

The Institut Català d'Oncologia Model of Palliative Care: An integrated and comprehensive framework to address the essential needs of patients with advanced cancer

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INTRODUCTION

In the 1990s, the World Health Organization (WHO) proposed the establishment of a palliative care (PC) program in Catalonia, Spain (1, 2). Since then, PC has become a key element of the Catalan public healthcare system. In terms of organization, several models have been proposed to deliver PC (3-5). But along with models for planning and organizing PC services, a model of care is required to ensure that the needs of patients and those of their families are addressed.

In our setting, 75 percent of patient deaths are due to chronic advanced diseases or conditions: approximately 25 percent of these deaths are from cancer, and 50 percent are the result of other chronic advanced diseases. Between 1.4 and 1.6 percent of the general population suffer from these conditions (6), which have multiple ramifications: they cause functional and nutritional decline, trigger frequent needs crises (7), place a high demand on resources, and give rise to ethical dilemmas (8). These issues often result in suffering for patients and patients' families; they are also a source of stress for healthcare professionals (9).

In this paper, we describe the creation of a conceptual model of care to address the essential

psychosocial and spiritual needs of patients with advanced cancer. We also identify which professional abilities are required by the healthcare personnel who attend to these needs at the Institut Català d'Oncologia (ICO) (the Catalan Institute of Oncology) in Barcelona, Spain. This model of care is intended to facilitate the provision of excellent support; it is based on a combination of personal values and clinic competencies.

THEORETICAL BACKGROUND

A Definition of Suffering

Several authors have attempted to define human suffering. Cassell's definition can be summarized as, "It is not bodies that suffer, but people" (10). Chapman and Gavrin see it as a "perceived threat to the integrity of self, the perceived helplessness in front of that threat and the exhaustion of psychosocial and personal resources for coping" (11). Loeser and Melzack believe that suffering is the result of "pain or other experiences such as fear, anxiety, loss, and some psychopathological states" (12). Twycross and Lack describe pain as a "psychosomatic experience" and its impact as a combination of "mood, morale, and meaning" (13). Finally, Barreto and colleagues portray suffering as the emotional impact of physical symptoms, comparing the severity of these symptoms with the extent of worry (14). Two aspects of suffering

are highlighted: a person suffers when he or she perceives an event as threatening; simultaneously, that person suffers when his or her resources to cope with the threat seem insufficient (15-17).

Models of Psychological, Social, and Spiritual Care and the Relief of Suffering

Frankl (18) and Yalom (19), considered to be the forerunners of the human-suffering approach, identify the individual's most important concerns: freedom, loneliness, a sense of meaning in life, and a sense of the imminence of death. Callahan (20) and the *Hastings Center Report* (21) highlight the relevance of viewing cure and care as the combined aims of medicine. Additionally, Mount and Kearney (22) interpret healing as a "relational process involving movement towards an experience of integrity and wholeness." Stedeford (23) sees the process of adapting to a disease as a flexible and dynamic one in which crises and adjustments are phases of the disease's evolution. Breitbart (24) proposes a model of intervention — a "meaning-centered psychotherapy" — that is related to the search for the meaning of life (18, 25). Chochinov (26) offers dignity therapy, a briefly employed, individualized approach to relieving the existential and psychosocial suffering of patients at the end of life (26, 27). Several authors have attempted to define spirituality in the PC context (28-30); the task of developing an integrated definition is underway.

Developing Models of Needs, Intervention, and Organization in Palliative Care

The British hospice movement implemented a pioneering model of care within palliative care (31). This model would evolve into the Square of Care (32, 33), which was a more pragmatic proposal.

In Spain, Bayés and colleagues developed the threat-resources model in the field of psychology (15; see also 34, 35). According to this model, a person suffers when he or she perceives an event as threatening and, simultaneously, perceives that he or she lacks the resources with which to cope with the threat.

Other Spanish authors have described the "essential needs" of patients suffering from advanced chronic conditions while referring to the notion of the "maximal ethical commitment" to care for patients at the end of life with confidence and with empathy (36-39). The Working Group on Spirituality of the Spanish Society for Palliative Care (Sociedad Española de Cuidados Paliativos) has defined the term "spirituality" and proposed a model of intervention (40). Additionally, the La Caixa Foundation and the WHO Collaborating Center's Spanish national program for enhancing

psychosocial and spiritual palliative care for patients with advanced diseases and their families manages 29 teams of professionals dealing with the psychosocial and spiritual needs of patients and their families (41).

The ICO has consolidated a comprehensive approach that includes PC (42) and psycho-oncology services (43) and specialist education and research programs (44). In 2008, the institution was designated WHO Collaborating Centre for Public Health Palliative Care Programmes. The QUALY Observatory was then set up to support the design and implementation of PC programs at the national and international levels (3, 45).

The Need for a Comprehensive Framework

Because there exists a range of models of psychosocial and spiritual care, we decided to create a comprehensive model of care. We believe that integrating diverse approaches into a broader inclusive framework could be very beneficial.

DESIGNING A COMPREHENSIVE MODEL OF CARE AT THE ICO

Methodology

We convened a core group of professionals to develop an integrated model of patient care at the ICO. This nuclear team was comprised of ICO-based professionals who had extensive experience in palliative medicine (Appendix 1). The group conducted a literature review and discussed specific topics in PC (for example, spirituality, dignity, hope, compassion, and suffering) over the course of several meetings. Transparent expert consultations were undertaken using consensus methods of nominal group and online voting. Finally, the group produced a preliminary document outlining its conclusions.

Another group of professionals was created within the ICO to review the document. This nominal group was comprised of experienced professionals from outside the field of palliative medicine, including physicians, nurses, a certified nursing assistant, administrative staff, and managers (Appendix 2).

Based on the nominal group's critical revision, the nuclear group rewrote its proposal for the model. Finally, the definitive proposal was presented to the hospital's steering committee for approval.

Characteristics of the New Model

Our model is focused on the direct and dynamic therapeutic relationship between the professional caregiver and the patient, and it responds to the patient's essential needs. Other relevant issues — such as controlling symptoms, caring for the

patient’s family members, and adopting a team approach to care — are not included.

We describe the model as a comprehensive combination of values, knowledge, skills, attitudes, and behaviours that address the essential needs of patients in the end-of-life period. The goal of this direct therapeutic approach is to achieve excellence through a full ethical commitment to care provision. By centring the model on patients’ psychosocial and spiritual needs, we hope to alleviate their suffering and help them adjust to their progressive, life-threatening disease.

The excellence of care that the model is designed to achieve can be defined as the capability of both the organization and the healthcare professional to fulfil patients’ needs through the best clinical and organizational practices and with the maximum ethical commitment. The principles, wishes, values, and preferences of patients and their families must be made central to the care provision process. (46)

Principles of the New Model

The model can be applied to specific patient-needs situations, as shown in Figures 1 and 2. Patients’ needs are grouped as basic and essential. Care providers require certain abilities and characteristics (values, attitudes, and behaviours) in order to respond adequately to these needs. Abilities include: basic clinical and communication skills, the ability to provide counselling and engage in ethical decision making, advance care planning skills, case management skills, the ability to offer continuity of care, the capacity to respond to essential patient needs, and the ability to provide excellent care with maximum commitment. Characteristics include: basic politeness and respect, derived from education; and such values and attitudes as hospitality, empathy, compassion, commitment, congruence, presence, confidence, and honesty.

Henderson (47) and Maslow (48) have described patients’ basic needs. These needs must be fulfilled if patients are to perform adequately the activities of daily living (ADL) and the instrumental activities of daily living (IADL). Henderson suggests that it is crucial not only to facilitate health recovery but also to allow patients to die with dignity. She also emphasizes the importance of patients’ independence, particularly in the decision-making process, and identifies 14 basic related needs. Of these, we have elected to focus on: breathing appropriately, eating and drinking adequately, sleeping well, and being capable of communicating with others and transmitting one’s feelings.

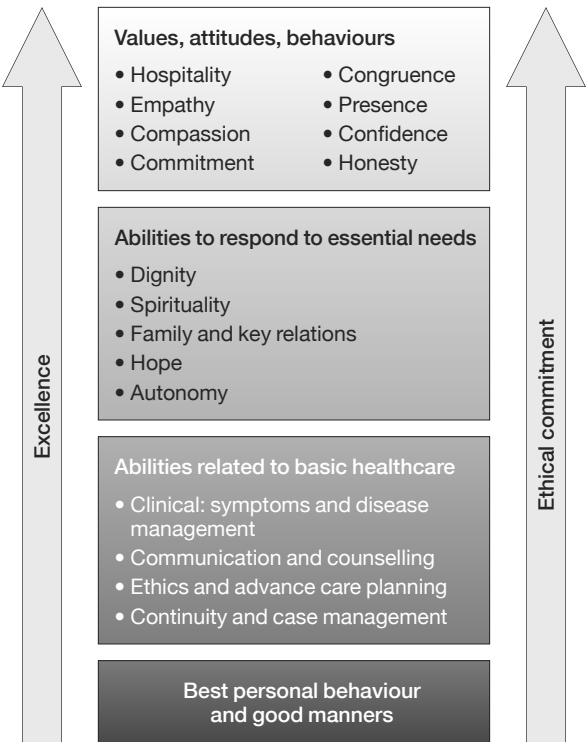
Maslow views human needs as contained within a hierarchical structure where higher needs are dependent upon lower ones — that is, once all their basic needs are satisfied, human beings tend to pursue the fulfillment of their higher needs. Indeed, the fulfillment of basic needs is considered a prerequisite to such a pursuit. Zalenski and Raspa (49) have applied this notion to palliative care in an attempt to develop an improved approach to care. In creating our model, we have thus borne in mind that the needs hierarchy signals the urgency of satisfying patients’ most basic needs first. For example, before we explore patients’ deep emotional reactions to their situ-

Figure 1 / Title?



* Activities of daily living.
** Instrumental activities of daily living.

Figure 2 / Title?



ations or begin to address with patients the meaning of life, we must first reduce or alleviate their pain or other physical symptoms.

The essential needs of patients arise most intensely in situations of advanced illness and vulnerability (36). Essential needs include: spirituality, which incorporates transcendence, the meaning of life, beliefs, values, practices, forgiveness, and unfinished business; dignity, which may be defined as the recognition and respect accorded to the individual patient’s personal values, social standing, legacy, and life story; autonomy, which implies freedom and the power to decide upon and prioritize goals and desires related to any aspect of physical and spiritual care; family and personal relationships, which includes the bonds between patients and their family members or anyone who offers them love, tenderness, emotional support, affection, communication, safety, and practical help; and hope, which encompasses adjusted, realistic, flexible, and reasonable expectations.

Clinical Care and Complex Situations

At the ICO, care providers frequently encounter complex care situations. In these special scenarios, patients and/or their family members must cope with particularly stressful circumstances and thus require greater levels of attention. Some examples of these scenarios include: the first diagnosis, the spread of the disease, the effects of anticancer treatments, treatment failure due to disease progression, refractory or complex symptoms, transfer between services, admission to emergency services, and the end-of-life process.

Seeking Excellence of Care: Professional Skills

Professional competence can be defined as the integrated knowledge, skills, values, attitudes, and behaviours employed by a healthcare professional to appropriately address the needs and demands of patients and their families as part of a team and within an organization. All of these different yet interdependent elements are necessary in order to achieve the highest quality of care. Organizational values oriented toward patients’ needs set the context and conditions for making our model feasible.

The required professional skills and values are: basic politeness, which includes respectful behaviour and thoughtfulness; and basic care skills, which encompass the aptitudes that all healthcare professionals in all clinical situations and settings must possess, such as knowledge of diseases and their symptoms and the ability to communicate with patients and offer counselling (see Table 1). Skilled communication involves active listening and the ability to establish a respectful, private

Table 1 / Recommended Attitudes and Behaviours of Healthcare Professionals toward Patients at the First Meeting

1.	Introduce yourself, your colleagues or team members, and your service.
2.	Always be formally respectful in verbal and nonverbal personal exchanges.
3.	Always ask for permission to question or explore, to enter the room, and so on (“Do you mind if...?”).
4.	Establish the objective and the purpose of the visit/consultation.
5.	Guarantee the patient privacy and intimacy, especially when conducting more serious conversations or explorations.
6.	Start with general, open, noninvasive questions.
7.	Always conclude by asking the patient if he or she has any doubts, has understood the information provided, or feels that there is something more that can be done by you and your colleagues or team members.
8.	Always clarify the decisions that have been made and the follow-up that is proposed.

atmosphere in which to begin a gradual, multi-pronged treatment process; the process itself will demand of healthcare professionals the ability to relate to patients in verbal and nonverbal ways and to understand patients’ adjustment mechanisms — their rhythms and their timing. The main elements of counselling include the ability to recognize what resources and emotional supports are available to the individual patient, as well as assertive communication skills, a problem-solving methodology, and the capacity for emotional regulation (15).

Our model highlights the methodology of decision making and advance care planning. We promote the involvement of patients in the care process and the consideration of their preferences, priorities, and values. We also encourage the attitudes and practices that support accessibility, availability, and the methodology of case management (50). The role of the referent professional — the healthcare provider who is seen by the patient as an advocate and a counsellor throughout difficult decision-making processes — is essential.

Competence in addressing the essential patient needs of spirituality, dignity, and hope requires careful assessment followed by gradual and highly skilled intervention. Specific training and personal work is needed. Tables 2 and 3 summarize some of the actions and key questions that healthcare professionals can employ to explore patient needs. Another key professional skill included in our model is the ability to care for patients with consideration of their principles and values; patients and their healthcare providers should agree upon the care patients will receive in the course of their disease.

Table 2 / Steps to Exploring and Covering Patients' Essential Needs

1.	Create a context in which to enact basic personal interactions and care competence: privacy, safety, comfort, symptom control, communication, active listening, counselling, ethical decision making, advance care planning, and case management and continuity.
2.	Start to gradually, gently, and slowly explore by asking open questions.
3.	Establish a common language, understanding, and goal orientation; ensure that the patient has confidence in the relationship.
4.	Explore the information on, the experience of, and the meaning of the disease; explore the patient's adjustment to the disease.
5.	Promote and explore a life review; identify goals, meaning, values, beliefs, legacy, and previous crises and experiences.
6.	Explore the quality of family and social relationships and promote high-quality relationships.
7.	Promote and explore reflection on unfinished business, forgiveness, and guilt.
8.	Promote and explore religious expression and practice.
9.	Review and readjust goals, language, and expectations in order to prevent misunderstandings and promote hope.
10.	Prevent crises and explore decision-making scenarios.
11.	Offer and guarantee support and accessibility.

Source: Adapted from Breitbart W (24); Chochinov HM, Hack T, McClement S, et al. (26); Gómez-Batiste X, Buisan M, Gonzalez MP, et al. (41); Walling A, Lorenz KA, Dy SM (53); Von Roenn JH, von Gunten CF (54).

Table 3 / Key Questions for Exploring Essential Needs

1.	"How do you feel?"
2.	"How do you see the current status of your condition?"
3.	"What are you worried about?"
4.	"How do you think things might go in the future?"
5.	"What helps you to cope with this situation?"
6.	"What would you like us to do for you?"

Also important is recognizing the patient's family as a unit of care. Family members can offer their loved ones emotional and practical support; they can facilitate communication with healthcare professionals and help the patient to adjust to illness and loss. Our model promotes the healthcare provider's role in helping patients' families through the bereavement process (51), adapted to our Latin context (52). This is but one aspect of the way in which healthcare professionals' attitudes, values, and behaviours influence the development of excellence in commitment to care provision (Table 4).

Table 4 / Definitions of Attitudes, Values, and Behaviours Related to Palliative Care Excellence

Hospitality	The ability to create a context in which to offer patients a sense of safety, confidence, and comfort.
Empathy	The capacity to perceive, understand, appreciate, and share the affective, cognitive, existential, and experiential components of patients' needs and to express this within the therapeutic relationship.
Compassion	Empathy applied to sharing and understanding patient suffering.
Commitment	Interest in and involvement with the patient, characterized by the phrase "You matter"; availability and accessibility.
Confidence	The result of applying all of the behaviour patterns and emphasizing the role of the reference professional, who acts as an advocate for patients, especially in situations when difficult decisions must be made.
Congruence	Coherence between explicitly expressed — in verbal, nonverbal, and emotional language — personal feelings and values.
Presence	Active attention and active listening.

In creating our model, our first step was to elaborate a conceptual framework and a set of clear definitions that adequately describe patients' basic and essential needs. Our ultimate goal is to use the model to teach healthcare professionals the concepts and the abilities they require to address these needs by means of several combined methodologies. Concepts and abilities include specific knowledge, personal and professional experience, personal empathy with suffering, and knowledge of human relationships with respect to end-of-life status. Methodologies include modelling, tutoring, and supervising in clinical practice.

CONCLUSION

At the ICO, we have built a comprehensive conceptual framework, based on over 20 years of professional experience and research, to describe the basic and essential needs of patients suffering from progressive advanced disease; the framework includes guidance on how to respond to these needs. The development process of the model included a nonsystematic literature review because our intention was to consider various key aspects of palliative care for incorporation into the model after a process of critical reflection.

Our model is suited to the different care provision situations that exist in our institution, but it could be adapted to care provision for all types of patients with advanced, progressive, chronic con-

ditions — patients who are suffering, and for whom fulfillment of their essential needs would be of paramount significance (50).

The model will be piloted as a research project within the PC service of the ICO in order to test its feasibility and acceptability. At this point, any necessary changes will be made. The implementation process of the model of care is:

- Distribute a survey among patients (both admitted and ambulatory) to grade healthcare professionals in terms of their competence.
- Ask patients and their families what their basic and essential needs are and how healthcare professionals can address these needs.
- Ask patients and their families what abilities healthcare professionals should develop in order to respond to these basic and essential needs.
- Distribute clinical documentation, including clinical protocols and formal policies, as well as teaching materials to all healthcare professionals at the hospital.
- Develop quality indicators.
- Arrange for referent personnel to undergo specific supervised training.
- Periodically assess staff abilities.

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Appendix 1 / Nuclear Group Participating in the Development of the Model

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