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Author

McGrath, Pamela

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# Haematology Patients' Information Needs and Experience with Late Effects of Treatment: Findings from Australia.

Assoc. Professor Pam McGrath, B.Soc.Wk., MA., Ph D

Senior Research Fellow

Centre for Community Science, Population & Social Health Program, Griffith Health Institute, LO5, Level 1  
Logan Campus, Griffith University, Meadowbrook Qld 4131, Queensland, Australia.

## ABSTRACT

*This article makes a contribution to the literature on late effects for adult on-set haematology patients by presenting findings from a major study on survivorship funded by the Leukaemia Foundation of Queensland. The qualitative study involved in-depth interviews with fifty individuals diagnosed with a haematological malignancy and one focus group. The article focus is on a subset of findings on the individual's perception of the major late effects experienced and their attitudes and perspectives on information required about late effects at the point of treatment. The evidence from the research points to positive outcomes from treatments with many participants reporting little or no problem with late effects. However, the findings also point to major difficulties for some patients associated with late effects such as CRF (cancer-related fatigue), neuropathy, and infertility. The findings demonstrate the complexity of haematology patients' informational needs that require active, ongoing, patient-centred understanding and care. The hope and expectation is that the findings will deepen the understanding of the experience of late effects for haematology patients and provide useful information for haematology/oncology health professionals for their important work in this area.*

## INTRODUCTION

Due to the improvements in early detection, supportive care, and treatment, the number of individuals now living with and beyond cancer is increasing.<sup>1-3</sup> Indeed, the current 5-year relative survival rate for all cancers combined is approximately 66.1%.<sup>3</sup> However, as both length and quality of survival are important endpoints,<sup>1,4</sup> with this success comes an increased awareness of and need to address the physical and mental sequelae of cancer.<sup>5,6</sup> As Ng and associates<sup>7</sup> point out, it is now essential to focus on the proper long-term follow-up care of these patients. It is estimated that the late effects or long-term sequelae of cancer and its treatment occur in nearly 75% of all survivors of cancer.<sup>8</sup> Research indicates that cancer-related health problems persist for decades among survivors.<sup>6</sup> Consequently, there are significant risks for developing physiologic and psychological late effects of cancer treatment that might lead to premature mortality and morbidity and a compromised quality of life.<sup>4</sup> As Wood and associates<sup>3</sup> argue, for some patients these advances in survival have been offset by the long-term late effects of cancer and its treatment. Thus, as Frei and Soefje<sup>9</sup> report, there is an imperative to address the impact of the late effects of cancer therapy.

Although there is a plethora of research on the late effects of paediatric cancers, to date the experience of those diagnosed and treated as adults is poorly documented.<sup>1</sup> In addition, most of the work that does exist focuses on the generic diagnostic category of cancer. With the exception of the recent data on Hodgkin's Lymphoma,<sup>7</sup> there is scant work on the sub-group of cancer known as haematological malignancies (these include the leukaemias, lymphomas, myelomas and related diseases). This article makes a contribution to the literature on late effects for adult on-set haematology patients by presenting findings from a major study on survivorship funded by the Leukaemia Foundation of Queensland (LFQ). The focus is on the individual's perception of the major late effects experienced and their attitudes and perspectives on information required about late effects at the point of treatment. The hope and expectation is that the findings will deepen the understanding of the experience of late effects for haematology patients and provide useful material for haematology/oncology health professionals for their important work in this area.

## The Research

The research project was funded by the Leukaemia Foundation of Queensland. The aim of the research was to explore and document issues associated with the experience of survivorship for haematology patients supported by LFQ.<sup>10</sup> The patients' experience with late effects and their thoughts about information provision on late effects were topics specifically explored in the study. The sub-set of findings on the topic of late effects is the material presented in this article.

Further findings from the study on a range of topics based on the same methodology have been published elsewhere.<sup>11-16</sup> As detailed discussion of the methodology is already available in the literature, a summary of the research process will be provided in this article. A qualitative design<sup>17,18,20</sup> based on a series of open-ended interviews and one focus group was utilised to explore and document the experience of survivorship (defined as from completion of primary treatment to end-of-life care).<sup>19</sup> The study explored the experience from the perspective of adult patients diagnosed with a haematological malignancy.

The CQUniversity Human Research Ethics Committee approved the study and full informed consent was obtained before participation in the research.

50 participants were interviewed (n = 26 male; n = 24

female) representing the major haematological diagnostic groups: Multiple Myeloma (n = 15), Lymphoma (n = 14), Leukaemia (n = 17) and Other (n = 4). Of the overall cohort, 11 participants had a Bone Marrow Transplant (BMT) and 15 had a Stem Cell Transplant (allogeneic and autologous transplants). The sample included a representation of ages across the adult life span and from metropolitan, regional, rural and remote locations. At the completion of data collection, the findings were provided to a group of seven focus group participants for comment. Project management and collaboration was managed using the online qualitative collaboration software, Quadrant ([www.quadrant.com](http://www.quadrant.com)).

The interviews and focus group were audio-recorded verbatim, transcribed, coded and analysed thematically. There were 43 codes from the data that were directly relevant to the topic of late effects presented in this article.

For the purpose of the discussion, the identifiers for the participants are as follows: LymNHL (Non-Hodgkins Lymphoma), LymHL (Hodgkins Lymphoma), MM (Multiple Myeloma), ALL (Acute Lymphoblastic Leukaemia), AML (Acute Myeloid Leukaemia), CML (Chronic Myeloid Leukaemia), MDS (Myelodysplastic Syndromes), APML (Acute Promyelocytic Leukaemia), BMTrans (Bone Marrow Transplantation), SCTrans (Stem Cell Transplantation), and Mini-Trans (Mini-Transplantation).]

## RESULTS

### Many individuals did not experience troubling late effects

As can be seen by the following example, there can be up to two years before individuals feel somewhat recovered from their treatments:

- (MM\_SCTrans) It took me you know up to two years I suppose to start to feel good.

There were many individuals who reported that they were presently in good health and functioning at a reasonably normal capacity, for example:

- (MDS/AML) Yes they are quite amazed that I feel okay, I don't feel sick.
- (MM\_SCTrans) I don't sort of have anything wrong with me.

Indeed, it is important to emphasise that the majority of patient interviewed indicated that they had minimal late effects.

#### For some, late effects can be troubling

However, for other participants there were a range of distressing late effects of treatment. The late effects were described as constant and ongoing and, for some, can alter the person's sense of self. It is important to note that for some individuals, the experience of late effects can be perceived as more difficult than the disease itself, for example:

- (MM\_BMT) That's (peripheral neuropathy) what I've suffered from. I have sort of suffered more from that I suppose over a few years than with the actual myeloma.

As detailed in **Table 1**, participants reported a range of late effects to be distressing, including:

- Fatigue
- Neuropathy (a problem with the functioning of the nerves outside the spinal cord with symptoms such as numbness, weakness, burning pain especially at night, and loss of reflexes),
- Fertility issues
- Graft Versus Host Disease (GVHD)
- Chronic sinusitis
- Bronchiolitis obliterans (an inflammation of the bronchioles that leads to restricted lung volumes and decreased vital capacity),
- Sleep disturbances
- Loss of tear ducts
- Allergies

**Table 1: Late Effects Referred to by Participants**

Late Effect	Participants' statement
Fatigue	(MDS_SCTrans) Absolutely, I reckon I went from a 60 year old to an 80 year old in the last eight years. I don't think I have necessarily mentally but I have physically. Where everything I need to do now, I need to sit down and do. (CML_BMTrans) Energy, to be honest it took me a couple of years to get back to where I was... you know I didn't have the same energy... I just was a lot more tired. (LymHL_SCTrans) I guess energy levels are not great. Yes, energy levels are my main one.
Neuropathy	(MM_SCTrans) ... or you're out and standing then you come home and you feel totally like your legs don't want to ...you feel there's something different about them. (MM_SCTrans) I've got a lot of tingling in my fingers (neuropathy) and the doctor says that's sort of part and parcel of it... sometimes it's hard for me to pick up little things you know, little pins or something. (MM_BMT) Well it does affect what I do. You know you have to be very careful sort of walking down steps... just miss the one and you're away sort of thing. (Spoke about not feeling temperatures of food/drink utensils and not being able to drive). (MM_SCTrans) My ankles are extremely painful ... I just push myself for long. My hands have got a constant sensitivity to them but the surface of your skin I've scolded myself a couple of times and didn't know it... my arm got burnt once when I reached over the top of the jug as it was boiling and didn't realise.
Fertility issues	(LymHL) I'm just going through my second miscarriage. Yes, a big issue.

Graft Versus Host Disease (GVHD)	(ALL_BMT) I do have little flare ups every now and again with the, like GVH but that's very minor... It just sort of come and went and every now and again I get problems. (CML_MiniTrans) I have less tolerance for certain foods now, before I use to be able to tolerate other foods a lot better... whether it is because my Graft versus Host disease that I had you know my gut was riddled with it as well. I have got problems with my digestion.
Chronic Sinusitis	(APML) Another thing is I have a drippy nose you know because one of the drugs I have use it just totally rots out the lining of your nose. (LymNHL_SCTrans) You know constantly have sinus issues, I've constantly got a cold, that wears me down
Bronchiolitis Obliterans <sup>3</sup>	(AML_BMT) Basically I've got to do everything sitting down because if I walk around too much I take on too much air...got a lot of different strategies now that I use to breathe and make things easier, you know I sit down in the shower, I've got a special stool but just to have a shower is an endurance test. (Doctor) said 'we know what you've got' and she said 'you are a classic example of a condition called bronchiolitis obliterans'.
Sleep disturbance	(ALL_SCTrans) Your sleep patterns gets thrown right out of whack. So that is another thing that I'm having, like a lot of difficulty dealing with, is actually sleeping. Like I'll go to sleep and then I'll wake up at half past ten or eleven o'clock wide eyed again. (MM) There have been times I suppose, probably ten or twenty times now, where I've gone to bed and it's too painful can't get to sleep because I feel sort of numb (from neuropathy).
Loss of tear ducts	(ALL_BMT) I don't have any tears left, (because of) radiation. I've got to have eye drops, I don't have any moisture in my eyes. I'm suppose to take them every hour.
Allergies	(APML) I have allergies now that I never had before which probably all to do with the fact that my immune system was wiped out and had to rebuild

Of these conditions, the major concern was with fatigue, neuropathy, and fertility issues, which will now be discussed in detail.

### Cancer-related Fatigue

An ongoing and sometimes profound late effect was tiredness. Tiredness was the most commonly reported late effect from treatment that affected the majority of participants from all diagnostic groups. This interfered with all daily activities including: walking, employment, having the energy for visitors, and recreation. Tiredness was described in strong terms such as: 'extremely tired', 'mammoth', 'biggest thing out of my whole experience', 'major problem', 'quite a big deal', 'incredible tiredness', 'ridiculously tired' and, 'always there'. Examples of statements of fatigue are in Table 1.

### Neuropathy

The individuals with Multiple Myeloma were most likely to suffer from neuropathy.

As detailed in Table 1, participants described how neuropathy can impact on the individuals' life, which can affect the ability to walk, cause difficulty holding objects, cause problems with their sense of touch and with sleeping, and cause pain and uncomfortable 'electric shock' type feelings.

### Fertility Issues

As many of the women interviewed for the study either had children prior to treatment or were post-menopausal, fertility was not an issue. However, for the women of

child-bearing age infertility was a major issue, as can be seen by the following statement:

- (CML\_BMTrans) The only thing I remember is saying to him of course, 'will I be able to have children?' And I just remember so clearly because you know that was so important to us. The worst case scenario of leukaemia is death or you don't have to live with that but I remember thinking, 'I can't live with not being able to have children'.

### Desire to be Informed of Late Effects

As detailed in **Table 2**, individuals differed in their desire to have information about late effects. Some participants had a strong desire to know any information about possible late effects. However information about long term effects was not often provided. Many required the information purely on a 'need to know' basis as the particular problem arose for that individual. For this group there was a sense of fear in knowing in advance and hence,

anticipating the full range of possible side effects. The perception was that as not all of the late effects will occur, it is best to avoid the worry unless necessary. There was a group of participants in which the fear of information on late effects was so acute that they were adamant that they did not want any information on late effects, even as part of informed consent to treatment. The concern for this group was that if they knew the full possibilities of late effects prior to treatment, they may not decide to undergo the treatment at all. The responsibility was on the doctor to be vigilant about late effects and inform the individual when appropriate.

Although for most issues concerning late effects there is a multiplicity of positions, there was one late effect that drew a common response. All of the women of child-bearing age were emphatic that they desired to know about the possibility of infertility. On this issue, there is a strong ethical imperative to ensure that the women in this age group are fully aware of the possibility of infertility and the strategies for fertility preservation, such as egg freezing.

**Table 2: Informational Needs with Regards to Late Effects**

Type of Informational Need	Participants' statement
Want to know as much information as possible in advance	(CML_BMTrans) I guess I wanted to know everything I think. I just wanted to know everything... well I asked and I got answers. (MDS_SCTrans) If you speak for me I'm more a customer in finding my own information but I think in general, people would like some more information, you know the fine print that you need to put binoculars on to read that comes with every medication. (LymNHL) Absolutely, the more knowledge I get the better. (CML) I'd like to know what I'm dealing with and I'll be dealing with you know. (LymNHL) I think you need that information before you leave the hospital. (MM_SCTrans) I think you should know ahead of time.
'Need- to- know' basis	(MM_SCTrans) Well they try to tell you as much as possible I feel, well those people scare you. It's good to have answers when the side-effects come up sort of thing, deal with it as it happens. (ALL) ... information when you need it. (ALL_BMT) I think as it happens. I'm a 'need-to-know' basis. (MM) We know enough. I feel you know whenever the time comes that'll be it you now, so we just take one day at a time, do the best we can for that day, we go from there. (ALL_SCTrans) I'll deal with them when they come and I'll ask questions about it then. I think that's the best way to go. I don't think that bombarding people with what may happen is a good thing because maybe you won't. I don't think bombarding people with information on things which may happen is a good thing.

Information not given on late effects	(MM_SCTrans) No, it was never mentioned, the concentration initially was on getting survival.
Prefers not to know	(APML) If you knew in advance what those drugs were going to do to you, you wouldn't take them. Ignorance is bliss I think in that respect... I guess that's the way you have to approach it cause otherwise you wouldn't even start. (LymNHL_SCTrans) I think you just have to deal with – maybe it could be mentioned casually but I think you've got enough to deal with going through that at the time. If they are major ones maybe like the brain not working properly... but then that would only worry you more and what can you do you know? (LymNHL) I wouldn't want to know about every possible side-effect that could happen because I think it worries you. (ALL_BMT) I think you should have the choice of you know, what you're going to be told because if you get told everything that's going to happen to you, it could screw you up before... anything happens.
Doctor should keep vigilant and ask right questions	(MM_SCTrans) [My] doctor keeps an eye on it which is why he's being quite vigilant. (CML_MiniTrans) I'll deal with them when they come along because... I believe everybody is so different and not everybody's going to be textbook and follow all those sorts of things. I think that it's up to the physician to ask questions.
Fertility Issues	
Wanted and were given full information	(ALL_BMT) I'm glad that they're (frozen eggs) there so that they can, if something does happen then you know. I think that they should put it to people, yeah.... She put it to me and I said 'yes, I'd like to do that' and I went in and I got a slice taken and it's been frozen at the moment, I'm happy about that. Putting all of my eggs in the miracle baby basket haven't got anything sorted out yet like with my ovaries, they can't really do anything yet but you know they could have something in a couple of years when I'm ready but I'm glad that they're there.
Wanted but were not given full information	(CML_MiniTrans) Apart from the infertility issue, that was probably the only thing I felt could've been dealt with better. ... I was only 35 and ... when I think back it was not made clear for me, it was naïve, in retrospect I think it was naïve. I had so much to take in but I actually didn't realise that by having chemo I would lose my fertility but that wasn't made clear to me. What happened was that about two or three weeks before I was due to have my transplant I was told to start HRT and I went 'HRT, what's that's for?' And that's when he said, 'aw well you know you'll lose your fertility'. But for me it was devastating because it was not even, you know it didn't even occur to me. (LymNHL_SCTrans) I reckon they should have. They asked every other woman if they wanted to freeze eggs. In a way they should have asked me if I wanted to have any more kids.
For very young the implications of infertility may not be obvious	(LymHL_SCTrans) When I first got diagnosed I was asked if I wanted children because that was a risk that I would become infertile but actually then I didn't think about it. I'd just developed.

As detailed in **Table 2**, there was a strong affirmation of the importance of doctors talking to women about the impact of treatment on fertility and the possibility of collecting and freezing the women's eggs. Some participants were satisfied that they were informed of the late effect of infertility and offered the option of fertility preservation through egg collection and freezing. However, others were dissatisfied with not being given information or the choice of fertility preservation. There is evidence that when women are very young and not thinking about wanting children, the importance of the issue may not be obvious. Thus, for the subset of women of child bearing age the issue of fertility is important and requires relevant information and sensitive communication from health and supportive care professionals.

## DISCUSSION

The fact that so many of the participants reported that they were presently in good health and functioning at a reasonably normal capacity with few late effects is a testament to the improved clinical supportive care for treatment and the successful therapeutic strategies for long term sequelae of treatment. Similarly, a Danish study that documented physical health from late effects indicated that more than half of the cancer patients (of which 48% had haematological cancers) reported good-to-excellent self-rated health, while fair-to-poor health was reported by 40%.<sup>2</sup> However, as the focus of the present study is on the individual's perception of late effects rather than clinical documentation, the high level of positive reports may in part, reflect a lack of detailed understanding of conditions that are associated with the sequelae of treatment. In particular, there was a 'loud silence' on cardiac conditions and yet cardiovascular toxicity is an important adverse effect of several classes of oncology drugs and cardiac disease a significant non-neoplastic late effect for haematology patients.<sup>7,9,21</sup> There is evidence that the long-term and late effects of cancer and its treatment are poorly understood among those diagnosed as adults.<sup>1</sup>

An ongoing and for some, profound late effect was tiredness, known in the literature as cancer-related fatigue (CRF). Fatigue was the most commonly reported late effect from treatment that was at some point in time, experienced by the majority of participants across all diagnostic groups. Fatigue interfered with all daily activities including: walking, employment, having the energy for visitors, and recreation. Described as one of the most common problems experienced by cancer

patients,<sup>22-25</sup> there is now extensive literature on cancer-related fatigue that affirms the present findings.<sup>26-28</sup> As Horneber and associates report,<sup>29</sup> fatigue contributes to a vicious circle of impaired physical performance, avoidance of exertion, inactivity, inadequate physical recovery, helplessness, and depressed mood. CRF can extend for many years after treatment<sup>22</sup> and unlike other forms of fatigue, CRF is not relieved by sleep or rest.<sup>30</sup> Although determining the etiology of CRF is reported as often perplexing,<sup>28</sup> in haematology patients it is usually associated with, and the result of cytotoxic chemotherapy or radiotherapy.<sup>23,25,31</sup> It is noted that as treatment options become more successful but also more exhausting, fatigue has become increasingly distressing and extreme for cancer patients.<sup>32</sup> The assessment and management of fatigue is frequently overlooked by healthcare professionals. Therefore the stress and impairment that it produces are inadequately appreciated and the opportunities for treatment are often neglected.<sup>29,32</sup>

The second major side effect noted is that of neuropathy, which was mostly reported by individuals diagnosed with Multiple Myeloma. The neuropathy was described as having a considerable impact on quality of life, creating difficulties in holding objects and walking, affecting the sense of touch, causing sleeping problems, and producing pain and uncomfortable 'electric shock' type feelings. Peripheral neuropathy is documented as one of the most common and troublesome symptoms experienced by cancer patients.<sup>33</sup> It is noted as a side and late effect of the drugs and treatments used in haematology for all diagnostic groups, including leukaemia, myeloma, and lymphoma,<sup>34-37</sup> with myeloma patients particularly affected with an estimated incidence of 37 to 83%.<sup>38-40</sup>

The third major late effect was impact on fertility and although it only affected a small number of individuals, it was described by the women affected as a major issue. Infertility represents one of the main long-term consequences of combination chemotherapy given for lymphoma, leukaemia and other malignancies in young women.<sup>41,42</sup> Infertility problems from cancer and treatment are reported to be especially disturbing to young women.<sup>43</sup> There are a range of options for trying to preserve fertility including ovarian transposition, in vitro fertilization (IVF) with embryo cryopreservation, IVF with donor oocyte, and more experimental options include oocyte cryopreservation for later IVF and ovarian tissue cryopreservation.<sup>44</sup> As Chasle and How<sup>45</sup> state, the provision of information on fertility is vital, particularly with the increase in the survival of women treated for cancer and the trend towards women starting a family later in life.



Other late effects reported as distressing were graft versus host disease (GVHD), chronic sinusitis, bronchiolitis obliterans, sleep disturbances, loss of tear ducts, and allergies. GVHD is a major long-term toxicity associated with transplantation for haematology patients that contributes to ill health in a significant minority of survivors.<sup>46,47</sup> Chronic sinusitis (associated with immunodeficiency) and the experience of allergies are linked to treatment outcomes in haematology.<sup>48,49</sup> Bronchiolitis obliterans is a pulmonary toxicity secondary to treatments such as transplants that negatively affect an individual's quality of life and has been described as often a greater problem than the disease itself.<sup>50,51</sup> Individually each condition can create considerable distress. Sleep disturbances for instance is among the most common and troublesome symptom experienced by cancer survivors.<sup>33</sup> However, there can also be an interrelationship between the varied late effects which can add to the stress of each individual condition.<sup>52</sup> For example, it is now documented that there is a strong and possibly reciprocal link between CRF and sleep problems.<sup>53,54</sup> However, the efficacy of pharmacological therapies in reducing both insomnia and CRF is largely lacking.<sup>54</sup>

Another significant area in the impact of treatment and the consequences of late effects is in regards to patient sexuality. The findings on this topic from the study have been published in full elsewhere.<sup>15</sup> There were also considerable and, at times, contradictory findings from the study on the notion of 'chemo brain', which has been published in full elsewhere.<sup>55</sup>

Recent research from the Netherlands<sup>56</sup> that documents a high level of satisfaction with information received by haematology patients demonstrates the importance of tailoring information provision to the individual needs of patients. An assumption made in research is that most patients want information as it assists with their coping ability.<sup>57</sup> However, the present research indicates that in terms of wanting to be informed about late effects, there are a variety of positions. Some individuals had a strong desire to know all the information about possible late effects. However, many required the information purely on a 'need to know' basis as the particular problem arose for that individual. Others out of fear, preferred not to know. The responsibility was on the doctor to be vigilant about late effects and inform the individual when appropriate. The findings resonate with Michel and associates'<sup>58</sup> work on monitoring and blunting as responses to information gathering. However, on the issue of infertility there was a commonality of concern that all women in child bearing age undergoing treatment should be informed of

the possibility of infertility and of the option of fertility preservation through egg freezing. To date, the research on informed consent and information giving focuses predominantly on disease, treatment, and prognosis.<sup>59</sup> The research reported in the present article provides up-to-date information on the neglected area of provision of information on late effects. The work demonstrates that the issues are complex and differ not only with regards to the individual, but also the late effect considered.

## CONCLUSION

The findings presented in this paper make a contribution to the neglected but important literature on the experience and informational needs of patients diagnosed with adult-onset haematological cancers in relation to the late effects of their disease and treatment. The evidence from the research points to positive outcomes from treatments with many participants reporting little or no problem with late effects. However, the findings also point to major difficulties for some patients associated with late effects such as CRF (cancer-related fatigue), neuropathy, and infertility. The findings demonstrate the complexity of haematology patients' informational needs that require active, ongoing, patient-centred understanding and care.

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