

Psychosocial cancer care

There is more to cancer care than medical management.

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This paper briefly reviews some of the current interests in the international field of psychosocial oncology, focusing on adults with cancer. The articles cited describe cancer in general – not specific cancers. It is not possible to give a comprehensive literature review on such a wide and dynamic field of care, but what follows may serve as an introduction, hopefully stimulating awareness of the many aspects of psychosocial cancer care.

Cancer is now being recognised as a chronic disease in countries with advanced health care.

Cancer as a chronic disease

In developed countries with adequate screening programmes and good access to timely treatment cancer survival rates are improving.^{1,2} Cancer is now being recognised as a chronic disease in countries with advanced health care. This extended survival profile brings with it a range of physical, emotional and social challenges in the longer term, including:

- role changes in the household, especially in terms of parenting functions
- social isolation and difficulty re-integrating into social or community circles³
- impact on decisions made around family size for patients of child-bearing age
- questions about potential genetic links in the case of a particular cancer
- adjustment to changed appearance, possibly with body image issues
- altered body functioning that may affect intimate relationships, mobility or elimination
- uncertainty about resuming employment (fatigue, workload)⁴
- disruption or interruption of career path
- potential prejudice when returning to the workplace, particularly when seeking new employment
- potential long-term loss or reduction of income
- financial depletion due to treatments, possible environmental modifications or equipment required
- regular encounters with social stigma

- possible psychological disorder, e.g. depression and/or anxiety, and in some instances PTSD⁵
- uncertainty about personal life expectancy, which can make future planning difficult
- emotional exhaustion and/or emotional withdrawal by carers, family and friends who find it difficult to sustain high levels of compassion for prolonged periods of time.

This list is not exhaustive, but hints at the profound impact that even a 'curable cancer' can have on the life of a patient and family.

It is understandable, therefore, that several more developed countries are now offering active rehabilitation programmes for people moving out of the active treatment phase of their cancer, typically including physical activity alongside emotional, social and economic reintegration with appropriate professional support during this 'phase' of cancer management.⁶

The need for cancer survivorship care plans is being discussed with greater intensity in Europe and North America, ideally with plans being tailored to the needs of individuals.^{7,8} Such plans help people to understand their medical care and surveillance after treatment for cancer, the survivor's own responsibility in terms of recommended lifestyle or lifestyle changes, and the linkage to relevant resources for ongoing support and education.⁹

Family members as carers have also been identified as being at risk of manifesting physical exhaustion and/or emotional stress and burnout.

Cancer as a family concern

With awareness of the impact of cancer beyond the patient, it is evident that entire family units may be affected by the diagnosis and its implications or by the course of the illness. Family members as carers have also been identified as being at risk of manifesting physical exhaustion¹⁰ and/or emotional stress and burnout.¹¹

The literature focuses on the importance of supporting partners,¹² children¹³⁻¹⁷ and parents of adults facing cancer. Running parallel to the concern about the emotional needs and responses of family members to cancer is an increasing interest in education, information, and access to relevant information with regard to diagnosis, treatment, and side-effects.¹⁸

Stages in the cancer journey

Because of the uniqueness of individual social contexts, the journey through cancer treatment and beyond presents a logistic, an organisational and, primarily, a physical challenge. In spite of medical and treatment advances and increasingly researched psychological interventions, people with cancer still face uncertainty and a sense of not being in control of their lives. If the medical team working with the patient has insight into some of the potential concerns that may arise, they can access and provide supportive care.

There are several stages in the journey through cancer where a heightened sense

of anxiety and stress can be expected from the patient and his/her immediate supporters. Anxiety, depression and distress¹⁹ have been major features in recent psycho-oncology research. It is not uncommon for these symptoms to require a multi-disciplinary approach to manage them well enough for the patient to continue functioning optimally.

Table I is a summary of some of the challenges encountered before, during and after treatment.

For readers not regularly involved in cancer care, the list above may appear to be self-explanatory and predictable, with the possible exception of the potential crisis experienced frequently at the end of treatment and during the period of

survivorship. This particularly challenging time has been dealt with in CME²¹ and is widely documented in other journals and texts.

Although not specifically discussed in the table above, it is vital to remember that throughout the abovementioned stages patients and families frequently deal with economic stresses and uncertainties that can become substantial burdens and influence decisions about treatments, continuation of employment, and type of care available should the patient become frail.

There are also two less discussed concerns that our patients face at any stage in their cancer journey. Both demand open-mindedness and support from the health care professional. These are the issues of

Table I. Summary of some challenges before, during and after treatment

Stage in cancer journey	Some of the psychosocial challenges facing patients and their families
Preliminary investigations and tests	<ul style="list-style-type: none"> • Awareness of the body functioning sub-optimally • Seeking or avoiding assistance and medical guidance/interventions • Possible awareness that a serious diagnosis could follow
Diagnosis	<ul style="list-style-type: none"> • Confronting own mortality, i.e. cancer remains a potentially life-threatening disease • Coping with overwhelming emotions, including uncertainty and a sense of not being in control • Processing information about the disease and treatment options • Making treatment decisions
Commencing treatment	<ul style="list-style-type: none"> • Understanding treatment schedule and procedures • Dealing with anxiety with regard to commencing treatment • Reorganisation of domestic situation to cope with role changes and support required
Coping with side-effects	<ul style="list-style-type: none"> • Managing possible ambivalence about treatment side-effects • Developing ways to manage side-effects • Rebuilding self-esteem regarding physical changes, i.e. body image, fatigue • Dealing with physical demands of day-to-day living and tasks
Ending treatment	<ul style="list-style-type: none"> • Coping with anxiety of less regular medical surveillance • Understanding and accepting that some problems before diagnosis may still be present • Managing possible ongoing physical limitations • Possible withdrawal of support from family and friends • Adjustment to 'new normal' after treatment
Survivorship	<ul style="list-style-type: none"> • Re-integration into former activities and relationships • Adjustment to bodily changes that are more permanent • Possible sense of emptiness or lack of direction after treatment • Fear that the cancer may return • Dealing with social issues, including stigma
Recurrence	<ul style="list-style-type: none"> • Making sense of new information • Finding a 'life focus' that is realistic and meaningful • Management of possible guilt or shame (sense of self-blame) • Making treatment decisions
Terminal illness	<ul style="list-style-type: none"> • Facing the disappointment of stopping active treatment and moving to best supportive care • Coping with losses at different levels while trying to maintain sense of meaning and purpose • Physical deterioration – possible frustration, dependency, discomfort or pain • Spiritual engagement or estrangement • Future planning for those who will remain behind
Bereavement	<ul style="list-style-type: none"> • Gradual understanding and acceptance of permanence of loss • Enduring the pain of grief • Adjustment to world without loved one • Eventual withdrawal of emotional energy from ended relationship to allow for investment in new interests/relationships

Table adapted from Grace Christ.²⁰

In spite of medical and treatment advances and increasingly researched psychological interventions, people with cancer still face uncertainty and a sense of not being in control of their lives.

sexuality²² and intimate relationships, and spiritual²³ or existential concerns.²⁴

The psychosocial care of the patient with advanced cancer requiring palliative care invites a separate discussion. This stage of illness has its own specific needs and challenges, many of which are admirably addressed by the hospice and palliative care movement. Nevertheless, during this phase of the cancer journey patients and families often feel a sense of personal helplessness and may believe that medical professionals have abandoned them.²⁵ A sensitive awareness of the patients' concerns and fears, together with a willingness to acknowledge uncertainties, conveys compassion and commitment to whole-patient care.

One of the sub-texts running through the stages outlined above, and the potential challenges they bring to a person facing cancer and his/her family, is the theme of loss.

Potential losses associated with cancer

As with many other chronic medical conditions, the diagnosis of cancer requires some adjustments that may relate to physical functioning or appearance, be linked to capacity for economic activity, or lead patients to reviewing their world view and values.

At the very least and even for a brief while a member of society is subjected to medical scrutiny and investigation and is faced with the label 'patient'. In sociological terms, this label carries with it certain roles and expectations from wider society and medical staff who generally require certain behaviours from their patients.

Even though not every person with every cancer will encounter these losses, the different levels at which a sense of loss may be encountered are summarised below:

- Relationship losses
 - role changes – adjusting to being a patient, parenting, social availability, intimate relationships, potential mental/intellectual capacity²⁶
 - social isolation – fewer or discontinued employment/studies/activities, abandonment, stigma and rejection
 - emotional distance from loved ones – difficulty in having conversations, caregiver fatigue/burnout, blaming, guilt about past behaviours or actions
 - disruption of sex life – may be linked to physical, attitudinal or relationship factors.
- Practical losses
 - loss of physical independence – mobility, hygiene, self-care, driving a car, declining fitness levels
 - economic losses
 - material changes – altered living conditions, financial hardship.
- Emotional and/or spiritual losses
 - lack of self-confidence and self-belief, uncertainty
 - body image concerns and reservations – may impact on intimate relationships
 - loss of dreams and aspirations – family dreams and hopes (possible infertility, not seeing children grow up, etc.), career or personal ambitions unfulfilled
 - existential uncertainty – spiritual beliefs challenged, sense of punishment or guilt, feelings of abandonment, alienation or remoteness from faith
 - loss of future – need to acknowledge and mourn the future that will not be experienced or shared.

Support from the medical team

In the face of this array of potential losses, what support can a medical team offer patients and their families on a day-to-day basis?

Internationally, there is a large body of psycho-oncology professionals who are equipped and well placed to offer specialist

interventions at all stages of the cancer journey. These different disciplines have formed large and active international psycho-oncology societies with their own publications, training courses and annual conferences, providing excellent opportunities and exchange of ideas (www.ipos-society.org). In South Africa we are reliant on a handful of mental health specialists who may have a particular interest in cancer and knowledge of the condition. Few of them work exclusively in oncology settings. A small group of social workers are employed directly in oncology units and clinics and are available to render therapeutic support together with more practical guidance where necessary.

For medical staff, there are several principles that should be incorporated into regular interactions with the patient or family. Of primary importance is an honest and direct approach to communication, combining patient-led telling of the truth and empathy. Much has been written about such communication, and specially designed training courses are available in countries such as England and the USA to assist oncologists with what can be an uncomfortable and difficult task.²⁷ Additionally, there is a push in the current literature to encourage greater use of evidence-based approaches and interventions so that services provided are indeed whole-patient focused and genuinely contribute towards an improvement in quality of life for patients.²⁸

Other supportive skills that can be honed by the whole medical team are set out in Table II.

Patients and families frequently deal with economic stresses and uncertainties that can become substantial burdens and influence decisions about treatment, continuation of employment, and type of care available should the patient become frail.

Table II. Supportive skills

Technique of practitioner	Impact on patient
Attentive listening	Feels 'heard' and respected
Clarifying concerns	Allows for catharsis, encourages questions
Reassurance	Decreases anxiety, conveys support
Encouragement	Allows for optimism and hope
Empathetic responses	Reflects understanding and genuine concern
Realistic acknowledgement of progress and improvement	Acknowledges independent efforts made by patient to be part of treatment process; boosts confidence in medical interventions

Table based on presentation by Walter Baile, 2007.²⁹

The above suggestions are simply a guide to providing a more supportive environment for the patient and family. People with a particular interest in this aspect of cancer care can avail themselves of the printed literature on this subject or can obtain information online.

Of primary importance is an honest and direct approach to communication, combining patient-led telling of the truth and empathy.

We all need to be mindful that referral to a mental health professional may be necessary in certain instances. Additionally, in a world where patients' rights are of increasing importance, there is a trend towards encouraging a more participative approach. Professionals, by offering support and encouragement, can help the patient with regard to a greater sense of ownership and control of the process.³⁰

Whole-person care

Psychosocial care of people with cancer has developed over the years and has become a special field of interest and study for psychiatrists, psychologists, social workers and other members of the medical team.³¹ However, there is always room for advancement and improvement.

To this end, the Institute of Medicine (part of the National Academy of Sciences in the USA) in 2007 produced a comprehensive report on cancer care, with extensive recommendations. The report, 'Cancer care for the whole patient: meeting psychosocial health needs', is available online at www.iom.edu – click on the section marked

'Reports'. It identifies barriers to accessing psychosocial oncology care and outlines minimum requirements for standardised psychosocial oncology care. It emphasises professional communication with the patient, and identifies individual needs and tailoring of psychosocial services to meet those needs.^{32,33}

In essence, the report highlights the need for accessible and equitable care for all people with cancer, extending beyond the physical management of their condition to support for their emotional, social, informational and other needs.

Much as it is tempting to dismiss this lengthy report as being too idealistic for a developing country such as South Africa, the content and principles of whole-person care are worth considering in everyday practice. An improved awareness of the potential psychosocial needs of individual patients and their families is a start.

We can, with limited resources in South Africa, begin to offer whole-patient cancer care in the following ways:

- awareness of emotional responses to cancer, treatments and beyond
- sensitivity to family and social circumstances surrounding the patient
- attention to the information needs of the patient, family and informal carers
- better utilisation of mental health and support professionals in multi-disciplinary teams to address and assist with psychosocial issues throughout the cancer journey

We all need to be mindful that referral to a mental health professional may be necessary in certain instances.

- improved education of medical professionals in basic but patient-focused communication.

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In a nutshell

- Cancer care is no longer exclusively limited to physical treatments and interventions.
- As a chronic condition, the impact of cancer on social, psychological and economic aspects of life cannot be ignored.
- Current developments in psychosocial care feature the following:
 - awareness of the impact of cancer on family units
 - need for appropriate and accessible information for patients
 - growing concern about survivorship issues, including the need for individualised survivorship care plans
 - promotion of the whole-patient cancer care concept in service provision
 - encouragement of people to take a more active role in their cancer management and to assume more responsibility for their ongoing wellness
 - ongoing training and up-skilling of medical personnel to work effectively with psychosocial concerns facing patients and families.

Single suture

Skin bacteria essential to skin defences

The bacteria living on our skin may play a vital role in checking the inflammation caused by injury and unwanted bacteria. This suggests that the current trend towards antibacterial hand gels and soaps may be exacerbating skin conditions caused by excessive inflammation.

Yuping Lai and colleagues from the University of California, San Diego, looked at the most common family of bacteria found on the skin, *Staphylococcus*, which are usually harmless unless they get into wounds. The team added molecules released by *Staphylococcus* to cells found in human skin. They found that one molecule, lipoteichoic acid (LTA), stopped some skin cells from releasing chemicals that trigger inflammation. LTA had a similar effect when added to the skin of live mice.

Lai points out that although inflammation is essential to recovering from injury, it is also important to be able to damp it down because prolonged inflammation can lead to skin diseases such as psoriasis. The team also noted that LTA's protective role seems limited to the skin surface. When applied to immune cells taken from deeper skin layers it provoked inflammation.

Lai Y, *et al.* *Nature Medicine* 2009; 15: 1366-1382.