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Original Research

Outpatient-Focused Advance Care Planning: Telehealth Consultation for Geriatric Primary Care Patients

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ABSTRACT

Introduction

Documentation of advance care planning (ACP) in the electronic health record (EHR) is a quality measure promoted by both the Centers for Medicare and Medicaid Services (CMS) and the Department of Veterans Affairs (VA). There is no best practice model for promotion of ACP in primary care. Clinic prompts reminders from staff, and provision of forms and handouts modestly increase ACP completion. Targeted advance care planning and goals of care discussions for high-risk high-need older patients may help promote ACP in primary care.

Methods

High-risk, high-need geriatric patients were identified by the clinical assessment of need (CAN) risk calculator for a telehealth intervention by an advanced practice nurse trained in palliative care and embedded in the geriatric patient-aligned care team (Geri-PACT) and provided telehealth outreach for ACP and goals of care discussions.

Outcomes

At baseline the Geri-PACT panel had a 54% prevalence of ACP in the EHR. Completion of a life-sustaining treatment note (LST) increased from 39% to 74% following the telehealth intervention producing a total of 89% ACP documents in the EHR. Additionally, 9% of patients received goals of care discussions and a need for additional home and community-based services was identified for 12% of patients contacted. Outreach to three practices in an established physician referral and patient visit network which included 10 providers indicated that primary care providers desired to approach their own patients for ACP. These providers were educated and provided tools and information about CMS and VA ACP quality improvement directives.

Conclusion

A focused telehealth intervention performed by a nurse trained in palliative care and embedded in a geriatric patient-centered medical home was able to significantly increase ACP documentation in the EHR for elderly patients in the practice. Primary care providers place core importance on the value of the patient-clinician relationship and prefer to approach their own patients rather than rely on consultation for ACP. Education for primary care providers and provision of resources to perform ACP and goals of care discussions for their patients may be a worthwhile strategy to improve ACP completion and documentation in the EHR.

Keywords

Advance directives; Primary care; Telehealth.

BACKGROUND

One third of Americans have a completed advanced directive¹ and fewer have this documented in the electronic health

record (EHR). The Centers for Medicare and Medicaid Services (CMS) and the Department of Veterans Affairs (VA) quality improvement objectives encourage completion of advance care planning (ACP) documents and inclusion in the EHR.² CMS encour-

ages documentation of the appointment of agent as well as a living will, while the VA requires a life-sustaining treatment note (LST), a formal documentation of goals of care and ACP. There is no best practice model of how to implement these recommendations. We describe a telehealth outreach to high-risk high-need patients in a VA primary care geriatric practice (Geri-PACT) utilizing a trained nurse practitioner who was an integral part of the clinic.

METHODS

Healthcare System Description

The Tennessee Valley Healthcare System (TVHS) is an integrated health care system of over 100,000 patients in middle Tennessee comprised of 2 medical centers located 40 miles apart, and 12 community-based outpatient clinics.

In 2011, TVHS developed a geriatric patient-centered medical home model for geriatric primary care—the geriatric patient-aligned care team (Geri-PACT). The Geri-PACT Team consists of the Geri-PACT provider (geriatrician or geriatric nurse practitioner with an outpatient panel size of approximately 800), a social worker, a clinical pharmacist, a registered nurse care manager, a licensed vocational nurse, and clerical staff. Geri-PACT is a special population PACT within primary care for complex geriatric and other high-risk vulnerable veterans providing integrated, interdisciplinary assessment and longitudinal management, and coordination of both VA-sponsored and non-VA sponsored (Medicare and Medicaid) services for patients and caregivers.³

The clinical assessment of need (CAN) is a clinical predictor of future hospitalization and death developed for VA populations.⁴ This methodology extracts predictors from 6 categories: social demographics, medical conditions, vital signs, prior year use of health services, medications, and laboratory tests and constructs logistic regression models to predict outcomes. CAN scores are from 1-99, with higher scores corresponding to an increased probability of future healthcare events.

We report our experience utilizing a trained advanced practice nurse who was an integral staff member of Geri-PACT to perform ACP and goals of care discussions for high-risk patients with CAN scores between 95-99.

Our overall study was designed to meet standards for quality improvement reporting excellence (SQUIRE) criteria,⁵ and this report meets the quality improvement minimum quality criteria set (QI-MQCS) domains for reporting quality improvement work.⁶

The TVHS Institutional Review Board (IRB) has determined this study as a quality improvement initiative.

OUTCOMES

The Geri-PACT practice of 793 patients included 139 patients with CAN scores between 95-99, with a mean probability of hospitalization or death of 56% within 12-months. Over a six-month follow-

up period, this high-risk population had a 10% mortality and 33.8% were hospitalized, with 59% receiving skilled and non-skilled home and community-based services. Some 12% of patients received additional home and community-based services as a result of the telehealth intervention including 5% who were referred for hospice care (Table 1). Baseline advance care documentation in the EHR showed 15% had appointment of agent or a living will and 39% had LST notes giving a prevalence of 54% documentation of ACP in the EHR at baseline. The telehealth intervention completed another 35% of LST notes providing a total of 89% of this high-risk population with ACP documentation in the EHR.

Table 1: Geri-PACT High-risk High-need Patients (CAN 95-99)

Population N=139

81 years mean age
16 mean number of medications
56% mean probability of event in 6 months

Diagnoses

10% dementia
32% congestive heart failure
23% cancer diagnosis
12% stroke

Residence

56% urban
44% rural
20% home alone
69% home with caregiver
6% assisted living residence
4% long-term care facility

Home and Community Based Services Utilization

47% None
55% Home health services
20% Homemaker home health
4% Adult day care

Outcome Measures at 6 months

90% Alive
10% Expired
33.8% Hospitalized

Advance Care Planning

15% advance directive in EHR
39% VA Life Sustaining Treatment note (LST) in place
35% LST completed with telehealth call
9% GOC discussion with telehealth call
8% referred to hospice

Additional Interventions during Telehealth Call (12%)

1% specialty clinic referral
2% referred for skilled home care
4% referred for non-skilled services (ADC, respite, H/HHC)
5% Hospice referral

ADC-adult day care; advance directives-appointment of agent, living will; CAN-clinical assessment of need risk score; H/H/HHA -homemaker, home health aide (non-skilled services); GOC-goals of care; LST-formal VA advance directive and goals of care discussion documentation.

Three affiliated practices comprising a total of 10 providers (6 physicians and 4 advanced practice nurses) in an established physician referral and patient visit network were approached with 30-50 high-risk patients identified for each provider. These practices had strong consultation relationships with Geri-PACT, which provided consultations for geriatric syndromes, falls, dementia, and palliative care services. Primary care providers stressed the value of the patient clinician relationship and expressed strong preferences to provide advance care and goals of care discussions for their own

patients. Individual providers were given education and tools to provide ACP discussions as well as information on CMS and VA quality improvement directives and documentation requirements. Providers indicated a desire to reserve referrals for selected palliative care services for individual patients.

DISCUSSION

Enhanced ACP discussions and completion of documents can be modestly increased by utilizing in-clinic prompts and reminders from staff, and provision of forms and handouts immediately available in the clinic.^{7,8} These processes can be further enhanced by the use of clinically derived risk scales to identify high-risk patients appropriate for ACP and goals of care discussions.^{9,10}

We found an advanced practice nurse trained in ACP discussions and who was an integrated member of the practice delivering a telehealth intervention as a focused outreach strategy greatly increased ACP documentation in the EHR. The intervention also identified a need for additional home and community-based services among 12% of patients contacted.

Barriers

Efforts to provide ACP discussions to affiliated primary care practices met resistance. Even though primary care providers referred patients for other geriatric syndromes as well as palliative care services, they appeared to wish to preserve the patient-provider relationship for advance directive discussions. We proceeded to educate primary care providers to facilitate discussions of ACP and to provide the tools for appropriate CMS and VA quality improvement documentation in the EHR.

CONCLUSION

There are not enough board-certified palliative care clinicians to provide all palliative care needs or ACP discussions. Many have advocated for a generalist model of palliative care with a coordinated palliative care model whereby the primary care physician could manage many palliative care problems, reserving palliative care consultation for more complex or refractory concerns such as symptom management. Education to enhance the skills of all clinicians to improve the ability to address basic palliative care needs and ongoing palliative care management reinforces existing patient-provider relationships and may be a more sustainable model.¹¹

Our experience validates the core importance of the patient clinician relationship and the strong preference of primary care providers to perform these advance directive discussions with their patients. These important discussions enhance the patient physician relationship and come from trusted providers. Education for primary care physicians to facilitate ACP and goals of care discussions is appropriate,¹² reserving consultation for palliative care specialty concerns for selected patients. The use of telehealth may help provide primary palliative care education to PCP's and increase access for specialty palliative care consultation.¹³

CONFLICTS OF INTEREST

The authors declare that they have no conflicts of interest.

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Opinion

The Dirty Business of Dying: From Charitable Endeavor to Cut-Throat Enterprise, Hospice in America is a Shameful Shadow of its Former Self

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I'm learning there comes a time in life – providing you are both willing and able – where you review where you've come. You take stock of where you've been. Have you made the world a better place or just endured existence from the cheap seats? As a nurse who has committed a life's work to easing the suffering of others, I applaud breakthroughs that have become best practices: the World Health Organization (WHO) ladder of pain control; use of the pain assessment in advanced dementia (PAINAD) in non-verbal dementia patients; advanced certification in hospice and palliative care (even in pediatrics); a myriad of ways to deliver comforting concoctions and so much more. However, the deepest and richest treasure in the clinician's toolbox remains the Medicare Hospice Benefit.

Had you been terminally ill before the mid-1980s, you might have received care in your home from well-intentioned volunteers or nurses who were paid for their services through philanthropic means (the hospice they worked for paid them through donations it received from others). But that changed in 1983 with the designation of the Federal Medicare Hospice Benefit. 'The Benefit' now provided Medicare beneficiaries with courage for high-quality end-of-life care by accredited agencies.

The idea of hospice wasn't new.

The United States borrowed the recipe for hospice from Europe, where the care began in the mid-1800s with terminally ill being cared for compassionately in homes by well-intentioned volunteers. The cornerstone of hospice is use of an interdisciplinary team, where each member addresses an aspect of care (social worker, chaplain, medical director, etc.) is paramount. Like most things ripped off from our European ancestors, we in America feel the need to improve it. Over time, the field of hospice – and its

cousin, palliative care – have become a well-researched, evidence-based field worthy of its own subspecialty. Considered the model for quality care for people facing a life-limiting illness, hospices seeking to be reimbursed for services were mandated to use this patient-centered, interdisciplinary team to deliver care. Best of all, hospice agencies could now bill Medicare a daily per diem rate for each appropriate patient. In exchange, hospices were now required to provide care, medications, equipment and oxygen to care for patients. The plan was to save millions of dollars by keeping patients home, out of the high-ticket hospital and costs could be contained. Finally, well-meaning agencies whose true passion was to care for those at life's end, could be reimbursed fairly, timely and predictably. Good hospices used the influx of funds to expand services, raise wages for care staff and strengthen programs, even adding adjuvant services, such as massage therapy, aromatherapy and other comfort-enhancing endeavors. Ambitious agencies expanded unfunded programs, such as pediatric palliative care and charity care. Family and staff satisfaction surveys of hospice care were largely positive and life – for those who cared for the dying – was oddly good. So good, it caught the eye of big business who smelled irresistible, fresh blood in a revenue stream.

Over time, those downwind of hospice (home health companies, nursing homes and hospital systems themselves) caught a whiff of something juicy and profitable. With reimbursement changing and regulations tightening, what better way to stack the deck but with the dying? Even non-healthcare companies jumped into the fray (think RotoRooter/Chemed owning a hospice). Agencies, both non-profit and private, began to pop up like creeping vines in a jungle. Forward-thinking agencies invested in hospice homes – stand-alone facilities where folks could stay if their symptoms were extreme or the family lost its collective marbles while caring for dying father or mother. Ironically, the re-

imbursement rate for patients in a hospice home was nearly seven times that of the daily per diem rate. The problem? The facilities, tastefully decorated and aromatherapy-infused, cost to run whether full or empty. If every patient was adequately managed at home, why bring them to the hospice home? Savvy leaders culled over their census and looked for obvious targets. While most were likely appropriate, the allure of the reimbursement was just too tempting and crafty CEOs found ways to keep their inpatient hospice homes full.

Alas, American greed has led us to the demise of true hospice care

I am unsure as to what and where the tipping point was. Some blame the same general economic downturn that caused General Motors to cut 75,000 jobs in the mid-90s; others point to military action in the Gulf. What I am sure of is that the tectonic plates on which hospice rested shifted and contorted. And in the newly-created spaces, leaders who had no business caring for the terminal ill, suddenly found a crack, blossomed and began blocking out the sun of proper agencies. The big hospices could out-market, out-advertise and out-incentivize well-intentioned, smaller providers. Perhaps the change was initially positive. Having trained eyes on expenditures, write-offs and revenue helped many agencies capture lost monies. But, slowly, it was the bottom line driving care, not patient needs. Colleagues of mine of both non-profit and private agencies felt it like an earthquake. Nurse to patient ratios crept higher and higher; contracts for durable medical equipment were negotiated aggressively and things like oxygen and bedside commodes hung in the balance like the market price of lobster. Cheap is king. Why buy the best gauze dressings for a wound when a patient is only going to live for a week? Why provide this medication or that supplement if it's not needed and spikes your pharmacy spend? Suddenly, coming on to hospice care meant something different: a nurse who used to care for 12 patients is now carrying a load twice that. There goes the intangible value of good nursing care. Call

centers are set up to handle the waterfall of after-hours requests for help and assistance. Patients ripe for inpatient use are shuttled to hospice homes for symptoms or family burnout – some warranted, some exaggerated to keep the beds full and reimbursement high. Families gripe about low-quality products, hit-and-run visits from haggard staffs and the results show: the soaring satisfaction surveys of a decade ago nosedive. According to a 2019 Department of Health and Human Services (HHS) Office of Inspector General (OIG) investigation this past July, hundreds of hospices across the US received 'failing grades.' Nearly 80% of agencies had at least one significant deficiency while most had '...multiple failures.'

While some facilities, their owners and staff faced criminal charges for care deficiencies, it's still all about the money. Federal investigators have their hands full. Just one investigation in North Texas found more than \$60 million in Medicare fraud. Multiply that by countless other programs still unknown and the bill hits the stratosphere. There goes cost savings. Woefully, the very program designed to save money and care for our nation's most vulnerable openly raped and pillaged. The OIG's answer? More oversight to hospices is needed.

I don't see that working, do you?

Perhaps the greatest and saddest loss in our American hospice experiment is the realization that capitalism – when applied to the dying – doesn't fit. We've taken an honorable model of care, steeped in European tradition, and killed it and watch big business dance on its grave in a red dress. While it's anyone's guess what end-of-life care will look like in the next decade, it's clear if it's Federally funded, it won't be around for long. If I'm still alive and breathing, look me up. If I'm able, come to my house and I'll take care of you for free.

I've got a big basement.

Editorial

Suffering from Pain: Reflexology as an Advantageous Adjuvant to Palliative Care

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Reflexology is a non-invasive, complementary therapy that is based on the theory that, by applying controlled pressure to certain reflex zones in the palm and foot, channels along the nervous system are stimulated, thereby facilitating energy pathways that may be blocked or congested.

The reflex zone is the region in zone therapy that illustrates its interconnection with all parts of the body. It is hypothesized that there is an invisible pathway which runs along the body vertically, from the top of the head down to the tips of the fingers and toes, while each zone represents a specific area of the body.^{1,2} A recent study in India examined the effectiveness of foot massage on the reduction of pain among cancer patients undergoing palliative care. The findings revealed a highly significant improvement in the degree of their pain as compared with that of control patients.³

Reflexology is currently being considered as a complementary therapy, widely used in palliative care to alleviate a problem without necessarily determining its underlying cause in order to improve a patient's emotional, physical, psychological and spiritual health and to upgrade the patient's value of life.⁴

Reflexology does not cause any harmful effects as long as necessary preventions are taken for patients with special medical conditions such as blood clot disorders, cancer and heart failure. Therefore, it is imperative that reflexology practitioners take their clients' overall health condition into consideration. Furthermore, practitioners should ask about and listen to their clients regarding their health status, which may be influenced by a variety of factors such as their psychological and emotional well-being. It is crucial to build a trustful rapport between reflexologist and client, through empathy, leading to a meaningful therapeutic relationship.⁴ Any ongoing reflexology treatment strives to reduce stress levels which, in turn, increases the quality of life as it is one way to interrupt the

pattern of repetitive stress stemming from by people's lifestyles.

We believe that the coordination and collaboration between this alternative therapy and mainstream medicine provides a beneficial avenue which may enhance and maintain general physical health *via* decreasing anxiety and stress.⁵

Since the late 1970's, studies have been conducted to assess the efficacy of behavioral and relaxation approaches to controlling nausea/vomiting, anxiety and other side effects associated with chemotherapy; it has become apparent that reflexology and foot massages can be considered a supportive treatment when used in combination with traditional medical treatments; this approach should be executed by an expert, qualified professional to help cancer patients undergoing chemotherapy to feel better and cope better with their disease.⁶

The modern vision of palliative care involves the management of emotional and spiritual needs of patients and their relatives. This is particularly relevant for developing countries, where extended families are still prevalent, religious values still strong and religious practices still common.⁷ Palliative care in general, and reflexology in particular, indeed represent unique approaches for communities and countries with both high- and low-tech medicine to cope with pain and suffering arising from various illnesses.

We recognize that the presence of reflexology services, regardless of the age of the patient, has the potential to carry intrinsic values to far corners of global health care, including personal dignity, maintaining hope for healing and bearing witness. The latter is the practice of actively listening and not shying away from difficult conversations, bad news or the unknown. It also means sharing personal experiences so that patients realize that they are not alone in this journey.⁸

CONFLICT OF INTEREST

The authors declare that they have no conflicts of interest.

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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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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	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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Opinion

The Reframing of Advance Care Planning: How Coronavirus Disease 2019 has Encouraged Us to Reflect More on our Values

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Coronavirus disease 2019 (COVID-19) has contributed to some unintended, yet valuable, reframing of advance care planning (ACP). Rather than perceiving ACP as merely being about death and dying, many healthcare providers and community members now acknowledge the need to plan in advance for healthcare decisions, especially if we are unable to communicate and consent for ourselves. Rather than perceiving ACP conversations as “*difficult conversations*”, many healthcare providers and community members now acknowledge them as important and essential conversations. And rather than perceiving that ACP is primarily for the elderly or seriously ill, many healthcare providers and community members now acknowledge that we are all mortal and could unexpectedly become sick or injured; therefore, ACP is of value for all.

As Sudore et al¹ concluded, “*Advance care planning is a process that supports adults at any age or stage of health*”. And the primary goal of ACP is “*to help ensure that people receive medical care that is consistent with their values, goals and preferences*”.¹ Due to discomfort with uncertainty and craving to feel some sense of control, particularly during times of crisis, many people presume that ACP is about considering and choosing specific medical treatments in advance. And yet, at the core of ACP is in fact values. Our values dictate most, if not all, of our choices and actions. Whether conscious or unconscious, our values influence what we wear, who we spend time with, what we eat, where we travel, what we listen to and watch, and what activities we engage in or events we attend. Similarly, our values directly inform our healthcare decision-making. Whether someone chooses to pursue a surgery, a new medication, or a feeding tube, those decisions are not merely made by considering the medical risks and benefits, but equally, if not more so, they are chosen because of how someone wishes to live as a result of the medical intervention. ACP is not about how we want to die, but rather how we want to live.

Reflecting on and naming our values can often be challenging as values seem far too abstract to identify at times. However, medical professionals who actively practice ACP have consistently observed how a few simple questions can help easily discover and record a person’s values. These include asking: What does a good day look like? What brings your life meaning and purpose? And what brings you joy? These questions often turn into an unexpected, yet valuable, *joy list* that highlights the things, people, places, and beliefs that are most important to us and bring meaning and happiness into our lives. A *joy list* whether short or long, is a gift to patients, healthcare providers, and substitute decision makers/health proxies, as it helps to ensure that the healthcare decisions made align with who you are and how you want to live. *Joy lists* and the prioritizing of your values, reminds the healthcare system that quality of life is equally important as quantity of life.

While COVID-19 has turned so much of our world upside down, it has simultaneously provided a unique opportunity for all of us to reflect a little more on our values, as we more intentionally consider what brings our life meaning and what brings us joy. Taking time to reflect on, record, and share our values is an imperative part of ACP. During a time when so many things feel uncertain and out of our control, ACP provides an invaluable sense of control over our health and future.

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