



Changes, challenges and support in work, education and finances of adolescent and young adult (AYA) cancer survivors: A qualitative study

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ABSTRACT

Purpose: An increasing number of adolescents and young adults (AYA) are becoming cancer survivors and are dealing with long-term effects of the disease and its treatment. We aimed to collect detailed self-reported information about the areas of work, education, and the financial situation of AYA survivors after acute treatment. We further examined sources of support that were perceived as particular helpful.

Method: We conducted semi-structured interviews with a sample of 11 AYA cancer survivors (on average 5 years from diagnosis; mean age at diagnosis = 25.7 years) that had been recruited for the AYA-Leipzig longitudinal study. Interviews were transcribed and data were analysed using qualitative content analysis.

Results: The following themes emerged as relevant: (1) career modifications and job loss, (2) career interruptions and delays, (3) uncertainty in the return-to-work process, (4) reduced work ability, (5) discrimination at the workplace, (6) changes in the personal importance of work and (7) financial burdens. Sources of considerable support included relatives as well as German social security institutions.

Conclusions: Health care providers should address the specific risk of a financial burden and the somewhat complex social legal situation of young adult survivors after cancer diagnosis. AYA cancer survivors need age-specific comprehensive cancer survivorship support programs. These should accompany them in the long term and be targeted to the individual need for career modification or reorientation - even after the completion of cancer treatment and rehabilitation.

1. Background

Approximately 80% of the 17,000 young people diagnosed with cancer every year in Germany survive for at least 5 years (Trama et al., 2019; Zentrum für Krebsregisterdaten im Robert Koch-Institut, 2019). Cancer survivorship encompasses a spectrum of long-term issues including late physical and cognitive impairments, follow-up medical care, risk of recurrence and secondary malignancies (Hawkins, 2004; Mellblom et al., 2021). Individuals who are diagnosed with cancer between the ages of 15 and 39 represent a patient population of adolescent and young adults (AYA) with cancer (National Cancer Institute, 2006), which is characterized by a unique spectrum of cancer types and psychosocial needs (Coccia et al., 2018; Zebrack, 2011). AYA cancer survivors are at a higher risk of psychosocial distress than both their cancer-free peers and older adult cancer survivors (Lang et al., 2018).

The transition from active cancer treatment to survivorship can bring

challenges, such as dealing with impairments of cognitive and physical functionality, body image concerns and fear of recurrence (Barnett et al., 2016; Prasad et al., 2015; Stein et al., 2008; Stepanikova et al., 2016; Yang et al., 2019). These influence multiple life domains of AYA cancer survivors, including their working life and financial situation (Bellizzi et al., 2012; Wong et al., 2017). Entering professional life, setting career goals and gaining financial independence from the parental home represent important developmental tasks that characterise the period of young adulthood (Arnett, 2000; Baird et al., 2019; Zarrett and Eccles, 2006). A return to paid work or education is perceived as important by young cancer survivors as it indicates a return to normalcy after illness, providing them with a source of identity, self-worth, social contacts, provision of structure and financial security (Isaksson et al., 2016; Saunders and Nedelec, 2014). Impaired work ability as a result of cancer and its treatment can represent a source of distress, not least because AYA survivors are mostly still in education, at the beginning or at an

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early stage of their career (Fardell et al., 2018; Stone et al., 2017). AYA patients who return to work, school or university after treatment report high levels of dissatisfaction and unmet needs (Leuteritz et al., 2018; Millar et al., 2010; Parsons et al., 2012; Pulewka et al., 2020; Sender et al., 2019; Wong et al., 2017). American data on the return to paid work show that around 70% of AYA patients go back to their former workplace, school or university after treatment, but with a proportion of 50% reporting problems with their work or studies on return (Parsons et al., 2012). We found similar results in our AYA-Leipzig study (Leuteritz et al., 2020). As an additional burden, financial problems are known to be a common issue among patients with and survivors of cancer. Individuals often experience a drop in income due to cancer-related work disruption, while at the same time facing increased expenses for medical treatments (Altice et al., 2017; Büttner et al., 2019; Salsman et al., 2019; Teckle et al., 2018).

The focus in AYA research has essentially been placed on health and psychosocial outcomes of cancer rather than the personal experiences of AYA survivors and associated developmental and psychosocial challenges. However, a deeper understanding of the personal situation of AYA survivors provides an important component for high-quality comprehensive AYA cancer care (Salchow et al., 2020). To our knowledge, comprehensive qualitative research work on AYA survivors' occupational and financial situation is limited.

Against this background, we explored the self-reported perceived long-term effects after cancer treatments in the life domains of (i) occupation, education and (ii) financial situation among AYA survivors of cancer. We further aimed to explore the support that AYA survivors perceived as helpful with regard to these particular life domains.

2. Methods

2.1. Study design

We implemented this qualitative cross-sectional study as part of a larger longitudinal study (AYA-Leipzig study) on quality of life, mental health, work situation and psychosocial care of AYA patients with cancer and survivors in Germany.

The four standardized quantitative surveys of the longitudinal study were supplemented by three qualitative surveys at the assessment time points (t1 to t3), each focusing on a different theme. The analysis of this present study is based on the third qualitative follow-up interviews at t3. The results of the previous two qualitative surveys t1 and t2 have been published (Breuer et al., 2017; Mentschke et al., 2017). A detailed description of the aims, study design, and recruitment procedures of the AYA-Leipzig study can be read in the work of Geue et al. (2021).

The findings of this study are based on guided semi-standardized interviews that were carried out and analysed by two research team members (female Master of Psychology students).

The study was approved by the local ethics committee of the medical faculty of the University of Leipzig (no. 372-13-16122013). All participants provided written consent and were informed about the background of this study.

2.2. Participant recruitment

The qualitative interviews at t1 took place in the year 2014 at the end of the patients' acute medical treatment, on average 16 months after the diagnosis. Interviews at t2 were conducted one year later. In this study, we refer to the qualitative interviews at t3 done in the years 2018 and 2019. Twenty participants from the main study sample of $n = 477$ were identified as eligible for the first qualitative interview measuring point (t1). Fig. 1 shows the patient flow, including drop-outs, leading to the final 11 qualitative interviews forming the study sample.

AYA study participants had a cancer diagnosis, were between 18 and 39 years old at diagnosis and had been diagnosed during the 4 years prior to t1 (first manifestation, all malignant tumour identities). In Germany, patients younger than 18 years are treated in paediatric oncology units. Therefore, we decided to focus on 18- to 39-year-old patients, even though the international AYA definition includes young people from 15 years of age.

The sample for this qualitative study was further selected by using the following criteria.

- gender distribution as equal as possible to the population of AYAs with cancer (Robert Koch-Institut, 2015),

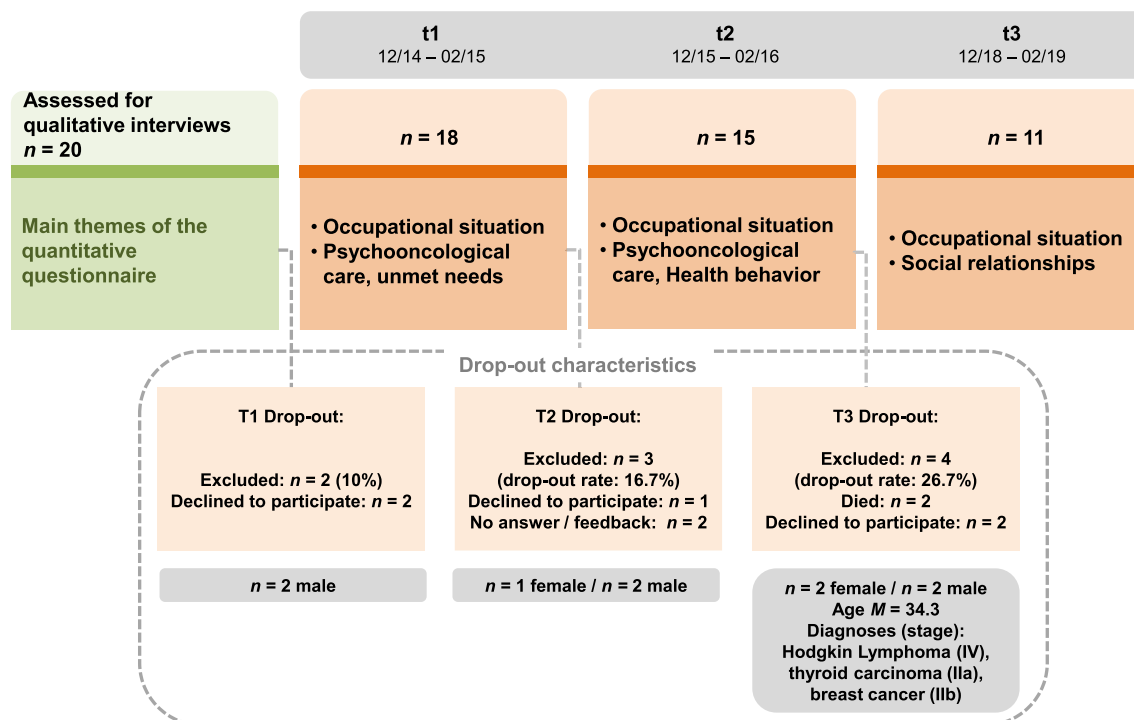


Fig. 1. Flowchart of the AYA-Le study participants - qualitative part and main survey themes.

- representation of the five most common and at least two rare diagnoses for AYAs with cancer among both genders (Robert Koch-Institut, 2015),
- preferably an even distribution of stages of cancer (I-IV) within the set of different diagnoses.

By including these criteria, we aimed to represent the widest possible range of variation of the target group (Köhler and Frommer, 2011).

2.3. Data collection

Two research team members conducted the interviews in person or by telephone between October 2018 and January 2019. Before, the interviewers had been trained by research members of the AYA-Leipzig study and had taken part in a test interview with a young cancer survivor.

We created a semi-structured interview guide based on existing empirical results and the research questions that framed this study. This included (interview-opening) questions about the course of illness, treatment, and different areas of life (occupational situation, housing, and financial situation since the end of acute treatment). We drafted the interview questions as follows.

1. Please tell me: To what extent has your occupational situation (work, education, school, studies etc.) changed due to cancer?
2. What kind of support (medical, psychosocial, social-legal care, personal support, etc.) has helped you the most regarding your occupational situation? In what ways?
3. What effects did the cancer disease have on your income/financial situation?
4. What kind of support (medical, psychosocial, social-legal care, personal support, etc.) has helped you the most regarding your financial situation? In what ways?

We collected sociodemographic data and medical information through the parallel quantitative questionnaire survey of the AYA-Leipzig study (t3). The interviews were audio recorded. All participants received an expense allowance of 10 Euros after the interview.

2.4. Data analysis

The two researchers who interviewed the participants transcribed the audio-taped interviews verbatim. Both coders used consistent transcription rules (Dresing and Pehl, 2018; Kallmeyer and Schütze, 2016). The transcripts were analysed based on Mayring's qualitative structuring content analysis modified by Steigleder (2008). One of the researchers who interviewed the participants created a detailed category and coding system and conducted the coding (Steigleder, 2008). The data material was first read through several times (step 1). Step 2 on the formation of meaningful content sections was omitted as this step had already been completed by the formation of subject areas in the interview guide. Then, various sub-categories and characteristics were added to each main category (steps 3 and 4). In addition, residual categories were created for the individual theme areas to be able to locate material that could not be assigned but was relevant. In step 5, the coding guide (with coding rules and prime examples) was created. Relevant text passages from the data material were marked and assigned to the previously identified categories (steps 6 and 7). Within each transcript, one segment of text could have been coded into more than one category. At each step, the plausibility of assignment to the categories was checked and the system was revised (step 8). The software 'MAXQDA 2020' (Kuckartz et al., 2019), a program for qualitative research, was used for the classification of the data material.

Coding was reviewed by another member of the research team. The intercoding agreement based on the relevant text passages of the transcripts was calculated. Both the percentage of matching encodings and a kappa value including the probability of a random match between the two coders were calculated (Brennan and Prediger, 1981; Cohen, 1960; Rädiker and Kuckartz, 2019).

3. Results

3.1. Sample characteristics

A total of $n = 11$ AYA completed the qualitative survey. The study sample ranged in age at interview from 24 to 44 years (mean = 31.5; $SD = 4.24$; table 1). At the point of the interview, most participants were employed or in education ($n = 9$; 81%). Three participants had haematological cancer (Hodgkin's lymphoma, non-Hodgkin's lymphoma, blood cancer) and eight had solid tumours (testicular cancer, $n = 2$; sarcoma, $n = 2$; ovarian cancer; brain cancer and melanoma).

Participants were interviewed on average 56 months after diagnosis ($SD = 19.80$). Interviews ranged in duration from 24 to 149 min. We conducted eight of the interviews via telephone and three in person at the Leipzig Department of Medical Psychology and Medical Sociology.

3.2. Inter-coder agreement

We calculated the inter-coder agreement at the level of all transcripts across all created coding categories. A total of 142 find-spots were coded. The percentage of agreement of all assigned codes between both coders was 74% with the random corrected coefficient $\kappa = .73$ (Brennan and Prediger, 1981).

3.3. Qualitative findings

3.3.1. Perceived changes and challenges: work and education

All participants reported experiencing one or more changes or challenges in the area of work and education after they had been diagnosed with cancer. Six overarching themes could be identified on the basis of the participants' interview statements: (1) career modifications and job loss, (2) career interruptions and delays, (3) uncertainty in the return-to-work process, (4) reduced work ability, (5) discrimination in the workplace, and (6) decreased importance of work in life.

(1) Career modifications and job loss

Even though the majority of the interviewed AYA survivors had returned to their (former) workplace or university after cancer treatment, they reported various interrelated changes in their career plans because of their disease. AYA survivors spoke about modified tasks at the workplace, for example a transition from field service to office work because of sunlight incompatibility. AYA participants explained these changes with physical and mental limitations caused by cancer and its treatment. They mentioned impairments in mobility and immune function, cancer-related chronic fatigue, sunlight and food intolerances as well as a changed physical appearance.

The majority of the interviewees had to face unfavourable developments in their career. Some AYA survivors underwent vocational retraining and experienced a lack of career orientation. They had to deal with the loss of their original place of work or studies, some more than once, because they struggled with physical problems and a recurrence of the disease. For instance, a young woman who had been diagnosed at the age of 24 had to break off two apprenticeships because she became ill twice. She was unable to manage working as a retail saleswoman or educator while being confronted with cancer and its associated physical impairments. Another 44-year-old woman had received a diagnosis of breast cancer at the age of 39 and had to undergo surgery. After that, her professional life had changed, as she explained:

The negative thing is that I [...] can no longer do what I wanted to do. I started an apprenticeship as a gardener. I also liked that very much, but then I could no longer practice or pursue it, because I can no longer do hard work with my arm. (44-yr-old female)

This woman had to wear a support stocking after cancer treatment and could no longer work as a gardener. She found a new job in data

management but was made redundant because she had been working too slowly with the support stocking on her hand. At the point of the interview, she was still searching for an appropriate workplace. She had received job proposals from the German federal agency of employment that would not fit her physical post-cancer condition.

Other AYA survivors also changed, and some even identified new career goals because of experiences they had made in the context of their illness and its treatment. After being asked how her professional situation had changed because of cancer, a participant reported the following:

Of course, it has changed completely [...] I got sick right after I graduated from high school, I was 18 then. I didn't have a precise idea yet. I knew I wanted to do something social, something with people. I got sick and then, within the two years I was in treatment, I developed the idea that I somehow wanted to go into the psychological field. [...] I went to [a] rehab[ilitation program] for six weeks and had a lot to do with psychologists and the job field was brought closer to me. (29-yr-old female)

One participant mentioned that his decision to take up a job far away from home was an attempt at breaking free from parental care. He wanted to move out of the parental protective comfort zone that had intensified during cancer treatment and beyond.

(2) Career interruptions and delays

The majority of the participants reported having to suspend their work or studies for treatment, aftercare and recovery. Survivors who were studying at the time of diagnosis reported the need to extend their university studies. One study participant described the situation as follows:

Well, I was a student then and I'm still a student now [...] I'm in the Master's programme now and it's progressing, but it has already cost time, so I had to break off the semester completely [...] which was of course lost [...] which I just don't mention in job interviews and that's why I'm always a bit floundering. (25-yr-old male)

For some survivors, returning to work after an absence due to the disease was a long process of gradual reintegration into the working life including a program to make changes in the organisation of the work, working hours and health protection regulated by the German statutory law ('Stufenweise Wiedereingliederung').

(3) Uncertainty in the return-to-work process

Some of the interviewed AYA survivors mentioned uncertainties and challenges when searching for a job after the experience of the cancer disease and its treatment. A 30-year-old participant who had been diagnosed at the age of 25 during his university studies reported for instance:

I just had the problem in the first one or two years [after treatment] that you somehow achieved something, but you really didn't get any credit for it, that's kind of funny. So you've done the worst shit for a year, somehow managed to get through it [...] then you're just standing there with an unfinished bachelor degree, have to somehow chum up to some companies that want you for [...] eight hundred euros as an intern. [...] You think that that's a bit unfair, but I think it's also very much due to the situation of your life, that you're somehow at the very beginning anyway. That was a pretty shitty point in time. (30-yr-old male)

AYA survivors also expressed being anxious about their professional future and feeling alone or helpless, such as this interviewee:

I really need to pay attention in which direction I want to go, where can I go from here? Where can I work now? [...] well, I am actually looking for support. I don't know where I could turn to now, who could give me assistance? (44-yr-old female)

Concerns about future stigmatisation because of the illness and the ownership of a disabled person's pass were a common issue among the participants. In the context of job application interviews, participants reported being unsure about disclosing their history of cancer, about not wanting to be perceived as disabled or less resilient, but also knowing that the illness still had a substantial influence on their body and life. In this context, participants spoke about being a potential economic risk for future employers in case of a recurrence or other consequences of the cancer disease. A 34-year-old woman with the diagnosis melanoma stated the following after being asked how her professional situation had changed because of cancer:

This is the area where I still feel the most enduring effects today. [...] It wasn't easy anyways because [...] I had two children. I basically went from one to the next parental leave. [...] And I know how hard it is to go back to the old place after having a child, without a disease. [...] I still remember that [the job application] was difficult for me at that time. What do I say, what do I tell? You don't want [...] to court pity like that [...] either, do you? On the other hand, [...] I had of course experienced that the illness or the diagnosis had turned quite a lot upside down, hadn't it? (34-yr-old female)

(4) Reduced work ability

Interviewed AYA survivors stated that they had experienced reduced performance capacity after returning to work or studies. They reported that physical and mental consequences of cancer and its treatment had affected their work performance negatively and led to absenteeism from work. At the same time, they felt considerable pressure to have to prove themselves at their workplace or training position:

When I had to work and felt the strain, I often had a cold [...] and was just not as efficient [...] Somehow, I still notice that I am not always one hundred percent fit. [...] You simply need a lot of energy [...] But if you have distractions all the time, such as follow-up treatment, yes, low leukocytes, a poor immune system, where you have a cold all the time, and have to justify yourself. As a trainee, you should not be sick at all, be permanently energetic, but to feel the opposite inside the whole time, that's just really [difficult]. [...] I was the whole time somehow so exhausted. (30-yr-old male)

The experience of reduced work ability was often accompanied by perceived pressure from others, such as employers, to return to a pre-cancer level of functioning, even if not feeling capable of it. A participant with melanoma told us the following:

I think the impression others around me had was: go ahead again. But I thought: no, somehow it's not possible, I can't do it [...] For one year, I thought every day about the fact that I may have to die and how will that be and so on? And now I am supposed to go back to my normal everyday life? (34-yr-old female)

(5) Discrimination in the workplace

A few participants pointed out experiences with cancer-related discrimination at work. The 34-year-old woman with melanoma who worked in public service was advised to go on special leave when she had to undergo cancer treatment. She felt betrayed and that her situation was not really understood by her employer.

Another interviewee stated that he did not participate in post-cancer rehabilitation because of his employer:

They said: well, if he wants to have a contract, but it is already known that he will be absent three to four weeks, then a permanent employment contract is not possible. They said: a new contract is requested and in case

this goes through, I would be advised to cancel the rehab[ilitation program]. (33-yr-old male)

(6) Decreased importance of work in life

AYA participants expressed lowering the priority of work in their life. In contrast, they paid more attention to themselves and their own health compared to the time before their cancer diagnosis. Participants mentioned focusing on an increased work-life balance, for example by not going to work when having a headache, because 'working is not everything in life' (33-yr-old male).

I do not pressure myself anymore. [...] I have said: I do not want to get it [cancer] again. [...] I said: Now I shift a gear. I was still at the [name of company] this year and around Christmas it has been very much, so that I said at some point: [...] if I cannot manage this, then I break off and then it [the working task] is left unfinished. In the end, it is not my problem. (33-yr-old male)

3.3.2. Perceived changes and challenges: financial situation

Most interviewed AYAs stated that they (1) had managed to get back to a pre-cancer financial status at the time of the interview (return to financial status quo), whereas some of the interviewees mentioned (2) financial burdens or (3) financial gain since having finished cancer treatment.

Return to financial status quo

Even though several interviewees stated that they had experienced financial losses during and right after cancer treatment, half of the research participants indicated that their financial situation was no longer an area of concern at the point of the interview. This applied especially to participants who could resume their original job without obstructions or who had financial support from their families.

Financial burdens

Interviewed participants reported financial burdens mainly because of expenses for the preservation of fertility (e.g. cryopreservation of germ cells). An interviewed AYA who was diagnosed with ovarian cancer said:

I still got my uterus, but I know that this will always be associated with money if I ever want to have a family someday and I find this sometimes a bit difficult. Just to be able to deal with this thought. I know, I need money as soon as I want to have a family. (29-yr-old female)

Financial burden was also reported in association with a lack of income despite financial compensation by social welfare benefits or financial unemployment assistance (in case of continuous cancer-related unemployment). The same patient who had to deal with fertility expenses also stated that she had received less money from the statutory health insurance and social welfare when the cancer disease re-occurred again, which led to financial problems (29-yr-old female).

Two survivors had received a disability pension after cancer treatment. They both had to reach out for financial support from the German federal agency of employment because the disability benefit they had received was too low to cover their costs of living.

Financial gain

Due to changes in work owing to cancer and its treatment, some respondents registered positive developments in the form of pay increases at work. When asked how the financial situation had changed due to cancer, an AYA reported the following:

It has changed for the better. Three years ago, I changed the employer and I am still working there. I could even climb up the career ladder [...] and I feel very comfortable there. In the end everything went well, yes. (33-yr-old female)

3.3.3. Support in the context of work and education

AYA participants pointed out certain characteristics of their workplace or university as helpful, such as empathetic colleagues and superiors as well as flexibility in their work schedule. A female cancer survivor who had been diagnosed at the age of 23 stated the following:

I work in the public sector, where I have [...] the advantage that I only have to formally report sick from the third day on [...] then you can say to yourself: 'it's just not possible', if you don't feel physically or mentally able to go to work. (28-yr-old female)

Interviewed AYAs had benefited from certain vocational support services regulated by German social law, for example the provision of employment participation benefits ('Maßnahmen zur Teilhabe am Arbeitsleben'). This may involve technical aids and ergonomic modifications at the training site or workplace as well as the possibility of undertaking vocational retraining or further education. For example, a young survivor of leukaemia benefited from a reintegration program at her workplace:

The first week I only had three hours and then it increased every week and that worked out very well. [...] The social worker at the rehab[ilitation] centre where I'd stayed organised the reintegration. [...] I didn't have to take care of anything. [...] that was also very easy. (27-yr-old female)

Moreover, the disadvantage compensations ('Nachteilsausgleich') through having the status of being a severely disabled person were mentioned as helpful. This led, for example, to less difficult access to a university place, compensation for disadvantages in university exams or additional paid leave for employees.

Finally, the interaction with the social environment, more specifically conversations with family (primarily parents), partners and friends, had been mentioned as helpful as well as psychological support in inpatient rehabilitation and in further aftercare.

3.3.4. Support with alleviating the financial situation

AYA participants' families (parents and spouses) were the most frequently named sources of economic support after cancer treatment. In most cases, support consisted of compensation for the increased (health) expenses or lost income, but it could also involve organising survivors' finances and providing housing to save the cost of rent. A cancer survivor who had been diagnosed aged 25 with Hodgkin's lymphoma described the following:

I was financially supported by my parents during my studies, got the same money during the cancer therapy and managed very well with it. And afterwards, until I earned money myself, I was also supported by them. [...] it helped me the most that my parents are financially secure, and therefore, I had no financial worries. I [...] could save a little bit [money]. Therefore, I did not get into financial trouble. (30-yr-old male)

Also deemed helpful were sick pay from the statutory health insurance and/or financial unemployment compensation from the German federal agency of employment and, in a few cases, disability pension in case of reduced earning capacity. A participant reported:

First I got the six weeks of normal continued pay by the employer and then for one and a half years [...] sick pay from the statutory health insurance and when that ran out, I then got this disability pension [...] Since I have not yet had such a long working life, I have also not paid a lot into the pension fund, so I got a little something and then had it topped up by the

job centre [unemployment financial compensation from the German federal agency of employment]. (39-yr-old male)

One young man indicated having received financial support from a special program of the German Cancer Aid fund, which had helped him a lot.

4. Discussion

All 11 interviewed AYA participants disclosed an impact of cancer on their work, career and financial situation on average five years after cancer diagnosis. The majority of them had to break up their career or studies for sick leave and treatment for a certain period of time. Some interviewees subsequently extended their university studies. Consistent with the literature (Parsons et al., 2012), the majority of the AYA survivors in this study had returned to their (former) workplace or university after cancer treatment. However, in other cases, the interviewees had lost their job or chosen to leave their original workplace or education facility. Major reported issues were physical and mental impairments because of the cancer disease and its treatment, affecting functional and work ability and, occasionally, the employment status. Earlier research similarly documented the significant impact of cancer and its treatment on AYA's self-reported physical and mental work capacity, a lowered self-reported cognitive functioning and greater perceived difficulties in coping with work compared to healthy subjects (Brock et al., 2022; Ketterl et al., 2019; Nugent et al., 2018). Furthermore, the participants in our study felt pressure to regain a high level of functioning in their work and educational life. This was explained by being at an early stage in their career and not having yet established a long-term, sustainable relationship with their employer compared to older colleagues. Thus, several interviewees had to reorient themselves towards embracing new career paths. AYA survivors had to adapt to vocational retraining or modified tasks and workplaces while being confronted with the cancer diagnosis, treatment and its multiple medical and psychosocial consequences at the same time. In this context, the study participants had benefited from certain vocational support services regulated by German law, for example the provision of employment participation benefits (as technical aids and ergonomic modifications of the workplace) or support for vocational retraining. Moreover, a flexible work schedule and an empathetic employer or educational institution were deemed helpful in this context.

The interviewees further reported uncertainty as to how to communicate with others about the disease and its impacts. They experienced discrimination and fear of stigmatisation by future employers, a phenomenon that was also reported in other studies (Bellizzi et al., 2012; Stepanikova et al., 2016; Vetsch et al., 2018). Targeted support for AYAs on how to manage the process of returning to work and how to communicate their experience of the illness and the associated breaks and changes in their career would therefore be a helpful intervention.

Considering work in a broader sociopolitical context, having a paid job, establishing career and working hard are not only individual values but rather societal expectations that have become as important as family relations (Matthews, 2019; Rasmussen and Elverdam, 2008). This can place a lot of pressure on a healthy working individual but might be even more challenging for young adults with cancer who are mostly at the beginning of their career and may also have to shoulder the financial responsibility for a family and young children.

For many AYA survivors, financial problems as a result of their illness were no longer an issue at the time of the interview. One explanation might be the consistent employment status of most of the AYA participants at that point. In addition, cancer-related financial burdens were often alleviated by relatives (in particular parents and spouses), who were seen as crucial sources of economic support by a large part of the interviewees. Some AYA respondents were burdened by out-of-pocket payments for fertility preservation, while others had further expenses.

Fortunately, since 2021, people with statutory health insurance in Germany could get financially reimbursed for fertility protection prior to a potentially germ cell-damaging therapy.

As employed young adults have often been in working life for only a short time when the disease is diagnosed, they have no or little claim to a disability pension provided by the German pension insurance. Survivors who are still in education and who are often only working in marginal part-time work (so-called 'mini-jobs') with specific student health insurance tariffs cannot claim sick pay from the statutory health insurance. This might lead to a (greater) financial dependency on parents, as shown in other studies (Kosir et al., 2020; Sisk et al., 2020). Since young adults usually aspire to gain independence from their family home, this might be an issue requiring special attention in cancer care for AYA survivors.

Earlier research indicated that cancer survivorship might lead to re-shifting priorities and modification of one's identity, also in working life (Bellizzi et al., 2012; Elsbernd et al., 2018; Fauske et al., 2019; Lehmann et al., 2014). This finding was also a recurrent issue in our interviews: the interviewees had invested a lot of their personal resources in their health and well-being as well as in their individual and professional development. Even if they did take a break from paid work or studies because of cancer, many of them had to cope with illness, shifts in their identity and household work in this time and even upon their return to paid work (Parsons et al., 2008; Pritlove et al., 2019).

To support AYA survivors in dealing with these changes and challenges, career and financial consultation services targeted to the specific situation of young adults with cancer should be provided during but also beyond medical treatment and rehabilitation. However, follow-up care in Germany has so far mainly focused on the five-year monitoring of a potential recurrence of the disease. An approach might be a socio-medical consultant constantly accompanying the AYA survivors during cancer treatment and for several years after its completion. One example is the Comprehensive Assessments and Related interventions to Enhance long term Outcome in Children, Adolescents and Young Adults program, which provides psychological, nutritional and physical exercise support for AYAs in medical care units (CARE-for-CAYA-Prevention Programm, Quidde et al., 2017). Individual career and financial advice focusing on personal abilities and cancer-related impairments, economic resources and potential new directions for the work and career of AYA survivors could be added. Since family members, especially parents and spouses, have proven to be a decisive factor in supporting AYAs with cancer, they should be involved in such psychosocial interventions. Including the employer, university, school, family, and friends might also help to establish a fit between the needs and expectations of cancer survivors and their social environment. Thereby, a re-conceptualisation of work as described, for example, by Parsons et al. (2008) might be essential for specialized and comprehensive support mechanisms. The perception of work as not only paid labour, but also as the experience of working through challenges in the domains of identity, illness, and health could provide a better understanding of the multifaceted challenges AYA survivors have to face.

4.1. Limitations

The results of this qualitative study provide a detailed insight into the psychosocial situation of young cancer survivors. However, the generalisability of these findings is limited for several reasons.

First, it is possible that the individuals who consented to participate perceived their situation as more influential, suffered more than others and therefore had a greater need to share their experiences. On the other hand, survivors who experienced fewer challenges might have been more likely to participate because it was easier for them to talk about their situation. It is also possible that participants who may have experienced the most detrimental changes in their working life after cancer might have been excluded because they suffered from cognitive and other limitations and may not have been able to take part in the interviews. We cannot exclude that the results are biased due to drop-outs

of study participants with a particularly severe stage of the disease who chose not to respond or had passed away.

Second, most of our participants had received education for more than 10 years and had a household net income equal to or higher than 2000 euros per month. Participants with lower income or education may have reported other experiences than our sample.

Third, we collected self-reported data based on a relatively small sample of cancer survivors at one measurement point. Because of this, we cannot conclude that the reported findings are entirely related to cancer and its treatment. Since we collected information in the form of participants' experiences that occasionally dated back up to several years, it is possible that interview statements were biased due to lack of memory of the participants.

Fourth, the sample of this study is fairly generalisable regarding the distribution of gender in the German population, with cancer slightly more often diagnosed in female than their male counterparts (Robert Koch-Institut, 2015). However, the applicability of our findings to a more diverse population (language, ethnicity, gender, geography, socioeconomic status) is unknown.

5. Conclusions

The findings of this qualitative study demonstrate how diverse, interrelated, and sometimes persistent, challenging and somehow enabling post-cancer trajectories can become for AYA cancer survivors. Even though most AYA survivors of cancer were employed and financially stable approximately five years after their cancer diagnosis, they went through extensive phases of reorientation in their working lives, accompanied by losses of perspective, physical and mental limitations, stigmatisation, and rejection from future employers as well as financial burdens. Having to deal with multiple demands, such as building one's career, gaining independence from the parental home and responding to high expectations regarding performance, AYA cancer survivors experience a significant drain on their resources and well-being.

Health care providers and psychosocial health services should address the specific risk in terms of the financial burden and the fairly complex social legal situation of young adult survivors. The latter need age-specific comprehensive cancer survivorship support programs that accompany them in the long term, even after the completion of cancer treatment and rehabilitation. Program flexibility based on the individual return to work or career modification process would be useful.

Appendix

Table 1
Sociodemographic characteristics of the study participants at interview ($N = 11$).

	<i>M</i>	<i>SD</i>	Range
Age at interview	31.5	4.24	24–44
Age at diagnosis	25.7	2.12	18–39
Months since diagnosis	56.4	19.80	48–82
			<i>n</i>
Diagnosis			
Haematological cancer			3
Solid tumours			8
Gender			
Male			5
Female			6
Vocation at t1^a			
Employed ^b			4
Not employed ^c			2
Vocational training/studies			5
Postmorbidity vocation (t3)			
Employed ^b			7
Not employed ^c			1
Vocational training/studies			3
Household net income (euros per month)			

(continued on next page)

Specialized psychosocial support by professionals in the form of career advice, information on financial support and resources, as well as involving close relatives and employers may help AYA survivors to negotiate the changes and challenges they face and enable them to successfully re-enter employment and education.

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CRediT authorship contribution statement

Isabella Braun: Conceptualization, of the study, Methodology, Formal analysis, interviewing, Investigation, Writing – original draft, preparation, Writing – review & editing, All authors read and approved the final manuscript. **Michael Friedrich:** Methodology, Writing – review & editing, All authors read and approved the final manuscript. **Larissa Morgenstern:** Formal analysis, interviewing, Investigation, All authors read and approved the final manuscript. **Annekathrin Sender:** Writing – review & editing, Funding acquisition, All authors read and approved the final manuscript. **Kristina Geue:** Conceptualization, of the study, Writing – review & editing, Supervision, Funding acquisition. **Anja Mehnert-Theuerkauf:** Writing – review & editing, All authors read and approved the final manuscript. **Katja Leuteritz:** Conceptualization, of the study, Writing – original draft, preparation, Writing – review & editing, Supervision, Methodology, All authors read and approved the final manuscript.

Declaration of competing interest

None declared.

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Table 1 (continued)

	n
1500–2000	1
2000–2500	2
2500–3000	3
3000–4000	2
4000–5000	2
5000–7000	1
Highest educational degree	
No educational degree	0
Basic educational degree (<10 years)	0
Secondary educational degree (10 years)	1
High school degree (>10 years)	10

Note. ^aData from the quantitative study at t1.

^bSalaried employees, workers, civil servants, judges, professional soldiers, self-employees, freelancer, marginal employees, other employment.

^cStay-at-home spouse/partner, parental leave, federal voluntary service (BFD), voluntary social year (FSJ), voluntary ecological year (FÖJ), (early) pensioner, unemployed, pupil.

References

- Alice, C.K., Banegas, M.P., Tucker-Seeley, R.D., Yabroff, K.R., 2017. Financial hardships experienced by cancer survivors: a systematic review. *J. Natl. Cancer Inst.* 109 <https://doi.org/10.1093/jnci/djw205>.
- Arnett, J.J., 2000. Emerging adulthood: a theory of development from the late teens through the twenties. *Am. Psychol.* 55, 469–480. <https://doi.org/10.1037/0003-066X.55.5.469>.
- Baird, H., Patterson, P., Medlow, S., Allison, K.R., 2019. Understanding and improving survivorship care for adolescents and young adults with cancer. *J. Adolesc. Young Adult Oncol.* 8, 581–586. <https://doi.org/10.1089/jayao.2019.0031>.
- Barnett, M., McDonnell, G., DeRosa, A., Schuler, T., Philip, E., Peterson, L., Touza, K., Jhanwar, S., Atkinson, T.M., Ford, J.S., 2016. Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review. *J. Cancer Surviv.* 10, 814–831. <https://doi.org/10.1007/s11764-016-0527-6>.
- Bellizzi, K.M., Smith, A., Schmidt, S., Keegan, T.H.M., Zebrock, B., Lynch, C.F., Deapen, D., Shnorhavorian, M., Tompkins, B.J., Simon, M., 2012. Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer* 118, 5155–5162. <https://doi.org/10.1002/cncr.27512>.
- Brennan, R.L., Prediger, D.J., 1981. Coefficient Kappa: some uses, misuses, and alternatives. *Educ. Psychol. Meas.* 41, 687–699. <https://doi.org/10.1177/001316448104100307>.
- Breuer, N., Sender, A., Daneck, L., Mentschke, L., Leuteritz, K., Friedrich, M., Nowe, E., Stöbel-Richter, Y., Geue, K., 2017. How do young adults with cancer perceive social support? A qualitative study. *J. Psychosoc. Oncol.* 35, 292–308. <https://doi.org/10.1080/07347332.2017.1289290>.
- Brock, H., Friedrich, M., Sender, A., Richter, D., Geue, K., Mehnert-Theuerkauf, A., Leuteritz, K., 2022. Work ability and cognitive impairments in young adult cancer patients: associated factors and changes over time results from the AYA-Leipzig study. *J. Cancer Surviv.* 16 (4), 771–780. <https://doi.org/10.1007/s11764-021-01071-1>.
- Büttner, M., König, H.-H., Löbner, M., Briest, S., Konnopka, A., Dietz, A., Riedel-Heller, S., Singer, S., 2019. Out-of-pocket-payments and the financial burden of 502 cancer patients of working age in Germany: results from a longitudinal study. *Support. Care Cancer* 27, 2221–2228. <https://doi.org/10.1007/s00520-018-4498-1>.
- Coccia, P.F., Pappo, A.S., Beupin, L., Borges, V.F., Borinstein, S.C., Chugh, R., Dinner, S., Folbrecht, J., Frazier, A.L., Goldsby, R., Gubin, A., Hayashi, R., Huang, M.S., Link, M. P., Livingston, J.A., Matloub, Y., Millard, F., Oeffinger, K.C., Puccetti, D., Reed, D., Robinson, S., Rosenberg, A.R., Sanft, T., Spraker-Perlman, H.L., Mehren, M. von, Wechsler, D.S., Whelan, K.F., Yeager, N., Gurski, L.A., Shead, D.A., 2018. Adolescent and young adult oncology, version 2.2018, NCCN clinical practice guidelines in oncology. *J. Natl. Compr. Cancer Netw.* 16, 66–97. <https://doi.org/10.6004/jccn.2018.0001>.
- Cohen, J., 1960. A coefficient of agreement for nominal scales. *Educ. Psychol. Meas.* 20, 37–46. <https://doi.org/10.1177/001316446002000104>.
- Dresing, T., Pehl, T., 2018, eighth ed.. *Praxisbuch Interview, Transkription & Analyse. Anleitungen und Regelsysteme für qualitativ Forschende Marburg*. https://www.audiotranskription.de/wp-content/uploads/2020/11/Praxisbuch_08_01_web.pdf. (Accessed 27 July 2021).
- Elsbernd, A., Pedersen, K.J., Boisen, K.A., Midtgaard, J., Larsen, H.B., 2018. On your own: adolescent and young adult cancer survivors' experience of managing return to secondary or higher education in Denmark. *J. Adolesc. Young Adult Oncol.* 7, 618–625. <https://doi.org/10.1089/jayao.2018.0058>.
- Fardell, J.E., Wakefield, C.E., Patterson, P., Lum, A., Cohn, R.J., Pini, S.A., Sansom-Daly, U.M., 2018. Narrative review of the educational, vocational, and financial needs of adolescents and young adults with cancer: recommendations for support and research. *J. Adolesc. Young Adult Oncol.* 7, 143–147. <https://doi.org/10.1089/jayao.2017.0086>.
- Fauske, L., Bondevik, H., Ahlberg, K., Bjørndal, A., 2019. Identifying bone sarcoma survivors facing psychosocial challenges. A study of trajectories following treatment. *Eur. J. Cancer Care* 28, e13119. <https://doi.org/10.1111/ecc.13119>.
- Geue, K., Mehnert-Theuerkauf, A., Stroske, I., Brock, H., Friedrich, M., Leuteritz, K., 2021. Psychosocial long-term effects of young adult cancer survivors: study protocol of the longitudinal AYA-LE long-term effects study. *Front. Psychol.* 29, 4207. <https://doi.org/10.3389/fpsyg.2021.688142>.
- Hawkins, M.M., 2004. Long-term survivors of childhood cancers: what knowledge have we gained? *Nat Clin Pract Oncol.* 1, 26–31. <https://doi.org/10.1038/npcnc0020>.
- Isaksson, J., Wilms, T., Laurell, G., Fransson, P., Ehrsson, Y.T., 2016. Meaning of work and the process of returning after head and neck cancer. *Support. Care Cancer* 24, 205–213. <https://doi.org/10.1007/s00520-015-2769-7>.
- Kallmeyer, W., Schütze, F., 2016. *Konversationsanalyse*. In: Schütze, F., Fiedler, W., Krüger, H.-H. (Eds.), *Sozialwissenschaftliche Prozessanalyse: Grundlagen der qualitativen Sozialforschung*, first ed. Budrich, Barbara, Leverkusen, pp. 151–180. <https://doi.org/10.2307/j.ctvdf09cn>.
- Ketterl, T.G., Syrjala, K.L., Casillas, J., Jacobs, L.A., Palmer, S.C., McCabe, M.S., Ganz, P. A., Overholser, L., Partridge, A., Rajotte, E.J., Rosenberg, A.R., Risendal, B., Rosenstein, D.L., Baker, K.S., 2019. Lasting effects of cancer and its treatment on employment and finances in adolescent and young adult cancer survivors. *Cancer* 125, 1908–1917. <https://doi.org/10.1002/cncr.31985>.
- Köhler, K., Frommer, J., 2011. Kriterien der Samplerekrutierung in der qualitativen Forschung [Criteria of sample recruiting in qualitative research]. *Psychother. Psychosom. Med. Psychol.* 61, e34–e35. <https://doi.org/10.1055/s-0030-1266114>.
- Kosir, U., Boves, L., Taylor, R.M., Gerrand, C., Windsor, R., Onasanya, M., Martins, A., 2020. Psychological adaptation and recovery in youth with sarcoma: a qualitative study with practical implications for clinical care and research. *BMJ Open* 10, e038799. <https://doi.org/10.1136/bmjopen-2020-038799>.
- Kuckartz, A., Gerson, J., Lori, R., 2019. MAXQDA 2020. VERBI software GmbH. <https://www.maxqda.com/legalinfo>. (Accessed 27 July 2021).
- Lang, M.J., Giese-Davis, J., Patton, S.B., Campbell, D.J.T., 2018. Does age matter? Comparing post-treatment psychosocial outcomes in young adult and older adult cancer survivors with their cancer-free peers. *Psycho Oncol.* 27, 1404–1411. <https://doi.org/10.1002/pon.4490>.
- Lehmann, V., Grönqvist, H., Engvall, G., Ander, M., Tuinman, M.A., Hagedoorn, M., Sanderman, R., Mattsson, E., Essen, L. von, 2014. Negative and positive consequences of adolescent cancer 10 years after diagnosis: an interview-based longitudinal study in Sweden. *Psycho Oncol.* 23, 1229–1235. <https://doi.org/10.1002/pon.3549>.
- Leuteritz, K., Friedrich, M., Sender, A., Nowe, E., Stöbel-Richter, Y., Geue, K., 2018. Life satisfaction in young adults with cancer and the role of sociodemographic, medical, and psychosocial factors: results of a longitudinal study. *Cancer* 124, 4374–4382. <https://doi.org/10.1002/cncr.31659>.
- Leuteritz, K., Friedrich, M., Sender, A., Richter, D., Mehnert-Theuerkauf, A., Sauter, S., Geue, K., 2020. Return to work and employment situation of young adult cancer survivors: results from the adolescent and young adult-leipzig study. *J. Adolesc. Young Adult Oncol.* <https://doi.org/10.1089/jayao.2020.0055>.
- Matthews, D., 2019. Capitalism and mental health. *Mon. Rev.* 49–62. <https://doi.org/10.14452/MR-070-08-2019-01.5>.
- Mellblom, A.V., Kiserud, C.E., Rueegg, C.S., Ruud, E., Loge, J.H., Fosså, S.D., Lie, H.C., 2021. Self-reported late effects and long-term follow-up care among 1889 long-term Norwegian Childhood, Adolescent, and Young Adult Cancer Survivors (the NOR-CAYACS study). *Support. Care Cancer* 29, 2947–2957. <https://doi.org/10.1007/s00520-020-05790-6>.
- Mentschke, L., Leuteritz, K., Daneck, L., Breuer, N., Sender, A., Friedrich, M., Nowe, E., Stöbel-Richter, Y., Geue, K., 2017. Krebs und Karriere? – Eine qualitative Untersuchung zur beruflichen Situation und Integration junger Erwachsener mit Krebs [Cancer and Career? – A Qualitative Study of Job Status of Young Adult Cancer Survivors]. *Psychother. Psychosom. Med. Psychol.* 67, 76–82. <https://doi.org/10.1055/s-0042-122712>.

- Millar, B., Patterson, P., Desille, N., 2010. Emerging adulthood and cancer: how unmet needs vary with time-since-treatment. *Palliat. Support Care* 8, 151–158. <https://doi.org/10.1017/S1478951509990903>.
- National Cancer Institute, 2006. Report of the adolescent and young adult oncology progress review group. Closing the gap: research and care imperatives for adolescents and young adults with cancer. <https://www.livestrong.org/content/closing-gap-research-and-care-imperatives-adolescents-and-young-adults-cancer>. (Accessed 27 July 2021).
- Nugent, B.D., Bender, C.M., Sereika, S.M., Tersak, J.M., Rosenzweig, M., 2018. Cognitive and occupational function in survivors of adolescent cancer. *J. Adolesc. Young Adult Oncol.* 7, 79–87. <https://doi.org/10.1089/jayao.2017.0043>.
- Parsons, J.A., Eakin, J.M., Bell, R.S., Franche, R.-L., Davis, A.M., 2008. 'So, are you back to work yet?' Re-conceptualizing 'work' and 'return to work' in the context of primary bone cancer. *Soc. Sci. Med.* 67, 1826–1836. <https://doi.org/10.1016/j.socscimed.2008.09.011>.
- Parsons, H.M., Harlan, L.C., Lynch, C.F., Hamilton, A.S., Wu, X.-C., Kato, I., Schwartz, S. M., Smith, A.W., Keel, G., Keegan, T.H.M., 2012. Impact of cancer on work and education among adolescent and young adult cancer survivors. *J. Clin. Oncol.* 30, 2393–2400. <https://doi.org/10.1200/JCO.2011.39.6333>.
- Prasad, P.K., Hardy, K.K., Zhang, N., Edelstein, K., Srivastava, D., Zeltzer, L., Stovall, M., Seibel, N.L., Leisenring, W., Armstrong, G.T., Robison, L.L., Krull, K., 2015. Psychosocial and neurocognitive outcomes in adult survivors of adolescent and early young adult cancer: a report from the Childhood Cancer Survivor Study. *J. Clin. Oncol.* 33, 2545–2552. <https://doi.org/10.1200/JCO.2014.57.7528>.
- Pritlove, C., Safai, P., Angus, J.E., Armstrong, P., Jones, J.M., Parsons, J., 2019. It's Hard Work": a feminist political economy approach to reconceptualizing "work" in the cancer context. *Qual. Health Res.* 29, 758–773. <https://doi.org/10.1177/1049732318803885>.
- Pulewka, K., Strauss, B., Hochhaus, A., Hilgendorf, I., 2020. Clinical, social, and psychosocial needs of adolescents and young adults (AYA) versus older patients following hematopoietic stem cell transplantation. *J. Cancer Res. Clin. Oncol.* 147 (4), 1239–1246. <https://doi.org/10.1007/s00432-020-03419-z>.
- Quidde, J., Koch, B., Salchow, J., Jensen, W., Grundherr, J. von, Escherich, G., Rutkowski, S., Schulz-Kindermann, F., Bergelt, C., Bokemeyer, C., Sokalska-Duhme, M., Bielack, S., Calaminus, G., Classen, C.F., Rössig, C., Faber, J., Faller, H., Hilgendorf, I., Langer, T., Metzler, M., Schuster, S., Niemeier, C., Pierce, A., Reinhardt, D., Sander, A., Köhler, M., Stein, A., 2017. Das CARE-for-CAYA-Programm. *Forum* 32, 479–484. <https://doi.org/10.1007/s12312-017-0340-9>.
- Rädiker, S., Kuckartz, U., 2019. *Analyse qualitativer Daten mit MAXQDA*. Springer Fachmedien Wiesbaden, Wiesbaden.
- Rasmussen, D.M., Elverdam, B., 2008. The meaning of work and working life after cancer: an interview study. *Psycho Oncol.* 17, 1232–1238. <https://doi.org/10.1002/pon.1354>.
- Robert Koch-Institut, 2015. Krebs in Deutschland 2011/2012. Gesundheitsberichterstattung des Bundes. <https://doi.org/10.17886/rkipubl-2015-004>, 10. Aug. 2015.
- Salchow, J., Mann, J., Koch, B., Grundherr, J. von, Jensen, W., Elmers, S., Straub, L.A., Vet-torazzi, E., Escherich, G., Rutkowski, S., Dwinger, S., Bergelt, C., Sokalska-Duhme, M., Bielack, S., Calaminus, G., Baust, K., Classen, C.F., Rössig, C., Faber, J., Faller, H., Hilgendorf, I., Gebauer, J., Langer, T., Metzler, M., Schuster, S., Niemeier, C., Puzik, A., Reinhardt, D., Dirksen, U., Sander, A., Köhler, M., Habermann, J.K., Bokemeyer, C., Stein, A., 2020. Comprehensive assessments and related interventions to enhance the long-term outcomes of child, adolescent and young adult cancer survivors - presentation of the CARE for CAYA-Program study protocol and associated literature review. *BMC Cancer* 20, 16. <https://doi.org/10.1186/s12885-019-6492-5>.
- Salsman, J.M., Bingen, K., Barr, R.D., Freyer, D.R., 2019. Understanding, measuring, and addressing the financial impact of cancer on adolescents and young adults. *Pediatr. Blood Cancer* 66, e27660. <https://doi.org/10.1002/pbc.27660>.
- Saunders, S.L., Nedelec, B., 2014. What work means to people with work disability: a scoping review. *J. Occup. Rehabil.* 24, 100–110. <https://doi.org/10.1007/s10926-013-9436-y>.
- Sender, A., Friedrich, M., Leuteritz, K., Nowe, E., Stöbel-Richter, Y., Mehnert, A., Geue, K., 2019. Unmet supportive care needs in young adult cancer patients: associations and changes over time. Results from the AYA-Leipzig study. *Journal of Cancer Survivorship: Research and Practice* 13, 611–619. <https://doi.org/10.1007/s11764-019-00780-y>.
- Sisk, B.A., Fasciano, K., Block, S.D., Mack, J.W., 2020. Impact of cancer on school, work, and financial independence among adolescents and young adults. *Cancer* 126, 4400–4406. <https://doi.org/10.1002/cncr.33081>.
- Steigleder, S., 2008. *Die strukturierende qualitative Inhaltsanalyse im Praxistest: eine kon-struktiv kritische Studie zur Auswertungsmethodik von Philipp Mayring*. Tectum-Verlag.
- Stein, K.D., Syrjala, K.L., Andrykowski, M.A., 2008. Physical and psychological long-term and late effects of cancer. *Cancer* 112, 2577–2592. <https://doi.org/10.1002/cncr.23448>.
- Stepanikova, I., Powrozniak, K., Cook, K.S., Tierney, D.K., Laport, G.G., 2016. Exploring long-term cancer survivors' experiences in the career and financial domains: interviews with hematopoietic stem cell transplantation recipients. *J. Psychosoc. Oncol.* 34, 2–27. <https://doi.org/10.1080/07347332.2015.1101040>.
- Stone, D.S., Ganz, P.A., Pavlish, C., Robbins, W.A., 2017. Young adult cancer survivors and work: a systematic review. *J. Cancer Surviv.* 11, 765–781. <https://doi.org/10.1007/s11764-017-0614-3>.
- Teckle, P., Peacock, S., McBride, M.L., Bentley, C., Goddard, K., Rogers, P., 2018. Long-term effects of cancer on earnings of childhood, adolescent and young adult cancer survivors - a population-based study from British Columbia, Canada. *BMC Health Serv. Res.* 18, 826. <https://doi.org/10.1186/s12913-018-3617-5>.
- Trama, A., Bernasconi, A., McCabe, M.G., Guevara, M., Gatta, G., Botta, L., Ries, L., Bleyer, A., 2019. Is the cancer survival improvement in European and American adolescent and young adults still lagging behind that in children? *Pediatr. Blood Cancer* 66, e27407. <https://doi.org/10.1002/pbc.27407>.
- Vetsch, J., Wakefield, C.E., McGill, B.C., Cohn, R.J., Ellis, S.J., Stefanic, N., Sawyer, S.M., Zebrack, B., Sansom-Daly, U.M., 2018. Educational and vocational goal disruption in adolescent and young adult cancer survivors. *Psycho Oncol.* 27, 532–538. <https://doi.org/10.1002/pon.4525>.
- Wong, A.W.K., Chang, T.-T., Christopher, K., Lau, S.C.L., Beaupin, L.K., Love, B., Lipsey, K.L., Feuerstein, M., 2017. Patterns of unmet needs in adolescent and young adult (AYA) cancer survivors: in their own words. *J. Cancer Surviv.* 11, 751–764. <https://doi.org/10.1007/s11764-017-0613-4>.
- Yang, Y., Li, W., Wen, Y., Wang, H., Sun, H., Liang, W., Zhang, B., Humphris, G., 2019. Fear of cancer recurrence in adolescent and young adult cancer survivors: a systematic review of the literature. *Psycho Oncol.* 28, 675–686. <https://doi.org/10.1002/pon.5013>.
- Zarrett, N., Eccles, J., 2006. The Passage to Adulthood: Challenges of Late Adolescence. *New Dir Youth Dev.* 7 (111), 13–28. <https://doi.org/10.1002/nd.179>.
- Zebrack, B.J., 2011. Psychological, social, and behavioral issues for young adults with cancer. *Cancer* 117, 2289–2294. <https://doi.org/10.1002/cncr.26056>.
- Zentrum für Krebsregisterdaten (ZfKD) im Robert Koch-Institut, 2019. Datensatz des ZfKD auf Basis der epidemiologischen Landkrebsregisterdaten, verfügbare Diagnosejahre bis 2016. Version: Epi2018_1. <https://doi.org/10.18444/5.03.01.0005.0014.0001>.