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Narrative Encounters in End of Life Care

Piret Paal

The whole is different from the sum of its parts.
(Gestalt theory)

The process of re-constructing and re-negotiating lived or embodied events is to be understood as a narrative. Jerome Bruner has defined narrative as a fundamental form of human sense making (Bruner 1986:16). Bruner's understanding of narrative goes beyond the act of storytelling; in fact, according to Bruner, narrative is to be understood as a fluctuation in human affairs that unfolds in certain contexts defined by time and space (see also Mattingly 2008:136ff). People who suffer severe health disorders may act and argue in countless ways, yet, in order to control their lives and minds they need time for self-organisation, space for self-reflection, and most importantly, a human connection for self-perception. Accordingly, clinical action and interaction predominantly delineate how individuals in vulnerable situations make sense of being terminally ill and not being cured anymore.

In order to overcome the shortcomings at the end of life in current health care practices and to avoid unintentional addition to suffering at the end of life, it is essential to present an argumentation regarding the importance of narrative encounters while addressing people in a vulnerable situation. Although the importance and power of spiritual care regarding end of life care has been established in different agendas, many healthcare providers feel themselves ex-

tremely insecure when it comes to constructing the endings (Good et al. 1994:860; Taylor 2012:627). The difficulty has been largely explained by the lack of sufficient communicative training (Russell & Ward 2011:192) and partly by the normative rules of healthcare institutions that do not acknowledge the importance and possibilities of spiritual healing (Puchalski & Ferrell 2010:20). On the other hand, it has been stated that all professional caregivers bring their humanity to the medical encounter (Anandarajah 2008:452). Throughout history, there is plenty of evidence that, in order to soothe and heal sufferers, humanity has been applied as first aid, providing comfort and hope.

Following Bruner's understanding of narratives as "unfolding human affairs," in this article I suggest that narrative encounters help to make sense and give meaning even in the most difficult life situations. In this context, narrative encounters are of particular significance; namely, narratives help to regain and maintain our humanity. Stanley and Hurst have suggested that narrative is a tool that helps caregivers (family or professional) to "attend to humanness amidst the draining, overwhelming, and, yes, dehumanizing aspects of giving care" (Stanley & Hurst 2011:42). However, narrative encounters go far beyond building empathy. Narratives carry a therapeutic value that helps to maintain human connectedness supporting the self-perception of patients under ever altering and intimidating circumstances. Yet, when trying to make sense of narrative encounters in end of life care, it is important to have in mind that lived or embodied experiences are by no means narratives on their own. Experience (event, feeling or wish) becomes a narrative only through the pre-selection and verbalisation process. The narrative encounter becomes an act that breaks the silence on an individual level: due to narration, personal experience becomes meaningful. Therefore, a narrative-based approach in end of life care cannot concentrate on narrative content alone. A more beneficial way to approach narrative encounters is to inquire how and why a narrative is articulated.

Spiritual Care and the Power of Narratives

Despite the cultural, religious, and individual differences of individual patients, the suffering at the end of life is associated with the recognition of loss of one's life (the sum of things we hold dear), the fear of dying (the loss of control, possible pain), and the fear of death (entering the place of no return). This kind of awareness combined with moderate or even overwhelming fear leads to spiritual distress that adds up to the overall suffering, which, in the terms of Cicely Saunders, results in "total pain" (Saunders 1959/2005:1032). According to the World Health Organization's definition (2008), the four pillars that guarantee sufficient end of life care are medical, psychological, social, and spiritual assessments and interventions. The currently adopted bio-psycho-social-spiritual care model underlines that "one cannot understand life-threatening illness only as a medical crisis. It is a psychological, social, and family crisis as well. Yet, moreover, it is a spiritual crisis often fraught with existential questions." (Doka 2011:99).

In relation to end of life suffering, the notion of "spirituality" is presented as a container concept, which may enclose moral, ethical, but also practical challenges for professional caregivers. The taskforce for spiritual care at the European Association for Palliative Care has agreed upon the following definition: "Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred" (EAPC 2010). Accordingly, appropriate and responsive spiritual care should be aware of the following three aspects of life: firstly, existential challenges (e.g., questions concerning identity, meaning, suffering and death; guilt and shame; reconciliation and forgiveness; freedom and responsibility; hope and despair; love and joy); secondly, value-based considerations and attitudes (what is most important for the individual, e.g. relations to oneself, family, friends, work, things, nature, art and culture, ethics and morals, and life itself); and thirdly, religious considerations and foundations (faith, beliefs and practices, the relationship with God or the ultimate) (Nolan et al. 2011:86–89). The central aim of spiritual

care is “to offer a framework for healthcare professionals to connect with their patients, listen to their fears, dreams and pain; collaborate with their patients as partners in their care; and provide, through the therapeutic relationship, an opportunity for healing” (Puchalski & Romer 2000:135). Puchalski and Ferrell’s understanding of spiritual care and the provision of healing overlaps considerably with a historical understanding of the physician as a healer who always cures, relieves, and comforts (Anandarajah 2008:448). Accordingly, in terms of healing and soothing, an evocative spiritual care, above all, aims for the recognition of the patient’s personal uniqueness due to a shared meaning making process, which makes recognising the power of narrative encounters extremely significant in this setting.

Narrative encounters have been accepted in healthcare as powerful assessment tools providing useful information for interventions in terms of monitoring and maintaining a patient’s quality of life (Sierpina et al. 2007:626–629). Elisabeth J. Taylor has argued that “stories are a medium for assessment and intervention in areas that essentially reflect an individual’s spirituality.” Consequently, she suggests that storytelling can be used to promote patients’ spiritual health (Taylor 1997:252), in order to ameliorate the anxiety that accompanies the dying person’s awareness of constricted time and to control the pain (Tuck et al. 2012:69–70). In the context of end of life care the therapeutic effect of narratives is undeniable: “Just as stories give meaning to our lives, stories help us to make sense of the end of life. A story has coherence and completeness, even when it does not neatly wrap up an experience or a lifetime of experiences.” (Stanley & Hurst 2011). Narrative encounters between professional caregivers and the patient help patients to maintain the feeling of being connected, and thus help patients to look for a purpose, to sense gratitude, awe, compassion, and mercy, and to enjoy a deep sense of inner peace (Goldstein 2007:1002). Furthermore, by unfolding the narrative, ordinary as well as holy experiences are captured as “little moments” or moments of connectedness that help to reduce stress and affect the patient’s state of mind even if the life itself is perceived as incomplete.

Therapeutic Emplotment and the Challenge of Constructing the Endings

In her works on narratives and their uses in a clinical setting, Cheryl Mattingly (1994) has introduced the concept of “therapeutic emplotment.” As it happens, the clinic or healthcare centre is an institution that normally operates by its own norms and rules. These norms and rules often contradict the patient’s individual and socio-cultural expectations. They make patients feel extremely uncertain in terms of discussing their needs and anxieties (Paal 2011:220–227). From a socio-cultural perspective, a healthcare institution represents a typical “border zone” where “beliefs, values, language, and scripts that govern daily life” (Mattingly 2008:147) have to be revised and (re-) negotiated frequently. The main problem is that in clinical practice the patient is often approached as a biomedical challenge. Matters concerning patients’ feelings and possible confusion regarding the self go unnoticed as long as the patient is seen as responding to treatments. Meanwhile, patients find it objectionable to be reduced to a set of biological functions in this way, and prefer to be approached as a whole person including body, soul and spirit. They simply wish that professional caregivers would notice and approach them as individuals (Paal 2011:229). In the following illness narrative, a breast cancer patient critically observes the physicians’ withdrawal in spiritual matters:

The support from doctors has been covert. Or to be correct, there has been no support at all. And how much one misses it during the reconstruction of one’s spirits. I have understood that they [doctors] try to avoid giving false hope to patients. The concept of “false hope” is mad. Living in hopelessness takes the rest of the energy that the patient needs to survive daily life. It has been difficult to face the attitude that stigmatizes all patients to one singular group, to people who experience their illness and all problems caused by it in the same way. Every one of us has his or her life story and despite our illness we stay individuals. (KRA Syöpä-ainestot 1994, p. 1717–1724 > Southern Finland, Satakunta > Woman, b. 1935)

In this context, “therapeutic emplotment” (Figure 1) is to be understood as an interpretive activity between healthcare professionals,

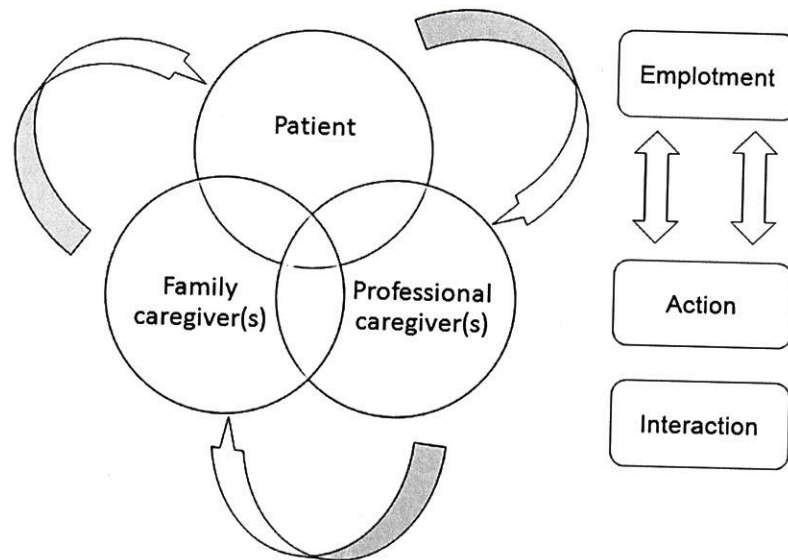


Figure 1. Therapeutic emplotment involves the patient, and formal and informal caretakers. The aim of therapeutic emplotment is to make sense of clinical action and interaction.

family caregivers and patients (Mattingly 1994:811–822). It is an effort to give meaning—“What is going on?”—to sometimes extremely fragmented action and interaction taking place between patients and their formal and informal caregivers within the healthcare setting.

Based on the gestalt theory of perception, the feeling of connectedness is essential in order to make sense of self. The patient’s self-perception is strongly affected by the socio-cultural ambiguity that rules interaction and meaning making in any institutionalised setting. Chiefly, the patient’s perception of self is influenced by the ways professional caregivers recognise and take care of the patient (Paal 2011:220–226). Particularly in a vulnerable situation, where suffering has reached its limits and the pain has become unbearable, the way in which the suffering person is approached and addressed has central significance. Hence, when a patient suffers from the loss of self and healthcare professionals approach him or her merely as a dysfunctional organ or body part, the patient feels like it as well. On the other hand, when the patient is recognised

as an individual, she or he perceives her- or himself as someone who still matters.

Within the biomedical healing drama, when it comes to constructing the endings, the therapeutic narratives often become interrupted: firstly, because among professional caregivers there is a high mandate to instil hope to avoid despair; secondly, palliative or terminal patients are removed from the curative surroundings to their homes or to “home-like” end of life care settings; thirdly, there is an overall inclusiveness in terms of further procedures (Good et al. 1994:860). When it comes to constructing the endings, it is important to consider how to mediate the changed situation without taking away hope, how to make the transfer to new surroundings acceptable for a patient, and what are the tasks that need to be taken care of to make the care whole. Therefore, it is vital that narrative encounters in the end of life care setting are approached systematically,¹ considering the particular position, importance and role of each participant within the border-zone surroundings.

The task of maintaining hopefulness has been described as an ethically complex challenge for healthcare professionals (Taylor 2012:627). A recent review on this matter suggests that there are no demographic, cultural or disease-specific factors to predict patients’ preferences regarding the delivery of detailed prognostic information at the end of life (Russell & Ward 2011:191). The authors suggest that professional caregivers should address their patients regularly in order to find out the preferences of the individual patient. It is particularly important that professional caregivers do not give up addressing their patients as the end is approaching. Listening and being present is the only way to figure out the further steps to be taken in terms of adequate “total care.”

In fear of giving false information or driving patients to hopelessness, many professional caregivers prefer to withdraw or become silent. Yet, deliberate silence can be worse than truth telling since the consequences, whether we discuss them openly or not, still remain evident (Paal 2011:76–78; van Dijk 2006:164). A palliative medicine physician recently explained to me how her colleagues basically plead with her to mediate the bad news, although she might not know the patient at all, every time a patient’s disease is not responsive to

curative treatment. She explained that her colleagues feel extremely liberated every time she agrees to help them out, even if, for her, it means running from one stranger to another to deliver the bad news. To make this clinical madness meaningful, she delivers bad news, simultaneously providing comfort and presence. In other words, withdrawing oneself or becoming silent results in additional suffering for patients.

From the patients' point of view, the end of life care situation is felt as another meaningful transformation in the illness process. Frequently, the symbolic transformation from a patient to a palliative patient facing the end of life becomes highlighted by the real transfer from the curative healthcare setting to a palliative or hospice care setting which partly, sometimes also entirely, breaks the previously established supportive framework. For suffering patients, both transformations are marked by the sensation of coming to an end—finding relief or letting go. For family members, it is usually a period of grief and an extremely high psychosocial burden. Thus, it can be difficult for a patient to discuss end of life matters with his or her family peacefully and with sufficient anticipation. This points to the fact that both the patient and family members are in need of solid professional support, but even more than that, of a human connection during this period.

Strivings, Sacred Strivings and the Power of the Future

James Rachels has suggested that when it comes to giving meaning to one's life and finding inner peace at the end of life, it becomes far more important to "work with the sense of incompleteness," with all the complexity the particular situation possesses, than trying to complete something that cannot be completed anyway (Rachels 1986:50). This statement applies to patients, family caregivers as well as professionals working in end of life care facilities. As a matter of fact, it is the incompleteness that despite everything keeps us hopeful. Patients at the end of life may still hope for a cure, for a sudden and long remission of disease, for a pain-free existence, for the resolution of interpersonal relationships, for self-forgiveness or to be remembered well (Taylor 2012:629–639).

Hence, hopelessness at the end of life “is not simply the absence of hope, but attachment to a form of hope that is lost” (Sullivan 2003:393). In case we observe life events retrospectively, “the whole” may appear different from the sum of its parts: dreams may have come true unnoticed, disappointments may have turned out to be good things, and complicated life events may seem a rich source of experience. By using their mind power, people are able to modify their biographical lives in a desired direction, even if they are not capable of “living” these in real situations in a social sense (Ruddick 2005:507–510). Therefore, narrative encounters help to control aggression, fear, grief, spiritual emptiness, and other distressing feelings. All this comes down to what James Rachels has labelled as being alive (Ruddick 2005:507–510). Namely, as long as we are able to control our minds and modify our consciousness in the desired direction, we perceive our self as being alive. A cancer patient describes it as having a “small glimmer of hope”:

Yeah, sometimes they are memories of the past, too. Yeah, in that I, who knows ... well, I have a hard time looking at photographs. That doesn't really work. But instead, I think about all of the things that I have experienced and then I think to myself: Man, you really have experienced a lot, a lot (emphasized) in your life, that has to suffice, right. And then sometimes you think to yourself: Well, maybe it will get better and then you can get back on your feet and can do something again. And then I usually felt better. And then I was able to do a few things again. And, uhm, yeah, and then this, this, this small glimmer of hope, that is what keeps you going, you know. (Attachment and Spirituality 2011: Man, 42 y.)

By using the power of our minds, we can keep control over our lives and make our lives meaningful even in the most complex situations, and not only retrospectively, but also prospectively. It is generally known that the importance of narrative encounters lies in recalling and reorganising memories of the past. However, as people grow weaker, and face suffering and pain, mind power becomes useful in order to maintain hopefulness and seek meaning beyond unfolding events. This leads to an interesting aspect of the future in the end

of life encounters and the impact of strivings in terms of finding inner peace.

Ken Pargament (2005:34–43) has proposed addressing individual “strivings” as the main key to an adequate assessment of personal needs, desires and fears. Pargament’s central statement regarding the idea of strivings is connected to keeping control over one’s mind by placing hopefulness in future prospects. The following examples indicate that people confronted with life-threatening illness can strive for different things in different situations. Some of these strivings include a longing for a response from healthcare professionals, others are recruited to make personal experiences meaningful in the critical situation. The first example describes the striving for nature and family connection:

In our yard grew a birch tree with two boughs. For some reason the second bough began to suffer, and together with my family we thought about cutting it down. It had been there all the time during our marriage. The birch grew under my daughter’s window and was a reminiscence from her childhood. In summer mornings birds used to sing happily on its branches. We did not want to destroy it. While I was in hospital because of breast cancer surgery, my husband came to see me. He said he had cut down the worse bough and now the tree is reminiscent of me. When I look at the tree I think that we both miss part of ourselves, but we may live, as we are still needed to bring joy and support our nearest and dearest. (KRA Syöpä-ainestot 1994, p. 4740–4741 > Pohjanmaa > Woman, b. 1939)

The second example implies the urge for a healthy body image despite the disease:

As I mentioned losing hair to one nurse, she told me that being bald is not so bad for a man. For me it was a really bad thing in addition to everything else. Nurses think that a cancer patient may look like whatever. The main thing is that he gets his treatments. (KRA Syöpä-ainestot 1994, p. 2525–2530 > Southern Finland, Satakunta > Man, b. 1940)

The third patient explains how humour and the family helped her to control her post-surgical pain:

The wound from the kidney cancer surgery reached almost from the backbone to the navel—a quite long wound across the waist. And then in the morning as I said to my son that I now have this kind of wound all over my stomach, my son answered me that “Mother, now you must change your profession. In the circus there is a place free for sawn women.” After that I felt so awful, because it was so funny, it was so close that the wound opened again. (KRA Syöpä-ainestot 1994, p. 0593–0595 > Northern Savo > Woman, 50+ y.)

The fourth example expresses a striving for a good joke and a human connection:

In spring, our unit got a really merry doctor. He often took a moment to have a chat with patients and I remember a case where there were three sporty men together [in the hospital room]. The others were younger than I. The doctor stopped again, smiling, to have a discussion. We were wondering how cancer might come, even if everyone of us had tried to keep himself in good condition by practising sports. The doctor listened smiling typically for him and calmly told us: “Well, there you have a good example of the dangers of sports.” There was no other way than to agree with him. (KRA Syöpä-ainestot 1994, p. 0823–0849 > Helsinki region, Uusimaa > Man, b. 1929)

These examples suggest how narrative encounters make individual strivings accessible. The assessment of strivings embedded in stories can give directions regarding people and places that are essential to find comfort and peace. The assessment of a narrated future can be beneficial in terms of making transformation at the end of life safer. Pargament and Mahoney (2005:187–188) have suggested that tapping into patients’ “sacred strivings,” that is, inquiring about aspects of life that take on spiritual character and meaning or God, higher powers, or the divine, is vital in terms of providing spiritual support,

maintaining the quality of life and helping to live until the very end. During narrative encounters, different metaphoric expressions, such as climbing a ladder, reaching the gates of heaven, and other images of reaching the final destination (see more in Southall 2013) can without difficulty be interpreted as reaching out for the transcendent. But again, it requires a certain sensitivity and understanding of narrative functioning to reach out for these strivings in order to elaborate further on anticipated issues. Nevertheless, by denying the fragmented action and interaction of the clinical setting, and concentrating on being present and listening to the strivings that emerge from narrative encounters, these can be used to create “little moments” that make people feel alive.

Towards Understanding Narratives

In discussing narrative encounters, Arthur Frank has put his finger on an important point: “Stories and storytelling are popular these days: narrative is in vogue; ... although this popularity has much to offer, we also need to be alert to the potential limitations and dangers of our approaches and work with narratives and stories” (Frank 2009:161). For example, when rational and irrational forms of knowledge collide, narrative-based communication may gain a counter-productive value in terms of making sense of unfolding situations. Hence, discussing the “lay theories” about possible causes of falling ill, for instance with cancer patients, is considered unnecessary, if not unprofessional, among professional caregivers (Paal 2011:158ff). In end of life care, powerful interventions, e.g., alteration of one’s autobiography, working on attachment issues or eliciting a spiritual history may seem inappropriate, although caregivers usually perceive such interventions as far more burdensome than patients do, not to mention the negative influence of fragmented communication in the clinical setting that does not provide a place for unfolding truly therapeutic narrative encounters. A polite “How are you?” can be perceived as offensive, even arrogant, if the caretaker is not prepared to take the time to really listen:

But it is like it was here [a palliative care unit], the first day that I was here one of them [a professional caregiver] came by and came in and asked: How are you doing? And I said: Well, not too good. And then he said (laughs): Oh yeah, aha, ok, aha. Okay then, well have a nice evening. Goodbye. And then I thought: Well, classic. Really. Classic ... No, I think that is pretty bad, the whole: how are you doing? You just noticed that it was just like a saying that someone says. This is how he comes in, with a grin on his face: How are you doing. And I said: Well, not so good, otherwise I wouldn't be here. And then he said: Aha, hmh, hmh, oh yeah, hmh, hmh. Well then have a nice evening. What am I supposed to do then? Should I say: No wait, don't go, we need to talk! Yeah. Just like when you ask someone "How are you." No one really cares. I mean if you tell someone how you are really doing then that will knock them out cold. Oh yeah, well, ohh... Well, it has to be the right place, yeah. The right place and the right situation. And then of course I would be thrilled if someone honestly cared to know. (Attachment and Spirituality 2011: Man, 42 y.)

In order to understand the external and internal limitations, but also the expectations on narrative encounters, it is important to take a look at how narratives work:

1. Inner Narrative

People use their cognitive skills to put together narratives in order to make sense of their experiences and mediate meanings. Constructing a narrative is affected by the following aspects: firstly, by the individual's ability to memorise and remember the embodied events (what?); secondly, by the purpose of the particular narrative encounter (why?); and thirdly, by the individual intentions and culturally defined norms of narration (how?) (Paal 2011:64). The ability and desire of an individual to analyse and interpret the final transformation affects the process of negotiation with the self and the formation of the inner narrative. The process of inner sense making or inner (re-)negotiation initially takes place in pre-narratives that exist in human minds. Pre-narratives, or inner narratives, are

understood as a process in which the person interprets the events of life relative to the opportunities offered by the current situation (Ricoeur 1991:27–28). To gain access to the inner narrative, a narrative encounter is needed. A purposefully presented narrative, even if only describing the flow of unfolding events, may shed some light on the inner meaning making process.

2. Breaking the silence

Narrative encounters are perceived as an opportunity to share individual knowledge, experiences and feelings with others. It is understood as a significant continuation of the inner negotiation process. The narrative encounter is an act that breaks the silence on an individual level. Therefore, narratives must be viewed as based on embodied experiences, but also as intended social speech acts targeted at a specific audience, with a particular goal. The recollection of individual memories has little to do with simply listing the embodied events. This is an active process in which events from the past evoke strong emotions and bring new thoughts and interpretations to light. Some memories may have lost their accuracy when connected to reality. Furthermore, when it comes to socio-culturally complex issues, such as life-threatening illness or dying and death, any kind of intentional “forgetting” or “silence” may be equally meaningful as remembering. Apparently, people do not share all of their inner concerns. Rather, they recall past events in order to find and give them new meanings. For individuals, such recollection, although psychologically and spiritually beneficial, may be challenging.

3. Socio-cultural limitations

Narration is a method for self-expression and for self-perception, but it is also a communicative act full of meaning. Thus, any narrative should be approached and evaluated in its particular context. One needs to bear in mind that it is the socio-cultural setting, such as the clinical surroundings described above, that above all governs the nature of narrative encounters. Accordingly, the clinic as an in-

stitution entirely holds the power to silence or distort any personal story (Frank 2009:164).

Composing a narrative is never based simply on individual knowledge and experience but is framed and modified by socio-cultural discourse. Dell Hymes has stated that by choosing or pre-selecting our personal voice, we always communicate something personal as well as cultural (Hymes 1985:391). The addressee or the listener simply needs the skills to recognise it. Dream narratives, for instance, can be employed as specific communicative paths by people who go through emotionally difficult times (Paal 2009). On the basis of the unfolding life events, dreams can be re-interpreted. The dream narratives can be told repeatedly, which adds to their therapeutic value. The most important aspect about narrating dreams, however, is that dream narratives can be used to utter individual fears and concerns without putting the listeners into an uncomfortable situation. Although individually significant, from a socio-cultural point of view (at least in Western societies), dream narratives are typically interpreted as entertainment. Accordingly, during narrative encounters, the socio-cultural value of dream narratives reduces the emotional load placed on the addressee(s).

In order to be successful in terms of making sense, the narrator must carefully consider the rules of performance (self-expression), social expectations (listeners) and the general socio-cultural context (discourse). The listener, on the contrary, has to be prepared to elaborate on the performed narrative with “what,” “how” and “why” questions in order to find the purpose and meaning hidden behind the narrative encounters, uttered words, metaphors, stories, and meaningful silence. Besides socio-cultural awareness and contextual limitations put on narrative encounters, attentiveness and human connectedness are definitely primary standards for achieving an in-depth understanding of “what is going on?”.

Comfort, Relief and Spiritual Healing

The main elements of spiritual care include compassion, presence, true listening, and the encouragement of realistic hope (O'Connor 1986:31–37). These elements do not require doing but rather being. When it comes to providing spiritual care, the healthcare professional

is not expected to inquire about specific beliefs or take more time than his or her usual tasks require. Spiritual care obliges healthcare professionals to augment their everyday activities with presence, compassion, and positive intention. By cultivating presence and active listening, caregivers provide a suffering individual with an opportunity for self-perception, self-reflection and self-negotiation.

The following spiritual empowerment pyramid (Figure 2) contains four elements that should guide the end of life encounters between patient, family and professional caregivers while aiming for “total care.” The pyramid indicates that the “total” care must be based on presence and in-depth listening in order to provide comfort. Being prepared to elaborate with the question of “what is going on?” instead of the more common “how are you?” allows professional caregivers to access the patient’s inner meaning-making process and reach out for his or her strivings that are perceived as meaningful. Accordingly, the strivings can be used as internal or external resources in order to provide relief via “little moments” that underline the sense of still being alive. At the top of the spiritual empowerment pyramid stands the task of maintaining hopefulness, which despite dismay, confusion and pain can bring patients closer to spiritual healing.

It is not uncommon that the end of life interaction and action between patient and professional caregiver becomes reduced to non-verbal encounters. This can be due to reduced cognitive abilities, but also to a language barrier, which is quite a common impediment in modern health care institutions. According to Jerome Bruner, even when communication fails, the narrative put together of interaction (healing touch, eye contact, sounds that mark our presence) and action (events taking place in a certain setting defined by time and space) keeps unfolding. This indicates that despite external and internal limitations, the caregiver’s main task is to be present in order to comfort and maintain the patient’s sense of being connected, and thus, living.

Conclusions

This article argues that truly evocative spiritual care should consist of “little moments,” of feelings of being connected to something or someone that maintain hopefulness reaching beyond the pain,

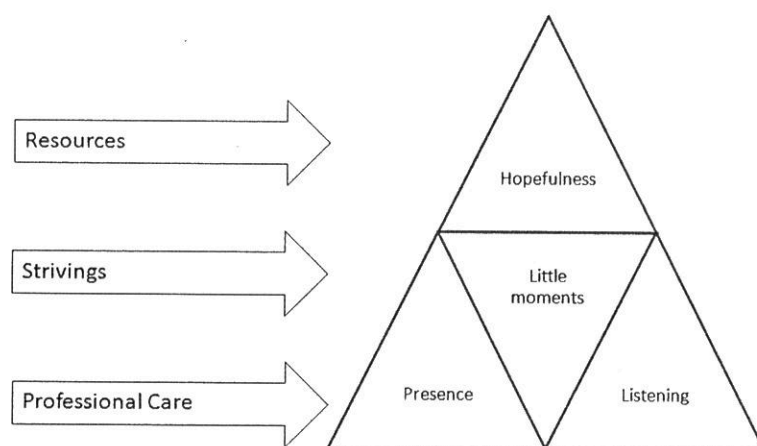


Figure 2. The spiritual empowerment pyramid aims for comfort, relief and spiritual healing.

beyond the suffering, and beyond the end of life. In this connection, the therapeutic effect of narrative encounters is undeniable in end of life care. First of all, narratives are tools for self-expression, but also for self-perception, and are thus essential in terms of making sense when facing the terminal transformation at the end of life. Secondly, with the help of narratives, patients can control their minds and make their lives meaningful, even if they are not able to direct and control their “social lives” anymore. Thirdly, narrative encounters represent “little moments” of human connectedness in the end of life setting. However, to achieve the desired human connection, professional caregivers need to be present and attentive to the patient’s self. When professional caregivers are prepared to provide comfort in terms of presence and listening, narrative encounters provide means for coping, and not only due to recalling resources from the past. By controlling their minds, patients can find hopefulness in strivings that connect them with significant people and places, but also with the transcendent, not only from the past, but also in the future.

All things considered, narratives give access to the human aspect of end of life discourse and help to make sense of life’s incompleteness for all parties involved. Despite the suffering and pain, fear and hesitation, narratives allow modification of the past and

the present into future prospects (even with comforting endings) in our minds, which best explains the therapeutic value hidden in narrative encounters.

Notes

- 1 The systemic approach is a form of therapy that conceives behaviour and especially mental symptoms within the context of the social systems people live in, focusing on interpersonal relations and interactions, social constructions of realities, and the recursive causality between symptoms and interactions (von Sydow et al. 2010:459).

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