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How can we help haematological cancer survivors cope with the changes they experience as a result of their cancer?

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ABSTRACT

Haematological cancer often necessitates that individuals make significant lifestyle and behaviour changes to protect themselves against infections. It is essential that haematological cancer survivors receive the support and information they require to adjust to such changes. This cross-sectional survey of 259 haematological cancer survivors found that over two thirds of haematological cancer survivors would like to receive: more detailed information or help with: diet and nutrition that takes into account their diagnosis and treatment; how to manage the symptoms from the cancer and/or treatment; signs and symptoms to be aware of that may indicate a possible infection and appropriate exercise. Over a third of survivors reported that they had to make changes to reduce their chance of infection; with social restriction the most commonly reported area of change survivors made. Improving communication and access to care and providing additional emotional support may assist survivors in making these additional changes. Health care providers should use this information to better support haematological cancer survivors in dealing with the effects haematological cancer has on their life.

Key words: lifestyle changes, information, support, survivors
A cancer diagnosis and its treatments often force people to make significant life changes. For some their employment or work situation will alter [1]; while many will face physical, psychological, cognitive and social-related impairments [2-7]. Although over time some of these changes may return to their pre-cancer state or close to [5], others may persist for extended periods [4,6]. The experience and persistence of some of these impacts may differ across characteristics, including: age, gender, marital status, income level, education level, ethnicity, comorbidities, cancer type and treatment type [8-10,6]. Due to the chronic nature of many haematological cancers the frequency and extent of changes that occur for this population as a result of their cancer, may be particularly extensive. For instance previous research suggests that some changes, such as employment-related changes, are more persistent for some haematological cancer types compared to other non-haematological cancer types [1].

Most haematological cancers cause some type of immunodeficiency [11]. In addition, many of the treatments used with haematological cancers, including bone marrow transplant, chemotherapy and monoclonal antibodies, lead to immunodeficiency [12,11]. Consequently, many haematological cancer survivors are at increased risk of developing infections [13-15], which often carry extensive morbidities and in many cases lead to death [16,17].

A number of recent studies have reported mortality rates of approximately 10% in haematological cancer patients as a result of infections [18-20]. It has been estimated that between 50% and 80% of haematological cancer survivors will develop an infection throughout their cancer journey [17]. To protect against infection many cancer survivors are required to take infection control measures that can require substantiative lifestyle changes [21,22]. Some recommended infection control practices include: increased hygiene practices, avoidance of crowds and those with illness, increased food hygiene and sanitation, food restrictions, avoiding contact with animal secretions, wearing protective clothing (e.g. gloves and footwear), increased cleanliness practices and receipt of certain vaccinations [23,22,24-26,11].

There has been a recent shift from providing haematological cancer treatment in inpatient settings to providing a greater amount of care as outpatient care [27]. This shift to outpatient care is in an attempt to maximise patient’s quality of life, reduce health care costs and reduce the risk of these immunosuppressed patients obtaining a hospital-acquired infection [27]. This change is supported by the availability of data to suggest that care and treatment for haematological cancer patients at home is a safe and advantageous alternative [28]. To ensure the safety and survival of haematological cancer patients receiving outpatient care, particularly high-risk patients
who are susceptible to acquiring infections, it is vital that patients successfully undertake infection control practices to reduce their risk of infection. There is a lack of research investigating adherence of haematological cancer patients to infection control measures. However, from research conducted on patient compliance to medical advice and more specifically on haematological cancer patients’ adherence to self-administered medication, we know that patients are often non-compliant with medical recommendations [29,30]. To maximise haematological cancer patients’ health and wellbeing it is important that efforts are made to support survivors in dealing with the numerous changes they are required to make as a result of their diagnosis, particularly those changes they make to help prevent infection. In order to provide haematological cancer patients with necessary and appropriate support we must understand what information and support they want. No previous research has investigated the type of support and information that haematological cancer survivors believe would best assist them in making or adjusting to the changes brought about by a diagnosis of haematological cancer, including infection control practices. This study will overcome the current knowledge gap and investigate, from a patient’s perspective, what changes they have made as a result of their cancer; and what information and support they would find beneficial in coping with such changes.

Aims

The aims of this study were to identify among haematological cancer survivors:

- The type of information and help they most want to help assist with managing the effects haematological cancer has had on their life;
- Behaviour and lifestyle changes survivors made to reduce their chance of infection;
- Help or information survivors would have liked to have received to assist them in making behaviour and lifestyle changes to reduce their chance of infection; and
- Characteristics associated with haematological cancer survivors’: (i) top three most frequently reported areas of help to assist them with managing the effects of cancer on their life; and (ii) making additional changes to reduce their risk of infection.

METHODS

Design

A cross-sectional study of haematological cancer survivors recruited from one Australian state.

Participants
Eligible survivors were diagnosed with an ICD-10 or ICD-03 haematological cancer and were aged between 18 and 80 years at the time of study recruitment.

**Procedures**

Haematological cancer survivors were identified and recruited from one Australian state population-based cancer registry. The standard recruitment methods employed by this registry were used, which are reported in detail elsewhere [31]. Briefly, eligible survivors were identified by registry staff and consent was sought from each eligible survivors’ clinician to approach their patient. Survivors with consent from their clinician were approached by the registry and asked to provide written consent for their contact details to be passed onto the researchers. Consenting survivors were then mailed a questionnaire package from the researchers, which included an invitation letter, information sheet, consent form for future research, a consent form to have their disease and demographic information released by the registry, a copy of the self-report questionnaire, and a reply-paid envelope. Survivors who did not return a completed questionnaire within 3 weeks were sent a second questionnaire package and contacted by telephone after a further 3 weeks of non-response.

The study received Human Research Ethics approval (HREC approval number: H-2009-0032) from the University of Newcastle Human Research Ethics Committee and the required cancer registry-related approvals.

**Measures**

**Information and help wanted by survivors**

Respondents were presented with a list of 11 possible types of information and/or help that haematological cancer survivors may want to assist them with managing the effects that haematological cancer has had on their life. The list of 11 items were derived from the literature and feedback from survivors who participated in a qualitative study on their unmet needs [32]. For each of the 11 items respondents were asked “I would find it helpful in managing the effects that blood cancer has had on my life to receive more detailed information or help with…”.

Questions included ‘appropriate exercise that is specific to people who have had blood cancer’, ‘how to reduce the risk of infection in public places’ and ‘how to manage the symptoms from the cancer and/or treatment’ (see Table 2 for the full list of 11 items). Survivors responded to each item using a four point Likert scale, with responses ranging from “strongly agree” to “strongly disagree;” a not relevant option was also available. An open ended ‘other’ option was also provided, which allowed survivors to indicate any other types of information or help they may have wanted.
Survivors were asked to indicate whether “beside the [11] areas listed., have you had to change your lifestyle or behaviour in any other ways to help reduce the chance of infection? (e.g. have to constantly wear your shoes, stop paid employment, not travel far from home etc.).” Those patients who answered yes to this question were then asked to describe, in an open-ended format what these changes entailed and to also “describe any help or information [they] would have liked to assist [them] in making the changes [they] have had to make”.

Socio-demographic and disease characteristics

Socio-demographic and disease characteristics obtained from the self-report survey and included in this study were: education level, marital status, employment status, whether the survivor has had another cancer diagnosis, cancer recurrence, health insurance status and stage in the cancer journey. Age, sex, rural/urban location at diagnosis, cancer diagnosis and diagnosis date were obtained directly from cancer registry records, for those survivors who provided consent.

Non-responder characteristics

De-identified data relating to non-participants’ age at diagnosis, cancer type, postcode of residence at diagnosis and sex were collected from the cancer registry.

Statistical analysis

Information and help wanted by survivors

For each of the 11 items the response options “strongly agree” and “agree” were combined, as were options “strongly disagree,” “disagree” and “not applicable”. Open-ended responses that were consistent with the 11 items listed were back coded into the items presented appropriately. Items that did not fit within the scope of the listed 11 items were left as other. The frequency, percentage and 95% confidence interval (95% CI) of haematological cancer survivors who “strongly agreed/agreed” that an item would have been helpful in managing the effects that blood cancer had on their life, was calculated for each of the 11 items and ranked in descending order.

Behaviour changes made to reduce infection
The frequency, percentage and 95% CI of survivors indicating that they had to make lifestyle and/or behaviour changes to help reduce their risk of infection in addition to the 11 items already listed, were calculated. An inductive process to content analysis was performed on the open ended responses provided by these survivors,[33] which indicated what additional changes they had to make and what help or information would have assisted them most in making these changes. One author (AH) reviewed and coded all open-ended responses and developed a coding scheme of relevant themes. A second author (ML) independently reviewed and coded a random 20% sample of the open-ended responses using the coding scheme. The coding conducted by both authors were compared and the coding scheme updated as necessary. Any discrepancies were resolved through discussion. If participants indicated more than one theme in their response, each theme was coded independently. Codes were then quantitized by calculating the frequency and percentage that each theme was reported across participants.[34] The most common themes of changes made and help/information required were reported. Content analysis was used as it allows patterns in the categories to be identified, allowing for the most common changes and types of assistance reported by haematological cancer survivors to be determined.[35] Some of the areas identified from these open-ended responses seemed to overlap with the 11 items survivors were asked to rate as to whether they would like help or information in these areas (e.g. diet changes). However, despite these similarities these open-ended responses were still coded as they often covered more specific details then what was already covered in the 11 items listed.

Characteristics associated with survivors: (i) top three areas of help identified; and (ii) making additional changes to reduce infection

Characteristics associated with survivors: (i) top three most frequently reported areas of help to assist them with managing the effects of cancer on their life; and (ii) making additional changes to reduce their risk of infection in addition to the 11 items already listed, were identified using a logistic regression analyses. These analyses were conducted as it allowed an opportunity to identify those subgroups of haematological cancer survivors who want additional assistance across the different areas of support; as well as those survivors seemingly making extensive changes to reduce their risk of infection and thus may require additional support and assistance to cope with such changes. Simple logistic regression analyses were initially conducted between each of the independent variables and the dependent variables. Independent variables included: sex, age group at diagnosis, education level, employment status, marital status, rural/urban location at diagnosis, cancer type, time since diagnosis, time in the cancer journey, health insurance level, whether experiencing a cancer recurrence, and
whether survivors had received another cancer diagnosis. To allow for adequate numbers to assess the
association between age and the outcome variables we combined the four original age groups into two (15-59
years vs. 60+ years). Variables with a \( p \)-value of 0.1 or less on the simple logistic regression analyses were
included in the final model, and those with a \( p \)-value less than 0.05 on the Wald Statistic in the final multiple
logistic regression models were considered statistically significant. A \( p \)-value >0.05 on the Hosmer-Lemeshow
test indicated that the data was not significantly different from the final model and thus adequately fit the final
model.

RESULTS

Participants

Six hundred and sixteen eligible haematological cancer survivors were contacted by the cancer registry. Of
these, 316 (51%) were sent a survey by the researchers and 259 completed the survey (response rate 42%). The
demographic and disease characteristics of the sample are provided in Table 1.

There were statistically significant differences between participants and non-participants with regards to age
group at diagnosis (\( p < 0.001 \)). Survivors aged 70 years and over at diagnosis recorded the highest response rate
(67%); while those aged between 15 and 39 years recorded the lowest response rate (29%). No differences were
found in relation to cancer type, sex or rural/urban location at diagnosis. Missing data for participant and non-
participant characteristics ranged from 12% to 45%.

Type of help and information most wanted by haematological cancer survivors

The majority (76%) of haematological cancer survivors indicated that they would like to receive more detailed
information or help with diet or nutrition that takes into account their diagnosis and treatment (Table 2). This
was followed by “how to manage the symptoms from the cancer and/or treatment;” (71%) and “signs and
symptoms to be aware of that may indicate a possible infection.” (70%). Other areas where more than half of
participants indicated that help was wanted included: appropriate exercise, mind and body therapies, reducing
infection at home and in public places, biological therapies, manual healing and safe travel. Less than half of
participants (44%) reported that detailed information on energy treatments (e.g. Reiki) would be helpful.

Lifestyle and behaviour changes made by survivors to reduce their risk of infection
Over a third of survivors (36%, n=92) indicated that they made additional changes to reduce their chance of infection; and of these 86 (93%) provided an open-ended response detailing the specific change they made. Table 3 details the broad lifestyle and behaviour changes that survivors indicated making, along with some specific examples as to what these changes entailed. From the open-ended responses social restriction was the most commonly reported broad area of change identified by survivors, and included specific changes such as: avoiding crowded or public places, and reducing contact with family, friends and other people. In most instances survivors indicated that such social restrictions were made to avoid others who may be unwell and therefore reduce their risk of falling ill. Employment changes, use of protective clothing and travel restrictions were the next most frequently cited changes made by haematological cancer survivors (Table 3).

Of the 92 survivors who indicated that they made an additional lifestyle or behaviour change to help reduce their chance of infection, 42 (46%) provided an open-ended response describing help or information that would have assisted them in making these changes. Table 4 details the broad areas of help or information that survivors would have liked to receive, along with some specific examples. Just over a quarter of participants who answered this question indicated that improved communication and access to care would have helped them deal with the changes they made, including increased coordination and communication between different health care providers, opportunities to ask health care providers questions, access to specific health care providers and details on which health care provider to speak to and in what circumstances. The next most commonly identified areas of assistance were: access to emotional support, information and support on how to stay healthy, and warning on what to expect from their disease and treatment.

Characteristics associated with survivors: (i) top three areas of help identified; and (ii) making additional changes to reduce infection

None of the characteristics assessed were found to be significantly associated with the first and the third top areas of help identified by survivors: “diet and nutrition that takes into account my diagnosis and treatment I have had” and “signs and symptoms to be aware of that may indicate a possible infection,” respectively. For the second top area of help identified: “how to manage the symptoms from the cancer and/or treatment,” the following independent variables obtained a p-value <0.1 on the simple logistic regression analyses and were included in the multiple logistic regression model: cancer type, education and insurance level. In the final logistic regression model only education level was found to be statistically significantly associated with survivors wanting help or information in this area. It was found that survivors with a trade certificate...
qualification reported significantly higher odds (OR 2.90; 95% CI 1.18, 7.16; \( p = 0.021 \)) compared to survivors with a university level degree. Based on the Hosmer-Lemeshow test the final model was an adequate fit to the data (\( p=0.83 \)).

From the simple logistic regression models assessing characteristics associated with survivors making additional changes to reduce infection the following independent variables obtained a \( p \)-value <0.1 and were included in the multiple logistic regression model: cancer type, whether the survivor was experiencing a cancer recurrence, time since diagnosis, time in the cancer journey, sex, rural/urban location at diagnosis, marital status and employment status. In the final logistic regression model none of the characteristics assessed were identified as statistically significantly associated with survivors making additional behaviour or lifestyle changes to reduce their chance of infection.

**DISCUSSION**

To ensure the health and wellbeing of haematological cancer survivors it is essential that survivors are offered appropriate and relevant support to help them cope with the changes they make as a result of their cancer. This study is one of the first to assess haematological cancer survivors’ perceptions about what information and help would be most useful in assisting them to manage the effects of blood cancer on their life. It also provides insight into the different changes survivors make to help reduce their risk of infection, an issue that is particularly pertinent to many haematological cancer survivors. This information can be used to better support haematological cancer survivors in dealing with the changes brought about as a result of their diagnosis.

*The type of information and support wanted by haematological cancer survivors*

The most frequently identified areas of information and help wanted by haematological cancer survivors related to living a healthy lifestyle, with a majority indicating a desire for additional support surrounding diet and nutrition, exercise, and strategies to reduce infection. Where possible tailoring such information and support to each individual survivor’s circumstances may be particularly beneficial in helping survivors deal with such changes. For instance, over 65% of survivors indicated that they would have liked help or information on “diet and nutrition that takes into account their diagnosis and treatment” and “appropriate exercise that is specific to people who have had blood cancer”. A minority also indicated in the open-ended responses a desire for additional information on how to stay healthy that is tailored to their individual personal circumstances. These findings are similar to other studies, which have found that individuals with various cancer types prefer receiving information that is tailored to their specific characteristics [36,37]. The provision of tailored
information is however particularly important for individuals with haematological cancers, as each individual’s risk of infection is highly variable and influenced by multiple factors, including type of cancer and treatments received [14]. Providing survivors with generic information is therefore unlikely to help survivors make informed decisions about the changes they should personally make, and instead may result in confusion. Furthermore, education level was found to be significantly associated with survivors wishing to receive help and information on “how to manage the symptoms from the cancer and/or treatment.” This finding again emphasises the need to tailor the information and support to survivor’s individual characteristics, particularly education level, as some subgroups of survivors may have different information and support needs. However, no other characteristics assessed were found to be associated with the top three areas of help and information wanted by haematological cancer survivors to assist them with managing the effects blood cancer has had on their life.

Despite its potential benefit there are some challenges in providing accurate and tailored information to patients. For example, there are a lack of standardised guidelines available to assist health care providers in providing appropriate and consistent infection control recommendations to their patients. As some health care providers may lack an intimate knowledge of the most up-to-date and evidence-based information relevant to their individual patient this could lead to patients receiving inappropriate and inconsistent information on what changes they should make. For instance, it has been common practice for health care providers to recommend a neutropenic diet for cancer patients receiving chemotherapy or stem cell transplant [38], yet evidence supporting this recommendation is conflicting and limited at best [39,38]. Furthermore, patients can freely access an abundance of publically available information from sources such as the internet, which may be incorrect or inappropriate to their individual circumstances. A lack of consistency in the information available to patients may cause patients to be confused about what behaviour changes they should make to help reduce their chances of infection. This could lead to some patients making inappropriate changes and perhaps ‘over protecting’ themselves, while others may not make the necessary changes to keep themselves safe. Consequently, there is a need to develop more efficient ways of providing information to survivors and their health care providers about what is most appropriate for their circumstances. Developing an online information system that employs algorithms to tailor information based on the individual characteristics of haematological cancer survivors against standard recommendations may be a strategy worthy of future investigation. Such a website could be based on the existing Centre for Disease Control, “Prevent Cancer Infections” website [40], which provides chemotherapy patients and their caregivers with tailored information on how to reduce their risk of infection.
Given the increased risk of infection for many haematological cancer survivors and the variability in disease and treatment characteristics of this population, a haematology specific resource may be warranted.

Information and support on how to manage cancer and treatment related symptoms was the second most frequently identified area for help and information identified by survivors; while “signs and symptoms to be aware of that may indicate a possible infection” was the third. These findings are consistent with our previous research exploring the unmet needs of haematological cancer survivors [41], which found survivors frequently identify a need for help in dealing with the numerous side effects and impacts of their disease. Educating patients on their condition, its impacts, how to manage it and when to seek medical assistance is recognised as an important component of cancer care [22]. While health care providers often report educating patients on their condition, including issues surrounding immunosuppression [42], the patients themselves often do not remember receiving such information [42]. Consequently survivors may require additional information and reinforcement about their condition and their immune status, as well as how to cope with such issues throughout the course of their cancer journey. The importance of continually assessing the information and support needs of survivors throughout their entire cancer journey, particularly at key points on the cancer trajectory, is recommended by consensus guidelines [43]. The open-ended responses from survivors in this study, emphasised the importance of receiving clear communication from their health care providers about issues relating to infection control.

Lifestyle and behaviour changes made by haematological cancer survivors that may require additional support

Over a third of haematological cancer survivors indicated making an additional lifestyle or behaviour change in order to reduce their risk of developing an infection. In some instances additional, and often more intensive treatments (e.g. bone marrow transplant and/or high dose chemotherapy) are used to treat certain types of haematological cancers [44]. As many of these treatments carry high-risk of infection, patients will be required to practice infection control behaviours. It is critical that health care providers are aware of the potential impact these changes may have on a person’s life, and provide appropriate support and information to help them cope with these changes. In this study none of the characteristics assessed were identified as being associated with haematological cancer survivors making additional changes to reduce their chance of infection, suggesting that support should be offered to all types of haematological cancer survivors. However, an exhaustive list of characteristics were not assessed in this study. Future research should aim to explore potential risk factors associated with haematological cancer survivors engaging in infection control behaviours. Such information will
assist health care providers in identifying those who may need additional assistance. Furthermore, this study did not assess what information survivors had received regarding behaviour changes they should make, and from what sources. Consequently, it is not possible to identify whether survivors were basing their additional behaviour changes on medical recommendations they received, or were making self-imposed changes based on self-sourced information. Future research should explore the differences in the occurrence and type of these two changes being made by haematological cancer survivors, and what information sources they are basing their behaviour changes on, so that appropriate support can be made, and survivors are not imposing unnecessary restrictions on themselves.

Over a third of survivors who made additional changes to reduce their chance of infection, indicated that such changes related to restricting their social interactions, such as avoiding crowds and public places, as well as reducing contact with other people including family and friends. This may be of concern as social support is an important protective factor against depression, anxiety and decreased quality of life in cancer survivors [45,46]. Consequently, it may be particularly pertinent for haematological cancer survivors to have access to strategies and mechanisms that help them increase their access to social support, while keeping them safe from developing possible infections. This need is supported by the open-ended responses in this study, with a substantial minority of survivors indicating that access to additional emotional support would have assisted them in making the lifestyle and behaviour changes they made to reduce their chance of infection. The emotional support identified as most helpful for these survivors included access to: support groups, contact with other survivors in similar situations, counselling and someone to talk to. These findings are also consistent with previous research assessing the unmet needs of haematological cancer survivors, which have identified the need to speak with other survivors in a similar situation [41,47,48], as an area of unmet need for this population. While the traditional face-to-face support programs may not be possible for all haematological cancer survivors due to the need to reduce the risk of infection and avoid contact with others who may be unwell, online support groups may be a valuable alternative. However, despite the possible benefit of online peer support programs for haematological cancer survivors, no well-controlled studies that we are aware of have assessed their effectiveness in this population. There is a need for more rigorous research to be conducted in this area. Research comparing the benefits of greater online contact with existing social support networks versus online peer support may be of benefit.

Other frequently reported changes that survivors made to reduce their risk of infection, which warrant further exploration included: changes to employment and use of protective clothing or devices. Changes in employment
are likely to impact on survivors’ social functioning and financial situation. This is somewhat supported by a minority of survivors who reported making additional lifestyle and behaviour changes indicating that it would have been helpful to receive financial assistance. It is essential that health care providers ensure their patients are aware of available financial assistance and are supported in accessing such services. This is particularly important given that increased financial burden as a result of their cancer has been found to be significantly associated with haematological cancer survivors reporting a high level of unmet needs [49,50,41]. Finally, the use of protective clothing or mobility devices could lead to a decrease in survivors' confidence and challenge their self-identity. Although research is needed to explore this theory.

**Limitations**

Several limitations must be taken into account when interpreting the results of this study. First, there was a significant difference in the response rates of older and younger survivors, with younger survivors recording a lower response rate than their older counterparts. Our sample of the youngest age group (15 to 39 years at diagnosis) was smaller (n=17; 7.5%) than the other age groups included. To allow for adequate numbers to assess the association between age and the outcome variables we were required to combine the four original age groups into two (15-59 years vs. 60+ years). From these analyses we found no association between age group at diagnosis and the top three most frequently identified areas of help and information wanted by survivors; and whether survivors made additional changes to reduce their chance of infection. However, previous research with haematological cancer survivors have found younger adults to report higher levels of unmet needs across a variety of areas [49,41,48]. Thus it is possible that a significant association between age and the outcomes assessed in this study may have been found if we had sufficient numbers to include the youngest age group as a separate category in the univariate and multivariate analyses. Future research should attempt to recruit a larger number of haematological cancer survivors aged between 15 and 39 years at diagnosis, and further explore the impact of age on haematological cancer survivors’ need for additional information and support to manage the effects blood cancer has had on their life. It should also be noted that there was a substantial proportion of missing data for responder and non-responder characteristics obtained from the cancer registry. The differences found in the response rates should be interpreted with caution. However, the investigators have previously found a similar association between response rates and age in another population-based study they conducted with haematological cancer survivors [51]. A previous study exploring the response rates of adolescent and young adult cancer survivors recruited from a population-based registry, has suggested that younger adults may be harder to recruit due to difficulties contacting this population as a result of a higher level of mobility [52]. It is
also possible that younger adults may find it difficult to find time to complete such research due to competing demands such as family and employment responsibilities. Future efforts should be made to try and increase the response rates of young cancer survivors to research.

Second, this study did not take into account what information about infection control survivors had received and from what sources. Future studies should explore what information haematological cancer survivors are basing their behaviour changes on. Finally the outcome measures used in this study were created for the specific purposes of this research and have not undergone psychometric evaluation. However, the outcome measures were developed based on the literature and previous research conducted by the investigators. Furthermore, open-ended comments were encouraged to be made by the participants to ensure an in-depth assessment of this topic was obtained from the target population.

CONCLUSION

This study provides important insight into what specific information and support may be most useful in helping haematological cancer survivors to deal with the changes they have made as a consequence of their disease. It also provides new knowledge regarding the specific changes haematological cancer survivors have made to reduce their chance of infection, and what support and information they would find most beneficial in making such changes. Where possible health care providers should tailor relevant information to a survivor’s specific disease, treatment and demographic characteristics. Ongoing assessment of survivor’s information and support needs should also be made throughout the cancer trajectory, with important information reinforced at each stage. Future research should strive to develop and assess the effectiveness of intervention strategies designed to support survivors with these changes, such as access to online support groups.
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Conflict of interest

The authors declare no conflict of interest.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent

Informed consent was obtained from all individual participants included in the study.
REFERENCES


Table 1: Participants’ sociodemographic and disease characteristics (n=259)

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<td>Leukaemia</td>
<td>43</td>
<td>19</td>
</tr>
<tr>
<td>Myeloma</td>
<td>44</td>
<td>19</td>
</tr>
<tr>
<td>Other lymphoma</td>
<td>19</td>
<td>8.3</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Partnered</td>
<td>213</td>
<td>83</td>
</tr>
<tr>
<td>Single</td>
<td>44</td>
<td>17</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school or below</td>
<td>125</td>
<td>50</td>
</tr>
<tr>
<td>Trade certificate qualification</td>
<td>72</td>
<td>29</td>
</tr>
<tr>
<td>University level degree</td>
<td>54</td>
<td>22</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Paid employment</td>
<td>111</td>
<td>43</td>
</tr>
<tr>
<td>Non-paid employment</td>
<td>145</td>
<td>57</td>
</tr>
<tr>
<td><strong>Time since diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-24 months</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>25-36 months</td>
<td>105</td>
<td>46</td>
</tr>
<tr>
<td>37+ months</td>
<td>100</td>
<td>44</td>
</tr>
<tr>
<td><strong>Cancer recurrence</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>48</td>
<td>20</td>
</tr>
<tr>
<td>No/not sure</td>
<td>188</td>
<td>80</td>
</tr>
<tr>
<td><strong>Stage in cancer trajectory</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Waitful-watching</td>
<td>22</td>
<td>9</td>
</tr>
<tr>
<td>Active treatment (curative and palliative)</td>
<td>91</td>
<td>36</td>
</tr>
<tr>
<td>Follow-up appointments only</td>
<td>118</td>
<td>46</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
<td>9</td>
</tr>
</tbody>
</table>

*Totals for individual characteristics may not add to the total sample of haematological cancer survivors who returned a survey due to missing responses for some items*
Table 2: Percentage of haematological cancer survivors who “strongly agreed/agreed” to each of the 11 items assessing the type of help and information they would have wanted to assist them with managing the effects blood cancer had on their life

<table>
<thead>
<tr>
<th>Rank</th>
<th>Type of help and information</th>
<th>Respondents who strongly agreed/agreed % (N)a</th>
<th>95% confidence Intervals</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Diet and nutrition that takes into account my diagnosis and the treatments I have had</td>
<td>76 (187)</td>
<td>0.71, 0.81</td>
</tr>
<tr>
<td>2</td>
<td>How to manage the symptoms from the cancer and/or treatment</td>
<td>71 (178)</td>
<td>0.66, 0.77</td>
</tr>
<tr>
<td>3</td>
<td>Signs and symptoms to be aware of that may indicate a possible infection</td>
<td>70 (174)</td>
<td>0.65, 0.76</td>
</tr>
<tr>
<td>4</td>
<td>Appropriate exercise that is specific to people who have had blood cancer</td>
<td>69 (173)</td>
<td>0.63, 0.75</td>
</tr>
<tr>
<td>5</td>
<td>Mind and body therapies (e.g. counselling, relaxation techniques, yoga etc)</td>
<td>66 (166)</td>
<td>0.60, 0.72</td>
</tr>
<tr>
<td>5</td>
<td>How to reduce the risk of infection in public places</td>
<td>66 (163)</td>
<td>0.60, 0.72</td>
</tr>
<tr>
<td>7</td>
<td>How to reduce the risk of infection at home</td>
<td>60 (150)</td>
<td>0.54, 0.66</td>
</tr>
<tr>
<td>7</td>
<td>Biologically based therapies (e.g. dietary supplements, herbal supplements)</td>
<td>60 (150)</td>
<td>0.54, 0.66</td>
</tr>
<tr>
<td>9</td>
<td>Manual healing (i.e. massage, chiropractor)</td>
<td>58 (144)</td>
<td>0.52, 0.64</td>
</tr>
<tr>
<td>10</td>
<td>Safe and appropriate travel</td>
<td>52 (130)</td>
<td>0.46, 0.59</td>
</tr>
<tr>
<td>11</td>
<td>Energy treatment (i.e. reiki)</td>
<td>44 (108)</td>
<td>0.37, 0.50</td>
</tr>
</tbody>
</table>

aTotals may not add to the total sample of haematological cancer survivors who returned a survey due to missing responses for some items
Table 3. Behaviour and lifestyle changes made by haematological cancer survivors to reduce their risk of infection.

<table>
<thead>
<tr>
<th>Broad change</th>
<th>Percentage(^a) (frequency) of participants reporting broad change</th>
<th>Example of specific changes made</th>
</tr>
</thead>
</table>
| Social restrictions                 | 36\% (31)                                                           | Avoiding crowded places  
Avoiding public places  
Reduced contact with family/friends  
Reduced contact with people |
| Employment changes                  | 28\% (24)                                                           | Stopped worked/retired  
Changed jobs/career/tasks  
Reduced hours  
Periods of leave |
| Use of protective clothing and devices | 27\% (23)                                                          | Shoes/orthotics  
Masks  
Gloves  
Incontinence pads  
Walking device  
Specialised equipment or furniture  
Scarf  
Wig  
Hat |
| Travel restrictions                 | 23\% (20)                                                           | Overseas  
Do not travel far from home  
Changes or restrictions in mode of travel  
Delays in being able to travelling  
Domestic  
Holidays  
Business |
| Reduced activity                    | 15\% (13)                                                           | Increased rest  
Regular breaks |
| Hygiene practices                   | 14\% (12)                                                           | Hand washing/sanitiser  
Caution with eating foods  
Avoid or take more care with injuries  
Grooming |
| Diet changes                        | 10\% (9)                                                            | Specific diet e.g. vegan  
Reduced fat intake  
Reduced sugar intake  
Reduced intake of preservatives  
Reduced alcohol consumption  
Organic foods  
Health foods |
| Reduced leisure activities          | 9\% (8)                                                             | Sporting  
Attending events  
Gardening  
Volunteering/community programs |
| Animal and environmental restrictions | 7\% (6)                                                             | Avoid contact with animals  
Avoid pollution  
Reduced time gardening  
Avoid soil |
| Use of medications                  | 7\% (6)                                                             | Side effects  
Immunisations  
Medications for other illnesses  
Supplements/immune boosters |
| Increased care                      | 7\% (6)                                                             | Taking additional precautions to avoid infections  
Being aware of what to do to reduce infections |
| Living arrangements                 | 4\% (3)                                                             | Down size  
Relocation |

\(^a\)Percentage calculated from the 86 survivors who reported a relevant open-ended response to this question
Table 4. Additional help or information that haematological cancer survivors would have liked to assist them with making behaviour and lifestyle changes to reduce their chance of infection.

<table>
<thead>
<tr>
<th>Broad area</th>
<th>Percentage(^a) (frequency) of broad area of support/information</th>
<th>Example of specific type of assistance</th>
</tr>
</thead>
</table>
| Improved communication and access to care | 26\% (11)                                                        | Co-ordination and communication between different providers  
Told who to speak to and when  
Access to specific health care professions (e.g. allied health services)  
Communication on treatment options  
Opportunities to ask questions |
| Emotional support                       | 21\% (9)                                                          | Support groups  
Contact with those in similar situations  
Someone to talk to  
Counselling  
Dealing with relationships  
How to cope emotionally  
How to cope with remission and its uncertainty  
Fear  
Seminars |
| How to stay healthy                     | 19\% (8)                                                          | Around germs and illness  
Diet  
Exercise  
Hygiene  
Immunisation and medication  
Travel  
Tailored to the person’s circumstances |
| Warned on what to expect                | 19\% (8)                                                          | Side effects/impacts  
How to cope |
| Practical assistance                    | 17\% (7)                                                          | Household chores  
Travel  
Side effects |
| Financial and employment assistance     | 17\% (7)                                                          | Financial support  
Easier access  
Awareness  
Building awareness in employers  
Flexibility in the workforce  
Help fitting into the workforce |

\(^a\)Percentage calculated from the 42 survivors who reported a relevant open-ended response to this question.