ORIGINAL ARTICLE

Returning to work after treatment for haematological cancer: findings from Australia

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Abstract

Purpose Despite the personal and economic importance of the issue of returning to work after cancer treatment, there are major limitations in the research literature on the topic. Indeed, in relation to the focus of the present article, the experience of return to work for Australian haematology patients, there is little research available.

Methods The return-to-work findings are a sub-set from a study examining survivorship issues conducted through indepth, qualitative interviews with a state-wide sample (n= 50) of individuals who were at least 1 year post-treatment for haematological malignancy.

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Research Associate, Institute of Health and Social Science, CQUniversity, Brisbane Campus, 160 Ann St, Brisbane 4000, Australia Results There were three groups identified in relation to employment: (1) those who were retired and work was not an issue, (2) those who had successfully re-entered the workforce and (3) those who wanted to work but were finding the process of return-to-work difficult. It is the third group that is the major focus for this paper.

Conclusions The clear indications are that group 3 requires assistance with return-to-work and were vulnerable to a range of psychosocial distress caused by inability to return to employment. Supportive care strategies to assist return to employment are provided.

Relevance of manuscript to inform research, policies and/or programs

Current improvements in cancer treatments have not only increased the number of cancer survivors but also peoples' ability to work during and following treatment. Maximising opportunities for cancer patients to return to work is a significant concern not only for individuals and employers but also economically for society. The findings reported in this article explored the individual story of a range of individuals with haematological malignancies in relation to their desire and efforts to return to work. Importantly, the findings not only provide insights on the work re-entry challenges faced by such individuals but also posit supportive care service delivery solutions to assist those who are vulnerable and frustrated in their efforts to find employment.

Keywords Haematological malignancies · Employment · Qualitative research · Supportive care

Current improvements in cancer treatments have not only increased the number of cancer survivors but also peoples' ability to work during and following treatment [1–3]. Due to the improved prognosis of many forms of cancer, an

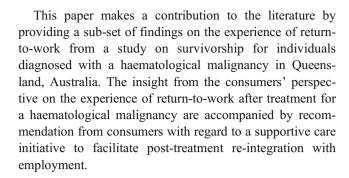


increasing number of cancer survivors are both willing and able to return to work after their treatment [4]. As Rasmussen and Elverdam [5] demonstrate, for cancer patients work contributes to creating the individual as a social being, partaking in social relations with others and plays a role in establishing the individual's identity.

From an international perspective, the employment of cancer patients has major economic and productivity implications. In the USA, for example, 40% of cancer survivors are working age [6]. Similarly, in Canada in relation to breast cancer alone, each year over 20,000 women are diagnosed, most of whom anticipate a considerable number of years of potential participation in the paid labour market [7]. In Korea, cancer diagnosis adversely affects employment status and the effects are widespread in almost all gender and age groups [8]. Thus, as Amir and associates [1] argue, maximising opportunities for cancer patients to return to work is a significant concern not only for individuals and employers but also economically for society.

Despite the importance of the issue, there are major limitations in the research literature on the topic. Indeed, in relation to the focus of the present article, the experience of return to work for Australian haematology patients, there is little research available. Most of the research completed on the topic is in geographical locations other than Australia and on the generic 'cancer patient' rather than specific diagnostic conditions. The work that has been done in Australia focuses on occupation as a cause of cancer rather than the integration of the cancer patient back into the workforce [9]. As Gordon and associates [10] point out, there are no Australian studies examining work participation after cancer or the potential barriers to work continuance. A rare example of research in this area on haematological malignancies is Cheung and associates' [11] study on work productivity for non-Hodgkin's lymphoma. These researchers emphasise the limited research in the area and the need for further studies [11].

Authors in the area provide a long list of issues yet to be explored such as the impact that both diagnosis and treatment has on cancer survivors' ability to fully engage in paid work [3], barriers to work return that can guide interventions and occupational services to keep survivors healthy and in the workplace [10, 12], why problems with employer support and work adjustment occur [13], interventions that will enhance return to work in patients with cancer [14], and social factors that support cancer patients to continue working [4]. As Rasmussen and Elverdam [5] note, little attention is given to individual experiences of returning to work. In short, all these requests for further studies indicate that research on this topic is still in its infancy with much work needed to inform service delivery and health policy.



The research

The research project is a collaborative initiative of the Leukaemia Foundation of Queensland (LFQ) and the International Program of Psycho-Social Health Research (IPP-SHR). The aim of the research was to document and explore issues associated with the experience of survivorship for haematology patients supported by LFQ. The haematology patient's experience with return to work was one of the issues explored through the research. The study provides practical insights to inform supportive care service delivery on how to effectively engage with and support individuals coping with a range of psycho-social issues associated with haematology diagnosis and treatment.

Research design

A qualitative design based on a series of open-ended interviews and one focus group was utilised for the research to explore and document the experience of survivorship from the perspective of adult patients diagnosed with a haematological malignancy. For the purpose of this research, a 'survivor' was defined as an adult individual with a haematological malignancy who was at least 1 year post-diagnosis. The focus group was used as a forum to return the findings to a separate group of haematology survivors to affirm or extend the conclusions reached.

Purposive sample of participants

Participants were purposively sampled from a database of patients maintained by LFQ. The participants were enrolled through two IPP-SHR project officers who were under contract with the University and independent of LFQ. Potential participants received a letter from LFQ informing them of the study and stating that if the person did not want to participate in the study they could contact LFQ to opt out. Any individual not wanting to be involved in the research was deleted from the list. At this stage, the database of patient contacts, excluding the details of those who chose to withdraw from the study, was provided to the



external Project Officers for the selection of participants. Thus, the actual identity of those who did participate remained confidential as LFQ was not provided with any detail on the actual selection. Potential participants were provided with a written project description and consent form and an initial telephone call inviting participation in the research. Prior to interviewing, participants were again informed of their ethical rights (e.g. informed consent, confidentiality, right to withdraw) and individual consent obtained. The University Human Research Ethics Committee approved the study.

All participants had to meet the criteria for survivorship in that they were an adult individual with a haematological malignancy who was at least 1 year post-diagnosis. One hundred and eighteen potential participants were contacted to participate in the research with 14 declining to participate and 54 being uncontactable (due to change in contact details). In total, there were 50 participants (n=26 male; n=24 female) which represented 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 and 15 had a stem cell transplant (allogeneic and autologous transplants). Due to the unique geography, population and services provision patterns of Queensland Australia, a custom regional classification system was designed and used to ensure the purposive sample include participants that had varying levels of access to haematological services based upon their home address. The sample also ensured a representation of ages across the adult life span. At the completion of the 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.

Interviews and focus group

The exploration of the experience of relocation from the consumers' perspective was conducted through an iterative, qualitative research methodology using open-ended interviews conducted by speaker-phone at the time and location chosen by each participant. The interviews began with the invitation to the participant to talk about their experience since diagnosis and treatment for a haematological malignancy. A list of topic areas to explore during the interviews was developed from consultation with LFQ, published research and anecdotal comment. However, in accordance with the iterative principle of qualitative research, the issues being explored evolved with the study with early insights informing the discussions in subsequent interviews. In relation to the sub-set of findings presented in this paper,

all participants were asked to talk about their work experience prior to diagnosis and after treatment. The interviews proceeded at the pace and direction of the interviewee and included techniques of probing, clarification, paraphrasing and summarising to explore each participant's experience. The interviews lasted for approximately 1 h and were audio-recorded and transcribed verbatim. The focus group participants were presented with a PowerPoint summary of the findings from the interviews and encourage to comment, by expressing agreement or disagreement and further thoughts on the issues. The focus group was recorded and transcribed verbatim. The focus groups findings were in complete agreement with the individual participant findings.

Analysis

The language texts were then entered into a computer-aided qualitative data analysis program, NVivo, and analysed thematically. All of the participants' comments were coded into 'free nodes' which are category files that have not been pre-organised but are 'freely' created from the data. The list of codes was then transported to a Word Computer Program (Word 2007) and organised under thematic headings. The coding was established by an experienced qualitative researcher and completed by a project officer who has extensive experience with coding qualitative data. There was complete agreement on the coding and emergent themes created from the transcriptions.

Thirteen of the codes related to the participants' experience with employment. It is the analysis of that data that forms the basis for the findings presented in this article. Further findings from the study based on the same methodology are starting to be published, for example, an article on 'chemo brain' [15].

Findings

Table 1 provides detail on the identifiers used for the quotes. There were three groups identified in relation to the experience of return-to-work. The major concern for this paper is on the third group who desire to work but have difficulty obtaining employment.

Group 1: return-to-work not an issue

Those who were near or past the age of retirement indicated that returning to work was not a survivorship concern relevant at the time of the interview, for example:

 (MDSAML_MP_F_59years) No concern, we were already retired.



Table 1 Participant identifiers

| - | |
|------------------|---|
| Diagnostic group | |
| MDS AML | Myelodysplastic syndromes and acute myeloid leukaemia |
| LeukCML | Chronic myeloid leukaemia |
| Lym Comorbidity | Lymphoma and comorbidity |
| MM | Multiple myeloma |
| Leuk APML | Acute promyelocutic leukaemia |
| Lym NHL | Non-Hodgkin's lymphoma |
| Amyloidosis | Amyloidosis |
| LeukAML | Acute myeloid leukaemia |
| Transplant | |
| BMT | Bone marrow transplant |
| SCTrans | Stem cell transplant |
| Locality | |
| MP | Metropolitan primary |
| MS | Metropolitan secondary |
| RR | Rural and remote primary |
| | |

Group 2: returned-to-work successful

Group 2 group were motivated to return to work and successful in their efforts to re-enter employment. Some individuals had sufficiently recovered physically and were able to return full-time to their previous positions with minimal impact from the disease and treatment, for example:

 (LeukCML_MP_M_53years) I come home from hospital on the Wednesday and I went back to work on about the following Tuesday, so very minimal impact.

Others embraced full-time work even though it was physically demanding as can be seen by the following descriptions, for example:

(LymCo-Morbidity_MS_F_48years_SCTrans) I got a
full time job and I was still only a casual but it was full
time hours and so I did that and I mean I was tired,
don't get me wrong, I'm not going to say that I wasn't, I
was tired.

The return-to-work was incremental for some, starting with part-time work and then increasing the hours.

The time of absence from work for treatment and recovery varied from months to years. Obtaining clearance from the treating physician to resume full-time work was noted as important. Most returned to previous positions but there was evidence of individuals applying for and obtaining new positions. Those able to return to work spoke positively about the opportunity, for example:

 (LymCo-Morbidity_MS_F_48years_SCTrans) Aw I love it, I love it. Yeah and so I've been back there for about four and a half months now (LymNHLComorbidity_Remote_M_52years) It was a good thing. It was a good thing because it was 984 bricks in the motel we were in. How bored we got.

The support of employers was noted as an important factor facilitating return-to-work. A key aspect of support from employers was the offer of flexibility in relation to the hours that needed to be worked. Flexibility with relation to working hours provided time cover for medical treatment, for example:

(LymCo-Morbidity_MS_F_48years_SCTrans) Yeah
and they're very good because we can work extra
hours so when I need to take time off once a month
to see the oncologist. I've got a very good manager.

Flexibility in time management provided the opportunity for individuals to return part-time who were not physically capable of full-time work, for example:

 (MM_MS_M_44years_SCTrans) The director of the centre has been very good to me. Once I was diagnosed and I couldn't do full time work anymore he found projects that required whatever I could do. It's been very flexible for me. I mean I feel very blessed in that regard.

Supportive employers were not only flexible in terms of hours but also in relation to the type of work the individual was required to do, for example:

 (LeukCML_MP_M_53years) My employer is super supportive I sort of worked half days for quite a while depending on if I was tired and if I needed time off—we sort of changed my role in the business.

There was a psychological dimension to the support that survivors valued from employers which included respect, compassion and care. Stories of such respect and care were usually associated with long-term employment, for example:

 (MM_RR_M_65years) I've been shown great respect by the company I work for they're always, always at my side saying are you alright, are you managing everything okay you know at work which is a big thing as I have worked for them for 26 years

For some, such respect and care translated into protection of the individual's right to return to the same position even though there were long time lapses associated with treatment and recovery.

Although for some there were compromises and daily struggles, overall this group (group 2) of individuals did find employment and were pleased to be part of the workforce again.



Group 3—problems returning to work

For the third group of individuals, there were major obstacles in the path of their return to work which resulted in significant difficulties finding work or being forced to reluctantly let go of the idea of working. The data indicated that there are a range of late effects that can impact on return to work such as ongoing digestive problems and stomach upsets, bouts of pneumonia, avascular necrosis, graft-versus-host disease (GVHD), shingles, pain, sleep problems, mental stress and physical exhaustion. Of all the physical complaints, the most significant problem that the majority of participants reported as interfering with return-to-work was fatigue, for example:

 (LeukAPML_MP_F_40years) ... one of my major problems is fatigue. I have not recovered from that side of it, I get very fatigued very quickly and I'm still only working part-time cause the fatigue is an overriding issue for me.

There were particular problems for those who had previously engaged in predominantly physical work such as labouring, for example:

(LymNHL_MP_M_38years_BMTandSCTrans) ... [it's]
not like I can't really go out and do sort of labouring
sort of work like I used to at the moment because you
just can't. [I] would not be able to handle it, like my
back especially...

Similarly, conditions such as sun sensitivity from treatment prevented others from returning to their previous positions. Others were forced to seek new employment because the employment in their previous position is terminated by the employer. For many in this group, the loss of the opportunity to work came as a shock and was difficult to accept, for example:

 (MM_RR_M_64years_SCTrans) I have no hope of getting back into work, I'm too disabled to be honest.
 And I was shocked (when told by the doctor I could not return to work).

For those still motivated to work despite the difficulties, re-entering the workforce was viewed as a major challenge, for example:

- (AmyloidosisMM_RR_M_56years_SCTrans) ... We're now a bit older and we're finding that we've got to sort of start at the middle or even lower in the job market.
- (LymNHL_MP_M_38years_BMTandSCTrans) it's just hard to try and find a reasonable job.

The loss of opportunity to work was associated with serious ongoing psychosocial consequences. It was noted that loss of work can impact on a person's sense of confidence and competence, for example,

 (LeukAML_MP_M_64years_BMT) At work I was very confident that I knew what I was doing and I was confident and competent. As soon as you leave work and have no feedback of what you're doing, being worthwhile, [you] start to feel that you're not worthwhile.

Another major psychosocial impact of the loss of work was the break from meaningful social relationships which can be a stressful experience, for example,

 (MM_MP_M_66years_BMT) Usually when you work that's where all your friends and people come from, you know your outside life, so we have a very limited outside life.

Individuals described a sense of uselessness associated with lack of work, for example:

• (Focus GroupP6): You feel useless. (Focus GroupP2): Yeah it makes you feel unnecessary.

Most importantly, the financial impact of not being able to work was acute, especially for younger individuals, for example:

(LymNHL_MP_M_38years_BMTandSCTrans) I'm just
waiting... to feel a lot better again so I can try and get a
job again. What really annoys me is I haven't got a
house for my kids, that's the part that really hurts. It's
had a major financial impact.

Consumer recommendations for a return-to-work supportive care initiative

A core concern for the third group is the fact that, although challenged by physical limitations, these individuals were motivated to return to work but do not have the knowledge, contacts and support to ensure that this can happen. The angst and frustration is clearly articulated in the following participant's description of the concern,

 (Focus GroupP6) And trying to find work in other fields using the skills that I have—I just found myself in tears it was just overwhelming. It's hard. And trying to find work in another field using the skills I have I don't have the experience in those areas. I get disqualified all the time. It is really hard.

The clear message from the research is that this group of people need support and assistance in order to overcome the obstacles to employment. As one participant emphasised the issue in relation to supportive care service delivery,



 (LymNHL_MP_M_38years_BMTandSCTrans) The work issue is really important and significant. The thing I do think there needs to be some attention to that.

It was noted that the usual government funded employment organisations for placing individuals in work would not be appropriate or useful for individuals coping with the impact of haematology disease and treatment, for example,

 (MM_RR_Male_63years_BMT) It's probably would be quite daunting to use the normal job network people that (government funded organisation) refer you to look for work. It probably would be quite daunting for someone that's recovering from a transplant and looking for work to use that sort of system.

In general, individuals did not know which services were available to help them with their special needs in relation to return-to-work.

The participants provided specific practical recommendations with regards to the best way supportive care organisation could assist survivors return to employment. As the study was funded by LFQ, the recommendations have direct practical application to LFQ support services. However, the recommendations also provide a blueprint for the way forward for other NGOs and supportive care programs in regards to addressing employment issues for individuals coping with haematological malignancy.

The first recommendation was the call for a support worker with knowledge and expertise in employment who could build up knowledge of organisations who would be welcoming and supportive of individuals challenged with the impact of disease and treatment for haematological malignancies. The role of such a worker would be to build up a database of potentially supportive employers. As one participant explains,

• (MM_MP_Male_63years_BMT) Yes, a database on organisations who could offer employment. You know maybe some sort of agency that's more sympathetic to the actual needs of the people coming from that situation. You can imagine they could build up even a database to do with other supportive care organisations and whatever, where people can you know, depending on their ability and their skills that they bring, could be matched.

With information from a database of suitable employers, the worker's role would be to establish networks with a range of organisation to facilitate the placement of individuals in position appropriate to their interest, abilities, physical and time limitations. The key resource would be the database of contacts and the significant professional activity would be the matching of the survivor with the appropriate position. As one participant explains,

• (LymNHL_MP_M_38years_BMTandSCTrans) The (supportive care organisation) could put somebody on who's got a bit of expertise in this area. What some people need is to find you work where the bosses or whoever run these companies do understand. You need something to ease yourself into work again and finding that job is hard. If they could look out for positions. If their job was just to do the networking to find out what's out there and do the matching.

The anticipation would be that the numbers seeking such help would not be large as many survivors are of retirement age or on Disability Allowance. Hence, the return-to-work scheme would probably only require a part-time position.

For some people, the re-entry to work has to do with seeking meaningful engagement with life rather than financial reward. For these people, volunteering would be a solution to the void in their life and a potential benefit for organisations engaging with them. The recommendation is for the employment support worker to also build up a database of organisation that are seeking volunteers or develop networks with organisations that are involved in providing networks and placements for those wanting to volunteer. The role of the worker would be to link the individual with volunteer work or, at least, refer to an organisation that is involved in engaging volunteers in suitable positions.

As discussed previously, lack of employment can create significant psychosocial distress. The recommendation to address such psychosocial distress is the provision of counselling to support and debrief the individual through the difficulties associated with employment problems.

The physical limitations of disease and treatment require some individuals to change directions in employment. Thus, retraining and further study are noted as important aspects of re-direction in employment seeking. Vocational advice and information on training and study options are essential for effective decision-making in regards to employment re-direction. In terms of a return-to-work supportive care initiative, a supportive care worker with a background in vocational counselling could be employed to offer support, advice and information on retraining and study options.

Discussion

In Australia, age is an important factor in relation to employment issues with regards cancer, and especially haematological malignancies, as these are primarily diseases which affect older people [17]. Thus, as the findings indicate, many of the individuals diagnosed with these conditions are either close to or in retirement. For this



group of individuals (group 1), the issue of return to work was not considered relevant or important. Research by Cheung and associates [11] demonstrated a similar trend to retirement with individuals diagnosed with non-Hodgkin's lymphoma. In their study, over 71% of patients were working while 14% were retired; however, this changed by the time of survey administration to only 41% still able to work with a significant proportion of patients (36%) having transitioned to retirement.

The second group of individuals identified by the present research were those who were motivated to return to work and had either successfully returned to prior positions or found new positions. This finding resonates with Rasmussen and Elverdam's [5] research that indicates that cancer survivors try to get back to work after treatment and try to re-establish their former structure of everyday life that is seen as a normal and healthy existence. A systematic review of the literature on the topic indicates that the rate of return to work for cancer survivors is greatly variable ranging from 37% to 89% [14].

For many in group 2, the disease and treatment had minimal impact on their working life; however, for others the demands of full-time work was a struggle with the only option to accept part-time employment. In contrast, research by Cheung and associates [11] on individuals diagnosed with non-Hodgkin's lymphoma who continued to work reported a minimal impact on their work productivity and on their daily activities attributable to their cancer. Physician approval, although documented elsewhere as a barrier [18], was in this study seen as a reassuring and necessary requirement. In the present study, as reported elsewhere [19], return to work can have powerful restorative properties.

As noted elsewhere [3, 18], the support of employers in terms of compassionate respect and flexibility about time and conditions of work was a major positive factor facilitating return to work for individuals with cancer. However, research on overcoming workplace obstacles is still in the early stages of development and, as yet, there is scant work that examines the specific issues for individuals diagnosed with haematological malignancies. Thus, further research is required to understand the myriad of factors that can impede or facilitate support from employers and the relevance of such factors to individuals coping with potentially life-threatening conditions requiring lengthy and often aggressive treatments associated with haematology. The present insights from the perspective of haematology patients need to be enriched by a better understanding of the complexity of the workplace and how best to educate and support employers on the issue of work re-entry.

The third group of individuals documented in the study were motivated to return to work but faced major obstacles in their efforts to reintegrate into the workforce. Physical late effects from the disease and treatment, especially fatigue, created major obstacles to negotiating and maintaining suitable employment. The inability to maintain physically demanding positions or to work outside because of sun sensitivity meant that some were forced to change employment positions. Problems with re-entry were met with shock and dismay along with a sense of being overwhelmed with the challenge of finding a new position or employment path. The loss of employment was accompanied by significant psycho-social problems such as decrease in sense of confidence and competence, lack of meaning, interference with social relationships and a sense of uselessness. These findings resonate with the work of Rasmusen and Elverdam [5] that indicate cancer patients who are unable to work lose a part of their identity through the lack of companionship and the many personal challenges and satisfactions related to work. Of major significance, especially for the young, was the impact on financial security. Similarly, Amir and associates [18] document that, along with the quest for normality, financial pressures are a principal motivation for cancer patients returning to work.

The findings from the present study affirm Park and associates' [20] call to focus on the vulnerable to minimise undesirable changes in employment status. The clear message from the present research is that the third group of people need support and assistance in order to overcome the obstacles to employment. Whilst the present study identified the existence of this group with acute work reentry stress, further research is required to measure the level of distress such individuals are experiencing and to develop work-related screening tools to assist with the identification of such individuals for supportive care follow-up.

The present findings respond to the lack of research by not only positing the return to work problems faced by a sub-group of individuals diagnosed with a haematological disorder but also by offering service delivery solutions from a consumer's perspective. The initiatives are predicated on the fact that individuals in this position do not have the knowledge or networks through which to engage in return to work, and their difficulties are exacerbated if they are in a weakened physical condition and/or have to redirect in their employment opportunities. There is considerable angst and frustration associated with the difficulties experienced in return to work. It was noted that special supportive care initiatives are required for individuals coping with the unique challenges associated with return to work after treatment for a haematological malignancy.

The findings were returned to LFQ, a leader in supportive care service delivery for haematology patients in Queensland, for consideration and advice with regards to a viable and practical response to the concerns highlighted in regards to group 3. The solution suggested was the appointment of a support worker with expertise in



employment issues to offer counselling and vocational advice. Cognisant of the fact that the research indicates that of the total population of haematology patients there will only be a sub-group (defined in this paper as group 3) that will need assistance, the work load for the vocational support worker is initially considered appropriate for a part-time position. The establishment of a database of employers with suitable positions and of organisations interested in engaging volunteers is a basic resource required. The worker would provide the contact with a suitable organisation. In addition, such a worker trained in employment issues would be available for counselling and vocational advice in retraining and further study.

In consideration of Tamminga and associates' [14] call for the need for future studies to evaluate well-structured work-directed components of supportive care for cancer patients, plans are initiated to translate the recommendations from the present study into LFQ service delivery initiatives which can be evaluated with further research. The projected outcomes are both the development of a much needed return-to-work supportive care service and an evaluation of the effectiveness of such an initiative that can make a contribution to the research literature in this area. In so doing, the paper responds to Short and associates' [16] call for further efforts on the part of public and private cancer organisations, researchers and clinicians to address the employment concerns of survivors.

Conclusion

The difficulty associated with the impact of cancer on individuals' capacity to work is an understudied survivorship issue [10]. As Rasmussen and Elverdam [5] keenly argue, cancer survivors have diverse and complex patterns of return to work, but little attention has been given to individual experiences of returning to work. In response to addressing this lack of attention, the study reported in this article explored the individual story of a range of individuals with haematological malignancies in relation to their desire and efforts to return to work. Importantly, the findings not only provide insights on the work re-entry challenges faced by individuals with a haematological malignancy but also posit supportive care service delivery solutions to assist those who are vulnerable and frustrated in their efforts to find employment.

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