



# ARTICLES

## HEALTH WORKERS' PERCEPTIONS OF PSYCHOSOCIAL SUPPORT SERVICES FOR CANCER PATIENTS IN RURAL VICTORIA\*

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### Abstract

Literature attests to the fact that psychosocial needs for cancer patients are not being adequately addressed. The tools, frameworks and guidelines developed, reflect differing professional perspectives and models of disease. Most studies have usually looked at what is happening from the patient and family's viewpoint in terms of medical and other needs. New national initiatives in psychosocial care include the organisation of nationwide practitioner workshops to encourage the implementation of the *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer*. These guidelines focus mainly on the emotional and existential areas of need.

The aim of this study was to: understand how a diversity of approaches and professional perspectives play out in everyday practice within a rural context; see how issues of distance and access affect this process; and highlight the deficiencies in the delivery of psychosocial services for cancer patients in rural Victoria. The study involved 59 questionnaire respondents (a 71% response rate), from which two interviews and six focus group discussions were drawn.

Key findings were: regional and metropolitan hospitals and specialists not referring for support services; private patients missing out; general practitioners not referring to support services; late referrals to palliative care and district nursing; haphazard continuity of care for support needs of patients; and disputed responsibility for initial assessment.

Literature attests to the fact that psychosocial needs for cancer patients are not being adequately addressed<sup>1-3</sup> and that professional intervention should occur early in the cancer patient's journey. McGrath<sup>4</sup> suggests that this should occur at the time of diagnosis. Hill et al,<sup>5</sup> Pascoe et al<sup>6</sup> and Marlow et al<sup>7</sup> acknowledge that the initial steps in the professional intervention, the process of need identification and the elicitation of patient concerns are specialised skills. By discussing the need for assessment skill training, Hill<sup>5</sup> reinforces this viewpoint. Furthermore, over the course of cancer, the diagnostic, pre-treatment, treatment and post-treatment phases, patients and their families needs do not remain static.<sup>8</sup> That is, their experience of illness changes.

Researchers from a range of health disciplines have studied cancer patient and family needs and concerns. The tools, frameworks and guidelines that they have developed reflect the authors' differing professional perspectives and models of disease, including reductionist biomedical and biopsychosocial models.<sup>9</sup> Some have developed tools to measure patient need such as the *Supportive Care Needs Survey*<sup>2</sup> and the *Breast Cancer Patients' Needs Questionnaire*.<sup>10</sup> Many of the tools incorporate patient or family, medical and non-medical needs.

Differing psychosocial frameworks and conceptions have been developed. Coates et al,<sup>11</sup> Sanson-Fisher et al,<sup>2</sup> Bloom et al<sup>12</sup> and Bonevski et al<sup>13</sup> categorise needs using concepts relating to the individual such as, emotional, physical, psychological, instrumental or tangible, and spiritual. The *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer*<sup>14</sup> focuses mainly on the emotional and existential areas of need, however also acknowledges the importance of the practical needs. The overarching schema of practical, emotional and existential needs is another useful typology.<sup>15</sup> Wright et al<sup>16</sup> break down the areas of need spatially into the domains of home, workplace and recreation and Marlow et al<sup>7</sup> also come from the patients' subjective experience using constructs such as "sense of control". Patient needs are multidimensional.<sup>7,12</sup> Furthermore, there is a presumption in some studies that psychosocial problems require an action, resolution or answer,<sup>2</sup> however sometimes validation<sup>7</sup> is all that is warranted. Overall, patient psychosocial needs can be perceived and constructed from worker/outsider perspectives or patient/family perspectives.<sup>7</sup>

Most studies have usually looked at what is happening from the patient and family's viewpoint in terms of

medical and other needs and have focused on the support received. Often the studies have presented findings that represent population types (for example rural, a particular cancer stream), rather than identifiable communities and specific healthcare organisations.

The current focus on improving cancer patient care has seen the production of guidelines at a national level for psychosocial care of adults with cancer.<sup>14</sup> New initiatives include the organisation of nationwide practitioner workshops to encourage the implementation of these guidelines<sup>17</sup> and the development of a tiered model of psychosocial care in oncology by The Cancer Council Queensland.<sup>18</sup> In the UK, guidelines have been developed to critique existing services and implement improved service delivery.<sup>19</sup>

Problems of delivery of health services in rural areas in Australia centre around shortages of specialised skilled workers, difficulties of services accessing resources<sup>20</sup> and the incorporation of new approaches in health care.<sup>21</sup> We know of the difficulties of costs, accommodation and separation of seriously ill patients travelling to access services.<sup>22</sup>

Often the tools, measures and frameworks discussed above reflect the diversity of approaches and professional perspectives involved in contemporary healthcare. The aim of this paper is to: understand how this diversity of approaches and professional perspectives play out in everyday practice within a rural context; see how issues of distance and access affect this process; and highlight the deficiencies in the delivery of psychosocial services for cancer patients in rural Victoria.

## Procedure

This study was carried out in the Grampians region, Victoria, in 2005. The region has 11 health services, including 23 public hospitals with acute beds, one private hospital and one private cancer treatment centre. From 2000-2002 there were 2992 new cancer cases diagnosed in the region.<sup>23</sup>

The overarching framework of practical, emotional and existential domains<sup>15</sup> was adopted because it covered the diversity of patient needs at a range of levels and was accessible from health professionals' perspectives, whether or not they were working within a biomedical model.

Participants targeted were nurses, occupational therapists, psychologists, social welfare workers and a lymphoedema physiotherapist. These workers saw most cancer patients, usually had most interactions with these patients and addressed most psychosocial needs either themselves or took the responsibility to refer on. Key organisations involved were hospitals, community health centres, treatment centres (chemotherapy and radiotherapy), carer services, district nursing and palliative care services. Eighty-two letters of introduction and accompanying questionnaires were mailed to all relevant known practitioners, in organisations delivering services

to cancer patients in the Grampians region. The study involved 59 questionnaire respondents (a 71% response rate), from which two interviews and six focus group discussions were drawn.

The breakdown of the 59 respondents to the questionnaire was:

### By profession:

Nurses	37
Occupational therapists	5
Social workers	8
Psychologists	1
Managers	8

### By organisation:

Hospitals	34
District nursing	4
Palliative care	4
Community health	10*
Carers	3
Radiotherapy/chemotherapy treatment	3
Lymphoedema clinic	1

*\*In some towns district nursing and palliative care operated out of community health centres and in other towns they were within the hospital setting.*

Questionnaire content included postcodes receiving services, number of consumers, a checklist of psychosocial services, referral pathways and worker assessment of cancer services strengths and gaps. Focus groups were semi-structured and elicited information on: local services; strengths and gaps in the continuum of cancer care; current local psychosocial assessment; the validity of questionnaire findings; and prioritisation of themes. The same focus group structure and content was used for the two interviews when only one focus group member was able to attend.

The qualitative data from questionnaires was analysed according to themes and geographic locations and then questionnaire respondent comments were checked with focus groups during discussions. Recordings of focus group discussions were analysed according to themes, then categorised according to whether they were common across the region or specific to a particular town. Themes for analysis were extracted in an evolving process, building first from questionnaire responses and then developed in interview and focus groups, where two more themes were added. An item had to be reiterated at least three times to be considered a theme. Findings were prioritised according to the rank ordering of themes by focus groups.

## Findings

The following six themes were deemed of highest significance by all focus groups:

- regional and metropolitan hospitals and specialists not referring for support services;
- private patients missing out;
- general practitioners (GPs) not referring to support services;
- late referrals to palliative care and district nursing;
- haphazard continuity of care for support needs of patients; and
- disputed responsibility for initial assessment.

### **Regional and metropolitan hospitals and specialists not referring to support services**

Workers across the region saw this as a problem. They described how patients would attend hospitals and specialists away from home (Geelong, Bendigo, Ballarat and Melbourne) and then would not be linked back into services when they returned. Unless patients presented to local hospitals or were referred by a family member who was aware of services, they would "struggle on" in the community unassisted. "Patients are diagnosed locally and sent off, mainly to Melbourne to get brain surgery, and then sent back to the community. We could have provided earlier support in terms of the management and education of the family regarding the changes that would come."

When describing surgeons not referring, one worker stated: "There's no case conferencing or anything like that. This is a really common problem... unfortunately. You don't know whether they've [patients] had news about chemo or radiotherapy...you don't know when to put your face in [to speak to the patient]. We often get the response, 'if only I'd seen you before surgery'."

### **Private patients missing out**

Many workers stated that if the patient was being treated in a private Melbourne hospital and followed up by a specialist privately, they were unlikely to be referred back to support services in their local community. "You can almost guarantee that if a patient from a major Melbourne hospital is a public patient they get great service. If they're a private patient, going to the private hospital, seen by a private practitioner in his [her] rooms, they're the ones that slip through the net. The only way we pick those up is if the family knows our service and ring us, or if the GP sees them quickly after their return and refers, or if a friend will ring up."

### **GPs not referring to support services**

Except for workers in Ballarat, GPs not referring patients to local support services was seen as a major concern. "There's no clear pathway from the medical centre to services. They've [GPs] known the person all their lives and they don't want to admit, even to themselves, that this person's in trouble. Sometimes GPs don't know what services are available."

### **Late referrals to palliative care and district nursing**

Workers across professions talked about a reticence in the community to accept help. Thus patients try to manage on their own even though they could have benefited greatly from the district nurse. "We know there are oncology patients out there and know we'll probably get dragged into it later down the track...why not step into it earlier so we can assist with symptom control, rather than [patients] tripping up and down to Ballarat all the time."

### **Haphazard continuity of care for support needs of patients**

Some district nurses and palliative care workers identified their initial assessment interview of newly referred patients as including psychosocial issues. Another worker said he/she depended on the day oncology nurses to identify services needed by patients. Workers on several sites said they depended on the social workers and nurses at radiotherapy and chemotherapy centres for assessments. All workers agreed that there was no comprehensive psychosocial assessment of all cancer patients and no one taking overall responsibility to help people address their psychosocial needs. That is, there was no psychosocial linking person. "There's no seamlessness...it's often a jerky journey [for the patient]. It's the luck of the draw."

According to workers, the longer the patient is in hospital, or the higher the number of patient/acute doctor or patient/acute nurse contacts, the greater the possibility of psychosocial assessment and consequent referral occurring.

### **Disputed responsibility for initial assessment**

Workers talked about what they saw as the "frontline" (the initial contact and ongoing contact person) and who should manage it. There was common agreement that the first contact has to occur at the time of diagnosis. Some suggestions about how this role should be undertaken included the introduction of new case managers or sharing the role of a case manager/guide amongst existing workers. Others saw that GPs with extra support and assistance could take on the role of the key contact person for the patient.

The following findings were common across all focus groups, but not consistently seen as the most pressing issues:

- increased funding needed for palliative care services;
- issues with transport and accommodation assistance; and
- limited service provision because of limited staff availability.

The following findings are the result of the researcher's observations of focus groups and analysis of questionnaires:

### **Differing professional perspectives**

During discussions with workers, in groups and individually, it was apparent that workers had differing professional models of practice, world views and

priorities. These differences impacted on their understanding of patient psychosocial needs, how they were identified and how they were addressed. So in discussions workers' ways of eliciting, prioritising and addressing commonly agreed gaps were often extremely different. Comments by three workers – a nurse, a psychologist and a social worker in a focus group discussion about supporting patients clearly demonstrate this – in the phrasing they used. The psychologist talked about "meeting people where they're at", the social worker about "leaving them [patients] in control" and the nurse applauded the fact that "everything was done for them straight away".

### **Quantifying difficulties - lack of cancer specific data**

When trying to quantify how many cancer patients they were helping, workers either found it difficult to access records, or had no statistics recording how many cancer patients they saw, or what percentage of their client group were cancer patients.

### **Discussion**

This study suggests that the delivery of psychosocial care for cancer patients in rural Victoria is haphazard. There is an overlap of some services and gaps in other services and apparently a diminution of services the more rural the setting.

There is a lack of clarity about the kinds of tasks undertaken by the different professions and health workers themselves have diverse perceptions about their roles. For example, one occupational therapist saw her/his role as providing grief counselling and another did not see he/she offered any psychosocial support at all. In another town, nurses and social workers were both providing assistance with financial needs of patients. In many cases these professionals were working from quite different models of disease, as formerly discussed by Sprenger,<sup>9</sup> sometimes because they represented different professions and sometimes just because of the kind of person they were and the world views they held. That is, just because they were all nurses for example, it didn't necessarily follow that they shared the same disease model. These factors, of themselves, are not necessarily a problem. However, for patients and doctors wanting to access services, the pathways can be extremely unclear.

With the challenge of distance, lack of services and shortage of specialised workers, healthcare workers are of necessity being creative and flexible in order to meet the needs of patients, as described by Wilkes et al<sup>22</sup> and Murray et al.<sup>24</sup> They are practising psychosocial care at varying levels. Some of the workers demonstrated a lack of understanding about the range and complexity of psychosocial needs. They were unfamiliar with existing frameworks and guidelines and unaware that validation was just as legitimate as an action or resolution, as Marlow et al<sup>7</sup> have argued. Furthermore, depending on a town's health worker networking and communication patterns, patients can be serviced appropriately, inadequately, ineffectively or not at all.

Phrases like "that's the way it's always been done here" were common when looking at referral patterns and patient pathways. Patterns that have evolved over time have been determined by the lack of a range of specialised staff and existing professionals having to take on extra roles. This was particularly the case in more rural towns, where historically there was only the bush nurse or a GP. So in some rural cultures "sharing patients" with other workers is still difficult for some doctors and nurses. In these towns and larger towns, the division of tasks has also been influenced by the skills, knowledge, power and practitioner or agency status. Murphy<sup>25</sup> identified that the introduction of models developed in urban communities does not succeed because local practices and values are not incorporated into proposed changes.

Statistical tracking and documentation of psychosocial services delivered to cancer patients is poor. Generalist services like hospitals, and community health centres, do not have clear or readily accessible information about how many cancer patients access their service and what kind of psychosocial services they are receiving.

Whatever their journey, patients and their families have complex needs that change over the trajectory of the illness, and patient and family needs can differ as well.<sup>8</sup> Workers need high level skills when working with the patient and/or family in the initial eliciting and identifying of need,<sup>5,7</sup> especially if the first contact occurs around the time of diagnosis when the patient is often numb with shock. A skilled worker will also have the capacity to tailor and time interventions so that patient or family trust and confidence are maintained.

### **Conclusion**

In a climate when internationally and nationally there are pushes to try to improve the delivery of psychosocial support services for cancer patients, this across-discipline and across-settings rural study identifies some of the complex realities of on-the-ground practice. The introduction of measures such as the development of doctors' communication skills, the creation of psychosocial support case managers or the development of checklists, will not in themselves succeed.

The terrain of across discipline perspectives and the culture of the local community and its professional networks are vital when considering the delivery of support services for cancer patients. There needs to be: clearer documentation of what support practices are occurring at the local level; increased understanding and acknowledgment of the complexities of the actual delivery of support services at the regional level; and greater appreciation of what is happening in day-to-day practice in rural Victoria at the state and national levels.

The immediate implication for cancer care at the national level is that there should be further specification of the practice guidelines and their implementation by services. However, before we are in a position to consider the desirability of such developments as a national standard of care for all patients and families, national standards for

the education of cancer professionals and the best way to facilitate psychosocial care, further research is warranted into the complexity of need and how this plays out in practitioner/patient interactions.

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