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Narrative approaches in palliative care

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Abstract
The narrative approaches touched rather recently psychology and medical sciences. An outline of the intersection between narrative therapy and palliative care comprises major constructs such as “response to trauma” and “absent but implicit”. Relevant to palliative care psychological support, the paper includes two practical examples and a general description of a “scaffolding” of themes designed to support a narrative-therapy conversation exploring responses to trauma. Narrative therapy practices, such as “Tree of Life” and “Remembering are implemented to support the development and sustenance of desirable identity claims, descriptions, and stories, engaging the person in palliative care in this narrative re-authoring process.

Keywords: narrative approaches; narrative therapy, palliative care

Rezumat
Abordările narative au atins destul de recent psihologia și științele medicale. O schiță a intersecției dintre terapia narativă și paliativă include constructe fundamentale precum „răspunsul la traumă” și „absent, dar implicit”. Relevant pentru suportul psihologic al îngrijirilor paliative, lucrarea include exemple practice și o descriere generală a unei „schele” de teme concepute pentru a sprijini o conversație de terapie narativă care explorează răspunsurile la traume. Practicile de terapie narativă, cum ar fi „Copacul vieții” și „Amintirea” sunt implementate pentru a sprijini dezvoltarea și susținerea revendicărilor de identitate, descrierilor și poveștilor dezirabile, implicând persoana în îngrijirea paliativă în acest proces narativ de redevenire autor al unei narațiuni preferate de viață.

Cuvinte cheie: abordări narative; terapie narativă

Introduction

Narrative approaches in palliative care may not sound so exotic, although developments in systemic, dialogical and collaborative approaches, the area in which narrative therapy has developed since the 1990s, are fairly recent. The last year of this generative decade offered the world the first book on “Narrative means to therapeutic ends” [1]. A few years later, more clinical cases in professional and academic journals indicate the beginning of qualitative research focused on narrative therapy processes and results. The year 2006 brought the first book on “narrative medicine” by Rita Charon, from Columbia University in New York [2], and a few years later, [3] SuEllen Hamkins published at Oxford University Press the first book on narrative psychiatry showing how narrative approaches slowly expand towards territories of psychology and medicine after decades of flourishing in other disciplines such as history, literature, arts, sociology, and anthropology. The list of initial areas of narrative approaches exploration and development is much longer.

A distinct difference between narrative approaches (based on a social constructionist view of narrative therapy) and storytelling and literary approaches resides in the invitational stance of the narrative therapist or narrative therapy-informed practitioner in creating a context for the person to become an active narrative agent of telling and re-telling his or her life experiences, crafting inspirational, relational identity forging accounts. In storytelling and literary approaches, the practitioner is performing, providing influential stories which may stand as “interventions”.

One key concept at the intersection of narrative therapy and palliative care is „responding to trauma”. This is an innovative perspective proposed by the founder of narrative therapy, Michael White [4]. This perspective has roots in what Michael names an „absent but implicit” attitude, based on which he proposed a conversational scaffold or a narrative practice map which proved to be influential in cases of persons looking for counselling or support due to traumatic experiences and their effects on their lives. One important aspect needs to be underlined, that is, the experience of trauma may include previous experiences of life of a patient in palliative care, and the current experience of facing body decay, suffering, and death.

Initiating and sustaining conversations based on “responding to trauma” perspective honours the person’s agency and invites to exploration the intentional identity descriptors of the person who requests support and care. The position of narrative therapy regarding the descriptors of intentional identity – of intentions, preferences, principles, values, hopes and dreams, convictions, pledges, declarations – is aligning with the view of spirituality, as it is described in Sulmasy [5]. Aspects of meaning, relationships, and value, at least, are core in sustaining supportive conversations about spiritual aspects of living of the palliative care patient.

The narrative facilitator focuses not on the aspects of the trauma or the suffering itself but on (often) small actions, gestures, bodily responses during and after the traumatic or adverse situation with the intent to assume them as "responses" to the traumatic or adverse context, responses that may be connected to aspects of importance, preference, or value for the person. That is, a context is traumatic or adverse in case of dramatically affecting something that is of great importance of value to the person, be it physical, affective, or mental functioning or well-being, and, to the palliative care patient, ultimately, life-threatening. In palliative care, the meaning of "traumatic context" is populated with the experiences near death and dying, at which may inadvertently contribute medical or professional procedures that may ignore or minimize the acute needs and suffering of the patient, including the difficulties of regaining some meaningfulness for the end of life, the fear of suffering, of dying, of maintaining dignity. According to Sulmasy [5] dignity refers to "the value human beings have by virtue of being just what they are—human beings" (p. 1387).

The narrative conversation aims not merely to resurrect past narratives but aims at re-engaging the persons in the centre of this consultation with possibilities of re-dignifying expressions of their experiences, knowledge, skills, and their preferences for living, including preferences for the passage to dying and the preferences for how their presence will be maintained after passing.

In this view, inviting the person to describe what may be something of value (intentions, preferences, values, principles, hopes, dreams for the future, etc.) being lost, forbidden, violated by the adverse conditions suffered. In this conversation the facilitator is supporting the person who is the subject of the trauma or adverse conditions to describe the absent but otherwise invisible criteria of well-being being contradicted or dramatically affected. With this perspective, the narrative work is supporting an alternative story of a preferred identity of the person which depicts a platform of understanding which may act as a counter-story to the traumatic descriptions which may be described as problem-saturated stories.

In line with Johns [6] views, we may look at such conversation as a narrative approach storying identity, story-making, not as a "storytelling" process. A facilitated collaborative process of self-storying having the person in the centre and the therapist decentred, while still narratively and relationally influential. The person in care is surrounded and contributes also to the traumatic stories that may abound in the beginning, as these are supported by the immediacy of the suffering, the traumatic and adverse effects, the perceptions of those around the person viewed as a victim of his or her traumatic circumstances, the diagnosis and labels attributed by professionals and lay people alike, etc. Complementing the traumatic or adverse experiences' stories, a narrative practice coupling absent but implicit attitude with the responding to trauma view is generative of rich, detailed, historicised and relational stories of the intentional identity descriptors of the person apart, beyond, and deeply rooted in personal, relational, and historical experiences and examples from the person's life.

We may consider that such a narrative approach is having a more complex and important impact on the reimagining of the interrupted meaningfulness of life and living. Trauma, the experience of approaching death and dying, both may be seen as acting as a "cutting" device, separating the conception of life of a person as "before" and "after" the traumatic situation or period, with an inability to express, connect, and maintain a sense of becoming, evolving, within a possibility to ensure some continuity for the self. Rendering possible to recapitulate, revise, circulate, and enrich descriptions of preferred identity the explicit self-defining stories create space to explore the spiritual and religious beliefs and practices in view of rendering their life and becoming through life meaningful and enlightened.

Yuen [7] mentions how Michael White [8, 9] "strongly emphasises the importance of creating a safe territory of identity for people to give expressions to their experiences of trauma" (p. 11) which is underlying the productive effect of narrative therapy in preventing re-traumatisation of the person by asking questions directly about the traumatic experience (thus, eliciting the traumatic story).

Narrative therapy offers a response to the limitations of traditional behavioural models of psychotherapy which may not be able "to fully capture what it means to be human" [10]. Exploring, recruiting stories of examples of aspects of principles and values, beliefs, and convictions – including spiritual and religious ones – opens avenues for richer incorporation of profound and expanded understandings of somebody's life within the specific personal, relational, historical contexts they lived and live in. Moreso, it allows, despite the imminence of death and dying, of imagining possible futures for the legacy, ideas, relationships, and ways in which their life may continue to connect and impact, and ways to get to a peaceful understanding of life despite the presence of unknown, uncertainty, suffering, and fear of death and dying.

Two examples of a narrative conversation and a more complex narrative practice describe how these ideas are applied in palliative care by narrative informed practitioners.

"Response to trauma" conversations

A typical conversation in line with the "response to trauma" strategy scaffolds a series of "zone of proximal development", ZPD-type invitations, using Vygotsky's ideas [11], adapted to therapeutic aims by Ribeiro et al. as "therapeutic zone of proximal development" (TZPD) [12]. "Similar to the application of the concept of proximal development to child development, the client's TZPD defines a segment of the developmental continuum of change that the client can reach with the help of the therapist" (p. 723). The conversation includes such themes, according to the suggestions of Michael White [8]:

- An investigation on the difficulty or harm that continues for the person who is in care (not about the incident or traumatic event or period lived), that is on the current effects of the suffering.
- An exploration on what is precious or valuable that was interrupted, affected, nullified, or minimized by the incident or the affliction; what is found to be valuable or important is named, using the person's words and descriptions.
- An archaeology of how the person, in various instances of his or her life, expressed what is found to be of value or importance; examples of what is lived in accordance with the preferences rendered visible.
- Conversing with the person, recruiting somebody from the person's life who may be knowledgeable about these lived instances illuminated by the precious and important values; finding how the witness of such instances describe the person – that is, imagining a description of the person's identity through the eyes of the witnesses of his or her life.

- Continuing the history of how the value or the important view already described entered in the person's life, if there are important characters who supported the relationship between the person and such values, and how they contributed to this preference and conviction.
- An exploration of how the value or the important aspect of life and living cherished by the person is present in the various responses that may be identified that the person had to the trouble, trauma, or their effects.
- A reflection on the meaning of such responses, during and after the incident or period of being affected, may be seen through the light of a continuous series of actions and gestures of resistance.

Through this kind of scaffolding, the conversation is inviting the person (and it invites the carers and the family members to join in this process) to reposition from a victim-perspective to a perspective of agency. Also, it supports an alternative, desirable story about the preferred identity characteristics (values, hopes, dreams, etc) in response to a problematic story of being a victim of the circumstances. Such a process is freeing up possibilities to further clarify, express, and understand the way the person prefers to see himself or herself, re-describing richly and strengthening an image of a capable and continuous relationship with special preferences, knowledge, and skills. The process also allows the carer, other carers and supporters, family members and alike, to join in supporting such descriptions, honouring the person's descriptions of identity, and creating possibilities to celebrate what is uniting them in processes, rituals, and communion exchanges.

Tree of Life narrative practice

Among various narrative practices that may be brought in beyond sustaining such inspirational intentional identity stories contingent to the present traumatic stories, the "Tree of Life" can aggregate and support the exploration, narrative performance, and identity celebration of what is of importance and central in the person's life, despite the presence of trauma, traumatic effects, and the pressure that comes with approaching end of life.

In the Tree of Life narrative practice, a drawing of a tree is structuring a space on a sheet of paper (poster formats always allow more possibilities) from roots, ground, trunk, branches, leaves, to fruits. Each area will be used to structure a conversation and to document in a few words aspects of lived experiences as such, adapted from Ncube and Denborough [13]:

- roots: place/places where the person was born and lived in childhood, preferred aspects of early life – preferred place to play, preferred music or dance, the most important person who touched their life.
- ground: where they live currently and daily activities.
- trunk: the abilities or skills they currently express and are known to others.
- branches: the hopes, dreams, and preferred directions for their life.
- leaves: important people who supported them during their life worth mentioning.
- fruits: the gifts, examples of support and sustenance, contributions of the important people to the person's life – with respect to the growth, relational skills, and life-sustaining skills they developed with support from the special people mentioned.

Such a practice can be adapted to an individual encounter and conversation, may be used as a document of these important life and identity descriptions which support a reinvigorated story about what was and is worthwhile for the person in the centre. If this narrative practice is used in groups of similarly affected people – such as in a hospital or hospice ward -, it may be applied as a collective narrative practice, exploring with the persons in the group, conversing with each person about their drawings and key words in front of the other members of the group (structuring a stage for a "telling" of each important life and identity story), and creating an area for an exhibition of "Forest of Life" of all documented "Trees of Life", allowing visitors and members of the group to explore, comment, and discuss.

Sometimes such collective narrative practice includes a stage of "Storms of Life" where the group members are contributing with examples of responses to difficulties, examples of acts of resistance, survival practices, of maintaining a dignified life, despite any drawbacks of the difficulties encountered.

Such a stage reinforces and multiplies the descriptions of agency and sustains the identity-related claims already visible in the "Tree of Life" initial activity. This process is supposed to end with a special protocol or ceremony to document and celebrate the gains and realizations of such a process using a "Tree of Life Certificate" and orchestrating a group celebration with other people invited along (other carers, family members and friends, etc).

These narrative practices were adopted and implemented in clinical settings in Iași, Romania, at the Geriatric Clinic of the Dr. C. I. Parhon Hospital of Iași in demonstrative projects in partnership with Psiterra Association and field practicum of psychology students in partnership with the Faculty of Psychology and Educational Sciences, „Alexandru Ioan Cuza" University of Iași from 2016 (with a pause during the pandemic period). The clinical experience of the team of psychologists who offered counselling informed by these narrative practices were varied, some patients who were agentic and able to participate benefited from Tree of Life practice, others from conversations informed by "response to trauma" attitude. The benefits of using such narratively informed conversations and practices extended beyond the re-energization of possibilities of meaning making, including explorations in spirituality, the re-humanisation of medical practice and involvement of family members.

"Remembering"

Another relevant practice for palliative care settings emerging from narrative therapy is "remembering' brought up by the work of Lorraine Hedtke [14]: "in contrast with a conventional stage model of grief, "remembering conversations" aim to keep the loved one's voice alive as a hope-filled resource when death brings crises of meaning and challenges our assumptive world" (p. 3). Being a narrative therapist who worked as a social worker with people in palliative care and their family members who accompany them, Hedtke, [15], synthesizes a set of narrative therapy principles guiding such work:

- *Affirming the ongoingness of life and relationships rather than dwelling on the finality of death.*
- *Appreciating how the emergency of death provides opportunities for the telling and performing of loving stories that I hope will linger long after the death.*
- *Asking questions to generate affirming and resourceful memories of this time for future times of reflection and re-membering.*

- *Using questions to bring forth creative thinking within the constraints of otherwise fixed realities, such as time and proximity.*
- *Seeking out with people the resources they can call on for handling the challenges of transition that death brings.*
- *Employing the power and flexibility of story to transcend physical mortality.*
- *Promoting the re-membering of lives and relationships.*
- *Refusing the assumptions that people should complete a process of farewell and letting go in order to progress healthily through the crisis of death.*

And, specifically to empower the physicians themselves, Sulmasy [5] recommends "to take a spiritual history, elicit a patient's spiritual and religious beliefs and concerns, try to understand them, relate the patient's beliefs to decisions that need to be made regarding care, try to reach some preliminary conclusions about whether the patient's religious coping is positive or negative, and refer to pastoral care or the patient's own clergy as seems appropriate" (p. 1388).

Narrative therapy in palliative care can draw from resources developed, since 1990, in the more general work in dealing with trauma, to applications emerging from within the palliative field, of caring for people surrounded and living with death and dying. The "responding to trauma" attitude and practice, the narrative practices of Tree of Life, and "remembering" add to and expand the multidisciplinary avenues of caring for people in palliative care.

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