Palliative Care: Exploring Spiritual and Existential issues in Families facing a Serious Illness

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- Explore Spirituality in Palliative Care
  - Findings of recent Australian research
  - Practical implementation
  - Role of the Chaplain

- Explore Existential issues at the End-of-Life
  - Commonly recognised existential issues
  - Routine screening
  - How to respond

Spirituality refers to the "way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, self, others, nature, and to the significant or sacred."

Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. J Palliat Med. 2009;12(10):885-904.

Health Strategies prioritise spiritual requirements of those affected by serious illness, incl. caregivers (Australian Palliative Care Standards, 2018 & Strategy, 2010)

Spirituality: sense of peace, meaning, connection with others

Religion: organised practices and beliefs to enable closeness with the transcendent and communal engagement (Handzo & Pulchalski, *Oxford Textbook Pall Med*, 2015)

For those with advanced illness:

- many report spiritual pain; high prevalence of depression, anxiety, and anticipatory grief[1]
- > levels spirituality/religiosity associated with < stress[2], depression[3,4], & anxiety[4]; > adaptation[5], coping[6]
- > anger at God associated with > depressive symptoms, < religiosity[7]
- Spiritual/religious care improves care satisfaction[8]

[1]Delgado-Guay, *AJPM*, 2013; [2]Colegrove, *Ann Beh Med*, 2007; [3]Ferrell, *Sem Oncol Nurs*, 2012; [4]Newbury, *ONF*, 2013;

[5]Choi, *PsychoOnc*, 2016; [6]Paiva, *Supp Care Ca*, 2015; [7]Exline, *J Pall Med*, 2013; [8]Johnson, *Crit Care Med*, 2014

- Exploring Spirituality and Religiosity in a cohort of Australian Palliative Care Patients

- Unmet Spiritual Needs – initial development and validation of a spiritual concerns checklist

SPIRITUALITY AND RELIGIOSITY IN A PALLIATIVE MEDICINE POPULATION: MIXED METHODS STUDY

	SPIRITUALITY		RELIGIOSITY	
PATIENT n=248 (%)		It's a quality that makes you focus on your inner spirit, the human spirit or soul. Focusing on that helps me to have a little bit of peace, to better understand the purpose of me being here (#171)		I think when you become seriously ill, you re-evaluate things important to you and rediscover your faith and beliefs that were put on the backburner until you discover you can draw down from these beliefs and find peace and tranquillity (#132)
Very important	99 (39.8)		77 (31.7)	
Somewhat important	73 (29.4)		70 (28.8)	
CAREGIVER n= 102 (%)				
Very important	25 (24.5)		29 (28.2)	
Somewhat important	45 (44.1)	I don't believe in any organised religions or doctrines and their belief system, however, I am strongly aware of the need to understand the meaning of life and am curious about how life started . . . The concept of "being" or "is" simply too complex to grasp. (#25)	37 (35.9)	One's faith provides a framework for understanding, coping with difficulties and for inspiration in life. (#13)

SPIRITUAL WELLBEING – FACIT SP-12

Original research

Table 2 FACIT SP-12 total and Meaning/Peace and faith subscores by religious affiliations

Religious affiliation	n (%)*	Total, mean (SD)	P value	Meaning/peace, mean (SD)	P value	Faith, mean (SD)	P value
Overall	261	31.9 (8.6)	0.003	23.3 (5.8)	0.681	8.7 (5.0)	<0.001
None	60 (23)	28.3 (6.4)		23.6 (7.4)		4.7 (3.9)	
Christian	154 (59)	33.4 (9.2)*		23.4 (5.9)		10.3 (4.7)†	
Buddhism‡	11 (4.2)	31.7 (8.0)		20.1 (7.1)		11.5 (1.4)†	
Judaism	15 (5.7)	30.3 (6.6)		22.5 (4.7)		7.1 (5.1)	
Other§	8 (3.1)	35.8 (7.9)		22.8 (7.4)		13.0 (2.4)†	

*13 missing (5%).

†2 also indicated Christian.

‡Unstated (4), Christian and Hinduism (2), Islam and Hinduism.

§Post hoc analysis indicated significant difference compared with no religious affiliation.

FACIT-SP-12, Functional Assessment of Chronic Illness Therapy-Spiritual Scale-12.

- Those with Christian backgrounds: Higher total FACIT-SP12 score compared to those with no religious affiliation (p=0.003)
- Christian and Buddhist backgrounds: Higher Faith subscale scores compared to those with no religious affiliation (p<0.001)

Palliative Caregivers' Spirituality, Views About Spiritual Care, and Associations With Spiritual Well-Being: A Mixed Methods Study

80% believed that Australian hospitals should support caregivers' spiritual requirements, (16% neutral; 4% disagreed)

Rationales:

- Stressed caregivers need support
- Spiritual support does/should strengthen and comfort
- Spiritual care involves human and material elements beyond 'standard care', e.g., chapel, dietary needs

Caregivers have lower spiritual wellbeing than elsewhere. *What does this mean?*

	Caregiver participants (PC = palliative care)	**FACIT Meaning/Peace Mean (SD)**	**FACIT Faith Mean (SD)**	**FACIT Total Mean (SD)**
Australia	Of adult PC patients (n=109)	19.3 (4.25)	8.2 (4.61)	27.4 (7.30)
Knapp (*J Pall Med*, 2011)	Parents of children in PC (n=129)	24.1 (6.2)	12.5 (4.1)	36.6 (8.74)
Kim (*JPSM*, 2007	Of cancer survivors (n=739)	-	-	34.4 (8.83)
Colegrove (*Ann Beh Med*, 2007)	Of cancer survivors (n=403)	-	-	35.7 (8.77)

CHANGES IN RELIGIOUS PRACTICES

	Patient Before	Patient After		Caregiver Before	Caregiver After	
Prayer ≥ once a week	32.5%	46.3%	$p<0.001$	29.8%	36.5%	$p=0.05$
Meditation ≥ once a week	27.7%	46.6%	$p<0.001$	27.5%	35.0%	$p=0.05$
Attendance at religious services ≥ once a week	15.2%	7.2%	$p<0.001$			

Facing my mortality reminded me of my early Christian upbringing. The peace this brings has eased my panic. #20

In here (hospital), I met a religious person and went back to my religion. #120

Prayer and meditation helped with my sadness, depressed thoughts and inability to cope. #95

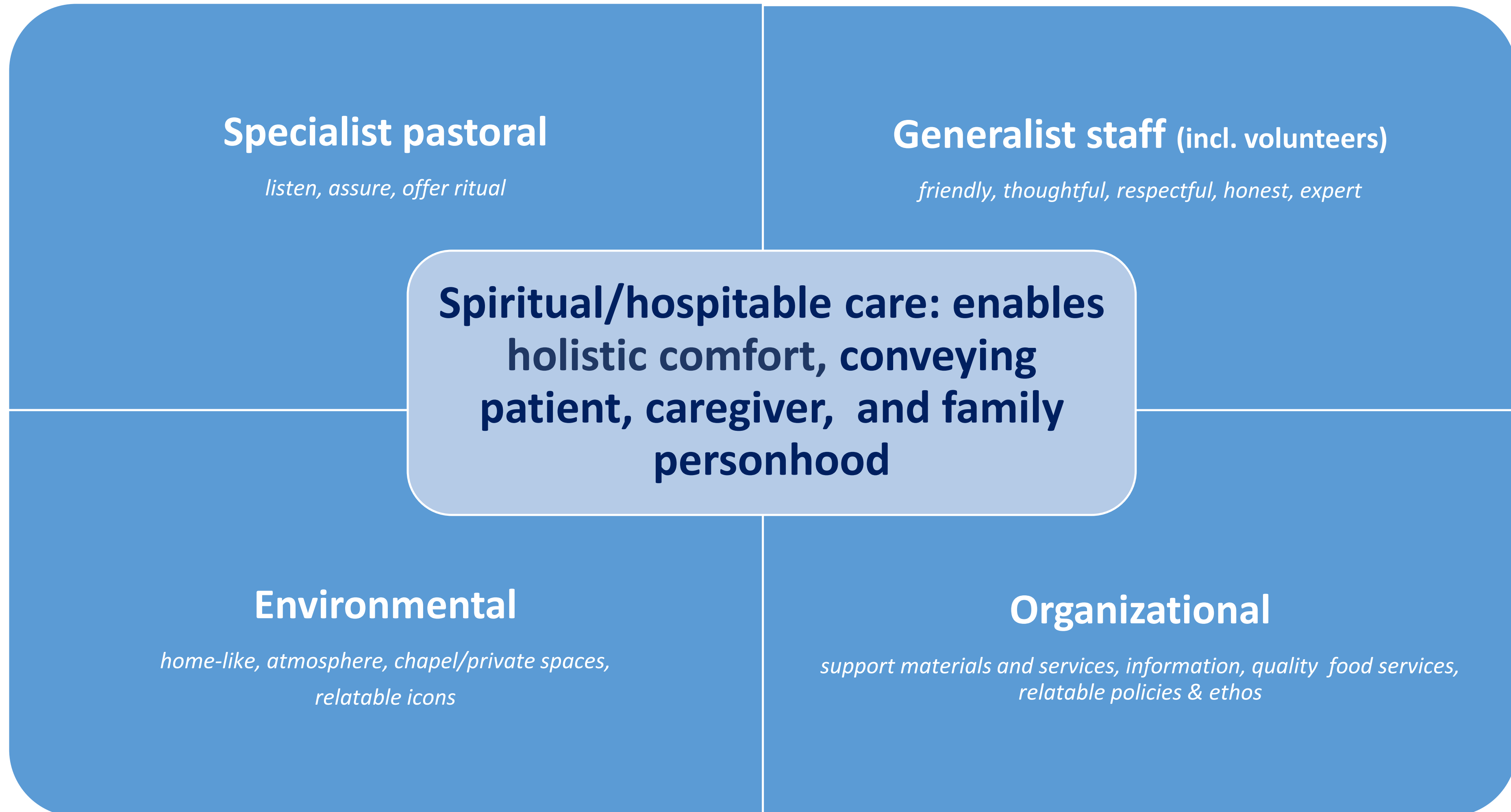
Pastoral Care Visits (PCV)

- Received by 33 (30%) of caregivers
- 85% found PCV comforting, calming, or helped them to feel better; Elicited discomfort in 5%
- Unexpected visits interpreted as meaning patient’s death imminent

Caregivers support spiritual care and find pastoral care helpful.
How is spiritual care best offered?

25% not spiritual nor religious. Many have secular rather than “spiritual” conceptions of how health services connect with what is valued. ***What does addressing spiritual requirements across the spectrum of palliative care mean?***

Important Care, Considered Spiritual or Hospitable by Palliative Caregivers



UNMET SPIRITUAL NEED IN PALLIATIVE CARE: PSYCHOMETRICS OF A SCREENIGN CHECKLIST

Items on Spiritual Concerns Checklist	Ranking by frequency of endorsement N (%) (total cohort 260)
Fear of dying process	84 (32.2%)
Fear of losing control	81 (31%)
Regret about past behaviours	53 (20.3%)
Concern about self-forgiveness	43 (16.5%)
Loss of meaning in life	40 (15.3%)
Forgiveness of others	36 (13.8%)
Loss of hope	35 (13.4%)
Guilt over past behaviours	35 (13.4%)
Uncertainty about an afterlife	35 (13.4%)
Religious doubts	32 (12.3%)
Fear of death	32 (12.3%)

Michael NG, Bobevski I, Georgousopoulou E, *et al*. Unmet spiritual needs in palliative care: psychometrics of a screening checklist. *BMJ Supportive & Palliative*

Conclusion

- "Spiritualized organizational culture": Core values of availability, compassion and hospitality, i.e., to be with another in their pain, confusion, appeal for understanding[1]
- Hospitality expressed when an individual is unconditionally available to others[2]
- "Unconditional hospitality" is impossible and dangerous[3]; hospitality is a reciprocal activity, framed within implicit and explicit rules[4]
- Generous but *prudent presence* needed by health workers/organizations/environments

What characteristics (human skills, organisational, environmental qualities) are associated with *prudent presence, and how can they be embedded into palliative care?*

[1]Pembroke, in: *Oxford Textbook Spirituality in Healthcare*, 2012; [2]Marcel, *The Philosophy of Existentialism,* 1995; [3]Derrida, *Politics of Friendship*, 1997; [4]Wood, in: *The Routledge Handbook of Hospitality Studies,* 2016

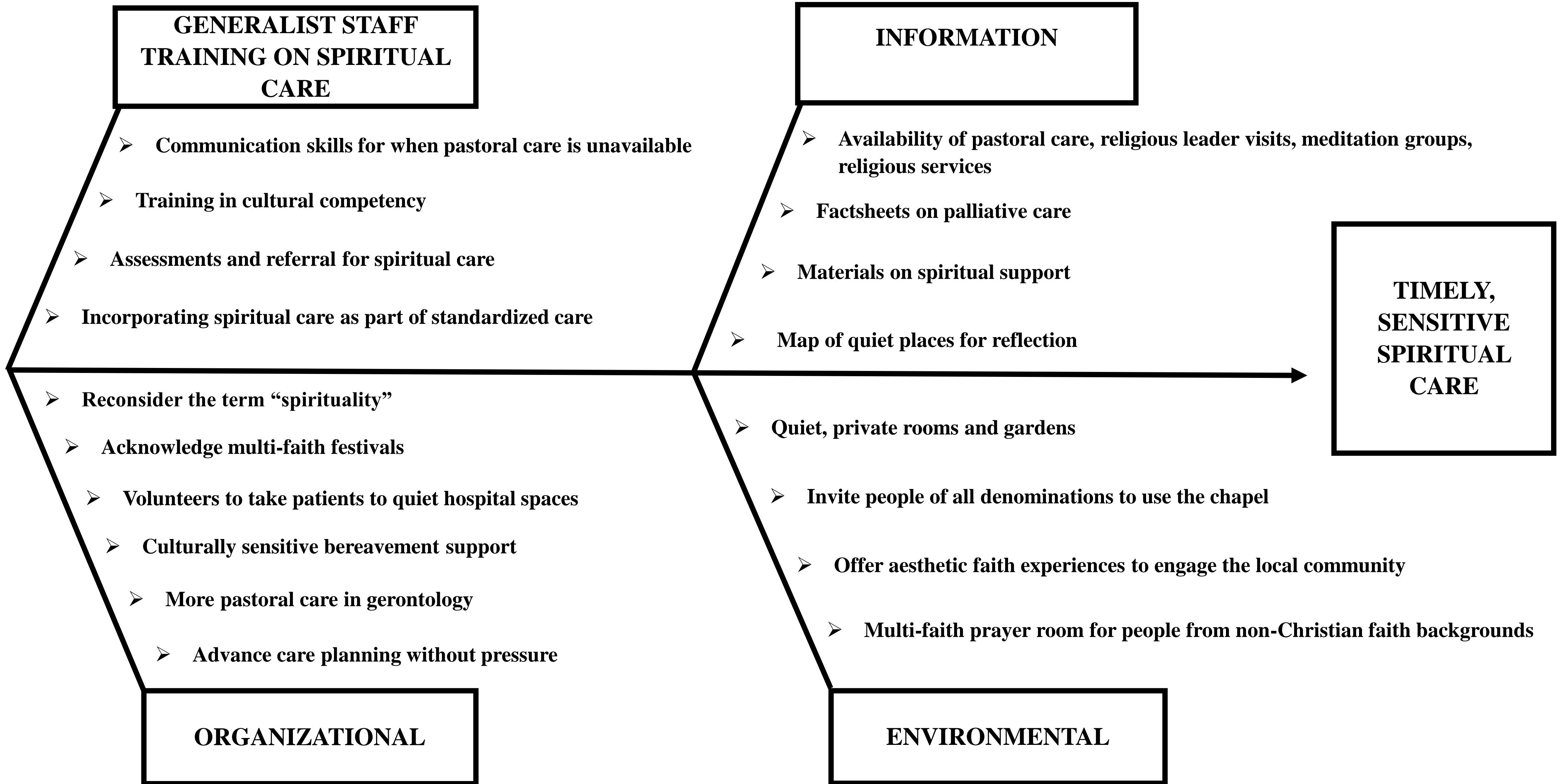
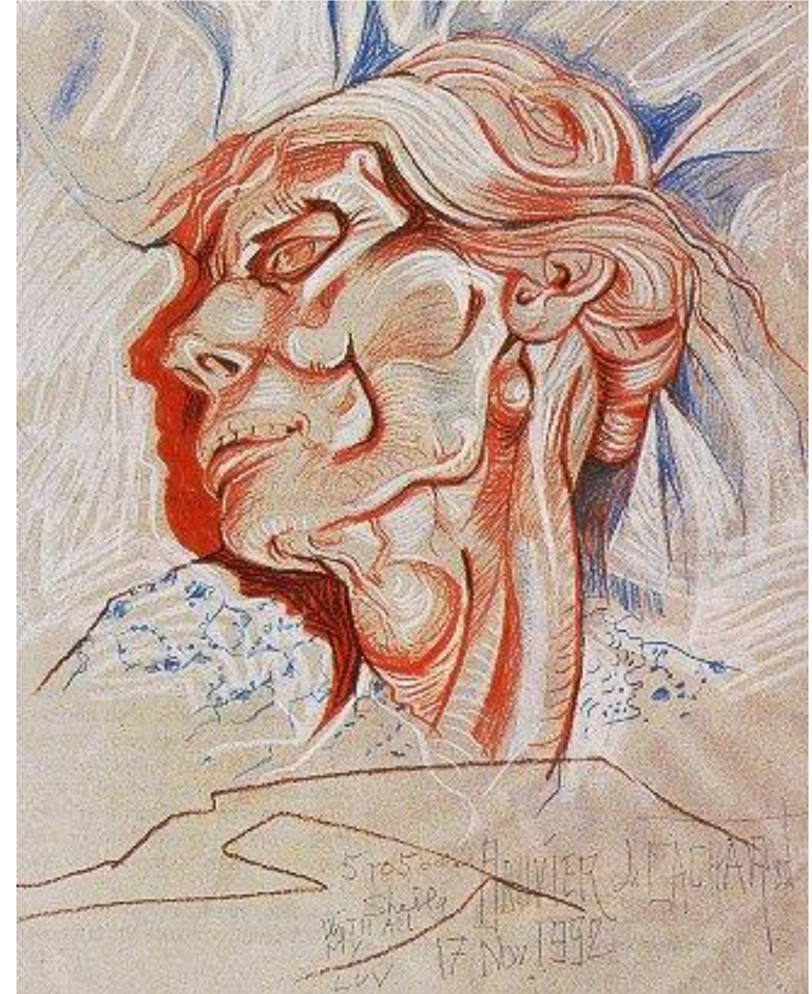


Fig. 4. Patients' and caregivers' suggestions to the health service

Dying brings decline in health, withdrawal from social networks, loss of normal roles, and the utter aloneness with the confrontation of the end of one’s existence.

Existential distress at the end of life has been defined as hopelessness, burden to others, loss of sense of dignity, desire for death or loss of will to live and threats to self-identity.

Existential Loneliness has entered the literature and 'is understood as an intolerable emptiness, sadness, and longing, that results from the awareness of one’s fundamental separateness as a human being.'



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Chochinov HM et al. Dignity in the terminally ill: revisited. J Palliat Med. 2006

Henoch I, Danielson E. Existential concerns among patients with cancer and interventions to meet them: an integrative literature review. Psychooncology. 2009

Ettema E et al. Existential loneliness and end-of-life care: a systematic review, Theor Med Bioeth. 2010

Basic Concepts

Yalom *Existential Psychotherapy (1980)*

Pioneered treatment from principles:

- Inevitability of death
- Reconciling freedom and responsibility
- Meaninglessness
- Existential Isolation

Viktor Frankl *Logotherapy 1990's*

'All existence has meaning, including suffering'

Nature of Existential Challenges

- Death anxiety
- **Grief at loss and change**
- Freedom and autonomy
- **Dignity**
- Fundamental aloneness
- **Quality of relationships**
- Meaning of life
- **Mystery and the unknowable**

The relief of existential suffering Kissane 2012

Education & Assessment for Psychosocial and Existential Wellbeing in Palliative Care National Palliative Care Grant Project GO1995

What Do We Routinely Measure in Health?

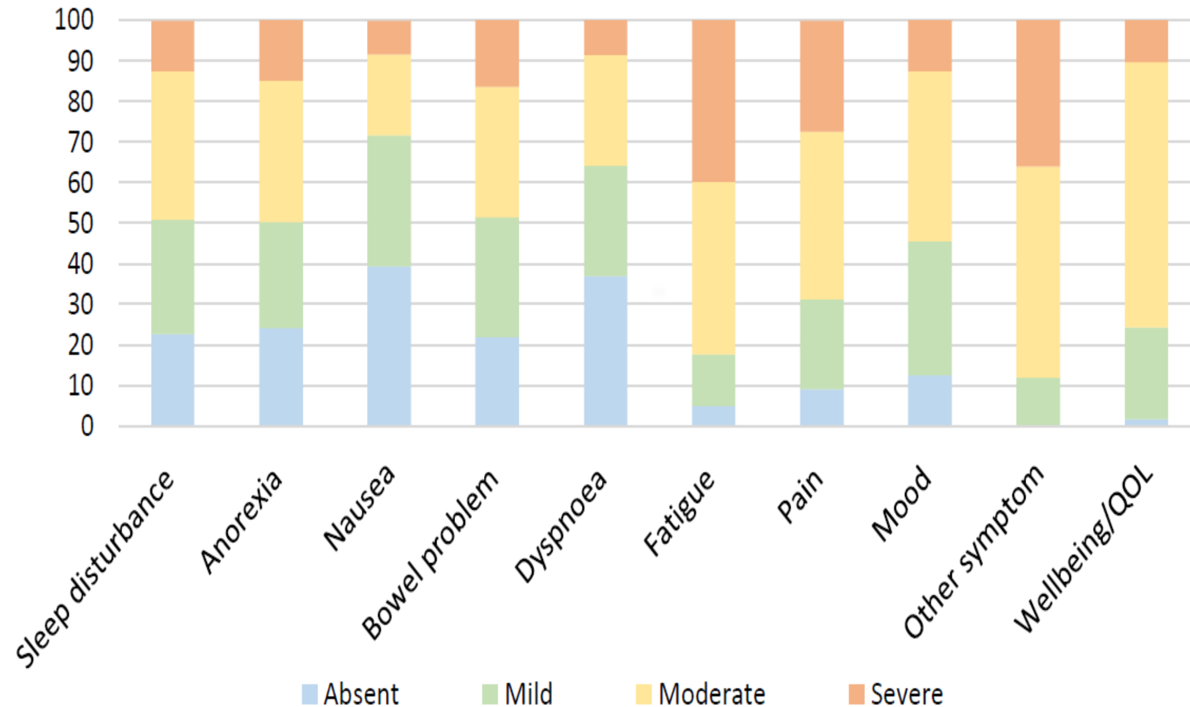

Fig. 2: Baseline Symptom Prevalence & Intensity

Symptom Assessment Scale

Please use this form to tell us about the symptoms that bother, worry or distress you. This information will help us to meet your needs.

0 1 2 3 4 5 6 7 8 9 10

Absent | Mild | Moderate | Severe

1. Write the day or date in the first row.
2. Use the scale above to choose a number between 0 and 10 that shows how bothered, worried or distressed you are.

Day or date									
Anxiety	8								
Discouragement	8								
Trapped by illness	8								
Hopelessness	9								
Pointlessness	5								
Loss of control	7								
Loss of roles	9								
Depression	10								
Wish to die	0								
Confusion	4								

How have we managed this?

Clinically:

- **Listening Deeply and Responding Mindfully**

Awareness of and Exploring the Existential

Ethically:

- **Non-Abandonment**

Moral Distress

THE NEED TO BE HEARD

"listening to respond" and "listening to understand."

Intent: It is one thing to be fully present to the other person.
It is another thing to go the extra mile and seek to understand them truly.

Deep listening springs from a desire to better understand a person or situation and authentically connect with them.

When we listen deeply, we do so without judgment or preconceived ideas. We are open to surprise and new insights. We view the conversation as a journey of discovery.

A mindful response

A mindful response often starts with a good follow-up question to acquire more information and understanding or to delve deeper.

An alternative is to summarize what the person has said in order to confirm we have correctly understood them.

Either way, our intent is to explore the other person's point of view and not impose our own agenda.

It is in that place of greater connection and vulnerability that true collaboration takes place.

Table 1: Overview of MaP therapy themes and illustrative meaning-centered questions

Session Number	Overall Objective of the Session	Illustrative meaning-centered questions from the repertory in the MaP Manual
1	**Getting to know the person**	How has your illness impacted your life? What specific memories stand out for you? What have you accomplished, stood for, and meant to others? What roles have you played in life? Who among family and friends has become central to your life?
2	**Defining personalized therapy goals**	What is meaningful in your life? What gives you a sense of purpose? Have you had a calling in life? What ordinary moments do you treasure? What goals can you create here to strengthen the meaning and purpose of the rest of your life?
3	**Enhancing meaning & purpose**	What questions can you ask your doctors to better understand your illness? What could you prioritize to enhance your physical wellbeing? What creates a sense of awe and wonderment about the world you live in? What attitudes toward coping help you the most?

Kissane DW et al. Meaning and Purpose (MaP) therapy II: Feasibility and acceptability from a pilot study in advanced cancer. *Pall Support Care*. 2019; 17: 21-8.

Non-abandonment is one of a physician's central ethical obligations:

it reflects a **longitudinal commitment** both to care about patients and to jointly seek solutions to problems with patients throughout their illnesses.

Non-abandonment places the physician's open-ended, long-term, caring commitment to joint problem solving at the core of medical ethics and clinical medicine. There is a world of difference between facing an uncertain future alone and facing it with a committed, caring, knowledgeable partner who will not shy away from difficult decisions when the path is unclear.

Nonabandonment: a central obligation for physicians Quill T Ann Int Med 1995