

PSYCHOSOCIAL PALLIATIVE CARE – THE EMOTIONAL AND SPIRITUAL ASPECTS OF THE JOURNEY

COVID-19 was a harsh teacher to many in the medical profession on the need for psychosocial and spiritual knowledge and skills when faced with someone's pending mortality. It has long been understood in the palliative care sector that equipping professionals with the skills and knowledge to understand what is required to assist a patient that has been given a life-limiting diagnosis, as well as knowing how to help them or to bring in the available support, is vital to both the person receiving the diagnosis and their loved ones. The journey to our final destination is one that can be ably supported. This article is the first in a series of three that outlines the psychosocial and spiritual aspects of palliative care and its importance as part of holistic care.

Millions of people worldwide are affected by life-threatening illnesses such as cancer, organ failure, neurological diseases and HIV/AIDS, which cause them and their families great suffering and economic hardship¹. In the developing world, there is often limited accessibility to prompt and effective treatment for these diseases. Palliative care services in this type of resource-restricted environment are usually effective and are able to apply low-cost approaches that respond to the urgent needs of those affected, or requiring care and improve their quality of life by:

- Relieving pain
- Controlling physical symptoms
- Relieving psychosocial and spiritual distress
- Alleviating fear and loneliness

The word 'palliative' is derived from the Latin word 'pallium' meaning 'a cloak'. Patients are cloaked in care. The primary aim of this approach is to promote comfort and provide relief from pain and suffering which are key components in palliative care².

The LINK between primary health care and palliative care is... potential and quality of life.

Palliative care focuses on:

- Holistic care
- Relief of suffering
- Pain and symptom control
- Active support of patient and family
- Dying with dignity
- Bereavement care

The current scope of palliative care in South Africa is a broad one, where any disease that is life-limiting qualifies, where multi-disciplinary teams work together, where it's recognised that palliative care should be introduced early on in the course of illness, that families and caregivers are involved and that physical, cognitive, emotional, social and spiritual needs are all considered.

The 'Total Pain' concept is an example of the importance of an approach that bears emotional, cognitive, social and spiritual needs in mind. A term coined by Dame Cicely Saunders, 'Total Pain' recognises the effect or impact of pain on an individual's overall

¹ (Sepulveda et al. 2002).

² (Twycross, 1999)

wellbeing. A person's experience of physical pain can be made worse by some of the following:

- Worries about finances
- Concerns that his or her partner is alone at home
- Deep spiritual anxieties about punishment for past sins and the questions of "Why me?" "Why now?" "Is God a loving God?"
- The distress of the family
- Fears of death and of suffering
- Poor communication with others

The 'Total Pain' concept sketches out what a patient might be experiencing, and goes some way towards explaining why psychosocial care is so important in palliative care.

Psychosocial practitioners form an integral part of the multidisciplinary team where they provide skilled consultations between professionals, the patient and family members, in which each draw on the expertise and knowledge of the other to assist with the physical, psychosocial or spiritual issues facing the patient and family. Psychosocial professionals usually receive a referral from the professional nurse who has already made contact with the patient and family and has done an initial assessment.

At the assessment, the nursing sister identifies key areas of psychosocial needs, and refers these to the appropriate psychosocial professional. Depending upon the urgency of the care required, this referral may be immediately after the initial assessment or at a report back at the interdisciplinary patient rounds.

The professional will then arrange to do a visit and explains their involvement in the patient's care. Depending on the reasons for referral, the identified needs will then be explored with the patient and his/her family and a discussion had on how these might be addressed. A comprehensive psychosocial assessment will also be undertaken, which may include the following areas:

- Family composition and genogram (a diagram illustrating the patient's family members, how they are related and their medical history)
- Emotions (denial, anger, anxiety, fear) and emotional resourcefulness (such as hope, resilience, acceptance)
- Insight into illness
- Housing
- Income and grant applications
- Will
- Funeral policy status
- Role of religion/spirituality; religious and spiritual support
- Social support structures which include family, church community, friends, and neighbours
- Presenting problems
- Plans for care

During the working phase, within the context of a counselling relationship, the psychosocial professional will spend time exploring the feelings, thoughts, and expectations of the patient and family in relation to the illness, as well as addressing practical issues that may arise, such as finances and future care planning. Mutually agreed upon goals are then acted upon, or facilitated, with the intention of achieving the desired care.

In summary, psychosocial palliative care is integral to the provision of quality palliative care in bringing care and comfort to patients and their families as they journey through a life-threatening or life-limiting illness.

This series contains information from the Association of Palliative Care Centres (APCC) Psychosocial Palliative Care Course manual.