



## A five-phase process model describing the return to sustainable work of persons who survived cancer: A qualitative study

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### ABSTRACT

**Purpose:** We investigated persons who survived cancer (PSC) and their experiences in returning to sustainable work.

**Methods:** Videotaped, qualitative, in-depth interviews with previous cancer patients were analyzed directly using “Interpretative Phenomenological Analysis” (IPA). Four men and four women aged 42–59 years participated. Mean time since last treatment was nine years. All participants had worked for more than 3 years when interviewed. An advisory team of seven members with diverse cancer experiences contributed as co-researchers.

**Results:** The entire trajectory from cancer diagnosis until achievement of sustainable work was analog to a journey, and a process model comprising five phases was developed, including personal situations, treatments, and work issues. The theme “return-to-work” (RTW) turned out to be difficult to separate from the entire journey that started at the time of diagnosis. PSCs were mainly concerned about fighting for life in phases 1 and 2. In phase 3 and 4, some participants had to adjust and make changes at work more than once over a period of 1–10 years before reaching sustainable work in phase 5. Overall, the ability to adapt to new circumstances, take advantage of emerging opportunities, and finding meaningful occupational activities were crucial.

**Conclusions:** Our process model may be useful as a tool when discussing the future working life of PSCs. Every individual's journey towards sustainable work was unique, and contained distinct and long-lasting efforts and difficulties. The first attempt to RTW after cancer may not be persistent.

### 1. Introduction

Although the incidence of cancer is increasing, earlier diagnosis and improvement of cancer care have led to an increase in survival rates in the Western world (Cancer Registry of Norway, 2016; Engholm et al., 2016; Torre et al., 2015). Further, according to Norwegian 2015 statistics (Cancer Registry of Norway, 2016), almost three out of four cancer patients (71%) now survive more than five years after treatment and about 40% of cancer patients are of working age (20–59 years) at the time of diagnosis. These numbers are comparable with other European and Nordic countries (Engholm et al., 2010; International Agency for Research on Cancer, 2017).

A substantial amount of research has reported the complexity of return-to-work (RTW) processes. Physical and psychological effects after cancer treatment influence the process, as well as psychosocial, economic, and environmental factors at work and in private life (Feuerstein et al., 2010; Mehnert et al., 2013). According to Mehnert

(2011), approximately 60–70% of persons who survived cancer (PSC) who are of working age return to work. They demonstrated that cancer survivors have a higher risk of ceasing work than others have. Clinical factors such as advanced cancer stage, chemotherapy and socio-demographic factors may increase the risk of unemployment (Mehnert, 2011). Working life is in itself considered valuable because it is associated with identity, normality, and a contribution to the community (Dorland et al., 2016; Kennedy et al., 2007); therefore, being unable to RTW can represent a personal defeat that may lead to lasting obstacles (Little et al., 2002; Wells et al., 2013).

PSC may need to change their occupation, type of work, or reduce working hours for successful RTW (Mehnert, 2011; Torp et al., 2012). Mehnert (2011) found that, on average, approximately half of employed PSC report changes in occupational role. In Norway, Torp et al. (2012) found that one fourth of employed cancer patients make adjustments at work. Research also shows that close collaboration and dialogue between the employer, the workplace, and healthcare

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providers in the planning of RTW has profound impact on positive RTW results (Grunfeld et al., 2010; Kennedy et al., 2007; Mehnert, 2011; Torp et al., 2012). However, despite this substantial amount of knowledge, there is more to learn about RTW after cancer.

Sustainable work is defined as a situation where “living and working conditions are such that they support people in engaging and remaining in work throughout an extended working life” (Eurofond, 2016 p. 1). In previous research, the aims in investigating RTW processes have often considered the initial phases of RTW and have rarely examined the lasting outcomes (Barnard et al., 2016; Mehnert et al., 2013; Torp et al., 2012). This represents a gap in the knowledge, because the entire RTW processes may be of longer duration and one's initial RTW may not always be successful or enduring.

Wells et al. (2013) suggests that the concept of RTW may be too simplistic, and points to the importance and need for individualized support for PSC in processes of defining work-related goals. Several other researchers also underline the importance of self-assessment regarding ability to work—independent of clinical factors and age—and note the importance of individualized support, techniques, and cooperation in the quest of RTW (Barnard et al., 2016; Boerger-Knowles and Ridley, 2014; de Boer et al., 2008; Keesing et al., 2015; Mehnert et al., 2013; Stergiou-Kita et al., 2016).

Little is known about RTW-promoting factors and the individual abilities of PSC to adapt to altered circumstances and the resources they need in divergent phases of the entire RTW process towards lasting and sustainable work. Therefore, due to the increasing number of people who live many years with the chronic effects from cancer, we investigated RTW factors and the long-term perspectives involved in sustainable RTW. Specifically, we explored experiences of PSC after they had re-established normality and returned to sustainable work.

## 2. Method

We applied Interpretative Phenomenological Analysis (IPA) as our research design (Smith et al., 2009) and performed recruitment of participants, in-depth interviews and case analyses as parallel processes, which endured approximately one year before the search for nuances and patterns across the cases began. During the interview and analysis phase, an advisory team with experience relevant to RTW after cancer participated in the research process. The members included former cancer patients, health and social work personnel, an immediate supervisor, a medical doctor, and next of kin. This team contributed with comments and questions and thereby heightened the quality of the study in the development of the theme guide and the analysis (Borg et al., 2012; Mjøsund et al., 2017).

### 2.1. Sample and recruitment

Twelve volunteers responded to our advertisements on Facebook, the websites of the University College of Southeast Norway, and the Norwegian Cancer Society. Three did not fill the inclusion criteria, and one withdrew because he could not find time for the interview. After interviewing eight participants, we found the information power to be satisfactory (Malterud et al., 2015). The persons selected were aged 25–59 and had experienced long-lasting, or invasive, cancer treatment with surgery, radiation, and/or chemotherapy (Table 1). Three participants were diagnosed with breast cancer, and the others had various diagnosis: brain cancer, leukemia, testicle & lymph cancer, kidney & non-Hodgins lymphoma, giant cell tumor & lung cancer. Except for the participant with leukemia, who was on medication when the interview took place, all the other participants were cancer free. Moreover, we prioritized sociodemographic and cancer type diversity and occupations/work tasks. Participants had all achieved sustainable work (i.e., working more than 3 years (part-time or full-time) after their last treatment) and had no recurrent cancer or new diseases influencing their work in that period. The mean time since the last treatment was

nine years.

### 2.2. Data collection

The videotaped interviews lasted 96 min on average. The participants chose the location; three preferred their homes and five preferred their workplace. Three participants were re-interviewed after the initial analysis process. We chose Britt, Grete, and Carl because we had some additional questions for them from the first interviews that needed clarification. In addition, we wanted to discuss our abstractions and the process framework to determine participants' opinions.

The first author performed all interviews, using a theme guide as a mental guide only and aimed to obtain participants reflections through reflexive dialogues (Borg et al., 2012; Malterud et al., 2015; Smith et al., 2009). The theme guide contained questions about the entire process from diagnosis, including treatment and how it affected working life, towards the process of RTW and what factors the participants stated as important for RTW and life normality. After initial conversations about the interview and its content, the opening question was, “Will you please tell me what you consider to be your most crucial factors in the process of successful RTW after cancer and cancer treatments.” Hence, the intention was to conduct almost entirely open interviews, and the interviews were thoughtful dialogues. The interviewer was aware of possible unequal power dynamics between the interviewer and the interviewee during the conversation and focused on respectful and empathic behavior (Malterud, 2001).

All videos, notes, conceptual maps, memos, abstractions and data gathered during the process were organized, coded, and filed in the database and NVivo 11 program (QSR International, 2016). Transcribed statements from the interviews illustrate the results of this study.

### 2.3. Data analyses

The IPA methodology was applied in accordance with Smith et al., 2009 recommendations. We analyzed each interview thoroughly before sampling and interviewing the next participant. Immediately after interview completion, the interviewer taped her reflections on the total impression of the interview. Thereafter, the complete case analysis of the current case was performed before the next interview took place.

To maintain closeness to the original data, we analyzed video directly without transcription (Beich et al., 2002), which allowed us to incorporate both tone of voice and body language in statement interpretation. Key statements were transcribed verbatim and added to the textual notes. Codes were inductively developed and interlinked. Finally, codes were abstracted into a mind map of categories for each case.

After the eight interviews were analyzed, we searched for nuances and patterns across the cases. In the final stage of the analyses, we utilized the NVivo mind maps and project maps of the coding from the eight case analyses. This process resulted in a mind map containing the overall themes and abstractions. The advisory team was engaged in the analyses process and contributed with comments and critical questions to the initial interpretations from the researchers (Malterud, 2001).

### 2.4. Ethics

The Norwegian Regional Ethical Committee (REK) evaluated and approved the project in April 2015 (reference no. 2015/1232). Orally and in writing, we informed participants about the project aim, interview content, use of videotaping, and confidentiality of the project (pseudonyms were used for participants' names). Participants provided informed, written consent and could withdraw from the project at any time without consequence. In accordance with the REK, only the main researcher had access to the raw material and videos that were stored on a secured area at the University server. All written material and video copies were stored in a locked safe.

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