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Craft Based

CONTINUITY OF CANCER CARE: WHERE DO PRIMARY CARE PRACTITIONERS FIT IN?

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Abstract

Cancer is the leading cause of illness in Australia and is a national health priority. Primary care in Australia is well positioned to support individuals diagnosed with cancer and their family/caretakers. However, obstacles exist that impact on the quality and continuity of care that primary care providers and community health professionals can provide. A rapid review of the research available revealed that the knowledge, attitudes and beliefs held by health professionals and patients can impact engagement in early detection, treatment and follow-up care. Health professionals have limited knowledge of evidence-based practices, while cancer literacy among minority groups, including Aboriginal Australians, is lower than the population overall. In this paper, we provide a summary of the rapid review of the literature and provide some recommendations based on our research.

Cancer is a leading cause of death and morbidity in Australia. Estimates suggest that in 2005, the total expected lifetime economic cost of cancer for people diagnosed is around \$94.6 billion and the total financial cost around \$11.2 billion.¹ According to Australian national research, by the age of 85 years, one in two males and one in three females will have been diagnosed with cancer at some stage in their life. Cancer was the leading cause of the burden of disease in Australia in 2010, accounting for 19% of the total burden.²

Care begins with referral and diagnosis, and continues through treatment to follow-up care. Beyond attending to the disease itself, care also includes attention to psychological and social aspects. Cancer is a multifaceted disease that requires a multipronged yet integrated approach to be successfully managed. In Australia, primary care is synonymous with general practice, however the public can access many other health disciplines directly such as community pharmacists, psychologists, nurse practitioners, occupational therapists or physiotherapists. Such practitioners are registered with the Australian Health Practitioner Regulation Agency and are often the first point of contact for a patient with cancer or symptoms suggestive of cancer.

Even though Australia has an established general practice sector, general practitioners (GPs) or primary care providers (PCPs) are not always supported in their efforts to be part of a multidisciplinary care team managing complex health

problems such as cancer. Moreover, the knowledge, attitudes and beliefs of healthcare professionals may hinder the development and delivery of an effective service.³ PCPs have a role to play in cancer care, but the efficacy of their involvement is affected by what they know, and by their own attitudes and beliefs along with those of specialists and patients. We provide a summary of the findings of a rapid review and present recommendations aimed at enhancing the role played by PCPs in cancer care.

Rapid review

A rapid review of published literature was conducted to assess the role of PCPs in cancer care. Rapid reviews are brief syntheses of research relating to a highly targeted question conducted over a very short time frame (a few weeks). Evidence is primarily drawn from existing high quality reviews and/or large scale trials, and some expert opinion may be offered.⁴ This review focuses on early diagnosis, screening, treatment and follow-up care of cancer. Our aim was to identify the impact of knowledge, attitudes and beliefs on the engagement of primary and community-based healthcare professionals in the delivery of cancer care.

A search strategy was devised and deployed. Source articles were published over the last ten years in English language primarily in PubMed and supported and supplemented by online abstracting and indexing databases which

included CINHAL, Cochrane, Embase, Psycinfo and InFormit. This was complemented with a search of grey literature. Of the 4212 publications identified, 162 were included in this review. Studies conducted in Australia and in other countries were analysed. Most of the publications reviewed were qualitative and observational studies with modest numbers. Many publications reporting Australian research are localised and do not necessarily represent the views of all Australian health professionals.

Three questions were posed for the rapid review:

- Question one: To identify the knowledge, attitudes and beliefs held by health professionals and patients which can impact on engagement of PCPs and community health professionals with early detection of cancer and following care.
- Question two: What is the evidence that attitudes and beliefs can be modified with measureable impact on primary and community based professionals with cancer care.
- Question three: Which attitudes and beliefs are most likely to be the NSW content drivers.

Levels of evidence were based on the NHMRC six primary levels of research evidence.⁵

Knowledge, attitudes and beliefs in primary care for cancer

Continuity of care is a key component of general practice. It begins at referral, through treatment to follow-up care and should be considered within the context of the individual in their community. In this section, knowledge, attitudes and beliefs that impact referral and early diagnosis, treatment and follow-up care are explored. Examples include different types of cancer and draw on research from Australia and other countries. The studies included are intended to provide an overview, but are by no means exhaustive.

Knowledge

Available literature reports that evidence (ie. knowledge) is not consistently reflected in practice. Consequently, there may be lost opportunities for early diagnosis. An Australian study found significant variation in PCP referral practices, which was greater for endometrial cancer, for which there were no clinical practice guidelines at time of publication.⁶ Guidelines for the management of abnormal vaginal bleeding were published in 2012.⁷ Lack of knowledge of national clinical practice guidelines can impact diagnosis, so strategies are needed to increase awareness.

An Australian publication on colorectal cancer reported poor patient treatment experiences in primary care.⁸ Several rural participants indicated that high staff turnover in their area hindered continuity of care. A lack of knowledge about local clientele, ineffective clinical networks and referral pathways inappropriate to the locale in which practices operate, may impact adversely on continuity of patient care, particularly in these communities. In urban settings, long wait times to see a PCP cause some people to seek medical care elsewhere, or increasingly self-diagnose using the internet.

Survivorship or shared care plans may facilitate access to knowledge in primary care, thereby improving prognosis. In a US study, PCPs found shared care plans were highly

valued; they increased PCP knowledge about survivors' cancer history and recommended surveillance care and influenced patient care.⁹ Another US study focused on prostate cancer, further concluded that without shared care plans, practitioners were not confident about their ability to provide appropriate care.¹⁰ To improve quality of care, implementing cancer survivorship care plans across specialties, or transferring primary responsibility to PCPs through survivorship guidelines, should be considered.

Integrated systems that use electronic health records are likely to facilitate shared cancer care by improving PCP - oncologist communication.¹¹ Strategies are needed to promote a more active role for PCPs in managing comorbidities, psychological distress and behaviour modification, and to overcome communication challenges between physicians who do not practice within the same integrated system. An example from a study conducted in Western Australia included screening of patients with unmet psychosocial needs in the specialist setting and subsequent referral to their GPs, with recommendations for care plans that could allow Medicare funded access to allied health practitioners.¹²

Concerns exist about the knowledge base patients expect PCPs to have; some rely on their PCPs to have the appropriate knowledge to 'fill in the gaps' with extra information or to clarify specialist advice. Traditionally patients have trusted their PCP to be competent in diagnosis, understanding their problem, advising referral if necessary and giving them appropriate counsel. One small RCT has shown counselling along with treatment as usual can improve depression symptoms and quality of life;¹³ a larger study is encouraged.

Attitudes

Awareness of the warning signs of cancer was reported to be low across all ethnic groups in a UK interview-based study, with lowest awareness in the African subgroup.¹⁴ Women identified relatively more emotional barriers and men, more practical barriers to help seeking, with considerable ethnic variation. These may be related to stigma and misconceptions about cancer. A study of women with gynaecological cancer highlights the problems associated with cancer treatment in a rural community. These women experienced personal and financial upheaval from having to leave home and their communities for treatment. These problems may be ameliorated by receiving care closer to home.¹⁵

Attitudes are also important in relation to family history discussions, especially with young people. In a recent US study, the perception that physicians were responsible for initiating family health history discussions was associated with being non-white and less than completely knowledgeable about cancer.¹⁶ Having a discussion with a physician was associated with being female, having a regular physician, perceiving genetics as a risk for developing cancer, and having a family member diagnosed with cancer. Attitudes and beliefs of families, both positive and negative, impacted upon the wellbeing of people undergoing treatment. However, literature from the UK suggested the needs and concerns of the partners of cancer survivors in caring for patients were seldom addressed.¹⁷ A proactive approach to patients, their partners and other family members at the time of diagnosis, through an offer of

support and their inclusion during treatment reviews, would be useful.

An observational study from Western Australia demonstrated that in 68% of cases, women with breast cancer did not consult their GP about breast cancer-related symptoms in the six months prior to their appointment at a specialist clinic, choosing instead to present to a breast care nurse.¹⁸ Similarly, women in rural Australia have identified limited psychosocial support and resources for breast cancer survivors in their areas.¹⁹

An Australian study concluded that there was strong support for the development and use of shared care plans for bowel cancer survivors.²⁰ Patients, PCPs and specialists endorsed the core elements of the shared care plans, including information about diagnosis, diagnostic tests, a summary of treatments received, surveillance plan and information regarding potential late and long-term effects. There was no clear consensus among hospital-based healthcare professionals regarding who should write and deliver the shared care plans.

Although PCPs provide the bulk of care for long-term survivors within the survivorship phase, only some provide multidimensional survivorship care. A US survey of specialists found approximately half thought specialists were more efficient at providing follow-up care than PCPs, but these same physicians recommended significantly longer and more expensive follow-up routines on average than others.²¹ PCPs were said to be important allies, especially in managing the psychosocial concerns of patients. Most specialists indicated they should remain involved in follow-up care, but this may result in increased resource use.

Beliefs

Timely diagnosis can be affected by patients' beliefs about the GP's role. In Australia, women with breast cancer and their families believed their primary sources of support should be medical practitioners (eg. surgeons, oncologists and GPs), with very few women or family members accessing mental health professionals.²² Given the importance of adequate support when diagnosed and treated for breast cancer, the authors concluded medical professionals should receive training in providing appropriate support and referrals to their patients.

A US study reported that some healthcare providers were not involved in psychosocial care and that oncologists and PCPs differed in their beliefs regarding who provided specific aspects of care. This underscored the need for better care coordination, informed by the respective skills and desires of physicians to ensure needs were met.²³ Other studies similarly concluded that patients did not believe GPs had the training or skills to monitor the physical or psychological sequelae of cancer.²⁴ However, many would be willing to have GPs share their follow-up care, with the caveat that they received extra training and were appropriately supported by secondary care specialists. In this study, GPs felt that attending the training seminars and shadowing at clinics enhanced their own skills, benefited their patients and improved communication with secondary care.

Recommendations

These recommendations can, in the opinion of the authors, help to enhance the role of PCPs in the primary

care of cancer patients. Gaps in PCPs' knowledge can be overcome through additional training. Evidence-based guidelines await development and as they develop they will assist PCPs identify patients with 'red flag' symptoms and should be in regular use. Research into innovations to create and implement decision support tools in practice would be beneficial.

Communication and advice to patients

- Patients need assurance that PCPs are able to follow specialists' treatments and strategies.
- Patients need strong reassurance of PCPs' clinical abilities.
- Specialists should, where possible, engage PCPs in follow-up.
- Specialists should ensure continuity of care and guarantee communication with PCPs.
- Planning shared care to involve the patient, specialists and PCPs before patient discharge could be most useful in appropriate circumstances.¹⁷

Recommendations for management of special groups

- Acknowledge that diffidence may occur among the young, the elderly, Indigenous patients and culturally and linguistically diverse patients and professionals.
- Develop evidence-based guidelines to facilitate seeking of help, patient referral and follow-up in these groups, and also in more easily managed groups.
- Acknowledge the strong need that exists for help with these groups.

Rural patients

- Ensure maximal use of appropriate facilities that are closer to patients' homes.¹²
- Support continuance of chemotherapy in local community settings where appropriate abilities, education, skills and inter-medical communication can be mutually achieved.

Wider support

The involvement of significant supportive, capable and empathetic lay and professional people could provide supportively trusted roles to assist patients on their cancer journey.

Conclusion

Cancer is of great concern to Australians, the public and practitioners alike. Continuity of care from referral right through to follow-up care is important, and PCPs have an important role to play. The knowledge, attitudes and beliefs held by patients, their families, PCPs and specialists impact the provision of care. In short, knowledge, attitudes and beliefs are necessary, but not sufficient for clinical engagement. Factors such as age, ethnicity, geography, gender and responsiveness of the patients, their support network and the practitioners all contribute to the need for a continuum of care from referral, through treatment, to follow-up care. Several steps can be taken to enhance

the role of PCPs in the delivery of care for cancer; the recommendations included here are, in the authors' opinion, a good starting point. Additional research and innovation is also encouraged to assist further development of evidence-based cancer care and the benefit it can bring.

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