

# Care of the haematology patient and their family

## The GP viewpoint

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### BACKGROUND

General practitioners play an important role in both the care of patients diagnosed with a haematological malignancy, and their families, along the continuum of care from the point of diagnosis to bereavement. There is scant research available on this experience from the GP perspective. This article presents insights from GPs who participated in a national study to develop a model of care in haematology.

### METHOD

Data was collected for this descriptive phenomenological study through open ended interviews. The two GP interviews were part of a national sample (n=96) from four states involving a diverse cross section of health professionals and consumers.

### RESULTS

The findings outline the GPs' perspective on their roles, provides insight into their concerns, and makes suggestions for ensuring quality work with haematology patients and their families.

### DISCUSSION

The insights indicate that GPs want to be involved along the continuum of care and because of their holistic knowledge of the patient and their family, are well placed to provide leadership in the coordination of community based care.

**The importance of general practitioner involvement in the care of cancer patients is clearly documented.<sup>1,2</sup> There is scant research however, on the specific contribution that GPs make to the care of both patients diagnosed with a haematological malignancy, and their families. It is known that GPs are a significant source of referral of patients to specialist haematology departments,<sup>3</sup> and that for haematology patients who have to relocate for specialist treatment, the GP provides a continuum of care that is especially significant when the patient returns home after treatment.<sup>4</sup> However, there are calls in the literature for clarification of the role and influence of the work of GPs with these diagnostic groups, and in particular it is noted that the influence of the GP in end stage cancer care is not well researched.<sup>2</sup>**

The following discussion presents a subset of findings on the experience of GPs caring for haematology patients and their families from a National Health and Medical Research Council (NHMRC) funded study. The aim of the study was to develop a model of care for haematology that extends

to bereavement. The full details of the model are published elsewhere,<sup>5,6</sup> and a booklet<sup>7</sup> with the model has now been distributed widely, both nationally and internationally. The booklet is available free on request from the International Program of Psycho-Social Health Research ([www.ipp-shr.cqu.edu.au](http://www.ipp-shr.cqu.edu.au)). The study was data rich and hence is being published in a number of discrete articles that address topics for specific professional audiences. The findings presented in this article document the viewpoint of GPs who have had experience caring for haematology patients on their role, concerns and strategies for ensuring quality care.

### Method

Data collection involved qualitative interviews (n=96) with a range of health professionals of which GPs were one group represented. Data was collected through open ended interviews that were transcribed verbatim, coded and thematically analysed. The data was collected in the four Australian states of Queensland, Western Australia, South Australia and Victoria. The models developed from the findings were peer reviewed by a national panel of experts and international journals.

## Results

The GPs interviewed clearly stated their desire to be involved along the full continuum of care from the point of diagnosis to bereavement. It was noted that GPs are not only the first point of contact, but often can have long term involvement with the patient and their family. As one participant summed up the situation: 'Like most of the GPs it tends to be longitudinal involvement. Usually I've known them as patients prior to their haematological condition'.

During the early stages of diagnosis and treatment the GP role can include making the original referral to specialist care, providing information on the condition and its treatment, responding to the need for independent clinical reflection away from the hospital setting, and encouraging patient self advocacy in the specialist system (eg. by articulating questions for the patient to ask about clinical concerns such as prognosis and side effects of treatment interventions). As one participant stated: 'What the patient can be encouraged to do is to ask questions such as "What are my odds?" Just giving them the opportunity to be asking direct questions about their own situation to the specialists'.

Participants indicated that GPs can also be in the position of clinical responsibility for other family members and so have a detailed knowledge of the family situation. The GP is described as having a patient centred, holistic knowledge of the patient and their family that is invaluable for providing support and being at the forefront of coordinating community based care, especially during the dying trajectory. The GP is seen as being aware of the 'full picture' and hence a key person to be involved in interorganisational decision making about the provision of community based care. The GPs interviewed wanted to play a key role in the coordination of multiagency involvement (where available involving community nursing, palliative care services, hospice services and support organisations) for those individuals choosing to die at home. As one GP stated: 'I guess for these sort of patients it is really more a team approach. Usually I am trying to do the overview thing as the GP'. It was noted that GPs have valuable information on which services are available in their geographical area.

Along with the need for a clear definition of their role, the GPs also noted concerns about their work with haematological patients and their families. As haematological malignancies only represent 4–7% of cancers, most GPs only see a few patients with these conditions per year. Therefore, they can be less familiar with such conditions. As the treatments for haematological malignancies are highly specialised and constantly advancing, GPs reported difficulties in keeping up with clinical knowledge in this area. As one participant noted: 'It is often you are hearing of medication that you are unlikely to hear of again'. The GPs also expressed a sense of being locked out when their patient with a haematological malignancy enters the specialist system: 'The patient disappears into the hospital and has all these treatments and we are left out of the loop a bit'. This is especially so in regional and remote areas where patients have to relocate to major metropolitan hospitals for specialist treatment.

The last major concern is about the administration of blood products in the home. During the dying trajectory a preferred option for many haematology patients is to receive blood products at home rather than having to travel to the hospital. The GPs interviewed expressed concerns about their skills in the home based administration of blood products.

Along with insights that clarified their role and indicated their concerns, the GPs made suggestions about strategies that would assist with their care of haematology patients and their families.

The benefits of shared care – a collaborative system of care that involves the GP and specialist working with the one patient and sharing patient held records – were affirmed. The GPs emphasised the importance of collegial team work, not only with the specialist but with all other professionals involved in the patient's care including palliative care and supportive care professionals. At the core of this collaborative team work is the need for effective communication with the specialist treating centre. As one participant summed up: 'I guess it would be nice to be involved along the way so we are seen as part of the team as you can get left behind with the changes'. This is seen as particularly important for patients who have to relocate for specialist care. The GPs emphasised the importance of interagency collaboration during

the dying trajectory and saw their role as the key professional in negotiating the collaboration. In response to their concern about administration of blood products at home, the GP saw this as the domain of specialist and palliative care health professionals, seeing these workers as already having the expertise in this area. However, there were also indications that some GPs would like the challenge of upskilling in this area. The GPs indicated they would value ongoing information on haematology and stated this would best be delivered as an e-newsletter. The participants supported the idea of the production of a booklet on haematology and palliative care. The GPs indicated the most effective strategy for gaining information and skill in this area was through direct involvement with other professionals when they are actually dealing with a case. As one participant stated: 'I would much rather have the information when I need it; when I have actually got the patient. I like the booklet idea and think that sort of thing would be very useful'.

## Discussion

The findings point to the willingness of GPs to play an important role in the care of haematology patients and their families: a role described as information giving, the provision of independent clinical advice, encouragement of patient advocacy, and the provision of community based palliative care. Bulsara et al<sup>8</sup> documented the appreciation of haematology patients for GPs who take the time to provide information, clinical reflection and encourage patient advocacy. As the participants in this research indicated, the GP not only knows the patient and their family, but is also aware of available local services. As a consequence, GPs are ideally placed to be a key player in coordinating a multiagency collaboration for community based care during end of life. It is documented elsewhere that patients with the support of their GP are more likely to die at home.<sup>9,10</sup> Humphreys and Rolley<sup>11</sup> affirm the notion that because of the holistic nature of general practice which focuses on the entire family, GPs are well situated to provide community based care. Effective communication skills are known to be as important as clinical skills for the successful GP.<sup>12</sup>

Recorded alongside the willingness to be involved are concerns about the process.

The GPs voiced concerns about their clinical knowledge in relation to this small subset of cancer patients who undergo highly specialised and technologically sophisticated treatments. This concern echoes findings elsewhere that indicate that GPs would appreciate support and education in relation to their care of patients with a haematological malignancy.<sup>4</sup>

Difficulties with communication and lack of access to specialist support are also documented elsewhere as crucial problems, especially for rural GPs.<sup>13</sup> General practitioner concerns about being locked out of contact with patients who have entered the specialist system have in recent years been addressed by work on shared care. Recent research on a model of shared care for haematology patients piloted in Western Australia indicates consumer satisfaction through a sense of empowerment.<sup>8</sup> A review of the literature has shown that shared care involving GPs achieves outcomes similar to, and in some instances better than, hospital care.<sup>14</sup>

Research also indicates that palliative treatments and the administration of blood products at home for haematological patients is safe, feasible, reduces the need for hospital in patient care, is satisfying for staff and carers and should be encouraged.<sup>15–17</sup> In recent years home transfusion services have become increasingly available with staff trained appropriately in cannulation and intravenous transfusion of blood and blood products, basic life support and the treatment of anaphylaxis.<sup>18</sup> British research indicates that most GPs are not in favour of home blood transfusion because of a perception that it would result in an increased workload in general practice.<sup>19</sup> However, initial resistance is overcome with information and the establishment of a protocol detailing the lack of increase work pressure.<sup>19</sup>

The findings highlight the role that GPs do and can play in the care of haematology patients and their families, especially in the provision of home based care during end of life. It is the hope and expectation that the insights generously provided by the participants in this research will provide direction to ensure that GPs are appropriately supported in their important work.

Conflict of interest: none declared.

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