

section 2.1: assessment guidelines

assessing palliative patients

Central principles which are essential to assessment of palliative patients include the following:

- assessment is not a single event but rather an ongoing and focused process which allows the treating team to respond to changing needs
- a systematic assessment with targeted questioning is more effective than self report¹
- all assessments must be clearly documented in the case notes
- care planning is directed by the needs and wishes of the patient, their caregivers and family² and requires active exploration and documentation.

A comprehensive approach to assessment relies on attention to detail of a relevant medical history, physical examination and appropriate investigations which focus on the question: "Will this investigation impact on my treatment plan?"

providing a holistic approach

Patient concerns are likely to focus on the medical management of their condition but to also extend to other components of their lives, including the effects of illness on their identity, their ability to maintain role responsibilities, relationships amongst family members, management of financial and legal concerns or issues of an existential nature.³ Responsibility for assessment of the patient across all domains of care including physical, psychosocial, spiritual, financial and sexual aspects must be shared by the whole team as needs are frequently diverse and complex.⁴

a. physical assessment

Key elements to the physical assessment include:

- a systematic approach which takes account of the patient's current and past illnesses
- a comprehensive physical examination
- focused questions to identify what may be multiple symptoms – it has been observed that patients have volunteer an average of 2-3 symptoms, a figure which increases significantly with a formal review of symptoms⁵
- the presence and details of distress caused by each symptom (scoring symptoms is a good way to obtain baseline information and allow comparison following interventions such as analgesia – tools for this purpose are outlined in Section 2.1.3 - *Related Assessment Tools*)
- consideration of likely causes of symptoms and underlying disease
- an understanding of the impact of disease and symptoms on the patient's quality of life.

A comprehensive assessment will facilitate the development of a treatment plan that can focus on treating reversible pathologic processes, alleviating distress, and promoting quality of life.

b. psychosocial assessment:

A psychosocial assessment considers the range of issues that the patient and their family are facing, the ways the illness has changed their lives and the meaning of the illness to them. This may include exploration of the patient's self-concept, their hopes for the future, their social and cultural context and previous coping strategies.

A psychosocial assessment includes the patient's context and their "family", the family being defined as:

"whoever the person says his or her family is. It may include relatives, partners and friends and those closest to the patient in knowledge, care and affection. This includes the biological family, the family of acquisition (related by marriage / contract) and the family of choice and friends."⁶

A psychosocial assessment may include exploration of some or all of the following elements:

- patient assessment
 - perceptions and feelings about the illness and prognosis
 - the way in which the patient coped with significant life events or past losses
 - the extent to which the patient feels supported
 - presence of anxiety, stress, confusion, dementia, delirium
 - exploration of sadness - "would you say that you are feeling sad or depressed?"
 - their sense of hopefulness or helplessness and the duration and frequency of these feelings - eg of a transient nature (a bad day) or frequent and lasting
- existing social and cultural network
 - family structure and geographic location using a genogram
 - supportive social relationships
 - lines of communication
- family assessment
 - the way in which the family have coped with past losses
 - information and education required to assist with care
- caregiver availability
 - ability and responses to providing care and support (see Section 4.1 - *Discharge to metropolitan Adelaide*)
- current accommodation/living arrangements
- work and school settings
- access to transportation
- access to equipment
- financial and living situation
- legal issues and medical decision-making.

Issues identified by the psychosocial assessment, including the values, goals and preferences of the patient, will be documented and a plan generated which will include referrals to appropriate services.⁷

Some people who experience severe emotional distress, such as anxiety or depression, may require specialised support. It is essential to explore the patient's feelings, to seek clarification about the depth or frequency of sadness, helplessness or hopelessness and to discuss with the medical team whether a referral for formal evaluation is appropriate should a clinical depression be suspected.

Living with advanced illness can be confronting and challenging. Strategies for minimizing psychosocial distress include providing information to the patient and family that is easily understood and paced to match their needs, ensuring continuity of care, and enhancing social interactions.⁸ It is essential that health care providers allow opportunities for patients to discuss difficult issues and are open to cues that they demonstrate, knowing that it is more likely for psychological needs to be overlooked than physical needs.⁹

c. spiritual assessment

Spirituality has been described as that aspect of our lives which is concerned with finding meaning and purpose in life, our values and beliefs and is how we “make sense” of the whole range of our experiences. This search for meaning or reflection on the past and the future can be a particularly significant dimension when we are faced with a life crisis such as advancing age, progressive disease or when facing death. The breadth of this experience can be as wide as times of questioning and loss of faith as well as discovery, growth and inner peace.¹⁰

In recent years the interpretations of spirituality have broadened significantly from solely religious understandings of faith and beliefs about the sacred to a sense of self and personal meanings – thus delivery of spiritual care must now be equally diverse. Unlike the majority of clinical care, which is about identifying problems and intervening to resolve them, spiritual care is about “making space that patients can use themselves”.¹¹ This may be in identifying and assisting patients to keep in touch with places and things that are important to them, or listening to the stories as people review their lives and sort out those enduring experiences and commitments that make them truly themselves. Sometimes it is about space for religious observance and ritual activities.

Exploring spirituality may be as simple as listening to what patients are willing to offer about their lives and their experiences.

A spiritual assessment may include but is not limited to:

- assessment of the patient’s hopes and fears, meaning, purpose and beliefs about an afterlife
- a life review
- thoughts about those important tasks to be completed in life
- issues of guilt and forgiveness
- identification of religious, spiritual or existential background
- identification of current religious/spiritual preferences, rituals or practices¹²

The goal of spiritual care is to identify the patient’s sources of hope and strength and those connections which are life-giving or life-preserving and exploring how these can be maintained. If maintaining these connections is no longer possible, are there ways in which the person can continue to draw strength from what remains rather than being overwhelmed by loss?

Are there connections from the past such as relationships, experiences or beliefs that might be revived? Are there any new or emerging sources of strength and resilience?

An example of a spiritual assessment tool is provided at the end of this section.

d. financial

The costs of caring can be very expensive and part of our assessment includes a review of the practical needs and financial resources of the patient and family. Loss of income and costs associated with illness can create significant burden.

Some pertinent questions for staff include:

- does the patient or caregiver have an identified source of income?
- do they have the capacity to cover prescription and over-the-counter medications, hire of equipment or engagement of nursing services at home? – can they afford the cost of petrol for frequent medical and related appointments?

- are the patient and family aware of the carer payment for full-time caregivers (subject to an income and assets test) or the carer allowance (non means tested)
- if the patient has private health insurance, are they aware of the benefits that can be accessed from their particular fund to cover home nursing costs?
- are there questions about superannuation payouts, sickness benefits or the role of Centrelink?

Requesting support and information from the social worker or discharge planner can be invaluable in this process.

e. intimacy and sexuality

Intimacy is thought of as intrinsic to our sense of self,¹³ and may be an emotional connection to others that is more important than physical expressions.¹⁴ Intimacy and sexuality are topics that are often overlooked by clinicians who may consider them less important than other health issues, or they may feel ill prepared or uncomfortable discussing such matters with patients and their families.

Issues of intimacy of relationships and sexuality do however continue to be important to patients when facing a life limiting illness and at the end of life – many would like the opportunity to discuss the impact of their disease and its treatment on their sexuality and it is important that staff offer them the opportunity to discuss their concerns.¹⁵ Patients often prefer these discussions to be initiated by the health professional rather than bringing them up themselves.

Changes in appearance and increasing fatigue due to chronic illness or treatment regimes can diminish an individual's self-esteem and tax close relationships. Additionally, changes to sexual desire and capacity for sexual activity, pain, incontinence, grief and depression are all likely to have impact. Exploring these issues with the patient and talking through strategies to manage these concerns with their partner may be helpful and a therapeutic tool in itself. Practical strategies include:

- giving patients permission to talk about their relationships by prompting the questions yourself – how are you and Peter managing to deal with all of this as a couple?
- using open ended questions and an attitude of acceptance and trust
- using the PLISSIT (permission/limited information/specific suggestions/intensive therapy) model can provide a valuable framework to match the clinician's skills and comfort with a graded counselling approach¹⁶
- providing information and advice about a range of ways of expressing sexuality (other than through intercourse)
- offering a referral to a specialised counsellor, eg couple therapy or family counselling.

negotiating goals of care

Following assessment a plan of care is considered. Understanding and negotiating these goals for each individual patient is a core feature of palliative care and one which focuses on the individual's wishes and preferences. Important aspects to consider when negotiating goals of care include:

- goals need to be realistic and flexible with the aim of maximising function and independence¹⁷
- goal setting is often undertaken within the context of an uncertain and progressive illness

- goals that foster insight and understanding may sometimes be more important than those that facilitate physical independence
- decisions about interventions are made considering the burden of treatment or intervention and its effect on their quality of life.¹⁸

Within this process it is critical for clinicians to be aware of their own limitations and scope of practice and to readily refer to other team members when required.

related resources and information:

See Section 2.1 3 - *Related Assessment Tools*

Spiritual assessment tools

There are a number of assessment tools have been developed that prompt exploration of patients' spiritual beliefs and concerns – one of these is the **FICA- spiritual assessment tool**.¹⁹ This tool poses a simple set of questions that assist in assessing patients' spiritual needs. An acronym, which can be used to remember what to ask in a spiritual history is FICA (Faith/Importance/Community/Address). Some specific questions you can use to discuss these issues include:

F: Faith or Beliefs

What is your faith or belief?

Do you consider yourself spiritual or religious?

What things do you believe in that give meaning to your life?

I: Importance and influence

Is it important in your life?

What influence does it have on how you take care of yourself?

How have your beliefs influenced your behaviour during this illness?

What role do your beliefs play in regaining your health?

C: Community

Are you part of a spiritual or religious community?

Is this of support to you and how?

Is there a person or group of people you really love or who are really important to you?

A: Address

How would you like me, your health care provider to address these issues in your health care?

General recommendations when taking a spiritual history:

1. Consider spirituality as a potentially important component of every patient's physical well being and mental health.
2. Address spirituality at each complete physical exam and continue addressing it at follow-up visits if appropriate. In patient care, spirituality is an on-going issue.
3. Respect a patient's privacy regarding spiritual beliefs; don't impose your beliefs on others.
4. Make referrals to chaplains, spiritual directors or community resources as appropriate.

5. Be aware that your own spiritual beliefs may support you personally and will be a part of your encounters with patients and families, adding a human element to interactions.

references

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