

Mapping the needs and psychological outcomes of Slovenian adolescent and young adult cancer patients: An exploratory mixed-method study

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Abstract

Objective: With improving survival rates, it is becoming increasingly important to understand the psychological aspect and needs of young cancer patients and survivors. Our goal was to describe the self-reported levels of psychological distress, subjective illness experience and needs of young Slovenian cancer patients and survivors.

Methods: Seventy-nine participants, aged 19–39 years, answered questionnaires about anxiety, depression, mental defeat, cancer worry and their experience of learning the diagnosis and being treated. We used visualisations to demonstrate the relationship between anxiety and depression. The qualitative responses were summarised using a content analysis approach.

Results: Twenty-eight (35%) participants scored in the clinical range for anxiety and fifteen (19%) for depression. Cancer-related worry was common (85% reported at least one worry). Mental defeat was positively associated with measures of psychological distress. Those who felt negative about learning their diagnosis emphasised the need for more time, empathy and dignity. Psychological support during illness was seen as crucial.

Conclusion: Anxiety and depression remain a problem for a subset of patients. Medical professionals working with young people with cancer should encourage a warm atmosphere as they attend to patients' needs and concerns.

KEYWORDS

adolescent cancer, anxiety, depression, needs, psychosocial, young adult cancer

1 | INTRODUCTION

Despite the continuous and rapid progress in the development of novel therapeutic approaches in oncology, which result in ever-increasing survival rates, there remain large discrepancies in outcomes between countries across Europe (Allemani et al., 2018). As the number of cancer survivors increases, so does the need to

attend to the patients' needs beyond treatment. A particularly vulnerable group of patients are adolescent and young adults (AYA), who have traditionally been overlooked, either placed together with children, or much older adults based on arbitrary age cut-offs, which vary between regions (Kosir, 2019). It has now been well established that the needs of AYA patients are different and unique to this age group (Barnett et al., 2016; Kosir, Wiedemann,

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Wild, & Bowes, 2019b; Sansom-Daly & Wakefield, 2013), and many efforts, as well as cross-border initiatives, are promoted in hopes to empower young patients and shift the public and medical opinion, and even policy in order to adapt a more developmentally sensitive approach to care (Aldiss, Fern, Phillips, & Gibson, 2018; Buchacz et al., 2018).

Both Youth Cancer Europe (YCE), a leading pan-European organisation for AYA patients, as well as UK's James Lind Alliance, emphasised the need for novel and tailored approaches to psychosocial care of young patients who face the diagnosis of cancer (Aldiss et al., 2018; Buchacz et al., 2018). Although psychological distress and anxiety are normal responses to life-threatening illness, many young patients continue to experience symptoms of distress upon reaching remission (Barnett et al., 2016; Kosir et al., 2019b; Sansom-Daly & Wakefield, 2013). The causes of such distress may be many and multifaceted; illness may impact cognitive processing and illness threat perceptions (Rooij et al., 2018; Fardell et al., 2016), cancer treatment may directly interfere with the endocrinological system (Jensen et al., 2018), illness can significantly derail achievement of normative milestones and disrupt education or an early career (Parsons et al., 2012; Vetsch et al., 2018), and it can compromise family planning (Benedict, Shuk, & Ford, 2016; Levine, Canada, & Stern, 2010) and cause a life-long disability (Barr, Ferrari, Ries, Whelan, & Bleyer, 2016) or significant financial strain (Parsons & Kumar, 2019).

Attending to the psychological needs of young patients and survivors is of vital importance as poorer psychosocial functioning can lead to missed medical appointments at outpatient clinics, and poorer quality of life (Klassen et al., 2015), which can in turn compromise the long-term outcomes. As poor mental health remains the leading cause of disability among young people (Gore et al., 2011), identifying the factors that contribute to psychological distress in young cancer patients and survivors will not only reduce the burden on individuals and their families, but also reduce the burden posed on national health services.

Cancer is not a single illness and it does not only attack cells, but rather attack the entire person and their environment. The approach to treatment and care inevitably depends on the cultural context, as well as on the healthcare system. Because survivorship is a complex construct, encompassing bio-psychosocial needs, developing novel psychosocial approaches must take into account one's environment and culture. A more thorough understanding of young Slovenian patients' needs is crucial for continued progress to improve outcomes on a national level, and it can highlight important factors that contribute to positive outcomes in AYAs, as well as areas of need that might have been overlooked abroad.

This study was guided by three main objectives: (a) to describe the self-reported levels of psychological distress among Slovenian AYAs and compare it to an international sample of AYAs, (b) to describe the experience of young Slovenian patients from diagnosis through remission and (c) to highlight areas on which nationally based strategies for improvement in holistic care could be based.

2 | METHOD

This study is based on baseline data from an ongoing longitudinal study exploring the predictors of psychological well-being and holistic recovery in AYA cancer patients. The study protocol has been registered and can be accessed at the following link: <https://osf.io/d4e59/>. This study has been approved by the Medical Sciences Inter-Divisional Research Ethics Committee at the University of Oxford (R61437/RE002).

Data were collected using Qualtrics, via an anonymous survey link distributed on social media and online through patient advocacy mailing lists. The survey has 2 equal arms, one that is fully translated into Slovenian, and the other, open to anyone who is able to complete the questionnaires in English. Participants are self-identified AYA cancer patients or survivors diagnosed with any form of malignant cancer. Prior to the study, everyone is provided study information outlining the aims and objectives of this research. To incentivise retention in research participation, individuals can opt-in to the draw for gift cards with value up to \$150.

In the current study, we included all Slovenian participants who completed at least 80% of the baseline questionnaires and were between 15 and 39 years of age at the time of their first diagnosis.

2.1 | Measures

2.1.1 | Demographic and medical information

Participants reported their age, gender, relationship status and level of education. They also reported information about their cancer and treatment type, age at diagnosis and time since treatment completion.

2.1.2 | Stressful and traumatic life events

In order to understand to what extent participants perceived their illness to be stressful or traumatic compared with other life events, they were asked to briefly describe up to 5 most stressful or traumatic life events and rank them in descending order.

2.1.3 | Patient Health Questionnaire (PHQ-9)

The PHQ-9 is a 9-item measure of depressive symptoms. Items are scored on a 4-point Likert scale from 0 (not at all) to 3 (nearly every day). A threshold score of 10 has been proposed to indicate the presence of clinical level of depressive symptoms (Kroenke, Spitzer, & Williams, 2001). The Cronbach alpha for the Slovenian version of the questionnaire was .87.

2.1.4 | Generalized Anxiety Disorder (GAD-7)

The GAD-7 is a 7-item measure of anxiety symptoms (Spitzer, Kroenke, Williams, & Löwe, 2006). Items are scored on a 4-point Likert scale from 0 (not at all) to 3 (nearly every day). A sum score of 7 or above can indicate the presence of clinical anxiety (Plummer, Manea, Trepel, & McMillan, 2016). The Cronbach alpha for the Slovenian version of the questionnaire was .89.

2.1.5 | Mental Defeat Questionnaire (MDQ)

The MDQ is an 11-item questionnaire, which asks about individuals' perceptions of their mental state during a traumatic event (in this case, cancer illness; Dunmore, Clark, & Ehlers, 2001). Agreement with statements such as *I lost any will power, I gave up and I felt like an object* is rated on a 5-point Likert scale from 1 (not at all) to 5 (very strongly). Higher total scores indicate greater presence of mental defeat during illness. The Cronbach alpha for the Slovenian version of the questionnaire was .91.

2.1.6 | Cancer-Related Worry

This 6-item Cancer-Related Worry scale asks about the degree respondents agree with different worries related to cancer (e.g. relapse, fertility) on a 4-point Likert scale ranging from "strongly disagree" to "strongly agree." The scale has been developed and validated in a sample of Canadian AYA survivors (Klassen et al., 2015). Only participants who were off-treatment completed this questionnaire. The Cronbach alpha for the Slovenian version of the questionnaire was .75.

2.2 | Patients' needs and experience

Individual patient's experience was captured with 5 questions. A sliding scale from 0 to 100, where higher values represent better or more positive answers, was used to (a) report participants' satisfaction with the way they received the diagnosis, (b) assess participants' relationship with the medical team and (c) describe the extent to which their needs as patients were met. The quantitative responses were supplemented with 2 open-ended questions that asked participants to briefly describe their experience with learning the diagnosis and to describe what worked well during treatment, or else, what could have been improved. These answers yielded qualitative data.

2.3 | Analysis

We carried out exploratory analysis to visualise the relationship between anxiety and depression, and to compare scores of Slovenian

participants to participants from abroad. Where relevant, we reported Spearman's correlation coefficients. All analyses, data manipulations and data visualisations were carried out using R Version 3.4.3 (Team, 2020).

Qualitative data were analysed using content analysis approach (Krippendorff, 2018), suitable for a mixed-method approach to describing phenomena in psychosocial science (Elo et al., 2014). Two researchers (UK and SR) independently read and coded all of the responses. The coding followed both a deductive approach by devising categories based on the research and survey questions, and an inductive approach by complementing the list with additional categories stemming from the data. The researchers compared ratings of positive versus negative experience in diagnosis and generated a list of categories describing such experience. The original categories were refined through discussion between the researchers upon which all the qualitative responses were mapped. The inter-rater agreement for this procedure was 94%, and any discrepancies were resolved in a consensus meeting.

3 | RESULTS

3.1 | Participants

Participants' characteristics are presented in Table 1. Slovenian participants were significantly older ($M = 33.7$, $SD = 7.2$) than English-speaking responders ($M = 29.3$, $SD = 5.75$). Twenty-nine (37%) of Slovenian responders were in treatment at the time of the study, and the rest completed treatment on average 5.4 years earlier.

3.2 | Psychological well-being

Participants completed questionnaires about depression, anxiety, mental defeat, cancer worry, and stressful and traumatic life events. Scores of depression and anxiety are visually represented in Figure 1 and plotted against data from the English arm of the same study. A similar proportion of Slovenian and other patients were in treatment at the time of the study (see Table 1). Higher scores in depressive symptoms were correlated with higher scores in anxiety in both groups (Spearman's rho; $r = .78$, $p < .001$). As a group, Slovenian participants reported lower scores of psychological distress and were older on average (see Table 1). Table 2 shows average scores on the self-reported measures for the Slovenian population. Seventy-six participants reported having stressful or traumatic life events, and among those, 53 (70%) reported cancer to be among the three most stressful or traumatic events in their lifetime. Mental defeat was also positively correlated with anxiety (Spearman's rho; $r = .4$, $p < .001$) and depression (Spearman's rho; $r = .41$, $p < .001$).

TABLE 1 Demographic and medical information of participants

Variable	Slovenian N, % M (SD) [range]	Other N, % M (SD) [range]	Test statistic (p)
Age	79, 100% 33.66 (7.2) [19–39]	80, 100% 29.34 (5.75) [18–39]	<.001 ^{*,a} (4.98e-05)
Age at diagnosis	79, 100% 28.73 (7.18) [15–39]	80, 100% 25.07 (6.5) [15–38]	<.01 ^{*,a} .001112
In treatment			
Yes	29 (37%)	28 (35%)	$p = .95^{**}$
No	50 (63%)	52 (65%)	
Months since treatment	78, 98.7% 41.06 (63.62) [0–281]	80, 100% 27.19 (44.18) [0–179]	$p = .48^{*,a}$
Gender			
Female	73 (92%)	67 (84%)	$p = .17^{***}$
Male	6 (8%)	12 (15%)	
Prefer not to answer		1 (1%)	
Relationship			
Single	18 (23%)	30 (38%)	$p = .08^{***}$
Romantic	20 (35%)	21(26%)	
Married/cohabit	39 (49%)	25 (31%)	
Divorced/separated	2 (3%)	4 (5%)	
Children			
Yes	38 (48%)	16 (20%)	<.001 ^{*,a} .0003521
No	41 (52%)	64 (80%)	
Type of cancer			
Breast	40 (51%)	9 (11%)	<.001 ^{*,a} (2.40e-09)
Haematologic	23 (29%)	25 (31%)	
Testicular	3 (4%)	1 (1%)	
Yolk sac	3 (4)	3 (4%)	
Other ^a	10 (13%)	42 (53%)	
Type of treatment			
Chemotherapy	7 (9%)	14 (18%)	$p = .09^{***}$
Chemotherapy and radiation therapy	6 (8%)	4 (5%)	
Chemotherapy and surgery	10 (13%)	13 (16%)	
Chemotherapy, radiation therapy and surgery	17 (22%)	14 (18%)	
Radiation therapy and surgery	1 (1%)	8 (10%)	
Surgery	4 (5%)	3 (4%)	
Other	34 (43%)	24 (30%)	

^aOther cancer types: Slovenian participants: multiple cancer diagnosis ($n = 2$), brain tumour ($n = 2$), thyroid ($n = 2$), uterine ($n = 2$), sarcoma ($n = 1$) and head and neck ($n = 1$); other participants: multiple cancer diagnosis ($n = 2$), brain tumour ($n = 8$), thyroid ($n = 4$), colon ($n = 3$), cervical ($n = 2$), sarcoma ($n = 15$), head and neck ($n = 2$), appendix ($n = 1$), rectal ($n = 1$), melanoma ($n = 1$) and myeloma ($n = 1$).

*Mann-Whitney test.

**Chi-square test of independence.

***Fisher's exact test.

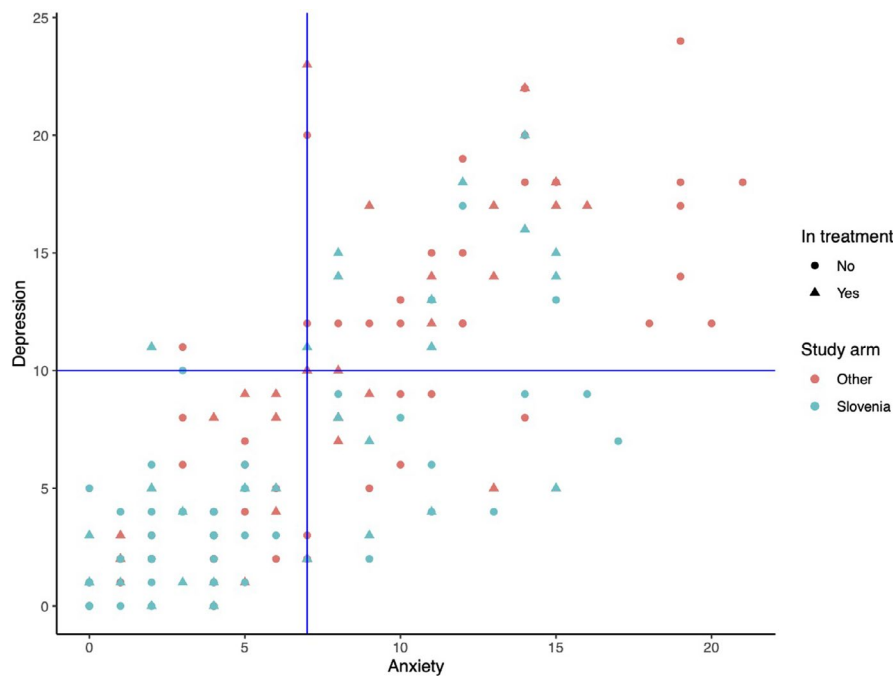


FIGURE 1 Scatter plot showing the relationship between anxiety and depression in Slovenia and abroad. Different colours represent different regions, while different shapes represent patients who were in- or off-treatment at the time of the study. The blue lines on the graph represent the clinical cut-off levels for anxiety and depression respectively. Participants labelled as Other were young patients and survivors who were able to respond in English. Most participants were from the UK, Sweden, Canada, the USA and Netherlands. Several other European nationals participated. Twenty-eight (35%) and 15 (19%) Slovenian participants scored in the clinical range for anxiety and depression respectively. Of the former, 16 were in treatment, while 11 of those who scored in the clinical range for depression were in treatment at the time of the study

TABLE 2 Mean scores on measures of psychological distress

	N, mean (SD) [range]
Anxiety	79, 5.7 (4.86) [0–17]
Depression	78, 5.27 (5.0) [0–20]
Mental defeat	76, 7.22 (7.69) [0–37]
Cancer worry ^a	47, 7.64 (3.7) [0–16]
	N (%)
Cancer as trauma	
Yes	53 (69.7)
No	23 (30.3)
Satisfaction with receiving diagnosis	76, 63.71 (37.34) [0–100]
Relationship with the medical team	76, 88.39 (18.99) [0–100]
Extent of needs met	76, 80.18 (22.36) [5–100]

^aCancer worry questionnaire was only administered to participants who completed their treatment in order to reduce bias and inflating worry. Questions ask whether a person thinks about cancer every day, which might be normal in the acute phase of cancer treatment.

3.3 | Experience

3.3.1 | Learning the diagnosis

Seventy-seven (97%) participants responded to an open-ended question about the way they learned their diagnosis. Three response

groups emerged; the majority (55%) reported the experience to be positive, some were ambivalent (6%), and many (39%) reported a negative experience.

The five most commonly reported factors endorsed by those with a positive experience in learning their diagnosis were as follows: experiencing a positive, encouraging and supportive atmosphere within the medical team, empathy, professional approach, adequate explanation and information provided, and having a clearly outlined treatment plan.

Ever since I found out about the diagnosis, I was very pleased with the treatment and attitude of the doctors and nurses. My oncologist took the time (over an hour) to explain the course of treatment and answer all of my and my husband's questions.

(Female, 39)

The top five reported factors that contributed to a negative experience in learning the diagnosis were as follows: being rushed or having inadequate time with the medical team, lack of empathy, lack of dignity, minimising or invalidating one's experience with cancer, and being given an overwhelming amount of information at once.

I received my diagnosis on the hallway of the clinic. The hallway was full of people. The doctor called me and told me the result of the puncture. She was with

me for 2 min, then she left. In consolation, she said that I would not die from this cancer.

(Female, 29)

Those who were ambivalent reported that their individual experience was not optimal; one person reported inappropriate use of humour by a medical professional, while another person reported that they did not appreciate that their parents were told before them. Figure 2 demonstrates categories of positive and negative factors in learning the diagnosis.

3.3.2 | Patients' needs

Participants were asked to estimate the extent to which their needs as young patients were met, as well as to provide a short descriptive answer about their experience to support their response. The ratings on the numeric scale were skewed to the left, with the majority reporting that their needs were met to a great extent (see Table 2). The extent of needs being met was positively correlated with the most positive experience at diagnosis (Spearman's ρ ; $r = .45$, $p < .001$), as well as with a better relationship with the medical team (Spearman's ρ ; $r = .73$, $p < .001$; Figure 3).

Sixty-nine participants provided short answers describing their experience, what worked, who offered most support and what could have been done better. Among those who made reference to

support, 18 endorsed their medical team as a great source of support, 14 emphasised the importance of their family, and 10 drew support from their close friends.

Participants provided varying degrees of detail in their answers about what helped them most during their illness. Beyond the already mentioned supportive framework within the medical settings, they described many ways in which they coped. Three most commonly endorsed aspects that most helped patients through their illness were as follows: receiving psychological support, participating in a patient support group (be it online or in person) and feeling heard and listened to, especially among the medical professionals.

The group for young women with breast cancer was the greatest support

(Female, 39)

The summary of other ways of coping to which patients made references is described in Table 3.

The majority of the patients also provided answers about what they thought could have been done better. These could be divided into personal experience and system-wide changes. In the former, the majority reported the need for a structured psychological evaluation and intervention, followed by the need to have more time with their primary oncologist, especially during the first consultation, and a more age-appropriate approach, services and resources.

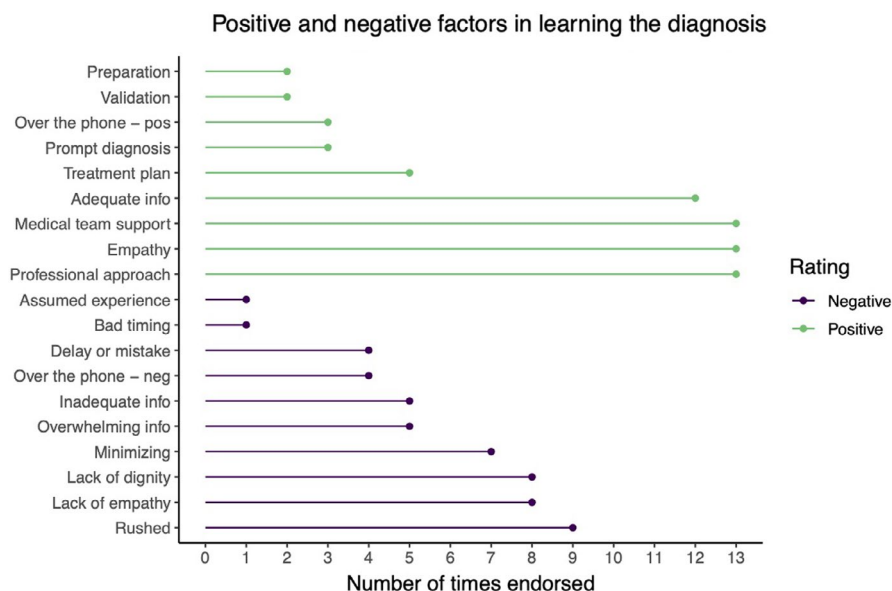


FIGURE 2 Positive and negative factors in learning the diagnosis. The figure demonstrates the number of times a specific factor, either positive or negative, contributing in the overall experience in learning the diagnosis was endorsed in short answers. *Adequate info* = participants report being happy with the amount of relevant information about their disease and treatment; *Treatment Plan* = having a clear plan and steps ahead; *Over the phone – pos/neg* = learning the diagnosis over the phone was positive for some, while negative for others; *Preparation* = feeling prepared for the bad news; *Validation* = validation of emotional distress; *Assumed experience* = because of medical background, medical doctors assumed the patients were well informed about the disease; *Delay or mistake* = lag in diagnosis or misdiagnosis; *Minimizing* = telling patients they have a “good cancer”; and *Rushed* = feeling rushed through the diagnosis

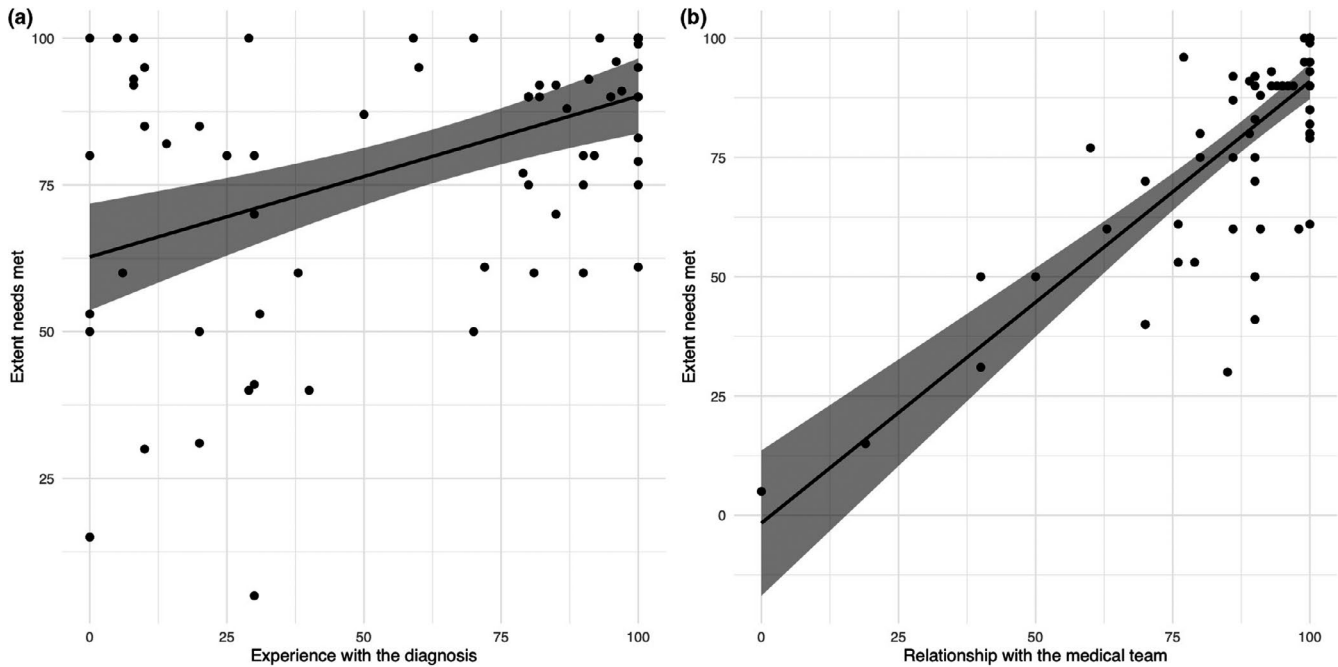


FIGURE 3 Scatter plots showing association between the (a) self-rated experience in learning the diagnosis and (b) relationship with the medical team (higher values indicate more positive experience) and the self-reported extent of patient's needs met (higher value indicates more needs met). The correlations reported are Spearman's rho coefficients, and the grey area around the line represents standard error

TABLE 3 A summary of participants' descriptions of what worked well and what could be improved during the illness experience

What worked well	What could have been done better	
	Individual level	System-wide level
<ul style="list-style-type: none">• Individual psychological support• Patient support groups (face-to-face and online)• Feeling heard and listened to• Adaptive coping mechanisms (positive reframing, optimism, humour)• Leisure activities (i.e. walking in nature)• Physical activities• Learning more about illness, treatment and side effects• Managing side effects• Alternative approaches to care (e.g. acupuncture)• Trust and good relationship with medical team	<ul style="list-style-type: none">• More individual psychological support• More time with one's oncologist• More information about treatment, side effects and symptom management (information about fertility, resources and nutrition was particularly missed)	<ul style="list-style-type: none">• Shorter waiting times• Less lag time to diagnosis• Better and more organised communication between departments and hospitals• Consistency in medical team• Assuring quality care at smaller, non-specialty clinics• Age-appropriate approach• Addressing hidden costs and financial needs• Holistic rehabilitation programmes

There is lack of guidance and tips on how to cope with cancer diagnosis on a psychological level.

(Male, 31)

experienced delays and conflicting results from separate biopsies.

(Female, 36)

Several patients also noted that there was a significant delay in their diagnosis due to long waiting times, and reported frustration with lack of, or poor communication between different departments (see Table 3).

I mostly wish for a better communication between the departments at the clinic. Due to the lack of coordination between surgery and radiology and pathology, I

4 | DISCUSSION

This is the first study to describe the psychological well-being and experience of cancer in a subset of young Slovenian cancer patients. The analyses were guided by three main objectives: to assess the level of psychological distress among Slovenian AYA patients and to compare it to an international sample, to describe the experience of

learning the diagnosis and to provide directions for national service and policy development.

Mental health outcomes and psychological well-being are increasingly considered and evaluated in young cancers patients (Aldiss et al., 2018; Barakat, Galtieri, Szalda, & Schwartz, 2016; Barr et al., 2016; De et al., 2019). Our analysis showed that symptoms of anxiety and depression often co-occurred, a relationship that has been previously observed in cancer populations (McCarthy et al., 2016; Mitchell, Ferguson, Gill, Paul, & Symonds, 2013). Regardless of treatment status (in- or off-treatment), there remains a subset of individuals who score in the clinical range for mood disorders based on the self-report assessment. As a group, young Slovenian patients scored lower on both measures of psychological distress compared with the international sample. However, it is important to note that the international sample was significantly younger, and not matched on demographic or illness characteristics.

Mental defeat, which has been proposed as a potential cognitive mechanism contributing to psychological distress in a pilot phase of this study (Kosir, Wiedemann, Wild, & Bowes, 2019a), shows strong association with both anxiety and depression; however, due to the cross-sectional nature we did not assess the causal mechanisms.

As previously reported (Kosir et al., 2019a; Wang et al., 2015), cancer-related worries remain highly prevalent among the AYAs, with 85% worrying about at least one aspect of their cancer illness. Interestingly, even though worry has been identified as a predictor of anxiety and even depression (Muris, Roelofs, Rassin, Franken, & Mayer, 2005; Segerstrom, Tsao, Alden, & Craske, 2000), the association between cancer-related worry and symptoms of anxiety and depression in our study remains weak. Such symptoms may be exacerbated by having a cancer diagnosis rather than the outcome of a diagnosis. Future research will need to tease apart the relationship between cancer worry and symptoms of anxiety and depression in AYAs.

The majority of young cancer patients have little experience in navigating medical systems yet have distinct preferences for their cancer care (Pannier et al., 2019). The idea that the initial experience can have an impact on the way one interacts with the medical team and can influence the rest of the experience is not far-fetched. Our results reveal that those reporting a more positive experience at diagnosis also reported having their needs met, as well as a better relationship with their medical team. A better relationship with the medical team was also associated with individuals' reports of having their needs met. This may be because the initial experience leads to patients' being more comfortable in voicing their concerns and needs, and results in a better, more patient-centred approach to care. Moreover, a better relationship with the medical team from an early stage may lessen the lag to cancer diagnosis, which has been observed previously and partly attributed to failure in recognising symptoms or signs of the disease (Barr, 2014; Barr et al., 2016). Longer waiting times to receiving the diagnosis can result in an increased uncertainty and frustration among young patients.

Despite the fact that in Slovenia it is not recommended to disclose a diagnosis to a patient over the phone, such has been the case for seven participants. Interestingly, receiving the diagnosis via a

telephone call has been considered both a positive experience and a negative experience. The former was the case, when the patients requested to learn the diagnosis in what they referred to as a more convenient way which also saved time otherwise lost to commuting to a follow-up appointment. Hearing the diagnosis over the phone was negative in cases when patients were not expecting to receive any call and would have preferred being told in person. This example illustrates the importance of individual differences and points at an important aspect to be discussed earlier in the initial phases when cancer is first suspected.

Because cancer impacts multiple domains in one's life, particularly at a younger age (e.g. school or vocational disruption, family planning) understanding the overall experience and what helps patients to cope best and what could be improved carries important implications for the development of age-appropriate services from the time of diagnosis through to the surveillance phase. A recent report by All.Can (All.Can, 2019), an international multi-stakeholder initiative to optimise policy in cancer care, which surveyed almost 4,000 adult patients from 10 countries across Europe (Slovenia was not included), described four main areas to be targeted for improvement of efficiency in cancer care. These were as follows: (a) swifter diagnosis (including more empathy), (b) more information and the need for shared decision-making, (c) better coordinated approach and the need for integrated and multidisciplinary care, and (d) lessening the financial burden of cancer. Our study highlights the importance of the first three aspects in the approach to cancer care and further calls for a developmentally sensitive, age-appropriate approach. The financial aspect seldom appeared in the responses of Slovenian participants. However, we did not explicitly ask about the financial impact of their illness. There may be substantial hidden costs (e.g. parking, transport) to cancer care and treatment in Slovenia, even with a nationally based healthcare system.

4.1 | Limitations and future directions

This is the first study addressing the needs and outcomes of AYAs in Slovenia. Despite valuable insights, certain limitations should be taken into account. The study is based on a small subset of young Slovenian patients, which only included six male participants. This may in part be due to cultural factors that mean men are less likely to disclose or talk about emotions. Optimising ways of reaching young men should be explored. Moreover, the online nature of the study implies a self-selected group of participants. Recall bias will influence the qualitative responses to the way patients received their diagnosis. Moreover, participants' current psychological state might have influenced answers to the open-ended questions. As such, generalisations should be made with caution.

Slovenian participants were compared to an international sample from the same study. The participants were not matched, nor do they stem from the same socio-cultural environment, which may be pertinent in considering the psychological effect of cancer diagnosis and treatment. Future studies and analysis should aim at

including a matched healthy population control in order to get a better sense of the psychological functioning of young Slovenian cancer patients relative to the Slovenian context. Lastly, most measures reported do not have an established construct validity, or have been fully validated in the Slovenian context. A comprehensive validation study of the Slovenian measures would benefit future research.

Additionally, half of the Slovenian sample had a diagnosis of breast cancer, which further limits the generalisability of our findings. This may also be due to the fact that EuropaDonna, a pan-European breast cancer organisation for women's empowerment, has among the longest and strongest presence in Slovenia, with a subsection for young patients. This suggests that establishing more type- and age-specific patient organisations could lead to increased empowerment and greater research participation in the future.

The findings presented in this article are based on data from the baseline of a larger study, which makes this research cross-sectional in nature. In order to gain a better understanding of how mental defeat influences psychological distress or cancer-related worries, longitudinal data are needed.

4.2 | Clinical implications

This study is the first study to conduct an in-depth analysis of Slovenian AYA patients' psychological functioning and needs. Our results show that a subset of Slovenian patients experience clinically elevated symptomatology of anxiety and depression. Targeting mental defeat early and during cancer treatment might alleviate anxiety and depression. Participants who reported receiving psychological support during their illness fared better and those who have not received psychological support reported a need for such support. The development of novel and age-appropriate services and resources, including patient support groups, should become a national priority. Additionally, medical professionals working with this population should aim to promote a warm and encouraging atmosphere, assure that patients feel heard and provide adequate information and explanation to help guide patients and their relatives through the initial phases of cancer illness.

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CONFLICT OF INTEREST

None to declare.

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