

1 Supportive Psychotherapy in Cancer Care: an Essential Ingredient of All Therapy

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1.1 Introduction

Supportive psychotherapy for patients with cancer and their families is the single most important tool of the psycho-oncologist (or psychosocial oncologist). With it, patients are often sustained through the whole fragmented course of their illness. Supportive psychotherapy is both the most simple and the most complex tool we have. Therapists must be knowledgeable about cancer as a medical disorder, skilled at assessing and managing patients psychologically and comfortable with their own subjective experience in the face of complex and tragic medical situations. It also requires sound clinical judgement to recognise the patient's changing psychological needs and to match them accurately with the flexibility of our therapeutic approach.

Psycho-oncologists come from different disciplines, use different theoretical frameworks and have different cultural backgrounds, yet all converge to deliver this vital service. Clearly, there is a human interaction, a crucial piece, that is hard to fit into so many different theoretical frameworks for which technical and theoretical terms are inadequate. We should not sound apologetic but speak of supportive psychotherapy with pride, as it requires the highest level of clinical skills and taxes our own emotional capacities to the fullest. It also cannot be done without personal involvement and 'caring'. Francis Peabody in 1927 wrote in the JAMA that 'the secret to caring for the patient is CARING for the patient' [1]. This is no less true today, almost a 100 years later. Human emotions are universal and unchanging – only medical treatments change.

In this chapter, we define supportive psychotherapy in cancer care and provide the beginner with the basic principles that guide therapy with patients and their families. It may give more experienced therapists a fresh overview. Most lessons apply equally to patients with other life threatening illnesses. We do not seek to provide solutions, but rather identify techniques to manage situations that could otherwise be overwhelming.

1.2 Definition

Supportive psychotherapy is a therapeutic intervention utilised intermittently or continuously that seeks to help patients deal with distressing emotions, reinforce pre-existing strengths and promote adaptive coping with the illness. It explores the patient's self, body image and role changes within a relationship of mutual respect and trust. The range of approaches includes:

- Knowing how to clarify and discuss highly charged information, which arouses overwhelming emotions that interfere with processing, and helping to manage those emotions constructively.
- Being familiar with methods of promoting learning and problem-solving and using cognitive and behavioural techniques at any stage of disease.
- Being comfortable with a range of therapeutic activity including crisis intervention and a quiet, supportive presence for patients too weak to interact, an exploration of deep dynamic patterns operating in

the patient's psyche as well as family counselling in many constellations.

- Standing ready to guide the patient and family to available resources.
- Working well with the medical caregivers and understanding the system in which they operate so as to allow the reciprocal flow of useful information. This means knowing how to discuss the coping abilities and the vulnerabilities of the patient, in ways that humanise without violating confidentiality.
- Understanding the medical information you are given, and asking if you need more help.
- Understanding your own emotional responses, especially in your early years as you learn to manage yourself for the long haul, in these demanding situations.

1.3 History and Evidence Base

Given its core requirement for flexibility, supportive psychotherapy is difficult to study in randomised controlled trials that follow strict guidelines and manuals to assure treatment fidelity. As a result, there are far more studies of cognitive behavioural therapy and other more focused therapies, because of their easier study design. However, numerous compelling studies from the last 20 years were reviewed in 2007 by a multidisciplinary committee of the Institute of Medicine (IOM), National Academies of Science and the Committee concluded that a sound evidence base exists to recommend supportive psychotherapy as a valid therapeutic intervention. This landmark IOM report, *Care for the Whole Person: Integrating Psychosocial into Routine Care*, highlights the vital quality standard of integrating the psychosocial domain into routine cancer care [2]. It recommends that all cancer patients be screened for distress/psychosocial needs, which should then be addressed in the patient's treatment plans. Those with a level of distress identified in a rapid screen which fits an algorithm for 'caseness' should be referred to a proper psychosocial resource for help. Caseness identifies the level of symptoms without providing a diagnosis, but raises a 'red flag' about unmet needs. A two-phase screening is recommended, first rapidly via one or two questions, (such as the Distress Thermometer) followed by a more in-depth appraisal as needed.

In the US, the Alliance for Quality Psychosocial Cancer Care is educating patients, families, oncology 'front line' doctors, nurses and social workers about

this mandate [3]. It is an official paradigm change wherein clinical practice guidelines and accreditation documents for training in different disciplines include psychosocial care as one of the criteria for good overall care. Supportive psychotherapy is an effective management of anxiety, depression and distress across all stages of cancer. In complex cases, it is the 'default condition', that is the home base from which the therapist guides the patient to other helpful therapies and resources.

1.4 Qualifications for Clinical Privileges to Provide Supportive Psychotherapy as a Psycho-Oncologist

Psycho-oncology is an inclusive discipline to which different professions make unique contributions. We assume appropriate psychotherapy training, which can come from many different programmes. Each therapist needs a framework to organise psychosocial data and the conclusions drawn from it. This is the structure on which new knowledge can more easily be incorporated as part of a coherent whole. We also assume basic familiarity with recognition and treatment of anxiety and depressive disorders, cognitive disorders and delirium [4].

Today, a number of different theories commonly underlie any therapist's technique. Some are psychoanalytically derived, like modern supportive-expressive psychotherapy, object relations theory, self psychology and relational approaches. They deal with self awareness, managing emotions and relationships, absorbing losses and struggling with existential issues. Cognitive and behavioural therapies, learning theories and problem solving techniques have a critical role in improving adaptive skills but can be applied across many points of the disease trajectory. Many varied approaches are detailed in the rest of the book.

1.5 Application of Supportive Therapy in Cancer Care

1.5.1 Location

This approach spans the outpatient, inpatient and home care settings; sometimes the telephone or e-mail must suffice to stay in touch. The important issue is that the patient knows you remain 'there for him'.

1.5.2 Timing

The patient's level of energy will vary, necessitating that some sessions be shortened, based on fatigue or

level of illness. These are still extremely important. Even with curtailed dialogue, the session may be meaningful, particularly when the patient is very ill.

1.5.3 Frequency

Again, this varies with level of illness. As patients recuperate and feel able to address issues beyond illness, outpatient visits are reinstated with the rules akin to those conducted with physically healthy patients. But each medical setback restarts the cycle.

1.5.4 Sense of Urgency

Patients often have a strong sense of their time being limited, with a need to work out problems and family conflicts rapidly, yet realistically. Therapists must maintain an accurate sense of time within which the work can be accomplished.

1.5.5 Flexibility of Approach

Good therapists are always flexible, but psycho-oncologists need to be gymnasts as patient's concerns change repeatedly, and change seems the only certainty [5]. The fears during the diagnostic work-up are different from the pain of adapting to its result. The toll of treatments with their significant side effects may be severe. Some refuse further treatment because the drugs are 'too toxic'. Others, who were focused on 'healthy living', feel betrayed by treatment side-effects, even when the treatment is effective. Much as they hate treatment, patients experience paradoxical anxiety when it ends, as they no longer have the security that came with it. This needs to be recognised, normalised and occasionally treated.

During difficult periods of acute illness, emotional reassurance and support may be all that should be attempted. Patients may have to adapt to an unexpected recurrence that forces them to face dark realities they had kept at bay. Or they have to accept the permanent loss of a body part or functions like walking, sexuality, sight, hearing or speech. These are devastating losses with profound grief. Listening, exploring and not offering false comfort is itself a gift which not all provide. Gentle exploring may or may not follow.

Patients are very anxious about the unpredictability of cancer. They repeat, 'If only I knew what was going to happen next! How long do I have? If only someone would tell me what to expect?' Helping the patient cope with uncertainty remains a central challenge, irrespective of the medical information they

receive. Patients struggle with anger at the doctors who tell them truthfully that they don't know what will happen next. Yet they feel stricken when given a prediction about survival. When they exceed that time, they crow with satisfaction and feel triumph over the doctor's inaccuracy – he does not begrudge them that pleasure.

As illness improves, patients may explore family issues or deeply personal problems. Shifting to a more dynamic approach gives patients something meaningful besides cancer to work through and allows them to relate consciously to who they were and how they got that way. This engagement is usually welcomed. The work may be disrupted by the next medical event, but it leaves greater trust between patient and therapist, while the latter has gained a better understanding of the patient's motivation and reactions. The course of many cancers is like a roller coaster, with sudden, severe episodes interrupting tolerably stable periods. Expect the therapy to have similar characteristics.

1.5.6 The Need for the Therapist to Understand the Disease

The initial evaluation must include the diagnosis, staging, prognosis, current therapy and usual side-effects of the treatment. You need this overall view to be able to match it against the patient's awareness of the illness and its seriousness. The patient's own subjective formulation is often very different from what you know to be the reality. Obtain permission to call the primary physician, the oncologist, a prior therapist and anyone who can help you to understand the medical facts that direct the patient's current existence. It is impossible to give valid psychological support if you do not understand the medical reality.

A man, whose self-esteem had been battered all his life, was afraid to make demands by asking questions, out of fear that he might push away the doctors. He presented himself as the ideal patient. The therapist was familiar with his disease and thus able to discuss his fears in concrete and practical ways. This made him feel more accepted and helped his trust of the therapist to develop.

1.5.7 Denial

In response to severe physical illness, patients employ remarkable flexibility in their use of denial, particularly in dealing with prognosis. It functions as a 'cushion' to give them time and space within which to absorb

'bad news'. It allows the development of two levels of co-existent knowledge, one realistic, one wishful. The words of a young woman with advanced colon cancer expressed it well: *'I know I am going to die, but I can't believe I am going to die'*.

Denial ranges from a nearly psychotic reaction to mature coping skills, with all intermediate variants. Distinguishing between pathological denial and affective denial is useful: (i) pathological denial is destructive because it delays consultation, invites poor compliance and embraces risks, all in the service of avoidance and (ii) affective denial can help the patient focus on hopeful options, without interfering with optimal care. Pathological denial is distressing to all, while positive avoidance may interfere with open communication in the family, but creates an atmosphere, that is easier for all, at least temporarily. If denial gets more intense as the disease progresses, it risks depriving the patient of a powerful source of comfort. In general, denial as a coping strategy varies considerably. Inconsistency should not cause surprise, but instead, define an area of fruitful exploration.

1.5.7.1 Ambivalence and Ambiguity

Both of these are often in the service of denial. Sometimes the treating team become frustrated when patients and families have unexpected and radical shifts in their thinking about important issues and decisions. One day they discuss a difficult option; the next, they ignore it. Or they withhold their decisions and keep things unsettled. This commonly relates to prognosis but can also occur when choosing between two equally undesirable treatments or when the needed decisions are too painful to face. It can be the main reason for avoiding medical care altogether. If it does not interfere with a necessary decision, it need not be addressed. But eventually, the reality must be discussed, and many doctors are able to do so in a kind and non-confrontational way.

A single mother had an aggressive, metastatic cervical cancer. She did not allow her daughter, aged 7, to visit because it would upset them both. They had cheery conversations over the phone and she talked to her therapist about 'fighting' so as to get home to her daughter. Yet she had already arranged for her brother, a family man, to be her daughter's guardian, had made financial arrangements and had been sending the child for visits there. Fortunately, the uncle was sensitive and after talking with the psychiatrist, was able to introduce a successful visit

between mother and child. Over time, the topics that would permit a loving farewell were covered.

1.5.8 The First Visit

For many, psychiatric referral adds insult to injury. Patients say 'I don't know why my doctor sent me!' or; 'My sister dragged me here!' Often a therapeutic alliance is created despite the odds, and the patient can acknowledge grief, suffering, fears and relief as they are normalised. If no change occurs, it is best to respect patients' wishes and let them go in a way that will allow them to return when ready with minimal embarrassment. They often get referred again or come back voluntarily.

A 58-year old business man with a recent diagnosis of lung cancer was being evaluated for secondaries before deciding on surgery. He was blunt about his low opinion of therapy and grumbled about his wife's insistence. The therapist commented that he seemed like a man who was not used to being ill and pressured by other people. He agreed. The therapist kept that theme unobtrusively present and he cooperated with a brief review of his current life and a few questions about depressive symptoms, which he denied, and anxiety symptoms, which were more prominent. He remained uninterested in treatment, so the therapist took the initiative and, emphasising his strengths, commented that his anxiety was not only understandable given what he was going through, but even inevitable. Saying that there were good medications for anxiety much more severe than his, she said he did not seem to need them right now, but should feel free to return if things got more difficult. He did return.

1.5.9 'I Am OK, Just Out of Control!'

We are trained to evaluate symptomatic patients according to DSM-IV, but cancer patients may not fit these diagnostic boxes. Some acutely distressed patients are upset at the referral, because they have always been cheerful, happy, resilient and competent; in brief, 'normal'. They feel that cancer is their only ticket of admission to our office, not 'psychiatric problems'. Even if we see issues, we must acknowledge and respond to their self-description. After all, they may be right. They were 'normal'. If we focus on the disrupted self too exclusively, the patient may feel diminished and unheard. We want to build a therapeutic alliance and avoid anger or demoralisation. We emphasise the strengths of the psychological self,

because there can be no reassurance about the physical self. Acknowledging life's accomplishments, both worldly and psychological, can be productive, at the right moment.

The mere suspicion of cancer, and the workup that ensues, generate a sense of loss of control which patients describe accurately as frightening and depersonalising. If the illness gets worse, patients may become depressed or demoralised as they absorb the reality of permanently losing the roles and human functions that defined them most deeply. Acknowledge their grief about losing their pre-illness self-image, because it is in their thoughts every waking moment and probably in their dreams as well. Help them remember the strengths that may still be theirs. This kind of early intervention may avoid the need for medication, because it helps patients hang on to their healthy self and gives them some continuity with 'who I was before', even as they become sicker.

An accomplished woman, always a support to others, presented in a tearful, disorganised state four months after diagnosis of stage II breast cancer. Her reaction was out of character and appalled her. 'I am a totally different person. It's terrifying!' She needed crisis intervention, medication and monitoring of her mood disorder. Only after several weeks did her strengths resurface and she began to cope in more characteristic ways. Throughout her treatment, the therapist recognised how important it was to acknowledge and honour her ability to manage again on her own.

1.5.10 All Patients Need to Tell Their Story

When you ask, it just comes tumbling out! Sometimes the story is about anger, disappointment or mismanagement; sometimes the impact of the illness is so strong that facts get lost along the way. Patients may be tired, agitated or anxious and do not remember events well. It helps if your familiarity with the disease enables you to volunteer information that allows the patient to realise you understand something about his ordeal. Unless there is a compelling reason to obtain other details, let the patient unburden. The story usually reveals interesting emotional information. Collaborative history from family members, with the patients' permission and a signed release for reports from other physicians are important. It reassures the patient that you are a member of his 'team'.

1.5.11 The Body Has a Voice; Listen to It

A patient may be suffering pain, revulsion or heart-break at changes to the body. The therapist must be

able to stay with it, without displaying discomfort or waning involvement. It is not always easy. While we are accustomed to focusing on the psychological aspects of patients' disclosures, we must also focus on the immediacy of the body, its losses, humiliations, embarrassments and exhausting routines that now dominate life. This requires varying degrees of conscious effort for different therapists. Many patients declare that the best support comes from fellow patients, who 'really know' what they are going through. The therapist cannot provide that, but must provide a helpful equivalent.

The opposite may also occur, when the body is initially silent. The diagnosis is made accidentally, and the patient never feels ill until treatment ushers in significant side effects. For such a patient, the diagnosis can bring unreality and bewilderment. He may be angry and develop a resentful attitude, or even a paranoid tinge. It is useful to normalise it by bringing it out in the open. If not, it may persist into the later phases of the disease, when the cancer is all too evident and anguish becomes high. Angst and anger will combine and be projected even more negatively, usually onto the medical caregivers, but also onto relatives in dysfunctional families.

Some patients go through treatment with minimal interference with normal life. Not all treatments are equally rigorous and not all patients are equally resilient. It is important to be aware of what your patient is going through. Some patients are proud and/or relieved to have gone through treatment without missing work. But they do feel fatigued and require rest. Others never return to work again, and it is not always obvious why from their physical state. If the outlook is not bleak, it is worth exploring why.

1.6 Boundaries in the Therapy Relationship: Therapeutic Activism

Much of what is taught about the boundaries of the therapeutic encounter with physically healthy patients must be modified when working with the medically ill [5]. Touching, usually taboo, becomes acceptable as a hug or a pat on the arm for encouragement. As a psychosocial-oncologist, you are more participatory as a fellow human being, but must always be conscious of valid therapeutic reasons for all your actions, and alert to patients who need the security of physical distance.

Hospital consultations make short work of standard guidelines. The ill patient can be positioned uncomfortably, unable to move or pull blankets higher. He may be thirsty and can't reach the glass, lost the call bell or

dropped the phone. Ignoring these obvious facts limits the effectiveness of any contact. The therapist must feel comfortable helping out with small problems that respect the patient's privacy and do not replace nursing care. Pulling up blankets, altering the bed controls to make it more comfortable, moving the glass and replacing the call bell can be viewed as the opening conversation. Ignoring those needs, while interviewing, is like neglecting verbal messages. The patient's body has betrayed him, and has been assaulted by rigorous treatments. The therapist must welcome any discussion of distortions in body image or sense of self, so as to encourage verbalisation of thoughts and feelings. This may extend to questions about physical details that may be upsetting. Every mental health professional should be attentive to an ill patient. But in psycho-oncology, it is part of the therapeutic duty. Ignoring the body sends the wrong message, one the patient dreads to hear, because in his own life, it happens all too often, and painfully isolates him from the healthy world.

When a patient is weak, in pain or in a wheelchair, attention to promoting comfort should not depend on being invited. The therapist must remain actively interested in the patient's medical course throughout. She will be committed to careful surveillance of the patient's overall state, the extent of compliance with treatment and the judgement used in seeking extra care when needed.

1.7 Themes Met in Advanced Cancer

Legacy, guilt, fear of dying, spirituality, transition to palliative care and end-of-life themes are grist for the mill in supportive therapy with patients with advanced cancer.

1.7.1 Family Legacies

These can find expression through the meaning of both the cancer and the illness.

1. **The meaning of cancer:** Despite many commonalities, having cancer means something different to each individual. It is essential to understand this fully, including aspects that may be unconscious. The loss of parents, other family members or a close friend to cancer all have a bearing on how the patient experiences the illness. Difficult memories become haunting and may need to be aired and discussed. Often they are decades old and seem writ in stone. But they belong to another age and the patient must be helped to confront

the difference between themselves then and now, and the treatment between then and now. It may address unfinished business, re-awakened grief, frightening memories of illness in the family, guilt around imagined misdeeds and usually, unrelieved, lonely suffering and helplessness never shared with a supportive adult. Thus, exploring a patient's associations with cancer is quite revealing. When not volunteered, it is elicited through a detailed family history, preferably using a genogram that includes grandparents and asks about good friends as well.

2. **The meaning of illness:** Being ill is somewhat different. It can be part of the family culture, or even more, the family of origin. It may never have been explicitly stated, but has been absorbed nonetheless and has strong ethnic variations. In some families, one does not complain and is as independent as possible. Any neediness is suspect, unless its causes are blatant. For others, illness itself carries a covert message of ill-doing or retribution. Some family members are illness-phobic and want to minimise it at any cost; others are too frightened to help. In such families, severe illness can be catastrophic. Sometimes one sees a role reversal with the patient providing comfort to distraught family members. In other families, being ill is a favoured status. The patient receives a freely offered cornucopia of extra care and attention, sometimes too much, if it interferes with the level of desired independence. But it is usually welcome. Fortunately, there are many families where there is a loving and competent caregiver, fewer where support from others prevents caregiver exhaustion. An awareness of the stresses and the price paid by primary caregivers is required to enable the therapist to ease their burden.

Discussion of these issues helps the therapist understand more, and helps the patient gain insight into his formative experiences. Most find these explorations interesting and feel a sense of release after discussing them. As the disease progresses, activities drop away and old interests no longer have the same traction, at which point this new self-understanding becomes even more important as it gives life greater coherence and meaning.

1.7.2 Guilt

Guilt is a common issue. Many feel they are being punished for previous misdeeds which they identify with unjustified certainty. This is not truly guilt, but

attribution as to cause. They can feel guilty about what they are doing to their family, leaving them to fend for themselves and causing grief and disruption. In turn, the families may contribute through blunt accusation about causality, or by nagging about self-care and having the 'right attitude to beat the cancer'. For other than heavy smokers, 'blaming the victim' is generally toxic and unjustified. (Not helpful to the lung cancer patient either.) Most other toxic exposures were not in the patient's control, although diet is being identified as causal for some. Human beings are well versed in the art of making themselves and others feel responsible for uncontrollable negative events.

Guilt is important in diagnosing major depression. The physically ill, depressed patient may not always display overt depression or active suicidality and the usual physical symptoms of depression are attributed to the cancer. Depressed patients are typically guilty, convinced they are not really worth saving, will not be saved and have lost agency over their life. This state of mind is accompanied by loss of interest in the things they once enjoyed, constricted affect, poor eye contact, personal neglect and imperviousness to outside input [6]. Such a patient needs referral for medication, as do patients with severe anxiety and panic attacks or confusional states [4–6].

1.7.3 Fear of Death

The thought of death barrels instantly into the mind of all newly diagnosed patients unless the tumour is so curable that the patient believes the physician's reassurances. Even then, the word 'cancer' is enough to bring fear into people's minds, sometimes overwhelming all else. For some, it is not fear of death but of dying, for which it is easier to offer some reassurance. But some patients are terrified at the prospect of being dead, which is much harder to explore. It may be related to some personal history, but often it is very primitive, and not readily available. It is not age related, since many children and adolescents face death with impressive courage, but it is a fear with deep and early roots. It is asking a lot to expect the patient to manage this amidst the insults and injuries of the disease. Discussing it repeatedly in a calm and secure setting can begin to make it a little easier. A life review with an emphasis on the underlying meanings that made it what it is, and some psychodynamic observations that highlight the unity of the narrative, can bring the patient to feeling better about what he has done and who he has been, thus capturing some of his attention. Medication for anxiety is usually beneficial,

but does not obviate the role of human conversation. The presence of a loving family or other valued friends lowers much anxiety. Relaxation techniques can bring momentary relief.

Some patients have an excellent prognosis, have already been discharged and yet are convinced they are going to die. This usually relates to the pre-morbid personality and is best treated outside a cancer centre or clinic.

1.7.4 Spirituality and Religion in Supportive Therapy

The need for cultural and religious sensitivity is well recognised. But in fatal illnesses, they play a very intense role. Patients with strong religious or spiritual beliefs will adapt to the illness and their death within these constructs. They may have a religious counsellor who will help maximise support and access to community resources. Clearly, the therapist supports the patient's prior beliefs. It is important not to impose one's own meanings and perceptions about existential issues. Obviously there is no place for proselytising.

For patients without such pre-existing resources, a number of relaxation and breathing techniques can relieve anxiety, while guided imagery can get the patient in touch with the inner self. Use conversations in which the patient describes the most meaningful, happy or peaceful moments or scenes in his life, and offer to make a tape based on that information and enriched by constructive and realistic elaboration. Patients often use them repeatedly. For people who do not locate transcendent feelings in a particular practice, moments of intense, facilitated introspection may bring them a different kind of peace.

1.7.5 Transition to Palliative Care

Ideally, the transition from curative to palliative care should be introduced early. Late transitions are psychologically more difficult, especially if the patient and/or family are shocked by the news. Therapists can alert oncologists to what patients/family are thinking about end-of-life concerns. They can help patients and families explore further, in a hypothetical mode: 'What would you do if...?' Existential issues come to the fore and the therapist is well positioned to discuss them with the family, and suggest a meeting with the medical staff. This speaks yet again to the necessity of being known and trusted by the staff.

1.7.6 *End-of-Life*

As death becomes a fully acknowledged outcome, education is needed about what to expect, what dying may be like, and most of all, what can be done to insure comfort for the patient and support for the family. Therapists can help the patient and family process medical information that was emotionally so loaded that it was misheard, altered by wishful thinking or forgotten. It is impossible to exaggerate the family's need for explanations about what is happening, what it means and what may come next.

Honest communication is critical at this time. The therapist can help the patient address unfinished business and support better communication about dying and saying goodbye. It is moving to see a family that is open about what is happening and hence surround the patient with warmth and love until the end. A patient who has been 'protected' from the truth, or, even more ironically, knows the truth, but has received the unspoken message that he cannot talk about it, dies alone no matter how many people are in the room. Therapists should try to minimise this. If the patient is dying at home, a therapist visit will be very meaningful. Being a welcome presence at such a profound moment is a privilege. Attending a funeral or a memorial is a personal choice, depending on one's need to honour the patient's memory, support the family and assist closure for one's self. Recognising this personal involvement is important. Not infrequently, the caregiver will seek bereavement therapy since the therapist is already known and trusted.

1.7.6.1 *Controversies*

Unfortunately, many difficult choices may arise in the final days [7], including decisions about what treatments to have or not have, whether to start protocols, when to stop nutrition and hydration. Family members may insist on useless, inappropriate care and become threatening about it. At such times, therapists can support the staff. Some patients want to select the time of their death and want staff help in achieving it, which is illegal in most venues. Such requests must be handled sensitively with advice about legal options, such as stopping treatments, nutrition and hydration. The proxy may be in a difficult position if the family is not united and should receive therapist attention. The best stance is to remain constant in support.

The completion of advanced directives is becoming more common and greatly facilitates clarity over the patient's wishes. Therapists do well to encourage completion of these when issues like completion of wills,

estate planning and appointment of health proxies are being considered.

1.8 Families as Part of Patients' Supportive Psychotherapy

1.8.1 *What Is a Family?*

For our purposes, a family is the collection of individuals recognised by the patient as an important part of their life and who are themselves very attached and emotionally impacted. We are not here to define it for them.

1.8.2 *Healthy Families*

Many patients show remarkable fortitude, courage and generosity while their families are loyal, loving and stay the course. They are realistic, show initiative in organising care, look after each other, discuss painful truths openly, take care of unfinished business and cherish their time together. But there are different profiles of strength and vulnerability in all families. Family members often cope differently and use different strategies that conflict with each other. Therapists must evaluate these differences and develop a plan to manage them that troubles the patient as little as possible.

1.8.3 *Patients without Social Support*

For patients who have no family or loyal friends, the course is infinitely more difficult. The therapist often becomes a crucial resource and must take on a heavier burden of fidelity than with more embedded patients. Finding support groups, calling in religious and community sources if appropriate and identifying community volunteers, becomes very important.

1.8.4 *Patient's Need for and Reaction to Family Involvement*

Dealing with the patient's family is not a choice, but a necessity. Relational concerns must be appraised and discussed. A surprisingly large number of patients request psychotherapy, not for their cancer, but for family or relationship concerns. Some of their issues are completely unrelated to the cancer, others were precipitated by it, but are not integrally related to it. Even patients, who initially focus on the disease, will sometimes in the first or second session move into a pre-existing personal problem. As the disease progresses, it eventually displaces these private

concerns, yet even stage III or IV patients will still focus on the personal problem.

A 76-year old school principal came for therapy during chemotherapy for locally invasive colon cancer. But she only wanted to discuss her profound guilt about the way she neglected her other children when her eldest daughter had died of Ewing's sarcoma at age 6, almost 45 years ago. She quickly bore a 'replacement child' and believed he must have been damaged too. She felt responsible for all their problems but had no other symptoms of depression. We reviewed the customs around handling childhood cancer at the time, as well as aspects of her childhood and adolescence that made her over-responsible and guilt-prone. One day, she announced that she could see her children were doing well and did not bear grievances and she terminated therapy.

A patient may initially be too stunned with his own fear and grief, and too consumed by his illness to process what is going on in the family, especially if there is a 'conspiracy of silence' meant to spare him. But quickly enough, the family attitudes intrude and generate varied feelings in the patient, ranging from gratitude, guilt and worry, to disappointment, resentment at lack of engagement or a deep yearning for signs of love, understanding and reassurance. These powerful feelings need to be explored.

A 58-year old man had stage IV renal cell cancer and depression, which responded fairly well to medication, but he continued to be unhappy and disaffected because he felt uncared for by his wife and teenage children. When his cancer took a turn for the worse, his family changed suddenly, with all of them showing affection, engagement and grief. He then became much more active and energetic, explored experimental options and went to another hospital for another protocol, while remaining in touch with the therapist.

1.8.5 The Family's Need for Involvement

1. **Emotional stressors:** Cancer is a family crisis. With a more serious diagnosis, family members react strongly. Some are grief stricken and jump to the worst conclusion; others are reassuring, present and supportive. They cry a lot, explore other treatments and often get contradictory advice. Finding out about a bad prognosis at the computer is a lonely way to learn about it. Guide the family to select a trusted person to do the online searches, if they are inevitable.

Losing one member to cancer and another to caregiving requires extensive reorganisation and cooperation from the remaining family members to fill the void and keep going. Many times, it cannot be done. There are many small, isolated families for whom the demands are overwhelming and the social safety net inadequate. It is crucial to search for outside support of any kind for them.

2. **Primary caregiver:** Usually one person takes on, by choice or by adjudication, the role of primary caregiver. They are at risk for anxiety, depression, neglect of their own health and a permanent downward mobility, yet moments of transcendence can give them joy and meaning. Many patients are very difficult, in which case the caregiver needs more support. Caring for the primary caregiver, or referring her for her own treatment, should always be on the therapist's radar [8].
3. **Environmental stressors:** In countries lacking socialised medicine, the financial stresses are severe and inevitable. Families can easily spend all their savings. Many bankruptcies are not due to profligate spending, but to medical expenses assumed out of devotion. This might be an issue to explore with the proxy or caregiver. There are many secondary losses, such as the loss of the patient's income, the caregiver's loss of work or shift to lower pay so as to accommodate more time off. Adolescents may stop college for financial reasons, but also because they are being parentified. Young children are shunted aside 'for their protection' and develop guilt-ridden fantasies to explain their exile. The therapist should address parenting issues early. Families always welcome reliable advice about how to manage children in dire situations and discussions of other issues will usually follow [9].

The family rallies during the acute periods, but attention wanes during remissions or lengthy, stable treatments. Devotion fatigue and variably controlled resentments may be expressed. If mild or episodic, they can be managed, but they can easily disrupt the fragile equilibrium. The therapist can discuss the siblings' simultaneous jealousy and guilt about the patient, help the parents understand and re-integrate the farmed-out children, work with a couple that is drifting apart and help them develop better communication, encourage the adolescent's continued education and support the family in seeking and accepting outside help. Highly stressed family become isolated and withdrawn and may neglect local resources. Most of

these events become known to the patient who may be very anxious about them.

1.8.6 Family Bereavement

The death of a loved one can be a profound loss but also a major trauma. Therapists have a responsibility to try to minimise traumatic outcomes from the circumstances of the death. Some terminal events such as acute bleeds or unhelpful customs like giving the proxy full responsibility for ‘pulling the plug’ despite complicated relationships in the family that lead to significant distress, anger or guilt, cannot be erased. Sometimes one of the health care team is unthinkingly brusque and offends the family that has little tolerance at this time. In fact, family members are easily oversensitive to any behaviour they construe, or misconstrue, as heartless and uncaring. The worst of all is when they feel the patient’s suffering has not been well treated. On the other hand, a sensitive physician, nurse or therapist will be long remembered with deep gratitude. Either way, these actions are deeply imprinted in the family’s memory bank, whether accurately interpreted or not.

A patient’s widow, who had had a good experience with the staff, and had good relationships with her children and friends in her community, came eight years later to speak to a group of oncology fellows about her experience with the death of her husband. Her first words were: ‘It is still in my mind as if it happened yesterday. It was his decision to disconnect the respirator. It was his decision alone. He did it’.

The last days of any patient’s life deserve the utmost attention, support and respect. This effort will bring comfort to the survivors instead of painful memories that rankle for the rest of their days, especially because they often embrace unjustified or unconscious guilty feelings for having ‘failed’ to prevent them.

The therapist can be helpful at defusing the impact of the events, but more importantly, should be available for bereavement therapy after the death. It is important to send a letter to the family, which confirms for them your understanding and concern for the patient and family. A phone call is good but does not carry the weight of a letter that families will cherish long after.

1.8.7 Working with Patient and Family: It’s about Communication!

Families that communicate well manage better after the death. Communication is an essential factor in family

adaptation, even when members differ with regards to other variables. The therapist must be attuned to family members’ coping and strengths, be ready to refer those in need and give special support to the caregiver and proxy, both in formal sessions or more casual meetings. The therapist needs to identify unspoken painful issues that have a bearing on the present and gently bring them out into the open. These can involve reactions to the illness and things too difficult to talk about, especially dying. But it can also be an inability to plan for the future, unresolved conflicts and an avoidance of sharing real feelings and grief. When a family fails to communicate openly, the patient will die more alone and family members will feel more isolated from one another. There will have been no goodbyes, no asking for forgiveness, no shared planning and no shared memories. For families with cohesiveness and an ability to manage conflict, opening communications may not be too difficult; indeed it is very powerful in its ability to promote changes. See Chapter 14 on Family therapy for further discussion.

1.9 Therapist Issues

Working almost exclusively with cancer patients is not easy. Many professionals cannot imagine doing it, and as a result, psycho-oncologists are a highly self-selected group. This does not diminish the need to monitor ourselves. Keep in mind the limits of what we can do and keep a good perspective on what we can’t do along with a healthy sense of humour. Among ourselves, ‘gallows humour’ certainly has a place in helping us cope, but nowhere else. Awareness of our counter-transference reactions is necessary given the exposure to wrenching human tragedies and death, the latter always hovering in the thoughts of both patient and therapist. This makes self-examination all the more important.

1.9.1 When the Therapist Is a Cancer Survivor

A number of cancer survivors wish to help patients going through the same ordeals they faced. They must have developed a stable adaption to their disease, and be immune to being hijacked by bursts of emotional memory. They must have the discipline to stay focused on the patient’s story despite their own dramatic experience. In truth, they do have special knowledge, but, as with other boundary crossings, they must only share what they clearly know will benefit the patient.

1.9.2 Role of Medications

Psychotropic medications can and must complement supportive therapy when patients need treatment of depression, anxiety or confusion. Refer these patients promptly [10].

1.10 Service Development Issues

Both identifying services and both building and sustaining skills are key issues.

1.10.1 Use of Referrals

Most cities today have cancer support groups, including telephone and online ones. Chat rooms and bulletin boards provide unsupervised support from others sharing the same experience. They bring both excellent and unhelpful support. Large advocacy groups such as Gilda's Club, Wellness Community and Cancer Care have online and 'buddy' systems which are reliable. They also offer a large variety of other helpful on-site activities. The American Psychosocial Oncology Society has a helpline to assist patients in finding a counselor with knowledge of cancer (1-866-APOS-4-HELP). Some well-developed, focused group approaches are described in other chapters.

Supportive therapy supports patients, it does not bind them. Realistic improvement is celebrated, safe exploration is encouraged and interruptions are appropriate. We cannot 'fix' all our patients' problems. Referral for complementary therapies, like art, music, meditation and yoga is helpful for patients who find 'talk' therapy difficult. There are limits to what our interventions can do and times when referral to someone else is the best option. The patients usually experience it as taking care of them.

1.10.2 The Psycho-Oncologist

Last but not least, we all need to review our life, especially our losses and must try to understand our motivation for doing this work. Many of us, not all, come because of personal losses or ordeals. They need not disqualify us, but we must be aware of them and how they might affect us. It is usually a satisfying awareness that solidifies our motivation and helps us understand ourselves. We need to recognise when a patient is touching us more deeply than others and put ourselves on alert about over-involvement or over-identification that will warp our judgement. We must also think about patients whom we dislike or who

make us angry. This is the usual counter transference work, except it is in a context which is skewed by illness, suffering, injustice and death. This is not a trivial difference. The same examination is appropriate for caregivers and family members [11].

We must learn to be involved enough to be authentic with patients, but not so involved that we let them invade our personal life more than rarely. Whenever it happens, we must pay attention and talk to a colleague, a mentor or a professional until it abates. We must give young therapists a lot of support because we have been there. If working in isolation, seek out peers, even if only by email, get on professional list-serves. Stay connected to them, do peer supervision if it is feasible, attend meetings and enjoy socialising as much as learning. Join a national psycho-oncology organisation or become part of the International Psycho-Oncology Society (IPOS) (www.ipos-society.org).

Recommended Reading & Resources

- American Psychosocial Oncology Society (2006) in *Quick Reference for Oncology Clinicians: The Psychiatric and Psychological Dimensions of Cancer Symptom Management* (eds J.C. Holland, D.B. Greenberg and M.K. Hughes), IPOS Press, Charlottesville, VA.
- A small basic handbook with handy tables, written for non-psychiatric physicians, but useful for everyone.
- Holland, J.C., Breitbart, W.S., Jacobsen, P.B. *et al.* (2010) *Psycho-Oncology*, 2nd edn, Oxford University Press, New York.
- A new edition of an exhaustive text, with clearly laid out sections and chapters that cover many topics.
- Kissane, D.W. and Bloch, S. (2002) *Family Focused Grief Therapy*, Open University Press, Buckingham, PA.
- A clear and detailed book which explains and manualises a powerful method of family therapy around the death of the patient. But it also teaches a great deal about family therapy at any time.
- Rauch, P.K. and Muriel, A.C. (2005) *Raising an Emotionally Healthy Child When a Parent is Sick*, McGraw-Hill, New York.
- The welfare of children in families of cancer patients is rarely optimally sustained without input from therapists or other knowledgeable health professionals. It can seem counter-intuitive and deserves some attention.
- Sourkes, B.M. (1982) *The Deepening Shade: Psychological Aspects of Life-Threatening Illness*, University of Pittsburgh Press, Pittsburgh, PA.
- A short and elegant classic that discusses both therapy and the needs of the therapist. As good now as when it first came out.
- Wise, M.G. and Rundell, J.R. (eds) (2005) *Clinical Manual of Psychosomatic Medicine: A Guide to Consultation-Liaison Psychiatry*, American Psychiatric Publishing, Inc., Washington, DC.

A short, well organised and readable manual that covers other diseases as well as cancer. Will be useful to therapists with a less specialised practice.

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3. Alliance for Quality Psychosocial Care <http://www.cfah.org/activities/alliance/cfm>, Access, 2010.
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5. Lederberg, M.S. (2010) Negotiating the interface of psycho-oncology and ethics, in *Psycho-Oncology*, 2nd edn (eds Holland, J.C., Breitbart, W.S., Jacobsen, P.B. *et al.*), Oxford University Press, Oxford, NY, pp. 625–629.
6. Miller, K. and Massie, M.J. (2010) Depressive disorders, in *Psycho-oncology*, 2nd edn (eds Holland, J.C., Breitbart, W.S., Jacobsen, P.B. *et al.*), Oxford University Press, Oxford, NY, pp. 311–318.
7. Lederberg, M.S. (2009) End of life and palliative care, in *Comprehensive Textbook of Psychiatry* (eds B.N. Sadock and V.A. Sadock), 9th edn, Lippincott Williams & Wilkins, Philadelphia, pp. 2353–2378.
8. Northhouse, L.L. and McCorkle, R. (2010) Spouse caregivers of cancer patients, in *Psycho-Oncology* (eds Holland, J.C., Breitbart, W.S., Jacobsen, P.B. *et al.*) 2nd edn, Oxford University Press, Oxford, NY, pp. 516–521.
9. Moore, C.W. and Rauch, P.K. (2010) Addressing the needs of children when a parent has cancer, in *Psycho-oncology*, 2nd edn (eds J. Holland *et al.*), Oxford University Press, Oxford, NY, pp. 527–531.
10. Holland, J.C., Breitbart, W.S., Jacobsen, P.B. *et al.* (2010) *Psycho-Oncology*, 2nd edn, Oxford University Press, New York.
11. Sourkes B.M. (1982) *The Deepening Shade: Psychological Aspects of Life-Threatening Illness*, University of Pittsburgh Press, Pittsburgh.