**Empowerment in adolescents and young adults (AYAs) with cancer: relationship with health-related quality of life**

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**Precis**

Empowerment is positively associated with health-related quality of life in AYA cancer patients. Interventions aiming at empowering AYAs can improve their HRQoL.

**Conflicts of interest**

The authors have no conflict of interest to declare.

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**Abstract**

Background

The difficulties adolescents and young adults (AYAs) encounter during a cancer experience may result in a reduction or absence of empowerment. Our aims were to assess levels of empowerment, associated (demographic, clinical or psychological) factors and examine the association between empowerment and health-related quality of life (HRQoL) among AYA cancer patients.

Methods

Patients aged 18-35 years at time of cancer diagnosis and who were seen by one of the members of the specialized multidisciplinary AYA team of the Radboud university medical center, were invited to complete questionnaires about empowerment, HRQoL, and sociodemographic, clinical and psychological characteristics (autonomy, coping, unmet social support needs and psychological distress).

Results

Eighty-three AYAs completed the questionnaires. The mean age of participants at diagnosis was 27.5 years. The vast majority had been treated with chemotherapy (86%), had more advanced stage of disease and had completed treatment at the time of participation (74%). Mean empowerment level was 154.1(SD=17.8) with a range of 114-200. Multivariate analysis showed that the autonomy subscales of self awareness (Beta=0.35), capacity for managing new situations (Beta=0.19) and social support (Beta= 0.35) were positively associated with empowerment. Coping difficulties (Beta=-0.19) were negatively associated with empowerment. Empowerment was independently associated with physical (Beta=0.31), psychological (Beta=0.50), social (Beta=0.39), religious (Beta=0.33) and total HRQoL (Beta=0.52; all p<0.01).

Conclusions

Low levels of empowerment were associated with low levels of autonomy and social support, female gender and more experienced coping difficulties among AYA cancer patients. Recognizing these patients as candidates for empowerment interventions could ultimately help improve HRQoL in late adolescence and young adulthood.

**Keywords**

Adolescent and young adult, AYA, cancer, empowerment, health-related quality of life.

**Introduction**

Adolescents and young adults (AYAs), diagnosed with cancer at the age of 18-35 years, form a distinct group between pediatric and adult oncology[1]. Our definition of AYA (18-35 years) is based on the organization of the health care system in the Netherlands, where there is a clear distinction between pediatric (0-18 years) versus medical oncology. According to Barr and colleagues “there is broad agreement but less than unanimity that adolescence ranges from 15 to 19 years of age, resulting in young adulthood beginning at age 20 years”. The age range of 18-35 years in our study therefore seems to indicate late adolescence and young adulthood[2]. In the Netherlands approximately 2,700 AYA patients are diagnosed with cancer annually - around five times the number of cases diagnosed in children aged 0-17 years[3]. In addition to differences in tumor biology, limited progress in survival, lower clinical trial participation rates and insufficient awareness of cancer symptoms among patients and professionals, this group has distinctive psychosocial and supportive care needs compared to their younger and older counterparts[1]. Late adolescence and young adulthood is a period of complex development during our lives for example creating our own identity and body image, establishing autonomy, responsibility and independence. A cancer diagnosis poses existential questions to AYAs about their future, encompassing premature confrontation with mortality, changes in physical appearance, increased dependence on parents, potential loss of reproductive capacity, disruptions in social life, education and employment due to treatment. These factors may have a negative impact on health related quality of life (HRQoL)[4].

Empowerment is a factor that may be associated with HRQoL and has become a topical issue in cancer survivorship over recent years[5-10]. With its roots in community psychology, empowerment was originally defined as “the mechanism by which people, organizations, and communities gain mastery over their lives”[11]. The topical nature and the extensive (mis)use of empowerment in health care, has led to a lack of clarity in regard to its definition and measurement[12]. For example, empowerment can be viewed as a *process* versus an *outcome*, and on an *individual* versus *collective* level[12-14]. For this study, we used the construct of psychological empowerment of Zimmerman[15] that views empowerment as an outcome measure on the level of the individual patient: ‘psychological empowerment is a feeling of control, a critical awareness of one’s environment and active engagement in it’. In accordance with a recent review on measuring and defining empowerment in cancer patients[16], Zimmerman states that empowerment reflects a broad construct and comprehends intrapersonal, interactional, and behavioral components[15]. The *intrapersonal* component refers to ‘how people think about themselves’ and includes perceived control, self-efficacy, perceived competence and mastery. The *interactional component* refers to how people think about and relate to their social environment, and the *behavioral component* of empowerment relates to concrete behaviors of a person to change his or her situation (e.g. active coping, and participation in decision making) [14, 15].

Empowered AYA cancer patients may be more likely to understand and participate in their own care by mobilizing resources and taking actions that can reduce distress, enhance strategies for dealing with cancer and improve HRQoL[5, 6]. In view of this knowledge, it is important to evaluate which sociodemographic (e.g. gender), clinical (e.g. treatment intent) and psychological (e.g. loss of autonomy, coping difficulties, high levels of psychological distress, unmet social support needs) factors are associated with low levels of empowerment among AYA cancer patients. This may also help us to identify those patients who might benefit from additional support or interventions.

In summary, the aims of the current study are to assess the: (1) levels and associated factors (demographic, clinical and psychological) of empowerment; (2) association between empowerment and HRQoL among AYA patients.

**Methods**

*Participants*

Patients aged 18-35 years at cancer diagnosis, and who had been seen by at least one of the members of the AYA team of the Radboud university medical center in The Netherlands, were invited to participate in this study. The AYA team is a dedicated multidisciplinary team including a medical oncologist, clinical nurse specialist, medical psychologist, and social worker. Patients consulting the AYA team receive regular medical care from their own treating medical specialist in the Radboud university medical center (medical oncologist, hematologist, surgeon, gynecologist etc.) and visit the AYA team for age-specific questions and care needs. In general, patients visiting the AYA team represent a group of patients with high disease severity, diagnosed with relatively advanced stage of disease and undergoing intensive treatments, and reporting more difficulties with coping. Patients with lower stage disease (e.g. cervical cancer, melanoma) treated solely by surgery, are not often seen by the AYA team.

For this study, AYA cancer patients were included independently of the status of treatment (during or after treatment), the type of treatment (surgery, chemotherapy, radiotherapy, immunotherapy/targeted therapy and hormonal therapy or combination), or the number of AYA team visits (some patients only had one introduction talk with one of the members of the team and did not receive specific care thereafter) to depict the real-life heterogeneous sample of AYA cancer patients visiting the AYA team. Inclusion commenced January 2012 and ended March 2016.

*Procedure*

Potential study participants were recruited via letters describing the study and inviting patients to participate in the study. Patients willing to participate had to actively opt-in to the study by providing written informed consent by email to a member of the AYA team. Participants were then sent a single set of questionnaires by email that could be completed online.

*Measures*

Empowerment

The Cancer Empowerment Questionnaire (CEQ) is based on Zimmerman’s theory of psychological empowerment and one of first empowerment questionnaires validated in cancer patients[8, 15, 16]. Validation in breast cancer survivors provided a four-factor structure representing the intra- and interpersonal strengths of cancer patients [8]. The CEQ consists of 40 items with 4 subscales: personal strength (19 items, range 19-95, α=0.90), social support (9 items, range 9-45, α=0.76), community (6 items, range 6-30, α=0.81) and health care (6 items, range 6-30, α=0.78). Personal strength encompasses intrapersonal aspects of empowerment regarding self-efficacy, self-esteem, optimism and personal competence. The remaining three subscales represent the interpersonal aspects of empowerment with items of perceived support from people close to the patient (social support), feelings of acceptance and support from the social community (community), and the perception of good and collaborative relationships with health care professionals (health care). Examples of questions regarding each subscale are: personal strength - “I think I am worthwhile”; social support - “the people around me accept me”; community - “the society respects my rights as a citizen” and health care - “my health care professionals are there when I need them”. The 40 items are rated on a 5-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree). Total scores (scale) can range from 40 to 200. Stronger feelings of empowerment are indicated by higher scores [8]. Baseline internal consistency was good (Cronbach’s α=0.93).

Health-related Quality of life

The Quality of Life for Cancer Survivors (QoL-CS) questionnaire measures the HRQoL of cancer patients. It consists of 41 items on the physical, psychological, social and religious impact of cancer on the life of the patient. Respondents rate themselves along an interval rating scale ranging from 0 to 10 for each item. For subscale scoring purposes, all items were ordered, so that 0 indicated the lowest or worst possible HRQoL, and 10 indicated the highest or best possible HRQoL outcome. An overall QoL score was computed by averaging all 41 items[17].

*Associated factors*

Sociodemographic and clinical characteristics

Demographic data, including age, gender, partnership, having children, living situation, educational level, and employment status were gathered by self-report. Medical data, including tumor type, disease stage, type(s) of treatment(s) received, treatment status (on/off treatment) and time since initial diagnosis were extracted from the patients’ medical records by two of the researchers [SK,SvD].

Autonomy-connectedness

The Autonomy Connectedness Scale (ACS-30) questionnaire measures individual differences in autonomy-connectedness, i.e. the capacity for self-governance, including in social relationships. It consists of 30 items divided into three subscales: self-awareness (seven items, e.g., ‘I often do not know what my opinion is’), sensitivity to others (17 items, e.g., ‘I often wonder what other people think of me’) and capacity for managing new situations (six items, e.g., ‘I quickly feel at ease in new situations’). All items are measured with 5-point scales, ranging from disagree to agree[18, 19]. Internal consistency in this study was good with alpha values of 0.81, 0.82 and 0.80, respectively.

*Psychological distress*

Psychological distress was assessed with the Hospital Anxiety and Depression Scale (HADS), with seven items each for assessing symptoms of anxiety and depression. All items were scored on a 0- to 3-point scale, with higher scores indicating more symptoms. A total score was calculated, with higher scores indicating more distress[20].

*Social support and coping*

Two items (amount of social support and coping difficulties) were added as separate correlates for empowerment. They were selected from the Quality of Life for Cancer Survivors questionnaire[17]. The question about the amount of social support was: ‘was the amount of support you receive from others sufficient?’ For coping difficulties the question was: ‘how difficult is it for you nowadays to cope with the effects of disease and treatment?’ Respondents rate themselves along an interval rating scale ranging from 0 to 10 for each item. For social support a higher score indicates sufficient social support, whereas a higher score on coping indicates more coping difficulties.

*Statistical analysis*

Analyses were performed using Statistical Package for the Social Sciences version 22 (SPSS), Chicago, IL, USA and two-sided *p* values of <.05 were considered statistically significant. Descriptive statistics and frequencies concerning socio-demographic, clinical data, levels of empowerment and correlates were calculated. Pearson and Phi correlations were calculated to examine associations between two continuous variables and continuous and dichotomous variables, respectively. First, this was done for correlates of levels of empowerment and thereafter this was done for correlates of HRQoL. To determine independent effects of covariates on levels of empowerment and HRQoL respectively, multivariate linear regression analyses were performed including only the covariates that were significant at the bivariate level.

**Results**

**Sociodemographic and clinical patient characteristics**

In total, 309 letters requesting participation in the study were sent to AYA cancer patients visiting one of the members of the AYA team. Eighty-nine patients, comprising 57% of those who opted-in to the study (*n*=155) and 29% of those invited (n=309), completed the online questionnaire. Six patients were excluded due to age criteria: four diagnosed with cancer <18 years and two aged >35 years at diagnosis. Table 1 displays sociodemographic, disease and treatment-related characteristics of the final sample (*n*=83). The mean age at diagnosis was 27.5(SD=4.6) years with a range of 18-35 years and a median age at diagnosis of 27 years. Three patients (3.6%) were 18 and 19 years of age. Average time since diagnosis was 2.1 (SD=2.6) years and 86% received curative treatment. Of the participants 52% were male. The most commonly diagnosed cancers were testicular cancer (34%) and sarcoma (19%).

**Levels of empowerment**

Mean empowerment level was 154.1(SD=17.8) with a range of 114-200. The mean scores(SD) for each domain were: personal strength 74(9.8), social support 36.5(4.1), community 19.7(4.6), health care 23.9(3.4).

**Associated factors of empowerment**

Factors associated with total empowerment and the four empowerment subscales are presented in Table 2. Female gender was negatively associated with total empowerment and all empowerment subscales except social support. Employment and education were positively associated with the empowerment subscale personal strength. Higher disease stage was positively associated with the subscale social support. Palliative treatment intent was negatively associated with personal strength. Regarding autonomy, self-awareness and capacity to handle new situations were positively associated with total empowerment and all subscales except self-awareness and the empowerment community subscale. On the autonomy subscale, sensitivity to others was negatively associated with total empowerment and the empowerment community subscale. Perception of social support showed a strong positive association with total empowerment and all empowerment subscales. Coping difficulties and psychological distress were negatively associated with total empowerment and all subscales except for the empowerment community subscale.

In multivariate linear analysis, using total empowerment as outcome, and including univariate significant correlates (except for psychological distress which was highly correlated with coping r>0.8), results remained significant for self-awareness (Beta =0.35;p<0.01), new situations (Beta=0.19;p=0.05), coping difficulties (Beta=-0.19; p=0.04), and social support (Beta=0.35; p<0.01), but not gender (Beta=-0.14;p=0.11) or sensitivity to others (Beta=0.08;p=0.38).

**Associations between empowerment and HRQoL among AYA patients**

Bivariate correlations showed that all empowerment subscales were positively associated with HRQoL, except for the community subscale which was not associated with physical and psychological HRQoL. Several sociodemographic, clinical and personal factors were also significantly associated with HRQoL(Table 3).

Female gender was negatively associated with all HRQoL subscales except for the religious subscale. Having work or attending school was positively associated with the religious HRQoL subscale. Completion of cancer treatment was positively associated with the physical HRQoL subscale. Palliative treatment intent was negatively associated with all HRQoL scales except the social subscale. The autonomy subscale self-awareness was positively associated with total and social HRQoL. The autonomy subscale showed that sensitivity to others was negatively associated with psychological, social and total HRQoL. In addition, the autonomy subscale capacity to handle new situations had a strong positive association with all HRQoL scales except the religious subscale.

In order to assess the independent association of empowerment with the five HRQoL scales multivariate linear regression analyses were conducted with HRQoL scales as outcomes, total empowerment score as an independent variable and including all significant correlates in univariate analyses. Empowerment remained significant for physical (Beta=0.31;p<0.01), psychological (Beta=0.50;p<0.01), social (Beta=0.39;p<0.01), religious (Beta=0.33;p<0.01) and total HRQoL (Beta=0.52;p<0.01).

Sensitivity analysis showed that the empowerment scales were only significantly associated with HRQoL for those treated with curative intent and not for those treated with palliative intent.

**Discussion**

This study showed that AYA cancer patients treated in a specialized care center had relatively high levels of empowerment. There was a wide range of levels of empowerment, indicating room for improvement. Empowerment levels in this study were comparable to a previous study in breast cancer patients, however this study only included female patients who were older than in our sample[21]. Our results showed that the most important factors associated with empowerment in AYA patients were autonomy, gender, social support, coping and psychological distress. This provides beneficial insight into groups which may benefit from support interventions that aim to empower AYAs. AYAs with higher levels of empowerment were more likely to be male, have higher autonomy scores and receive more social support. These patients also reported fewer difficulties in coping and lower levels of psychological distress. Our data has demonstrated the importance of high levels of empowerment as this was positively associated with HRQoL.

Autonomy was strongly associated with empowerment. Self-awareness and the capacity to handle new situations were independently associated with total empowerment. Developing autonomy is generally experienced as young people mature[22]. Although many AYAs have developed decision-making skills regarding their own health or life goals[22], others will still look to others to help them with decision-making and indeed they may return to a state of dependency when faced with cancer[23]. (Health related) information should be delivered in a manner which is appropriate to the age of the patient as this is critical in helping AYAs learn to cope with their disease and navigate the health care system[24]. The capacity to handle new situations is closely related to the concept of coping. In their relatively short lives, most AYA patients have not encountered many major life events. AYA patients may require more support as they have not had the opportunity to develop skills which enable them to cope with new and challenging situations. We found that being female had a significant, negative correlation with empowerment. This may be explained by the findings of a study which showed that women tend to use less effective, emotion-focused coping strategies, whereas men use more effective problem-focused or instrumental methods of handling stressful experiences[25]. Additional support for female AYA patients may be warranted, however we should not assume that all male AYA patients will require less social support.

AYA patients often feel isolated, however perceived social support from family and friends contribute to high levels of empowerment[7]. A cancer diagnosis and its treatment leads to increased dependency on parents and/or partners and sets AYA patients apart from their healthy peers. AYA autonomy and the development of identity in general depends largely on peer acceptance and relationships[26]. Not unexpectedly, studies have shown that support from other AYA cancer patients is incredibly important for this age group in helping them to cope with their disease[27]. In addition, AYAs want to provide support to their own family and friends in order to create a sense of self-worth, however this contribution is not always possible during their disease trajectory due to the effects of cancer and its treatment[28]. Those with high levels of sensitivity towards others, more commonly women, have greater difficulty accepting this realization and therefore feel less empowered[25]. As our results show, return into society, through employment or education contributes further to empowerment by creating a sense of self-worth/confidence and perceiving oneself as being useful. A perceived lack of social support, absence of self-worth and appropriate coping skills may all have a negative effect on psychological distress, which itself was a strong negative correlate of empowerment. Lastly, our results show that treatment intent (curative vs. palliative) also contributes to the levels of personal strength. The needs of AYAs with advanced cancer intensify as they near the end of their lives[29]. The physical changes associated with advanced disease result in loss of capacity to manage activities of daily living and aspects of medical regimens[5]. In addition, the stress of living with an enduring sense of loss brings new challenges, such as when to hand responsibilities to others and whether to discuss emotional or spiritual concerns and end-of life decisions. Providing appropriate support in order to allow patients to maintain a level of autonomy is very important in this phase[5].

Given the strong correlation between empowerment and HRQoL found in our study and others[30] and relatively high levels of empowerment measured in this AYA sample, strategies to reinforce empowerment in AYAs should be explored. Interventions could focus on one or all four domains of empowerment. Firstly, personal strength can be positively influenced by self-management i.e. the comprehensive engagement of the AYA patient in problem-solving, decision-making, and daily health-related behaviors in partnership with health care professionals and community[31]. Self-management will help patients to manage the medical aspects of cancer, managing life roles (including changes in roles brought by cancer), and managing psychosocial consequences of cancer[32]. Such a self-management intervention might include cognitive behavioral therapy components such as psycho-education, cognitive reframing, goal planning and process evaluation[33]. Secondly, social support can be enhanced by offering real life and digital platforms for AYA patients where they can virtually meet and share information and feelings with peers[34]. For example, (online) peer support groups and age-specific information portals for AYAs have been shown to significantly reduce feelings of social isolation, improve knowledge, self-efficacy, problem-solving skills and effective interpersonal interactions[35]. With regard to the third empowerment dimension, community, attention should be paid to reframing the perception of AYAs to be a burden to society. The fourth empowerment dimension, health care, can be improved by creating inpatient and outpatient dedicated multifunctional spaces to suit AYA needs, training AYA dedicated professional caregivers and setting up education programs for healthcare professionals. For example, additional medical training in fertility preservation or AYA survivorship care could be provided at the (under)graduate level, in primary care residencies and adult oncology fellowships. Future research should explore the best ways to increase levels of empowerment among AYA patients.

This study has several limitations. First, all participants were treated in a single center and received multidisciplinary care by a dedicated AYA team. It could therefore be that the empowerment levels of our sample are higher than those of AYA patients treated in other centers in The Netherlands without age-specific care. However, the patients in our sample were diagnosed with relatively advanced stage of disease and were intensively treated, mostly with more than one treatment modality. This might be an overestimation in disease severity of the entire AYA cancer population, where lower stage disease (cervical cancer, melanoma, thyroid cancer, brain tumor) treated solely by surgery, is more common. Both factors limit the generalizability of our results. A second limitation of our study is the low response rate, which is not unusual in studies in young cancer patients, but was even lower than in previous questionnaire studies[36, 37] among AYAs (29% response rate in our sample versus 43% and 52% in previous studies). Unfortunately we do not have information about the reasons for none participation. Since demographic data were not collected of the non-responders we could not rule out selection bias. Third, empowerment is rarely formally assessed as outcome and few validated questionnaires exist, particularly for the cancer setting[6], making it difficult to compare our results to other groups of cancer patients. Fourth, the cross-sectional design limits the determination of causal associations between the study variables. Longitudinal research is needed to assess changes in empowerment levels over time to determine the best time to intervene for those with low levels. Fifth, the question remains whether the higher levels of empowerment are caused by the fact that all AYA patients consulted at least one member of the multidisciplinary AYA team, or is caused by the psychometric properties of the empowerment questionnaire. Although the CEQ has showed good psychometric properties, the sensitivity/specificity of this instrument is not tested and there is no validated cut-off point in the cancer setting.

In conclusion, empowerment is an important factor related to HRQoL in late adolescence and young adulthood. Empowerment levels as measured in this study were quite high in AYA patients treated in a specialized care center. Autonomy, female gender, social support, coping and psychological distress were strongly associated with empowerment indicating groups at risk for low levels of empowerment. Future research should explore the best ways to increase empowerment in identified risk groups.

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Table 1 Characteristics of the AYA patient study sample

|  |  |
| --- | --- |
|  | **Total N=83(%)** |
| **Gender**  Male  Female | 43(52%)  40(48%) |
| Age at diagnosis M(SD) | 27.5(4.6) |
| Age at survey M(SD) | 29.6(4.8) |
| Time since cancer diagnosis M(SD) | 2.1(2.6) |
| **Cancer diagnosis**  Testicular cancer  Sarcoma  Breast cancer  Lymphoma/Leukemia  Gynecological cancer  Melanoma  Other\* | 28(34%)  16(19%)  10(12%)  10(12%)  9(11%)  3(4%)  7(8%) |
| **Stage**  NA  Stage 1  Stage 2  Stage 3  Stage 4  Unknown | 9(11%)  11(13%)  25(30%)  13(16%)  18(22%)  7(8%) |
| **Treatment intention**  Curative  Palliative | 71(86%)  12(14%) |
| **Treatment status**  Active  Completed | 22 (26%)  61 (74%) |
| **Treatment type(yes)**  Surgery  Chemotherapy  Radiotherapy  Immunotherapy/targeted therapy  Hormonal therapy  Systemic therapy other | 70(84%)  72(87%)  24(29%)  13(16%)  7(8%)  13(16%) |
| **Partner**  Yes  No | 58(70%)  24(29%) |
| **Children**  Yes  No | 27(33%)  55(66%) |
| **Living situation**  With parents  On own  With partner | 14(17%)  24(29%)  44(53%) |
| **Highest completed education**a  Low/ Intermediate  High | 38(46%)  44(53%) |
| **Employed/studying**  Yes  No | 68(82%)  15(18%) |
| **Received social support meeting needsb**  **M(SD)** | 8.1(1.8) |
| **Coping with effects of cancer and its treatmentc**  **M(SD)** | 4.1(2.6) |
| **Psychological distressd**  **M(SD)** | 11.0(6.6) |
| **Autonomy connectedness M(SD)**  Self-awarenesse  Sensitivity to othersf  Handle new situationsg | 25.9(6.1)  57.2(10)  19.2(5.5) |

Not all numbers add up to 83 because of missing data

\* brain tumor(n=1), sigmoid carcinoma(n=1), orofaryngeal cancer(n=1), neuroendocrine tumor(n=1), salivary gland cancer(n=1), adrenal carcinoma(n=1), lung cancer(n=1)

a0=low/intermediate vocational education or less;1=high-level vocational education/university

bScore ranging 0-10,higher score=more social support

cScore ranging 0-10,higher score=more coping difficulties

dScore ranging 0-42,higher score=more distress

eScore ranging 7-35,higher score=more self-awareness

fScore ranging 17-85,higher score=more sensitivity to others

gScore ranging 6-30, higher score=easiness to handle new situations

M=mean,SD=standard deviation,NA=not applicable

Table 2 Associated factors of empowerment

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Personal strength** | **Social support** | **Community** | **Health care** | **Total** |
| **Sociodemographic and clinical** | | | | | |
| Age diagnosis(yrs) | -0.05 | -0.10 | -0.01 | -0.16 | -0.08 |
| Gender 0=male;1=female | -0.26\* | -0.21 | -0.28\* | -0.31\*\* | -0.32\*\* |
| Partner 0=yes;1=no | -0.21 | -0.12 | -0.13 | -0.06 | -0.19 |
| Educational levela | 0.20 | 0.09 | -0.04 | 0.05 | 0.13 |
| Living statusb | -0.05 | -0.03 | -0.08 | -0.09 | -0.07 |
| Work/school 0=no;1=yes | 0.22\* | -0.03 | -0.13 | -0.02 | 0.07 |
| Children 0=no;1=yes | 0.04 | -0.01 | -0.03 | -0.09 | -0.01 |
| Time since diagnosis(yrs) | 0.07 | -0.03 | -0.18 | 0.03 | -0.01 |
| Disease stage c | -0.12 | 0.26\* | 0.11 | 0.17 | 0.01 |
| Treatment statusd | 0.03 | -0.12 | -0.09 | 0.06 | -0.02 |
| Treatment intente | -0.23\* | -0.10 | 0.01 | -0.08 | -0.16 |
| Chemotherapy 0=no;1=yes | 0.13 | 0.09 | 0.03 | 0.09 | 0.12 |
| **Autonony connectedness** | | | | | |
| Self-awareness | 0.55\*\* | 0.47\*\* | 0.19 | 0.27\* | 0.51\* |
| Sensitivity to others | -0.21 | -0.14 | -0.24\* | -0.07 | -0.22\* |
| Capacity new situations | 0.51\*\* | 0.42\*\* | 0.23\* | 0.27\* | 0.48\*\* |
| **Other** | | | | | |
| Amount social support meeting needs | 0.34\*\* | 0.46\*\* | 0.39\*\* | 0.46\*\* | 0.48\*\* |
| Coping difficulties | -0.47\*\* | -0.23\* | -0.11 | -0.25\* | -0.38\*\* |
| Psychological distress | -0.66\*\* | -0.48\*\* | -0.16 | -0.37\*\* | -0.58\*\* |

\*p<0.05;\*\*p<0.01

a0=low/intermediate vocational education or less;1=high-level vocational education/university

b0=with parent;1=independent/together with partner(children) or friends

c0=stage 1 and 2, 1=stage 3 and 4

d0=under treatment;1=completed

e0=curative;1= palliative

Table 3 Correlations between empowerment, other covariates and health related quality of life (HRQoL)

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **Physical** | **Psychological** | **Social** | **Religious** | **Total HRQoL** |
| **Empowerment** | | | | | |
| Personal strength | 0.45\*\* | 0.63\*\* | 0.42\*\* | 0.29\*\* | 0.65\*\* |
| Social support | 0.26\* | 0.43\*\* | 0.40\*\* | 0.22\* | 0.46\*\* |
| Community | 0.21 | 0.21 | 0.22\* | 0.24\* | 0.28\* |
| Health care | 0.41\*\* | 0.42\*\* | 0.45\*\* | 0.27\* | 0.52\*\* |
| Total | 0.44\*\* | 0.58\*\* | 0.47\*\* | 0.32\*\* | 0.63\*\* |
| **Sociodemographic and clinical** | | | | | |
| Age diagnosis(yrs) | -0.18 | -0.11 | 0.01 | -0.05 | -0.12 |
| Age survey(yrs) | -0.13 | -0.05 | 0.10 | -0.05 | -0.05 |
| Gender 0=male;1=female | -0.35\*\* | -0.39\*\* | -0.35\*\* | -0.16 | -0.43\*\* |
| Partner 0=yes;1=no | -0.11 | -0.09 | 0.05 | -0.15 | -0.09 |
| Educational levela | 0.15 | 0.01 | -0.18 | 0.15 | 0.03 |
| Living statusb | -0.01 | -0.07 | 0.02 | 0.01 | -0.03 |
| Work/school 0=no;1=yes | 0.22\* | 0.17 | -0.09 | 0.37\*\* | 0.20 |
| Children 0=no;1=yes | 0.11 | -0.04 | 0.04 | -0.01 | 0.02 |
| Time since diagnosis(yrs) | 0.04 | 0.03 | 0.11 | 0.02 | 0.06 |
| Disease stagec | -0.11 | -0.17 | -0.04 | -0.23 | -0.19 |
| Treatment statusd | 0.27\* | 0.16 | 0.04 | 0.10 | 0.18 |
| Treatment intente | -0.27\* | -0.31\*\* | -0.13 | -0.30\*\* | -0.35\*\* |
| Chemotherapy 0=no;1=yes | 0.14 | 0.18 | 0.10 | -0.05 | 0.16 |
| **Autonomy-connectedness** | | | | | |
| Self-awareness | 0.14 | 0.20 | 0.25\* | 0.12 | 0.25\* |
| Sensitivity to others | -0.01 | -0.31\*\* | -0.32\*\* | 0.07 | -0.24\* |
| Capacity new situations | 0.31\*\* | 0.36\*\* | 0.25\* | 0.20 | 0.40\*\* |

\*p<0.05;\*\*p<0.01

a0=low/intermediate vocational education or less;1=high-level vocational education/university

b0=with parent;1=independent/together with partner (children) or friends

c0=stage 1 and 2, 1=stage 3 and 4

d0=under treatment;1=completed

e0=curative;1=palliative