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Title page

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Title: Returning to work following curative chemotherapy: A qualitative study of return to work barriers and preferences for intervention.

Vikki Knott¹, Stephanie Zrim², Michael E. Shanahan³, Peter Anastassiadis⁴, Sharon Lawn⁵, Ganessan Kichenadasse², Shawgi Sukumaran², Christos Karapetis², Bogda Koczwara²

¹Menzies School of Health Research

²Department of Medical Oncology, Flinders Centre for Innovation in Cancer, Flinders University and Flinders Medical Centre

³Department of Rheumatology, Southern Adelaide Local Health Network, Flinders University

⁴Department of Rehabilitation and Aged Care, Repatriation General Hospital

⁵Department of Psychiatry, Flinders University

Corresponding Author: Vikki Knott

Menzies School of Health Research

Vikki.knott@menzies.edu.au

Abstract

Purpose This study aimed to explore barriers to return to work (RTW) and preferences for intervention and support for cancer patients treated with curative intent from the perspectives of cancer survivors and oncology health professionals. *Methods* Participants attended a focus group (N = 24) or an individual interview (N=14). A topic guide and a semi-structured recorded interview format were used to gather data, which were later transcribed and analysed for global themes and subthemes. *Results* With regard to barriers, the global theme ‘work capacity’ captured an array of barriers encompassing financial pressure, preparedness for work, lack of confidence as well as other key physical, practical and psychosocial barriers. Participants expressed a preference for RTW models that focus on objective and structured assessment whilst allowing for flexibility to address individual needs. *Conclusions* Cancer survivors perceive multiple barriers when attempting to RTW. These barriers were perceived to impact upon work-capacity, where ‘capacity’ was defined broadly to include practical, physical and psychosocial concerns. RTW is an important concern for cancer survivors and structured RTW interventions should be incorporated into the care of cancer survivors.

Key words: Return to work (RTW); barriers to RTW; RTW interventions; supportive care; occupational rehabilitation.

Introduction

Nearly half of patients diagnosed with a curable malignancy are employed at the time of diagnosis [1]. Following cancer, approximately one third of working cancer survivors do not return to employment [2]. While this may be as a result of a patient's preference, research indicates that for many cancer survivors work ability is impaired more than for workers with any other chronic disorder [3]. Approximately 20-30% of working cancer survivors report one or more limitations in work capacity [4] underscoring the need for quality interventions to assist survivors return to work.

Maintenance of employment, following the diagnosis of and treatment for cancer has substantial benefits to an individual in enhancing their sense of personal worth and identity as well as providing financial security [5]. Moreover, returning to work can signify recovery [1] and provide for a sense of normality and control [6, 7] with the workplace seen as a place of support and social connections that can enhance emotional wellbeing and self-esteem [8, 7]. Employed survivors have better physical and psychosocial functioning and improved quality of life than their unemployed counterparts [9-12]. Conversely, loss of employment has significant negative financial implications at an individual and societal level [13].

Many cancer survivors identify limitations in their work capacity and experience altered relationships within their workplace, potentially hindering their return to work (RTW) [14-17]. At present there is no standardised approach to the RTW rehabilitation (occupational or vocational rehabilitation) of cancer survivors though pilot research indicates a high level of acceptability for the inclusion of RTW strategies within a psychosocial care model [16]. A limitation of previous research is that whilst it is clear that a range of factors can impact on RTW processes, little is known regarding the preferences of cancer patients for RTW interventions. A further limitation of previous research is the lack of inclusion of oncology professionals, and other specialist health care professionals providers (e.g., occupational and/or rehabilitation medicine physicians). Their perspectives are important when attempting to design and deliver effective RTW interventions for cancer patients. Thus, the aim of this study was to explore, from the perspectives of survivors (treated with curative intent with

chemotherapy) and oncology health professionals, the barriers to RTW as well as the preferences for intervention and support regarding RTW.

Methods

A qualitative research design with focus group discussions and interviews was utilised for the current study.

Participants and sampling

Two participant groups were recruited for this study: survivors treated with curative intent and oncology healthcare professionals (OHPs). Cancer survivors attending a medical oncology clinic were recruited via opportunistic sampling involving direct approach. They were invited to participate in the study by investigators during their clinic attendances. To be eligible for participation, survivors had to be ≥ 18 years; currently being treated with curative intent chemotherapy or in attendance at a follow-up appointment; were in paid employment at the time of cancer diagnosis; and, have the ability to communicate sufficiently in English.

OHPs were invited to participate using the principles of purposive sampling [18]. Representation from a variety of OHPs, including those involved in the provision of supportive care, were purposively sought by direct invitation, either by e-mail or personal approach by investigators.

Interviews and focus groups

All participants were offered the option of participating in focus groups (cancer survivors; n= 11, OHPs; n= 13) or individual interviews (cancer survivors; n= 6; OHPs; n= 8). Author SZ conducted the focus groups and interviews with patients and OHPs. Shown in Tables 1 and 2 are examples of questions used to direct conversation within interviews and focus groups.

Insert Table 1 approximately here

Analysis

Interviews and focus groups were digitally recorded and professionally transcribed. Participants' names were changed to maintain anonymity. Author SZ analysed all transcripts using Braun and Clarke's 6-phased approach for the coding of qualitative data [19]. Then, Authors BK and VK performed analyses on a subset of transcripts, again using the coding approach described by Braun and Clarke [19]. SZ, VK and BK discussed their results. There was significant overlap among themes developed between SZ, VK and BK, and minor discrepancies in themes appeared to reflect the researchers' professional orientations. Discussion continued until the authors were confident that biases in interpretation were minimised and then the authors reached consensus with regard to the emergent themes.

Approval for the conduct of this study was gained from the Institutional Human Research Ethics Committee, Flinders Medical Centre.

Results

Seventeen cancer survivors, the majority female (n=13) and 21 OHPs, the majority female (n=12), participated in the study; two family members were in attendance at focus groups but their data were not included in any analyses. The OHPs included medical (n=9), nursing (n=7) and allied health professionals (n=5). Further demographic detail of participants is provided in Table 3.

Insert Table 2 Approximately here

Major Theme 1: Work Capacity

Survivors and OHPs identified a range of barriers regarding RTW. These barriers generally reflected issues of work capacity, as shown in Figure 1.

Insert Figure 1 about here

Challenges fulfilling job requirements/reduced capacity

Survivors spoke of the challenges fulfilling job requirements including meeting its physical and emotional demands. In addition, returning to fulltime working hours was commonly discussed as a significant challenge. OHPs also emphasised survivors' limitations with regard to work capacity:

To think of returning to work, it would be, how I am going to cope with a 12 hour day?
(Yvonne, ovarian cancer survivor, age 47)

What they're capable of doing within the realm of some of the operations they have [had]. Capacity issues, as well as the change in priorities. They're not always able to get back to what they were doing before or perhaps the same degree.
(Peter, Cancer Nurse)

Financial pressure – forced to RTW

Many survivors commented that they returned to work due to financial necessity; however, some cancer survivors indicated that they felt unprepared. As indicated by the following response from a cancer survivor, some were risking their safety.

Some days you are climbing up on top of roofs ... I could go and stand on the edge of a roof and that and look down for three or four stories - [it] wouldn't worry me in the past. Now I don't know if I'm going to lose my balance. I came off site for the first couple of times from working too many hours and then having to drive an hour home, which nearly got me into a few little nasty incidents.

(Phil, testicular cancer survivor, age 39)

I know people who never stopped working during their treatments, they just keep pushing hard and struggle through the treatment and at the same time work and they don't need any changes. They're comforted to work because of financial constraints, the family needs them to work, they have to pay the mortgage off otherwise they'll be selling their house.

(Gordon, Medical Oncologist)

Lack of confidence

Cancer survivors frequently discussed the impact of cancer on their confidence. For some, it was the major barrier for them returning to work after a cancer diagnosis; this issue was reiterated by OHPs.

I've lost a lot of my self-confidence, I don't know whether I could cope with it, or cope with other people. I'm not sure I have the confidence to be sure that I'm making the right decisions. I think that's just the whole cancer; it's undermined my self-confidence.

(Marilyn, breast cancer survivor, age 52)

If you've been totally focused, or your whole focus for one year has been your diagnosis and your treatment, then getting back, it's like having a child when you get back into the workforce. You've been out of that contact for a long time and you do have confidence issues in trying to get back into the world.

(Fiona, Breast Nurse)

Practical and physical barriers

Survivors and OHPs identified a range of additional barriers to fulfilling work capacity. At a practical level, managing multiple doctors' appointments and/or not having the ability to drive a care were described as barriers to RTW. OHPs and cancer survivors identified physical barriers such as nausea and vomiting. Fatigue, and to a lesser extent chemo brain, were considered by cancer survivors to be significant physical problems. In addition, longer-term physical symptoms such as neuropathy, lymphoedema, and managing stomas were also identified as impeding RTW outcomes.

Psychosocial barriers

Psychological barriers, especially a fear of recurrence, were considered by OHPs as possibly more difficult to address.

What I'm often doing is I'm providing a little bit of education that actually the stress from working will not bring the cancer back. And the benefits derived from going back to work will actually outweigh the potential risks from it. But that can be quite a significant psychological barrier.

(Jennifer, Clinical Psychologist)

A fear of recurrence was discussed by the majority of survivors and in some cases limited their ability to concentrate on work. Many cancer survivors described themselves as depressed, anxious,

distressed, self-conscious, and lacking in confidence at some point over the treatment, recovery or with regard to their ongoing wellbeing.

Every little niggly pain, you just don't know what it is. And that just affects your whole day when you go like that. I mean before my last check up, a while ago, I wasn't feeling 100% quite right. For the next couple of days, my mind was all over the place instead of where it should have been - working.

(Aaron, testicular cancer survivor, age 39)

Although several survivors described supportive work environments, a minority spoke about other psychosocial barriers reflecting difficulties communicating with others at work. A number of survivors expressed concern over clients' or colleagues' insensitive comments, such as "Has the cancer come back?"; "Why haven't you got any hair?"; "How do you feel now that you've got something in your body attacking you?"; and, "What does it feel like to only have one boob?"

OHPs often discussed community attitudes toward cancer and used the term, social stigma, when describing a need for society to be educated that cancer does not mean death.

There's [sic] individuals that get back to work with cancer but there's no cultural expectation that someone you know [with cancer] will come back to work"

(John, Rehabilitation Physician)

What are you doing back here? You've got cancer. And might be discouraging for them to get involved, or the other element of that might be they might say to them, well, you know, you poor old thing, put your feet up, we don't want you working here because you need to be resting.

(Dennis, Occupational Physician)

Lack of knowledge regarding organisational policy/legislation

Other system level barriers were described. These barriers referred to issues pertaining to a lack of knowledge regarding organisational policy or legislation. Survivors expressed a lack of knowledge regarding leave entitlements, rights to return to work, workplace obligations, risks and also potential supports to access this information.

I knew I had the support but I knew that the sick leave would eventually run out and that's when the financial things kicked in and not knowing where I could go and who I need ... I'd have to keep the cancer thing secret because I think there would be some prejudice.

(Brooke, ovarian cancer survivor, age 50)

How are they are going to react? Are they going to sack me because I didn't ring in? Or [will they] see that I'm not capable of doing my job?

(Merlyn, breast cancer survivor, age 52)

... we give them the fitness certificate at the end of treatment or whenever they're ready. I don't actually put a date on it. When they're ready, you know, I just leave it for them.

(John, Medical Oncologist)

Major Theme 2: Preferences for RTW intervention

Cancer survivors and OHPs were explicitly asked to identify preferences for intervention with regard to addressing RTW barriers. A thematic map depicting the emergent themes is shown in Figure 2.

Insert Figure 2 about here

Raising Awareness

Cancer survivors and OHPs alike commented on the need for a greater awareness that RTW is a potential issue for survivors and should be considered a component of survivorship care. Most OHPs acknowledged that they did not play a role in the return to work of survivors in the current system.

However, those who did indicated that survivors often needed reassurance.

...It's the reassurance that what they do is not going [to] bring back the cancer.

(Greg, Cancer Nurse)

If they're not for discharge that day [then] because we're sort of driven by this hospital system of seeing people to get them out ... they would probably not even get referred.

(Hayley, Occupational Therapist)

Structured Approach

A key recommendation with regard to developing RTW interventions was that they needed to be structured. OHPs and cancer survivors suggested an approach similar to that applied when a physical injury occurs at the work place. Participants expressed a preference for a structured and objective approach consisting of social, physical, psychological, work role and environment assessments; consideration of modified roles or the establishment of a graded RTW plan if necessary; follow up and evaluation; and, links to established community support services.

They have guidelines in terms of, you know, getting people back to work when you've had an injury at work, you know, and they phase in your return to work based on your capabilities and what you can do based on your injuries.

(Yvonne, ovarian cancer survivor, age 47)

There would need to be clearance [for RTW] by the key clinicians, and then the assessments required, and then mapping out a [RTW] pathway. Some of it might be fairly straight forward; other people are going to need a more intensive, longer program, much more negotiation with employment, with employers, maybe some sort of extended work trials, work hardening, physical activity.

(John, Rehabilitation Physician)

Expert Advice

Cancer survivors expressed the need for increased access to financial and legal advice for themselves and their employees. Survivors also wanted authoritative advice regarding their wellbeing and ability to RTW. They saw value in providing official documentation to their employees to support their RTW.

If they [workplaces] have information about what your needs are, and what could occur, then they're going to be better prepared to deal with what might happen, so those times when you get too tired, get confused, someone to come in and [say] it's alright, I'll deal with this now. So that the patient doesn't feel like they've let people down. Sometimes employers work better getting that information from somebody that they see as 'officially knowing'.

(Merlyn, breast cancer survivor, age 52)

Some patients ask for letters to give to their employer on occasion. Something to the effect of “I am recovering from treatment and these are the expected side effects and this is how long it’s likely to recover but I am capable of doing A, B and C”. But I might not yet be ready for D”

(Kerry, Cancer Nurse)

Advocacy

OHPs and survivors identified the need for a patient advocate to contact to direct to appropriate services and/or to assist in negotiations with their workplace regarding RTW. Survivors also thought it would be beneficial to have a contact person that their employer could access to answer workplace queries.

A person who is a representative of the patient, and that’s like a go-between, or a communication link between an employer and patient who understands what the impact of that cancer is, and the treatment, and you know, the prognosis and the sort of timeframe for recovery for different stages of recovery and so on.

(Bronwyn, Physiotherapist)

Like an advocate from the hospital to help you deal then with your employer or the super people or something

(Jayne, breast cancer survivor, age 48)

Customisation

Although a structured approach was preferred, OHPs and survivors emphasised that the approach needs to be flexible to meet the needs of individuals. They emphasised that it cannot be a ‘one size fits all’ approach.

It [the approach] needs to be patient centred. What might be appropriate for one person might not be appropriate for another and it's going to depend on what the nature of their occupation is, what their job roles are, what supports they get from their employers as to how effective the return to work program will be.

(John, Rehabilitation Physician)

Multidisciplinary approach

Participants were unclear about who would conduct this assessment and identified a range of professionals; including cancer care coordinators, medical oncologists, general practitioners, and occupational therapists. OHPs spoke frequently about the necessity of a multidisciplinary approach.

I really don't think it's one person that can do it, I mean, there's the Physio, there's the OT, there's all sorts of people that are involved in the wellness of the person, and in assisting them to get back to work, ...it might be a coordinator that might do it, but it's not – that one person can't do everything.

(Alicia, Social Worker)

Discussion

Cancer survivors identified a range of barriers impacting upon their capacity to return to work (RTW), broadly defined to include practical, physical, emotional and psychosocial concerns. Both survivors and cancer professionals express a desire for a broad, objective and structured approach to RTW incorporating input and advocacy from experts across multiple disciplines.

RTW is seen as promoting recovery, providing for a sense of control and a return to normalcy [1, 5, 6-7]. The findings highlighted in our study suggest that a premature RTW for cancer survivors may lead to an increased risk of workplace injury. For example, our study highlights that survivors who are still experiencing symptoms from treatment, and who RTW prematurely, in order to service ongoing financial responsibilities, are at significant risk for injury. Survivors working in fields including building and construction (as was the case with a participant in this study) or where the operation of machinery is core to one's job, appear to be particularly at risk. Thus, too early a return to work could have catastrophic effects for the survivor, and also possibly for those with whom the survivor engages with whilst at work, emphasising the need for structured RTW plans for cancer survivors.

Limitations in work capacity and or ability have been noted as barriers in many RTW studies (14-17). Research identifies that survivors' subjective assessment of their work ability is a strong predictor of RTW [1]; however, in this study survivors lacked confidence with regard to judging their capacity for RTW. The implication of this finding is that part of a structured RTW process may need to involve education and psychological counselling to better match patients' perceptions of their capacity to the realities of their work demands. Cancer survivors also lacked knowledge with regard to their entitlements at work with regard to sick-leave and/or discrimination. Survivors wanted definitive or authoritative advice concerning their rights at work, and their work ability defined by participants to include their psychosocial or emotional wellbeing. Their preference was that a professional with legitimate authority provided this information to their workplace, preferably in writing, or perhaps acted as an advocate or contact person that liaised between the survivor and their workplace. Institutions providing comprehensive cancer care should consider the option of a dedicated person to provide the requisite support for cancer survivors. Whilst survivors indicated a preference for a

structured approach, health professionals noted the need for customisation in order to address the individual needs of patients. Suggestions for the application of RTW processes and procedures implemented for work-place injuries were made. According to participants such approaches would include regular and objective assessment of work-ability, and consist of measures assessing for social, physical, and psychological capabilities.

Cancer survivors and OHPs called for a greater emphasis to be placed on promoting the importance of a focus on RTW issues as part of usual psychosocial care. As identified in previous research, this method for the delivery of RTW interventions appears to be acceptable to patients and feasible to implement (16). Although a multidisciplinary approach to RTW support was emphasised, participants were not clear about which particular health professional should ultimately be responsible.

A major strength of this study is that it included both health professionals as well as survivors, thus our study provided for an in-depth exploration of issues pertaining to RTW. However, there are a number of limitations with regard to the study's methodology. The sample size, whilst appropriate for qualitative research, cannot be considered adequate to generalise across all populations and settings. Furthermore, the majority of participants in both the survivor group and health professional group were women; therefore, the issues and barriers identified in this study may not be reflective of the views of all cancer survivors, or all health professionals working in oncology. Similarly, the sampling framework did not purposively sample for individuals from Aboriginal or Torres Strait Islander backgrounds or for those individuals from Culturally and Linguistically Diverse Communities. Thus, these results may not be applicable to these populations. The study involved an Australian sample; therefore, findings may not be applicable to other jurisdictions with potentially different workplace legislation and structures.

Conclusion

This research identifies a range of barriers to successful RTW for survivors of cancer treated with curative intent chemotherapy. Uniquely, however, this study identifies that some survivors RTW in sub-optimal health which poses further risks for their, and potentially others', health and safety. The

level of unmet need with regards to knowledge regarding legislation concerning individuals rights at work were highlighted in this study with results underscoring the need for a structured (yet customised) approach to the vocational rehabilitation of cancer survivors. Further research is required to delineate the precise role of healthcare providers in facilitating successful RTW outcomes.

Table 1. Topic Guide and Question Prompt List for Cancer Survivors

Primary Question	Prompts
1. Tell us about yourself?	What is/was your work role, capacity and current employment status? Could you tell us about your cancer diagnosis and treatment? Are you during or post treatment?
2. What were your expectations for work before cancer diagnosis?	Had you planned to continue working for some time? Had you planned to reduce/increase your capacity? Had you considered changing occupations etc?
3. What are your expectations for work after cancer diagnosis?	What capacity do you expect to work now following you cancer treatment and diagnosis?
4. What is your view of the impact of cancer and its treatment on future work?	Have you expectations for work changed from due to a cancer diagnosis and treatment? Has there been any effect on your employment? Does having cancer impact on your desire to change jobs? Do you think it hinders you in getting/ going for new positions?
5. What do you see as the barriers to returning to work?	Consider medical, physical, psychological and practical issues.
6. Who do you feel would be the best able to address these barriers?	How could they help? Which health care professionals (or other) do you think would be best to address XX problem? Could you expand on that?
7. What would be the ideal format for such resources?	When provided with information in the past what form has been most beneficial to you?
8. Of all the topics and issues discussed today, what do you see as the most helpful assisting you successful return to work?	
9. Is there any questions/topics you would like to discuss that weren't covered to today?	

Table 2. Topic Guide for Oncology Health Professionals (OHPs)

Primary Questions
1. Tell us who you are, your profession and your role in cancer patient treatment.
2. What are your employment expectations for cancer patients treated with curative intent?
3. From your point of view, how does cancer and its treatment impact on the future employment of your patients?
4. What do you see as the most significant barriers for your patients returning to employment after cancer treatment?
5. Who do you think is best able to address these barriers? How could they help?
6. What supports and resources relating to employment would you have liked to have access to for your patients?
7. What would be the ideal format for such resources?

Table 3. Participant Characteristics

Cancer Survivors (n=17)	n (%)	Health Care Professionals (n=21)	n (%)
Age (yrs ± SD)	52.3 ± 10.2	Gender	
Gender		Female	12(57.1)
Female	13 (76.5)	Occupation	
Relationship Status		Medical	
Married/defacto relationship	13 (68.4)	Medical Oncologist	2(9.5)
single/divorced/separated	4 (23.5)	Radiation Oncologist	1 (4.8)
Cancer Diagnosis		Surgeon	1 (4.8)
Breast	8 (47.1)	Rehabilitation Physician	1 (4.8)
Colorectal	3 (17.6)	Occupational Physician	1 (4.8)
Non-Hodgkin's lymphoma	2 (11.8)	General Practitioner	3 (14.3)
Ovarian	2 (11.8)	Allied Health	
Other	2 (11.8)	Dietician	1 (4.8)
Treatment Status		Psychologist	1 (4.8)
Post treatment	14 (82.4)	Occupational Therapist	1 (4.8)
During treatment	3 (17.6)	Social Worker	1 (4.8)
Work Conditions at Diagnosis		Physiotherapist	1 (4.8)
Full time	7 (36.8)	Nurse ^o	7 (33.3)
Part time	2(11.8)	Qualitative Research Method	
Casual	5 (29.4)	Focus Group	13(61.9)
Other	2(11.8)	Interview	8 (38.1)
Work Role [#]			
Managers	5 (26.3)		
Professionals	6 (31.6)		
Clerical Support Workers	2 (10.5)		
Service and Sales Workers	1 (5.3)		
Elementary Occupations	2 (10.5)		
Retired	1 (5.3)		
Qualitative Research Method			
Focus Group	11 (64.7)		
Interview	6 (35.3)		

[#] Participants work roles classified as per International Standard Classification of Occupations 2008 <http://www.ilo.org/public/english/bureau/stat/isco/isco08/index.htm> . ø Breast and Upper GI clinical practice consultants, and general oncology cancer care coordinators, survivorship coordinators, chemotherapy day unit, oncology wards clinical service coordinators were among the nurse participants. (May want to just refer to them as senior oncology nurses?)

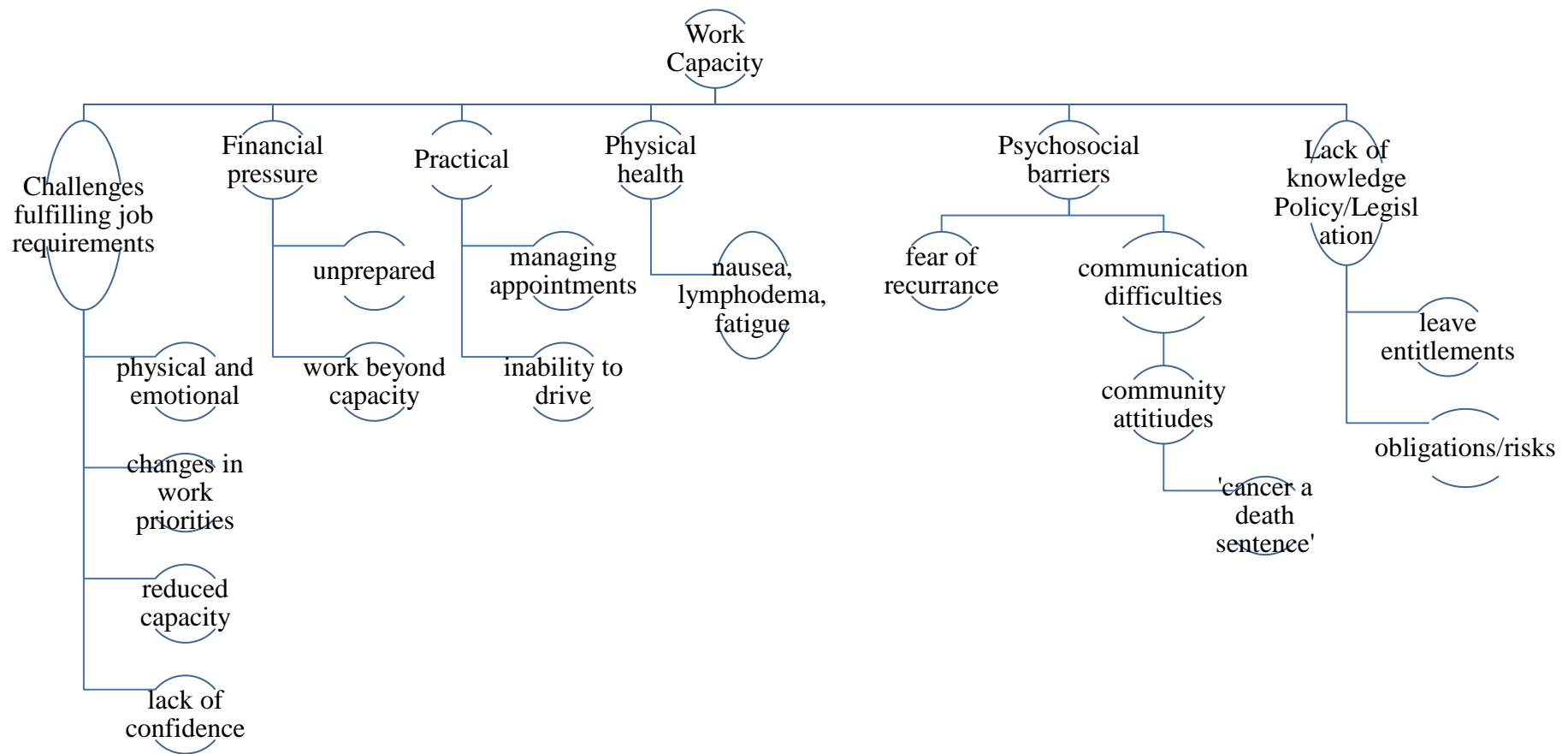


Figure 1. Barriers to RTW

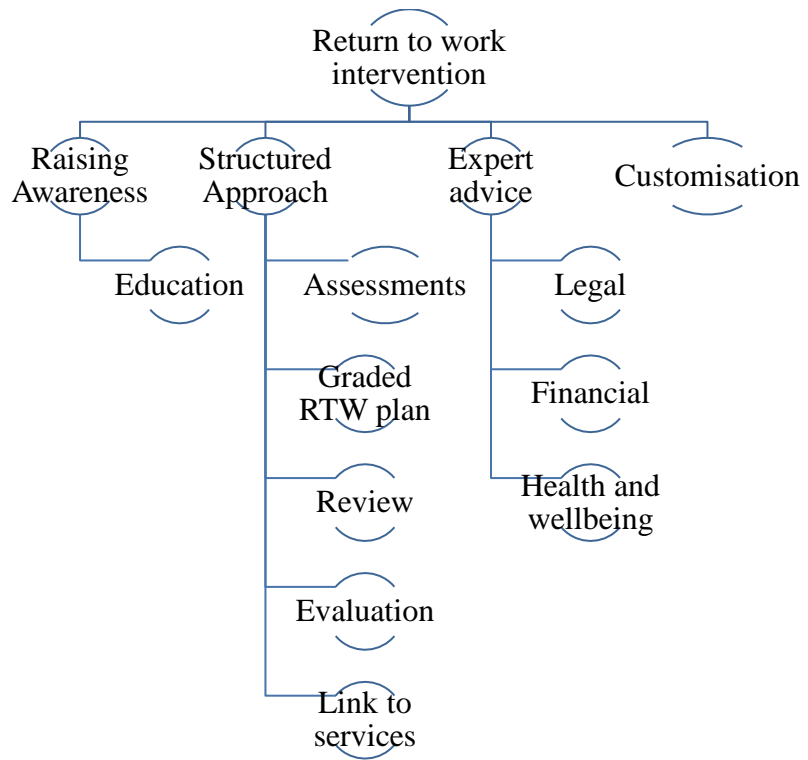


Figure 2. Preferences for RTW intervention

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