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Psycho-oncology in young adults with cancer – Current evidence and future challenges

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List of Abbreviations

adj	adjusted
AYA	Adolescents and Young Adults
AWMF	Association of the Scientific Medical Societies
COPSOQ	Copenhagen Psychosocial Questionnaire
EORTC QLQ-FA12	European Organisation for Research and Treatment of Cancer Quality of Life Fatigue Module Questionnaire
HADS	Hospital Anxiety and Depression Scale
IF	Impact factor
FLZ-M	Questions on life satisfaction
ISSS-8	Illness-Specific Support Scale
MHB	Multiple health behaviour
LS	Life satisfaction
M	Mean
NCCN	National Comprehensive Cancer Network
PACIS	Perceived adjustment to chronic illness
ROC	Receiver Operating Characteristic
SCNS-SF34G	Supportive Care Needs Survey-Short Form
SD	Standard Deviation
WAI	Work ability index
WHO	World Health Organisation

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Publications utilized in the habilitation thesis

This cumulative habilitation thesis is based on 17 selected peer-reviewed publications on young adults with cancer. They have been published in leading international journals between 2017 and 2023. In terms of authorship, my contributions include three publications as the first author, ten as the senior author, and four as a co-author. The original publications can be found in the attachments.

· Braun I, Friedrich M, Morgenstern L, Sender A, **Geue K**, Mehnert-Theuerkauf A, Leuteritz K. Changes, challenges and support in work, education and finances of adolescent and young adult (AYA) cancer survivors: A qualitative study. European Journal of Oncology Nursing 2023, 64: 102329, doi: 10.1016/j.ejon.2023.102329.
IF 2023: 2,8; Scopus citations: 4; Google-Scholar citations: 7

· Brock H, Friedrich M, Sender A, Richter D, **Geue K**, Mehnert-Theuerkauf A, Leuteritz K. Work ability and cognitive impairments in young adult cancer patients: associated factors and changes over time-results from the AYA-Leipzig study. Journal of Cancer Survivorship 2022, 16(4):771-780, doi: 10.1007/s11764-021-01071-1.
IF 2022: 3,70; Scopus citations: 17; Google-Scholar citations: 26

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IF 2021: 3,96; Scopus citations: 3; Google-Scholar citations: 4

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IF 2021: 4,23; Scopus citations: 5; Google-Scholar citations: 7

· Sender A, Friedrich M, Leuteritz K, Nowe E, Stöbel-Richter Y, Mehnert A, **Geue K**. Unmet supportive care needs in young adult cancer patients: associations and changes over time: results from the AYA-Leipzig study. Journal of Cancer Survivorship 2019, 13(4):611-619, doi: 10.1007/s11764-019-00780-y.
IF 2019: 3,30; Scopus citations: 35; Google-Scholar citations: 51

· **Geue K**, Göbel P, Leuteritz K, Nowe E, Sender A, Stöbel-Richter Y, Friedrich M. Anxiety and depression in young adult German cancer patients: Time course and associated factors. Psycho-Oncology 2019, 28(10):2083-2090, doi: 10.1002/pon.5197.
IF 2019: 3,00; Scopus citations: 24; Google-Scholar citations: 35

· Nowe E, Friedrich M, Leuteritz K, Sender A, Stöbel-Richter Y, Schulte T, Hinz A, **Geue K**. Cancer-Related Fatigue and Associated Factors in Young Adult Cancer patients.Journal of Adolescent and Young Adult Oncology 2019, 8(3):297-303, doi: 10.1089/jayao.2018.0091.
IF 2019: 1,73; Scopus citations: 18; Google-Scholar citations: 28

· **Geue K**, Götze H, Friedrich M, Leuteritz K, Mehnert-Theuerkauf A, Sender A, Stöbel-Richter Y, Köhler N. Perceived social support and associations with health-related quality of life in young versus older adult patients with haematological malignancies. Health and quality of life outcomes 2019, 22;17(1):145, doi: 10.1186/s12955-019-1202-1.
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· Mütsch J, Friedrich M, Leuteritz K, Sender A, **Geue K**, Hilbert A, Stöbel-Richter Y. Sexuality and cancer in adolescents and young adults - a comparison between reproductive cancer patients and patients with non-reproductive cancer. BMC Cancer 2019, 22;19(1):828, doi: 10.1186/s12885-019-6009-2.
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  IF 2017: 1,25; Scopus citations: 45; Google-Scholar citations: 75
- Leuteritz K, Friedrich M, Nowe E, Sender A, Stöbel-Richter Y, **Geue K**. Life situation and psychosocial care of adolescent and young adult (AYA) cancer patients - study protocol of a 12-month prospective longitudinal study. BMC Cancer 2017, 28;17(1):82, doi: 10.1186/s12885-017-3077-z.
  IF 2017: 3,29; Scopus citations: 29; Google-Scholar citations: 35

1 Introduction

1.1 Definitions

Cancer

The term 'cancer' encompasses various forms of diseases (BMG 2023). According to the World Health Organization (WHO), a characteristic of cancer is abnormal cell growth that exceeds normal limits and is invasive (WHO 2023). The malignant development of body cells involves uncontrolled growth and a lack of organ-specific function in all cancer cases, in contrast to the controlled growth and organ specificity of healthy body cells. During cancer, degenerated cells invade or displace healthy tissue. In advanced stages, cancer cells can travel through the blood and lymphatic system, forming secondary tumours in other organs, also known as metastases. The factors contributing to the development of cancer are not fully understood. Genetic predispositions, lifestyle factors (such as tobacco and alcohol consumption, lack of physical activity), risks in the workplace and environment (such as exposure to carcinogenic substances, and increased radiation exposure), and infections with certain types of viruses all play a role as contributing factors. It remains unsatisfactorily answered why some individuals develop cancer while others, despite having a similar risk profile, do not (BMG 2023).

According to the World Health Organization (WHO), cancer is the second most common global cause of death. In 2018, an estimated 9.6 million people worldwide succumbed to cancer (WHO 2023). In Germany, a total of 497,900 people were newly diagnosed with cancer in 2018, with lung, breast, prostate, and colorectal cancers being the most frequently diagnosed. The relative 10-year survival rate was approximately 60% (Erdmann et al. 2021). Despite improved early detection and oncological therapies leading to a continuous increase in survival rates for many types of cancer, especially in industrialized countries over the past decades, the burdens caused by cancer are rising steadily. Societally, cancer diseases and their treatments pose immense structural and financial challenges to the healthcare system. On an individual level, those affected, as well as their families or close relatives, face significant physical, psychological, and social strains (WHO 2023).

Cancer in adolescents and young adults

As age increases, the risk of developing cancer rises steadily, primarily leading to older individuals receiving a cancer diagnosis. The average age of onset is currently around 70 years. Nevertheless, approximately 3% of malignant new cases in Germany each year occur in young adulthood (Erdmann et al. 2021). Various definitions exist internationally for the age range of young adults with cancer, also referred to as Adolescent and Young Adults (AYA) (JAYAO 2011). The most comprehensive age range available for the AYA patient population was published by the National Cancer Institute in 2006. The Institute defines AYA as adolescents and young adults who develop cancer between the ages of 15 and 39 years. This habilitation thesis adheres to this age definition, although patients under 18 are excluded, as they are usually treated in pediatric oncology in Germany.

Only in the last two decades, this relatively small patient group in oncology has received increased attention in scientific research. Consequently, little is known about biological, genetic, epidemiological, therapeutic, and psychosocial factors influencing the disease, its progression, and the quality of life for AYA individuals (National Cancer Institute 2006). The participation rate of young adults in clinical studies is low and has even declined since 2010 (Bleyer et al. 2018). Given that cancer in young adulthood is rarely predictable and occurs infrequently, those affected face significant coping challenges.

Psycho-oncology

In the S3 guideline "Psycho-oncological Diagnosis, Counselling, and Treatment of Adult Cancer Patients," psycho-oncology, synonymous with "psychosocial oncology", is defined as "a distinct field of activity in the oncological context that deals with the experiences and behaviours, specific stressors and coping abilities, as well as the social resources of cancer patients in connection with their cancer diagnosis, its treatment, and associated issues" (AWMF 2023). The task of psycho-oncology is to scientifically investigate psychological and social factors related to cancer and implement appropriate support services in both inpatient and outpatient care. This includes the patients themselves, their family and their social environment, as well as all professional groups involved in the treatment. Psycho-oncology is understood as an interprofessional field within oncology, incorporating content from various disciplines such as medicine, psychology, sociology, nursing science, ethics, theology, social work, and education. Consequently, various professions (including psychologists, social workers, physiotherapists, and chaplains) are involved in psycho-oncological care (AWMF 2023).

Quality of life

In the WHO‘s definition, quality of life encompasses the entire life situation and cultural peculiarities of individuals, with individual perception being crucial, taking into account their own values, goals, expectations, and standards of judgment (WHO 1995). The investigation into the quality of life in medicine commenced in the 1970s and has expanded steadily since then (Bullinger 2014). The term "health-related quality of life" has become prevalent. Quality of life is defined as a multidimensional construct that captures physical, emotional, mental, social, spiritual, and behavioural components of subjective well-being and functionality (Schumacher et al. 2003). In other words, health-related quality of life extends beyond mere statements about an individual's health status, encompassing all dimensions proclaimed by the WHO for health - physical, psychological, and social (Robert Koch Institute 2024). Conceptual approaches to quality of life also include models of subjective well-being and satisfaction, assuming a high quality of life with high well-being or satisfaction in many life areas (Schumacher et al. 2003). Thus, the term life satisfaction, based on an individual's self-assessment of their overall life situation (Dorsch 2024), is challenging to differentiate from the construct of quality of life. Both terms are used synonymously in this habilitation thesis.

1.2 Epidemiology of cancer in young adulthood

In the year 2019, a total of 16,600 young people between the ages of 18 and 39 were newly diagnosed with cancer in Germany (ZfKD 2023). Gender-specific data reveal that among those under 30, men are more frequently affected than women. This trend reverses among individuals aged 30 to 39. A characteristic of the AYA patient population is the age-specific accumulation of certain cancer types. Malignant melanoma, breast and gynaecological tumours, B-cell lymphomas, testicular cancer, leukaemia, and thyroid carcinomas are particularly prevalent in young adulthood (Erdmann et al. 2021). For breast cancer, malignant melanoma, and lymphocytic leukaemia in the AYA patient cohort, often distinctive biological characteristics, such as specific mutation patterns, have been found compared to older cancer patients (Tricoli et al. 2016). Genetic risk factors are more pronounced in young cancer patients than in older cohorts.

The above-average chances of recovery in the AYa cancer population are reflected in a 5-year overall survival rate exceeding 80% (National Cancer Institute 2006; Keegan et al. 2016). Over the past decades, the overall survival of young adult cancer patients has not improved to the same extent as it has for older or paediatric cancer patients, despite medical advances in oncological treatment (Rabin et al. 2011; Keegan et al. 2016). Jin and colleagues refer to the so-called "AYA gap" and cite delayed access to care as a reason, as well as inconsistent treatment and follow-up (Jin et al. 2021). The mentioned age-specific mutation patterns of certain tumours may also contribute to this. The remarkably high survival rates result in a continuously increasing number of individuals who receive a cancer diagnosis and treatment in young adulthood. Figure 1 illustrates the high overall survival in young adulthood compared to other age cohorts across all cancer types in Germany. More than 10,000 young adults in Germany join the group of AYA cancer survivors every year. Thanks to this high long-term survival, the lifelong follow-up and optimal tertiary prevention of this patient population become increasingly important. The likelihood of developing a second malignancy over the course of life for the AYA patient group is approximately 10% (Engel et al. 2011). Beyond that, AYAs have a twofold increased risk of dying from other health-related causes (e.g., circulatory, respiratory, and infectious diseases) (Armenian et al. 2020; Chao et al. 2020).

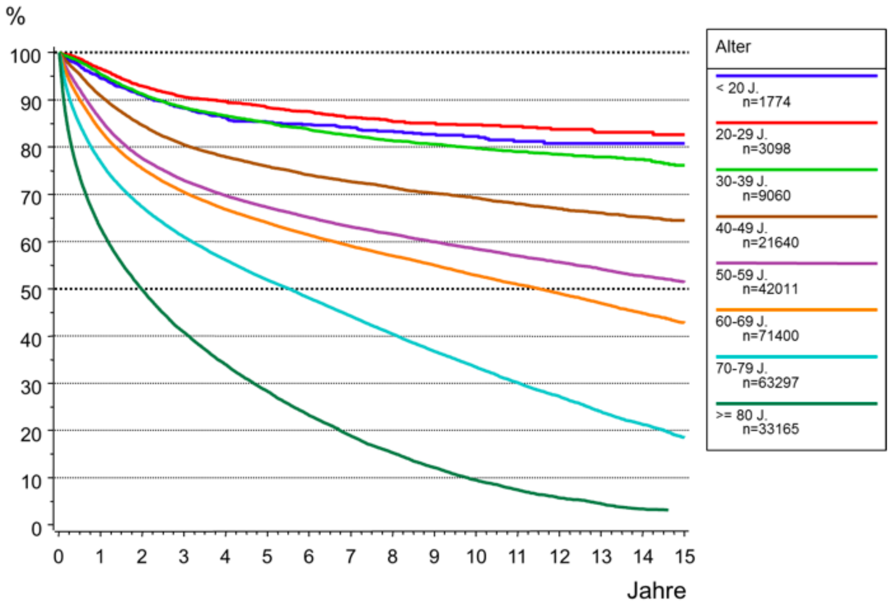

Figure 1: Overall survival by age (Tumour registry Munich, N= 245,445)

1.3 Medical oncological care of young adults with cancer – an overview

Diagnosis of cancer

To detect cancer, the field of medicine now employs a range of diagnostic methods. Various screening tests for the early detection of specific cancers are now being used. For young adults, these include the analysis of cervical smears (PAP smear), examination of the skin for suspicious moles (skin cancer screening), self-examination of the breast for lumps, or genetic tests for suspected hereditary/familial carcinoma such as ovarian or breast cancer. To confirm a cancer diagnosis, various imaging techniques such as X-rays, scintigraphy, computed tomography, ultrasound, and magnetic resonance imaging are used. The analysis of cell and tissue samples (blood and serum analyses, biopsies) is also crucial in the diagnostic process (Aigner and Stephens 2016).

Cancer therapy

Oncological diagnosis and therapy schemes for young adults do not fundamentally differ from those of older patients. Recommendations from cancer-specific guidelines of the Association of the Scientific Medical Societies in Germany (AWMF) are used for treatment. Therapies are based on the results of individual histology and cytology, the stage of the disease, genetic risk factors, and existing comorbidities (Hilgendorf et al. 2011). Due to the often very good overall physical condition and the lack of significant comorbidities in young cancer patients, more intensive and multimodal treatment concepts are often employed. This implies that young adults are administered higher doses and undergo longer durations of therapy compared to older patients (Hughes and Stark 2018). As more aggressive treatments can lead to more pronounced acute side effects and more long-term physical and psychosocial consequences, appropriate symptom management is an integral part of the treatment for young adults with cancer (Bhatia et al. 2023).

The goal of any cancer therapy aimed at a complete cure is to eliminate or destroy all malignant cells while preserving as many healthy cells as possible. Local and systemic treatment concepts include surgery, chemotherapy, radiation therapy, nuclear medicine procedures, immunotherapy, antibody therapy, hormone therapy, and autologous or allogeneic stem cell transplants for hematologic diseases (DKfZ 2024).

Surgery

For many cancers, tumour removal through surgery is possible. Various surgical techniques (open vs. minimally invasive) are being used. Ideally, tumour cells can be completely removed, and, ideally, lymph node involvement or metastasis can be ruled out.

Chemotherapy

Treatment with chemotherapeutic agents is necessary when tumour cells have already spread to the lymph or bloodstream, or metastases are detectable in distant organs. Chemotherapy is also prophylactically performed after surgeries to eliminate remaining and undetectable tumour cells, to prevent later relapse. Administered cytostatics prevent cell growth or increased cell division. They are cytotoxic agents that act systemically, affecting both malignant and healthy cells, leading to side effects such as hair loss, dry mouth, or nausea. Due to the toxicity, great care and constant treatment monitoring are necessary. Administration often occurs on an outpatient basis, with multiple cycles and corresponding recovery phases planned.

Radiotherapy

The principle of radiotherapy is to destroy malignant cells using ionizing radiation that attacks the cell nucleus, preventing further cell division of tumour cells. While healthy cells have a repair system for this, malignant cells largely lack it. Both the local radiation field and the radiation dose are precisely determined beforehand according to the principle of using as much as necessary and as little as possible. This means sparing as much healthy tissue as possible while irradiating as much tumour tissue as necessary. The calculated radiation dose is fractionated, so several, mostly outpatient, sessions are conducted to keep the radiation dose per treatment low and minimize side effects.

Transplantation

The transplantation of bone marrow or blood stem cells is mainly applied in hematologic cancers, relapses, or previous unsuccessful treatments. The goal is to transfer cells that can develop into further blood and immune system cells throughout life. Autologous blood stem cells can be collected and processed for retransplantation (autologous transplantation). In allogeneic transplantation, foreign blood stem cells are transferred, if there is tissue compatibility. Before transplantation, high-dose chemotherapy is necessary to ensure that no malignant cells remain in the blood. This therapy is physically and psychologically demanding for those affected.

Immuno- or antibody therapy

Drug-based antibody therapy aims to strengthen the body's natural defences. Antibodies can stimulate the body's immune system to destroy malignant cells or block tumour cell growth. It is used for tumours that are structurally targeted by the antibodies. Antibody therapy is often administered in combination with chemotherapy.

Hormone therapy

Since the growth of some tumours (e.g., certain forms of breast cancer) is hormonally dependent, so-called (anti-) hormone therapies are indicated. The mechanism of action is to prevent the formation of certain hormones, thereby slowing down tumour growth. Hormone therapies are also used in combination with other oncological treatments (Aigner and Stephens 2016).

Rehabilitation

After the successful completion of necessary medical cancer therapies, patients in Germany are offered the opportunity for follow-up treatment or oncological rehabilitation, which can be provided either as outpatient or inpatient care. The aim of these rehabilitation measures is to improve the quality of life in all areas or to restore physical, cognitive, and mental performance. Patients are supported in coping with the disease and in returning to social and professional participation. There are a few rehabilitation facilities specialized for the AYA patient population (DKH 2021).

Cancer aftercare

The objectives of cancer aftercare encompass the timely identification and treatment of both physical and psychological comorbidities or sequelae, as well as tumour recurrence.

Oncological follow-up as tertiary prevention includes regular follow-up examinations with a specialist or general practitioner, as well as counselling on psychological, social, family, physical, and professional rehabilitation (DKH 2024). Physical follow-up examinations depend on the type of tumour that occurred. After five years without tumour recurrence, follow-up is considered complete, and the patient is considered cured. Young cancer patients also have an increased risk of second malignancies even decades after cancer treatment. Therefore, experts advocate for cancer aftercare beyond those five years (DKH 2021). So far, there are no uniform recommendations or guidelines for extended aftercare. Compared to older cancer patients, another challenge in the cancer aftercare of young adults is the more frequent change of location associated with changes in healthcare providers.

1.4 Developmental psychological aspects of young adulthood

In the model described by Havighurst (Havighurst 1974), each life phase is associated with specific developmental tasks that shape an individual's thinking, feelings, and actions. These tasks arise from personal values, goals, and societal expectations, encompassing both internal and external demands. Engaging with these age-typical developmental tasks cultivates skills and competencies crucial for addressing potential challenges later in life (Schmid 2015).

While developmental tasks in childhood and adolescence often align with specific ages or social norms (e.g., starting school), those in young adulthood are less bound by biological age or predefined social structures (Silbereisen and Pinquart 2008). Key developmental processes during young adulthood include emancipation from the family of origin, career training and entry, partner selection, and desires for parenthood and parenting (Oerter and Montada 2008). This phase is characterized by a reorientation in various life domains, involving increased autonomy both spatially and financially. Career choices are influenced by familial, social, and personal factors, and job market trends. Partner selection often centres around perceived and meaningful similarities in education, values, attitudes, and finances. Despite a declining trend in societal desires for children, the majority of young adults express a wish for parenthood, with a shift toward parenting in the third decade of life observed in most industrialized nations (Oerter and Montada 2008). Young adults have numerous opportunities and freedoms to shape their lives, especially compared to middle and late adulthood. Each developmental task demands decision-making that significantly influences one's future. It is important to note that these developmental tasks do not follow a fixed sequence and can unfold at varying paces (Rogge 2020).

It is critical to acknowledge that deviations from these normatively postulated developmental tasks are not necessarily considered wrong or pathological. The complexity of possible life experiences and their effects in our globally interconnected world challenges this model based on generalizable life experiences. Contemporary phenomena such as changes in the working world regarding working hours and locations, sexual and gender pluralism, the expansion of cultural diversity, the digitalization of every aspect of life, and the established presence of social media must be considered when examining young adulthood (Levin et al. 2019). It should be noted that during the period of adolescence and young adulthood, mental disorders often occur and are diagnosed (Solmi et al. 2022).

The occurrence of cancer in young adulthood typically results in the postponement or stagnation of age-appropriate developmental tasks and life goals. Instead, coping with the cancer disease, including the necessary medical treatments, takes precedence. Since confronting one's own mortality in the face of a potentially life-threatening disease is not a typical developmental task of young adulthood, young adults face immense challenges, physically but also psychologically and socially. Developmental competencies or coping strategies are required that may not have been sufficiently developed solely based on age. These challenges do not align with the typical patient profile of adult oncology or pediatric oncology.

1.5 Conclusion

Individuals confronted with a cancer diagnosis experience an existential and emotional exceptional state. Schwarz & Singer posit a considerable traumatic valence in oncological diseases, especially considering that cancer is not a one-time, isolated event (Schwarz and Singer 2008). A cancer diagnosis in young adulthood poses a series of challenges for the patient and their relatives due to the life phase. The entire life often undergoes rapid changes with the diagnosis, where familial, social, and professional roles may be temporarily or partially relinquished due to impending medical treatments and their side effects, as well as long-term consequences. "Survival" takes centre stage.

Young adults facing cancer experience restrictions and losses that starkly contradict the life phase of young adulthood. In a developmental phase marked by autonomy, reorientation, and vitality, factors including illness, invasive treatments, death, and dying become suddenly relevant. Frequently, young adults must reconsider and, if necessary, adapt or redesign their life visions. Unlike cancer in later adulthood, being diagnosed in young adulthood means having to live with the disease and its potential consequences for many decades. Consequently, psychosocial aspects remain significant over a very long period, both on an individual level and from a societal perspective.

In order to establish appropriate psycho-oncological care for this patient population and prevent psychosocial burden, it is essential to first understand the psychosocial life and care situation of young adults with cancer. Several AYA research projects have been initiated and conducted since 2011 to address this need. Three AYA research projects were funded by German Cancer Aid as part of a longitudinal study from 2014 to 2022 to investigate the following key research questions:

- How does the quality of life of young adults with cancer manifest itself and what influencing factors can be identified?
- How does the psychological and social well-being of young adults with cancer manifest itself and what influencing factors can be identified?
- What needs for psychosocial support do young adults with cancer have and how do they perceive the existing psycho-oncological care services?
- How do psychological well-being, quality of life and psychosocial supportive care change over time?

The published empirical results as well as the study design are presented in the next chapter. Finally, implications for future psycho-oncological care and research for the AYA cancer population will be addressed.

2 Own research findings on young adults with cancer

2.0 Research background – then and now

Until the year 2013, only a few longitudinal studies exploring psychosocial issues for young adults with cancer were identified in PubMed (Epping-Jordan et al. 1994; Harlan et al. 2011; Emmons et al. 2013; Kwak et al. 2013a, 2013b; Krüger et al. 2009). The only available German longitudinal study was an age group comparison, with the sample consisting of 75% breast cancer patients (Krüger et al. 2009)). Other publications in this decade focused on medical aspects or outlined the field of the problem (e.g., D'Agostino et al. 2011; Ferrari et al. 2010; Hilgendorf et al. 2011; Thomas et al. 2010; Zebrack et al. 2010). This contrasts with several studies that examined the quality of life of older cancer patients and those who had experienced cancer in childhood or adolescence (Carpentier and Fortenberry 2010; Ladehoff et al. 2011; Zebrack et al. 2010).

Overall, the number of published studies on psychosocial outcomes for the AYA cancer population has steadily increased in the past decade. Although there has been a growing number of psycho-oncological AYA research studies published, current reviews emphasize the need for further high-quality studies for this particular patient population.

A recent systematic review by Bradford et al. (2022) on longitudinal studies concerning psychological, functional, and social outcomes in adolescent and young adult cancer survivors encompassed a total of ten studies (included in our paper Leuteritz et al., 2018). The authors assert that results from longitudinal studies with larger sample sizes are necessary to understand the impact on the long-term health and well-being of AYA cancer survivors. They highlight that, there is currently insufficient research for young cancer survivors (Bradford et al., 2022). Tanner and colleagues state in their current review, comprising 12 included studies on the mental health of AYA, that more longitudinal research is needed to describe and continuously improve the mental health of AYA (Tanner et al. 2023). Regarding multicomponent, biopsychosocial, and age-specific rehabilitation for AYA, we are still at an early stage, as summarized by Aagesen et al. (Aagesen et al. 2023). Stoneham also emphasizes that there is still much research to be done regarding AYA survivorship and survivorship programs (Stoneham 2020).

2.1 Description of the research investigations

Chapter based on the following publications:

· Leuteritz K, Friedrich M, Nowe E, Sender A, Taubenheim S, Stoebel-Richter Y, **Geue K**. Recruiting young adult cancer patients: Experiences and sample characteristics from a 12-month longitudinal study. European Journal of Oncology Nursing 2018, 36:26-31, doi: 10.1016 /j.ejon.2018.05.001.

· Leuteritz K, Friedrich M, Nowe E, Sender A, Stöbel-Richter Y, **Geue K**. Life situation and psychosocial care of adolescent and young adult (AYA) cancer patients - study protocol of a 12-month prospective longitudinal study. BMC Cancer 2017, 28; 17(1):82, doi: 10.1186/s12885-017-3077-z.

· **Geue K**, Mehnert-Theuerkauf A, Stroske I, Brock H, Friedrich M, Leuteritz K. Psychosocial Long-Term Effects of Young Adult Cancer Survivors: Study Protocol of the Longitudinal AYA-LE Long-Term Effects Study. Frontiers in Psychology 2021, 29; 12:688142, doi: 10.3389/ fpsyg.2021.688142.

The selected AYA research projects aimed to provide a detailed and differentiated insight into the life situation of AYA patients, describing risk groups, and developing recommendations for their psycho-oncological care and age-specific survivorship programs. The methodological approach has been detailed in two study protocols (Geue et al. 2021; Leuteritz et al. 2017).

The longitudinal study comprised six measurement time points, during which young adults with cancer were longitudinally surveyed on aspects like life satisfaction, mental health, and fatigue. Cross-sectional assessments covered factors such as occupational situation, health behaviour, and psychosocial care (refer to Figure 2). Standardized questionnaires from the German-speaking region were predominantly used, previously tested in psycho-oncological studies. Inclusion criteria for participation included age at diagnosis (18–39 years), first manifestation of cancer (all malignant tumour identities), diagnosis within the last four years, and completion of acute medical cancer treatment. In the initial survey, a total of 577 AYA cancer patients participated. A control group of healthy young adults without cancer was established at the third (N= 406) and fourth survey time points (N= 372).

To gain more detailed insights, qualitative interviews were conducted with a subgroup of the sample during the first three measurement points. Figure 2 illustrates the inclusion of AYA patients from 2014 to 2021, as well as the longitudinal and cross-sectional themes of both quantitative and qualitative investigations.

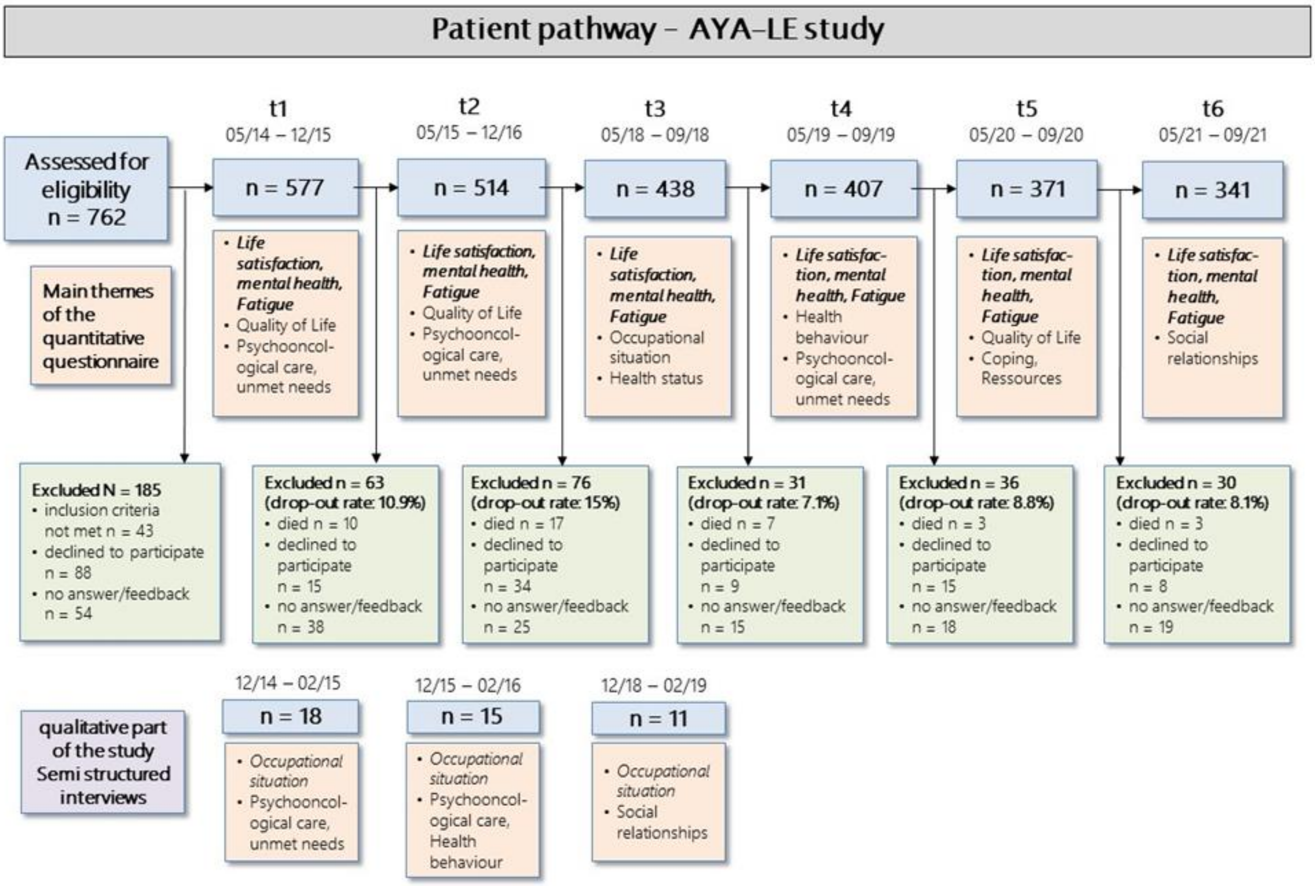

Figure 2: Flowchart of the AYA participants and outcomes

The data analysis aligns with the respective research aims and questions and was conducted using the IBM SPSS Statistics software. Descriptive statistics such as mean, standard deviation, median, minimum, and maximum were used. Graphical representation involves histograms and boxplots. For group comparisons, T-tests (with normal distribution) or Mann-Whitney U-tests (without normal distribution) are employed for continuous target variables. All conducted statistical tests were two-sided, and a result was considered significant with a type-I-error-probability $p<0.05$. Exploration of associated variables and group comparisons will use analysis of variance, multiple linear regression (for metric dependent variables), and multiple logistic regression analysis (for binary dependent variables).

Recruiting a larger German AYA study population poses challenges due to the AYA patient group constituting only a small fraction (approximately 3%) of the cancer patient population. German data protection laws prohibit research institutions from accessing patient data from cancer registries without explicit patient permission, and hence access to centralized cancer registries would facilitate the identification of representative samples of low-incidence cancer populations such as AYA. The study recruitment strategies were detailed in a separate paper (Leuteritz et al. 2018). The majority of study participants were recruited through face-to-face approaches in AYA-specialized rehabilitation clinics (39.5%), followed by written contact through two tumour registries (30.2%). AYA study participants were recruited from 16 acute care hospitals (11.3%) and through self-registration on the project website (19.1%). To maximize participation, various strategies were implemented, including a compensation fee of 10€, reminders, and seasonal greetings. A strong preference for using the online form of the follow-up questionnaires was observed over hard copies. Overall, recruiting a larger German AYA sample is feasible but requires intensive efforts.

The sociodemographic and medical characteristics of the AYA study sample at measurement time points t1 and t2 are presented in Table 1. A comparison of the AYA study sample with official cancer registry data from the Robert Koch Institute revealed some disparities regarding gender and cancer site distribution. While women between 18 and 39 years are diagnosed with cancer more frequently than men, the imbalance was more pronounced in the study sample (75% women) compared to official cancer registry data (59.2% women; Cramers‘V= 0.17; p= 0.0177). Regarding the distribution of cancer sites in the AYA sample compared to the German young cancer population, nine out of ten diagnoses in this study were consistent with nationwide incidence rates. The only exception was melanoma patients, who were underrepresented in the study sample (3.3% vs. 17.6%; Cramers‘V= 0.36, p= 0.0046).

Table 1: Sample characteristics of the AYA study participants (N= 514)

variable (at the survey time point)	**t1 – N (%)**	**t2 – N (%)**
sociodemographic characteristics		
gender: female	386 (75.1)	
age at diagnosis (mean (SD) in years)	29.6 (6.1)	
18-25 years	158 (30.7)	
26-39 years	356 (69.3)	
own children: yes	169 (32.9)	176 (34.2)
relationship	355 (69.1)	363 (70.6)
housing situation		
living alone	117 (22.8)	114 (22.2)
with partner	271 (52.7)	292 (56.8)
with roommates	27 (5.3)	38 (7.4)
with parents	78 (15.2)	53 (10.3)
high school degree (>10 years): yes	309 (60.1)	
medical characteristics		
sick leave: yes	278 (54.1)	60 (11.7)
time since diagnosis (mean (SD) in months)	12.1 (8.1)	23.9 (8.2)
cancer diagnosis		
Solid tumour	353 (68.7)	
Breast	139 (27.0)	
Gynaecological	46 (8.9)	
Testicular	42 (8.2)	
Thyroid	29 (5.6)	
Melanoma	17 (3.3)	
Sarcoma	21 (4.1)	
Gastrointestinal	24 (4.7)	
Others	35 (6.8)	
Non-solid tumour	161 (31.3)	
Hodgkin's lymphoma	93 (18.1)	
Non-Hodgkin's lymphoma	32 (6.2)	
Haematological cancer	36 (7.0)	
medical therapies: yes[a]		
Chemotherapy	392 (76.3)	
Radiotherapy	242 (47.1)	
Surgery	379 (73.7)	
Transplantation[b]	30 (5.8)	
medical treatment status off-treatment: yes	476 (92.6)	

[a]Multiple answers possible; [b]Including bone marrow transplantation or stem cell transplantation

An initial overview of the included published papers is presented in Table 2. The analysis and publication of additional AYA data are continuously ongoing.

Table 2: Methodology and content of the published research papers

publication	**design**	**Outcome variables**
study design		***Chapter 2.1***
Leuteritz (2017)	t1 / t2	description of the study design
Leuteritz (2018)	t1 / t2	recruiting process/strategies
Geue (2021)	t1 to t6	description of the study design
qualitative investigations		***Chapter 2.2***
Breuer (2017)	cross-sectional t1	social support
Mentschke (2017)	cross-sectional t1	occupational situation
Braun (2023)	cross-sectional t3	financial situation
methodical investigation		***Chapter 2.3***
Friedrich (2018)	cross-sectional t1	psychometric properties of the fatigue questionnaire
quantitative cross-sectional investigations		***Chapter 2.4***
Geue (2019)	t1	social support in comparison to older cancer patients
Mütsch (2019)	t1	sexuality
Nowe (2019)	t1	cancer-related Fatigue
Leuteritz (2021)	t2	work employment
Sender (2021)	t2	psychosocial aftercare
quantitative longitudinal investigations		***Chapter 2.5***
Leuteritz (2018)	t1 / t2	life satisfaction
Geue (2019)	t1 / t2	mental health – anxiety and depression
Sender (2019)	t1 / t2	unmet supportive care needs
Stroske (2021)	t1 / t2	health behaviour
Brock (2022)	t1 / t2	work ability and cognitive impairment

2.2 Qualitative investigations

Chapter based on the following publications:*

- Braun I, Friedrich M, Morgenstern L, Sender A, **Geue K**, Mehnert-Theuerkauf A, Leuteritz K. Changes, challenges and support in work, education and finances of adolescent and young adult (AYA) cancer survivors: A qualitative study. European Journal of Oncology Nursing 2023, 64: 102329, doi: 10.1016/j.ejon.2023.102329.
- Mentschke L, Leuteritz K, Daneck L, Breuer N, Sender A, Friedrich M, Nowe E, Stöbel-Richter Y, **Geue K**. Krebs oder Karriere? - Eine qualitative Untersuchung zur beruflichen Situation und Integration junger Erwachsener mit Krebs. Psychotherapie, Psychosomatik und medizinische Psychologie 2017, 67(2):76-82, doi: 10.1055/s-0042-122712.
- Breuer N, Sender A, Daneck L, Mentschke L, Leuteritz K, Friedrich M, Nowe E, Stöbel-Richter Y, **Geue K**. How do young adults with cancer perceive social support? A qualitative study. Journal of psychosocial Oncology 2017, 35(3):292-308, doi: 10.1080/07347332.2017.1289290.

To enhance our comprehension of the psychosocial circumstances of young adults dealing with cancer, we conducted qualitative semi-structured interviews. In particular, we explored topics that lacked adequately robust quantitative measurement tools through qualitative interviews. Engstrom's recent scoping review (Engstrom et al. 2023) underscores the scarcity of qualitative studies on these matters in the AYA patient population, identifying eight qualitative investigations for occupational situations, seven for financial situations, and 11 for relationships.

Qualitative methods

Recruitment of participants for the qualitative interviews started eight months after the quantitative questionnaire investigation in November 2014. Participants for interviews were gradually selected to gain the greatest possible variability by applying the following criteria as well and even possible: gender distribution as equal as possible; representation of the five most common and at least two rare cancer diagnoses for young adults between both genders; distribution of stages of cancer within the different diagnoses. At the initial interview time point (t1) between November 2014 and February 2015, 18 AYA cancer patients were interviewed. They were re-interviewed 12 months later (t2: N= 15), and a third time between November 2018 and January 2019 (t3: N= 11). The interviews were conducted and recorded by research assistants holding diplomas in psychology and graduate Master of Psychology students, either by phone or in person based on the participant's location. Following the interviews, all participants received a compensation of 10€ as an expense allowance.

*All cited quotes in this chapter have been translated literally from German into English.

Operationalization – the interview guides

Semi-structured interview guides were created based on existing research and the research questions framing this study. The interview questions were subsequently evaluated and revised by four members of the project staff, including psychologists and sociologists. The interview guide is formulated in a way that encourages participants to provide a narrative (e.g., it begins with a question about the course of the person's disease and treatment to open up the conversation). It encompasses different areas of life (e.g., occupational situation, social support). The following presents a part of the published interview questions along with their corresponding outcomes.

Social support: Exchanges with other young cancer patients (Breuer et al. 2017)

· Has it been important for you to meet other cancer patients?
· Does age play a role? In what way?
· Have you participated in peer cancer patient exchanges?
· If so, where did you meet?
· What topics did you talk about or what topics would you like to talk about? How often?
· What would such interactions with other cancer patients ideally look like?

Occupational situation (Mentschke et al. 2017)

· Has your occupational situation changed since the diagnosis?
· Have your occupational plans changed due to the illness?
· How would you describe the support from your occupational environment?
· What has been/is the most significant burden related to your occupational situation?
· How did your return to work proceed?
· What would you have needed (or still need) for a successful return to work/entry/new orientation?

Financial situation (Braun et al. 2023)

· What effects did the cancer disease have on your income/financial situation?
· What kind of support (medical, psychosocial, social-legal care, personal support, etc.) has helped you the most regarding your financial situation? How?

Analysis of the interview data

The researchers who conducted the interviews, adhering to consistent transcription rules (Dresing and Pehl 2018), transcribed the audio-recorded interviews verbatim. The transcripts were analyzed using Mayring's qualitative structuring content analysis, modified by Steigleder (2008), with the assistance of MAXQDA 2020 software (Kuckartz et al. 2019), a program designed for qualitative research.

To structure the data, theory- and empirically-guided categories were formed. The following 9-step procedural model was implemented: In the preparatory phase, all interviews were read at least once (*Step 1*). Prestructuring of the data (*Step 2*) was deemed unnecessary due to the subject areas covered in the interview guide. Main content categories were initially developed based on knowledge of the essential research literature to organize the data (*Step 3*). Subsequently, categories were added, dropped, or redefined based on the content of the interviews. The same procedure was applied to define content manifestations of the main categories (*Step 4*). The coding guideline was created (*Step 5*), encompassing encoding rules and examples. Every passage relevant to the research question was marked as a find-spot (*Step 6*) and allocated to one of the content manifestations (*Step 7*). Within each transcript, one text segment could be coded into more than one category. A second person double-checked this step (*Step 8*). The intercoding agreement, based on relevant text passages in the transcripts, was calculated. The percentage of matching encodings was calculated. Any find-spots coded differently by the two independent raters were discussed to reach a consensus. The subsequent descriptive presentation of results constitutes the final step (*Step 9*) of this analysis model.

Results of the qualitative studies

Sample characteristics

The most important sociodemographic and medical characteristics of the interviewed AYA participants are presented in Table 3.

Social support: Exchanges with other young cancer patients *(Breuer et al. 2017)*

In the interviews, the majority (N=14) indicated that they had encountered other young cancer patients in the past. Consequently, the respondents' statements were primarily grounded in actual experiences and influenced by ideas and wishes to some extent.

Category 1: Relevance of exchanges with other YA

Sixteen participants expressed a preference for exchanging experiences with other young adults rather than with older or significantly younger cancer patients. They argued that peers share similar circumstances, fears, concerns, interests, and themes (e.g. starting a family).

> *“But then I talked to someone who is 60, well, this is twice as old as I am. And there was the issue: Will I see my grandchildren grow up? and me, I am wondering: Will I see my children grow up?“* (Interview 4)

Table 3: Sample characteristics of the interviewed AYA participants at t1

Nr.	gender	age at diagnosis	cancer diagnosis	time since diagnosis
1	male	28 years	Testicular cancer	11 month
2	female	18 years	Ewing-sarcoma	24 month
3	female	36 years	Breast cancer	17 month
4	female	30 years	Melanoma	5 month
5	female	39 years	Breast cancer	12 month
6	male	20 years	Liposarcoma	12 month
7	female	24 years	Ovarian cancer	14 month
8	female	22 years	Leukaemia	15 month
9	male	29 years	Testicular cancer	12 month
10	male	29 years	Hodgkin‘s-Lymphoma	13 month
11	female	27 years	Hodgkin‘s-Lymphoma	8 month
12	male	25 years	Hodgkin‘s-Lymphoma	12 month
13	female	23 years	Non-Hodgkin‘s-Lymphoma	13 month
14	female	32 years	Thyroid carcinoma	11 month
15	male	31 years	Parotid carcinoma	45 month
16	female	27 years	Breast cancer	18 month
17	male	31 years	Astrocytoma	42 month
18	male	19 years	Testicular cancer	5 month

Category 2: Topics of interchange

The interviewed AYA patients mentioned that they discussed or would like to discuss the following subjects with other young adults dealing with cancer: disease and treatment (N= 12), personal life and everyday experiences (N= 11), mental well-being including fears (N= 8), social environment (N= 6), and long-term effects, particularly fertility (N= 5).

> *"Well, they have the same fears … fears about the future and problems, just like you … to talk about the fear and to tell each other: Come on, you made it. The disease will not come back."* (Interview 14)

Category 3: Ideas about interchange with other young adult cancer patients

While two participants identified the hospital as a suitable location for meeting with other patients, eight interviewees expressed a preference not to meet in the hospital. The preferred frequencies for in-person meetings varied from daily (N= 4) to once or twice a week (N= 3), once or twice a month (N= 2), and two to four times a year (N= 3). Nine interviewees expressed a preference for non-structured, free-form interactions with other young cancer adults. They emphasized that conversations should occur without guidance from a professional, without predefined topics, and in a relaxed atmosphere. Three respondents suggested the idea of establishing a mentoring program, where young adults who have completed cancer treatment are paired with newly diagnosed young cancer patients.

> *"You meet weekly or so at a cafe or pub. I don't drink beer, but that would probably be the best. In any relaxed group ... cancer-cafe for young adults ... I would have liked something like that."* (Interview 11)

Category 4: Positive effects of exchange with young adult cancer patients

Taking all participants into consideration, an average of 1.8 positive effects of interchange (ranging from a minimum of one to a maximum of five) were articulated. As positive effects were mentioned: to feel understood (N= 5); to feel connected (N= 5); to not feel alone (N= 4); Exchange information and advice (N= 4); to improve well-being (N= 4); to make friends (N= 3); and Exchange support (N= 2); Assistance in reintegration (N= 2); Compensation for distancing of friends (N= 1); Reassurance (N= 1); Hope and confidence (N= 1).

> *"Sometimes you wonder: Why me of all people? and Why am I torn out of life all at once? and ... It helped me to talk to peers going through the same thing because– suddenly you feel you are not alone."* (Interview 2)

Category 5: Negative effects of exchange

Eight interviewed AYA patients emphasized that exchanges with young cancer patients can also have negative effects in specific circumstances. In this context, complicating the return to normality (N= 5); feelings of guilt (N= 4); exposure to negative disease progressions (N= 1) and cancer gaining greater presence (N= 1) were described as unhelpful.

> *"There was one guy, he was 25 or 27, he had a cancer type that, in Germany, is currently considered 0% curable. So sometimes I had a bad conscience, because I was getting off more easily. I didn't lose my hair. I was fine again relatively rapidly. So I felt bad, because I was better off than others."* (Interview 9)

The inter-rater reliability of all find-spots was 0.87.

Occupational situation *(Mentschke et al. 2017)*

Two-thirds of the respondents (N= 12) had already completed their education and were on parental leave, self-employed, employed, or actively seeking employment. For all interviewees, the cancer disease had an impact on their professional situation. Prior to the diagnosis, one person was seeking work or education; at the time of the interview, this number had increased to four participants. Almost half of the participants (N= 8) expressed that they had reduced their occupation or professional development activities, or were planning to do so. One reason for this was diminished work ability.

> *"Actually, I know that I can't do what I used to do anymore, how I used to do it (...) my doctor thinks that maybe I can still manage a three-day week, like 18 hours a week."* (Interview 14)

Category 1: Experienced Strains in the Professional Environment

Only three out of the 18 respondents report having no strains in their professional lives, with 10 participants expressing physical problems and nine participants indicating cognitive or psychological issues. Psychologically, the recurring fear of a cancer relapse was particularly described as restrictive. More than half of the respondents (N= 10) reported a disruption in their career planning.

> *"One also can't concentrate for as long anymore because you're just not used to it anymore (...) so there, I had the feeling that everything is too much for me."* (Interview 10)

Category 2: Supportive Assistance from the Professional Environment

Eleven of the interviewed AYA perceived their supervisors as supportive. Similarly, 11 participants could recount helpful situations in interaction (understanding and empathy) with colleagues.

> *"I'm fortunate to have the possibility to arrange many things very flexibly (...) so if I see that it's somehow getting too much here or today is not my day, then I can also say I'll work the afternoon at home or stay in home office tomorrow."* (Interview 11)

Category 3: Unsupportive Assistance from the Professional Environment

Four respondents found their supervisors to be burdensome, and seven participants experienced their colleagues as unhelpful.

> *"Now, I was at the Christmas party just 3 weeks ago, and that was really a bit strange. Because there, I felt like everyone was trying to avoid the topic somehow... so, no one asked how I was doing."* (Interview 4)

Category 4: Occupational (Re-)Integration

The majority of respondents (N= 11) were back in employment at the time of the interview; all those who had not returned were women. Five employed interviewed AYA utilized gradual reintegration to the workplace. Half of the interviewees (N= 9) spoke about economic and/or bureaucratic barriers. The significant effort involved in correspondence with authorities was particularly perceived as a strain in the reintegration process. This reflected an increased sense of helplessness and dependency on the decisions of the authorities.

> *"I've been waiting since last May for approval from the pension insurance for the retraining... but the pension insurance declined it in September last year, and after I filed an appeal, I'm still waiting for a response today."* (Interview 16)

Category 5: Wishes & Concerns

Half of the participants (N= 9) articulated desires for their future or current employers. More frequently, the interviewed AYA patients wished for greater consideration and expressed the concern that potential employers should understand reduced performance capabilities.

> *"Simply understanding. That one deals with you understandingly and acknowledges that you're just not as high-performing as before. And not being labelled as a failure."* (Interview 5)

The intercode agreement of all assigned find-spots between both coders was 84%.

Financial situation *(Braun et al. 2023)*

At the time of the third interview, the majority of participants were either employed or pursuing education (N= 9 out of 11; 81%). Half of the research participants expressed that their financial situation was no longer a source of concern at the time of the interview. This was particularly evident among participants who were able to resume their original employment without hindrance or had financial backing from their families.

Category 1: Financial Burdens

Interviewed participants disclosed financial burdens primarily stemming from expenses related to fertility preservation (e.g. cryopreservation of germ cells). Financial strain was also reported in connection with insufficient income, despite receiving financial compensation through social welfare benefits or financial unemployment assistance. Two patients had been granted a disability pension post-cancer treatment. Both had to seek additional financial support from the German Federal Agency of Employment as the disability benefits they received were insufficient to meet their living expenses.

> *"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."* (Interview 16)

Category 2: Financial gain

Due to modifications in employment resulting from cancer and its treatment, certain respondents experienced positive developments in the form of salary increases at their workplace.

"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." (Interview 14)

Category 3: Support with alleviating the financial situation

The families of AYA participants (parents and spouses) were the most frequently mentioned sources of economic support post-cancer treatment. In most instances, support entailed compensation for heightened (health) expenditures or lost income.

"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." (Interview 1)

The percentage of intercoder agreement of all assigned find-spots between both coders was 74%.

2.3 Methodical investigation

Chapter based on the following publication:

- Friedrich M, Nowe E, Hofmeister D, Kuhnt S, Leuteritz K, Sender A, Stöbel-Richter Y, **Geue K**. Psychometric properties of the fatigue questionnaire EORTC QLQ-FA12 and proposal of a cut-off value for young adults with cancer. Health and quality of life outcomes 2018, 15;16 (1):125, doi: 10.1186/s12955-018-0949-0.

The aim of this study was to validate the European Organisation for Research and Treatment of Cancer Quality of Life Fatigue Module Questionnaire (EORTC QLQ-FA12) for young adults with cancer. Cancer-related fatigue, as defined by the National Comprehensive Cancer Network (NCCN), is characterized as a distressing, persistent, subjective sense of physical, emotional, and/or cognitive tiredness or exhaustion related to cancer or its treatment. This fatigue is not proportional to recent activity and interferes with usual functioning (Berger et al. 2015). Existing evidence indicates that cancer-related fatigue is the most prevalent and common symptom experienced by cancer survivors (DSilva et al. 2023), including young adults with cancer (Poort et al. 2017). The essential nature of this methodological study is highlighted by Nowe's review (2017). The review identified only 12 studies since 1990 that have investigated cancer-related fatigue in young adult cancer individuals. Only two of the 12 studies utilized a multidimensional fatigue measurement instrument; all other studies assessed fatigue using subscales of quality of life questionnaires or one-item scales (Nowe et al. 2017).

Description of the EORTC QLQ-FA12

This instrument is a newly developed module of the Quality of Life Questionnaire Core 30, specifically developed by the EORTC group for the assessment of cancer-related fatigue (Weis et al. 2017). The EORTC QLQ-FA12 comprises ten unidirectional items and two criteria variables, all rated on a four-point Likert scale ranging from 1= not at all to 4= very much (higher values indicating elevated levels). The two criteria variables measure the extent to which fatigue interferes with daily activities and social life, assessing interference with two forms of customary functioning, as described in the NCCN definition. The ten items are allocated to three hypothetical subscales: *physical* (five items), *emotional* (three items), and *cognitive fatigue* (two items). The scores are standardized to create a range of 0 to 100 (higher scores indicating increased fatigue levels); no composite score has been suggested thus far. Cronbach’s alpha for the three subscales ranges from 0.79 to 0.90 (Weis et al. 2017).

Results of the methodical study

Psychometric properties of the EORTC QLQ-FA12

The psychometric properties of the EORTC QLQ-FA12 comprise confirmatory factor analyses to validate the conceptualized three-factorial Model and to evaluate a factor model for a general fatigue score. For these models, we investigate the following psychometric properties: model fit, composite reliability (≥ 0.6 is adequate), item reliabilities with squared multiple correlations, and discriminant validity. Furthermore, the items should share on average more than 50% of their variance with their composite (average variance extracted).

The model fit for the AYA sample used proved to be good (Comparative Fit Index= 0.96, standardized root mean square residual= 0.04), and every subscale showed discriminant and convergent validity (composite reliabilities: physical: 0.92; emotional: 0.89; and cognitive: 0.74). On average the three composites extracted 70% (physical fatigue), 73% (emotional fatigue), and 59% (cognitive fatigue) of the variance within their corresponding items.

Item reliabilities ranged from 0.60 to 0.80 for the physical fatigue scale, from 0.65 to 0.80 for the emotional fatigue scale, and from 0.45 to 0.73 for the cognitive fatigue scale. The correlations between the three scales ranged from 0.63 to 0.70. The instrument is statistically valid and can discriminate between physical, emotional, and cognitive fatigue.

Overall fatigue score for the EORTC QLQ-FA12

The modelling for a General Fatigue Score considers the fact that the items belong to different scales and posits that general fatigue is a construct equally constituted by the three subscales. Attaining an acceptable fit for this model would provide statistical justification for employing a score composed of the three domains as a measure for general fatigue. This one-dimensional model presupposes general fatigue as constituted by ten items, irrespective of the component to which the item belongs. To assess model fit, we applied a combinational rule of the comparative fit index and the standardized root mean square residual. Models are deemed acceptable if the comparative fit index exceeds 0.95, and the standardized root mean square residual is less than 0.06.

The factor model presents the three domains as composing first-order composites for general fatigue. Model fit was acceptable (Comparative fit index= 0.96 and standardized root mean square residual= 0.05). The composite reliability for general fatigue was 0.87 and the average variance extracted was 0.68; squared multiple correlations are 0.63 (*physical fatigue*), 0.77 (*emotional fatigue*), and 0.65 (*cognitive fatigue*).

Cut-off score for EORTC QLQ-FA12

For the implementation of the Receiver Operating Characteristic (ROC) analysis, thirteen individual items from four standardized instruments were assigned, which best correspond to the proposed cancer-related fatigue diagnostic criteria. All criterion symptoms are summed to a single value. To characterize the ROC analysis, we present the area under the curve, representing the probability that the test can correctly identify the conditions of the standard variable. Table 4 presents the calculated coefficients with the cut-off values.

Two cut-off values (≥ 11 and ≥ 12) had sufficient sensitivity (≥ 90) and specificity (≥ 70) and the cut-off value of ≥ 12 had the higher sum of sensitivity and specificity. The difference between the true positive rate minus the false positive rate was 68 percentage points (Youden J≥12= 0.68). Out of 100 positive predictions, nearly 50 were correct (positive predictive value= 52) and out of 100 negative predictions, only 3 were incorrect (negative predictive value= 97). Altogether, 4 of 5 predictions were correct (Accuracy= 80). The area under the curve was excellent (0.91, confidence interval: 0.88–0.94).

Table 4: ROC-analysis for the general fatigue index (0-30) in the AYA sample

Cut-off	**Value (95% confidence interval)**					
(case ≥ ...)*	**Sensitivity**	**Specificity**	**Youden J**	**Positive predicted value**	**Negative predicted value**	**Accuracy**
8	98 (96–100)	53 (48–57)	0.51 (0.48–0.53)	37 (31–42)	99 (98–100)	63 (59–67)
9	97 (93–100)	60 (55–65)	0.57 (0.53–0.59)	40 (34–46)	98 (97–100)	68 (64–72)
10	94 (90–98)	66 (61–70)	0.60 (0.56–0.62)	43 (37–49)	98 (96–99)	72 (68–75)
11	92 (88–97)	71 (67–75)	0.64 (0.60–0.66)	47 (41–53)	97 (95–99)	76 (72–79)
12	**91 (86–96)**	**77 (73–81)**	**0.68 (0.64–0.70)**	**52 (45–59)**	**97 (95–99)**	**80 (77–83)**
13	89 (83–95)	81 (77–84)	0.70 (0.66–0.73)	56 (49–63)	96 (94–98)	82 (79–86)
14	83 (76–90)	83 (79–86)	0.66 (0.62–0.69)	57 (50–65)	95 (92–97)	83 (80–86)
15	81 (74–88)	86 (83–90)	0.67 (0.63–0.71)	62 (55–70)	94 (92–96)	85 (82–88)
16	72 (64–80)	89 (86–92)	0.62 (0.57–0.65)	65 (57–73)	92 (89–95)	86 (83–89)
17	62 (53–71)	92 (89–94)	0.54 (0.49–0.58)	67 (59–76)	90 (87–93)	85 (82–88)
18	52 (43–61)	94 (92–96)	0.46 (0.41–0.51)	70 (61–80)	88 (85–91)	85 (82–88)

*values with Sensitivity or Specificity below 50% are not presented; Sensitivity= ratio of true positive predictions to all positive conditions; Specificity= ratio of true negative predictions to all negative conditions); Youden Index= difference between sensitivity and specificity; Accuracy= ratio of correct predictions to all predictions of the standard variable conditions

2.4 Quantitative cross-sectional investigations

Chapter based on the following publications:

- **Geue K**, Götze H, Friedrich M, Leuteritz K, Mehnert-Theuerkauf A, Sender A, Stöbel-Richter Y, Köhler N. Perceived social support and associations with health-related quality of life in young versus older adult patients with haematological malignancies. Health and quality of life outcomes 2019, 22;17(1):145, doi: 10.1186/s12955-019-1202-1.
- Mütsch J, Friedrich M, Leuteritz K, Sender A, **Geue K**, Hilbert A, Stöbel-Richter Y. Sexuality and cancer in adolescents and young adults - a comparison between reproductive cancer patients and patients with non-reproductive cancer. BMC Cancer 2019, 22; 19(1):828, doi:10.1186 /s12885-019-6009-2.
- Nowe E, Friedrich M, Leuteritz K, Sender A, Stöbel-Richter Y, Schulte T, Hinz A, **Geue K**. Cancer-Related Fatigue and Associated Factors in Young Adult Cancer patients. Journal of Adolescent and Young Adult Oncology 2019, 8(3):297-303, doi:10.1089/jayao.2018.0091.
- Leuteritz K, Friedrich M, Sender A, Richter D, Mehnert-Theuerkauf A, Sauter S, **Geue K**. Return to Work and Employment Situation of Young Adult Cancer Survivors: Results from the Adolescent and Young Adult-Leipzig Study. Journal of Adolescent and Young Adult Oncology 2021, 10(2):226-233, doi: 10.1089/jayao.2020.0055.
- Sender A, Friedrich M, Leuteritz K, Stuckenberg E, Richter D, Stöbel-Richter Y, Lordick F, **Geue K**. Psychosocial aftercare of adolescent and young adult cancer survivors in Germany: Awareness, utilisation, satisfaction and associated factors. Psychooncology 2021, 30(8):1311-1321, doi: 10.1002/pon.5678.

For the following examined psychosocial outcomes, including occupational situation, sexuality, cancer-related fatigue, social support, and psychosocial care, there is currently a deficiency of adequate international and national research findings with appropriate sample sizes for young cancer survivors. There is a need for national research findings on occupational situations and psychosocial care, considering German-specific factors such as gradual work reintegration and social legal counselling. Jannsen and colleagues identify sexuality, cancer-related fatigue, relationships, and work employment as crucial key points in AYA-specific survivorship research in their overview (Janssen et al. 2021).

Operationalization of the examined psychosocial outcomes

Social Support (Geue et al. 2019b)

In assessing social support, we employed the German version of the Illness-specific Social Support Scale (ISSS-8), as adapted by Ramm and Hasenbring (2003) from the original version developed by Revenson et al. (1991). The ISSS-8 comprises two scales: *Positive Social Support* (four items) and *Detrimental Interactions* (four items). These scales aim to assess perceived helpful behaviours and stressful behaviours, respectively, exhibited by individuals in response to the participant's illness. The instructions for ISSS-8 prompt respondents to reflect on their relationships with significant individuals such as partners, family members, friends, acquaintances, colleagues, and neighbours. Respondents evaluated items using a five-point Likert scale, ranging from 0= never to 4= always, resulting in a score range of 0 to 16 for each scale. Higher scores on the *Positive Social Support* subscale indicate stronger perceived support, whereas elevated scores on the *Detrimental Interactions* subscale signify more pronounced negative interactions between the patient and their support network. The internal consistencies of the two scales, as measured by Cronbach's alpha, are .88 for *Positive Social Support* and .68 for *Detrimental Interactions* (Ramm and Hasenbrink 2003).

Sexuality (Mütsch et al. 2019)

To evaluate satisfaction with sexuality, we used the Sexuality Scale within the Life Satisfaction Questionnaire (FLZ-Sex). This scale consists of seven items, and respondents provided ratings on a seven-point Likert scale, ranging from 1= very dissatisfied to 7= very satisfied. The individual item scores were aggregated to compute a total scale score ranging from 7 to 49, where higher scores indicate increased sexual satisfaction across various items (e.g. sexual efficiency, sexual contacts, sexual response, sexual partner interaction*)*. The Sexuality scale exhibits robust internal consistency, as evidenced by a Cronbach's α coefficient of 0.92 (Fahrenberg et al. 2000).

Fatigue (Nowe et al. 2019)

Cancer-related fatigue was assessed using the European Organization for Research and Treatment of Cancer Quality of Life Fatigue Module Questionnaire (EORTC QLQ-FA12), which was previously introduced in Chapter 2.3.

Work employment (Leuteritz et al. 2021)

Regarding changes in employment status, patients were surveyed approximately two years after their cancer diagnosis about their employment status both retrospectively prediagnosis and their current employment status. The potential answer categories included: employed (encompassing full-time employment, part-time employment, or self-employment); student or in vocational training; unemployed; on a disability pension; and all others not employed (including homemakers, individuals on parental leave, and others). From these specifications, we calculated the return-to-work rate, defining the variable *changes in employment status* as either *changes* (indicating a modification in the employment status between prediagnosis and t2) or *no changes* (indicating no alteration in the employment status between prediagnosis and t2).

Within the subgroup of patients who returned to work, inquiries were made regarding work-related characteristics both retrospectively prediagnosis and at the time of assessment. This included information on the number of contractual weekly working hours, occupational position, presence of a short-term employment contract (yes/no), and the period of sick leave absence since diagnosis. A cancer-related financial distress item was utilized (1= not at all to 4= very much).

Psychosocial care (Sender et al. 2021)

Self-development items were employed to assess psychosocial care, encompassing three distinct categories: *psychological counselling, social-legal counselling*, and *other psychosocial care* (in an open-answer format), each evaluated separately. Participants were prompted with the following query: "Please indicate for the following psychosocial care services whether they were available in your immediate environment and which you have used within the last 12 months."

Subsequently, participants provided specific responses in accordance with a sequence of questions based on branching logic:

- Availability of Psychosocial Care (Response options: Yes/No (no included the responses “No” and “I do not know”))
- Utilization of Psychosocial Care (Response options: Yes/No; - relevant only if the response to availability was “Yes”)
- Frequency of Utilization (Response options 1 time; 2–3 times; and >3 times)
- Satisfaction with the used service (five-point Likert scale ranging from 1= not at all to 5= very; relevant only if the response to utilization was “Yes”).

Results of the cross-sectional studies

Description of the psychosocial outcomes and examined group differences

To explore the research questions regarding the extent of quality of life and psychological and psychosocial well-being, various psychosocial outcomes were examined at the first and second measurement time points. Differences in the examined variables or group differences were evaluated utilizing the Student’s t-test or McNemar’s test for independent samples.

Social support (Geue et al. 2019b)

This study compared the perceived social support among young adult and older adult cancer patients diagnosed with haematological malignancies (AYA: N= 179; older adult patients > 70 years: N= 200). The mean score on the *Positive Social Support* subscale was 13.21 (SD= 3.4). No significant difference was observed between the younger and older cancer patients (refer to

Table 5, p= .313). Among older adult patients, 40.0% achieved the maximum score of 16, compared to 29.1% of AYA patients. Regarding the *Detrimental Interactions* subscale, the mean score was 2.8 (SD= 3.0). AYA patients reported significantly stronger *Detrimental Interactions* than older adult patients (refer to Table 6, p< .001; Cohen's d of 0.9). Notably, 54.0% of older adult patients reported no *Detrimental Interactions* (score= 0), in contrast to 12.3% of AYA patients.

Table 5: Social support subscales and items for AYA and older adult patients

ISSS-8	**AYA (N= 179)**		**Older adult patients (N= 200)**	
Amongst the people you feel close to, is there someone who...	**M**	**SD**	**M**	**SD**
Positive Social Support subscale	**13.40**	**2.81**	**13.04**	**3.82**
Is there for you when you need him/her	3.8	0.6	3.8	0.6
Gives you comfort	3.4	0.9	2.9	1.5
Talks about important decisions with you	3.1	1.1	3.3	1.3
Spends part of his/her time working some things out for you	3.2	1.1	3.1	1.4
Detrimental Interaction subscale	**4.16**	**3.10**	**1.63**	**2.42**
Worries too much about your illness	1.4	1.1	0.8	1.2
Gives you information or makes suggestions that you find unhelpful or upsetting	1.3	1.1	0.4	0.9
Makes you feel you cannot care for yourself	0.8	1.2	0.3	0.8
Tries to change the way you're coping with your illness in a way you don't like	0.6	0.9	0.1	0.4

Sexuality (Mütsch et al. 2019)

The aim of the study was to investigate whether young adults diagnosed with reproductive cancers (breast, testicular, and gynaecological cancers) differ in sexual satisfaction compared to those with non-reproductive cancers. Overall, the results suggest that approximately one-third of AYA participants, both with reproductive and non-reproductive cancers, experience sexual dissatisfaction. Table 6 indicates that there were no significant group differences between non-reproductive and reproductive AYA cancer patients for both men (p= 0.75) and women (p= 0.56).

Table 6: Sexuality for the AYA sample at t1

	Non-reproductice cancer		**Reproductive cancer**		**t**	**p**
	M	SD	M	SD		
Sexuality (FLZ-Sex) - men	33.48	8.59	33.95	7.84	- .319	.75
Sexuality (FLZ-sex) - women	30.58	9.07	28.81	9.73	1.918	.56

Cancer-related fatigue (Nowe et al. 2019)

The highest fatigue scores were observed on the *physical* subscale (M= 45.6; SD= 28.15), followed by *emotional* (mean= 26.7; SD= 28.82), and *cognitive* subscale (mean=19.7; SD=22.71). Women reported significantly higher fatigue scores than men for all three subscales (refer to Table 7).

Table 7: Cancer-related fatigue for the AYA sample at t1

subscale	**total**		**women**		**men**		**t**	**p**
	M	SD	M	SD	M	SD		
Physical fatigue	45.57	28.2	48.29	28.8	37.98	24.9	-4.20	< .001
Emotional fatigue	26.72	28.8	29.92	29.8	17.84	23.8	-5.01	< .001
Cognitive fatigue	19.70	22.7	21.66	23.8	14.25	18.4	-3.92	< .001

Work employment (Leuteritz et al. 2021)

The purpose of this study is to examine changes in the employment situation of the study participants. The *return-to-work rate* among individuals who were employed at the time of diagnosis in the AYA sample was 83.4% at t2 compared to the prediagnosis period. Among those who were studying or undergoing vocational training at the time of diagnosis (20.2%), 43.1% returned to university or vocational training.

Significant changes in work-related characteristics were observed from pre-diagnosis to t2, particularly in the variable of contractual weekly working hours, showing an average reduction of 1.1 weekly working hours. More than half of the patients (58.2%) had been on sick leave for more than six months since the time of diagnosis, while approximately one-fifth of AYA patients (19.9%) had been on sick leave for less than six weeks since diagnosis.

Over a quarter of employed AYA patients (24%) reported experiencing quite a bit to very much cancer-related financial distress (M= 27.80; SD= 35.15). In contrast, 67.8% of the 59 former employed patients who did not return to work reported financial distress (M= 65.54; SD= 37.12). This difference between the groups was statistically significant with a large effect size (t= 7.46; p< .001; Hedges'g= 1.06).

Psychosocial aftercare (Sender et al. 2021)

The analysis revealed that among the AYA study participants, 30.2% utilized one psychosocial service, 17.5% utilized two, and 6.8% utilized all three psychosocial services, respectively.

Psychological counselling. 54.3% of the patients were aware of available psychological counselling in aftercare. Regarding the utilization of psychological counselling, more than two-thirds of AYA (69.1%) who affirmed their awareness visited a psychologist in the last 12 months. In terms of utilization frequencies, 81.1% of all users turned to a psychologist twice or more. Two-thirds of patients (66.5%) were highly satisfied with psychological counselling (Figure 3).

Social-legal counselling. Approximately half of all participants (44.6%) were aware of social-legal counselling. Out of all participants, 74.2% of survivors who were aware of social-legal counselling used it in aftercare. More than half of all social-legal counselling users (53.3%) attended two or more appointments, and 75% of all users reported high satisfaction.

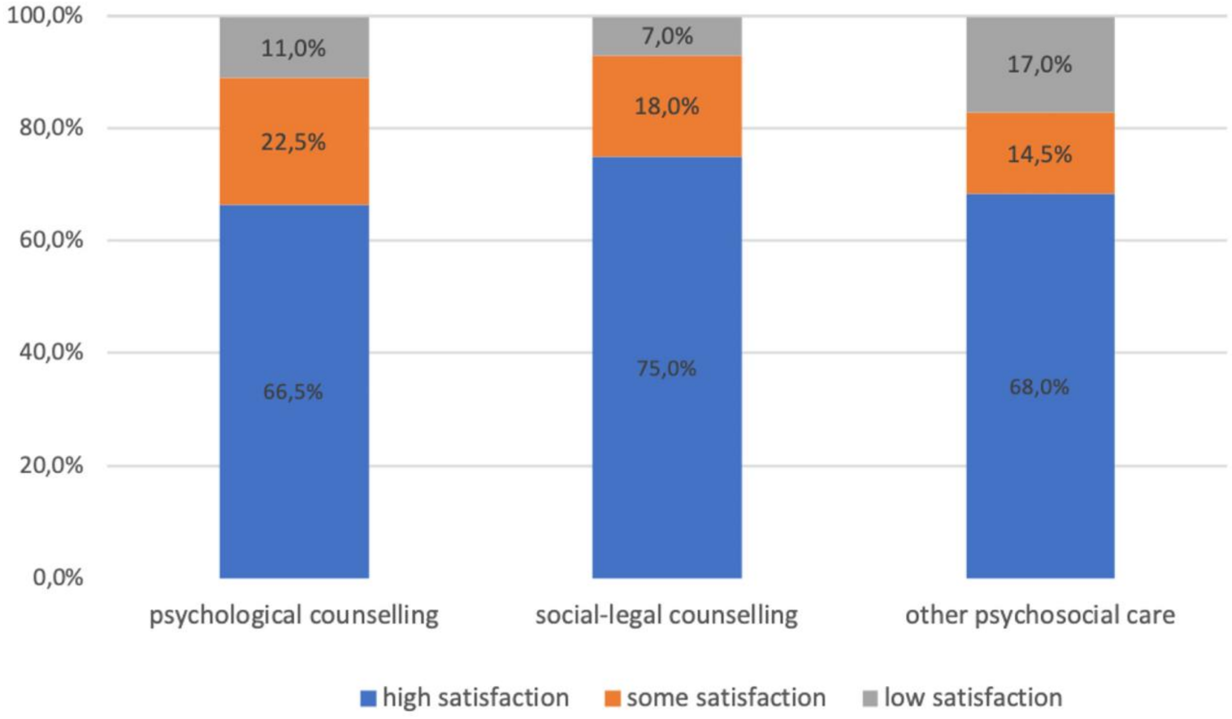

Figure 3: Satisfaction with psychosocial care for the AYA sample at t2

Other psychosocial care services. About one-fourth of AYA cancer patients (23.9%) were aware of other existing psychosocial care services. The most frequently mentioned services were self-support groups (N= 41), therapeutic exercise (N= 20), and art/music therapy (N= 19). Overall, 63.4% of participants who confirmed their awareness used one of the mentioned psychosocial care services. Most users (81.8%) attended two or more meetings, and 68% reported high satisfaction with the services.

Associated variables with the psychosocial outcomes at t1 or t2

The significant findings from the multiple regression analyses, aiming to identify potential predictors (as independent variables) for psychosocial outcomes (as the dependent variable), are detailed in Table 8. The considered influencing factors vary based on substantive considerations for each target variable. Due to the explanatory variance of the model for sexuality being below 10%, it was not included in the presentation.

Regression analyses revealed a significant impact of the partnership on *Positive Social Support*, with no significant effects observed for other included sociodemographic factors. A notable association between *Detrimental Interactions* and age groups was identified, indicating that younger patients (AYA) had higher scores compared to older adult patients (> 70 years).

Influence on the three fatigue subscales was evident for the female sex, financial challenges due to the disease, and the presence of additional diseases.

Higher anxiety scores were linked to an increased likelihood of utilizing *psychological counselling* and *other psychosocial care*. The utilization of *psychological* and *social-legal counselling* was associated with the female gender.

Return to work was found to be associated with the medical factors additional diseases and tumour type. Patients with haematological cancer and sarcoma revealed the lowest return to work rates, while the highest rates were observed for patients with melanoma and thyroid cancer.

Table 8: Results of the regression analysis for the psychosocial outcomes

		significant factors (p< .05)	**β**
Social support (ISSS-8) at t1			(Geue et al. 2019b)
Positive Social Support ***adj. R^2= .10***	sociodemographic	+ partnership	2.3
	medical	no variables were included	
	psychosocial	no variables were included	
Detrimental Interaction ***adj. R^2= .18***	sociodemographic	+ younger age (AYA)	2.6
	medical	no variables were included	
	psychosocial	no variables were included	
Cancer-related fatigue (EORTC QLQ-FA12) at t1			(Nowe et al. 2019)
physical fatigue ***adj. R^2= .16***	sociodemographic	+ gender: female	0.11
	medical	+ additional disease: yes	0.19
	psychosocial	+ financial problems: yes	0.26
emotional fatigue ***adj. R^2= .21***	sociodemographic	+ gender: female	0.12
	medical	+ additional disease: yes	0.22
	psychosocial	+ financial problems: yes	0.32
cognitive fatigue ***adj. R^2= .10***	sociodemographic	+ gender: female	0.11
	medical	+ additional disease: yes	0.19
	psychosocial	+ financial problems: yes	0.26
Work employment at t2			(Leuteritz et al. 2021)
Return to work ***adj. R^2= .22***	sociodemographic	/	-1.601
	medical	- additional disease: yes	-1.546
		- tumour type: haematological & sarcoma	
	psychosocial	no variables were included	
Utilisation of Psychosocial aftercare at t2			(Sender et al. 2021)*
Psychological counselling ***adj. R^2= .21***	sociodemographic	+ gender: female	2.08
		- children: yes	0.47
	medical	/	1.19
	psychosocial	+ anxiety	
Social-legal counselling ***adj. R^2= .16***	sociodemographic	+ gender: female	2.18
	medical	/	
	psychosocial	/	
Other psychosocial care ***adj. R^2= .395***	sociodemographic	- partnership: yes	0.23
	medical	/	1.38
	psychosocial	+ anxiety	

/= the included variables were not significant; *= odds ratio for the logistic regression

2.5 Quantitative longitudinal investigations

Chapter based on the following publications:

- Leuteritz K, Friedrich M, Sender A, Nowe E, Stoebel-Richter Y, **Geue K**. Life satisfaction in young adults with cancer and the role of sociodemographic, medical, and psychosocial factors: Results of a longitudinal study. Cancer 2018, 15; 124(22):4374-4382, doi: 10.1002/cncr. 31659.
- **Geue K**, Göbel P, Leuteritz K, Nowe E, Sender A, Stöbel-Richter Y, Friedrich M. Anxiety and depression in young adult German cancer patients: Time course and associated factors. Psychooncology 2019, 28(10):2083-2090, doi: 10.1002/pon.5197.
- Sender A, Friedrich M, Leuteritz K, Nowe E, Stöbel-Richter Y, Mehnert A, **Geue K**. Unmet supportive care needs in young adult cancer patients: associations and changes over time: results from the AYA-Leipzig study. Journal of Cancer Survivorship 2019, 13(4):611-619, doi: 10.1007/s11764-019-00780-y.
- Stroske I, **Geue K**, Friedrich M, Sender A, Schmidt R, Richter D, Leuteritz K. Health Behavior and Associated Factors in Young Adult Cancer Patients. Frontiers in Psychology 2021, 12:697096, doi: 10.3389/fpsyg.2021.697096.
- Brock H, Friedrich M, Sender A, Richter D, **Geue K**, Mehnert-Theuerkauf A, Leuteritz K. Work ability and cognitive impairments in young adult cancer patients: associated factors and changes over time-results from the AYA-Leipzig study. Journal of Cancer Survivorship 2022, 16(4):771-780, doi: 10.1007/s11764-021-01071-1.

The findings presented in the following subchapter significantly contribute to addressing existing research gaps in longitudinal psycho-oncological investigations of young adult cancer survivors, specifically in relation to life satisfaction, mental health, health behaviour, supportive care needs, and work ability.

Operationalization of the examined psychosocial outcomes

Life satisfaction (Leuteritz et al. 2018)

The operationalization of life satisfaction utilized module A ("general life satisfaction") from the Questions on Life Satisfaction (FLZ-M) (Henrich and Herschbach 2000). This validated instrument measures subjective life satisfaction and was developed for use across all age groups. Respondents were queried about their satisfaction levels ("How satisfied are you with...") over the past four weeks in eight life domains: *friends/acquaintances*; *leisure activities/hobbies*; *health*, *income/financial security*; *work/profession*; *housing situation*; *family life/children*; and *partnership/sexuality* - areas typically relevant to individuals in the Western world. To meet the needs of young adults with cancer, we differentiated two areas of the original FLZ-M questionnaire more distinctly. Consequently, we evaluated the *partnership/sexuality* domain as two distinct items (*partnership* and *sexuality*) to capture information on sexuality from both single and partnered patients. Furthermore, we separately assessed the *family life/children* domain using two items: *family life* and *children/family planning*. Participants rated the 10 measured areas of life on a five-point Likert scale (1= unsatisfied to 5= very satisfied). Subsequently, a global satisfaction score (referred to as *global life satisfaction*) was derived by calculating the mean of the satisfaction values across the 10 areas. The FLZ-M demonstrates a commendable reliability score of Cronbach's alpha= .82.

Mental health – anxiety and depression (Geue et al. 2019a)
Anxiety and *depression* were assessed using the German version oft he Hospital Anxiety and Depression Scale (HADS). This instrument is specifically designed for individuals with somatic diseases. The 14 items are rated on a four-point Likert scale (0 – 3), forming two subscales for *anxiety* and *depression*. A score (0-21) can be calculated for each subscale to derive a total score. Higher scores indicate elevated levels of *anxiety/depression*. The original test authors defined three ranges for the subscales: 0 to 7 (noncases), 8 to 10 (borderline cases), and 11 to 21 (cases). The reliability of the HADS was deemed appropriate (Cronbach alpha> .80) (Herrmann et al. 1995; Bjelland et al. 2002).

Unmet supportive care needs (Sender et al. 2019)
The German version of the Supportive Care Needs Survey-Short Form (SCNS-SF34G) was utilized to assess the supportive care needs of young cancer survivors. The self-report questionnaire consists of 34 items and encompasses five domains of needs: *psychological*; *health system/information; physical/daily living; patient care/support;* and *sexuality*. For the AYA group, we introduced a domain - *fertility/desire to have children* - with two additional relevant items (fertility and the desire to have children) using the same response format. Patients rated their perceived level of need for help over the last week for each item on a five-point Likert scale (1= no need, not applicable; 2= no need, satisfied; 3= low need; 4= moderate need; 5= high need). Domain scores were calculated by summing all item scores and rescaling to a 0 – 100 range, where higher scores indicate a greater extent of unmet need. The SCNS-SF34-G demonstrated very good reliability (Cronbach’s alpha 0.82 – 0.94) (Lehmann et al. 2012).

Health behaviour (Stroske et al. 2021)
Utilizing the Questionnaire of Multiple Health Behaviour (MHB), a 39-item German self-report questionnaire designed to assess habitual health-related behaviour (Wiesmann et al. 2003), we curated a concise list of seven items to investigate health behaviour in the research project. During the item-selection process, we prioritized high content-relevance to cancer patients' health based on previous research literature and considered relevance to the AYA group if

literature was available. The items were assessed on a five-point Likert scale (0= never to 4= always), encompassing both positive and negatively formulated items. The analysis was conducted at the item level.

Work ability and cognitive impairment (Brock et al. 2022)
Due to economic considerations, we incorporated one item from the Work Ability Index (WAI) to assess work ability. The WAI, a validated instrument with seven items, evaluates the work ability of employed individuals concerning personal resources and working conditions (Ilmarinen 2009). The selected WAI item exhibits a strong correlation with the overall WAI scale and has been utilized in various studies as an economical alternative to assess work ability (Ahlstrom et al. 2010). Subjective work ability was rated on an 11-point Likert scale (0= completely unable to work to 10= maximum attained work ability). A cut-off of 8 for the WAI item was employed (<8= low work ability and ≥8= high work ability) (Torp et al. 2017).

To operationalize the extent of cancer-related cognitive impairments, we used four items from the standardized self-reported Copenhagen Psychosocial Questionnaire (COPSOQ) (Kristensen et al. 2005). Individuals rated the following questions on a five-point Likert scale (1= always to 5= never/hardly ever): “How often during the past four weeks have you (1) had problems concentrating; (2) had difficulty making decisions; (3) experienced difficulty remembering; and (4) found it difficult to think clearly?“. As recommended by the authors, we calculated the average overall score (0 - 100) across all four items of the cognitive impairments subscale for evaluation. A higher score indicates greater cancer-related cognitive impairments (<20= never/hardly never; 21-40= seldom; 41-60= sometimes; 61-80= often; 81-100= always). The subscale of cognitive impairments demonstrates a Cronbach's alpha between .85 and .87 (Nübling et al. 2006).

Results of the longitudinal studies

Changes over time (t1 to t2) for the psychosocial outcomes

To investigate the research question regarding the potential changes in the examined variables over time, the initial survey of 577 AYAs was followed by a second survey 12 months later (follow-up). The analytical framework involved 514 AYAs, ensuring a focused exploration of changes in various domains. Differences in the examined variables between baseline and follow-up were assessed using Student’s t-test or McNemar’s test for dependent samples.

Life satisfaction (Leuteritz et al. 2018)

Life satisfaction exhibited a significant increase between t1 (M= 3.39; SD= 0.74) and t2 (M= 3.52; SD= 0.76) (p< .00001), with an associated effect size of Hedges`g amounting to 0.17 (Figure 4). Five out of the 10 domains demonstrated statistically significant increases from baseline to follow-up, characterized by small effect sizes. Across both survey time points, participants expressed increased satisfaction in the domains of *housing situation*; *family life;* and *friends/acquaintances*. AYAs at baseline exhibited the least satisfaction with the domains of *income/financial security* and *children/family planning*, followed by *work/profession*. At follow-up, their least satisfaction was observed in the domains of *sexuality*; *children/family planning*; and *income/financial security*. Stratified by cancer type, melanoma patients (N= 17) reported the highest life satisfaction (t1: M= 3.94; SD= 0.59; t2: M= 4.21; SD= 0.57), while those with sarcoma (N= 21) expressed the lowest (t1: M= 3.11; SD= 0.73; t2: M= 3.22; SD= 0.73).

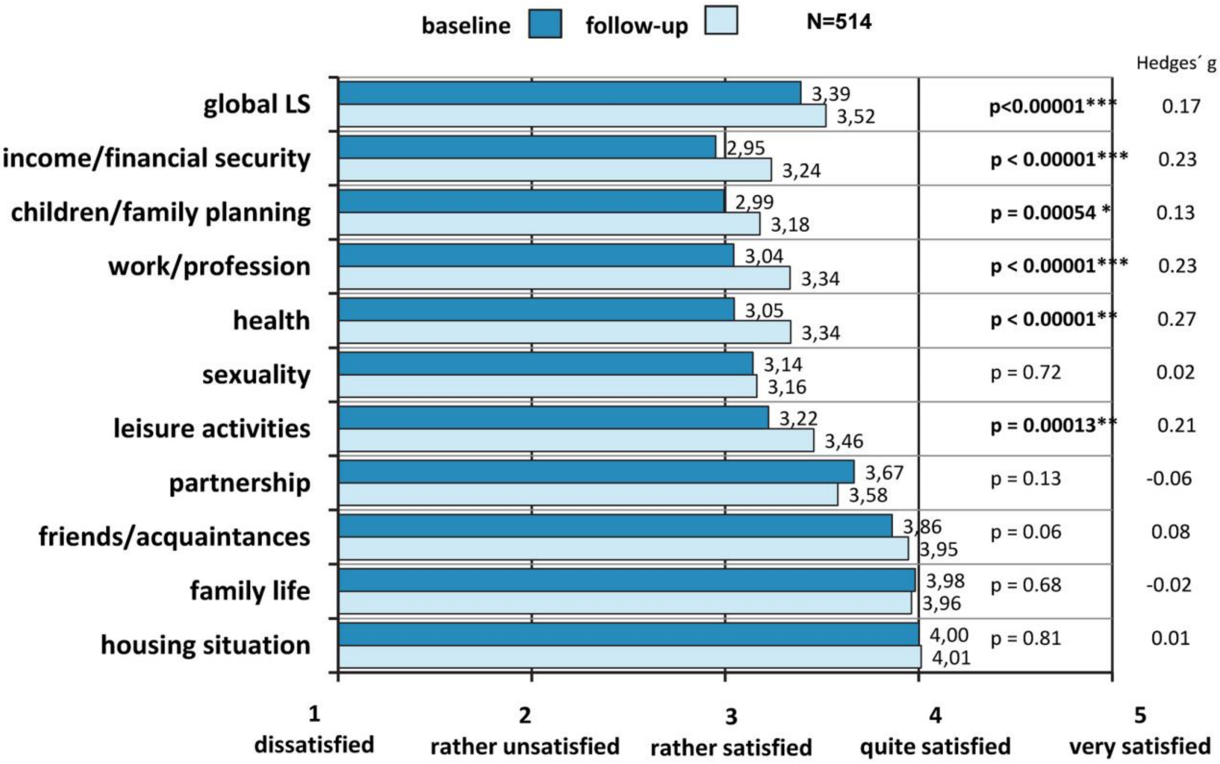

Figure 4: Life satisfaction (FLZ-M) for the AYA sample at t1 and t2

Mental health – anxiety and depression (Geue et al. 2019a)

A total of 42.2% (N= 217) of the AYA patients at t1 and 45.3% (N= 233) at t2 showed elevated levels of *anxiety* (≥ 8). The correlation coefficient was r = 0.65 (p< 0.001), indicating a strong positive correlation. Regarding *depression*, 16.9% (N= 87) of patients at t1 and 17.7% (N= 92) at t2 had elevated levels (≥ 8), with a correlation coefficient of r= 0.61 (p< 0.001). Elevated levels of both *anxiety* and *depression* were reported by 14% (N= 72) of participants at t1 and 15.2% (N= 78) at t2. The median score for *anxiety* (median= 7) exceeded that for *depression* (median= 3) at both time points (refer to Figure 5). Neither *anxiety* nor *depression* exhibited significant changes over time. Specifically, 482 patients in relation to *anxiety* and 479 patients in relation to depression showed no significant intra-individual changes (calculated by the Reliable Change Index) between t1 and t2. Those patients showing significant improvement in *anxiety* and *depression* values over time had received psychological care between t1 and t2 more often than had patients showing no reliable change (*anxiety*: 67% vs. 36%; p< .040; *depression*: 76% vs. 35%; p< .004).

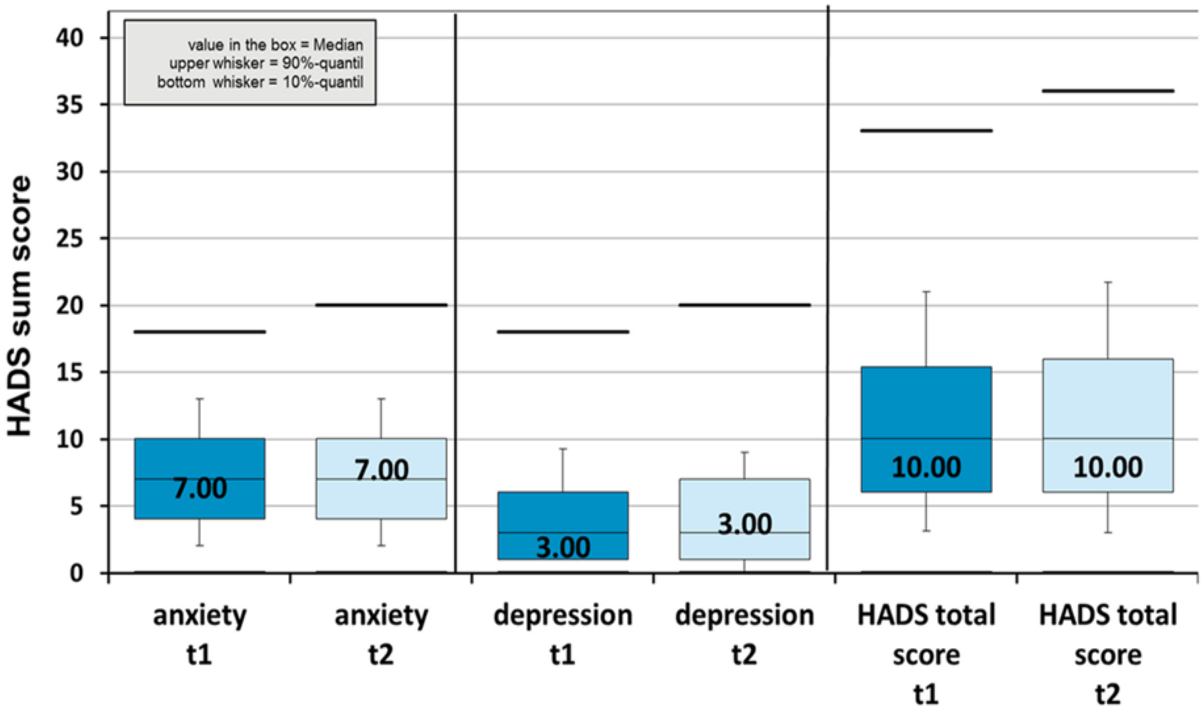

Figure 5: Mental health (HADS) for the AYA sample at t1 and t2

Unmet supportive care needs (Sender et al. 2019)

The domains receiving the highest ratings at both measurement points were *psychological supportive care needs* (t1: M= 35.72; t2: M= 32.09) and supportive care needs related to the *health system/information* (t1: M= 32.18; t2: M= 29.04). In total, 78% of participants reported experiencing at least one unmet *psychological supportive care need* at t1, and 74.7% at t2. Significant temporal changes were observed for the need for *psychological supportive care need* (p= 0.0007), *health system/information needs* (p= 0.021), and *patient care/support needs* (p= 0.00026), with unmet needs decreasing between t1 and t2 (refer to Table 9). The other three domains were found to be stable.

Table 9: Supportive care needs for the AYA sample at t1 and t2

	Mean (SD), t-test *p*			**Effect size *d***	**Reported at least one unmet need; N (%)**	
SCN domains	**t1**	**t2**	**p**		**t1**	**t2**
Patient care/ support	23.24 (25.80)	19.10 (24.24)	***0.0002***	−0.165	266 (51.8)	246 (47.9)
Physical/daily living	24.44 (20.24)	22.77 (21.37)	0.075	−0.08	337 (65.6)	323 (62.8)
Sexuality	27.97 (32.14)	25.76 (31.29)	0.103	−0.07	355 (49.6)	241 (46.9)
Fertility/desire to have children	28.36 (26.70)	29.67 (35.12)	0.392	0.042	246 (47.9)	218 (42.4)
Health system /information	32.18 (29.53)	29.04 (29.76)	***0.021***	−0.106	365 (69.3)	343 (66.7)
Psychological	35.72 (26.86)	32.09 (27.56)	***0.0007***	−0.133	401 (78.0)	384 (74.7)

Health behaviour (Stroske et al. 2021)

At t1, the health behaviours most frequently reported were *following medical orders* (M= 3.39; SD= 0.76) and the *consumption of nicotine* (inverse item: M= 0.47; SD= 1.06). In contrast, patients reported less health-conscious behaviour for *physical activity* (M= 2.40; SD= 1.09) and *keeping an appropriate and balanced diet* (M= 2.57; SD= 0.93). More than every fifth patient reported never engaging in *physical activity*. Significant changes from t1 to t2 were noted for the item *regular health screening* (Hedges'g= 0.44), which showed a significant increase (refer to Table 10).

Table 10: Health behaviours for the AYA sample at t1 and t2

Operationalization of health behaviour		**t1**	**t2**	**difference t2 – t1**
Regular health screening (e.g., medical check-ups; functional testing)	***Mean (SD)***	***2.78 (1.22)***	***3.28 (1.07)***	***Hedges'g= 0.44*** ***(p< 0.001)***
	Never N (%)	94 (18.3)	48 (9.3)	
	Frequently N (%)	121 (23.5)	79 (15.4)	
	Always N (%)	299 (58.2)	387 (75.3)	
Following medical orders (e.g., medication intake)	***Mean (SD)***	***3.39 (0.76)***	***3.45 (0.80)***	Hedges'g= 0.08 (*p*= 0.090)
	Never N (%)	10 (1.9)	13 (2.5)	
	Frequently N (%)	54 (10.5)	48 (9.3)	
	Always N (%)	450 (87.5)	453 (88.1)	
Keeping an appropriate and balanced diet (rich in vitamins, minerals, and fibre)	***Mean (SD)***	***2.57 (0.93)***	***2.52 (0.92)***	Hedges'g= -0.05 (*p*= 0.212)
	Never N (%)	57 (11.1)	64 (12.5)	
	Frequently N (%)	184 (35.8)	192 (37.4)	
	Always N (%)	273 (53.1)	258 (50.2)	
Consumption of nicotine* (smoking cigarettes, cigars, pipes)	***Mean (SD)***	***0.47 (1.06)***	***0.53 (1.14)***	Hedges'g= 0.05 (*p*= 0.060)
	Never N (%)	449 (87.4)	445 (86.6)	
	Frequently N (%)	28 (5.4)	20 (3.9)	
	Always N (%)	37 (7.2)	49 (9.5)	
Consumption of "harder" alcoholic beverages* (liquor, etc.)	***Mean (SD)***	***0.54 (0.62)***	***0.55 (0.66)***	Hedges'g= 0.02 (*p*= 0.616)
	Never N (%)	494 (96.1)	492 (95.7)	
	Frequently N (%)	16 (3.1)	16 (3.1)	
	Always N (%)	4 (0.8)	6 (1.2)	
Being considerate in road traffic (e.g., respecting speed limits and avoiding high speed)	***Mean (SD)***	***3.03 (0.89)***	***3.01 (0.88)***	Hedges'g= -0.02 (*p*= 0.643)
	Never N (%)	32 (6.2)	29 (5.6)	
	Frequently N (%)	91 (17.7)	97 (18.9)	
	Always N (%)	391 (76.1)	388 (75.5)	
Physical activity (ensuring regular exercise)	***Mean (SD)***	***2.40 (1.09)***	***2.37 (1.07)***	Hedges'g= -0.03 (*p*= 0.460)
	Never N (%)	110 (21.4)	127 (24.7)	
	Frequently N (%)	175 (34.0)	155 (30.2)	
	Always N (%)	229 (44.6)	232 (45.1)	

*= Inverse items

Work ability and cognitive impairment (Brock et al. 2022)

In the AYA study sample, work ability improved from t1 (M= 6.0) to t2 (M= 6.83; p< .01). While at t1, over three-quarters of the patients (76%; N= 380) did not reach the cut-off for work ability of 8, at the second measurement point, this percentage decreased to 57% (N= 287). Regarding cognitive functioning, 88 patients (18%) reported cognitive impairments at t1, and 82 (16%) at t2, with no significant changes observed over time (refer to Table 11).

Table 11: Work ability and cognitive impairments for the AYA sample at t1 and t2

	t1		**t2**		**t**	**p**	**d / φ**
	M	SD	M	SD			
Work ability	6.0	2.3	6.8	2.2	−9.3	**<. 001**	d= .38
Cognitive impairments	36.2	22.8	35.2	23.0	1.3	.216	d= .05
	N	%	N	%	$\chi^{2\,a}$		
Low work ability (< 8)	380	76%	287	57%	56.8	**<. 001**	φ= .39
Cognitive impairments (> 60)	88	18%	82	16%	.3	.594b	φ= .38

Associated factors for the psychosocial outcomes at t2

Multiple regression analyses were performed to determine sociodemographic, medical, and psychosocial factors (as independent variables) predicting the psychosocial outcomes (as the dependent variable). As the examined influencing factors vary for each publication, examples are provided below:

· sociodemographic variables: gender, relationship, children, education degree
· medical variables: time since diagnosis, sick leave status, solid tumour
· psychosocial variables: perceived adjustment to illness (PACIS), psychosocial support (ISSS-8), distress

The PACIS is a single-item measure for coping with chronic illness. On a scale of 1= none to 100= a great deal it states the subjective effort to cope with chronic illness (Hürny et al. 1993).

A presentation of significant influencing factors at the second measurement point for life satisfaction, mental health, two domains of the Supportive Care Needs Questionnaire, and work ability is available in Table 12.

Table 12: Results of the regression analysis for the psychosocial outcomes at t2

		significant factors (p< .05)	**β**
Life satisfaction (FLZ-M)			(Leuteritz et al. 2018)
global life satisfaction ***adj. R***^{2}***= .54***	sociodemographic	+ Relationship: yes	0.10
	medical	/	
	psychosocial	+ Positive social support (ISSS-8)	0.16
		- Detrimental interactions (ISSS-8)	-0.09
		- *Perceived adjustment to chronic illness (PACIS)*	-0.16
		+ life satisfaction at t1 (FLZ-M global score)	0.46
Mental health (HADS)			(Geue et al. 2019a)
Anxiety ***adj. R***^{2}***= .59***	sociodemographic	/	
	medical	+ sick leave status: yes	0.06
	psychosocial	- Positive social support (ISSS-8)	-0.09
		+ *Perceived adjustment to chronic illness (PACIS)*	-0.18
		+ unmet need: anxiety (SCNS-item)	0.25
		+ unmet need: fear of recurrence (SNCS-item)	0.11
		+ anxiety at t1 (HADS)	0.37
Depression ***adj. R***^{2}***= .58***	sociodemographic	/	
	medical	+ sick leave status: yes	0.06
		+ time since diagnosis: more time	0.09
	psychosocial	- Positive social support (ISSS-8)	-0.14
		+ *Perceived adjustment to chronic illness (PACIS)*	0.24
		+ unmet need: feeling of sadness (SCNS-item)	0.14
		+ unmet need: feeling depressed (SCNS-item)	0.13
		+ depression at t1 (HADS)	0.32
Unmet supportive care needs* (SCNS-SF34G)			(Sender et al. 2019)
Psychosocial ***adj. R***^{2}***= .32***	sociodemographic	+ gender: female	0.08
	medical	/	
	psychosocial	+ distress (distress thermometer)	0.10
		+ *Perceived adjustment to chronic illness (PACIS)*	0.47
Health system / information ***adj. R***^{2}***= .12***	sociodemographic	+ age at diagnosis: older	0.15
	medical	/	
	psychosocial	+ *Perceived adjustment to chronic illness (PACIS)*	0.24
Work ability (WAI)			(Brock et al. 2022)
adj. R^2***= .48***	sociodemographic	- children: yes	-0.08
	medical	- additional disease: yes	-0.20
		- time of sick leave: more days	-0.12
	psychosocial	- cognitive impairments (COPSOQ)	-0.34
		- *Perceived adjustment to chronic illness (PACIS)*	-0.28

/= the included variables were not significant; *= two domains are selected

The adjusted explained variances of the regression models range between 12% and 59%. The calculated regression models for the seven health behaviour items are not considered due to the low explanatory power of the models (adj. R^2 between .01 to .10). Medical factors play a subordinate role, and significance can be demonstrated for mental health and work ability. While none of the included sociodemographic factors show explanatory power for anxiety and depression, a sociodemographic influencer can be identified for life satisfaction, supportive care needs, and work ability, respectively. This influence varies (relationship, age at diagnosis, gender, or children). In all regression models, psychosocial factors have a substantial and significant impact, especially the perceived adjustment to chronic illness, which consistently emerges as a predictor in each model.

2.6 Strengths and limitations of the AYA research projects

The AYA research projects exhibit significant strengths, notably its comprehensive collection of longitudinal data on psychosocial outcomes with adequate sample size, facilitating different subgroup analyses. Additionally, it encompasses all malignant cancer types, a departure from previous studies (Quinn et al. 2015). A diverse cross-sectional thematic focus is explored at each measurement point. Emphasizing the low dropout rate over six measurement points, this can be attributed to the heightened interest of patients, who desire recognition as a unique patient population. The recruited sample aligns comparably with the age and cancer site distribution of the nationwide German AYA population, providing crucial insights within the specific German medical care system.

The studies have notable limitations. The overrepresentation of women and individuals with a high level of education is acknowledged, consistent with findings in other cancer trials (Dawson et al. 2018; Kaul et al. 2017). The 1:4 ratio of men to women in similar studies indicates a pattern of lower male involvement, potentially associated with social desirability. Variances in burden and coping strategies between genders may further explain participation discrepancies. The recruitment process, including methods like posting on Facebook or in-person approaches in cooperating clinics, may have contributed to the observed gender mismatch. The study also lacks systematically documented refusal rates for all recruitment settings. The option for patients to self-register may introduce selection bias, potentially favouring those with greater relevance to the study's focus. Similarly, the research projects exclusively targeted patients with curable cancer diseases. No statements can be made about the psychosocial situation of the relatives of AYA cancer patients.

2.7 Closing summary

The diverse insight into the life situation of young adults with cancer can be summarized as follows. Approximately every second participant reported clinically increased anxiety at both time points, indicating a significant need for support. Critical life areas affected were the financial and occupational situation, as well as family planning and sexuality. The results suggest that about a third of AYA cancer survivors experienced sexual dissatisfaction. The occurrence of cancer in young adults often leads to substantive and/or temporal changes in their occupational situation. Most AYAs returned to work, often by reducing weekly working hours, but achieving maximum work ability posed a major challenge for AYAs. Cognitive impairments occurred in approximately every fifth patient in both surveys. A substantial proportion of AYA cancer survivors reported financial concerns. There was an unmet need regarding psychological issues and the healthcare system. AYA cancer patients who were aware of psychosocial services in aftercare were motivated to use them and expressed high satisfaction with their use. The perceived adjustment to chronic illness is a significant factor influencing mental health, life satisfaction, work ability and unmet supportive care needs. For cancer-related fatigue, influences were identified in all three examined dimensions (physical, emotional, cognitive): female gender, additional diseases, and financial problems. The study results demonstrate that the newly developed multidimensional instrument has good psychometric properties and can be used as a comprehensive measure of cancer-related fatigue in the AYA patient population. Concerning health behaviour, AYA cancer patients exhibited a predominantly health-conscious lifestyle, with no temporal changes observed, except for participation in regular health screenings. Social support emerged as the most decisive factor associated with life satisfaction at both time points and also for anxiety and depression. The difference in negative perceptions of social support in young vs. older adult cancer patients emphasizes the necessity of differentiating between positive and negative social support in the AYA patient group. In the qualitative investigation, participants considered social exchanges with other young adult cancer patients as an important source of support.

The demonstrated burdens across various life domains of AYA patients emphasize the necessity of implementing integrated psycho-oncological care for this patient population.

3 Conclusions and Implications

3.1 The need for psycho-oncological care for the AYA cancer population

In both our AYA studies and recent international AYA literature, there is consistent advocacy for specific and adequate psychosocial care tailored to the young adult cancer patient population. In their recent practical guidelines for Adolescent and Young Adult Oncology, Bhatia and colleagues emphasize the need for age-appropriate and personalized supportive care for AYA cancer patients. They succinctly encapsulate that AYA cancer patients constitute a distinct population deserving tailored interventions (Bhatia et al. 2023). This extends beyond minimizing the medical long-term consequences of cancer and its treatment, as well as the risk of relapse and secondary malignancies, aiming also to alleviate psychological and social long-term effects. The likelihood of psychological distress or a psychiatric disorder is significantly elevated for young adults with cancer compared to older cancer patients and healthy individuals, as evidenced by two recent reviews (De et al. 2020; Osmani et al. 2023). Forbes and colleagues, in their review, highlight fatigue as a substantial concern within the AYA cancer group, often remaining undetected and underreported (Forbes et al. 2023).

In the recent German S3 guideline "Psycho-oncological Diagnosis, Counselling, and Treatment of Adult Cancer Patients," AYA cancer patients are identified as one of eight specific patient groups with particular challenges, along with the group of long-term survivors. This is especially relevant for young adults who must live with a cancer diagnosis in their life history for several decades. The guideline specifies autonomy loss, altered social relationships, career interruptions, financial problems, fertility, sexual impairments, genetic predisposition, as well as prolonged anxiety and depression as problem areas for the AYA cancer population. The promotion of social integration or participation in all aspects of life is considered crucial for the well-being of AYA cancer survivors (AWMF 2023).

Murphy and colleagues identified a total of 93 studies on psychosocial intervention trials for AYA cancer patients in their review from 2007 to 2021. Only one study originating from Germany focused on improving gait in young people with tumour endoprostheses of the lower extremity. They emphasize the necessity for enhanced evaluation using standardized quality of life measurement instruments for psychosocial AYA interventions (Murphy et al. 2023). In a meta-analysis of available psychosocial interventions for paediatric, adolescent, and young cancer survivors, Zhang and colleagues (2021) reported significantly greater effects of the existing supportive care for paediatric cancer survivors compared to their AYA counterparts. The authors observe that despite recent international attention to the survivorship needs of AYA cancer survivors, psychosocial interventions remain insufficient for this population. This underscores the need for ongoing clinical and research efforts to enhance survivorship care programs for the AYA cancer population (Zhang et al. 2021).

3.2 Proposal for psycho-oncological care program for the German AYA cancer population

Building upon insights gained from AYA research findings, international research findings, and existing national health and care structures, an attempt is made to delineate a systemic multimodal psycho-oncological care approach for the AYA cancer patient population in Germany. Initially, the challenges and aims of AYA-specific psycho-oncological care are addressed, followed by a description of an AYA psycho-oncological care program.

Challenges in psycho-oncological care for AYA

In comparison to the typically much older cancer patients, several challenges highlight the complexity of the demanded and necessary psycho-oncological care for the AYA cancer population. The challenges mentioned in Table 13 require, on the one hand, a broad knowledge of the professionals and, on the other hand, a high degree of flexibility regarding the structural framework and the therapeutic setting. A systemic approach involving close relatives and multimodal therapeutic treatment approaches are recommended.

Table 13: Challenges in the field of AYA psycho-oncological care

Diversity	· diverse life situations possible – students as well as working mothers
Multiple life areas	· diverse problem issues simultaneously – fertility as well as finances
Change of residence	· frequent change of residence – complicates ongoing follow-up care
Relatives	· relatives are shown parents and often underage children
Number of cases	· low case numbers at a location or oncology centre
Information	· increased information needs with simultaneous online affinity
Follow-up phase	· longer duration of the follow-up care – “lifelong aftercare“

Objectives of psycho-oncological care for AYA

The overarching aim is to ensure continuous psychosocial care, with the same professionals as much as possible, as an integral part of healthcare for young adults with cancer. Given that a cancer diagnosis during young adulthood inherently constitutes an additional risk factor for psychosocial issues, the program should be made available to every AYA cancer patient. The psychosocial care for AYA cancer patients also extends to their immediate relatives.

In Table 14, the aims for psycho-oncological treatment during acute oncological treatment are outlined. These aims may vary medically and temporally. Additionally, the aims for cancer aftercare, following the successful completion of acute oncological treatment, are presented. The program's emphasis is on AYA cancer patients with curable diseases, as interventions have different objectives in a palliative setting.

Table 14: Objectives of psycho-oncological care for AYA

Aims in acute treatment	Aims in cancer aftercare
• Emotional stabilization (acceptance of the diagnosis, coping with the new life situation, promoting hope)	• Support with illness processing – encouragement of personal growth
• Maintenance of existing resources – physical, psychological, and social	• Prevention of psychological burden or disorders, particularly fear of recurrence
• Support with all emerging psychological issues (e.g., fertility, changes in social relationships, fears)	• Assistance with professional and social reintegration or potential reorientations
• Assistance with all social legal matters (e.g., sick pay, rehabilitation)	• Support in building or maintaining a health-promoting lifestyle
• Navigational function - mediation and coordination of the support system	• Navigational function - coordination of the support system

Description of the proposed integrated psycho-oncological care program for AYA

To achieve the aforementioned aims of psycho-oncological care for the German AYA cancer population, the implementation of a systemic multimodal intervention concept is necessary. The proposed care program is designed for newly diagnosed AYA patients with cancer and their relatives, who must undergo at least three months of oncological treatment. Figure 6 summarises the integrated psychosocial care program. Ideally, the AYA care program, with its specific emotional and social objectives, will be offered by the lead oncologist, acknowledging that a cancer diagnosis brings psychosocial burdens, for which treatment options in psycho-oncology exist.

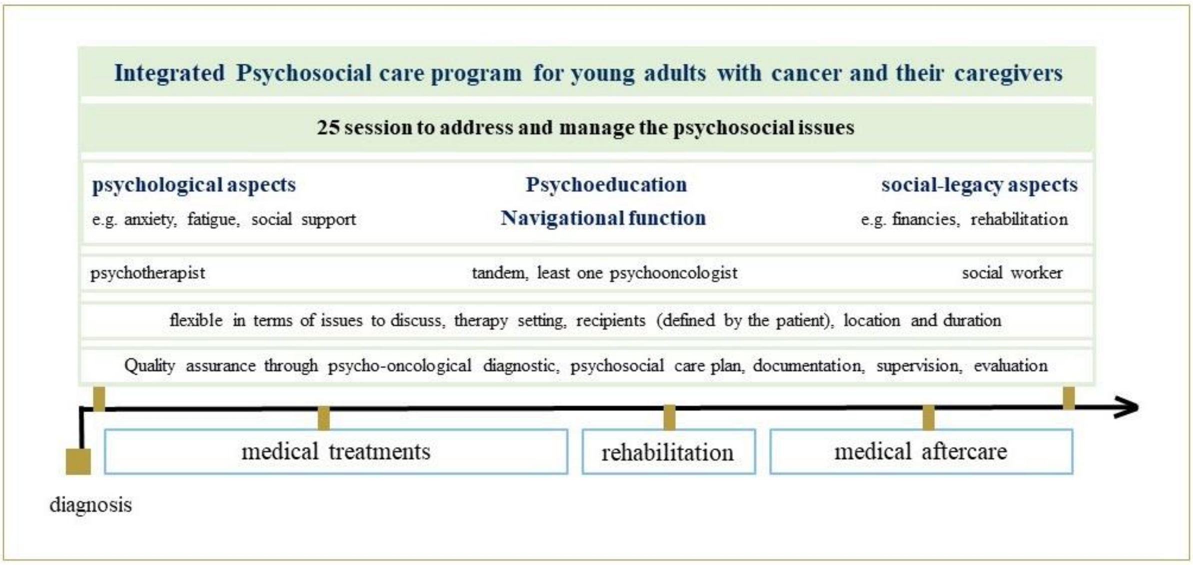

Figure 6: Psycho-oncological care program for the AYA cancer population

The AYA psycho-oncological care program should be established as early as possible. It is anticipated that shortly after receiving the cancer diagnosis, patients themselves may not yet express or specify aims related to the psychosocial domain. At this stage, both patients and their relatives are in an emotional state of shock, and they may not yet foresee the changes in various aspects of their lives resulting from the cancer disease or its medical treatment, and where they will require psychosocial support. The primary objective is complete tumour remission. Therefore, emotional stabilization and providing continual support, alongside a coordinating function, are initially the central tasks of the program. By adapting to their new life situation and building a trusting relationship with psychosocial helpers, it becomes possible to establish aims for psychosocial issues together. Hence, it is crucial to establish an AYA psycho-oncological care program that is flexible concerning setting, duration, location, and recipients, similar to the home-based family therapy offered in German child and youth services. The psycho-oncological baseline assessment includes evaluating current psychological distress, life satisfaction, unmet supportive care needs, and the subjective perception of illness processing of the AYA cancer patients and the involved relatives (decided by the AYA patient). This assessment must be conducted initially before the completion of the fifth session, repeated after 12 sessions, and again at the end of the program (25 sessions). The assessment serves both as an evaluation tool and as a means to adjust psychosocial care. Premature termination or extension of the care program is possible in principle. The decision depends on whether this form of psychosocial care appears suitable for achieving the individual aims of the AYA patient and their relatives. The AYA psycho-oncological program is conducted in tandem by two professionals with expertise as psycho-oncologists. Expertise in psychology and social law is required. Additional qualifications of the helpers, such as expertise in relaxation techniques or support for children and adolescents, are desirable. The initial session occurs with both helpers present; afterwards, depending on the predominant issues, a determination is made regarding which helper will lead the sessions, or if both will be present. Furthermore, other stakeholders, such as sports therapists, self-support groups, creative therapists, and nutrition therapists, can be integrated into the AYA care program if deemed beneficial by the helpers, AYA patients, or their relatives. The quality characteristics are shown in Table 15.

Table 15: Quality characteristics of the AYA psycho-oncological care program

Assessment	· psycho-oncological diagnosis to establish treatment goals
Qualification	· a psychologist and a social worker; at least one psycho-oncologist
Setting*	· flexible: face to face; online; individual, family; Co-therapy possible
Duration*	· flexible: maximum 25 sessions a 90min (at least 25 weeks to 52 weeks)
Location*	· flexible: clinic, therapy room, outreach, online
Recipients*	· flexible: AYA cancer patients and their relatives (defined by the patient)
Navigation	· involvement of other necessary stakeholders such as peers, sports therapists
Quality assurance	· psychosocial care plan; documentation, supervision, evaluation

*in joint agreement

Essential steps for implementation of the AYA psycho-oncological care program

The next crucial step is to scientifically evaluate the proposed AYA psycho-oncological care program for its clinical feasibility and effectiveness. Within a pilot study in close collaboration with an oncology centre, based on qualitative and quantitative methods, the practical implementation will be tested initially, methodological questions such as the choice of outcome variables will be clarified, and a meaningful cost-benefit analysis will be discussed. The working title is “A pilot study on the effectiveness of an integrated psychosocial care program for young adults with cancer and their caregivers“. If the pilot study demonstrates success, it will be imperative to conduct a randomized controlled study that meets evidence-based criteria and includes appropriate follow-up time points. Funding possibilities for this health services research include governmental institutions (e.g., Federal Ministry of Education and Research, German Research Foundation) as well as foundations, health or insurance companies, and child and youth services. The goal is to establish a quality-assured psycho-oncological standard care for the AYA cancer population in both the acute treatment and follow-up phases.

3.3 Future psycho-oncological research for the AYA cancer population

Defining future research tasks more precisely, it is time to summarize the existing findings regarding the psychosocial life situation of the young adult cancer population in an umbrella review.

A future task of epidemiological research remains to further focus on long-term AYA cancer survivors (> 10 years) and their trajectory across the lifespan regarding specific psychosocial issues such as fertility and family planning, sexuality, occupational and financial situation, fatigue, as well as mental health, and to compare them to young adults without a history of cancer. This also includes studies addressing the AYA patient group with advanced cancer or palliative situations. Personal growth and resilience factors in the AYA cancer population should be examined to promote one’s own resources for psychosocial health early on. The psychosocial burdens of family members/relatives of the AYA cancer population should be more closely investigated. It is well known that relatives of cancer patients experience a significant burden. It can be assumed that this is even more pronounced for the loved ones of AYA cancer patients, as a life-threatening disease at such a young age is considered non-normative. Involving and strengthening the social network of the AYA cancer patient from the beginning is essential to reduce the psychosocial consequences of cancer and to appropriately process and integrate them into their own lives.

Every AYA cancer patient and their relatives have the right to psycho-oncological care tailored to their needs, enabling them to process their experiences with cancer and integrate them positively into their own life course. For healthcare research, the evaluation of AYA survivorship interventions and programs including peer-mentoring-programs is crucial to achieve the aim of consistent and widespread psycho-oncological care for AYA cancer survivors and their relatives.

4 Summary

Approximately 3% of the nearly half a million new cancer cases diagnosed each year in Germany occur in young adults aged 15 to 39. A cancer diagnosis during young adulthood presents existential and emotional challenges, disrupting the typical developmental tasks of this life phase. Young adulthood is characterized by developmental tasks such as emancipation, career training, partner selection, and desires for parenthood. Specific cancers, such as melanoma, breast and gynaecological tumours, lymphomas, testicular cancer, leukaemia, and thyroid carcinomas, are more prevalent in this age group. Despite high survival rates exceeding 80%, young adults often receive more intensive oncological treatments, leading to acute and long-term physical, psychological, and social side effects. Coping with illness, invasive treatments, and potential long-term consequences requires a re-evaluation and adaptation of life visions. Understanding the psychosocial life situation of young adults with cancer is crucial for establishing effective psycho-oncological care.

For this purpose, three research projects were initiated, aiming to examine the psychosocial life and psycho-oncological care situation of the German young patient population. The study aimed to provide a detailed and differentiated insight into different life domains of AYA patients, describe risk groups, and develop recommendations for their psycho-oncological care and age-specific survivorship programs. The longitudinal study comprised six survey time points, during which young adults with cancer were longitudinally surveyed on aspects such as life satisfaction, mental health, and fatigue. Cross-sectional assessments covered factors such as occupational situation, health behaviour, and psychosocial care. Inclusion criteria for participation included age at diagnosis (18–39 years), first manifestation of cancer (all malignant tumour identities), diagnosis within the last four years, and completion of acute medical cancer treatment. In the initial survey, a total of 577 AYA cancer patients participated. This cumulative habilitation thesis summarizes the findings of the 17 published research papers to date. Approximately every second participant reported clinically increased anxiety at both time points, highlighting a significant need for support. Critically affected life areas included financial and occupational situations, as well as family planning and sexuality. Results suggest that about a third of AYA cancer survivors experienced sexual dissatisfaction. The occurrence of cancer in young adults often results in substantive and/or temporal changes in their occupational situation. While most AYAs returned to work in the medium term, achieving maximum work ability posed a major challenge. A substantial proportion of AYA cancer survivors reported financial concerns. There was an unmet need regarding psychological issues and the healthcare system. AYA cancer patients who were aware of psychosocial services in aftercare were motivated to use them and expressed high satisfaction. Perceived adjustment to chronic illness emerged as a significant factor influencing mental health, life satisfaction, work ability, and unmet supportive care needs. The influencing factors for the commonly existing cancer-related fatigue were identified as female gender, additional diseases, and financial problems. Social support emerged as the most decisive factor associated with life satisfaction at both time points and also for anxiety and depression. The difference in negative perceptions of social support in young vs. older adult cancer patients emphasizes the necessity of differentiating between positive and negative social support in the AYA patient group. In qualitative investigations, participants considered social exchanges with other young adult cancer patients as an important source of support. The identified challenges experienced by AYA patients across different aspects of life strongly support the necessity of introducing mandatory psycho-oncological care for this patient group.

In both our AYA research projects and papers and recent international AYA literature, there is consistent advocacy for specific and adequate psychosocial care tailored to the young adult cancer patient population. A systemic multimodal psycho-oncological care approach for the AYA cancer patient population in Germany is proposed here. During acute oncological treatment, which can vary medically and thus temporally, psycho-oncological care for AYA cancer patients and their relatives has the following aims: emotional stabilization (acceptance of the diagnosis, coping with the new life situation, promoting hope); maintenance of existing resources - physical, psychological, and social; support with all emerging psychological issues (e.g., fertility, changes in social relationships, fears); assistance with all social legal matters (e.g., sick pay, rehabilitation, domestic help); and navigational function - mediation and coordination of the support system. With the completion and success of oncological treatment, and thus the transition to cancer aftercare, psycho-oncological care for AYA cancer survivors and their relatives serves the following tasks: support with illness processing - encouragement of personal growth; prevention of psychological burden or disorders, particularly fear of recurrence; assistance with occupational and social reintegration or potential reorientations; support in building or maintaining a health-promoting lifestyle; and navigational function - coordination of the support system.

The proposed AYA care program is designed for newly diagnosed AYA patients with cancer and their relatives, who must undergo at least three months of oncological treatment. The quality criteria are assessment; qualification; navigation, flexible setting, duration, location, and recipients; and quality assurance. The AYA psycho-oncological care program should be established as early as possible. Emotional stabilization and providing continual support, alongside a coordinating function, are initially the central tasks of the program. By adapting to their new life situation and building a trusting relationship with psychosocial helpers, it becomes possible to establish aims for psychosocial issues together. Hence, it is crucial to establish an AYA psycho-oncological care program that is flexible concerning setting, duration, location, and recipients. The AYA psycho-oncological program is conducted in tandem by two professionals, with expertise in both psychology and social law being necessary.

Each AYA cancer patient and their relatives deserve psycho-oncological care tailored to their specific needs. This personalized approach empowers them to effectively navigate their cancer experiences and integrate them positively into their life journey. In healthcare research, it is crucial to evaluate AYA survivorship interventions and programs. Such evaluations are essential for achieving the goal of comprehensive and widespread psycho-oncological care for AYA cancer survivors and their families.

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6 Attachments

Declaration of independence

"I hereby declare that I independently conducted the habilitation thesis submitted to the Medical Faculty with the title '*Psycho-oncology in young adults with cancer – Current evidence ans future challenges*' on the Department of Psychosomatic Medicine and Psychotherapy without any additional assistance and no resources other than those listed below were used. In preparing the cumulative habilitation thesis, no rights of third parties have been violated. I have not submitted the habilitation thesis to any other university, either domestic or foreign, for habilitation. I grant the Medical Faculty of Otto-von-Guericke-University the right to reproduce and distribute further copies of my habilitation thesis."

Date Signature Dr. Geue

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Original publications of the habilitation thesis

- Braun I, Friedrich M, Morgenstern L, Sender A, **Geue K**, Mehnert-Theuerkauf A, Leuteritz K. Changes, challenges and support in work, education and finances of adolescent and young adult (AYA) cancer survivors: A qualitative study. European Journal of Oncology Nursing 2023, 64: 102329, doi: 10.1016/j.ejon.2023.102329.

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