Addressing the information needs of patients with prostate cancer: A literature review

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Abstract

Psychosocial support is a cornerstone in the holistic care of cancer patients. The provision of information is a key tool in the psychosocial management of the cancer patient, and it is important that the therapy radiographer is cognizant of the patient's need for information.

This article reviews the importance of information to the psychosocial well-being of cancer patients in general, with specific emphasis on patients with prostate cancer. The information services at a large Canadian cancer facility are also reviewed to gain some insight into how the needs of patients with prostate cancer are addressed at the author's workplace.

Most patients with prostate cancer have an expressed need for considerable amounts of information at various stages of their cancer journey. The provision of information has a range of benefits to the prostate patient such as helping the patient deal with their diagnosis, assisting with the decision-making process and reducing anxiety.

Interpersonal sources of information such as face-to-face communication with the oncologist or radiation therapist are preferred by many patients, including patients with prostate cancer. Other sources that include the internet and written hospital material are also used with varying degrees of effectiveness to deliver information.

The provision of quality information in a timely and effective manner cannot be taken for granted. Access to appropriate information resources can be impeded because of poorly designed information material, inadequate communication, ineffective signposting, resource constraints and lack of knowledge/comprehension on the part of frontline health-care workers dealing with the patient. Radiation therapists are encouraged to be advocates for their patients' information needs and to be involved in initiatives that will improve the quality, dissemination and efficacy of information.

Keywords

Psychosocial support; information needs; prostate cancer

BACKGROUND

The need for psychosocial intervention at all stages of the cancer journey has been well recognized within the oncology community.1–3 The
term psychosocial care is generally used in reference to the patient’s physical, psychological and interpersonal challenges\(^4\) and how these are interrelated to health and illness. The term ‘psycho-social oncology’ or ‘psycho-oncology’ is used specifically for cancer patients with the implication that cancer affects family members, friends and society in addition to the individual patient.\(^1\)

The impetus to recognize and integrate psychosocial interventions at all levels of cancer care has come from a multitude of stakeholders. These advocates for psychosocial oncology include cancer patient organizations,\(^5\) voluntary/charity organizations,\(^6,7\) professional associations\(^8\) and government bodies who have developed national guidelines on psychosocial care of the cancer patient.\(^9,10\) This apparent unquestioned acceptance of the efficacy of psychosocial oncology does however detract from the fact that the concept is relatively new. In his review of the history of psycho-oncology, Holland\(^11\) points out that the formal beginnings of this subspecialty of oncology began in the mid-1970s. He argues that the ‘double stigma’ of a cancer diagnosis and the long-held stigma attached to mental illness have in some ways acted as a barrier to cancer patients acknowledging their psychological needs.\(^12\)

A significant proportion of patients can expect to suffer some degree of psychological, social and emotional distress at any point in the disease trajectory.\(^2\) A range of psychosocial issues has been identified including: depression, anxiety, shock, disbelief, confusion, isolation, spiritual crisis and financial problems.\(^1,13\) Strategies such as guided imagery, cognitive-behavioural therapy, group and individual therapy, informational and educational interventions have been suggested as beneficial psychological interventions for cancer patients.\(^3\) A four-tier model of psychological intervention has been proposed by the UK’s NHS.\(^9\) General psychological support, compassionate communication, information giving and problem solving are the responsibility of health- and social-care professionals who deal directly with the cancer patient. At the higher levels of psychological intervention, psychological specialists deal with more serious psychological distress. Clinical practice guidelines on the psychosocial care of cancer patients explain the rationale and benefits of this essential service. In her article reviewing the international development of psychosocial guidelines for cancer patients, Turner\(^14\) observes that these guidelines provide a description of the psychosocial issues patients face, along with supporting evidence of the benefits of specific psychosocial interventions.

The information needs of the cancer patient have been highlighted in a number of health policy documents and reports.\(^6,9,15\) Information allows patients and their families to cope with their disease and to make decisions about their treatment options.\(^16\) In addition, information can improve compliance, reduce anxiety, enhance sense of control, increase preparedness for events and increase satisfaction with treatment.\(^9\)

Although the provision of information is a key tool in the psychosocial management of the cancer patient, it is evident that patients’ information needs are not consistently met.\(^7,9\) It is also important to remember that patients are individuals and can therefore expect to have a range of information needs and sources across the cancer care continuum.\(^17\)

There is some evidence to suggest that the information needs of male patients are poorly addressed.\(^9,18\) It has been argued that the psychosocial issues of patients with prostate cancer have been somewhat neglected\(^19\) and indeed some consumer rights groups are drawing attention to the disparity between prostate and breast cancer resource allocation.\(^20\) Prostate cancer is recognized as the leading cancer affecting males in North America\(^21\) and diagnosed patients face very specific challenges because of uncertainties regarding optimum treatment and quality-of-life issues such as impotency and incontinence.\(^18\)

The prevalence of prostate cancer and the possibility that barriers exist to the provision of appropriate psychosocial care indicate that investigation is warranted. In particular, the information needs of prostate patients and their families are of key importance.
THE ROLE OF INFORMATION IN PSYCHOSOCIAL ONCOLOGY

The provision of information to all cancer patients is central to quality psychosocial care and is often included as a key recommendation in official guideline documents. A study by the Canadian Cancer Society dealing with cancer patient needs highlights the obvious importance and benefits of information to the patient and their carers. Access to clear and unbiased information helps with the emotional, psychosocial and physical needs of the patient and leads to increased compliance with treatment, increased satisfaction, a sense of control, and improved relationship with the health provider. The UK’s NICE guidelines on supportive and palliative care support many of the findings from the cancerBACUP report, but in addition conclude that improvement in knowledge and understanding, increased preparation for events and reduced anxiety result from the delivery of quality information.

More specific benefits of information to the cancer patient can be gleaned from the literature. Mallinger et al. analyzed the results of 182 questionnaires from patients with breast cancer and concluded that patients who are satisfied with information experience better psychosocial outcomes, including less anxiety, fewer depressive symptoms and less mood disturbance. According to Van der Molen, information can be viewed as a form of cognitive control that allows the individual to participate actively in the decision-making process. Information not only helps with the management of the physical effects of illness and treatment, but it also assists patients with feelings of vulnerability, instils a sense of control and helps overcome confusion that results from a cancer diagnosis.

The information needs of patients with prostate cancer are unique as this group of patients is faced with many challenges about the appropriate treatment management. The controversy that surrounds the management of prostate cancer only adds to the confusion and frustration faced by patients and their carers. It is however recognized that the provision of complete and unbiased information to prostate patients can increase the sense of trust between the patient and physician and can reduce the decisional conflict for the patient.

THE CANCER PATIENT’S INFORMATION NEEDS

Rees and Bath completed a comprehensive review of the literature over a 10-year period to examine the information needs and source preferences of patients with breast cancer and their family members. A number of key conclusions were possible after reviewing the large body of research articles. The information needs of patients with breast cancer are not static and tend to change over time. At the diagnosis stage the main needs centre around information about the likelihood of cure, stage of the disease and treatment options. Information about treatment, tests and the chances of recurrence become important as the patient commences treatment regimens. As the patients move into the remission and recovery stage they continue to seek information about cure, but they also have more questions about risks to other family members and self-care behaviours. Other systemic reviews of the literature on patient information needs also point to changing needs throughout the treatment continuum.

Although the studies clearly show that there is variability in information categories, it is still possible to establish key information requirements at specific disease junctures. Information needs about stage of disease, treatment options and side effects seemed more prominent during the diagnosis/treatment stage, while patients continued to seek information about treatment and recovery at the post-treatment stage.

A survey of mainly breast and prostate radiation therapy patients found that most patients wanted as much information as possible. The most common information requirement for all patients was information about treatment, prognosis and recovery. The patients’ appetite for substantial amounts of information is supported by other large- and medium-sized studies. The vast majority of patients sampled want as much information as possible, both good and bad. The patients also demonstrated a strong...
need for detailed and specific information about different aspects of their disease and treatment.

In an attempt to discover whether there is a gender difference between the information and support requests of cancer patients, Boudioni et al. studied the information and support needs of male prostate and colorectal patients versus female colorectal patients. The study results indicate that requests about site-specific information, emotional support, publications and specific therapies were similar for male and female cancer patients. The authors were unable to identify a single pattern of information and support seeking for male patients, but did conclude that the patterns are complex. The different treatments and research activities associated with prostate and colorectal cancer may explain why this particular study failed to associate a unique pattern of information seeking behaviour with male patients. The fact that the information needs of male and female patients were not dis-similar is somewhat reassuring as it might suggest that some of the more generic cancer information satisfies the needs of both groups.

**INFORMATION NEEDS OF THE PROSTATE CANCER PATIENT**

The information, support and care delivery needs of patients with prostate cancer have been analyzed by Boberg et al. and the provision of information has been identified as the greatest need for improvement. Patients ranked information as the most important need that remained largely unmet, especially the need for information on side effects of the disease and its treatment, and on issues related to recurrence. A review of published articles that addressed the information needs of patients with prostate cancer and/or their partners allowed the authors to arrive at a number of conclusions about this group. Before treatment, the patient and/or his partner require substantial information specifically about cure rates, stage of the disease and treatment options. At the treatment phase, the patient needs specific information about the treatment modality and at the completion of treatment the patient generally requires information about side effects and probabilities of recurrence. It is also noted that the type and amount of information required can vary considerably between individuals. Wong et al. found similar information needs about disease, treatment and survival among Canadian patients with prostate cancer. More specific differences in information needs and preferences are noted because of psychological functioning. Patients with lower mood prefer more specific information about psychological support, whereas more optimistic men tended to want more detailed information about treatments, side effects, etc.

Patients with prostate and their wives are likely to agree on the type of information that is important to them as a couple, although they may have different views on how this information is best delivered. Prostate-surviving couples require information on how to manage their relationship after treatment and are receptive to receiving information from couples who have survived prostate cancer. While women showed a preference for focus groups, men tended to prefer written material such as a guidebook or manual with a checklist of things to expect.

It has been recognized that out of all the potential psychosocial issues facing cancer patients, questions about sexuality are probably the most difficult to address. The higher potential for impotency in prostate patients treated with surgery or radiation therapy suggests that these patients are likely to have psychosexual type questions and can expect to have an expressed need for psychosexual intervention. The need for physicians to offer information about erectile function before and after treatment is considered paramount. Most patients want more information on the effect of treatment on sexual function and on available treatments for erectile dysfunction.

The literature seems to indicate some degree of consensus on what type of information prostate patients deem important. However, the same level of agreement may not be true for those professionals who are involved in the direct care of the patient. In a study designed to find out what questions health-care professionals
believe to be important to patients with early stage prostate cancer, Feldman-Stewart et al.\(^4\) surveyed oncologists, nurses, urologists and radiation therapists from nine regional cancer centres in Ontario, Canada. She found relative agreement on what questions were considered essential to the patient between the professions, but also observed little agreement on the relative importance of questions within the four professional groups. A similar type of study from Italy again showed that although there can be agreement between professionals on what questions are essential to patients with prostate cancer, there is a corresponding disagreement within the same professional group.\(^4\) A significant benefit of this Italian study is that the authors compared the views of the healthcare professionals with the patients and when compared to doctors and nurses, radiation therapists showed the highest level of relative agreement with patients about their essential information needs.

SOURCES AND PREFERENCES OF INFORMATION

A study of cancer patients and caregivers needs in Ontario, Canada, found that despite the plethora of information available to patients and caregivers, many experience problems accessing specific information or knowing which sources to trust.\(^6\) This report provided valuable suggestions from consumers about how to disseminate information, but few clues on preferred information sources used by patients and their caregivers. The NICE guidelines on psychosocial care of cancer patients\(^9\) offer more specific direction on the possible information sources for cancer patients. Obvious sources such as patient leaflets, face-to-face communication, support groups, help lines and cancer-specific textbooks are suggested. Information can also be made available using audiotapes, videocassettes, CD-ROMs, DVDs and internet websites.

Sources of information can be divided into interpersonal and mass media sources.\(^4\) Family/friends, voluntary organizations, support groups and health-care professionals can be considered interpersonal sources of information. Mass media sources include books, magazines/newspapers, TV/Radio, the internet and written hospital information. Mills and Davidson\(^14\) completed a large study of oncology outpatients that convincingly showed that, out of 19 commonly available sources of information, the hospital consultant was the most frequently used source of information. The general practitioner (GP), chemotherapy/radiation therapy staff and ward staff were the next most likely source of information. This preference for interpersonal sources of information among oncology patients is supported by other studies.\(^4\) It is perhaps not surprising that verbal communication is preferred by radiation therapy patients at the pre-treatment stage while written material is generally more acceptable at later stages in the treatment journey.

As we have previously seen, the information needs and sources of information can vary depending on what stage of the cancer journey the patient happens to be at. The hospital consultant was found to be the most likely source of information for patients with breast cancer at the time of diagnosis, followed by the breast care nurse and information leaflets. To a lesser extent GPs, nurses in the clinics, family/friends and magazines were considered sources of information. At the follow-up period, there was a shift in the prominence of certain information sources. Hospital consultants, TV/radio and women’s magazines were equally favoured by slightly more than 40% of the women. Relatively few of the women were receiving their post-treatment information from professional sources, despite the fact that several had expressed a need for more professional information at the follow-up stage. The finding that the post-treatment information needs of breast cancer patient are not being adequately met has been somewhat validated by similar studies.\(^48\) The breast care physician was overwhelmingly regarded as an excellent source of information, while the primary care physician who normally provides the majority of follow-up care was rated as a poor information source. This apparent disparity in the provision of quality information at the pre-and post-treatment stage seems to endorse the importance of consistent quality information throughout the cancer journey.
The internet provides the patient with a very obvious and attractive source of information. A Canadian study found that 50% of patients used the internet to search for information and 7% cited the internet as a primary source of information for their particular illness. More specifically, internet use by prostate patients has been found to be prevalent and has the potential to influence some patient’s decision about treatment. Because of the nature of the internet, it is possible to post information from potentially dubious sources. To determine the quality of prostate cancer information on the internet, Black and Penson rated the accuracy and comprehensiveness of 39 websites containing information on prostate cancer. Although the study found variability and lack of balance with many of the sites, the overall standard of information was of sufficient quality to assist with the patient’s decision-making.

The search for information is unlikely to be a solo endeavour for the newly diagnosed patient. Family members, including spouses will probably want to participate in the quest for information. Considerable variation has been found in the partners of patients with prostate cancer, with some partners seeking significant amounts while others seek no information. For those partners who decide to seek information, a variety of sources are accessed, including health-care professionals, their partner (the patient), family members, leaflets, booklets, the internet and the media.

**BARRIERS TO ADDRESSING INFORMATION NEEDS**

The benefits of providing clear, accurate and appropriately tailored information to the cancer patient and their caregivers are evident. There are however potential barriers that might impede the effective delivery of this information. Mills and Sullivan managed to identify four possible reasons why there are problems providing information to cancer patients. Deficiencies in levels of education and training may hinder professionals delivering the degree of information required by the patient. Time pressures can prevent staff providing the appropriate depth of information and some patients may not retain the information they have received. The fourth reason for inadequate information provision is that staff may assume that they know what the patients’ information needs are. In reality, there can be a serious disjoint between what information the patient really needs and what the staff perceive to be important.

Van der Molen also suggests that lack of time prevents patients receiving and absorbing the vast amount of information that might be useful to them. Patients are often acutely aware of the time pressures experienced by their medical team and the scarcity of resources that have to be shared with other patients. It is possible that, out of a sense of charity to what they perceive as more deserving individuals, patients may refrain from asking questions and receiving the information they need. The fragmented nature of cancer care and the numerous health-care professionals involved make it difficult for the patient to identify who can respond to their questions. The frustrations resulting from an uncoordinated approach to cancer-specific information and lack of signposting to information resources has been clearly voiced by Ontario cancer patients.

Information is developed for cancer patients with the expectation that it will meet the patients most immediate information needs. However, as previously mentioned this is often not the case. There are also concerns about the quality and value of information offered to patients with indications that much of the information in the form of leaflets is poorly written and not used by significant numbers of patients. It is important that information reflects current practice and is delivered uniformly by all professionals involved with the patient’s care. Radiation therapists who treat patients with prostate cancer, for example, must be intimately aware of all possible side effects and recommend appropriate management strategies according to locally developed patient care policies. Conflict-
Appropriate levels of infrastructure, staff and resources are required to facilitate the effective delivery of information to cancer patients. A hospital-based information service is considered the most appropriate strategy to pursue when attempting to address patients' information needs.55 These services do however require a substantial amount of support in terms of equipment, training, marketing, staffing and managing. Problems with the establishment and maintenance of information services may occur when an organization does not place sufficient value and priority on psychosocial services, including information resources.3 It is conceivable that at times of fiscal constraints, the budgets for information services will be curtailed to meet the more immediate medical needs of the cancer patient. The designated cancer centre envisioned in the Calman-Hine report15 is likely to have the volume of patients, professional expertise, support services and infrastructure to allow the establishment and continuation of optimum information support for cancer patients.

If information is to be communicated in a meaningful way then it is important that communication skills be well developed. Health-care professionals should be empathetic, supportive and strive to deliver information that is understandable and retained by the patient.56 Communication skills are an essential requirement for all health-care professionals and often referred to in professional standards of practice documents. In Canada, the Canadian Association of Medical Radiation Technologists (CAMRT) clearly indicates that communication is a key component of professional practice.57 The communication skills of doctors and other professionals have been found to be inadequate,58,59 and so it is possible that ineffective communication skills of radiation therapists may hinder the delivery of information. Patients may also lack the communication skills to engage in the information gathering process. Those patients who do not speak English, have English as a second language or who have poor literacy skills are potentially at a serious disadvantage unless translation and extra support services are made available. Visual, auditory and cognitive impairment of the patient are also likely to frustrate the delivery of information.

Cancer information services such as toll-free lines, internet-based services and community information services are often not accessed by cancer patients and/or their caregivers due to lack of awareness.60 More specifically, male patients may be particularly underrepresented users of national cancer information services.32 This lack of awareness also applies to the health-care professional who fails to refer the patient to potentially valuable sources of information. It seems that the combined lack of awareness of patients and cancer care professionals can be a significant impediment to accessing well developed, accredited and relatively accessible site-specific cancer information.

ADDRESSING THE PROSTATE CANCER PATIENT’S INFORMATION NEEDS

The various review articles and studies cited in this article give some indication of the variety and complexity of the prostate cancer patient’s information requirements. The patient will have changing information needs depending on the stage of the cancer journey they are at. Individual patients can expect to have preferences for the type of information they consider important and the way they would like this information delivered. There are, however, a number of parallels in the information needs of patients with prostate cancer. Many of the patients have indicated a need for as much information as possible about key topics such as treatment, side effects, cure rates and prognosis. Receiving information via face-to-face communication with the health-care professional seems to be highly favoured by the majority of patients with prostate cancer. Although the radiation oncologist and urologist are prime sources of interpersonal information, other members of the cancer care team, including radiation therapists and specialist nurses are potential sources of information. Written material, the internet and support groups are also used to differing degrees by the patient and his caregiver as information sources.

The results from qualitative studies on the information needs of cancer patients, combined with guideline documents such as NICE57 give
health-care professionals a better understanding of what is required at the local level to improve the service to all patients. A review of the information services at Princess Margaret hospital (PMH) gives some indication about how effectively patients with prostate cancer can expect to have their information needs met. It is however important to bear in mind that PMH is a comprehensive cancer centre and the only one in Canada that is devoted exclusively to cancer research, treatment and education. It is therefore highly likely that the resources and infrastructure for patient information services found at PMH are not universally available at all Canadian cancer facilities.

INFORMATION SERVICE FOR PROSTATE PATIENTS AT PMH

The initial consultation for newly diagnosed patients with prostate cancer takes place in the multi-disciplinary prostate cancer centre where the patient has the opportunity to discuss treatment options with an urologist and radiation oncologist. The expectation is that the patient will receive the appropriate information about specific treatments and to assist with the sometimes-difficult decision-making process. This centre also offers access to a patient and family support centre which includes a patient library containing up-to-date written material, videos, CD-ROMs and internet access. The prostate centre website provides very comprehensive prostate cancer-related information, including information about alternative treatments, prostate anatomy, impotency and support groups. Volunteers from a prostate cancer support group “man-to-man” are available to answer questions during clinic visits. Considerable effort is made at this stage to provide a private and comfortable atmosphere for the patient and his family so that they can receive the information they need in a supportive and unhurried atmosphere.

The internet is a recognized source of information for patients with prostate cancer. However, the volume of information to navigate through can be an extremely daunting task for the patient and his family. To assist with the patient’s search of internet-based information, PMH provides guidelines on searching the internet and a list of suggested websites that provide detailed information about prostate cancer. Examples of these sites include American Cancer Society’s “All about prostate cancer”, Canadian Cancer Society’s “Prostate cancer: what you need to know” and “Understanding cancer of the prostate” by the UK’s CancerBACUP. Volunteers are also available in the radiation therapy department to help patients use internet terminals situated in the waiting room areas.

A range of brochures and pamphlets are available to the prostate cancer patient who is receiving radiation therapy. This literature addresses a comprehensive range of frequently asked questions about prostate cancer, in addition to very specific details about the planning, treatment and side effects of conventional and conformal radiation therapy to the prostate. The patient can receive this information either in paper format or they can access the relevant pamphlets from the PMH website. Many of the key information pamphlets are available in languages other than English to meet the needs of the multi-ethnic patient population in Toronto.

The prostate cancer patient who is a candidate for radiation therapy receives their initial information from the radiation oncologist. This discussion includes details about the rationale, intent and predicted outcome of the treatment. As part of the consent process, the patient must also receive information about the acute and chronic side effects of the treatment. An integral part of the education/preparation process includes a 30-minute presentation hosted by the radiation therapist approximately one week before the CT-simulation appointment. The prime function of this presentation is to ensure that the patient comprehends the bladder and bowel preparation that is required for the conformal planning process. The CT-simulation process, specific treatment details and side-effects management are also reviewed during this one-on-one presentation.

The fractionated nature of radiation therapy dictates that patients with prostate cancer generally must attend for six to eight weeks of treatment. Although this is obviously arduous for
the patient and their family, it may actually assist with the delivery and retention of information. The patient has multiple opportunities to ask questions from both the treatment unit team and the radiation oncologist who reviews the patient on a weekly basis. The oncologist can elaborate on questions about treatment rationale, survival rates and chronic side effects, such as impotency and incontinence. At the beginning of treatment, the radiation therapist confirms that the patient has a basic understanding of the treatment process and that they have received the necessary written material about treatment and side-effects management. As treatment progresses, therapists review this information and provide the patient with clarification as needed.

Time pressures resulting from a busy treatment schedule often make it difficult to address the patient’s specific information needs in detail. The therapist must therefore have a unique knowledge of the information sources available so that they can refer the patient and their family as necessary. These information sources consist of other members of the multi-disciplinary team including dieticians, oncology nurses and psychosocial staff. Directing the patient to recommended websites, support groups and the prostate centre can also assist greatly in addressing the prostate patient’s information needs.

CONCLUSION

The relationship between the cancer patient and the physician has evolved over the last number of decades. The previous paternalistic approach has developed into a more patient-centred care philosophy, where the patient is treated in an increasing holistic manner. Current policy on cancer care dictates that patients receive optimum management of their disease, along with quality psychosocial care. A critical component of this care is the provision of timely, up-to-date and accessible information that meets a broad spectrum of patient information needs.

The clear mandate from government healthcare policy makers provides impetus to those who are directly charged with providing information for the cancer patient and his caregiver. The information from official toll free lines and internet services is extremely comprehensive and can provide the patient and family members with quality information about specific cancers. Although it is impossible to comment about other cancer centres, the information services at PMH are extensive and are designed to address a wide range of information preferences. Resources such as the prostate cancer centre, patient library, cancer websites, patient support groups and an on-site psychosocial department can be accessed directly by prostate patients treated in the department.

The infrastructure that will facilitate the delivery of information and support obviously exists, yet it is possible that patients are not consistently directed to these resources. Radiation therapists, along with other members of the cancer care team, can play an integral role in ensuring that all patients have their information needs dealt with. Therapists can respond well to the patient’s questions about treatment and side effects, but they should also regard themselves as advocates for the patient’s additional information requirements. Signposting the patient to existing resources and following up at subsequent appointments is a simple but effective strategy to ensure that the patient’s information needs are met. Finally, it must be remembered that although good quality information sources may exist, it is possible that this information fails to meet the specific needs of individual patients. It is therefore imperative that departments audit patient satisfaction and/or undertake more extensive research that will highlight the effectiveness of their information resources.

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