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Helping Cancer Survivors Return to Work: What Providers Tell Us About the Challenges in Assisting Cancer Patients with Work Questions

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Abstract *Introduction* Cancer patients and survivors report receiving little work-related advice from healthcare providers about how to manage their work during treatment or when to return after completing primary treatment. This study explores the extent to which health professionals involved with colorectal cancer patients address work matters during active treatment. *Methods* Eighteen health professionals from oncology, occupational health and general practice were interviewed. Interviews were transcribed verbatim and analysed using thematic analysis. *Results* Health professionals provide conflicting and limited information to patients regarding ability to work during treatment, or when to return to work thereafter. Lack of knowledge about impacts of treatment and symptoms on work ability and sustainability, particularly in relation to different occupations and work tasks resulted in providers offering minimal guidance to patients. Current practices relied on providers' previous experiences with employed patients, rather than a sound evidence-base. *Conclusions* The type of work-related information given to patients by providers is not systematic. It is necessary to develop a better knowledge base about the impacts of cancer and its treatment on work ability, sustainability and return to work that would help providers to offer more tailored advice to patients, consistently. Therefore, it is appropriate to recommend that formal training for providers is necessary. Enhancing the quality of information and training for health professionals to provide better work-related support to patients during the early stages of treatment could enable individuals to manage their work more effectively and facilitate a successful transition from patient to survivor.

Keywords Cancer · Return to work facilitation · Work-related advice · Rehabilitation · Professional-patient relations · Qualitative

Introduction

Despite colorectal cancer being diagnosed with increasing age [1], recent economic trends, and changes in retirement age legislation and increased life expectancy have altered the demographic make-up of the work-force [2–4]. Coupled with improved detection and treatment, this means more of those affected by colorectal cancer are likely to transcend from patient to survivor. Understanding what may facilitate or hinder this transition is important [5], particularly in relation to supporting resumption of activities, such as work. Return to work (RTW) rates for colorectal cancer seem promising, with up to 89% resuming work [6]. However, other studies found that 46% of colorectal cancer patients experienced job loss within 3 months

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of diagnosis and of these only 31% were re-employed within 24 months [7]; with another study reporting that 33% of colorectal cancer survivors had still not resumed work 5 years post diagnosis [8]. Unemployment is attributed to treatment modality and symptoms such as fatigue, depression and functional and cognitive impairments [9–15]. These factors are also associated with diminished work ability reported in patients and survivors [16]. Work ability is defined as "…how able is a worker to do his or her job with respect to the work demands, health and mental resources," ([17], p. 3). This suggests poor work ability can render it difficult to return to, or sustain work [18–20]. However, the extent to which healthcare providers (e.g. surgeons, oncologists, nurses, general practitioners [GP] or occupational health [OH]) offer information to patients or survivors about how cancer may impact their work ability and sustainability, or how to manage their work during treatment is relatively limited [18, 21–25]. One study reports providers left decisions regarding RTW up to the individual [18]. Reasons for limited provision of work-related guidance by providers include pre-existing job demands [26, 27] and that they may be unaware of their role in the RTW process [22, 28]. Not knowing enough about how to assist patients and survivors who wish to work during treatment or RTW thereafter is emphasised further by there being relatively few interventions aiming to enhance these outcomes (e.g. [29–31]).

The study explores the extent to which health professionals involved with patients especially during treatment address work matters, particularly because this may influence the nature of their transition from patient to survivor. We explored what work-related information and advice is currently provided by health professionals to those being treated for colorectal cancer, with curative intent. Specifically, we explored when (if any) advice is given during the cancer treatment journey (e.g. during initial receipt of active treatment or following the end of active treatment); what factors, including whether any barriers and facilitators influenced the information and/or advice given by providers and, whether health professionals required any support in providing work-related guidance.

Method

Participants

Eighteen health professionals were interviewed. Participants were recruited via National Health Service (NHS) Trusts and wider research networks. Inclusion criteria was that individuals were currently treating at least one colorectal cancer patient employed at diagnosis, either post surgery or undergoing active treatment (chemotherapy/radiotherapy). This ensured accurate recall of information provided early during treatment. Provider interaction with patients varied according to health professionals' field. Surgeons, nurses and oncologists are heavily involved during diagnosis, during treatment/immediately following completion (patient phase). During the RTW process, GPs are responsible for issuing the fit note to indicate whether a patient is currently unable to work (requires sick leave), or can continue working with appropriate work adjustments (e.g. reduced working hours). Finally, OH interaction depends on employer initiation, but likely to encompass assessments during patient (management of work during treatment) and survivorship phases (e.g. phased RTW). Interviews were conducted between January and June 2009. The study was approved by an NHS Research Ethics Committee.

Table 1 Summary of participants

N = 18	*n*	(%)	M	SD	Range
Age (years)			46.50	8.09	34–57
Sex (male)	10	(55)			
Job type					
Consultant surgeon	5	(27)			
Oncologist	3	(17)			
Specialist nurse	3	(17)			
Occupational health physician	3	(17)			
General practitioner	2	(11)			
Occupational health advisor/nurse	2	(11)			

M mean, *SD* standard deviation

Participation was voluntary and those wishing to take part provided informed consent. After 18 interviews, data was saturated [32] and no further participants were invited to interview. Participants were aged between 34 and 57 years and 10 were male (Table 1). The sample comprised of five consultant surgeons, three occupational health physicians (OHP), three colorectal specialist nurses, three oncologists, two general practitioners (GP) and two OH advisors.

Interview Procedure

The interviews were conducted face-to-face (MB) at participants' place of work. A semi-structured interview guide was designed based on the findings/gaps reported in relevant literature (e.g. [18]). The guide explored the nature of work-related guidance provided by each health professional over the entire cancer treatment journey (e.g. from point of diagnosis to end of primary treatment), factors influencing information given and how the provision of work-related guidance could be improved. This flexible approach allowed the researcher to probe matters raised by participants, ensuring interviews were participant-led. Interviews lasted between 15 and 40 min, were audio-recorded and transcribed verbatim.

Analysis

Transcripts were analysed using inductive thematic analysis [33]. Two researchers (MB, FM) systematically reviewed the interview transcripts separately. Each transcript was read at least three times and initial themes were noted each time, by hand. This guided the development of preliminary themes. Segments of data were split into data units (sub-themes) which were clustered together because of some commonality they shared. Higher-order themes (umbrella term) which emerged during the initial stages of analysis and were broad in nature were allocated to each cluster to represent the set of sub-themes [34]. Two higher-order themes, each with corresponding sub-themes (four and two) were derived. This allowed clarification regarding the specific nature and content of each higher-order theme that resulted in a codebook (Microsoft Word^{TM} document), with examples of quotes comprising each theme. The codebook allowed themes to be discussed and reviewed between the researchers to ensure consistency (three transcripts double-coded). Following agreement of the codebook, NVivo 8 (QSR International Ltd, Melbourne, Australia) was used as a data management tool, where extracts corresponding with appropriate themes were taken from each transcript. This enabled the researchers to report quotes that reflected the overall accounts reported by participants.

Results

Two higher-order themes were identified: (1) Information used by providers to address work matters with patients, and (2) Barriers to providing work-related information to patients. Themes and corresponding sub-themes are summarised in Table 2.

Table 2 Summary of higher order themes and corresponding sub-themes

Higher-order theme	Corresponding sub-themes
Information used by providers to address work matters with patients	Using diagnosis and prognosis to inform provision of work-related advice
	Taking into account patients' active treatment
	Variability in symptoms results in generic level of advice
	Patients' type of occupation and work tasks
Obstacles to providing work-related information to patients	Lack of knowledge about impacts of cancer and treatment on work ability, sustainability and RTW
	Limited resources available to providers for assisting patients in employment

Information Used by Providers to Address Work Matters with Patients

Irrespective of their field, most participants provided basic work-related advice to patients during treatment, such as taking 6 weeks to recover from surgery and avoiding heavy lifting. However, discussions were often instigated by patients soon after diagnosis. When providing advice, participants took into account patients' diagnosis and prognosis, treatment, symptoms and nature of employment.

Using Diagnosis and Prognosis to Inform Provision of Work-Related Advice

The importance of, and purpose in using diagnosis and prognosis information for providing work-related guidance differed between participants. Consultant surgeons and oncologists used stage, grade and prognosis of cancer to plan the most appropriate treatment for a patient. However, they did not feel as confident using such information to provide advice on how this may impact sustainability of work, particularly during treatment. One oncologist discussed how a poor prognosis was likely to lead to the patient withdrawing from the workplace almost immediately; in these situations, work decisions were often left to the individual patient:

> Sometimes we see poor prognostic cancer, so in the short-term it may affect everything, so they may decide to go off work at an early stage.
> Oncologist, Female.

In contrast, an OHP who often saw individuals with good prognosis would use their diagnosis and prognosis to understand the potential impact this would have on their work ability. However, it was often difficult to obtain information from oncologists and surgeons:

> We're a little limited in that because as Occupational Health we're not part of the medical loop, we're agents of the employer…we don't have their medical records to look at…I do often write to the specialist…so at some point we will have the specialist's report, which will give us a diagnosis and possibly an indication of prognosis…the focus of my role would

> be to look at functional capabilities and to see how the cancer is affecting them both in their home life and also at work.
> OHP, Male.

Taking into Account Patients' Active Treatment

Healthcare literature is given to patients by nurses pre-operatively suggesting at least 6 weeks are required to recover from surgery. During this time, patients are advised to refrain from driving and avoid tasks involving heavy lifting or handling (not specific to work). In practice though, health professionals from the same field, such as specialist nurses showed disparity in advising patients on length of sick leave:

> Generally we say take the first six weeks and see how you are, to recover from the surgery.
> Specialist Nurse, Female.

> We discuss discharge information with them, and we are telling them not to go back to work until three months after surgery.
> Specialist Nurse, Female.

Regarding chemotherapy and/or radiotherapy treatment, the level of work-related advice given to patients varied between participants. This was because some health professionals (e.g. oncologists and specialist nurses) had more contact with patients over others during this time. Therefore, when issuing sick-notes, rather than contacting specialists at the hospital directly, GPs questioned patients about whether the hospital had given any indication about how best to manage work:

> When we give them a sick note, so if you were the person we'd be saying how are you doing, all the rest of it; has the hospital given you any idea of how long this is going to take, how you might feel.
> GP, Male.

Further into treatment, GPs admitted that they had less contact with patients and therefore found it increasingly difficult to provide tailored work-related advice; this was due to not knowing enough about the different types of cancers and treatments. For one GP, specialist nurses were seen to be best placed to discuss when a RTW would be possible:

> It's difficult for us to give a time limit…There's usually a cancer nurse where they have the treatment, they review them every so often and check whether they are ready to go back to work.
> GP, Female.

Conversely, specialist nurses mentioned that although they liaised with oncologists and surgeons to provide some guidance during treatment, they felt patients needed to go back to their GP to assess fitness to resume or RTW:

> You need to go back to your general practitioner to make sure that you're fit to work…to be quite honest the information we're giving is just based on treatment that they're having at the hospital really.
> Specialist Nurse, Female.

Further inconsistencies emerged, where one oncologist discussed how some patients were informed by other oncologists that they would be unable to work during chemotherapy treatment, when in fact there was no reason why they could not. The absence of a systematic approach resulted in consultant surgeons, specialist nurses and oncologists adopting common sense approaches rather than an evidence-base:

> If it's very aggressive chemotherapy which might leave them open to infection, I would advise not returning to work. If it's very gentle, easy chemotherapy I'd say, if you want to go back to work and you find treatment easy then go back to work.
> Oncologist, Male.

Variability in Symptoms Results in Generic Level of Advice

As symptoms (e.g. fatigue, nausea and diarrhoea) associated with diagnosis and treatment varied from patient to patient and over time, participants discussed how it was simpler to provide basic advice. This went back to avoiding heavy lifting than more specific advice on how symptoms may impact work ability and management of work:

> We're a little bit uncertain as to what the treatment effects will be; so we're a bit hesitant about discussing that [management of work]. If there is an awful lot of bending and lifting, it might not be a suitable environment.
> OH Advisor, Female.

Therefore some participants, such as the nurses felt that patients needed to decide whether to work during treatment:

> It depends on the symptoms really and I think the patient himself is the best judge on whether they are able to work or go off sick.
> Specialist Nurse, Female.

Patients' Type of Occupation and Work Tasks

Participants agreed that manual work was harder for patients to maintain following surgery and during treatment. A consultant surgeon stated that due to diminished physical work ability, patients were advised to temporarily amend their tasks, where possible. Subsequently, patients taking part in manual work were advised to take more time off than those in non manual jobs:

> If it is a heavy manual job you don't expect them to return quickly, you need to continuously assess them, what they can perform, and advise appropriately.
> GP, Female.

Consultant surgeons, oncologists and specialist nurses also acknowledged that patients that were self-employed were keen to work during treatment or return as early as possible, due to fewer benefits. Consequently, work matters were discussed either prior to, or early on during treatment; typically because the patient had raised the topic:

> The self-employed people will probably want to get back before those that have got sick pay and things. They tend to recover quicker because they haven't got any choice really.
> Specialist Nurse, Female.

Other than this, except for OHPs, the remaining participants felt that not knowing enough about what a patient's job role (tasks) involved, limited the guidance they could offer:

> They'll usually say I work in a factory, I'm an IT consultant…I have my own imaginings about what being an IT consultant means. But I don't actually know exactly what they do every day or what their job demands are.
> Consultant Surgeon, Male.

Obstacles in Providing Work-Related Information to Patients

Participants discussed obstacles, such as lack of knowledge and limited resources about the impacts of cancer and treatment on work ability, sustainability and RTW. This made it difficult to know the specific work-related support to give patients.

Lack of Knowledge about Impacts of Cancer and Treatment on Work Ability, Sustainability and RTW

Some participants expressed that not knowing about the proportion of colorectal cancer patients and survivors that work during treatment, or RTW following treatment made it difficult to provide work information:

> I tend to give as much information as I can, within my limitations. I will not be commenting about something I don't know a lot about.
> GP, Male.

> It might be my complete lack of knowledge, but I don't really have a handle on how many patients do get back into the workplace successfully.
> Oncologist, Female.

The absence of guidance for health professionals on the most appropriate information to provide during treatment (e.g. whether to work), or when to RTW resulted in most participants drawing on prior experiences with patients:

> We haven't got that much information to give patients, we're just going from what we've advised other patients in the past.
> Specialist Nurse, Female.

Limited Resources Available to Providers for Assisting Patients in Employment

Nearly all participants reported that within each of their professions, there were limited resources or guidance about how providers could assist patients to decide whether to sustain work during treatment, when to RTW or how to manage their cancer (symptoms) within the workplace:

> I'm not given any real guidance; there are no guidelines to me to say, this is what you should or shouldn't say. There is not much guidance from the Department of Health, as to what should be the advice. There is very little information, especially for cancer patients with a stoma.
> Consultant Surgeon, Male.

A consultant surgeon disclosed that because little guidance was available about when patients should resume work, advice was wide-ranging. There were concerns that conflicting opinions between providers about when or whether patients should resume/continue to work were likely to lead to different patient outcomes:

> Even if I said you'll be back at work in a month, there are other things beyond our control, like OH, like their GPs who will override that…So whatever we think doesn't make a difference…I think keeping people off work is very bad for their brains, I really do.
> Consultant Surgeon, Male.

Several participants, such as several OH professionals made the most of what resources they felt could help them in providing work-related guidance. However, these individuals were using RTW management plans devised for other conditions (e.g. back pain); which they considered to be transferable to cancer. Other resources were accessed by GPs via cancer charity websites. These were likely to be tailored for patients and discuss different types of cancers and treatments, generally. Hence, these resources were unlikely to be specific to work:

> I'm quite good with the internet. I read and update my knowledge through [cancer charity website], so I know each and every cancer, at least in a superficial way.
> GP, Male.

Other participants such as an oncologist utilised quality-of-life data related to treatments, to gauge which treatments may have more profound impacts on work ability. The implications of providers not having access to specific guidance about assisting patients with work matters led some participants to suggest patients were left with unanswered questions:

> What emerges is that a lot of people seem to feel that they've not got adequate information from their hospital appointment, and sometimes their GP, and they've still got unanswered questions…the evidence base in much of occupational health is pretty limited to the very basics.
> OHP, Male.

Discussion

The study explored what work-related guidance was provided to individuals being treated for colorectal cancer. We investigated the information provided by different healthcare providers to understand whether the advice influences some survivors to work during treatment and others to withdraw from employment altogether. Our findings indicate that work-related information given to patients during treatment is not systematic. Lack of knowledge and the absence of guidelines and evidence about how many patients work during treatment or successfully RTW resulted in varied practice by providers (e.g. length of time to recover after surgery). Similar patterns are reported in other healthcare settings (e.g. [35, 36]). A key finding from our study is that absence of guidelines resulted in most participants adopting common sense approaches to providing work-related advice. Participants expected individuals receiving aggressive treatment and those in manual rather than non manual work would be least likely to work during treatment, or that they would take longer to RTW. Although evidence supporting this exists [10, 20, 24, 37], providers based this on prior experiences with patients rather than on a sound evidence-base.

Whilst work interventions are being designed and implemented for patients and survivors [29–31], our findings suggest that providers' role in this domain needs improving. Developing a better knowledge base (knowledge dissemination, guidance and training) about the impacts of colorectal cancer and its treatment on work ability, sustainability and RTW would help providers to offer tailored work-related information to patients, consistently. Additionally, throughout each theme, communication, particularly between professionals seemed to be a problem. We found that certain providers, such as nurses assumed another health professional (GP) was responsible for work-related advice and therefore rarely touched on work matters with patients; whilst others were reluctant to offer guidance out of concern that it would be overruled by another professional. These findings extend previous research [26, 38] and highlight the importance of improving the flow of information between different providers because poor communication may result in support being provided some way into the RTW process [38].

Our study also found that work-related advice was often provided after patients initiated the discussion. This supports other studies [18, 21] and raises the importance of the role of the individual. Patients and survivors could be empowered to learn about the information available to them. To help, providers could utilise theoretical frameworks to assist patients and survivors favourably. The *Work and Cancer Model* [39] suggests seven factors (e.g. survivor characteristics, work demands) that could pose as barriers to individuals achieving optimal work outcomes. Providers could use the model to identify problem areas which could enable them to give more tailored work-related guidance to patients, taking into account the individual's circumstances.

There are a number of limitations to this study. First, the sample size was small. However, the richness of the data generated by interviews is reflected by our findings. Finally, due to the way occupational and health systems differ internationally our findings may not be generalisable. Although, the fields providers were drawn from are likely to be representative of those involved in cancer care, internationally.

In summary, developing guidance for providers regarding the impacts of cancer upon work ability, sustainability and RTW is necessary. This would enhance the quality of information and care provided to patients during treatment that could result in more informed decisions about how to manage work during treatment, or when to RTW. Ultimately, this could improve individuals' work ability and facilitate their successful transition from patient to survivor.

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