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# Spiritual Experiences of Transcendence in Patients With Advanced Cancer

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#### Abstract

**Purpose:** Spirituality encompasses a wide range of meanings between holistic wellbeing and mysticism. We explored advanced cancer patients' spiritual experiences of transcendence. **Methods:** A total of 251 patients with advanced cancer were included and observed (participant observation) over 12 months by a psycho-oncologist/music-therapist. She recorded and documented patients' spontaneously expressed spiritual experiences during hospitalisation. Interpretative Phenomenological Analysis was applied. **Results:** 135 patients communicated a spiritual experience, as expressed by altered body-awareness, less pain, less anxiety, higher acceptance of illness/death, new spiritual identity. Spiritual experiences were communicated by patients across different religious affiliations/attitudes. We identified types of spiritual experiences. **Conclusion:** The occurrence of spiritual experienced-based spiritual care may complement current needs-based approaches.

#### **Keywords**

spirituality, spiritual care, palliative care, mysticism, music therapy, connectedness, transcendence, empathy

# Introduction and Background

Spirituality and spiritual care are recognized as an integral component of palliative care.<sup>1-3</sup> The term spirituality encompasses a wider range of meaning than religiosity<sup>4</sup> and surpasses cultural differences.<sup>5</sup> Guidelines for interdisciplinary spiritual care and an implementation model have been developed.<sup>6</sup> Spiritual care has been associated with "patient satisfaction with care,"<sup>7</sup> with quality of life, and treatment options at the end of life.<sup>8</sup> Spiritual care can be performed by all members of the health care team but "complex spiritual issues" should be referred to a chaplain, as a Consensus Conference agreed.<sup>6</sup> Currently, spiritual care in palliative settings is largely needs-based, and the spiritual experience of the dying is often overlooked. In this study, the authors explore the spiritual experiences of patients.

Needs-based spiritual care typically begins with assessment. A number of assessment tools for taking a spiritual history (eg, FICA,<sup>9</sup> SPIR<sup>10</sup>) and spiritual needs<sup>11</sup> have been developed and validated. Alcorn et al<sup>1</sup> describe 5 prevalent domains of spiritual needs (coping, practices, beliefs, transformation, and community). There are several evaluated interventions such as meaning-centered group-based<sup>12</sup> or forgiveness therapy,<sup>13</sup> meaning-centered individual therapy,<sup>14</sup> brief individual psychotherapies (eg, Managing Cancer and Living Meaningfully,<sup>15</sup> mindfulness-based stress reduction, and mindfulness-based cognitive behavior therapy<sup>16</sup>). In the case of dignity therapy, 2 randomized controlled trials showed inconsistent results regarding whether dignity therapy might be helpful in spiritual distress

or not.<sup>17,18</sup> Many authors emphasize the importance of compassionate care, of being empathetically present to patients.<sup>2,19,20</sup> This may imply an individualized approach to the "here and now" of patients.<sup>21,22</sup> Terminal lucidity and deathbed phenomena and their effects have been studied.<sup>20,23,24</sup> There are narratives and case vignettes by physicians, nurses, and chaplains.<sup>19,25-28</sup> They often delineate, in contrast to empirical studies, spiritual experiences of transcendence.

However, the various and sometimes incompatible definitions of spirituality are confusing, which in turn complicate assessments and interventions.<sup>4,29,30</sup> There are numerous definitions with a wide range of meanings between well-being and mysticism. In their review of research literature on spiritual needs, Cobb et al<sup>31</sup> identified only one study analyzing the theological content of the belief of palliative care patients, exploring the image of God, and its influence on religious coping.<sup>32</sup> Spiritual distress, along with spiritual pain, is a complex issue in palliative cancer care<sup>22</sup> and as diffuse as the term total pain. Concerning the

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topic of finding meaning, the question must remain open if the meaning is the goal in itself or a "by-product" in the search for a sense of connectedness.<sup>19,33</sup> Given the wide range of spirituality definitions, the focus of spiritual care also becomes vague. Each medical profession tends to have its own definition.<sup>34</sup> The specific roles of physicians and nurses in providing spiritual care and the adequate training remain a challenge.<sup>3,6</sup>

Second, the focus on spiritual needs tends to blur other aspects of spirituality. Cobb et al criticized research literature on spiritual needs as mostly too reductionist and functionalistic, that is, concerned only with the impact of spirituality on health outcome and personal benefit.<sup>31</sup> Palliative patients may decline intimate conversations about their spiritual attitude. The needs-based approach may neglect final transformation processes (eg, from unconscious fear and the need of control to spiritual connectedness).<sup>35</sup> Temporary needs may be overrated, and neurotic inclinations may be underrated; Rodin and Zimmermann talk about "contradictory self-states."<sup>36</sup> A mainly needs-based approach provides the impression that spirituality is manageable (eg, "materialized spirituality"<sup>30</sup>).

There is a lack of knowledge about patients' spiritual experiences of transcendence, their occurrence, frequency, contents, preconditions, and effects, except for the phenomenon of deathbed vision that mostly happens shortly before death (within an hour,<sup>37</sup> within 12 hours,<sup>20</sup> or within 24 hours<sup>38</sup>). Furthermore, for a better understanding we need an interpretative and epistemological framework. Many spiritual experiences go unnoticed when spiritual caregivers are not sensitive to them<sup>20,24,39</sup> and to their different manifestations. There is a lack of training for professionals<sup>24</sup> and a lack in spiritual care.<sup>3,6</sup>

# The Aim

The aim of the study was to explore patients' spiritual experiences of transcendence (henceforth called spiritual experiences). Based communications with patients, we addressed on the following questions: How many patients have such experiences in suffering/illness? Can the contents of spiritual experiences be categorized? Second, we wanted to know whether patients communicated associated reactions after spiritual experiences (physical, psychological, spiritual reactions/changes, particularly reactions alleviating suffering). Third, is there a relation between the occurrence of spiritual experiences and patients' religious affiliation/identity? Fourth, we are interested in what therapeutic-spiritual interventions, specific circumstances, or inner experiences (eg, dream) preceded them. What do the results suggest for the implementation of spiritual care?

#### Methods

The study was conducted in two inpatient units of a cancer center in Eastern Switzerland. All patients had advanced cancer or hematological malignancies. As it is often difficult to prognosticate the ongoing course of the disease, palliative patients who were not terminally ill at the time of inclusion but suspected to become soon/suddenly terminally ill were also included. In weekly meetings, physicians, nurses, and therapists discussed which patients should be offered therapeutic-spiritual support. Then, physicians and nurses suggested it to patients. If patients accepted and had good communication skills in German or English, they were eligible for the study. Patients with acute psychosis, patients with the diagnosis of dementia, and patients who already had an altered state of consciousness in the beginning of the therapeutic-spiritual support were excluded. The publication of the study data was approved by the local ethics committee.

In a 3-month prephase of the study, the therapist focused on spiritual experiences and asked often spontaneously during conversations whether patients had spiritual experiences. Some patients with a spiritual interest tried on their own to achieve spiritual experiences. However, only 3 of more than 60 patients expressed a spiritual experience, much less than expected according to the previous experiences. Several patients felt distressed or even irritated. That's why the methodology was changed back to the setting of previous research.<sup>35</sup> The therapist collected spiritual experiences of patients using participant observation: she observed patients within the regular professional therapy only focusing on the "here and now" of patients: The therapist offered music therapy combined with body awareness exercises, psychotherapy (dream interpretation, trauma therapy, information about coping with cancer), and spiritual care. Whenever patients wanted, the therapist worked together with pastoral caregivers and chaplains. A mixed methods design was used: We tried to define themes and characteristics of spiritual transcendental experiences qualitatively and to present their occurrence quantitatively.

# Theoretical Framework

To better understand and integrate the spiritual experiences of palliative patients, an interpretative and epistemological framework and an adequate vocabulary is vital.<sup>30</sup> The major religious traditions contain such a framework, however not explicitly. In mystical traditions, we can differentiate between experiences of unity ("unio mystica") and experiences of a relationship with God/the divine.<sup>5,40</sup>

Researchers of states of altered consciousness found categories for the elements of these experiences (eg, Grof and Bennett).<sup>41</sup> Researchers of near-death experiences documented feelings of peace, leaving one's body, entering a region of darkness, seeing a brilliant light, and life review. The salient feature of these experiences is that they are nonlocal, superposed over ordinary reality.<sup>42</sup> Deathbed visions and coincidences (eg, the apparition of a dying person to a family member) are described.<sup>20,43</sup> Types of visions included God, Jesus, angels, parents and siblings, and evil spirits.<sup>43,44</sup> Often palliative patients seem to undergo a transformation of perception as the therapist's previous research suggested.<sup>35</sup> They oscillate between time and timelessness, between an egocentered and a so-called "ego-distant perception,"<sup>35</sup> with or without a spiritual transcendental experience. Patients' social, spiritual, and even musical preferences seem to change.45 Fenwick talks about an oscillation between two different

worlds.<sup>24</sup> To understand patients' symbolic language, methods of dream interpretation (C. G. Jung's "subjective approach," his archetypical approach, and Grof's transpersonal approach) might foster the understanding.<sup>41,46</sup>

# Data Collection

This prospective study with a convenience sample is based on participant observation over 1 year. Participant observation has been used traditionally in anthropology/ethnology<sup>47</sup> and recently in health science.<sup>48</sup> Participant observation is well suited to tackle issues that are difficult to address.<sup>49</sup> There is often a kind of relationship between researcher and participants. The intimate dimension of spiritual experiences and their ineffability<sup>39,40</sup> could easily be lost in a cognitive approach. Participant observation supports exploration into broader areas of consciousness such as spirituality and patients' nonverbal signs (eg, nodding, physical reactions).<sup>50</sup> Taking into account that the therapist's attitude, sensitivity, and interaction (transference/countertransference) may effect that spiritual experiences get noticed, the method should be unobtrusive.<sup>50</sup> It is important that patients can *have* spiritual experiences or *not*, talk about them or not.

In our study, we did not previously define spiritual experiences of transcendence (see also the study design by McGrath<sup>51</sup> and Arnold and Lloyd<sup>39</sup>) in order to abstain from any influence. Most patients narrated spontaneously their spiritual experiences, contents, reactions, and received associated intervenspecific circumstances, and/or preceding inner tion, experiences; seldom—if it happened naturally in the course of the therapy-they were asked about them and could affirm or decline. Only if the patient as well as the therapist agreed that an experience was "spiritual," it was included. In case of doubt it was excluded. In case the patient seemed confused, the therapist discussed with the physicians and nurses, and if they were of the same opinion, the experience was not counted. The religious affiliation was copied from patients' hospital identification card. We asked patients about their religious attitude and previous spiritual experiences only if it happened naturally during a therapeutic conversation.

### Procedures

The therapist focused on patients' here and now experience, for example, current anxiety. Therapeutic interventions included music-mediated, active imagination combined with relaxation (= "Klangreise", see Strobel et al<sup>52</sup>), deep conversations about dreams or (previous) existential experiences,<sup>41,46</sup> information about coping with cancer/grief,<sup>45</sup> praying (including wrestling with God), giving a blessing, or being empathetically present to patients and relatives.

The therapist asked questions and suggested interventions in a way that allowed affirmative as well as negative answers/signals. The therapist paid attention to her own reactions and discussed them with her external supervisor (psychiatrist).<sup>50</sup> Therapeutic interpretations were asserted, refuted, or modified by discussions with relatives and the research team. The therapist documented

key points for the patient chart. These notes were important for the daily interaction with physicians and nurses concerning the ongoing process (physical–psychological–spiritual) of patients. Later, she noted in a narrative description<sup>50</sup>: (1) the spiritual experiences; (2) communicated reactions; (3) religious attitudes or previous spiritual experiences (if patients talked about and consented); and (4) associated preceding circumstances, inner experiences, or received spiritual/psychological interventions by professionals or relatives. The therapist meticulously separated observation from interpretation.<sup>50</sup>

#### Data Analysis

First, patients with spiritual experiences were counted quantitatively. Second, the spiritual experiences were analyzed qualitatively using Interpretative Phenomenological Analysis (IPA). Interpretative Phenomenological Analysis attempts to explore the insider's view of participants and also recognizes the active role of the researcher in interpreting the data. It is applied to gather the data by semistructured interviews or observational methods. Small samples (3-6 participants) are the rule, but larger samples are possible.<sup>53</sup> Interpretative phenomenological analysis is an ideographic approach assessing themes and reflecting wider concepts of shared meanings without testing the data for significance or saturation.<sup>53</sup> Interpretative Phenomenological Analysis was used previously in metaphor research, to comprehend unexpressed emotions of participants.<sup>54</sup> In our study, all recorded spiritual experiences were read by the therapist and an independent coresearcher with a background in Jungian psychology and theology. The therapist and the coresearcher discussed what they had individually found (1) commonalities and differences of the descriptive contents (eg, to feel oneness with nature; to feel a deep appreciation), (2) commonalities and differences of associated reactions which patients related as unexpected and unexplained by perceived medical intervention (eg, less pain, less anxiety), (3) communicated religious attitudes and previous spiritual experiences, and (4) commonalities and differences of communicated received interventions, preceding specific circumstances, and/ or inner experiences (eg, a blessing, a dream). They were all grouped into types. If the therapist and the coresearcher could not interpret consensually, a third person was consulted.

Third, types as well as individual case stories were discussed with members of the study team to reflect interpersonal reliability. Then, an independent theologian and international mystic expert studied the types of contents. In the end, the therapist and the coresearcher checked independently all records for consistency and identified the frequency of each type. The final tables were designed.

# Results

#### Occurrence

A total of 251 patients with advanced cancer (N = 251) received therapeutic-spiritual support. This amounted to



Figure 1. A, Contents and types (N = 135 of 100%). B, Subtypes of experiences of Being/God/Wholeness (see Fig. 1A).

approximately 25% of all patients with advanced cancer hospitalized in the two inpatient units during the data collection period. Of the 251 patients, 135 (N = 135) patients described one or more spiritual experiences. Of the 135 patients, 30 died shortly (minutes up to one hour) after expressing a spiritual experience and 42 died several days/weeks after the experience. Of the 135 patients, 63 didn't die during the data collection period but within two years from the beginning of data collection. Most of the 135 patients (N = 135) had at least one spiritual experience which they communicated *spontaneously*.

The contents of spiritual experiences could be categorized into types. In a first step, we made a difference between experiences of getting just in touch with a "border area" including a change in consciousness (eg, angels, N = 66) on one hand and deep experiences of Being/God/Wholeness (N = 101) on the other hand. Some patients described experiences of both types. In all, 68 explicitly talked about God, among them were 9 patients who had previously called themselves atheist/agnostic. In a second step, we subdivided the deep experiences of Being/ God/Wholeness into the following types:

- Experiences of oneness/unio mystica (41 patients), wherein patients could feel free, peaceful, and manifested a transformed perception or consciousness. Some patients described the divine as "a great being" or "a brilliant light." A quadriplegic said, "Up to now I have been waiting all the time, now I essentially *am*." He described himself in a state "beyond time, space, and body."
- 2. Experiences of God/the divine as "Otherness"<sup>4</sup> (N = 44). Many patients heard an awe-inspiring voice in a dream speaking or singing to them, for example, appreciation (see case vignette).

- 3. Experiences of God as father/mother (N = 34). Patients felt warm, protected. They saw someone like a big father/mother/shepherd, the Earth as womb holding and sustaining them. These experiences alleviated fear.
- 4. Experiences of God/the divine amid suffering/darkness (N = 33). Patients could feel/see that within suffering/ powerlessness, a light/God/Jesus was coming. A woman described that —in anxiety and just before an operation—she was hearing the flute her husband had always played at home. It was as if he was standing at her bedside and God with him. This type set patients free from fear.
- Experiences of the Spirit/energy (N = 49). Patients described pure energy or color, a driving force, a light seen/felt as energy. They were peaceful after struggling (Figure 1A and B).

Some patients had just one spiritual experience, some experienced different types and some experienced the same type more than once. Many spiritual experiences were characterized by great intensity, abundance, and awe. Several patients described a transformation of perception (see Renz et al<sup>35</sup>). If patients only remarked their doubts and asked about God's presence in suffering (theodicy, 108 patients), we categorized these cases separately and did not include them as a spiritual experience. Fiftysix patients also expressed besides a good experience a difficult spiritual struggle or they passed through a region of darkness (see Fig. 1A).

# **Communicated Reactions**

All 135 patients expressed a better body awareness and an altered sense of the "here and now"; most communicated spontaneously.

#### **Case vignette**

Mr. E., born in 1949, teacher, an anxious person, belonging to the Protestant Church, has been hospitalized for recurrent acute leukaemia for several weeks. He already knows me. He liked my music mediated relaxations and needed my and his family's empathic listening. He doesn't talk about God and spirituality. One night he has a deep dream nobody knew about. Nurses note pondering silence. The physician is alarmed, the patient's pulse rate is very low. She orders an echocardiogram. During the day his pulse gets normal again. Mr. E. wants to tell me about his dream: He had dreamt about death:

"There was a strange threshold consisting of some sort of ether. I immediately knew: Here is death. First I was just staring at the threshold. Then I was hunted by every single and all enemies of my life. There was struggle. Suddenly the threshold got lower. I came into a sacred room. It was filled with blue atmosphere. In the middle there was a strange light. I was struck by awe. I looked at the light. It slowly changed into a chair or a throne. I realized: This was God's throne. I saw nothing but heard God's voice calling me. He said: "You did so well." It was a judgement, holy and beautiful. I knew immediately that I would never have to be afraid of death again. Now the threshold appeared and I found myself again on the other side. I woke up." Mr E. has tears in his eyes. He feels his body as transparent, and present. From now on his fears disappeared. He is relaxed and joyful. He talks about life and death with his grown-up children. He tried to paint his dream and relived it in music mediated relaxations. He can go home again and enjoys life. Weeks later he comes back to our hospital and dies peacefully.

About half the patients reported less/no pain (N = 71) and less/ no anxiety (N = 75), and 15 of these expressed less dyspnea. Sixty-two patients indicated both less pain and less anxiety. Half of the patients mentioned a different attitude to their illness (N = 62), to life and (impending) death (N = 71), and a new spiritual identity, that is, altered attitude toward God/the divine (N = 68). The communicated reactions seemed to be recurrent in 39 patients and long term (for hours and days) in 29 patients (Figure 2A and B).

#### Religious Affiliation/Attitude

According to the official religious affiliation, there were 44 Protestants, 68 Catholics, 5 Orthodox Christians, 2 Anthroposophists, 4 Muslims, and 12 no religious tradition. Members of Free Churches were assigned to the other categories (Figure 3A). These numbers correspond approximately to the population of Eastern Switzerland (Figure 3D). In spontaneous conversation about religious *attitudes* (N = 114), 55 said that religion and church were important, 39 were estranged from their traditional church but somehow religious, and 20 called themselves atheist/agnostic. Religious identity was no topic for 21 patients (Figure 3B). In spontaneous conversation about previous spiritual experiences/practices (N = 91), 49 said they had never had a spiritual experience before, 42 patients related that they knew the phenomenon from meditation (N = 13), as part of a faith experience (N = 25), from a near-death or similarly deep experience (N = 11), and from a spiritual crisis/psychosis (N = 5). Previous spiritual experiences/practices were no topic for 44 patients (Figure 3C).

What preceded spiritual experiences? The following associated received interventions/circumstances/inner experiences were recurrent: remembering/talking about a near-death experience (N = 6); presentiment of death and deathbed visions (N = 22); dreams (N = 42); music-mediated active imaginations/relaxations (Klangreisen; N = 98); empathy by relatives, friends, and professionals (N = 84); a solemn gathering of relatives at the bedside (N = 49); maturation, reconciliation, and integration of the dark sides of personality (N = 40); and religious support (prayers, blessing, sacraments, interpretation of holy scriptures; N = 85); among them a wrestling with God was important in 49 cases (see Figure 4).

# Discussion

Spirituality seems to be important to patients with far advanced cancer<sup>1-3</sup> and encompasses a wide range of meanings between well-being and mysticism.<sup>4,6</sup> The focus on spiritual experiences of transcendence (in this article called spiritual experiences) may induce a reinterpretation of patient's spiritual processes.

#### Occurrence

The occurrence of spiritual experiences seems to be a frequent phenomenon in patients with advanced cancer (N = 135 of 251). Another study noted that 15.3% of terminally ill patients, who could be interviewed, had transcendental experiences.<sup>39</sup> Perhaps they occurred frequently because patients in grave suffering and with illness feel at wits' end and let go. This interpretation is backed up by the fact that spiritual experiences often embrace an altered awareness of body and the "here and now." Fenwick et al affirmed that end-of-life experiences help patients to let go.<sup>24</sup> Spiritual experiences don't only occur just before death; 63 patients didn't die during the data collection period but within 2 years from the beginning of data collection. Most of them went home again for a short or longer time. However, spiritual experiences also seem to announce death or facilitate the dying process: 30 patients died immediately/shortly (minutes up to 1 hour) after expressing a spiritual experience and 42 patients had spiritual experiences during their last few weeks. Osis and Erlendur<sup>37</sup> reported that 27% of the patients had end-of-life experiences within an hour before death. According to Fenwick and Brayne, 54% of the patients had deathbed visions in the 12 hours



Figure 2. A, Spiritual experiences and associated reactions (N = 135 of 100%). B, Intensity and associated reactions (N = 135 of 100%).

before death.<sup>20</sup> Barbato et al<sup>38</sup> found experiences of deathbed visions in 50% of the patients within 24 hours before death.

# Contents and Types

The categorization of themes was challenging, given the fact that spiritual experiences are personal and intimate. Some patients experienced the same type more than once; others had spiritual experiences of different types. Knowledge about mysticism helped to differentiate between experiences of oneness/ unio mystica and experiences of God/the divine as "the Other." As to the fundamental question of mysticism whether there is finally a unio mystica or a relationship with God/the divine,<sup>5,40</sup> our study would support the conclusion that there could be both the one amidst the other. Many described details correspond to the traditional religious images of God; others were different (eg, case vignette). Deep experiences of being/ God/wholeness were surprisingly frequent (101 patients). These patients communicated experiences that seemed to go beyond just getting in touch with a supernatural being (eg. an angel) or attaining an altered consciousness. The atmosphere described corresponds to reports of near-death experiences.<sup>42</sup> The fact should not be neglected that besides a good experience 56 patients also had one or more experiences of grim struggle or darkness (see Greyson and Bush for distressing near-death experiences<sup>55</sup>). The question about God amid suffering (theodicy) was often posed (108 patients) as expected (see similar rates by Alcorn et al<sup>1</sup>). They were categorized separately. Existential questions are crucial to all suffering.<sup>22</sup>

# Associated Reactions

As communicated by the patients, spiritual experiences seemed to be associated with profound and powerful reactions (physical, psychological, spiritual, and also reactions alleviating suffering). All patients who communicated a spiritual experience (N = 135) expressed a better body awareness and an altered sense of the "here and now," most of them spontaneously. Arnold and Lloyd reported "an altered sense of self, dying and death" as a hallmark of transcendental experiences.<sup>39</sup> This may be a characteristic feature of spiritual experiences comparable to the nonlocal of near-death experiences,<sup>42</sup> although spiritual experiences are nearer to our everyday consciousness. Near-death studies help us to understand the phenomenon and what patients experienced. Half of the patients remarked reduced pain, less anxiety, some of them for hours and days. A recent study suggests that religious/spiritual beliefs do not affect anxiety or depression in patients with advanced cancer.<sup>56</sup> According to our study, the occurrence of spiritual experience seems to be associated with alleviating anxiety. Perhaps there is a difference between patients' spiritual attitude and what they experience. It is notable that spiritual experiences were observed in patients with various religious affiliations/attitudes, with or without previous spiritual experiences (Figure 3A-C). Half of the patients described a different attitude to illness, life and death, and God/the divine.<sup>2,3</sup>

#### Religious Affiliation/Attitude

Our study suggests that spiritual experiences can shape religious/spiritual identity (N = 68). The importance of experience in religion for the grounds of religious beliefs has also been emphasized by others.<sup>40,57</sup> However, spiritual experiences were communicated by patients across different religious affiliations/attitudes, with or without previous spiritual experiences. This is consistent with a study affirming that about twothird of the patients without religious/spiritual inclinations identified at least 1 spiritual issue.<sup>1</sup> The importance of the



Figure 3. A, Religious affiliation of patients (N = 135 of 100%). B, Religious attitude of patients (N = 135 of 100%). C, Previous spiritual experiences/practices (N = 135 of 100%).

*experiences* of spirituality in contrast to the attitude/belief may imply an experience-based spiritual care complementing the needs-based approach.

What preceded the spiritual experiences? Our 3-month prephase made us careful. As long as the therapist focused on spiritual experiences and asked patients often spontaneously during conversations whether they had spiritual experiences, patients seemed rather distressed. They had less spiritual experiences than expected according to previous experiences. However, in the unobtrusive context of participant observation spiritual experiences frequently occurred. However, even in that context we don't know what directly triggers them. We merely have hints what from patients' point of view *immediately* preceded them (therapeutic–spiritual interventions, specific circumstances, inner experiences; Figure 4): The importance of music-mediated relaxation (N = 98) is not surprising, as music transcends consciousness<sup>52</sup> as shown in shamanistic rituals. Music therapy has been recognized as enhancing spiritual issues in patients with cancer, although the evidence has not yet been established in research.<sup>58</sup> Empathy/ love (N = 84 patients) and religious support/symbols (N = 85) were also crucial, wherein 49 of them also had to be allowed to wrestle with God. However, the occurrence of spiritual experiences seems to be rather independent of several parameters: time/place (nonlocal, see van Lommel<sup>42</sup>), religious affiliation/attitude, and perhaps even of the ego state of the patient.<sup>35</sup> Perhaps spiritual experiences depend partly on and remain grace.

| Population                    |  |
|-------------------------------|--|
|                               | Population of the Cantons AR,AI and SG |
| Total                         | 520 959                                |
| Swiss                         | 422 059                                |
| Foreign population            | 98 900                                 |
| European countries            | 91 432                                 |
| Africa                        | 1 271                                  |
| America                       | 1 295                                  |
| Asia                          | 4 791                                  |
| Oceania                       | 87                                     |
| Unknown nationality           | 24                                     |
| Religion                      |  |
| Protestant Church             | 156 873                                |
| Roman Catholic Church         | 264 928                                |
| Christ Catholic Church        | 377                                    |
| Orthodox Church               | 14 492                                 |
| Other Christian communities   | 852                                    |
| Jewish religious community    | 276                                    |
| Islamic religious communities | 29 778                                 |
| Other religious communities   | 3 488                                  |
| No religious affiliation      | 49 895                                 |

Figure 3. D, Population of Eastern Switzerland (Cantons of Appenzell Innerrhoden, Appenzell Ausserrhoden, and St Gallen) based on the Switzerland population census 2000.



- 1. Music mediated relaxation (Klangreisen) (98/73%)
- 2. Religious support (prayers, blessing, sacraments, wrestling with God)
- (85/63%)
- 3. Empathy, love (84/62%)
- 4. A solemn gathering of relatives at the bedside (49/37%)
- 5. Dreams (42/31%)
- Maturation, reconciliation, integration of the dark sides of personality (40/30%)
- 7. Presentiment of death/deathbed vision (22/16%)
- 8. Remembering a previous near-death experience (6/4%)

Figure 4. Preceding therapeutical spiritual interventions/circumstances/ inner experiences (N = 135 of 100%).

#### Limitations

There are several limitations to consider in interpreting the findings from this study. Most patients were socialized in Western Europe, in a Christian tradition. Only a few patients of different culture and faith were part of the study. Application of these findings to patients of other cultural backgrounds should be done with caution.

The generalization of these findings may also be limited by influences of the referring physicians and nurses and by patients' preferences. Patients had to agree to receive therapeutic–spiritual support. This study was performed in a setting with a high level of interprofessional reports/evaluations including the indication of therapeutic–spiritual support. Moreover, among the 251 cared for, only 135 had spiritual experiences. A considerable number of patients may have spiritual experiences but were unable or too shy to communicate (see William James' defining mark of this kind of experience as "ineffability" and impossibility to impart such a spiritual experience<sup>40</sup>). The estimated number of unreported cases may be high.<sup>38,59</sup>

Another limitation is that we don't fully understand the influence of medications on the spiritual experiences of palliative patients. We couldn't clearly know how patients' level of consciousness was at the time of their spiritual experience. However, the close interaction with physicians/nurses and the possibility of exclusion of confused patients may reduce doubts. Previous research has found that spiritual experiences also happen in clear consciousness.<sup>24,44</sup> In one study, 50% of the patients who die in clear consciousness had end-of-life experiences.<sup>60</sup> Further research is warranted to understand the mediating or moderating role of medications in spiritual experiences in palliative care.

The methods may have influenced the results.<sup>47</sup> Given the fact that data collection was done by a sole researcher, the recorded spiritual experiences are comparable. Vice versa, the background of the therapist may have influenced the interpretation of experiences, moreover as sometimes the topic came up inadvertently during a conversation with the therapist. Four strategies were applied to reduce the impact of this limitation: the close interaction with physicians/nurses/relatives concerning interpretations and processes, the supervision, the recording separated meticulously observation from interpretation,<sup>50</sup> and the review by the independent coresearcher and mystical expert. We refrained from introducing an independent observer because participant observation requires "a naturalistic setting, with as little intrusion as possible into ongoing events."<sup>61</sup> Further observation studies should be done with the whole palliative team.<sup>2,62</sup>

Another limitation consists of the fact that all experiences were reported subjectively from the patients' point of view. Furthermore, the study focused only on patients' spiritual experiences without considering other preceding and ongoing processes (eg, family processes, medication effects). Communicated reactions were not reevaluated.

As further limitation, it has to be noted that the study only explored the experiences of transcendence without taking into account other aspects of spirituality listed by Alcorn et al<sup>1</sup> (eg, church going as part of religious/spiritual community).

#### **Clinical Relevance**

*Hope.* Patients communicated spiritual experiences of transcendence associated with profound and powerful reactions: physically (less pain, sometimes less dyspnoea), psychologically (less anxiety, better coping with illness, life and death), and spiritually (altered spiritual identity). As described by others, patients may have "a healing connection."<sup>19</sup> To get an idea about what can positively happen in illness is comforting to patients, families, professionals, and the general public. The frequent occurrence of spiritual experiences gives hope amidst suffering and immense distress and is an important answer for patients in spiritual pain. At the same time, we have to consider that there were *also* a remarkable number of distressing/difficult/dark spiritual experiences.

Spiritual care. The relevance of our results for the implementation of spiritual care includes:

a. *Interpretative and epistemological framework.* The 5 types of contents of spiritual experiences may contribute to a needed interpretative and epistemological framework of spiritual processes and for further development of assessments. The focus on spiritual experiences does not replace but complement psychotherapeutic support.<sup>30</sup>

- b. Training of professionals as well as raising awareness of one's own spiritual experiences. The applicability of these findings to general practice in palliative care also depends on the competence and practice of health care professionals. Physicians, caregivers, therapists, and pastoral workers might have to foster their sensitivity for spiritual experiences. Training is important<sup>20,24</sup> even if it does not replace personal competence. As described by others, spiritual caregivers have to be in touch with their own spiritual experiences.<sup>30</sup> Raising awareness of one's own person/self helps toward an authentic religious/agnostic attitude and may avoid unconscious manipulative tendencies.
- c. *Experience-based spiritual care* may become an important component of "individualized spiritual care."<sup>21</sup>

Further research should evaluate the types including the clinical environment and drug effects. Further participant observation could be performed by all members of the care team.

#### Conclusion

As communicated by our patients, their spiritual experiences of transcendence seemed to be associated with profound and powerful reactions and may induce a reinterpretation of patients' spiritual processes. An experience-based approach can improve spiritual care by focusing on patients' inner processes, including transcendental dimensions.

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#### References

- Alcorn SR, Balboni MJ, Prigerson HG, et al. "If God wanted me yesterday, I wouldn't be here today": religious and spiritual themes in patients' experiences of advanced cancer. *J Palliat Med.* 2010;13(5):581-588.
- Puchalski CM. Spirituality in the cancer trajectory. *Ann Oncol.* 2012;23(suppl 3):49-55.
- Peteet JR, Balboni MJ. Spirituality and religion in oncology. CA Cancer J Clin. 2013;63(4):280-289.

- Walton MN. Assessing the construction of spirituality: conceptualizing spirituality in health care settings. J Pastoral Care Counsel. 2012;66(3-4):7.
- 5. Zaehner RC. *Mysticism, sacred and profane; an inquiry into some varieties of praeter-natural experience.* Oxford,: Clarendon Press; 1957.
- Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the consensus conference. *J Palliat Med.* 2009;12(10):885-904.
- Astrow AB, Wexler A, Texeira K, He MK, Sulmasy DP. Is failure to meet spiritual needs associated with cancer patients' perceptions of quality of care and their satisfaction with care? *J Clin Oncol.* 20 2007;25(36):5753-5757.
- Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol.* 2010;28(3): 445-452.
- Borneman T, Ferrell B, Puchalski CM. Evaluation of the FICA tool for spiritual assessment. *J Pain Symptom Manage*. 2010; 40(2):163-173.
- Frick E, Weber S, Borasio GD. SPIR Halbstrukturiertes klinisches Interview zur Erhebung einer "spirituellen Anamnese". 2002; www.hfph.mwn.de/.../frick/interviewleitfaden-spir-herunterladen [accessed Nov 7, 2013].
- Sharma RK, Astrow AB, Texeira K, Sulmasy DP. The spiritual needs assessment for patients (SNAP): development and validation of a comprehensive instrument to assess unmet spiritual needs. *J Pain Symptom Manage*. 2012;44(1):44-51.
- Breitbart W, Rosenfeld B, Gibson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psychooncology*. 2010; 19(1):21-28.
- Hansen MJ, Enright RD, Baskin TW, Klatt J. A palliative care intervention in forgiveness therapy for elderly terminally ill cancer patients. *J Palliat Care*. 2009;25(1):51-60.
- Breitbart W, Poppito S, Rosenfeld B, et al. Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *J Clin Oncol.* 2012;30(12): 1304-1309.
- Nissim R, Freeman E, Lo C, et al. Managing cancer and living meaningfully (CALM): a qualitative study of a brief individual psychotherapy for individuals with advanced cancer. *Palliat Med.* 2012;26(5):713-721.
- Hoffman CJ, Ersser SJ, Hopkinson JB, Nicholls PG, Harrington JE, Thomas PW. Effectiveness of mindfulness-based stress reduction in mood, breast- and endocrine-related quality of life, and wellbeing in stage 0 to III breast cancer: a randomized, controlled trial. *J Clin Oncol.* 2012;30(12):1335-1342.
- Chochinov HM, Kristjanson LJ, Breitbart W, et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. *Lancet Oncol.* 2011;12(8): 753-762.
- Juliao M, Barbosa A, Oliveira F, Nunes B, Carneiro AV. Efficacy of dignity therapy for depression and anxiety in terminally ill patients: early results of a randomized controlled trial [published online March 19, 2013]. *Palliat Support Care*. 2013:1-10.

- Mount BM, Boston PH, Cohen SR. Healing connections: on moving from suffering to a sense of well-being. *J Pain Symptom Manage*. 2007;33(4):372-388.
- Fenwick P, Brayne S. End-of-life experiences: reaching out for compassion, communication, and connection-meaning of deathbed visions and coincidences. *Am J Hosp Palliat Care*. 2011;28(1):7-15.
- 21. Phelps AC, Lauderdale KE, Alcorn S, et al. Addressing spirituality within the care of patients at the end of life: perspectives of patients with advanced cancer, oncologists, and oncology nurses. *J Clin Oncol.* 2012;30(20):2538-2544.
- Krikorian A, Limonero JT, Roman JP, Vargas JJ, Palacio C. Predictors of suffering in advanced cancer [published online July 17, 2013]. *Am J Hosp Palliat Care*. 2013.
- Nahm M, Greyson B, Kelly EW, Haraldsson E. Terminal lucidity: a review and a case collection. *Arch Gerontol Geriatr.* 2012; 55(1):138-142.
- Fenwick P, Lovelace H, Brayne S. Comfort for the dying: five year retrospective and one year prospective studies of end of life experiences. *Arch Gerontol Geriatr.* 2010;51(2):173-179.
- 25. Byock I. *Dying Well: The Prospect for Growth at the End of Life.* New York: Riverhead Books; 1997.
- 26. Kearney M. Mortally Wounded: Stories of Soul Pain, Death, and Healing. New York: Scribner; 1996.
- Callanan M, Kelley P. Final gifts: Understanding the Special Awareness, Needs, and Communications of the Dying. 1st Simon & Schuster trade pbk. ed. New York, NY: Simon & Schuster Paperbacks; 2012.
- Cooper RS. Case study of a chaplain's spiritual care for a patient with advanced metastatic breast cancer. *J Health Care Chaplain*. 2011;17(1-2):19-37.
- Hefti R, ed. Spiritualität und Gesundheit: Ausgewahlte Beitrage im Spannungsfeld zwischen Forschung und Praxis. Bern etc: Peter Lang Pub Inc; 2012.
- Scagnetti-Feurer T. Himmel und Erde verbinden: Integration spiritueller Erfahrungen. Würzburg: Königshausen & Neumann; 2009.
- Cobb M, Dowrick C, Lloyd-Williams M. What can we learn about the spiritual needs of palliative care patients from the research literature? *J Pain Symptom Manage*. 2012;43(6): 1105-1119.
- van Laarhoven HW, Schilderman J, Vissers KC, Verhagen CA, Prins J. Images of god in relation to coping strategies of palliative cancer patients. *J Pain Symptom Manage*. 2010;40(4): 495-501.
- Bucher AA, ed. *Psychologie der Spiritualität: Handbuch.* Weinheim: Beltz PVU; 2007.
- Jobin G, Guyon A-C, Allard M. Wie Spiritualität in palliative care verstanden wird: eine systematische analyse. *Spiritual Care*. 2013;2(1):17-26.
- 35. Renz M, Mao MS, Bueche D, Cerny T, Strasser F. Dying is a transition. *Am J Hosp Palliat Care*. 2013;30(3):283-290.
- Rodin G, Zimmermann C. Psychoanalytic reflections on mortality: a reconsideration. J Am Acad Psychoanal Dyn Psychiatry. 2008;36(1):181-196.
- 37. Osis Ka, Erlendur H. *At the Hour of Death*. New York, NY: Avon; 1977.

- Barbato M, Blunden C, Reid K, Irwin H, Rodriguez P. Parapsychological phenomena near the time of death. *J Palliat Care*. 1999;15(2):30-37.
- Arnold BL, Lloyd LS. Harnessing complex emergent metaphors for effective communication in palliative care: a multimodal perceptual analysis of hospice patients' reports of transcendence experiences [publishesd online May 26, 2013]. *Am J Hosp Palliat Care*. 2013.
- James W. *The Varieties of Religious Experience*. New York, NY: Library of America; 2010.
- Grof S, Bennett HZ. The holotropic mind: the three levels of human consciousness and how they shape our lives. 1st ed. San Francisco, CA: HarperSanFrancisco; 1992.
- Lommel Pv. Consciousness Beyond Life: The Science of the Near-Death Experience. 1st ed. New York, NY: HarperOne; 2010.
- Lerma J. Into the Light: Real Life Stories About Angelic Visits, Visions of the Afterlife, and Other Pre-Death Experiences. Franklin Lakes, NJ: New Page Books; 2007.
- Osis Ka. Deathbed Observations by Physicians and Nurses. New York: Parapsychology Foundation; 1961.
- 45. Renz M, ed. Zeugnisse Sterbender: Todesnähe als Wandlung und letzte Reifung. 4. Aufl. Paderborn: Junfermann; 2008.
- Patton JF. Jungian spirituality: a developmental context for latelife growth. *Am J Hosp Palliat Care*. 2006;23(4):304-308.
- Steinhauser KE, Barroso J. Using qualitative methods to explore key questions in palliative care. *J Palliat Med.* 2009; 12(8):725-730.
- Bluebond-Langner M, Belasco JB, Goldman A, Belasco C. Understanding parents' approaches to care and treatment of children with cancer when standard therapy has failed. *J Clin Oncol.* 2007;25(17):2414-2419.
- Becker H, Geer B. Participant Observation and Interviewing: a Comparison. In: Seale C, ed. Social Research Methods: A Reader. London: Routledge; 2004:246-251.
- Finlay L, Evans K. Relational-Centred Research for Psychotherapists: Exploring Meanings and Experience. Chichester, UK; Malden, MA: Wiley-Blackwell; 2009.

- McGrath P. Developing a language for nonreligious spirituality in relation to serious illness through research: preliminary findings. *Health Commun.* 2005;18(3):217-235.
- Strobel W, Huppmann G, eds. *Musiktherapie: Grundlagen, Formen, Möglichkeiten.* 2. Aufl ed. Göttingen; Zürich, etc.: Verl. für Psychologie C.J. Hogrefe; 1991.
- Smith JA, Flowers P, Larkin M. Interpretative Phenomenological Analysis: Theory, Method and Research. Los Angeles: Sage; 2009.
- Shinebourne P, Smith JA. The communicative power of metaphors: an analysis and interpretation of metaphors in accounts of the experience of addiction. *Psychol Psychother*. 2010; 83(pt 1):59-73.
- 55. Greyson B, Bush NE. Distressing near-death experiences. *Psychiatry*. 1992;55(1):95-110.
- King M, Llewellyn H, Leurent B, et al. Spiritual beliefs near the end of life: a prospective cohort study of people with cancer receiving palliative care. *Psychooncology*. 2013;22(11):2505-2512.
- Alston WP. Perceiving God: The Epistemology of Religious Experience. Ithaca, NY: Cornell University Press; 1991.
- Bradt J, Dileo C, Grocke D, Magill L. Music interventions for improving psychological and physical outcomes in cancer patients. *Cochrane Database Syst Rev.* 2011(8):CD006911.
- Mazzarino-Willett A. Deathbed phenomena: its role in peaceful death and terminal restlessness. *Am J Hosp Palliat Care*. 2010; 27(2):127-133.
- Wills-Brandon C. One Last Hug Before I go: The Mystery and Meaning of Deathbed visIons. Deerfield Beach, FL: Health Communications; 2000.
- Koenig BA, Back AL, Crawley LM. Qualitative methods in end-of-life research: recommendations to enhance the protection of human subjects. *J Pain Symptom Manage*. 2003; 25(4):S43-S52.
- Holloway M, Adamson S, McSherry W, Swinton J. Spiritual Care at the End of Life: a Systematic Review of the Literature. 2011. Accessed April 6, 2012.