Evaluation of Spiritual Needs of Patients with Advanced Cancer in a Palliative Care Unit

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Abstract

Introduction: Spiritual needs play an important role in palliative care as both a clinical dimension and a therapeutic strategy. However, recent studies have shown that the management of this dimension still remains a challenge at the clinical level of palliative care.

Goals: Our goal was to evaluate the spiritual needs of patients diagnosed with advanced and terminal cancer by the palliative care unit of a hospital in Barcelona, Spain.

Methods: An observational study was conducted that involved 50 patients who were recruited between May 2007 and January 2008. A questionnaire was used which included 28 items selected from a review of the literature; the responses were analyzed using a five-point Lickert scale. The results were grouped in 11 categories corresponding to different spiritual needs.

Results: Two spiritual needs emerged as the most relevant for the patients: their need to be recognized as a person until the end of their life and their need to know the truth about their illness. The least important spiritual needs were identified as those: for continuity and an afterlife; to get rid of obsessions; to achieve freedom from blame and to be able to forgive others; and the need for reconciliation and to feel forgiven by others.

Conclusions: When patients knew the truth about their illnesses and they were treated with dignity, their most important needs were likely to be covered. These results suggest that patients receiving palliative care wish to live for the present with as much normality as possible and show only minor concern for their past and future.

Introduction

SEVERAL AUTHORS have already studied the spiritual dimension of patient needs, taking into account the multiple facets of each individual. They have analyzed the patient as a set of aspirations, convictions, values, and beliefs that can be organized into a single project: the patient's life. This project includes their search for purpose as a human being and/or their search for the meaning of life. In some cases, it also includes their quest to attain certain transcendent values. Spirituality is something that is found in all cultures¹ and which constantly grows within the individual, with the nature of its growth seeming to depend on the cultural environment in which the individual develops. At the same time, palliative care aims to optimize the patient's own resources in order to enable them to face up to an agonizing process²⁻⁷ with as much normality as possible and with the least pain possible.

Cicely Saunders⁸ described spiritual pain as total (physical, emotional, social, and spiritual) pain. This spiritual pain can derive from the deep anxiety associated with the prospect of the elimination of existence, which implies the loss of the meaning and purpose of life.

Within our cultural context, we also found that it is extremely important during consultations to be aware of patients' opinions, to assess their perceived spiritual needs, to determine what these needs are, and to decide how clinically relevant they may be.⁹ All these needs are reconsidered in the face of death and may cause a spiritual crisis. On some occasions, this can impair adaptation resources, making early diagnosis and treatment necessary.¹⁰ With this in mind, we designed an exploratory study to assess the importance that patients gave to a set of commonly described needs that had been outlined in the literature.

We carried out initial background research and compiled a series of bibliographic sources relating to spirituality within

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the field of health care. We then selected the 11 spiritual needs' commonly repeated variables to be assessed using 28 items.

The principal aim of our work was to assess the spiritual needs that could be incorporated into the treatment of patients in palliative care. We studied these needs in order to measure and/or elucidate the most relevant spiritual aspects of palliative care, based on a bibliographical review of the relevant literature.

A secondary objective was to create a clinical instrument which would help in the analysis of patients' needs when they are diagnosed with a terminal illness. This instrument would be based on the survey we have created for this study.

Methods

Since the study was primarily exploratory, and no inferences were to be sought, we thought that 50 patients would provide a significantly sized sample to offer an initial analysis of general spiritual needs. The study included patients who were seen at the outpatient clinic of the palliative care service of the Institut Català d'Oncologia (Hospitalet de Llobregat, Spain). All of the patients had been diagnosed with advanced or end-stage cancers between May 2007 and January 2008. The inclusion criteria for this study were: patients over 18 years old; diagnosed with advanced cancer; with a sufficient level of educational attainment to answer the questions posed; with monitoring by the outpatient clinic; and with the patient's agreement through an informed consent document. The following exclusion criteria were adopted: patients with cognitive impairment and/or with a general state of health that did not allow assessment. In order to avoid any possible sources of bias due to the emotional impact, no patients were recruited at the first visit. The study was approved by the ethics committee of the hospital where the study was conducted.

The first task was to research the philosophical, theological, and psychological literature that addressed spiritual concepts in the clinical setting and the control of the symptoms of terminal illness.

After reflection on the relevant literature and examining preexisting questionnaires that also looked into the spiritual needs of patients, we found that there was no means of measuring our parameters that would allow us to achieve the principal aim, so we had to design a simple, effective, and easily utilized tool.

Here we present a brief overview of the different phases that were involved in the compilation of the questionnaire.

Compiling the questionnaire

The phases of compiling the questionnaire were from the thesis of A. Vilalta.¹¹ First, we considered the type of patient who had to answer the questionnaire and used a style of language that would be familiar to them and make them feel comfortable. This implied using everyday vocabulary, free from technical jargon.

Phase 1. We carried out initial background research and compiled a series of bibliographic sources relating to spirituality within the field of health care.

For the selection of the literature review we consulted specialist databases: MEDLINE: www.ncbi.nlm.nih.gov/

pubmed, using the key words: palliative care, terminal illness, dying, quality of life, spiritual needs. Also, starting with the bibliographic references attached to the articles, we used the program Referent Manager 10.0 in order to search for scientific publications.

Phase 2. We selected 246 papers and chose the 30 articles most related to our objectives, which exposed the more frequent spiritual needs. We then selected the 11 most commonly repeated typologies reported within the field of spiritual needs: the need to be recognized as a person until the end of life; the need to reinterpret life; the need to find a meaning for existence; the need to be free from blame and to forgive others; the need for reconciliation and to feel forgiven; the need to see life as something that extends beyond the individual; the need for continuity for an afterlife; the need for religious expression; the need for hope; the need for truth; and the need for freedom and to be free. We did not find any reference questionnaires for assessing the selected needs.

Phase 3–4. In order to assess the 11 spiritual needs chosen we decided that it was necessary to use a questionnaire to gather the information that we wanted to assess, as well as to incorporate variables representing the different dimensions involved. We did this in collaboration with a group of experts who were specialists in theology, ethics, and bioethics; psychologists; and oncologists. This group chose the 28 different variables that were assessed.

Phase 5. We compiled the questionnaire. The category variables were described by frequency tables and percentages. A five-point Lickert scale was used to analyze spiritual needs, with the response options ranging from 1 to 5. The scales used considered both quantitative (not at all, a little, quite a lot, a lot, totally) and temporal (never, rarely, sometimes, often, always) factors. The data values were linearly scaled so that the scores obtained ranged from 0 to 10. The values of the variables were ordinal and categorical. In order to make the results fully comprehensible within a quantitative scale, values of 2.5, 5, 7.5, and 10 were used to facilitate the calculation of a single indicator for each of the 11 needs and also for each of the 28 variables.

Phase 6. A pilot study involving 10 patients was carried out in order to check for any possible deviations and to make sure that the patients questioned would understand the questionnaire. No significant anomalies were apparent and so we decided that there was no need to modify the questionnaire.

We also prepared a short survey to collect the opinions of the patients on how well they understood the original questionnaire and its possible clinical use. The patients completed a self-administered questionnaire. The data analyses were performed using SPSS 15.0 (IBM, Armonk, NY).

Results

Of the 50 patients involved in the study (see Table 1), 19 (38%) were women and 31 (62%) were men. The average age was 60.9 years (with a range of between 33 and 81 years). Of all the clinical variables considered, 92% of the participants knew their medical prognosis and 88% knew their diagnosis.

TABLE 1. PATIENTS' SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS

<i>Variables</i>	<i>Categories</i>	<i>Frequency</i>	<i>Percentage</i>
Gender	Woman	19	38%
	Man	31	62%
Age	≤60	26	52%
	>60	24	48%
Awareness of the illness prognosis	Unaware of prognosis	3	6%
	Aware of prognosis	46	92%
	No reply/did not know	1	2%
Awareness of the illness diagnosis	Superficially aware	5	10%
	Aware of diagnosis	44	88%
	No reply/did not know	1	2%
Religious belief	Practicing Catholic	8	16%
	Nonpracticing Catholic	37	74%
	Agnostic	2	4%
	Atheist	1	2%
	No reply/did not know	2	4%

There were 11 spiritual needs that were evaluated (see Tables 2 and 3). Needs that were afforded the greatest importance were those related to the recognition of the patient as a person in their different aspects, with an evaluation of 8.6 (on a scale from 0 to 10, on which 0=totally unsuitable and 10=very suitable).

The importance of knowing the truth about the illness was regarded as important, as it was evaluated at 8.3. In contrast, to be free from blame and forgiving others was measured at 1.5, while being forgiven, at 1.4, was regarded by many patients as being of only limited relevance.

In relation to the feelings towards reinterpreting life, to look for meaning in existence, or the hope that there is still something more to be achieved, these spiritual needs were only valued at a medium level. In relation to the spiritual indicators, normally considered part of the religious sphere, they had low evaluations.

The results obtained from evaluation by the patients of the questionnaire referring to the utility and relevance of treating their spiritual aspects directly and explicitly: 85.7% of the patients consulted considered the questions asked to be very

suitable, and 89.8% of participants reported adequate comprehension of the survey.

Discussion

Inside palliative care, many of the questions are subjective; this makes it difficult to know up to a certain point whether a reliable and viable measure has been obtained. The results of the spiritual needs of a patient in a concrete moment can be influenced by his or her physical, psychological, and social welfare; and by cognitive deterioration.¹²

In our study we observed that two spiritual needs were highly evaluated by patients (see Table 2). The first was to be recognized as a person until the end of their life. This score showed that the patients consulted attributed great value to not losing their identity; to being treated with deference; and to receiving comprehension, consideration, kindness, and nonverbal communication to help mitigate their misery. Patients expressed the need to feel valued until the end of their lives. These findings relating to the appreciation of humane treatment largely coincided with the ideas presented by Rousseau.¹³ The second most highly valued need was to be told the truth about illness before the end of the patient's life. Most of the patients consulted said that they wanted to know the truth and also believed that it should be communicated to patients when they wanted to know it. We agree with several other authors on the need to communicate an appropriate amount of the comprehensible truth to the patient at a suitable moment. In a prospective study, Centeno and Núñez¹⁴ reported that 75% of informed patients could talk without having any doubts about their illness and that this helped their understanding of the explications that they received. If patients know the truth about their illness, they can participate in the therapeutic project with a sensation of being in control of the situation; they consider it useful to be able to decide with freedom.^{15,16}

Other spiritual needs received medium-high scores (see Table 2). These were needs that could be placed in a religious or existential context: to reinterpret life; to look for a meaning in existence; the need for hope; to see life beyond the individual; the need for religious expression.

TABLE 2. DESCRIPTIVE STATISTICS FOR THE SPIRITUAL NEEDS ASSESSED

<i>Spiritual needs</i>	<i>Mean ± SD^a</i>
To be recognized as a person until the end of life	8.6 ± 1.3
The need for truth	8.3 ± 2.7
To reinterpret life	6.2 ± 1.9
To look for a meaning to existence	5.7 ± 2.5
The need for hope	5.7 ± 3.5
To see life beyond the individual	5.2 ± 2.5
The need for religious expression	4.9 ± 2.5
The need for continuity and an afterlife	4.0 ± 2.0
The need for freedom and to be free	3.8 ± 3.4
To be free from blame and to forgive others	1.5 ± 2.0
To be reconciled and to feel forgiven	1.4 ± 2.2

^aOriginal values range, 0–10.
SD, standard deviation.

TABLE 3. DISTRIBUTION OF THE AVERAGE POINT SCORE OBTAINED FOR EACH NEED AND ITS GROUP (ON A SCALE OF 0–10)

<i>Spiritual needs</i>	<i>Global score average</i>
Recognition as a person until the end of life	8.6
Be treated as a person	8.3
Take opinion seriously	7.9
Be called by name	9.3
Recognition of life's value	9.0
Reinterpret own life	6.2
Explain life experiences	6.0
Organize scale of values	6.8
Recognition of life achievements	5.7
Find a meaning for existence	5.7
Finish off projects	5.7
Fulfill deferred desires	5.7
Freedom from blame and guilt and forgiving others	1.5
Illness as a punishment	1.4
Lifestyle and its influence on death	2.3
Need to forgive	0.8
Reconciliation and forgiveness	1.4
Need for solace	1.4
Need to be forgiven	1.4
Life beyond the individual	5.2
Listening to music, reading, writing	5.5
Sharing opinions, beliefs, and emotions	5.0
Need for continuity and an afterlife	4.0
Someone to continue the work	2.2
Belief in reincarnation or resurrection	3.1
Bad feelings about unfulfilled obligations	4.2
Discovering interior peace	6.6
Need for religious expression	4.9
Faith tested by disease	7.2
God curing serious illness	4.7
Support from sacraments	4.3
Need for self-discovery	3.4
Need for hope	5.7
Hope that everything will end well	5.7
Need for truth	8.3
Need to know the truth	8.5
Tell the patient as much of the truth as possible	8.2
Need for freedom and to be free	3.8
Freedom from obsessions	3.8

When we analyzed the need to reinterpret a person's life, we observed that patients tended to make a positive and significant revision of their past and that this helped them to recover their self-esteem. This finding coincided with similar findings reported by J. Vimort.¹⁷

The approach of death seems to create a need to find a meaning for human existence and we think that this explained the medium valuation of 5.7 to 6.2 given to this factor. For V. Frank,¹⁸ what is important to the individual is not the meaning of life in general terms, but rather its precise meaning as seen by the individual at any particular moment in time.

We observed that the need for hope received a 5.7 valuation; this finding coincided with reports from various experts

in spirituality, including E. Kübler-Ross,¹⁹ Hawthorne, and Yurkovich,²⁰ who observed that many patients maintained hope of a possible cure and that on many occasions this hope helped to mitigate their misery.

The need for continuity was valued at 4.0 and for a life beyond the individual received a valuation of 5.2. Patients received the strength and the resources they needed to transcend the situation through the contemplation of art, nature, meetings, and cults.²¹

Religious needs received a medium-low score in the evaluation. If a person's faith is tested before a serious illness, this can result in a low value being given to religious factors. In our modern society we often observe a degree of religious indifference, with people moving away from religious rituals due to negative experiences and expressing feelings of rejection towards the Church.

It is particularly relevant to highlight the lack of importance that a large majority of the patients consulted (82%) assigned to the need for forgiveness and to rid themselves of feelings of guilt relating to their state of illness, evaluated at 1.5. The same was observed for the 84% of patients who did not feel a need for reconciliation or to be forgiven by other people, in the most transcendental and religious senses, evaluated at 1.4. One possible explanation for these findings was that when these patients did our questionnaire they had already started their treatments and so this necessity had probably already been covered; this would demonstrate a good therapeutic approach.

A limitation in our study that is present in the interpretation of the results obtained is that our goal was not to develop a new test to assess the spiritual needs for any patient under palliative care. Our survey is observational and its results can serve to critically detect and discuss some of the most relevant issues regarding these kinds of patients. Nevertheless, we believe these results can set the stage for further investigations and development of questionnaires to measure these important issues.

The results obtained in this study relating to spirituality were in line with those cited by H. Chochinov,²² who supports including the therapy of dignity in daily clinical practice; for this author, a good spiritual diagnosis could help a patient to have a more dignified death.

It is crucial to incorporate simple tools to help measure the spiritual dimension of palliative care in order to improve its quality and the impact of the indicator assessment used by the palliative care programmer. It is also important to continue making new studies until we can establish a series of concrete steps and confidence-building measures that could be supported by a conceptual and theoretical framework. This will require further measures with a greater capacity than those currently available and must present a series of definitive and universally acceptable conclusions. With this in mind, spiritual or existential malaise should be a concern for palliative care professionals assessing and assisting patients.²³

In future work, we think that the evaluations of the spiritual needs obtained from the present research could be used to establish the basis for implementing and validating an official questionnaire that could be used to evaluate and measure the spiritual needs of palliative care patients.

Conclusions

Our study concluded that there are several needs related to the religious sphere that were little valued by the patients.

When patients knew the truth about their illnesses and they were recognized as a person until the end of their life, their most relevant needs were likely to be covered. These results suggest that patients receiving palliative care wish to live for the present with as much normality as possible and show only minor concern for their past and future. For patients, what is important is the present. Overall, our results underline the importance of considering spiritual aspects of treatment, especially at the present moment, when addressing the question of clinical management in palliative care.

Author Disclosure Statement

No competing financial interests exist.

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APPENDIX 1. QUESTIONNAIRE ABOUT SPIRITUAL NEEDS

To be completed by the patient

Case history number _____ Code __/__/__/__/_/

This is a study for patients like you. We would like to have your opinion about people's spiritual needs.

Instructions: After reading each sentence, circle the reply that you find most appropriate (from 1 to 5). As you know, this questionnaire is confidential. Take as much time as you need to complete it.

1. The need to be recognized as a person until the end of life

1.1. As well as being treated as a patient, to what extent do you feel that you would also like to be treated as a person and to receive kindness and respect?

Not at all	A little	Quite a lot	A lot	Totally
1	2	3	4	5

1.2. Do you think that your opinion should be taken into account before taking any therapeutic decisions?

Not at all	A little	Quite a lot	A lot	Totally
1	2	3	4	5

1.3. Do you think that when you are a patient you should be called by your own name and not referred to by your room number or the name of your illness?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

1.4. Would you be grateful if people would recognize that your life has a value and is worth living?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

2. The need to reinterpret life

2.1. Do you feel the need to explain the experiences that you have had in your life?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

2.2. In your present state of health, do you think that you need to organize yourself according to a new scale of values? Do you now give more importance to things that you previously did not value?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

2.3. Do you think that you need other people to recognize the best things that you did in your life?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

3. The need to find a meaning for existence

3.1. Do you feel the need to finish off certain projects relating to your family, friends, or profession?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

3.2. Do you feel the need to fulfill a wish that you could not fulfill when you were in better health, such as to travel or go on a pilgrimage?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

4. The need to be free from blame and to forgive others

4.1. Do you see your illness as a form of divine punishment or as a punishment for your life in general?

Not at all	A little	Quite a lot	A lot	Totally
1	2	3	4	5

4.2. Do you think that how you have lived could influence when and how you die?

Not at all	A little	Quite a lot	A lot	Totally
1	2	3	4	5

4.3. At this time, do you feel the need to forgive something related to your family, friends, or acquaintances?

Not at all	A little	Quite a lot	A lot	Totally
1	2	3	4	5

5. The need for reconciliation and to feel forgiven

5.1. For your inner solace, do you feel that you have a need for reconciliation, to be forgiven by others, or to resolve any pending matters?

Not at all	A little	Quite a lot	A lot	Totally
1	2	3	4	5

5.2. To face death in a more calm and serene way, do you think that you need to be forgiven by other people?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

6. The need to see life as something that extends beyond the individual

6.1. Do you feel the need to listen to music, to read, or to write?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

6.2. Do you feel the need to socialize with other people and to share your thoughts, feelings, and religious beliefs with them?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

7. The need for continuity and an afterlife

7.1. Do you feel the need for someone to continue your work?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

7.2. Do you believe in reincarnation or in the Christian resurrection?

Not at all	A little	Quite a lot	A lot	Totally
1	2	3	4	5

7.3. Do you feel bad inside when you see that you have not fulfilled your obligations?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

7.4. Do you feel at peace with yourself if you are approaching the end of your life with a clear conscience and with the feeling that you have fulfilled your obligations?

Not at all	A little	Quite a lot	A lot	Totally
1	2	3	4	5

8. The need for religious expression

8.1. Do you feel that your faith is put to the test by serious illness?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

8.2. Do you believe that God can intervene to cure a serious illness?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

8.3. Do you believe that receiving religious sacraments can help you to continue and to reconcile with or overcome a serious illness?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

8.4. Do you think that people feel the need to be alone and to discover themselves when they are faced with a serious illness?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

9. The need for hope

9.1. Do you hope that everything will end well and that everything will be like a dream?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

10. The need for truth

10.1. Faced with a serious illness, do you feel the need to know the truth about your illness, whether or not you are prepared to hear it?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

10.2. When someone is seriously ill, do you think that it is important to tell them the truth about their illness, to the extent that the patient is able to understand and accept it?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5

11. The need for freedom, and to be free

11.1. Do you feel the need to be free from certain obsessions or internal worries?

Never	Rarely	Sometimes	Often	Always
1	2	3	4	5