

# Palliative care and haematological malignancy: a case study

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## Abstract

*There is now substantial evidence that patients with haematological malignancies are not referred to the palliative system. Findings from the in-depth qualitative analysis of a successful case study are presented as a paradigmatic example of creative solutions that are available to begin to address this issue of inequity of access. The data provides important insights on the factors that facilitated timely referral to the palliative system, factors that facilitated the opportunity to die at home, a description of important elements of the dying experience, and the outcome of the palliative care experience for the carer. The opportunity for a satisfying dying experience can be afforded to haematology patients. This case study highlights some aspects that need to be considered during the development of palliative services for these diagnostic groups.*

## Introduction

The findings presented in this article provide insights on the topic of caring for those dying from a haematological malignancy. In modern western society terminal care is difficult at best, for as explained by one participant in the research, "I think our society has just got away from death. I am 53 and my husband's death was the first death close to me. And because people tend to die in hospitals so much nowadays it is taken out of their hands and they have lost the ability to cope with it". As the following discussion will show, this situation is exacerbated for families coping with a haematological malignancy.

Hospice or palliative care is now acknowledged to be best practice in end-of-life care (Aranda, 2000; Doyle et al, 1998; Jones et al, 1999; MacDonald, 1998; Maddocks, 1990). Increasingly over the last three to four decades, it has acted as a buffer between the patient and the increasingly technological approach of bio-medicine to the management of human suffering, disease, and dying. However, it is now known that such services are not presently available to all who are dying in our community. In particular, there is now substantial evidence to indicate that patients with haematological malignancies are not receiving appropriate or timely referrals to the palliative system (Hunt & McCaul, 1998; Maddocks et al., 1994; Mander, 1997; McGrath, 1999; Shapiro et al., 1997).

Recent research on the experience of patients dying from haematological malignancies indicates that they are most likely to die in the curative system exposed to invasive technology, aware that they are dying but with no knowledge of or referral to palliative care, and in a hospital situation that is not designed to be responsive to the support or spiritual needs of the patient or their family (Hunt & McCaul, 1998; Maddocks et al., 1994; Mander, 1997; McGrath, 1999; Shapiro et al., 1997). A high proportion of the carers suffer post-traumatic stress related to the experience and are left, unsupported, to deal with regrets and spiritual pain (McGrath, 2002; 2001d; 1999). There are clear indications that both patients and their families would prefer the dying to take place in the comfort of their own home (McGrath, 2001c).

In this discussion, the findings from the in-depth qualitative analysis of a successful case study will be presented as a paradigmatic example of the creative solutions that are available to address the problems patients face dying in haematology. The hope and expectation of presenting the analysis of this case material is to make a positive contribution to beginning to develop solutions to the suffering associated with the present inequity of access to palliative care for these diagnostic groups.

## Case details

A 50 year old employee of an irrigation systems firm was referred in 1995 after routine colonoscopy revealed a lymphocytic infiltrate. Bowel habit had been irregular with some diarrhoea and ribbon stools since an emergency appendectomy two years earlier. There were no B symptoms; he had no significant past medical history and he was on no medications. His father had died of bowel cancer at the age of 50. Full blood count, serum lactic dehydrogenase, and ESR were normal. Endoscopic biopsies showed lymphomatous polyposis throughout the large bowel with an infiltrate of irregular small lymphoid cells. Lympho-epithelioid lesions were not seen. Subsequent histological review of the 1993 appendix specimen was equivocal. Upper gastro-intestinal endoscopy was normal. CT scans revealed para-aortic and mesenteric lymphadenopathy and a suggestion of rectal wall thickening. The marrow was extensively infiltrated with the same disease. He was diagnosed with stage IVE mantle cell lymphoma involving bowel. There was no symptomatic improvement with chlorambucil/ prednisolone, or with six cycles of CEOP (cyclophosphamide, epirubicin, vincristine and prednisolone). He was experiencing faecal urge as well as diarrhoea and was unable to attend work. Using cyclophosphamide at 2 gm/m<sup>2</sup>, and G-CSF 10 mcg/Kg, 4.2 and 2.1 x 10<sup>6</sup> CD34+ cells /kg were collected on a COBE SPECTRA leukapheresis machine in two collections.

In June 1996, he received BEAM conditioning (BCNU, etoposide, cytarabine and melphalan) and subsequent infusion of 2.1 x 10<sup>6</sup> CD34+ cells /kg. Acyclovir, fluconazole, and septrin prophylaxis were used. Engraftment was prompt with minimal side effects. There was good symptomatic remission for two years. With radiological and symptomatic disease progression, he received alternating prednisolone/ adriamycin/ cyclophosphamide & cladribine (total of 6 cycles until August 1998), and once again symptom control was achieved.

Symptoms recurred in May 1999. In July, he was autografted a second time, using BEAM conditioning again. A total of 3.2 x 10<sup>6</sup> CD 34+ cells/ kg were infused with prompt engraftment and minimal hospitalisation. This was followed by MabThera (4 infusions over 4 weeks of 375 mg/m<sup>2</sup>). Quality of life was essentially normal for 12 months, but there was bilateral peri-renal thickening, caecal wall thickening on CT scans in July 2000. Soon after, the white cell count rose rapidly with a lymphoblastoid population detected, and the marrow revealed 90% lymphoblasts, expressing CD 10, CD 19 and lambda light chains. Advised of the poor prognosis of blastic transformation of mantle cell disease, the patient opted for supportive and palliative care. Support services were mobilised and he was discharged. He died at home.

## Methods

The present research was conducted as part of a post-doctoral program of research into palliative care and haematological malignancies funded by the National Health and Medical Research Council (Australia) and supported by the Leukaemia Foundation of Queensland. Full ethical approval for the project was obtained from the University Ethics Committee.

A carer with a declared satisfying experience caring for a partner who died of a haematological malignancy at home was approached with the request for an interview focusing on this experience. The carer was a fifty-three year old woman, with three married children and two grandchildren, who resided in Perth. The interview was conducted by a psycho-social researcher with a counselling background and many years of experience working with families coping with a member with a haematological malignancy. The interview was open-ended and focused on the experience of the dying trajectory.

The interview was audio-recorded and transcribed verbatim. The language texts were then entered into the NUD\*IST computer program and analysed thematically. A phenomenological approach was taken to data

collection and analysis. The aim of phenomenology is to describe particular phenomena, or the appearance of things, as lived experience (Polit & Hungler, 1995). The process is inductive and descriptive and seeks to record experiences from the viewpoint of the individual who had them without imposing a specific theoretical or conceptual framework on the study prior to collecting data (Polit & Hungler, 1995; Streubert & Carpenter, 1995).

## Results

### Factors facilitating timely referral to the palliative system

Six important factors that facilitated the timely referral to the palliative system were noted. Firstly, the carer was non-typical as she had a working knowledge of hospice and palliative care and an awareness of services that were available. Secondly, the carer expressed appreciation for reliable and honest information from the specialist and health care team responsible for treatment. "We wanted to know and so we always asked the questions and they were always honest with us. We were much happier knowing what was going on because at least that way you know what is happening, you are not in the dark". The information gained included a prognostic estimation of three to four months for the acute terminal stage of leukaemia.

Thirdly, both the patient and the carer were forewarned of the possibility that the condition could change to terminal quickly and were informed immediately and honestly of the change when it did occur. In the words of the participant, "He (the patient) went for some blood tests and they told us that it had changed to leukaemia. It had jumped the tracks which we had been told. We knew that was always a possibility".

Fourthly, as the condition progressed into the terminal stage the timeline was detailed in quite specific terms of days or weeks for the benefit of the patient, as can be seen by the statement, "He said to the doctor, 'What is the story? What is happening? How long have I got? Because I would really like to know'. And the doctor said days to weeks. And that was on the Thursday and he died on the Monday".

Fifthly, there was considerable evidence that both the patient and the carer had a strong acceptance of death, summed up in the statement, "We always said whatever we were getting was a bonus from the point that he was diagnosed". However, consistent with what is now known about hoping in terminal illness, this acceptance was accompanied by the contradicting emotion of hope for cure. The couple were able to accept the inevitability of death whilst believing that "We were going to beat it".

Importantly, however, they both talked to each other about the seriousness of the disease and shared thoughts about dying, "He didn't want to die, but he wasn't frightened of dying. Because we couldn't alter things, all we could do is try and make them the best we could for anyone involved".

Lastly, an early and direct referral was made to palliative care services. "I think it was the doctor or his registrar who told us about Silver Chain and the social worker at the hospital came to see us and helped us with the paper work". This was a pro-active step. "We got involved with Silver Chain even though we didn't need it at this stage. They just said to just get on their books. So everything was in place so that when we did need it everything would just flow smoothly".

### Factors facilitating opportunity to die at home

One of the important factors that facilitated the opportunity to die at home was seen to be the simple fact of just knowing that such an option is possible. Second was the carer's awareness of the patient's wish to die at home. "It was his desire to die at home. I said about dying what do you want to do and he said I would like, firstly, to be pain free, secondly quality of life and thirdly, to die at home".

Third was the availability of the carer and her willingness to care for her partner at home. "I just gave up work straight away. I was more than happy for him to die at home." However, even for such an enthusiastic carer there is the ever present self-doubt about such a challenge. "I said to him I think that is great if we can do it, but I don't know how long, whether it is achievable".

Although now known to be the preferred option of most people, the option of dying at home can be initially challenging and frightening. As this carer explained, "In some ways people are scared". The reduction of this

fear is an important aspect of the process of empowering families to care for their loved ones at home. In this case it was assisted by the fact that both the patient and carer entered the terminal stage with trusting and positive relationships with their doctors and other health professionals who were readily available for medical consultation and advice. This professional help was backed-up by timely and appropriate provision of information, "We had knowledge and we were kept informed".

A fourth and very important factor in facilitating the opportunity to die at home is the provision of adequate support, which was stated in unequivocal terms to be an essential element in the process of coping. "I had so much support it was wonderful. You couldn't do without it". Significantly, in this case the support was co-operatively provided from a number of organisations. "With the support of all the different organisations that are there to support you, you can do it definitely. There is no way I could have done it on my own. I would probably have been scared stiff and thought Oh I can't cope with this".

The cross-institutional support is a major theme emerging from this case study, where there was evidence of many organisations working effectively and co-operatively together whilst maintaining their own clear role definitions. Importantly, such co-operation fostered continuity of care allowing the patient to maintain contact with the curative system whilst accessing support from palliative sector. As the carer explained, "We still stayed in the mainstream. He was in the hospital on the Thursday before he died. So the two were working in conjunction. There was total co-operation between the two". Duplication of services was avoided by clear role definitions communicated to the patient and carer.

The sophisticated co-operation eliminated service duplication whilst allowing the patient and carer to maintain well establish bonds with the curative system. These bonds were reported as important. "The ward was like home. I think they were just wonderful, they were almost like an extended family. Some had been there for the five years during his treatment".

The outcome of such cross-institutional co-operation was the communication of the important message to the family that the task of caring for them was the paramount consideration. In the words of the carer, "I always felt that all of the people who were involved their main interest was doing the best they could for my husband and supporting me".

Fifth is the continuous provision of pro-active knowledge: that is, the forewarning of events and suggestions of strategies before needed. This is important, for as the carer explained, "when you know that this is going to probably happen then you are not going to be frightened by it and you are not given a shock. That was a huge benefit, knowing what was likely to happen". Such information was provided to the patient as well as the carer and included information on the possible likely scenarios of the dying scene. "It may be just a slow gradual decline. Or it maybe pneumonia. Or it may be a haemorrhage. And they told us all these things that were possibly the way he was going to die. He wanted to know and so did I".

The carer noted the importance of this information during the terminal stage. "I accepted that there was nothing anyone can do, he was going to die, so I wasn't really nervous about what do I do now". Consequently, as the condition worsened the carer was not frightened into calling for an ambulance to go to the hospital.

In haematological malignancies, excessive terminal bleeding is often perceived as an important obstacle to allowing people to die at home, as it is seen as unacceptable for carers. This carer spoke in detail about the experience of dealing with the bleeding, which was summed up as "... I think of all the other options (pneumonia, blood infection), it was probably the easiest one to us". The situation was constructively handled as both patient and carer were forewarned and given pro-active strategies such as using dark towels to clean up the bleeding.

The sixth important factor in facilitating the home death was the provision of choice. That sense of choice eliminated the risk of either the patient or carer from feeling trapped in their situation and provided them with a strong sense of control. The carer related several vignettes of times when the choice was exercised such as the patient's refusal to be hospitalised for transfusion in the last stage, the decision not to undergo further chemotherapy, and arrangements to enter the hospice in-patient facility if this became a necessity. "I think the more involved you are then the more control you have over what is happening around you, the easier it is to accept".

Finally, when the carer's need for assistance, because of the demands of physical care, became acute the hospice responded quickly and provided twenty-four hour total support. Importantly, the hospice nurse gave clear

indication of the closeness of death which allowed friends and family to be at the bedside to share in the intimacy of the dying. At this stage the hospice health professionals provide expert help in pain and anxiety management. The hospice also took responsibility for organising the funeral, which was appreciated by the family.

## The dying experience

The actual time of dying which was described in very positive terms such as 'wonderful', 'beautiful' or 'really lovely'. Friends and family were aware that death was imminent and were there to share the experience. "It was just wonderful because I stayed up all night. I sat beside him all night on the bed and all night long there were people coming in. They wanted to be with him all night."

Importantly, the children in the family were able to share directly and constructively in the dying as can be seen by the following description. "They came in and said 'Goodbye Granky'. They came down (after he had died) and gave him a cuddle and kissed him goodbye. It was really, really lovely".

During the actual dying the patient's pain and anxiety were managed well and the terminal stages were described as non-distressing and peaceful where "his breathing just got slower and slower". After the death the patient stayed at home for five hours whilst "there was the option for our close friends to say goodbye to him while he was at home".

## Outcomes

The principal outcome from the dying experience was that the family was left with a strong sense of satisfaction about their efforts to care for their loved one. This included a profound sense of rightness. "I think we made the right decisions. We did all the things we wanted to do with the pain pretty well managed. Really until the Saturday night he was totally involved in the family. He had quality of life right up until then... because of that then he was able to die peacefully at home. I feel I fulfilled all his wishes". Underpinning this satisfaction was a sense that living rather than dying dominated the experience, "It is about living. Even when you are dying you have to live. We were living".

Another strong aspect of the satisfaction was the way friends and family were so successfully involved in the very special moments of dying. "We couldn't have had fifteen people around us if we had been in the hospital. It would have been so different if it had been in the hospital". The feed-back from those involved was "how pleased they were in being able to share his dying and to be involved and to feel part of it".

Another important outcome of the death was the affirmation of a sense of continuity of care. The bonds with the hospital were not broken and the carer was able to return with gifts to thank those involved in the oncology ward. Uncharacteristically for haematology patients, the carer was provided with offers for follow-up grief counselling. As the carer summed up, "... support was there if I need it. They made me very aware it is there if I need it".

Most importantly the carer assertively stated that she felt she was coping better now because of experience. "I think because we did all the things we wanted to do and the death the way he wanted it, I think I am coping far better now because of that. I don't have any guilt or wish I had done this or that". For this carer there were neither regrets nor spiritual pain, but instead a peaceful sense of closure. The process of caring for a loved one dying of a haematological malignancy at home is a challenging process but for this carer is was a satisfying experience, that, in her words, "... I think made it so much easier for me to cope with his death".

## Discussion

The findings from this case study indicate that there are number of factors that will facilitate a timely and appropriate referral to the palliative care for haematology patients. In relation to health professionals, these factors include the sensitive provision of honest information about prognosis, pro-active information giving about possible changes in the condition and prompt indications when the condition worsens, along with early and direct referral to palliative care services. For the patient and carer, facilitating factors include a degree of acceptance of the condition (which will always be accompanied by the contradictory hope for cure), an ability to talk about the possibility of dying and what is expected in terminal care, and knowledge of hospice and palliative care.

For a patient to die at home there usually, but not always, has to be an available carer who is willing and able to commit to the journey. It is now known that the majority of people wish to die at home, but that can be a frightening prospect for carers. Factors which were shown to be associated with empowering individuals to cope with this challenge included an appreciation that home deaths were a possibility, knowledge about the practice of hospice care, a sharing of the patient's desire to die at home, positive relationships with the health care team responsible for treatment, the provision of honest and pro-active information that forewarns of conditions and provides effective strategies to deal with difficult situations, a high level of cross-institutional support with clear definition of roles, continuity in the provision of care between the curative and palliative system, and the task focus for service provision remaining predominantly on the needs of the patient and their family. Underpinning the development of all service provision should be a respect for the individual's choice and a desire to place control as much as possible in the domain of the patient and their carer. During the final stage of terminal care, the provision of full-time holistic hospice care will be required.

This case study indicates that patients with haematological malignancies can experience all of the satisfactions of dying at home that are usually associated with hospice care. They include the intimate sharing of a spiritual event with close family and friends, and the respect and dignity that can be afforded to a patient in their own home.

Positive outcomes were documented in relation to the home death including a strong sense of satisfaction and closure, where the family was left with a sense of rightness about their decision-making and a deep-felt sense of having made every effort to fulfil the needs of the dying. An orientation to living, rather than dying, pervaded the experience and those involved were left with the sense of having shared a 'quite wonderful' experience. Post-traumatic stress, regrets and spiritual pain, documented as more expected outcomes of terminal care in haematology, were not present. The carer was left well supported and nourished by the experience, not left to deal with difficult emotions alone. Such a positive experience provided a firm foundation for the acceptance of the death and coping with the challenges of bereavement.

## Conclusion

This case study provides important insights into a positive experience in terminal care for a patient with a haematological malignancy. In the words of the research participant, "... all those things made it better and I felt we had done the best we all could". Hopefully, the information provided here will act as a stimulus to further articles that will share positive experiences to provide insights on the way forward to address the presently neglected palliative needs of patients from these diagnostic groups and their families.

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