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

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

57 INTRODUCTION

79

receipt of certain vaccinations [23,22,24-26,11].

58 A cancer diagnosis and its treatments often force people to make significant life changes. For some their 59 employment or work situation will alter [1]; while many will face physical, psychological, cognitive and social-60 related impairments [2-7]. Although over time some of these changes may return to their pre-cancer state or 61 close to [5], others may persist for extended periods [4,6]. The experience and persistence of some of these 62 impacts may differ across characteristics, including: age, gender, marital status, income level, education level, 63 ethnicity, comorbidities, cancer type and treatment type [8-10,6]. Due to the chronic nature of many 64 haematological cancers the frequency and extent of changes that occur for this population as a result of their 65 cancer, may be particularly extensive. For instance previous research suggests that some changes, such as 66 employment-related changes, are more persistent for some haematological cancer types compared to other non-67 haematological cancer types [1]. 68 Most haematological cancers cause some type of immunodeficiency [11]. In addition, many of the treatments 69 used with haematological cancers, including bone marrow transplant, chemotherapy and monoclonal antibodies, 70 lead to immunodeficiency [12,11]. Consequently, many haematological cancer survivors are at increased risk of 71 developing infections [13-15], which often carry extensive morbidities and in many cases lead to death [16,17]. 72 A number of recent studies have reported mortality rates of approximately 10% in haematological cancer 73 patients as a result of infections [18-20]. It has been estimated that between 50% and 80% of haematological 74 cancer survivors will develop an infection throughout their cancer journey [17]. To protect against infection 75 many cancer survivors are required to take infection control measures that can require substantiative lifestyle 76 changes [21,22]. Some recommended infection control practices include: increased hygiene practices, avoidance 77 of crowds and those with illness, increased food hygiene and sanitation, food restrictions, avoiding contact with 78 animal secretions, wearing protective clothing (e.g. gloves and footwear), increased cleanliness practices and

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

86	who are susceptible to acquiring infections, it is vital that patients successfully undertake infection control		
87	practices to reduce their risk of infection. There is a lack of research investigating adherence of haematological		
88	cancer patients to infection control measures. However, from research conducted on patient compliance to		
89	medical advice and more specifically on haematological cancer patients' adherence to self-administered		
90	medication, we know that patients are often non-compliant with medical recommendations [29,30]. To		
91	maximise haematological cancer patients' health and wellbeing it is important that efforts are made to support		
92	survivors in dealing with the numerous changes they are required to make as a result of their diagnosis,		
93	particularly those changes they make to help prevent infection. In order to provide haematological cancer		
94	patients with necessary and appropriate support we must understand what information and support they want.		
95	No previous research has investigated the type of support and information that haematological cancer survivors		
96	believe would best assist them in making or adjusting to the changes brought about by a diagnosis of		
97	haematological cancer, including infection control practices. This study will overcome the current knowledge		
98	gap and investigate, from a patient's perspective, what changes they have made as a result of their cancer; and		
99	what information and support they would find beneficial in coping with such changes.		
100	Aims		
101	The aims of this study were to identify among haematological cancer survivors:		
102	• The type of information and help they most want to help assist with managing the effects		
103	haematological cancer has had on their life;		
104	• Behaviour and lifestyle changes survivors made to reduce their chance of infection;		
105	• Help or information survivors would have liked to have received to assist them in making behaviour		
106	and lifestyle changes to reduce their chance of infection; and		
107	• Characteristics associated with haematological cancer survivors': (i) top three most frequently reported		
108	areas of help to assist them with managing the effects of cancer on their life; and (ii) making additional		
109	changes to reduce their risk of infection.		
110	METHODS		
111	Design		

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

113 Participants

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

116 Procedures

117 Haematological cancer survivors were identified and recruited from one Australian state population-based 118 cancer registry. The standard recruitment methods employed by this registry were used, which are reported in 119 detail elsewhere [31]. Briefly, eligible survivors were identified by registry staff and consent was sought from 120 each eligible survivors' clinician to approach their patient. Survivors with consent from their clinician were 121 approached by the registry and asked to provide written consent for their contact details to be passed onto the 122 researchers. Consenting survivors were then mailed a questionnaire package from the researchers, which 123 included an invitation letter, information sheet, consent form for future research, a consent form to have their 124 disease and demographic information released by the registry, a copy of the self-report questionnaire, and a 125 reply-paid envelope. Survivors who did not return a completed questionnaire within 3 weeks were sent a second 126 questionnaire package and contacted by telephone after a further 3 weeks of non-response.

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

129 Measures

130 Information and help wanted by survivors

131 Respondents were presented with a list of 11 possible types of information and/or help that haematological 132 cancer survivors may want to assist them with managing the effects that haematological cancer has had on their 133 life. The list of 11 items were derived from the literature and feedback from survivors who participated in a 134 qualitative study on their unmet needs [32]. For each of the 11 items respondents were asked "I would find it 135 helpful in managing the effects that blood cancer has had on my life to receive more detailed information or 136 help with...". Questions included 'appropriate exercise that is specific to people who have had blood cancer', 137 'how to reduce the risk of infection in public places' and 'how to manage the symptoms from the cancer and/or 138 treatment' (see Table 2 for the full list of 11 items). Survivors responded to each item using a four point Likert 139 scale, with responses ranging from "strongly agree" to "strongly disagree;" a not relevant option was also 140 available. An open ended 'other' option was also provided, which allowed survivors to indicate any other types 141 of information or help they may have wanted.

142 Behaviour changes made to reduce infection

- 143 Survivors were asked to indicate whether "beside the [11] areas listed.., have you had to change your lifestyle
- 144 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
- 147 information [they] would have liked to assist [them] in making the changes [they] have had to make".

148 Socio-demographic and disease characteristics

- 149 Socio-demographic and disease characteristics obtained from the self-report survey and included in this study
- 150 were: education level, marital status, employment status, whether the survivor has had another cancer diagnosis,
- 151 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.

154 Non-responder characteristics

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

157 Statistical analysis

- 158 Information and help wanted by survivors
- 159 For each of the 11 items the response options "*strongly agree*" and "*agree*" were combined, as were options
- 160 "strongly disagree," "disagree" and "not applicable". Open-ended responses that were consistent with the 11
- 161 items listed were back coded into the items presented appropriately. Items that did not fit within the scope of the
- 162 listed 11 items were left as other. The frequency, percentage and 95% confidence interval (95% CI) of
- 163 haematological cancer survivors who "strongly agreed/agreed" that an item would have been helpful in
- 164 managing the effects that blood cancer had on their life, was calculated for each of the 11 items and ranked in
- descending order.
- 166 Behaviour changes made to reduce infection

167 The frequency, percentage and 95% CI of survivors indicating that they had to make lifestyle and/or behaviour 168 changes to help reduce their risk of infection in addition to the 11 items already listed, were calculated. An 169 inductive process to content analysis was performed on the open ended responses provided by these 170 survivors,[33] which indicated what additional changes they had to make and what help or information would 171 have assisted them most in making these changes. One author (AH) reviewed and coded all open-ended 172 responses and developed a coding scheme of relevant themes. A second author (ML) independently reviewed 173 and coded a random 20% sample of the open-ended responses using the coding scheme. The coding conducted 174 by both authors were compared and the coding scheme updated as necessary. Any discrepancies were resolved 175 through discussion. If participants indicated more than one theme in their response, each theme was coded 176 independently. Codes were then quantitized by calculating the frequency and percentage that each theme was 177 reported across participants.[34] The most common themes of changes made and help/information required 178 were reported. Content analysis was used as it allows patterns in the categories to be identified, allowing for the 179 most common changes and types of assistance reported by haematological cancer survivors to be 180 determined.[35] Some of the areas identified from these open-ended responses seemed to overlap with the 11 181 items survivors were asked to rate as to whether they would like help or information in these areas (e.g. diet 182 changes). However, despite these similarities these open-ended responses were still coded as they often covered 183 more specific details then what was already covered in the 11 items listed.

184 *Characteristics associated with survivors: (i) top three areas of help identified; and (ii) making additional*185 *changes to reduce infection*

186 Characteristics associated with survivors: (i) top three most frequently reported areas of help to assist them with 187 managing the effects of cancer on their life; and (ii) making additional changes to reduce their risk of infection 188 in addition to the 11 items already listed, were identified using a logistic regression analyses. These analyses 189 were conducted as it allowed an opportunity to identify those subgroups of haematological cancer survivors who 190 want additional assistance across the different areas of support; as well as those survivors seemingly making 191 extensive changes to reduce their risk of infection and thus may require additional support and assistance to 192 cope with such changes. Simple logistic regression analyses were initially conducted between each of the 193 independent variables and the dependent variables. Independent variables included: sex, age group at diagnosis, 194 education level, employment status, marital status, rural/urban location at diagnosis, cancer type, time since 195 diagnosis, time in the cancer journey, health insurance level, whether experiencing a cancer recurrence, and

- 196 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
- 198 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
- 200 logistic regression models were considered statistically significant. A *p*-value >0.05 on the Hosmer-Lemeshow
- 201 test indicated that the data was not significantly different from the final model and thus adequately fit the final
- 202 model.

203 RESULTS

204 Participants

- 205 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.
- 208 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
- 210 (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-
- 212 participant characteristics ranged from 12% to 45%.
- 213 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
- 216 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
- 218 participants indicated that help was wanted included: appropriate exercise, mind and body therapies, reducing
- 219 infection at home and in public places, biological therapies, manual healing and safe travel. Less than half of
- 220 participants (44%) reported that detailed information on energy treatments (e.g. Reiki) would be helpful.
- 221 Lifestyle and behaviour changes made by survivors to reduce their risk of infection

222 Over a third of survivors (36%, n=92) indicated that they made additional changes to reduce their chance of 223 infection; and of these 86 (93%) provided an open-ended response detailing the specific change they made. 224 Table 3 details the broad lifestyle and behaviour changes that survivors indicated making, along with some 225 specific examples as to what these changes entailed. From the open-ended responses social restriction was the 226 most commonly reported broad area of change identified by survivors, and included specific changes such as: 227 avoiding crowded or public places, and reducing contact with family, friends and other people. In most instances 228 survivors indicated that such social restrictions were made to avoid others who may be unwell and therefore 229 reduce their risk of falling ill. Employment changes, use of protective clothing and travel restrictions were the 230 next most frequently cited changes made by haematological cancer survivors (Table 3).

231 Of the 92 survivors who indicated that they made an additional lifestyle or behaviour change to help reduce their 232 chance of infection, 42 (46%) provided an open-ended response describing help or information that would have 233 assisted them in making these changes. Table 4 details the broad areas of help or information that survivors 234 would have liked to receive, along with some specific examples. Just over a quarter of participants who 235 answered this question indicated that improved communication and access to care would have helped them deal 236 with the changes they made, including increased coordination and communication between different health care 237 providers, opportunities to ask health care providers questions, access to specific health care providers and 238 details on which health care provider to speak to and in what circumstances. The next most commonly identified 239 areas of assistance were: access to emotional support, information and support on how to stay healthy, and 240 warning on what to expect from their disease and treatment.

241 *Characteristics associated with survivors: (i) top three areas of help identified; and (ii) making additional*242 *changes to reduce infection*

243 None of the characteristics assessed were found to be significantly associated with the first and the third top 244 areas of help identified by survivors: "diet and nutrition that takes into account my diagnosis and treatment I 245 have had" and "signs and symptoms to be aware of that may indicate a possible infection," respectively. For the 246 second top area of help identified: "how to manage the symptoms from the cancer and/or treatment," the 247 following independent variables obtained a p-value <0.1 on the simple logistic regression analyses and were 248 included in the multiple logistic regression model: cancer type, education and insurance level. In the final 249 logistic regression model only education level was found to be statistically significantly associated with 250 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.

261 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.

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

270 The most frequently identified areas of information and help wanted by haematological cancer survivors related 271 to living a healthy lifestyle, with a majority indicating a desire for additional support surrounding diet and 272 nutrition, exercise, and strategies to reduce infection. Where possible tailoring such information and support to 273 each individual survivor's circumstances may be particularly beneficial in helping survivors deal with such 274 changes. For instance, over 65% of survivors indicated that they would have liked help or information on "diet 275 and nutrition that takes into account their diagnosis and treatment" and "appropriate exercise that is specific to 276 people who have had blood cancer". A minority also indicated in the open-ended responses a desire for 277 additional information on how to stay healthy that is tailored to their individual personal circumstances. These 278 findings are similar to other studies, which have found that individuals with various cancer types prefer 279 receiving information that is tailored to their specific characteristics [36,37]. The provision of tailored

280 information is however particularly important for individuals with haematological cancers, as each individual's 281 risk of infection is highly variable and influenced by multiple factors, including type of cancer and treatments 282 received [14]. Providing survivors with generic information is therefore unlikely to help survivors make 283 informed decisions about the changes they should personally make, and instead may result in confusion. 284 Furthermore, education level was found to be significantly associated with survivors wishing to receive help and 285 information on "how to manage the symptoms from the cancer and/or treatment." This finding again emphasises 286 the need to tailor the information and support to survivor's individual characteristics, particularly education 287 level, as some subgroups of survivors may have different information and support needs. However, no other 288 characteristics assessed were found to be associated with the top three areas of help and information wanted by 289 haematological cancer survivors to assist them with managing the effects blood cancer has had on their life. 290 Despite its potential benefit there are some challenges in providing accurate and tailored information to patients. 291 For example, there are a lack of standardised guidelines available to assist health care providers in providing 292 appropriate and consistent infection control recommendations to their patients. As some health care providers 293 may lack an intimate knowledge of the most up-to-date and evidence-based information relevant to their 294 individual patient this could lead to patients receiving inappropriate and inconsistent information on what 295 changes they should make. For instance, it has been common practice for health care providers to recommend a 296 neutropenic diet for cancer patients receiving chemotherapy or stem cell transplant [38], yet evidence supporting 297 this recommendation is conflicting and limited at best [39,38]. Furthermore, patients can freely access an 298 abundance of publically available information from sources such as the internet, which may be incorrect or 299 inappropriate to their individual circumstances. A lack of consistency in the information available to patients 300 may cause patients to be confused about what behaviour changes they should make to help reduce their chances 301 of infection. This could lead to some patients making inappropriate changes and perhaps 'over protecting' 302 themselves, while others may not make the necessary changes to keep themselves safe. Consequently, there is a 303 need to develop more efficient ways of providing information to survivors and their health care providers about 304 what is most appropriate for their circumstances. Developing an online information system that employs 305 algorithms to tailor information based on the individual characteristics of haematological cancer survivors 306 against standard recommendations may be a strategy worthy of future investigation. Such a website could be 307 based on the existing Centre for Disease Control, "Prevent Cancer Infections" website [40], which provides 308 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.

311 Information and support on how to manage cancer and treatment related symptoms was the second most 312 frequently identified area for help and information identified by survivors; while "signs and symptoms to be 313 aware of that may indicate a possible infection" was the third. These findings are consistent with our previous 314 research exploring the unmet needs of haematological cancer survivors [41], which found survivors frequently 315 identify a need for help in dealing with the numerous side effects and impacts of their disease. Educating 316 patients on their condition, its impacts, how to manage it and when to seek medical assistance is recognised as 317 an important component of cancer care [22]. While health care providers often report educating patients on their 318 condition, including issues surrounding immunosuppression [42], the patients themselves often do not 319 remember receiving such information [42]. Consequently survivors may require additional information and 320 reinforcement about their condition and their immune status, as well as how to cope with such issues throughout 321 the course of their cancer journey. The importance of continually assessing the information and support needs of 322 survivors throughout their entire cancer journey, particularly at key points on the cancer trajectory, is 323 recommended by consensus guidelines [43]. The open-ended responses from survivors in this study, emphasised 324 the importance of receiving clear communication from their health care providers about issues relating to 325 infection control.

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

327 Over a third of haematological cancer survivors indicated making an additional lifestyle or behaviour change in 328 order to reduce their risk of developing an infection. In some instances additional, and often more intensive 329 treatments (e.g. bone marrow transplant and/or high dose chemotherapy) are used to treat certain types of 330 haematological cancers [44]. As many of these treatments carry high-risk of infection, patients will be required 331 to practice infection control behaviours. It is critical that health care providers are aware of the potential impact 332 these changes may have on a person's life, and provide appropriate support and information to help them cope 333 with these changes. In this study none of the characteristics assessed were identified as being associated with 334 haematological cancer survivors making additional changes to reduce their chance of infection, suggesting that 335 support should be offered to all types of haematological cancer survivors. However, an exhaustive list of 336 characteristics were not assessed in this study. Future research should aim to explore potential risk factors 337 associated with haematological cancer survivors engaging in infection control behaviours. Such information will 338 assist health care providers in identifying those who may need additional assistance. Furthermore, this study did 339 not assess what information survivors had received regarding behaviour changes they should make, and from 340 what sources. Consequently, it is not possible to identify whether survivors were basing their additional 341 behaviour changes on medical recommendations they received, or were making self-imposed changes based on 342 self-sourced information. Future research should explore the differences in the occurrence and type of these two 343 changes being made by haematological cancer survivors, and what information sources they are basing their 344 behaviour changes on, so that appropriate support can be made, and survivors are not imposing unnecessary 345 restrictions on themselves.

346 Over a third of survivors who made additional changes to reduce their chance of infection, indicated that such 347 changes related to restricting their social interactions, such as avoiding crowds and public places, as well as 348 reducing contact with other people including family and friends. This may be of concern as social support is an 349 important protective factor against depression, anxiety and decreased quality of life in cancer survivors [45,46]. 350 Consequently, it may be particularly pertinent for haematological cancer survivors to have access to strategies 351 and mechanisms that help them increase their access to social support, while keeping them safe from developing 352 possible infections. This need is supported by the open-ended responses in this study, with a substantial minority 353 of survivors indicating that access to additional emotional support would have assisted them in making the 354 lifestyle and behaviour changes they made to reduce their chance of infection. The emotional support identified 355 as most helpful for these survivors included access to: support groups, contact with other survivors in similar 356 situations, counselling and someone to talk to. These findings are also consistent with previous research 357 assessing the unmet needs of haematological cancer survivors, which have identified the need to speak with 358 other survivors in a similar situation [41,47,48], as an area of unmet need for this population. While the 359 traditional face-to-face support programs may not be possible for all haematological cancer survivors due to the 360 need to reduce the risk of infection and avoid contact with others who may be unwell, online support groups 361 may be a valuable alternative. However, despite the possible benefit of online peer support programs for 362 haematological cancer survivors, no well-controlled studies that we are aware of have assessed their 363 effectiveness in this population. There is a need for more rigorous research to be conducted in this area. 364 Research comparing the benefits of greater online contact with existing social support networks versus online 365 peer support may be of benefit.

Other frequently reported changes that survivors made to reduce their risk of infection, which warrant furtherexploration included: changes to employment and use of protective clothing or devices. Changes in employment

368 are likely to impact on survivors' social functioning and financial situation. This is somewhat supported by a 369 minority of survivors who reported making additional lifestyle and behaviour changes indicating that it would 370 have been helpful to receive financial assistance. It is essential that health care providers ensure their patients 371 are aware of available financial assistance and are supported in accessing such services. This is particularly 372 important given that increased financial burden as a result of their cancer has been found to be significantly 373 associated with haematological cancer survivors reporting a high level of unmet needs [49,50,41]. Finally, the 374 use of protective clothing or mobility devices could lead to a decrease in survivors' confidence and challenge 375 their self-identity. Although research is needed to explore this theory.

376 Limitations

377 Several limitations must be taken into account when interpreting the results of this study. First, there was a 378 significant difference in the response rates of older and younger survivors, with younger survivors recording a 379 lower response rate than their older counterparts. Our sample of the youngest age group (15 to 39 years at 380 diagnosis) was smaller (n=17; 7.5%) than the other age groups included. To allow for adequate numbers to 381 assess the association between age and the outcome variables we were required to combine the four original age 382 groups into two (15-59 years vs. 60+ years). From these analyses we found no association between age group at 383 diagnosis and the top three most frequently identified areas of help and information wanted by survivors; and 384 whether survivors made additional changes to reduce their chance of infection. However, previous research with 385 haematological cancer survivors have found younger adults to report higher levels of unmet needs across a 386 variety of areas [49,41,48]. Thus it is possible that a significant association between age and the outcomes 387 assessed in this study may have been found if we had sufficient numbers to include the youngest age group as a 388 separate category in the univariate and multivariate analyses. Future research should attempt to recruit a larger 389 number of haematological cancer survivors aged between 15 and 39 years at diagnosis, and further explore the 390 impact of age on haematological cancer survivors' need for additional information and support to manage the 391 effects blood cancer has had on their life. It should also be noted that there was a substantial proportion of 392 missing data for responder and non-responder characteristics obtained from the cancer registry. The differences 393 found in the response rates should be interpreted with caution. However, the investigators have previously found 394 a similar association between response rates and age in another population-based study they conducted with 395 haematological cancer survivors [51]. A previous study exploring the response rates of adolescent and young 396 adult cancer survivors recruited from a population-based registry, has suggested that younger adults may be 397 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.

401 Second, this study did not take into account what information about infection control survivors had received and 402 from what sources. Future studies should explore what information haematological cancer survivors are basing 403 their behaviour changes on. Finally the outcome measures used in this study were created for the specific 404 purposes of this research and have not undergone psychometric evaluation. However, the outcome measures 405 were developed based on the literature and previous research conducted by the investigators. Furthermore, open-406 ended comments were encouraged to be made by the participants to ensure an in-depth assessment of this topic 407 was obtained from the target population.

408 CONCLUSION

409 This study provides important insight into what specific information and support may be most useful in helping 410 haematological cancer survivors to deal with the changes they have made as a consequence of their disease. It 411 also provides new knowledge regarding the specific changes haematological cancer survivors have made to 412 reduce their chance of infection, and what support and information they would find most beneficial in making 413 such changes. Where possible health care providers should tailor relevant information to a survivor's specific 414 disease, treatment and demographic characteristics. Ongoing assessment of survivor's information and support 415 needs should also be made throughout the cancer trajectory, with important information reinforced at each stage. 416 Future research should strive to develop and assess the effectiveness of intervention strategies designed to 417 support survivors with these changes, such as access to online support groups.

418 COMPLIANCE WITH ETHICAL STANDARDS

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428 Conflict of interest

429 The authors declare no conflict of interest.

430 Ethical approval

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

434 Informed consent

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

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- 578

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

Characteristic	$\mathbf{N}^{\mathbf{a}}$	%
Sex		
Male	117	51
Female	111	49
Age group at diagnosis		
15-39 years	17	7.5
40-49 years	30	13
50-59 years	67	29
60-69 years	85	37
70+ years	29	13
Cancer type		
Non-Hodgkin's Lymphoma	122	54
Leukaemia	43	19
Myeloma	44	19
Other lymphoma	19	8.3
Marital status		
Partnered	213	83
Single	44	17
Education level		
High school or below	125	50
Trade certificate qualification	72	29
University level degree	54	22
Employment status		
Paid employment	111	43
Non-paid employment	145	57
Time since diagnosis		
1-24 months	23	10
25-36 months	105	46
37+ months	100	44
Cancer recurrence		
Yes	48	20
No/not sure	188	80
Stage in cancer trajectory		
Waitful-watching	22	9
Active treatment (curative and palliative)	91	36
Follow-up appointments only	118	46
Other	23	9

^aTotals 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

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

^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.

Broad change participants reporting broad change Example of specific changes made Social restrictions 36% (31) Avoiding consider places Reduced contact with family/friends Reduced contact with people Employment changes 28% (24) Stopped worked/retired Changed jobs/carce/tasks Reduced hours Use of protective clothing and devices 27% (23) Shoes/orthorizs Travel restrictions 23% (20) Shoes/orthorizs Washs Gloves Incontinence pads Washing device Specialised equipment or furniture Scarf 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 Hygiene practices 14% (12) Hand washing/samitiser Caution with eating foods Avoid or take more care with injuries Grooming Diet changes 10% (9) Special index of preservatives Reduced leisure activities 9% (8) Avoid or take more care with injuries Grooming Animal and environmental restrictions 9% (6) Avoid or cate with animals Avoid soil Use of medications 7% (6) Side effects Immunisation Medications for other illnesses Supplements/munue boosters		Percentage ^a (frequency) of	
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^aPercentage 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.

Additional help or information			
Broad area	Percentage ^a (frequency)	Example of specific type of assistance	
	of broad area of		
	support/information		
Improved communication and	26% (11)	Co-ordination and communication between different	
access to care		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	17% (7)	Financial support	
assistance		Easier access	
		Awareness	
		Building awareness in employers	
		Flexibility in the workforce	
		Help fitting into the workforce	

^aPercentage calculated from the 42 survivors who reported a relevant open-ended response to this question.