

Original Research

Impact of the Use of Non-Pharmacological Care Tools in Building the Perception of Dignity in Ailing People at the End-of-Life

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Article information

Received: February 25th, 2020; **Revised:** July 16th, 2020; **Accepted:** August 7th, 2020; **Published:** August 12th, 2020

Cite this article

Radosta DI, Ham S, Alvarado C, Fernandez I, Pincemin I. Impact of the use of non-pharmacological care tools in building the perception of dignity in ailing people at the end-of-life. *Palliat Med Hosp Care Open J.* 2020; 6(1): 7-13. doi: [10.17140/PMHCOJ-6-135](https://doi.org/10.17140/PMHCOJ-6-135)

ABSTRACT

Objective

This paper examines the link between non-pharmacological care tools carried out by volunteers in a hospice and the development of the perception of dignity in people with end-of-life terminal illnesses.

Materials and Methods

We interviewed volunteers from a hospice institution in Argentina, who carried out non-pharmacological care activities aimed at people at the end-of-life. The results of these interviews were analyzed with the Atlas Ti software, using the grounded theory as a form of qualitative codification.

Results

From the codification of the interviews, we obtained the following analysis categories: 1. Caring after the caregivers (mentioned 14 times), 2. Caretaking into account the temporal needs of others (mentioned 7 times), 3. Active listening (mentioned 11 times), 4. Environmental aesthetic factors (mentioned 18 times) and 5. Enhancement of autonomy and selfhood (mentioned 22 times).

Discussion

We examined ways in which volunteers associated with the care of people with end-of-life terminal illnesses understand their work from the explanation of the non-pharmacological care activities developed within the institution, as well as the link that these have with the different dimensions of the human sense.

Conclusion

The non-pharmacological care tools, as they alleviate existential/spiritual suffering, impact positively in the possibility of a terminal person's capacity to perceive herself/himself as worthy.

Keywords

Hospice; Non-pharmacological care; Dignity.

INTRODUCTION

Since the end of the World War II, palliative care, hospice movement worldwide and the development of bioethics, have been able to critically question the biomedical model that focuses on healing sickness rather than caring for the person.¹⁻³ These movements brought a new holistic and comprehensive perception of the person as opposed to the one upheld by the biomedical model. This implies recognizing the human individual as formed by multiple dimensions (biological, psychological, social, spiritual/existential, and ethical) and at the same time, these dimensions cannot be

approached separately as they maintain a close connection which functions dynamically as a whole.

This concept was able to emphasize the notion of dignity, established as an intrinsic condition of humankind, inseparable of its corporeal-spiritual essence.⁴ At the same time, this idea of dignity works in a relational way, as it is built in relation to the people that surround us. This generates various consequences: on the one hand, it is understood that nobody may take away or give another person its dignity (as it is an intrinsic condition of that person). On the other hand, this conceptual framework enables us to under-

stand that the ties held between a person and her/his social entourage have the capacity of affecting, positively or negatively, the way that a person perceives her/himself as dignified (what is known as dignity perception). By not considering the other as a person, by taking into account only one of its dimensions (the biological one, as in the case of biomedicine) one is implying the negative impact on the person's capacity to perceive her/himself as dignified—for he is unable to perceive her/himself as a person. The kernel person/dignity, understood as inseparable, requires as a result an holistic and overall approach in the care of an ill person.

This conception of a person has led many different physicians specialized in palliative care, the hospice movement, and oncologists to visualize different types of situations which may lead to a person not being able to integrate his life's meaning; therefore, perceiving himself as undignified. One of these conceptualizations has to do with the way in which the Spanish Association for Palliative Care (SECPAL) defines existential/spiritual suffering,^{5,6} as the “*impairment of the capability to experience and integrate the meaning and purpose of life in connection with the self, the others, art, music, literature, nature and/or to a higher power beyond the self*”.^{5,6} This type of suffering, according to the authors, is reflected in the sick person as existential/spiritual needs. Even though in the bibliography used this matter appears as spiritual need, we consider existential and spiritual as analogous, as we understand that in the conceptual frameworks used for the analysis and investigation of end-of-life care, both terms imply the search that a person undertakes to integrate the meaning of his existence. There are two needs that we consider to be of utmost importance and which we would like to introduce prior to analysis: the need to be recognized as a person and the need to give meaning to life (both related to the need of avoiding the disintegration of the self). This paper examines the link between non-pharmacological care carried out by volunteers in a hospice and the existential/spiritual needs put forward by the SECPAL. We hypothesize, according to our conceptual framework that the activities developed by volunteers who look after patients with a terminal illness at the end-of-life care, have a positive impact in the mitigation of existential/spiritual suffering, thus achieving an improvement in the person's capacity of perceiving her/himself as worthy.

MATERIALS AND METHODS

This paper was the result of the work of the interdisciplinary research team of San Camilo Hospice Center, formed by the authors. The research was developed by interviewing each team of volunteers at the hospice (San Camilo Hospice Center has more than 180 volunteers), who carry out non-pharmacological care activities aimed at the people residing in our institution and their families. Volunteers were asked to explain in detail about the non-pharmacological care tools they used in their daily work.

The institutional review board (IRB) of the San Camilo Hospice Center approved this study, which follow the principles of qualitative research ethics in human beings for social sciences⁷ and the ethical values of the institution in which we develop the research.

RESULTS

The results of these interviews were analyzed with the Atlas Ti software, with the use of the grounded theory—or data-based theory's.⁸ The following are the categories of our analysis: 1. Caring about the caregivers (mentioned 14 times), 2. Caretaking into account the temporal needs of others (mentioned 7 times), 3. Active listening (mentioned 11 times), 4. Environmental aesthetic factors (mentioned 18 times) and 5. Enhancement of autonomy and selfhood (mentioned 22 times). All coding results are displayed in Table 1.

Once encoding data was achieved, the result was analyzed using the SECPAL's conceptual framework, specifically related to the link between existential/spiritual suffering and its possible expression as needs.

We worked with the following hypothesis: the non-pharmacological care tools used by the volunteers in our hospice, show a positive impact in the mitigation of existential/spiritual suffering of the sick person as they address their needs and helps them to perceive themselves as worthy. Results are discussed in the next section

DISCUSSION

One of the spiritual/existential needs expressed by the SECPAL is about the need of being recognized as a persona. Taking into account all the theoretical questions concerning the holistic and overall understanding of the notion of persona, we find that this acknowledgement has to do with the need of avoiding the disintegration of the self, that is, the core of the identity of the sick person. We also agree with Schwartz,⁹ that in our western cultural configuration, autonomy and independence have taken an essential role in the making of identity. This partially explains that the respect of the autonomy of the individual has been one of the main boosts for the promotion of movements for patient's rights from the second half of the 20th Century onwards.¹⁰ Due to multiple causes—in general connected to the inability to move—a terminal disease can affect a person's autonomy in a negative way, causing a disintegration of herself/himself and therefore producing an existential/spiritual need: being recognized as such, both in his individuality as by others.

Recognizing and acting in favour of autonomy and self-determination appears then as a way to encourage the integration of her/his identity nucleus, promoting the relief of his spiritual/existential discomfort and her/his perception of worth.

Many activities carried out by volunteers at the hospice belong to the scope of non-pharmacological care at the end-of-life and relate to the afore-mentioned. When asked about the kind of tasks carried out within the institution, some volunteers directly mentioned the work done in more than one way for the enhancement of autonomy and individuality of the ailing person. One of them is referred directly to the enhancement of mobility. In one of the interviews, a volunteer mentioned that “*some patients that were admitted after various days of being bedridden, were accompanied and helped in*

Table 1. Coding Results

Code	Extract from the Interviews	Subcode
1. Caring after the caregivers	Caring after the nurses and amongst ourselves, the volunteers.	1.1
	Support for the guest's family both emotional and in day to day matters.	1.2
	Assist guests and their families.	1.3
	Offer water, tea or coffee to the accompanying relatives.	1.4
	We converse and support our guest's families.	1.5
	Be aware of every need that may appear, both from the guests or their families.	1.6
	Offer beverages or food to the families.	1.7
	Give support to families by sharing information as to the guest's present state – phases through which he is going through, his needs, etc.	1.8
	We pamper our guests as well as their families.	1.9
	We offer beverages, we give out hugs, and we show closeness and empathy.	1.10
	We strive so that those at end of life may live this last phase at their homes. We try to organize their families so that this might happen, giving them support and assistance.	1.11
	We accompany the loved ones in this moment, remembering the person and his life story.	1.12
	Readiness to accompany families and listen when they are moved and need to talk and be heard.	1.13
	Entertain the children who accompany visitors.	1.14
2. Caring taking into account the other person's time	Breakfast without time restrictions.	2.1
	Patience to show respect for the other person's time.	2.2
	Show the unconditionality of time. There is no hurry whatsoever.	2.3
	Bring joy to our work and to our guests, always bearing in mind what the guest needs at that precise moment.	2.4
	Be very patient, pay a lot of attention when feeding those guests that have difficulty in swallowing. Be sure not to give up with the excuse that "he doesn't want" when perhaps he would eat more and what is required is much patience.	2.5
	Respect the guest's need for sleep, he might have spent a bad night and breakfast can wait.	2.6
	Look closely to realize when to take action or not.	2.7
3. Active listening	Respect silences, need to talk, need for active listening.	3.1
	Attentive listening, active accompaniment without preconceptions or judgements.	3.2
	Listen with the heart. Step into their shoes. Be guests ourselves.	3.3
	When speaking on the phone, listen, listen for a long time.	3.4
	Listen to our guests with an open heart and "closed mouth" without judging them and in silence.	3.5
	We try to detect when there is a guest eager to be heard.	3.6
	Listen and pay attention to all needs, both from our guests or their families	3.7
	Listen.	3.8
	We offer support by listening attentively.	3.9
	Walk into the bedrooms with an open attitude. Listen, support, no judging.	3.10
	Readiness to accompany families and listen when they are moved and need to talk and be heard.	3.11

4. Aesthetic and environmental factors	Illumination: we try to light the rooms with bedside lamps rather than with those on the ceiling because they provide a sensation of coziness and warmth. During the summer months, we darken the rooms to keep them cool.	4.1
	Washing is carried out taking into account the guest's clothes, their preferences, if they want it back in a hurry or any relevant indication they might give.	4.2
	Consider the conditions of THAT room in which they are (air conditioning, natural illumination, noise level)	4.3
	Wash their faces with a damp cloth and wipe their eyes clean.	4.4
	Have their clothes neatly arranged and clean.	4.5
	We intend our garden to be tidy so that it may be a place of relax and enjoyment,.	4.6
	We change the water and flower in the vases regularly.	4.7
	Cook and clean with dedication.	4.8
	Take care of our house. Tidy it, clean it and make it look nice.	4.9
	Arrange the bedding. Tidy up the sheets.	4.10
	We provide an aesthetic and tidy environment. Cheerful. (The external manifestations are very much a reflection of the internal ones. Looking at this aspect we strive for a balance. There is an external order which expresses the internal one).	4.11
	Once a person passes away, without haste and very calmly, we cleanse his body. We treat this body with the utmost respect as it was the soul's embodiment of the ailing person we accompanied. We dress him properly and put some flowers in his hands.	4.12
	Get the bedroom ready with his name on his bedside and tidy his closet.	4.13
	Have a flower on each tray when giving out supper.	4.14
	Maintain a calm and silent atmosphere in the house.	4.15
	Cleansing of "fluid". Cleaning the elevator.	4.16
	Cleaning and tidying night tables. Disinfection, mouth hygiene (teeth and prostheses). Assistance while taking a shower.	4.17
	Caring for the hospice's pet. (Cleaning the cat's litter, playing with it and feeding it).	4.18
5. Promote the autonomy/individuality of the ailing person	Encouraging guests to take a bath, get up, and go out into the garden or for a walk according to their possibilities.	5.1
	Favour autonomy.	5.2
	Help generate a meeting between guests and their distant relatives.	5.3
	Talk and discuss about what makes them unique. Give value to details, preferences, personal tastes and specific things.	5.4
	We arrange the fresh flowers, making each vase something special. A pamper of colour.	5.5
	We bring things they like such as sandwiches, some special magazine for C, salad for the nurses, etc.	5.6
	Hugs, a good shave or even nail painting for a coquettish guest.	5.7
	Getting to know each guest individually, who they are, their preferences, their tastes, their worries, and how we can help them if possible.	5.8
	Getting to know what their interests are (playing cards, dancing, art).	5.9
	If they need some of their clothes urgently or have a request in that respect.	5.10
	Lunch, trying to take into account their preferences. Buying something they want or need.	5.11
	Priority of the other person's desire, not our desires.	5.12
	When possible, songs which might be familiar to the guest or to his childhood.	5.13
	We pamper or guest at tea time by giving them chocolate or cold drinks their families provide. We keep that special treat families bring, labeled and in the refrigerator.	5.14
	We promote autonomy whenever possible i.e. feeding or walking.	5.15
	We take them out for a walk.	5.16
	Some patients who have been bedridden for several days at the hospital, once in the hospice are encouraged and accompanied so that they might be able to go to the toilet, or downstairs to the garden, and if possible for a walk.	5.17
	We have received trach patients which after dedication and much patience have begun to feed by mouth. We even give those with difficulty in swallowing a bit of ice cream or something sweet as a treat for their palate	5.18
We allow our guests to stick their photographs or drawings on their bedroom walls.	5.19	
We get their beds ready, with their names by their bedside and their closets empty and ready.	5.20	
Getting to know our guest so as to be able to accompany them as best as possible.	5.21	
Cooking special meals.	5.22	

the use of the toilet or with their self-hygiene, and even were encouraged to visit the garden or go for a walk” (5.17).

In this way, we deviate from the perspective of a caregiver with resources taking care of patients in need. Care consist in the stimulation and development of resources already present in the terminally ill. This has a positive impact as it recognizes her/him as a person. In the case mentioned by the volunteer, we can see the acting concern to show the other person that he is still able to carry out certain activities—accompanied as needed—and which are essential for his growth as a person (amongst these, use of the toilet, self-hygiene, outdoor recreation).

Another volunteer added that care activities are directly related to *“favoring autonomy for e.g. feeding and walking around” (5.15)*. In this case, accompanying the person enables the reestablishment of his autonomous feeding mechanism, promoting his self-determination, and autonomy. Another volunteer further states that they *“have received trach patients which after dedication and a lot of patience have begun to be feed by mouth. We even give those with difficulty in swallowing a bit of ice cream or something sweet as a treat for their palate” (5.18)*.

This allows to let the person know that still maintains—through the care received—certain capacities such as swallowing and movement, activities both which are basic in the identity of humankind. Moreover, in our culture, they are positively related to the capacity of oneself to integrate the meaning of life, to being accepted as a person, and to be perceived as worthy.

Other care activities aim to the promotion of the ailing person’s individuality and in that sense, are directly related to their need for recognition as persons (in those aspects that make them unique). Volunteers illustrate this respect *“we let our guests [name by which San Camilo Hospice Center identifies those who are under their care] place their own photographs and drawings on the walls” (5.19)* so as to promote a positive appropriation of space, letting patients realize that, although they are not in their own homes, they are not strangers occupying a space. In a more general way, another volunteer insists that part of their care job requires *“knowing each guest individually. Learning who they are, their tastes, their worries, in what specific manner we may be able to help each of them” (5.8)*. This acknowledgement of the sick person’s individuality later shows up in every activity, like *“it’s preparing the meals that will satisfy each person’s taste”*, chatting about their preferences, or even shaving someone, trimming his hair or painting nails. Each one of these activities were mentioned in the volunteer’s narrative as being an essential part of the non-pharmacological care they develop within the institution. This knowledge implies that the vast majority of people build their identity based on questions related to body aesthetics. Once again this aspect is tied to the ways western culture conceives the human body.¹¹

Given the preeminent social character of the human condition, the fact of being recognized as a person not only appears as relates to the strengthening and respect given to autonomy and self-determination, but also to the necessity of considering the ailing person as part of the nucleus of social relations to which he belongs. This entourage is confirmed not only by family but also by health care professionals, caregivers, and close supporters.

Swiss psychiatrist Elizabeth Kübler-Ross¹² during World War II criticized the way in which hospitals—entirely dedicated to the cure of diseases, abandoned and isolated those whose prognosis was unfavorable. She proved that the isolation of a dying person from the natural circle of human relations which constitute him as a person, is a negative factor in the relief of psychological suffering. This suffering relates to terminal illness a similar theory was also developed by Norbert Elías.¹³ These findings and further theories allowed palliative care and the hospice movement to introduce the patient’s family as the fundamental stepping stone in their care. Not only as providers of care but also as receptors of this care.¹⁴ Most of the references linked to palliative care take into account the achievement of a good death or a death with dignity. This perspective is not only from the point of view of the ailing person but from their families and/or health professionals and is linked to the possibility of continuing with social and family relations.¹⁵⁻¹⁹

One of the main factors associated to the search for keeping the ailing’s personal capacity to consider itself worthy has to do with the fact of making him/her feel so, showing them they are still part of their social environment—thus avoiding what is otherwise known as social death.²⁰ To this end, hospice promotes firstly and foremost, that the ill person’s family visit him whenever necessary. In the volunteer’s vision, the family appears as primordial: *“we strive to encourage those who are at the end-of-life to may live these last moments with their families. We try to organize and help families so that this may be possible by assistance and support” (1.11)*. Non-pharmacological care tools help them in connecting patients and their social environment. Another factor is related to the possibility that ailing persons may reestablish their social and family ties with those whom they have become distant, whatever its cause may be. On this matter, a volunteer points out that part of the care they offer is to directly *“help each guest to generate a meeting with those family members who they estrange” (5.3)*. Thus families play an important role in recognizing the other as a person, therefore non-pharmacological care tools directed to this purpose are linked in a positive way in keeping the patient’s capacity to find himself worthy.

Volunteers also suggested the importance of what they understand as the aesthetic and environmental factors of non-pharmacological care tools. These comprise both the patient and their milieu. Actions such as “bedding” (4.10), “cleaning the guest’s face with a cool washcloth” (4.4), “cleaning his eyes” (4.4), “brushing his teeth or dental prostheses” (4.17), may fall under the theoretical framework used as non-pharmacological care tools and as part of the person’s standing in society, as the aesthetic point of view does not work against the biological components of the disease. Caring for such things allows the other person to understand that she/he is still part of the relationships that make up his social environment.

As from the Helsinki Declaration after the World War II, respect for the patient’s autonomy was introduced as a priority in clinical practice; this gave way to a change in research with human beings.⁴ This also modified the doctor-patient relationship: from a paternalistic attitude to a fuller engagement towards the ailing person in the health/disease/health care process.²¹

In this same way, volunteers at the hospice, care “*in accordance with the guest’s time*”²² which implies engaging him/her in decision-making throughout the whole care process. This involvement again takes into account the needs of the other of being recognized as a person; as it upholds his autonomy, expresses his dignity, showing that these decisions will be taken into account by the team of caregivers.

CONCLUSION

Using the data-based theory and analyzing the data obtained, we were able to prove the existing connection between the care provided by the team of volunteers at San Camilo Hospice Center and the ability of the ailing person of perceiving him/herself as worthy.

Our starting point was the conceptual framework of the bioethical principles of the Hospice Movement of Argentina and the statements put forward by the SECPAL regarding the theory of existential/spiritual suffering in human beings. The relational character of dignity is expressed as the necessity of being recognized as worthy from the perspective of others. This is an inalienable characteristic of the human condition, and as such, inherent to the person. This has allowed us to understand the spiritual/existential need for being recognized as a person. This need is directly linked to respect for the person’s autonomy and possibility of participation. It does not only relate to the health/disease/cure trio but mainly to the core of relations which make up his or her social environment.

The activities carried out by the team of volunteers at the hospice are known as non-pharmacological care tools and have proven to be directly bound to the recognition of the other as a person.

Taking into account that the spiritual and existential needs express themselves throughout the patient’s suffering due to a loss in her/his capacity to integrate the meaning of life in the face of the disintegration of the self (as a result of an end-of-life illness and due to an unidimensional approach). Due to the presence of non-pharmacological care tools developed within the hospice as an answer to these kinds of necessities, we firmly believe that these

tools have a positive impact in the relief of spiritual/existential suffering.

The relief of this type of suffering allows the other to be recognized as a person for he is treated in a dignified way—throughout an integral and holistic approach that respects its autonomy. This enables the patient to recognize her/himself as worthy.

Summing up, the non-pharmacological care tools, as they alleviate existential/spiritual suffering, have a positive impact in the possibility of a person’s capacity to perceive her/himself as worthy.

Lastly, to systematize this motion in a more schematic way we put forward the grid drawn up by the SECPAL named Spiritual Resources at the End of Life.⁶ This chart shows some modifications with respect to the original, as it aims to facilitate the understanding of the practical application of the non-pharmacological care tools mentioned in the above paper (Table 2). The numbers on the non-pharmacological tools label correspond to the internal coding shown in Table 1 (only used for coding process purposes).

The order of the positive and negative categories has been inverted for more linear reading, at the same time we have placed between them the category of “non-pharmacological care (NPC) tools” as a proposed intervention. Not every category of the original chart was contemplated (we decided to concentrate on those which we found more adequate to our proposed analysis).

At the same time, we found a similarity between the care activities performed by the volunteers at the hospice and the proposal for the intervention of the North American Nursing Diagnosis Association (NANDA) when non-pharmacological treatment is prescribed.

This type of intervention is defined as remaining close to the other person, physically and psychologically when needed. It is carried out through activities such as being sensitive and open to the traditions and beliefs of the patients, listening to their worries, and showing an attitude of acceptance. This translates—in our case—in a readiness to actively listen and to favor autonomy and individuality.

Table 2. Non-Pharmacological Care Tools Associated with the Spiritual Needs at the End-of-Life Developed by Sociedad Espanola de Cuidados Paliativos

Resource	Timing	Negativity (P: Patient; HCP: Health Care Professional)	Non-pharmacological care tool	Positivity
To be acknowledged as a person by others and by himself	Present	P: “I don’t recognize myself when I look at the mirror” HCP: underestimate, ignore, and forget the name. i.e.: “the lung of bed 203”	2. Caring taking into account the other person’s time. 4 Aesthetic/environmental factors. 5 Building up the ailing person’s autonomy/individuality.	Feeling unique and incomparable. Being able to hear someone say: “I love you just the way you are”. Recognize oneself in being, not in doing.
To be able to find meaning in the situation I’m going through	Present	P: “Everything is absurd” HCP: Not helping the patient and his family in finding THEIR meaning of the situation	1. Caring after the caregivers. 3 Active listening. 5 Building up the ailing person’s autonomy/individuality.	Feeling that everything fits, that life is not in vain and neither is the situation through which I am undergoing.
To be able to forgive myself	Past	P: Self loathing HCP: Has no time available to listen to the patient’s woes	3. Active listening. 5 Building up the ailing person’s autonomy/individuality.	Feeling free of past suffering. Acknowledging his weakness but feeling worthy.
To be able to forgive and reconcile	Past	P: Animosity HCP: Does not encourage a meaningful connection ⁰⁰	1. Caring after the caregivers. 5 Building up the ailing person’s autonomy/individuality.	Feeling reconciled. Feeling that we may all be weak but nevertheless, worthy.

Non-pharmacological care tools, as they alleviate existential/spiritual suffering, impact positively in the possibility of a terminal person's capacity to perceive her/himself as worthy.

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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