*-value (ANOVA)
F1.1	spiritual attitude	2.32±1.15	1.48±1.33	0.002
F1.2	does not need spiritual advice	2.19±1.40	1.69±1.26	0.096
F1.4	renewed interest in SpR questions through illness	2.41±1.26	1.69±1.26	0.010
F1.5	finding access to a spiritual source can have a positive influence on illness	2.47±1.32	1.79±1.26	0.017
F1.7	others might teach and help to develop spirituality	2.41±1.32	1.79±1.21	0.039
F1.9	urged to spiritual/religious insight	2.37±1.23	1.72±1.03	0.013
F2.1*	life is fixed by fate	2.16±1.24	2.76±1.09	0.023
F3.2	illness as a hint to change life	3.14±0.90	2.55±0.99	0.004
F3.4	illness has meaning.	2.95±0.96	1.83±1.40	0.001
F3.5	illness as a chance for development	3.00±0.95	1.82±1.25	0.001
F3.7	reflect on what is essential in life	3.56±0.50	3.17±0.72	0.036
F4.4	SpR helps to cope better with illness	2.79±1.17	2.31±1.17	0.061
F4.6	SpR helps to view disease as a beneficial challenge for development	2.37±1.22	1.69±1.17	0.010
F4.8	practising with others deepens SpR	1.78±1.39	1.28±1.28	0.091

Items with *p*-values > 0.10 are not shown.
*due to a low reliability, item was eliminated

(cancer service of the Herdecke Community Hospital) and experts' statements (physicians, priests and chaplains working with patients) (24), rather than from theoretical concepts. Nevertheless, the SpREUK questionnaire heeds the concept of "locus of control" by Rotter (27) and Levenson (28), "passive, active or collaborative religious coping" by Pargament (28), and the search for "meaning in life" described by Emmons (19,20). In the final step of the questionnaire design, the items were improved with respect to already existing questionnaires dealing with the topics of religion and spirituality in patient care.

The items were scored on a 5-point scale from disagreement to agreement (0 - does not apply at all; 1 - does not truly apply; 2 - don't know; 3 - applies quite a bit; 4 - applies very much). Some questions have a reverse rating scale or a negative statement to prevent a bias towards positive answers. The SpREUK scores are referred to a 100% level (4 "applied very much" = 100%).

Sub-scale analysis was performed according to a previously conducted reliability and factor analysis (23) that resulted in the following scales: (1) Search for meaningful support, (2) Guidance, control and message of disease, (A) Support in relations with the external through SpR, and (B) Stabilizing the inner condition through SpR. As some items require a positive attitude towards spirituality and religiosity, sub-scales A and B were separated from sub-scales 1 and 2. The internal consistency for the preliminary 29-item SpREUK 1.0 was sufficiently high. Further details of the validation have been described elsewhere (23).

In order to more precisely differentiate the three topics guidance, control and message of disease in scale 2, for the current version of the questionnaire, some new items were added. Factor analysis of this 32-item construct SpREUK 1.1 enrolling 290 subjects (Büssing *et al.*, in preparation) resulted in five dimensions: (1) Search for meaningful support, (2) Positive reinterpretation of disease ("Message of disease"), (3) Guidance and trust, (4) Support in relations with the External life through SpR, and (5) Support of the Internality through SpR. The reliability of the sub-scales is high (Cronbach's alpha for scale 1: 0.8462; scale 2: 0.7626; scale 3: 0.6819; scale 4: 0.9307; scale 5: 0.6907). Sub-scales 1-3 explain 50.6% of total variance, while sub-scales 4 and 5 explain 58.5% of variance. Thus, the previously found sub-scales remained stable.

Statistical analysis. Reliability and factor analysis were performed according to the standard procedures. Differences in the SpREUK scores were tested using the Kruskal-Wallis test. To measure associations between the frequencies of given answers and distinct variables, we used Pearson's Chi^2 test or ANOVA as indicated. We judged $p<0.05$ significant, and $0.05<p<0.10$ as a trend.

Statistical analysis was performed with SPSS for Windows 10.0.

Results

Almost all of the 115 cancer patients enrolled in this study were in search of purpose and meaning in their life (85%), but only 49% were convinced that finding access to a spiritual source can have a positive influence on the illness, and only 41% were searching for access to SpR. Forty-four per cent of the cancer patients reported that they do not need spiritual advice because they know by themselves what should be done.

More than half of the cancer patients were convinced that their illness has meaning (63%), regarded their illness as a chance for their personal development (63%) and viewed it as a hint to change life (73%). Almost all patients too reflected on what is essential in life because of the illness (94%), but for only 53% has their illness brought a renewed interest in SpR questions.

Only 38% of the cancer patients accepted their illness and bore it calmly and were convinced that they have no influence on their life, because it is fixed by fate. However, several patients relied on both, an external helping source (77% of cancer patients trust in a higher power) and in an inner source (69% trust in their inner strength and 70% were convinced that they are able to affect the course of their illness by themselves).

SpREUK scores. The measurability and operability of SpR and its concerns remains a basic problem. Thus, we developed the SpREUK questionnaire (23-26). For this investigation, we analyzed the answers of 115 cancer patients according to 5 sub-scales of SpREUK 1.1. The highest SpREUK scores were found in sub-scales 2 and 3. Means and standard deviations for study variables are provided in Table I. As described previously (23), the SpREUK scores did not correlate significantly with age, living area, or duration of disease.

In contrast to women, men had significantly lower scores in sub-scales 1, 2 and 4. The educational level had a significant influence, as lower levels were associated with significantly lower scores in sub-scales 1 and 2. Thus, the search for meaningful support and some kind of life changing aspects of the illness were of minor relevance in this group.

Cancer patients living alone or with a partner, though not married, had higher scores in sub-scale 1 than married patients. This may suggest that support has to be found outside a stable partnership. In agreement with this suggestion, patients living alone had the highest scores in sub-scale 4 ("Support in relations with the External life through SpR").

A Christian denomination was reported by 84% of our patients, while only 4% had other denominations, and 11% had none. Since denominational affiliation is not necessarily identical with religiosity or spirituality, we asked whether the patients would describe themselves as religious or spiritual. Thirty-five % reported themselves as both religious and spiritual (R+S+); 37% as religious, but not spiritual (R+S-); 12% as neither religious nor spiritual (R-S-); 13% as spiritual, but not religious (R-S+). Thus, the numbers of patients with denominational affiliation was somewhat higher than the self-reported religious attitude. More women than men were R+S+ (w/m: 42% *vs.* 16%), while more men than women were R+S- (w/m: 32% *vs.* 52%). However, these differences are statistically not significant ($p=0.089$; Pearson's Chi^2 test),

As the SpREUK questionnaire was designed to examine the patients' attitudes towards spirituality and religiosity, significant differences were of course observed with regard to religion and spiritual attitude. Patients without religious bindings had the lowest scores in the sub-scales 1, 3, 4 and 5, while their score of sub-scale 2 ("Message of disease") did not differ from patients who denominated themselves as Christians. The differences were statistically significant for the sub-scales (3) "Guidance and trust", (4) "Support in relations with the External life through SpR" and (5) "Support of the Internality through SpR".

Similar results were observed with regard to the spiritual attitudes (Table I). Surprisingly, R+S+ had higher scores in sub-scales 1, 4 and 5 than R+S- patients, while patients with a R-S+ attitude had higher scores in the "search" sub-scale 1 than R+S- patients. Thus, the "Search for meaningful support" is associated with a spiritual attitude rather than a religious attitude. Probably the religious patients were not in search of a helping source, as they find support in their faith. In fact, religious patients (R+S- or R+S+) had higher scores in the "Guidance and trust" sub-scale 3 than R-S+ patients.

While it is clear that R-S- had the lowest scores in sub-scales 1, 3, 4 and 5, it is remarkable that their score did not differ from the other attitude groups with regard to the "message of disease".

Differences between the attitudes of women and men. As shown in Table II, several of the answers significantly differed between women and men. Women more than men regarded themselves as spiritual; are convinced that finding access to a spiritual source can have a positive influence on their illness and think it possible that others might be able to teach and help to develop their spirituality; report a renewed interest in SpR questions through illness; are convinced that illness has meaning and reflect on what is essential in life; regard illness as a chance for their own development and as a hint to change life. As a trend, more of them are convinced that SpR helps them to cope better with illness, and they experience and deepen their SpR when practising their faith with others. However, more men than women believed that they have no influence on their life, as it is fixed by fate.

Discussion

Given the importance of spiritual well-being to seriously ill patients, integrating systematic assessment of such needs into medical care is crucial. Several studies have shown that religious involvement and spirituality are associated with better health outcomes, coping skills, and health-related quality of life, as well as with lower rates of anxiety, depression, and suicide (3-13), and that addressing the spiritual needs of the patient may enhance recovery from illness (9). Moreover, research has confirmed that spiritual well-being is positively-associated with quality of life, fighting-spirit, but also fatalism, yet negatively-correlated with helplessness/hopelessness, anxious preoccupation, and cognitive avoidance (30).

However, religious or spiritual involvement is beneficial only when it is well integrated into a person's life. Interest in an institutional religion has drastically declined in Europe (31), while in the USA different kinds of religion and a strong belief in God are vital (32, 33).

It is not surprising that a growing group of patients seems to be less interested in these topics. Murray *et al.* (22) found that dying patients are reticent to raise spiritual issues, but that many were able and willing to talk about them when allowed to tell their stories in an open atmosphere.

In our study population, R-S- patients were not interested in "faith communities", "divine support", "transcendental meaning", and they did not believe in the beneficial effects of spiritual engagement. However, many of them referred to an inner power, and went to specific places to deepen some kind of "spirituality" (24, 25). These findings have to be addressed in further studies as they have important implications for the care of patients, since an individual approach rather than spiritual care-groups is called for.

Levine and Targ (14) mentioned that asking patients about the role of spirituality in their lives may be a useful marker to predict the patient's ability to cope with stress in their lives and of their quality of life. Nevertheless, knowledge of a patient's spirituality can help service providers predict aspects of psychosocial needs and to respond sensitively and appropriately. Therefore, in medical cancer care one has to define the patients who are more in need of help than others. In our study, the patients with the highest scores in sub-scales 4 and 5, which reflect the "profit" from SpR, had a R+S+ attitude. These R+S+ patients had the highest scores in the sub-scales dealing with the search for meaningful support and in the finding of meaning in their illness. However, 57% of R+, 74% of R-S+ and 58% of R-S- patients accept their illness and bear it calmly (24).

The educational level has an impact on spiritual aspects, too. Patients with a higher level of education were more in search for meaningful support and regarded their illness as a life changing sign. Moreover, women with cancer were more in search for spirituality than men, as they are highly convinced that finding access to a spiritual source can have a positive influence on their illness. This is in agreement with the finding that women use more emotionally-oriented coping strategies, while men use more problem-oriented strategies (34). However, using the German version of the Systems of Belief Inventory (SBI-15) by Holland and co-workers, Albani *et al.* (35) reported that higher religiosity was observed for women, older people and people with lower education. With regard to the educational level, we can confirm that lower education was associated with lower scores of SpR engagement, *i.e.* conventional religious practise, unconventional spiritual practise, humanistic practise and nature-oriented practise, but not existentialistic practise (26).

An additional finding of our study was that especially patients living alone or outside a stable partnership were in search for meaning and support from other sources, *i.e.* spirituality. This is in accordance with the findings of Umberson *et al.* (35), who reported that women give their partner more emotional support than men and are more active in social networks, and the results of Lubben (37), who observed that women are often the main, or even the sole, source in a partnership providing social support.

Holland *et al.* (38) observed that the use of religious and spiritual beliefs was associated with an active form of coping. They suggested that such beliefs provide a helpful active-cognitive framework for many individuals from which to face the existential crises of life-threatening illness. Thus, SpR may help one to adapt by finding meaning, hope and coherence in illness. In a study enrolling Swedish breast cancer patients, Wallberg *et al.* (39) investigated different categories of "meaning of illness" (*i.e.* 'challenge', 'enemy', 'punishment', 'weakness', 'irreparable loss', 'relief', 'strategy' and 'value') and found that 33% of all patients and 40% of patients in middle life (51-65 years) reported 'challenge', while older patients (>65 years) chose 'relief', 'strategy' or 'value' more often than younger patients. The patients with metastatic disease chose 'enemy', 'punishment', 'weakness' and 'irreparable loss' more often than patients in the earlier stages of disease. In a study enrolling Canadian breast cancer patients, a much higher number of patients reported 'challenge' (57%) and 'value' (28%) to describe the meaning of the breast cancer (40). Those patients who ascribed a negative meaning to illness with choices such as 'enemy', 'loss', or 'punishment' had significantly higher levels of depression and anxiety and poorer quality of life within the following 3 years than women who indicated a more positive meaning (40). In our investigation, more than 90% of all patients (irrespective of their spiritual attitude) claimed that, because of their illness, they would reflect on what is essential in their life, and more than 2/3 of R+ or S+ patients viewed their illness as a chance for their personal development, and even 50% of those patients who have a R-S- attitude

Faith plays an eminent role even in medical decision making (41), and several patients considered spiritual health and physical health as equally important (42). Spiritual issues are, in fact, significant for many patients with inoperable cancer and end-stage heart failure in their last year of life (22). Today, health policies focus on fast access to healing and throughput and, thus, addressing spiritual needs is not practical for health professionals. It may be true that many of them have neither the time, courage, skills or interest to uncover and address such issues (4, 22, 43, 44), and thus call for the experts, *i.e.* chaplains and priests. Regardless of their own belief system, physicians should not allow their own bias to blind them to the possibility that

religion and spiritual beliefs play an important role for many of their patients. On the other hand, religiosity/spirituality should not be reduced to that function of "last hope" which remains when doctors, psychologists, social workers *etc.* have left the patient. Research indicates that health professionals can play an important role in enhancing psycho-spiritual well-being, *i.e.* self-awareness, coping and adjusting effectively with stress, relationships, sense of faith, sense of empowerment and confidence, and living with meaning and hope (45).

Acknowledgements

We are grateful to our patients and to Dr. Cristina Stumpf for her help in recruiting them.

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Received August 25, 2004
Revised December 27, 2004
Accepted February 3, 2005