Dying is a Transition

Monika Renz, Miriam Schuett Mao, Daniel Bueche, Thomas Cerny and Florian Strasser

AM J HOSP PALLIAT CARE published online 12 July 2012
DOI: 10.1177/1049909112451868

American Journal of Hospice
& Palliative Medicine®
00(0) 1-8

DOI: 10.1177/1049909112451868
http://ajhpm.sagepub.com
SAGE

Dying is a Transition

Monika Renz, PhD[1], Miriam Schuett Mao, PhD[1], Daniel Bueche, MD[2], Thomas Cerny, MD[3], and Florian Strasser, MD, ABHPM[4]

Abstract

Purpose: End-of-life care is designed as response to patients' verbally communicated needs. The concept of dying as a process would allow us to improve care. This concept may combine the needs of the dying, their outburst of emotions, gradual maturation, family processes, acute problems such as decreasing independence, with their inner experience and transformation of perception. In this study we explored dying patients' mode of perception, and deeper reasons for anxiety and existential suffering. **Methods:** Dying inpatients of a major cancer centre treated by an interdisciplinary team were eligible. Psychotherapy records of cancer patients (course, reactions, discussions with nurses and physicians) provided the data. Participant observation and Interpretative Phenomenological Analysis (IPA) was applied. **Results:** Our data (pilot study N=80/follow-up-study N=600) suggest that patients undergo transition into another state of consciousness beyond anxiety, ego, and pain. Transition appears to have three stages. Anxiety, struggle, denial/acceptance, family processes, and maturation (ie, finding meaning and dignity, coping with trauma) may depend on the transitional process and also hinder or facilitate this transitional process. **Conclusions:** Understanding dying as transition may induce a radical reinterpretation of what patients need.

Keywords

end-of-life care, anxiety, spirituality, terminally ill/psychology, terminal care, family/psychology

Introduction

"Quality end-of-life care" is a universal demand. Palliative care developed as an academic discipline, with substantial improvements in patient care. Key aspects include the humanistic approach, the multidimensional model, structured communication,[1] and symptom control. Professionals acknowledge emotions of the patients, their hopelessness,[2] spirituality,[3] and seldom individuation processes.[4,5] Dignity-centered therapy concepts were developed,[6] and also concepts of family-centered interventions, often beginning early in the course of disease.

However, palliative care is designed as response to the (verbally communicated) needs of the dying person,[7] typically exploring patients' history and living wills. Complex problems such as severe pain with emotional, spiritual, or existential components[8] are hardly treatable by a needs-based approach only. This approach entails the misleading interpretation that dying is manageable and thus furthers the claim for a right to die without suffering.[9] Models of dying (Kubler-Ross 1969,[10] Corr 1992,[11] Buckman 1993,[12] Copp 1996[13]) deal with patients' emotions and their coping.[14] Chochinov's dignity model describes different areas of waning dignity in patients facing impending death, addressing their distress and despair by providing dignity therapy, a means of life review responding to their needs for generativity.[6] The big questions of life (why me? where am I going?) and finding meaning[4,15] seem to be intense close to death.[4,5,16]

But none of these models addresses the nonverbal dimension and symbolic communication. There is lack of knowledge about patients' *own* experiences and their perception, about deeper reasons for pain, anxiety, but also for peace. We need a "developmental" perspective on dying, which is similar but also different from Kubler-Ross that embraces the verbal aspects of people facing impending death as well as the nonverbal and unconscious aspects in near death awareness. Kubler-Ross depicts only *denial and acceptance* of illness. A new perspective has to combine the needs of the dying, their outburst of emotions (eg, despair), gradual maturation (eg, life review, finding of meaning),[5,6] and their acute problems (eg, decreasing independence),[6] with their inner experience and changing perception. The

[1] Psychooncology, Oncology, Cantonal Hospital, St.Gallen, Switzerland
[2] Palliative Center, Cantonal Hospital, St.Gallen, Switzerland
[3] Oncology, Cantonal Hospital, St.Gallen, Switzerland
[4] Oncological Palliative Medicine, Cantonal Hospital, St.Gallen, Switzerland

Corresponding Author:
Monika Renz, PhD, Cantonal Hospital, PO Box, CH - 9007 St.Gallen, Switzerland
Email: monika.renz@kssg.ch

aim of this study was to explore the dying patients' inner experiences and modes of perception.

Methods

The study was conducted in inpatient units of a cancer center in Eastern Switzerland. Physicians and caregivers referred patients for psychological or spiritual help. The therapist offered music therapy combined with relaxation, psychotherapy (psychoanalysis, dream interpretation, and trauma therapy), body awareness exercises, information about coping with cancer and spiritual care. A mixed methods design was employed. A pilot study defined themes of the dying process. A follow-up study reviewed the characteristics of themes, explored their occurrence, and presented them in a quantified format.[17]

Theoretical Framework

To better imagine inner experiences of dying patients, including the unconscious and nonverbal dimensions, the knowledge about (a) near-death experiences, (b) early human experiences such as intrauterine hearing sensitivity, and (c) archetypical approaches might be required.

Researchers have documented that feelings of peace and happiness, leaving one's body, entering a region of darkness, seeing a brilliant light often happen in near-death experiences and their aftermath.[18] They can be peaceful but also unpleasant and fraught with fear.[19] For Greyson near death experiences are similar to extreme stress situations where persons react by dissociating. He also certifies feelings of deep joy and peace.[20] Van Tellingen compares them to hibernation where neural connections and networks disintegrate. He thinks that during near-death experiences similar processes may "release" reminiscences, building stones of personal identity, and evoke feelings of time travel and life review.[21]

Studies on intrauterine hearing suggest that the fetus can differentiate sounds, namely the mothers' voice und heart beat.[22] The fetus and the baby have a high musical sensitivity and so have the dying and the comatose.[23] Even if we do not know what really happens, experiences with selected dying patients suggested that they oscillate between time and timelessness; Fenwick talks about an oscillation between 2 worlds.[24] Owen and Coleman demonstrated "islands" of preserved language processing even in vegetative states.[25] We also observed in dying patients a fundamental change in their social, religious, and even musical needs. The therapist's preliminary observations of some dying people as well as of patients in early trauma may help finding interpretations for a shift of perception at the end similar to that at the beginning of human life,[26,27] and Jung's approach might foster our understanding of the symbolic language of the dying.[15] According to her experiences, symbol patterns emerge neither logically nor randomly but often analogically comparable to our dream language.

Data Collection

This work is based on participant observation, a qualitative method developed in anthropology,[28] which was also applied to the study of care decisions.[29] Participant observation is best suited to the observation of themes people find difficult to talk about.[30] Researchers may often establish and remain in a relationship with participants. By using a purely cognitive approach nonverbal phenomena could easily be missed. Participant observation allows exploring broader areas of consciousness including nonverbal interactions with patients and signs such as nodding, uttering sounds, and physical reactions.[31]

Researcher Requirements

In order to get close to the dying patient's personal world, the therapist should have a background in Jungian psychotherapy (especially in understanding symbols and dream interpretation) and spiritual care or a similar education and training.

Procedures

The therapist focused on patients' here and now experience, for example on current emotions or existential questions. Therapeutic interventions included music-mediated active imagination (=Klangreise), body awareness exercises, interpretation of symbols and dreams, information about coping with cancer or grief,[32] giving a blessing, or an empathic presence. 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). Therapeutic interpretations were asserted, refuted, or modified by discussions with relatives and the research team. The therapist documented key points for the patient chart. Later she noted in a narrative therapy record the course, interventions, reactions of patients and meticulously separated observation from interpretation.

In the follow-up study, all relatives who were interested to better understand the inner processes of the dying and who were able to understand German (56%) were eligible for information about a putative transition process. Later on, they were asked whether this information was helpful.

Data Analysis

The data of the pilot study were analyzed using interpretative phenomenological analysis (IPA). The IPA attempts to explore the insider's view of participants but also recognizes the active role of the researcher in interpreting the data. It is applied to data gathered by semistructured interviews or observational methods. Small samples (3-6 participants) are the rule, but an analysis of larger samples is possible. The IPA is an ideographic approach assessing themes and reflecting wider concepts of shared meanings without testing the data for significance or saturation.[33] To comprehend unexpressed emotions of participants, IPA was used previously in metaphor research.[34]

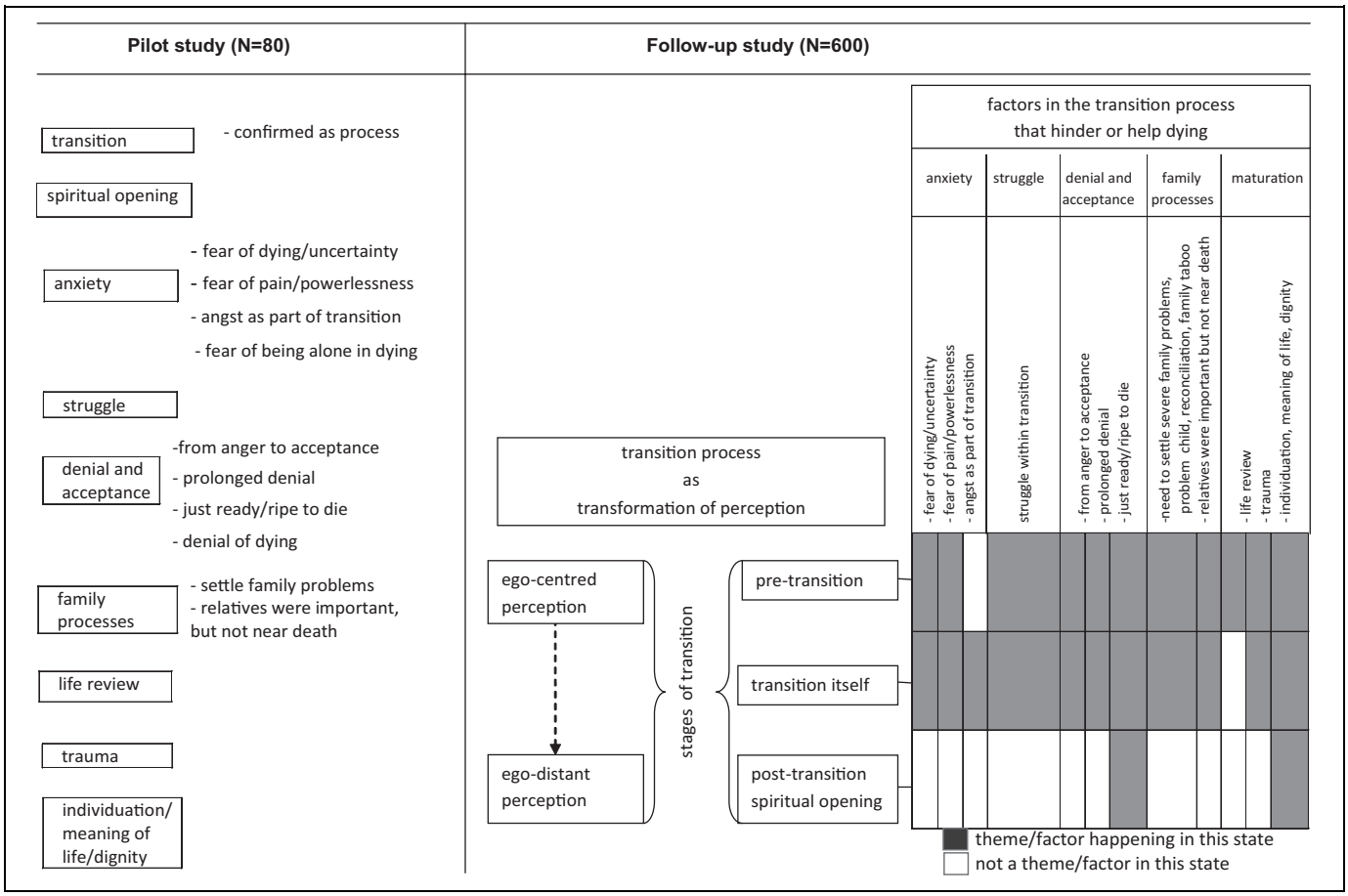

Figure 1. Table of Themes.

All therapy records were studied by the therapist and an independent coresearcher with a background in Jungian psychology and in theology. After studying 40 reports, the therapist and the coresearcher discussed emerging themes (eg, anxiety) and subordinate themes (eg, fear of dying/uncertainty) they had individually found. If they could not interpret consensually ambiguous nonverbal signals, they consulted a third person. Themes conceived were discussed with the study team and influenced the ongoing therapies. Later the therapist and the coresearcher checked independently another 40 reports and discussed their results until they achieved consensus. Most themes were recurrent (they happened 20% and more); 1 theme (trauma) and some subordinate themes were perceived as important even if seldom. They were all included.

In the follow-up study the therapist and coresearcher independently reviewed the characteristics of themes and subthemes based on the first 200 therapy records. Findings were consensually refined and discussed with the study team. A final table of themes was designed (Figure 1). After another 400 records, the therapist and the coresearcher independently read all 600 records and assigned the frequency of themes and subthemes (Table 1). Inconsistencies were discussed consensually. Finally, the study team explored the relations of associated factors and phases of transition. They converged them into a putative model of dying processes.

Results

Nine themes emerged in the pilot study: transition (transformation of perception), spiritual opening, anxiety, struggle, denial and acceptance, family processes, life review, trauma, and individuation/meaning of life/dignity (Figure 1).

The follow-up study indicated that *transition* seems to be the key process which is unfolding in 3 stages (pre-transition, transition itself, post-transition). Spiritual opening was seen as a characterization of the post transitional stage, wherein patients feel serene, beyond anxiety and pain. The other 7 themes emerged as factors associated with transition. Life review, trauma and finding meaning were subsumed under the factor maturation (Figure 1).

Transition

The phenomenon transition was often manifested indirectly. Patients signaled not during but after a transitional process that "something" had happened. They expressed verbally or nonverbally to be serene (54% pilot /51% follow-up). Patients who clearly confirmed by words or understandable utterances the transitional process (48%/25%) served to define the characteristics of transition. Transition implies a transformation of

Table 1. Occurrence of Themes, and Factors

Demographics	**Pilot study** (80 patients)	**Fellow-up study** (600 patients)	
Age range; sex	27-84; 43 f, 37 m	21-86; 307 f, 292 m	
Themes			**Key theme transition**
Transition confirmed as a process	38 (48%)	149 (25%)	
Spiritual opening/post-transition	43 (54%)	305 (51%)	
information about transition helps relatives		335 (56%)	
		what hinders/helps in dying?	**Factors in the transition process**
Anxiety		397 (66%)	**Anxiety**
Fear of dying/uncertainty	11 (14%)	61 (10%)	
Fear of pain/powerlessness	28 (35%)	302 (50%)	
Angst as part of transition	30 (38%)	261 (44%)	
Fear of being alone in dying	15 (19%)	----	
Struggle within transition	24 (30%)	180 (30%)	**Struggle** within transition
Acceptance	55 (69%)	541 (90%)	**Acceptance**
From anger to acceptance	24 (30%)	272 (45%)	
Prolonged denial	13 (16%)	198 (33%)	
Total denial of death	6 (8%)	----	
Just ready/ripe to die	12 (15%)	71 (12%)	
Relatives important	66 (82%)	466 (78%)	**Relatives important**
Need to settle severe family problems	25 (31%)	155 (26%)	
Family members important, but not near death	41 (51%)	311 (52%)	
		374 (62%)	**Maturation**
Life review	37 (46%)	292 (49%)	
Trauma	15 (19%)	122 (20%)	
Individuation, meaning of life	25 (31%)	181 (30%)	

perception. Patients thereby find to an ego-distant state of consciousness, comparable to near-death experiences. The normal everyday consciousness and perception, which is responsible for the fact that oneself feels as an ego and that all thoughts/needs/emotions are governed by an ego (called ego-consciousnes) disappears. Ego-consciousness is different from self-consciousness.[35] The phenomenon of ego distant consciousness was confirmed by 54%/51%. In the pilot study we conceptualized a spiritual opening which, as we realized later, corresponds to the serenity of the ego distance in post-transition. In the follow-up study we informed about transition and almost all relatives were relieved (335 of 337; Table 1).

Stages of transition in dying. Dying does not seem to be a linear process (for a case vignette see Figure 2 and Table 3). We suggest 3 states:

- *Pre-transition* happens before an inner transformation of perception when patients feel needs (e.g. thirst, need for bonding), pain, and emotions (fear, joy). Many patients express their suffering about losing control and dignity. Dying is inevitable. Our findings suggest that patients can be *locked* in the pre-transition due to denial, reactivated traumas, anxiety, struggle, or unresolved family distress. In turn, support and release in these issues and progressing maturation such as finding meaning *help* patients to move on in the process. A growing auditory sensitivity is a foreboding sign of a progressing transition.
- *Transition itself* implies loosing ego consciousness. Patients typically show physical signs of anxiety and struggle (the body may convulse, pour with sweat, other patients are in a state of staring or in restlessness). Traumas are reactivated. Several patients may experience transition in symbolic scenarios such as apocalyptic fights (Table 2).
- *Post-transition/spiritual opening:* The ego is not dominant any more (ego distant consciousness). Patients seem to be serene, in a state of being beyond anxiety, pain, or powerlessness. Most are unable to speak but are still hearing. They communicate by gestures, uttering, or single words. Sometimes reconciliation, vision, and peace are observed. Such transformative experiences may be comparable to a spiritual awakening or a patient self-realization, also called post-need phenomena.[17]

Some patients wait for a long time in the pre-transitional stage. Some seem to enter the transitional stage but shrink back again. Some even revert from the post-transitional stage. Transition itself usually occurs, comparable to childbirth, within hours not days.

Experiences of Transition. Patients (48%/25%) often confirmed the fact of "transition" verbally as transformation or

Table 2. Metaphors of Transition

Transition itself	Post-transition
Horrible tunnel	I can't find words for the light thereafter
There's a deafening noise, machine, hell	I hear heavenly flutes
There's shooting	Great reception
Devil - fighting	Angel, radiant light
Starring	Closed or misty eyes
Restlessness	Peace
Fear of falling	Being held or falling into a beautiful place, changing sense of gravitation
Frowning	Awe, joy

symbolically as a feeling of falling, a tunnel, a journey, or crossing. Some felt stuck. Each patient had his personal manifestation (by way of sounds, mythical images, or body sensations). The manifestation mode for the escalation in transition itself and for its release in post-transition is the same, for example restlessness and peace (Table 2). Our study suggests *hindering or facilitating factors* associated with transition:

Anxiety: Anxiety had to be differentiated. Only a few patients had fear of death/uncertainty (14%/10%), many expressed fears of pain and powerlessness (35%/50%) and/or were overcome by fear in the transitional process (38%/44%), among them were even patients who initially declined anxiety. In the pilot study, we had also counted patients who felt fear of dying alone (19%); in the follow-up-study this phenomenon was seen as part of family processes. Our data suggest that transition may intensify anxiety but in turn anxiety can only be experienced in the ego-related perception: no patient was found expressing anxiety in post-transition.

Struggle: Patients manifested struggle explicitly or were gripped by agitation. Struggle is different from anxiety even if the distinction is sometimes vague. Struggle is a spiritual problem: the ego is unable to let go and fights against fate (refusal). In other cases, patients gained insight into spiritual energies between good and evil, black and white; 30%/30% of patients expressed struggle. They needed psychotherapeutic and spiritual support. After struggle, patients mostly emanated peace (post-transition). No patient experienced struggle in post-transition.

Denial and acceptance: For many patients accepting illness/dying was crucial (69%/90%). The first subgroup underwent the typical coping process from anger to acceptance (30/45%). When they finally accepted, the transitional process went on. The second group (24%/33%) which expressed prolonged or total denial seemed to undergo additional tension and pain. Only 15%/12% were simply ready to die.

Family processes: Family processes were essential (82%/78%). The first group had grave unresolved conflicts (taboos, quarrelling, problem children; 31%/26%). The problems aggravated transition and patients seemed to get stuck in the dying process. They needed family support for reconciliation and letting go. Whenever problems could be dealt with or solved patients could smoothly go through transition or enter into post-transition. In turn, problems became so urgent due to the imminent transitional process that they prompted family process. In the second group without grave problems (51%/52%), relatives seemed to become less and less important even if they had been close to the patient during life. Near death the inner transitional process seemed dominant.

Maturation: 62% of patients experienced maturation, a term introduced in the follow-up study.[5] But if maturation came up it seemed important whether patients obeyed the inner urge. Many reflected about life and biography in the pre-transition (46%/49%). Grief often resulted in acceptance and maturation and this facilitated transition. Some patients had reactivated trauma and refractory pain (19%/20%). They often got stuck. They needed psychotherapy. If they felt consciously or symbolically supported, their blockades disappeared, maturation happened, and the dying process could go on; 31%/30% of patients experienced a process of individuation, finding meaning of life was important and seemed to facilitate their transitional process. Sometimes the same patients carried out a life review, had to cope with trauma, and went through a process of individuation (Table 1).

Discussion

The concept of dying as a transition with 3 phenomenologically distinct stages resulting in an ego distant mode of perception may help to understand patients' inner experiences and nonverbal signals.

Current care approaches are mainly *needs-based* and may provide the impression that dying is manageable, as the discussion about euthanasia and sedation therapy convey.[36,37] According to our findings, dying also seems a spiritual-existential process including a transformation of perception, thus transcending *conscious* needs. Arnold talks about post-needs.[17] Our study reflects the development of an inner process encompassing more than particular aspects. Kubler-Ross also embraced a teleological process but only dealt with denial and affirmation, raising criticism of being too narrow, linear, and pathologizing.[38,39] Our hypothesized transformation of perception is consistent with prior data that patients can react physiologically and emotionally to music, voices, and other verbal signals, even if they are hearing impaired, comatose, and vegetative.[23,25,26] Compared with other models of dying,[14] our model embraces nonverbal dimensions and focuses on the changing perception that may generate experiences similar to those in near-death experiences.

The transformation of perception may be interpreted as delirium.[40] However, numerous therapy records indicate that

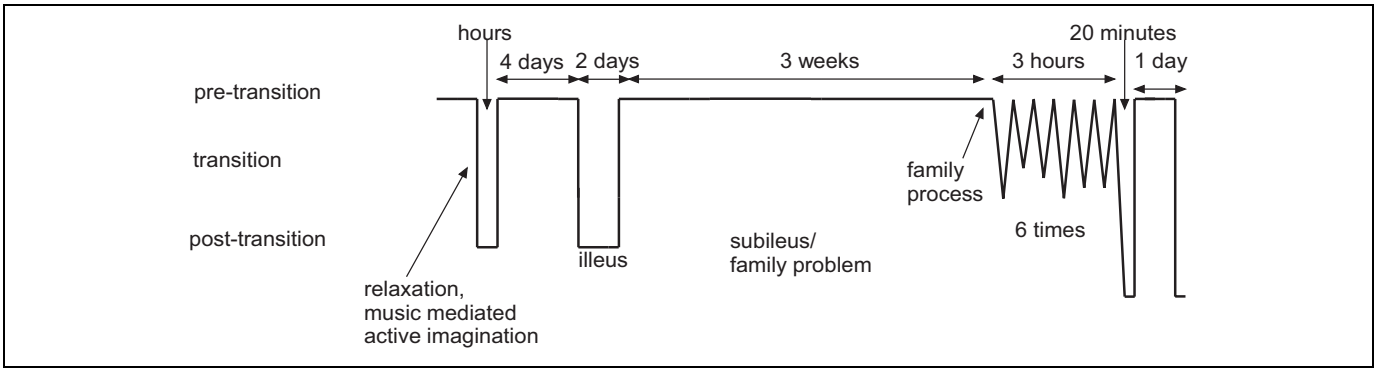

Figure 2. Transition Process of Patient I: Mr A.

Table 3. Case Vignette Patient 1: Mr A

Mr A with progressing Urothel-CA has severe local pain. Medically it was not clear why he could not die for a long time and why he suddenly passed away. He had huge family problems. His wife was going to have a physical check-up. Eight days prior to this date, he was willing to try a relaxation exercise and a "Klangreise" (music-mediated active imagination). After the intervention, he was relaxed for hours and quiet as if mentally far away. Later he told us that he felt serene and had no pain.
Four days later, I heard that he was terminally diagnosed with an ileus. He nodded when I asked him whether he felt serene but otherwise remained in an uncommunicative state for 2 days, even in the presence of his relatives. When his wife's check-up was brought up he got immediately awake. The ileus had developed into a subileus.
Three weeks later, when he accepted his fate, giving up his demand for physician-assisted suicide, and after finding a way of resolving unsettled family matters, he got terminal again. For 3 hours, he was in transition.
He was afraid of falling and desperately clutched to the bed frame. I held his hand in mine and interpreted his fear. He relaxed. Then he was anxious and restless again. I told him, "You are safe." He relaxed. He then shoveled his feet around as if pushing off from the bed. I put my hands up giving his feet resistance and encouraged him to continue. He followed my instruction and calmed down again. He had a rapt, wondering expression on his face. Serenity—Then he cried out as if actually threatened. I interpreted for him the feeling of threat. This obviously alleviated his fear. I blessed him and said that many biblical quotes mentioned a crowd of angels overpowering darkness. He relaxed, got a serene expression on his face and uttered "Flowers."
Twenty minutes later he was alert again disappointed because he had not died yet. For the night he was given a sedative medication (Dormicum). The next day, he conveyed that it had been beautiful "over there." The following night he died peacefully.

transitional processes may even occur in delirious patients with a fluctuating level of consciousness. Dying as a transition seems to go beyond a simple disturbance of consciousness, attention, and cognition. The change follows an inherent logic. For palliative care, it is important to understand the inner development at a symbolic level (Table 2). Therefore, patients can not only be supported with drugs but additionally with associative psychotherapy. Our study did not take into account the psychiatric approach to schizophrenia, and so on. If necessary, patients received psychiatric treatment.

Our data may serve to better interpret the phenomenon of total or existential pain, that is pain affected by physical, emotional, social, and spiritual components[5,8] but also reveal a state of total serenity. They allow the interpretation of a development from total pain (in transition itself, sometimes in pre-transition) to total serenity (in post-transition).

Dying processes can be hindered and facilitated whenever understood as inner development. Hindering factors seemed to be anxiety, struggle, denial, grave family problems, and blockades due to a lack of appreciation or reactivated trauma. Our data suggest that anxiety[41] can be differentiated into the common fear of dying/uncertainty, the fear of pain/powerlessness,[2] and angst overwhelming patients as part of transition. This seems to be a novel finding and so is as our finding about serenity. It has practical implications for the care of distressed patients and relatives. In turn, dying can be *facilitated* by acceptance of illness/dying, by maturation[4] (finding meaning,[16] by dignity interventions,[6] by coping with trauma), and presumably by professional empathetic support including the symbolic and nonverbal dimensions.

Our results merit cautious interpretation. Only in half of all patients a state of serenity (post-transition) was manifested and only 48%/25% confirmed expressively the phenomenon of transition itself. Given this fact, the applicability to all dying patients is currently not yet justifiable. But it has to be taken into account that the dying were often unable to communicate though inner processes may still be unfolding and that the high number of cases allows relevant statements about dying patterns of transition. Moreover, the data analysis procedure required a consensus of the 2 researchers and a high threshold to identify a transition process in patients who were already in a noncommunicative state. According to Chochinov 7.5% patients reported a severe loss of dignity and 46% reported some sense of lost dignity. Since loss of dignity was associated with hopelessness and depression, he strongly advocated dignity-conserving care as "an overarching therapeutic aim and standard of care for all patients close to death."[42]

The work presented is limited to patients with cancer. Near-death experiences suggest a transferability to other diseases.[18] Most patients were socialized in the West or in a Christian tradition. An application to patients of other cultural backgrounds is uncertain but not impossible, as a few experiences showed. The generalizability might also be limited by a selection bias of referring physicians and nurses and also by patients' preferences for accepting a psychological and spiritual approach.

The methods chosen for data collection and for data analysis may have influenced the results.[28] The relatively selected and broad professional background of the therapist may have influenced the emerging themes due to, even unconscious, predetermination of expected findings. But the 3 strategies applied might have substantially reduced these influences: the close interaction with physicians, nurses, and family members concerning interpretations, the meticulous recording, and their review by the independent coresearcher. We refrained from introducing an independent observer because participant observation requires "a naturalistic setting, with as little intrusion as possible into ongoing events."[43]

The potential clinical relevance of our findings applies to the practice of sedation therapy, challenging symptom control issues,[44] family support, and advance directive processes. Sedation therapy for the so-called uncontrollable symptoms or existential distress might require reconceptualization in the light of a transition process and potential therapeutic interventions alleviating distress and suffering. The practice might change insofar as regular sedation drugs may be reduced to still allow verbal or semiverbal interactions. Likewise, the need for medication for symptom control, typically opioids and psychotropic drugs, might decrease substantially after effective psychological or spiritual interventions. Family members might profit from the acquisition of strategies for letting go, interpreting signals of the dying, and for communication. Moreover, an early education about the transitional phases, including an often observed total serenity, might influence decisions in regard to advanced directives.

The applicability of these findings to general practice in palliative care depends on the competence and practice of health care professionals. Physicians, carers, and pastoral and social workers might have to acquire psychotherapeutic skills and develop a sensitivity for transitional processes and nonverbal signals.

For the science of religion, the concept of transition offers a differentiation between phenomenological observation and hermeneutical interpretation of a dying person's messages. Both might be important for the neuroscience of different states of consciousness.

Dying can no longer be understood as a biological process manifested in unrelated somatic symptoms and in patient needs. It is also an inner development consisting of a transformation of perception that can be hindered or facilitated. The concept may help patients in letting go and going through, it may support relatives and improve care and symptom control.

Authors' Note

The results of this study were presented in Testimonies of the Dying: Maturation in Dying. 4th rev. and enl. ed. Paderborn: Junferman; 2008 [Book in German]; and at the 12th Congress of the European Association of Palliative Care (EAPC) in Lisbon, May 18-21, 2011.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

References

1. Pantilat SZ. Communicating with seriously ill patients: better words to say. *JAMA*. 2009;301(12):1279-1281.
2. Sand L, Strang P, Milberg A. Dying cancer patients' experiences of powerlessness and helplessness. *Support Care Cancer*. 2008; 16(7):853-862.
3. 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.
4. Patton JF. Jungian spirituality: a developmental context for late-life growth. *Am J Hosp Palliat Care*. 2006;23(4):304-308.
5. Kearney M. *Mortally Wounded: Stories of Soul Pain, Death and Healing*. Dublin, Ireland: Marino; 1996.
6. Chochinov HM. Dignity-conserving care–a new model for palliative care: helping the patient feel valued. *JAMA*. 2002;287(17): 2253-2260.
7. 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*. 2007;25(36):5753-5757.
8. Strasser F, Walker P, Bruera E. Palliative pain management: when both pain and suffering hurt. *J Palliat Care*. 2005;21(2):69-79.
9. Shaw DM. Euthanasia and eudaimonia. *J Med Ethics*. 2009;35(9): 530-533.
10. Kubler-Ross E. *On Death and Dying*. New York: Simon & Schuster/Touchstone; 1969.
11. Corr CA. A task-based approach to coping with dying. Omega (Westport). 1992;24(2):81-94.
12. Buckman R. Communication in Palliative Care: A Practical Guide. In: Doyle D, Hanks, G.W.C., MacDonald N., ed. *Oxford Textbook of Palliative Medicine*. Oxford: Oxford Medical Publications; 1993: 51.
13. Copp G. Facing Impending Death: The Experiences of Patients and their nurses in a Hospice setting. PhD thesis. Oxford: Oxford Brookes University; 1996.
14. Copp G. A review of current theories of death and dying. *J Adv Nurs*. 1998;28(2):382-390.
15. Welman M, Faber PA. The dream in terminal illness: a Jungian formulation. *J Anal Psychol*. 1992;37(1):61-81.
16. 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.

17. Arnold BL. Mapping hospice patients' perception and verbal communication of end-of-life needs: an exploratory mixed methods inquiry. *BMC Palliat Care*. 2011;10:1.
18. Parnia S, Fenwick P. Near death experiences in cardiac arrest: visions of a dying brain or visions of a new science of consciousness. *Resuscitation*. 2002;52(1):5-11.
19. Orne RM. The meaning of survival: the early aftermath of a near-death experience. *Res Nurs Health*. 1995;18(3):239-247.
20. Greyson B. Dissociation in people who have near-death experiences: out of their bodies or out of their minds? *Lancet*. 2000; 355(9202):460-463.
21. van Tellingen C. Heaven can wait—or down to earth in real time: Near-death experience revisited. *Neth Heart J*. 2008; 16(10):359-362.
22. DeCasper AJ, Fifer WP. Of human bonding: newborns prefer their mothers' voices. *Science*. 1980;208(4448):1174-1176.
23. Schroeder-Sheker T. Subtle signs of the death bed vigil: responding to hearing-impaired, comatose, and vegetative patients. *Explore (NY)*. 2007;3(5):517-520.
24. 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. Owen AM, Coleman MR. Detecting awareness in the vegetative state. *Ann N Y Acad Sci*. 2008;1129:130-138.
26. Renz M. *Zeugnisse Sterbender: Todesnähe als Wandlung und letzte Reifung*. erg. überarb. 4. Aufl. ed. Paderborn, Germany: Junfermann; 2008.
27. Renz M. *Zwischen Urangst und Urvertrauen: Aller Anfang ist Übergang. Musik, Symbol und Spiritualität in der therapeutischen Arbeit*. Erw. u. aktualis. Neuaufl. ed. Paderborn, Germany: Junfermann; 2009.
28. Steinhauser KE, Barroso J. Using qualitative methods to explore key questions in palliative care. *J Palliat Med*. 2009;12(8): 725-730.
29. 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.
30. Becker H, Geer B. Participant observation and interviewing: a comparison. In: Seale C, ed. *Social Research Methods: A Reader*. London, UK: Routledge; 2004:246-251.
31. Flick U. *Designing Qualitative Research*. Thousand Oaks, CA: SAGE; 2007.
32. Renz M, Koeberle D, Cerny T, Strasser F. Between utter despair and essential hope. *J Clin Oncol*. 2009;27(1):146-149.
33. Smith JA, Flowers P, Larkin M. *Interpretative Phenomenological Analysis: Theory, Method, and Research*. Los Angeles, CA: SAGE; 2009.
34. 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.
35. Hohwy J, Reutens DC. A case for increased caution in end of life decisions for disorders of consciousness. *Monash Bioeth Rev*. 2009;28(2):14-1-12.
36. Rietjens JA, van der Maas PJ, Onwuteaka-Philipsen BD, van Delden JJ, van der Heide A. Two Decades of Research on Euthanasia from the Netherlands. What Have We Learnt and What Questions Remain? *J Bioeth Inq*. 2009;6(3):271-283.
37. Cherny N. The use of sedation to relieve cancer patients' suffering at the end of life: addressing critical issues. *Ann Oncol*. 2009; 20(7):1153-1155.
38. Carr J. The dying process: a psychological continuum. A refinement of Kubler-Ross' five stage theory. *Am J Hosp Care*.1986; 3(4):34-38.
39. Kuczewski M. Re-Reading On Death & dying: what Elisabeth Kubler-Ross can teach clinical bioethics. *Am J Bioeth*. 2004; 4(4):W18-W23.
40. Breitbart W, Alici Y. Agitation and delirium at the end of life: "We couldn't manage him". *JAMA*. 2008;300(24):2898-2910, E1.
41. Chochinov HM. Dying, dignity, and new horizons in palliative end-of-life care. *CA Cancer J Clin*. 2006;56(2):84-103; quiz 104-105.
42. Chochinov HM, Hack T, Hassard T, Kristjanson LJ, McClement S, Harlos M. Dignity in the terminally ill: a cross-sectional, cohort study. *Lancet*. 2002;360(9350):2026-2030.
43. 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.
44. Portenoy RK. Treatment of cancer pain. *Lancet*. 2011;377(9784): 2236-2247.