WILEY

Work resumption and retention in patients with advanced cancer: Experiences and perspectives of general and occupational health care professionals

Amber D. Zegers^{1,2} | Emma S. van Andel³ | Donna C. E. Beerda^{3,4} | Desiree J. S. Dona⁵ | Eline J. Aukema⁶ | Linda Brom^{3,7} | Saskia F. A. Duijts^{1,2,3,8}

¹Department of Public and Occupational Health, Amsterdam UMC location Free University, Amsterdam, The Netherlands

²Societal Participation and Health, Amsterdam Public Health Research Institute, Amsterdam, The Netherlands

³Department of Research & Development, Netherlands Comprehensive Cancer Organisation (IKNL), Utrecht, The Netherlands

⁴Department of Public and Occupational Health, Amsterdam UMC location University of Amsterdam, Amsterdam, The Netherlands

⁵Department of Human Resources, Radboud University Medical Center, Nijmegen, The Netherlands

⁶Center for Psycho-Oncology, Ingeborg Douwes Centrum, Amsterdam, The Netherlands

⁷Netherlands Association for Palliative Care (PZNL), Utrecht, The Netherlands

⁸Department of Medical Psychology, Cancer Center Amsterdam, Amsterdam UMC location Free University, Amsterdam, The Netherlands

Correspondence

Dr. Saskia F.A. Duijts, Netherlands Comprehensive Cancer Organisation (IKNL), Godebaldkwartier 419, 3511 DT Utrecht, The Netherlands. Email: s.duijts@iknl.nl

Funding information No funding was received for this study.

Abstract

Objective: The objectives of this study were to explore the experiences and perspectives of general and occupational health care professionals regarding work resumption and work retention of patients with advanced cancer, and to identify barriers and facilitators these professionals may encounter.

Methods: A qualitative design was applied, and individual semistructured interviews were conducted. General and occupational health care professionals were eligible to participate if they were involved in the work participation guidance of patients with advanced cancer, and were recruited through the network of the research team. Interview data were transcribed verbatim and analysed thematically via ATLAS.ti 9.

Results: Interviewees (N = 17) had various occupational backgrounds, for example, occupational physician, reintegration consultant, and general practitioner. Four main themes emerged from the data: (1) Assumptions and hesitations, (2) Patient initiates stakeholder communication, (3) Role dispersion: who is in charge of what? and (4) Experience with legislation creates opportunities.

Conclusion: Whereas most interviewees had positive experiences with, and/or optimistic expectations of, the work resumption and work retention of patients with advanced cancer, several barriers to the work participation guidance of these patients were identified. Suggestions for improvement include creating widespread awareness of the possibility of work participation of patients with advanced cancer and developing reintegration guidelines for advanced cancer.

KEYWORDS

advanced cancer, metastatic, palliative care, qualitative research, return to work

1 | INTRODUCTION

Improvements in screening and treatment are enabling cancer patients to live longer and with better quality of life, even in the face of advanced (i.e., incurable, usually metastatic) disease (American Cancer Society, 2021; Kassianos et al., 2018; Netherlands Comprehensive Cancer Organization, 2020). Due to these improvements, patients with advanced cancer and involved general and occupational

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

WILEY European Journal of Cancer Care

health care professionals are increasingly faced with questions pertaining to work resumption and work retention. Cancer patients may wish, or feel financially incentivised, to continue their working lives (Chow et al., 2015; Greidanus et al., 2018; Netherlands Comprehensive Cancer Organization, 2020). Studies among cancer patients have indicated that being in paid employment enhances patients' financial security and offers social support, which can contribute to their overall guality of life (Duijts et al., 2017; Faas, 2018; Mills & Payne, 2015; Nachreiner et al., 2007). Moreover, the ability to work can offer cancer patients a sense of identity and purpose (Chow et al., 2015; Faas, 2018; Greidanus et al., 2018). However, many cancer patients experience barriers when resuming work during or after treatment, for example, fatigue (Nielsen et al., 2019; Paltrinieri et al., 2018; Zegers et al., 2022). For those with advanced cancer, additional barriers may arise due to disease progression, symptom burden, and/or ongoing (palliative) treatments (Glare et al., 2014).

Being diagnosed with advanced cancer is related to higher unemployment rates (Mehnert & Koch, 2013). In a study on women with advanced (i.e., metastatic) breast cancer, it was found that whereas 70% of women was working prediagnosis, 21% was working when surveyed, i.e., after having lived with advanced cancer for on average 2.5 years (Lyons et al., 2019). Furthermore, in a study by Tevaarwerk and colleagues in workers with metastatic cancer, 58% reported a change in employment due to illness, i.e., having stopped working (Tevaarwerk et al., 2016). Reduced employment in patients with advanced cancer has been linked to higher symptom burden and lower functional status; aspects that can be targeted in (vocational) rehabilitation (Kochovska et al., 2018; Lyons et al., 2019; Tevaarwerk et al., 2016).

Vocational rehabilitation of cancer patients is influenced by myriads of factors, for example: personal, medical, socio-legal, and employer-related factors (Greidanus et al., 2018; Paltrinieri et al., 2018; Van Muijen et al., 2013). Thus, not only cancer patients encounter barriers during work resumption and work retention; general and occupational health care professionals can experience difficulties guiding patients throughout this process as well (Greidanus et al., 2018; Morrison et al., 2015; Tiedtke et al., 2014; Yagil et al., 2019; Zegers et al., 2022). Findings of Glare et al. (2017) showed that work remains an important topic for many patients with advanced cancer, and involved professionals therefore need to be competent in discussing work-related issues with them and providing tailored supportive care (Glare et al., 2017).

In the Netherlands, approximately 124,000 individuals are diagnosed with cancer annually, of whom an estimated 38,000 with advanced cancer (Netherlands Comprehensive Cancer Organization, 2020). Though the general and occupational health care systems in the Netherlands are organised separately (Buijs et al., 2012; Senden et al., 2019), various professionals from both systems can play a role in the vocational rehabilitation of cancer patients (e.g., medical specialists, occupational physicians, insurance physicians, reintegration coaches, and employers). Experiences and perspectives of general and occupational health care professionals regarding work resumption and work retention of cancer patients have been described elsewhere, but have largely focused on patients treated with curative intent (Morrison et al., 2015; Tiedtke et al., 2014). As the number of patients who live longer with advanced cancer is increasing, and work resumption and work retention are more often an option, the role of involved professionals needs to be considered.

In this study, we aimed to explore the experiences and perspectives of general and occupational health care professionals regarding the work resumption and work retention process of patients with advanced cancer, and to identify barriers and facilitators these professionals may encounter in providing work participation support to this patient group.

2 | METHODS

2.1 | Design

Applying a qualitative design, semistructured interviews were conducted until data saturation was reached (i.e., no new data emerged from the interviews). A patient-centred counterpart study was conducted during the same timeframe. Together, these studies formed the PalliaTurn research project. This project was designed and reported on the basis of the Consolidated Criteria for Reporting Qualitative research (COREQ) checklist (Tong et al., 2007) (Supporting Information S1).

2.2 | Sample and recruitment

General and occupational health care professionals (e.g., occupational physicians and reintegration consultants) were eligible to participate in an individual interview if they were in any way involved in the work participation guidance of patients with advanced cancer. Professionals were recruited via purpose sampling (i.e., known professionals were invited via members of the research team) and via snowball sampling (i.e., known professionals were asked to recommend other professionals for study participation). A professional relationship between some authors and professionals existed prior to study commencement. All professionals were invited for study participation via e-mail. Professionals who indicated interest in study participation received an information package containing a study information letter explaining study procedures and defining the target population, an informed consent form, and a brief questionnaire indexing sociodemographic information (e.g., occupation and years of experience with the target population). Upon receipt of the signed informed consent form and completed questionnaire, professionals were contacted to schedule an interview.

2.3 | Data collection

Due to restrictions pertaining to the COVID-19 pandemic, interviews were held online through Microsoft Teams. Interviews were led by one author (EvA, a research intern trained in qualitative research), with a second author (DB, a research intern trained in qualitative research) present to facilitate audio recording and make field notes to capture non-verbal communication. Both interns were supervised by authors

ADZ, LB, and SFAD (a PhD candidate, postdoctoral researcher, and senior researcher, respectively, all with a research focus on psychosocial oncology and/or palliative care). ADZ, LB, and SFAD have experience in conducting qualitative research (e.g., Zegers et al., 2022).

Interviews followed a semistructured interview guide, which was constructed on the basis of previous scientific literature (e.g., Chow et al., 2015; Faas, 2018; Greidanus et al., 2018; McKay et al., 2013; Mills & Payne, 2015) and brainstorming sessions within the research team. The following topics were included in the interview guide: (1) Experiences with providing work participation support for patients with advanced cancer, (2) sufficiency of existing laws and regulations concerning sick leave, reintegration, and work disability benefits, (3) perspectives regarding the ethical aspects of work resumption and work retention in the context of advanced cancer, (4) experiences with employer flexibility in the context of reintegration and work adjustments, and (5) recommendations for improving work participation guidance of patients with advanced cancer. The interview guide was pilot-tested with an independent colleague to assess comprehensibility of questions, resulting in the final guide. Interviews were audio-recorded using a USB device, and lasted on average 60 min. Audio recordings were transcribed verbatim. To protect confidentiality, directly identifiable information was redacted from transcripts. Audio files were destroyed post-transcription. No repeat interviews were held, and transcripts were not returned to participants.

2.4 | Analysis

Using a semantic approach (i.e., themes were derived from explicit meanings of the data), interview data were analysed thematically in ATLAS.ti9. Thematic analysis was performed based on the six phases described by Braun and Clarke (2006): (1) Familiarising oneself with the data, (2) labelling data and generating initial codes, (3) combining codes into themes, (4) reviewing themes against the data, (5) defining and naming the themes, and (6) writing up the final report. In phase two, two transcripts were independently coded by two authors (EvA and ADZ) to ensure inter-coder reliability. Any coding discrepancies were resolved in a consensus meeting between the two authors. In phase five, themes were defined and named in a consensus meeting with the research team (EvA, DB, ADZ, LB, SFAD). Codes and themes were data-driven, not theory-driven. Relevant stakeholder quotations were selected and translated into English by the research team. Participants did not provide feedback on the findings. IBM SPSS Statistics version 24 was used to analyse descriptive data derived from the completed questionnaires.

3 | RESULTS

3.1 | Sample characteristics

Seventeen professionals involved in the work participation guidance of patients with advanced cancer participated in this study.

ropean Journal of Cancer Care -WIIFY

Participants had a mean age of 52.5 years (SD = 8.5, range 35-70 years) and were predominantly female (64.7%). Working experience with the target population varied between 5 months and 38 years and occupational backgrounds were diverse (Table 1). Professionals mostly worked in the hospital setting or had their own company, for example, a reintegration consultancy company.

3.1.1 | Theme 1: Assumptions and hesitations

According to participants, work participation of patients with advanced cancer was rarely discussed in the recent past. It was common to think that this patient group should be left alone to spend their remaining time with loved ones. Participants described a persistent societal misconception concerning the (un)importance of and (in) ability to work, in the face of advanced cancer. Participants stated to observe this misconception in other professionals as well, for example, employers. However, participants noted that work often remained an important aspect in the lives of patients with advanced cancer: being able to work was observed to contribute meaningfully to some patients' remaining time.

> There is still a widespread assumption that patients with advanced cancer do not work or do not want to work. That is just so untrue. [director of reintegration agency]

TABLE 1 Study sample characteristics (*n* = 17)

	n (%)
Gender, female	11 (64.7)
Age, mean (SD)	52 (8.5)
Profession ^a	
Occupational physician specialised in oncology	2
Insurance physician	1
Reintegration consultant	3
Clinical psychologist	2
Oncologist	2
General practitioner	1
Nurse practitioner	2
Employer	2
Representative patient organisation	2
Tenure in years, mean (SD)	12.1 (10.7)

^aOccupational physician oncology (*bedrijfsarts consulent oncologie - BACO*): In the Netherlands, occupational physicians can specialise in oncology, after which they are able to advise patients, general occupational physicians, and the medical team, on work-related issues and cancer. Reintegration consultant (*reintegratieconsulent*): In the Netherlands, a private reintegration agency can be consulted for support of cancer patients and their employers during work resumption, work retention, or work cessation. 4 of 9

-WII FY- European Journal of Cancer Care

Participants stated that professionals' expectations regarding advanced cancer patients' work resumption and work retention did not always match the views of patients themselves. These opposing views could leave deep emotional impacts on patients:

I've heard stories from people [with advanced cancer] who really wanted to work. But when the occupational physician hears that they have incurable cancer, he tells them 'to just do fun things'. And people feel deeply hurt. [nurse practitioner]

Participants noticed that involved professionals are sometimes hesitant or overly cautious to initiate a conversation about work with patients with advanced cancer. This attitude was related to the aforementioned misconception about the unimportance of work in the face of advanced cancer. According to several participants, employers also tend to have a hesitant attitude to discussing work with employees with advanced cancer, due to uncertainty concerning the sustained employability of this patient group and potential costs related to sickness absence.

> Employers are quite afraid to let people who have had cancer return to work completely, because employers still assume that, especially when the disease is advanced, cancer patients often drop out due to illness, causing employers to pay the price. [oncological occupational physician]

The abovementioned hesitancy could lead to avoidance of workrelated conversations, causing supervisors and colleagues to drift away from the employee with advanced cancer. Some participants indicated that the longer a conversation about work is postponed, the more uncomfortable employers become to initiate such a conversation.

> You see that people [managers] are afraid to [...] make demands on an employee [with advanced cancer]. But that's what you, as a manager, should actually do. [...] The word 'cancer' evokes a kind of restraint. With metastatic cancer, that [restraint] triples. [director of reintegration agency]

Participants mentioned that these feelings of hesitancy and discomfort could easily cross the boundary from consideration, to professionals thinking they know what is best for the patient with advanced cancer. Some participants adopted the latter attitude themselves:

> I think that when someone receives an advanced cancer diagnosis, they'll go into a long course of treatment, and then it's unnecessary to talk about work. [employer]

Most participants saw this attitude as a pitfall, as it removes agency from patients with advanced cancer, to decide over their own lives. In effect, participants indicated that this attitude could lead to ill-suited and nontailored work-related advice. For example, participants said that patients were often urged by their employer or occupational physician to take on full disability benefits and to stop working.

> Often, it's proclaimed early on that there is not much perspective [concerning work, when diagnosed with advanced cancer], and that therefore it's more responsible to apply for full disability benefits. This can come across as very hurtful to someone who says "I was just diagnosed [with advanced cancer], but I still feel fine. I just want to go to work." [reintegration consultant]

3.1.2 | Theme 2: Patient initiates stakeholder communication

In line with the above-mentioned misconception about the (un)importance of work in the face of advanced cancer, participants explained that, out of consideration for the patient, some professionals avoid the topic of work entirely in conversations in order not to exert any pressure to return to work. Participants said that professionals often wait for patients to broach the topic of work. Consequently, communication about work was sometimes observed to be delayed, or to not take place at all.

> I first let people tell their story (...) People always start off by telling what's most important to them. So you dive into that. And sometimes work is discussed later, or not [at all]. [nurse practitioner]

Although most participants indicated that they let patients initiate a conversation about work, several participants recognised the importance of taking the lead towards the patient.

> If it [conversation about work] is not initiated by the patient, then I [oncologist] will initiate it myself, because it's an important aspect of life. [oncologist]

According to participants, the hesitancy to communicate about work with a patient with advanced cancer could also stem from a lack of relevant knowledge, for example, concerning the consequences of the disease/treatment or relevant laws and regulations regarding sickness absence and reintegration. Yet, medical developments, prolonged life expectancies, and improved quality of life of patients with advanced cancer were said to have contributed to work being discussed more often with this patient group now, compared to the recent past.

uropean Journal of Cancer Care -WIIFY

3.1.3 | Theme 3: Role dispersion: Who is in charge of what?

According to participants, work should first be discussed within the general health care system, for example, at the hospital or at the general practitioner's (GP's) office. Participants pointed to oncologists and nurse practitioners as professionals who could take on the role of being the first point of contact about work in the hospital setting. However, participants mentioned that work was often not discussed in this setting.

You go to the hospital (...) to cope with your illness by limiting the medical consequences and the burden of the disease. But the concrete conversation about (...) what this [illness] means [for you and your life] outside the hospital; too few people talk about that. [representative of patient organisation]

Oncologists and nurse practitioners were also said to play a vital role as good listeners, information providers, and referrers to appropriate work-related support inside and outside the hospital setting. Some participants mentioned that general and occupational health care are divided in the Netherlands, hindering general health care professionals to find their appropriate role in this context.

> As a hospital-based doctor, I [legally] have nothing to say about work resumption and everything that has to do with it. (...) So what I mainly try to do is ask people [patients with advanced cancer]: "Are you in touch with the occupational physician and how is that going?" [oncologist].

Outside the hospital setting, participants saw GPs as the central point of contact for patients with advanced cancer, including for conversations about work.

The importance of good communication between the employee with advanced cancer, their employer, and occupational physician was mentioned by several participants. The employer and occupational physician were seen as key professionals in the arrangement of reintegration guidance for the employee with advanced cancer. Yet, these professionals were often said to lack (advanced) oncology-related knowledge to support patients in a targeted and personalised way. This support is considered essential, as for example, what may be suitable work for an employee with advanced cancer legally needs to be determined by an occupational physician.

According to participants, various professionals can be involved in the work participation process of patients with (advanced) cancer, for example, oncologists, GPs, occupational physicians, and employers. Participants noted that the roles of these various professionals are often not clearly delineated or understood. Differing opinions and conflicting interests were said to add to this role ambiguity. As a result, role dispersion was observed to occur. Role dispersion was described as the shedding of responsibility to take on a certain role within the work participation process, because it would not fit within a professional's job description. Several participants indicated that in order to optimise the work participation process of patients with advanced cancer, a stakeholder network should be established around the patient. Currently, some vital linking pins were said to be missing.

> I've been in 'this world' [work participation guidance for cancer patients] for about eight years, and it never ceases to amaze me how institutions and organisations that are all aimed at the same target group, do not work together. [director of reintegration agency]

3.1.4 | Theme 4: Experience with legislation creates opportunities

Participants indicated a lack of knowledge among various professionals, including themselves, regarding the legislative aspects of reintegration (e.g., sickness absence and work disability legislation). According to most, a lack of legislative knowledge was mainly seen among health care professionals and employers.

> I do not know very much about legislation. [oncologist]

> [As an employer] You suddenly have all kinds of legal obligations, while employers often do not know what to do. [representative patient organisation]

According to participants, Dutch legislation concerning sickness absence and reintegration of employees with an advanced illness is illsuited to patients with advanced cancer who wish to participate in work. Participants explained that current Dutch legislation assumes that an employee will eventually get better, which is not the case for those with advanced cancer or other incurable illnesses. Participants did not suggest changing current laws and regulations to facilitate reintegration of patients with advanced cancer. Rather, participants indicated that having a better understanding of current laws and regulations creates opportunities for customisation for employees with advanced cancer.

> Making existing [legislative] solutions easier to find and more accessible is low-hanging fruit to me. (...). [director of reintegration agency]

4 | DISCUSSION

4.1 | Main findings

Main findings of this study are that (1) a persistent societal misconception concerning the (un)importance of and (in)ability to work, in patients with advanced cancer, exists; (2) while recognising the potential benefits of initiating a conversation about work with this patient group, professionals may be hesitant to do so, resulting in delays; (3) though various professionals can be involved in work participation guidance of patients with advanced cancer, role ambiguity and role dispersion hinder effective multidisciplinary collaboration; and (4) professionals experience the current Dutch legislative framework regarding sick leave, reintegration, and work disability insurance as insufficient for patients with advanced cancer and other incurable illnesses.

4.2 | Interpretation of findings

The societal misconception about the (un)importance of and (in)ability to work, in the face of advanced cancer, may stem from at least two factors: (1) A lack of knowledge concerning advanced cancer and work in professionals involved in the work participation guidance of this patient group, and (2) a tendency to equate advanced cancer with terminal cancer. Concerning the latter factor, misconceptions about palliative versus end-of-life care have been found to exist within the general public and the health care community (Buss et al., 2017). That such misconceptions can be harmful, was underlined by Flieger and colleagues, who showed that a lack of communication about palliative care undermines patient-centred care (Flieger et al., 2020).

As general and occupational health care professionals tend to take a wait-and-see approach to initiating a conversation about work with patients with advanced cancer, patients are often necessitated to display high levels of self-efficacy and actively seek out relevant support themselves. To illustrate, in a study by Zegers and colleagues, it was found that only 32% of cancer patients reported to have had a conversation about work in the hospital setting (Zegers et al., 2021). For patients with certain medical (i.e., advanced cancer), sociodemographic (i.e., older age and lower educational level), or personal characteristics (i.e., more passive attitude and lower health literacy), such relevant work-related support might be even more difficult to locate and consequently benefit from. This is in line with previous research showing that cancer patients with low self-efficacy regarding reintegration at work have more adverse work outcomes (Bains et al., 2012; Wolvers et al., 2018).

Access to work-related support might further be hindered by role ambiguity and role dispersion among professionals involved in work participation guidance of patients with (advanced) cancer. The issue of role dispersion in providing work-related support has been addressed in other countries as well. To illustrate, in a study involving 10 physicians in Canada, it was found that physicians did not spontaneously address work-related issues with cancer patients, due to boundaries related to their professional training (Morrison et al., 2015). Physicians believed that other professionals, for example, occupational therapists, are better equipped to provide workrelated support to cancer patients. However, physicians did not systematically refer cancer patients to such professionals, due to, for example, lack of resources (Morrison et al., 2015). Furthermore, in a

study involving 157 health care professionals in Israel, it was shown that occupational physicians viewed providing work-related guidance to cancer patients as one of their role responsibilities more than other health care professionals did (Yagil et al., 2019). However, most other health care professionals did tend to view providing workrelated guidance as part of their role. A belief in the benefits of RTW, and viewing RTW of cancer patients as a team responsibility of health care professionals, was positively related to assumed role responsibility (Yagil et al., 2019). In the Dutch socio-legal context, as is the case in several other countries, role dispersion might be related to the organisation of general and occupational health care in separate (financial) systems (Glare et al., 2014; Petersen et al., 2019; Tevaarwerk et al., 2016; Tiedtke et al., 2014). Specifically, general health care professionals perform (curative) health care tasks, whereas occupational health care professionals provide, for example, sick leave assessments and reintegration guidance. Although this separation appears to clearly delineate tasks between the general and occupational health care settings, in practice, several issues might occur, for example, professionals are cautious not to overstep their respective roles, and communication between the systems is dependent on, among others, explicit consent of the patient. Difficulties in coordination of tasks and responsibilities was also described by Gorin and colleagues, who explained that lack of coordination in cancer care is associated with poor symptom control, medical errors, and higher costs (Gorin et al., 2017).

The role of the GP in providing work-related guidance for cancer patients has not often been mentioned in the literature (de Jong et al., 2018), but might be of particular relevance for patients with advanced cancer as part of ongoing routine care (Halkett et al., 2015). In some countries, GPs are actively involved in providing follow-up care to (advanced) cancer patients. To illustrate, in a study involving 317 GPs in Norway, it was found that many GPs provided follow-up care to cancer patients and that they generally felt confident in their ability to do so (Fidjeland et al., 2015). Further, in a study involving 1130 medical oncologists and 1021 primary care physicians in the United States, it was shown that about half of oncologists and primary care physicians reported involvement in psychosocial care for cancer patients (Forsythe et al., 2012). However, their results did underline a need for better care coordination due to a lack of involvement of some providers, and a difference in beliefs regarding who should provide which aspect of psychosocial care (Forsythe et al., 2012).

Lastly, participants in this study stated that current Dutch legislation concerning sick leave, reintegration, and work disability benefits, is insufficient for patients with advanced cancer. According to participants, a better understanding of current legislation could provide opportunities for this target population. Findings of Tiedtke and colleagues showed that legislation did not hamper reintegration of cancer survivors in their study, if professionals were willing to look for tailored options within existing legislation (Tiedtke et al., 2012). Moreover, in an interview study in 12 insurance physicians in the Netherlands, it was found that this group of professionals missed practical tools to assess work disability claims in individuals with a limited life expectancy (Muller & Hoving, 2018). Interviewed insurance physicians stated a need for up-to-date, nuanced, and practical information, for example, in the form of a dedicated guideline or revised guideline, to assess work disability claims in this population (Muller & Hoving, 2018). Further, the concept of limited life expectancy needs defining within the work field. Thus, it would be beneficial if, for example, the Dutch Employee Insurance Agency provided clearer, and more accessible and tailored, information on work disability insurance structures for patients with advanced cancer and other incurable illnesses. Though this recommendation is specific to the Dutch social security system, it is possible that guidelines for work disability claims of patients with advanced cancer are missing in other jurisdictions as well.

4.3 | Strengths and limitations

As little research has been performed investigating the experiences and perspectives of general and occupational health care professionals regarding work resumption and work retention of patients with advanced cancer, this study provides new insights. Various sectors and professions were represented in the study sample. Participants also varied in age and tenure, giving insight into a broad spectrum of experiences.

The following limitations should be mentioned. The limited sample size prevented comparison between sectors and professions, and some professions were not represented at all (i.e., general occupational physician). While data saturation was reached on various topics of discussion, it could not be reached for separate sectors or professions. Lastly, all participants had a positive attitude towards work resumption and work retention of patients with advanced cancer, which could indicate selection or volunteer bias.

4.4 | Implications for practice and research

The results of this study have highlighted the importance of considering the advanced cancer patient in his/her wider psychosocial context and of providing personalised care, including work-related guidance. Therefore, we suggest launching national educational campaigns in which patients with advanced cancer and patient advocates share their needs, experiences, and perspectives, concerning psychosocial topics, including work. Further, to reduce role ambiguity and role dispersion, we recommend that multidisciplinary teams come to an agreement concerning who to put forward as first point of contact regarding work, for example, nurse specialists, and to clearly delineate what information, and which referrals, can be provided by this first point of contact.

To help general and occupational health care professionals to delineate their roles within the work participation guidance of patients with (advanced) cancer, and to provide professionals with relevant information, we underline Yagil and colleagues' suggestions to (1) incorporate work-related guidance and referral structures into basic education of general and occupational health care professionals, (2) include the topic of work into professional meetings and work conferences of these professionals, and (3) establish better teamwork to address RTW in cancer patients, including those with advanced cancer (Yagil et al., 2019). Further, we suggest expanding existing digital tools such as the MiLES intervention (Greidanus et al., 2020). This is an online toolbox to aid employers during the work resumption process of employees with cancer. Such a toolbox should include information on specific cases, for example, advanced cancer. Lastly, we recommend that Employee Insurance Agencies consider various opportunities within existing legislation for patients with advanced cancer and other incurable illnesses, who wish to continue working for as long as possible or desired.

4.5 | Conclusion

Widespread societal misconceptions and incorrect assumptions concerning the (un)importance of, and (in)ability to, work, in patients with advanced cancer may hinder general and occupational health care professionals in offering timely work-related guidance. Role ambiguity and role dispersion seem to impede effective multidisciplinary collaboration and patients with advanced cancer are often required to actively seek out relevant support themselves. Opportunities for tailoring legislation concerning sick leave, reintegration, and work disability benefits exist and should be made more accessible. Various recommendations have been provided to address encountered barriers.

CONFLICTS OF INTEREST

The authors have no conflict of interest to declare.

CONSENT TO PARTICIPATE

All participants provided written informed consent.

CONSENT FOR PUBLICATION OF AN IMAGE

Not applicable.

DATA AVAILABILITY STATEMENT

The data and coding tree are available in Dutch, upon reasonable request.

ORCID

Amber D. Zegers D https://orcid.org/0000-0002-3800-0829 Saskia F. A. Duijts https://orcid.org/0000-0001-6025-5361

REFERENCES

- American Cancer Society. (2021). Cancer Facts & Figures 2021. Retrieved July 30th from https://www.cancer.org/content/dam/cancer-org/ research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/ 2021/cancer-facts-and-figures-2021.pdf
- Bains, M., Munir, F., Yarker, J., Bowley, D., Thomas, A., Armitage, N., & Steward, W. (2012). The impact of colorectal cancer and self-efficacy beliefs on work ability and employment status: A longitudinal study.

European Journal of Cancer Care, 21(5), 634–641. https://doi.org/10. 1111/j.1365-2354.2012.01335.x

- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. https://doi.org/10.1191/ 1478088706qp063oa
- Buijs, P., Gunnyeon, B., & van Weel, C. (2012). Primary health care: What role for occupational health? *The British Journal of General Practice*, 62(605), 623–624. https://doi.org/10.3399/bjgp12X659141
- Buss, M. K., Rock, L. K., & McCarthy, E. P. (2017). Understanding palliative care and hospice: A review for primary care providers. *Mayo Clinic Proceedings*, 92, 280–286. https://doi.org/10.1016/j.mayocp.2016. 11.007
- Chow, S. L., Loh, S. Y., & Su, T. T. (2015). Perceived barriers and facilitators for return to work among colorectal cancer survivors: Malaysian healthcare professionals experience—A qualitative inquiry. *Journal of UOEH*, 37(2), 127–138. https://doi.org/10.7888/juoeh. 37.127
- de Jong, F., Frings-Dresen, M. H., Dijk, N., van Etten-Jamaludin, F. S., van Asselt, K. M., & de Boer, A. G. E. M. (2018). The role of the general practitioner in return to work after cancer—A systematic review. *Family Practice*, 35(5), 531–541. https://doi.org/10.1093/ fampra/cmx114
- Duijts, S. F., Kieffer, J. M., van Muijen, P., & van der Beek, A. J. (2017). Sustained employability and health-related quality of life in cancer survivors up to four years after diagnosis. Acta Oncologica, 56(2), 174–182. https://doi.org/10.1080/0284186X.2016.1266083
- Faas, J. (2018). Met kanker aan het werk? Tijdschrift voor Bedrijfs- en Verzekeringsgeneeskunde, 26(6), 285. https://doi.org/10.1007/s12498-018-0210-0
- Fidjeland, H. L., Brekke, M., & Vistad, I. (2015). General practitioners' attitudes toward follow-up after cancer treatment: A cross-sectional questionnaire study. *Scandinavian Journal of Primary Health Care*, 33(4), 223–232. https://doi.org/10.3109/02813432.2015.1118836
- Flieger, S. P., Chui, K., & Koch-Weser, S. (2020). Lack of awareness and common misconceptions about palliative care among adults: Insights from a national survey. *Journal of General Internal Medicine*, 35(7), 2059–2064. https://doi.org/10.1007/s11606-020-05730-4
- Forsythe, L. P., Alfano, C. M., Leach, C. R., Ganz, P. A., Stefanek, M. E., & Rowland, J. H. (2012). Who provides psychosocial follow-up care for post-treatment cancer survivors? A survey of medical oncologists and primary care physicians. *Journal of Clinical Oncology*, 30(23), 2897– 2905. https://doi.org/10.1200/JCO.2011.39.9832
- Glare, P. A., Nikolova, T., Alickaj, A., Blinder, V., & Patil, S. (2014). Returnto-work issues in outpatient palliative care. *Journal of Clinical Oncology*, 32, 35. https://doi.org/10.1200/jco.2014.32.31_suppl.35
- Glare, P. A., Nikolova, T., Alickaj, A., Patil, S., & Blinder, V. (2017). Work experiences of patients receiving palliative care at a comprehensive cancer center: Exploratory analysis. *Journal of Palliative Medicine*, 20(7), 770–773. https://doi.org/10.1089/jpm.2016.0478
- Gorin, S. S., Haggstrom, D., Han, P. K., Fairfield, K. M., Krebs, P., & Clauser, S. B. (2017). Cancer care coordination: A systematic review and meta-analysis of over 30 years of empirical studies. *Annals of Behavioral Medicine*, 51(4), 532–546. https://doi.org/10.1007/ s12160-017-9876-2
- Greidanus, M., de Boer, A., De Rijk, A., Tiedtke, C., Dierckx de Casterlé, B., Frings-Dresen, M., & Tamminga, S. (2018). Perceived employer-related barriers and facilitators for work participation of cancer survivors: A systematic review of employers' and survivors' perspectives. *Psycho-Oncology*, 27(3), 725–733. https://doi.org/10.1002/ pon.4514
- Greidanus, M. A., de Boer, A. G., de Rijk, A. E., Frings-Dresen, M. H., & Tamminga, S. J. (2020). The MiLES intervention targeting employers to promote successful return to work of employees with cancer: Design of a pilot randomised controlled trial. *Trials*, 21(1), 1–11. https://doi. org/10.1186/s13063-020-04288-0

- Halkett, G., Jiwa, M., & Lobb, E. (2015). Patients' perspectives on the role of their general practitioner after receiving an advanced cancer diagnosis. European Journal of Cancer Care, 24(5), 662–672. https://doi. org/10.1111/ecc.12224
- Kassianos, A. P., Ioannou, M., Koutsantoni, M., & Charalambous, H. (2018). The impact of specialized palliative care on cancer patients' healthrelated quality of life: A systematic review and meta-analysis. *Supportive Care in Cancer*, 26(1), 61–79. https://doi.org/10.1007/s00520-017-3895-1
- Kochovska, S., Luckett, T., Agar, M., & Phillips, J. L. (2018). Impacts on employment, finances, and lifestyle for working age people facing an expected premature death: A systematic review. *Palliative & Supportive Care*, 16(3), 347–364. https://doi.org/10.1017/S1478951517000979
- Lyons, K. D., Newman, R. M., Sullivan, M., Pergolotti, M., Braveman, B., & Cheville, A. L. (2019). Employment concerns and associated impairments of women living with advanced breast cancer. Archives of Rehabilitation Research and Clinical Translation, 1(1–2), 100004. https://doi. org/10.1016/j.arrct.2019.100004
- McKay, G., Knott, V., & Delfabbro, P. (2013). Return to work and cancer: The Australian experience. *Journal of Occupational Rehabilitation*, 23(1), 93–105. https://doi.org/10.1007/s10926-012-9386-9
- Mehnert, A., & Koch, U. (2013). Predictors of employment among cancer survivors after medical rehabilitation-a prospective study. *Scandinavian Journal of Work, Environment & Health*, 39, 76–87. https://doi.org/10. 5271/sjweh.3291
- Mills, K., & Payne, A. (2015). Enabling occupation at the end of life: A literature review. Palliative & Supportive Care, 13(6), 1755–1769. https:// doi.org/10.1017/S1478951515000772
- Morrison, T., Thomas, R., & Guitard, P. (2015). Physicians' perspectives on cancer survivors' work integration issues. *Canadian Family Physician*, 61(1), e36–e42. PMID: https://www.ncbi.nlm.nih.gov/pubmed/ 25756147
- Muller, E., & Hoving, J. (2018). Visie van verzekeringsartsen op de claimbeoordeling van mensen met een beperkte levensverwachting. TBV-Tijdschrift voor Bedrijfs-en Verzekeringsgeneeskunde, 26(10), 533–537. https://doi.org/10.1007/s12498-018-0311-9
- Nachreiner, N. M., Dagher, R. K., McGovern, P. M., Baker, B. A., Alexander, B. H., & Gerberich, S. G. (2007). Successful return to work for cancer survivors. AAOHN Journal, 55(7), 290–295. https://doi.org/ 10.1177/216507990705500705
- Nielsen, A. F., Zinckernage, L., Tofte, J. B., & Timm, H. (2019). Cancer survivors on the process of returning to work: A Danish focus group study. *Scandinavian Journal of Work, Environment & Health*, 45(4), 370–375. https://doi.org/10.5271/sjweh.3794
- Paltrinieri, S., Fugazzaro, S., Bertozzi, L., Bassi, M. C., Pellegrini, M., Vicentini, M., Mazzini, E., & Costi, S. (2018). Return to work in European Cancer survivors: A systematic review. *Support Care Cancer*, 26(9), 2983–2994. https://doi.org/10.1007/s00520-018-4270-6
- Petersen, K. S., Momsen, A. H., Stapelfeldt, C. M., & Nielsen, C. V. (2019). Reintegrating employees undergoing cancer treatment into the workplace: A qualitative study of employer and co-worker perspectives. *Journal of Occupational Rehabilitation*, 29(4), 764–772. https://doi.org/ 10.1007/s10926-019-09838-1
- Senden, T., Dona, D., & Janssen, J. (2019). Radboucumc overbrugt kloof tussen zorg en arbeidsdomein: Klinisch arbeidsgeneeskundige heeft sleutelrol. Medisch Contact, 8–10. https://www.medischcontact.nl/ tijdschrift/medisch-contact-thema/thema-artikel/radboudumcoverbrugt-kloof-tussen-zorg-en-arbeidsdomein.htm
- Tevaarwerk, A. J., Lee, J. W., Terhaar, A., Sesto, M. E., Smith, M. L., Cleeland, C. S., & Fisch, M. J. (2016). Working after a metastatic cancer diagnosis: Factors affecting employment in the metastatic setting from ECOG-ACRIN's Symptom Outcomes and Practice Patterns study. *Cancer*, 122(3), 438–446. https://doi.org/10.1002/cncr.29656
- The Netherlands Comprehensive Cancer Organisation (IKNL). (2020). Uitgezaaide kanker in beeld [Focusing on advanced cancer]. Retrieved

12 March from https://iknl.nl/getmedia/6ddb80c4-254f-4763-943f-1a50f5321b83/uitgezaaide-kanker-in-beeld-rapport.pdf

- Tiedtke, C., Donceel, P., de Rijk, A., & Dierckx de Casterle, B. (2014). Return to work following breast cancer treatment: The employers' side. Journal of Occupational Rehabilitation, 24(3), 399–409. https:// doi.org/10.1007/s10926-013-9465-6
- Tiedtke, C., Donceel, P., Knops, L., Désiron, H., Dierckx de Casterlé, B., & de Rijk, A. (2012). Supporting return-to-work in the face of legislation: stakeholders' experiences with return-to-work after breast cancer in Belgium. *Journal of Occupational Rehabilitation*, 22(2), 241–251. https://doi.org/10.1007/s10926-011-9342-0
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349–357. https://doi.org/10.1093/intqhc/mzm042
- Van Muijen, P., Weevers, N., Snels, I. A., Duijts, S., Bruinvels, D. J., Schellart, A. J., & Van Der Beek, A. J. (2013). Predictors of return to work and employment in cancer survivors: A systematic review. *European Journal of Cancer Care*, 22(2), 144–160. https://doi.org/10. 1111/ecc.12033
- Wolvers, M., Leensen, M., Groeneveld, I., Frings-Dresen, M., & De Boer, A. (2018). Predictors for earlier return to work of cancer patients. *Journal* of Cancer Survivorship, 12(2), 169–177. https://doi.org/10.1007/ s11764-017-0655-7
- Yagil, D., Eshed-Lavi, N., Carel, R., & Cohen, M. (2019). Return to work of cancer survivors: Predicting healthcare professionals' assumed role responsibility. *Journal of Occupational Rehabilitation*, 29(2), 443–450. https://doi.org/10.1007/s10926-018-9807-5

9 of 9

- Zegers, A. D., Coenen, P., Bültmann, U., van Hummel, R., van der Beek, A. J., & Duijts, S. F. (2022). Tailoring work participation support for cancer survivors using the stages of change: Perspectives of (health care) professionals and survivors. *Journal of Cancer Survivorship*, 1–14. https://doi.org/10.1007/s11764-022-01196-x
- Zegers, A. D., Coenen, P., van Belzen, M., Engelen, V., Richel, C., Dona, D. J. S., van der Beek, A. J., & Duijts, S. F. A. (2021). Cancer survivors' experiences with conversations about work-related issues in the hospital setting. *Psychooncology*, 30(1), 27–34. https://doi.org/10. 1002/pon.5529

SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

How to cite this article: Zegers, A. D., van Andel, E. S., Beerda, D. C. E., Dona, D. J. S., Aukema, E. J., Brom, L., & Duijts, S. F. A. (2022). Work resumption and retention in patients with advanced cancer: Experiences and perspectives of general and occupational health care professionals. *European Journal of Cancer Care*, *31*(6), e13714. <u>https://doi.org/10.1111/ecc.13714</u>