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# Empowerment in Adolescents and Young Adults With Cancer: Relationship With Health-Related Quality of Life

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**BACKGROUND:** The difficulties adolescents and young adults (AYAs) encounter during a cancer experience may result in a reduction in or absence of empowerment. The aims of the current study were to assess levels of empowerment and associated (demographic, clinical, or psychological) factors and examine the association between empowerment and health-related quality of life (HRQOL) among AYA patients with cancer. **METHODS:** Patients aged 18 to 35 years at time of cancer diagnosis and who were seen by 1 of the members of the specialized multidisciplinary AYA team of the Radboud University Medical Center were invited to complete questionnaires regarding empowerment; HRQOL; and sociodemographic, clinical, and psychological characteristics (autonomy, coping, unmet social support needs, and psychological distress). **RESULTS:** A total of 83 AYA patients completed the questionnaires. The mean age of the participants at the time of diagnosis was 27.5 years. The vast majority had been treated with chemotherapy (86%), had a more advanced stage of disease, and had completed treatment at the time of participation (74%). The mean empowerment level was 154.1 (standard deviation, 17.8) with a range of 114 to 200. Multivariate analysis demonstrated that the autonomy subscales of self-awareness ( $\beta = .35$ ), capacity for managing new situations ( $\beta = .19$ ), and social support ( $\beta = .35$ ) were found to be positively associated with empowerment. Coping difficulties ( $\beta = -.19$ ) were found to be negatively associated with empowerment. Empowerment was independently associated with physical ( $\beta = .31$ ), psychological ( $\beta = .50$ ), social ( $\beta = .39$ ), religious ( $\beta = .33$ ), and total HRQOL ( $\beta = .52$ ; all  $P < .01$ ). **CONCLUSIONS:** Low levels of empowerment were associated with low levels of autonomy and social support, female sex, and coping difficulties among AYA patients with cancer. Recognizing these patients as candidates for empowerment interventions ultimately could help to improve HRQOL in late adolescence and young adulthood. *Cancer* 2017;123:4039-47. © 2017 The Authors. *Cancer* published by Wiley Periodicals, Inc. on behalf of *American Cancer Society*. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

**KEYWORDS:** adolescent and young adult (AYA), cancer, empowerment, health-related quality of life.

## INTRODUCTION

Adolescents and young adults (AYAs) diagnosed with cancer between the ages of 18 to 35 years form a distinct group between pediatric and adult oncology.<sup>1</sup> Our definition of AYA (those aged 18-35 years) is based on the organization of the health care system in the Netherlands, in which there is a clear distinction between pediatric (ages birth-18 years) versus medical oncology. According to Barr et al, “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.” Therefore, the age range of 18 to 35 years used herein appears to indicate late adolescence and young adulthood.<sup>2</sup> In the Netherlands, approximately 2700 AYA patients are diagnosed with cancer annually, which is approximately 5 times the number of cases diagnosed in children aged birth to 17 years.<sup>3</sup> 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 with their younger and older counterparts.<sup>1</sup> Late adolescence and young adulthood is a period of complex development; for example, it is during this period that one creates one’s own identity and body image, and establishes autonomy, responsibility, and independence. A cancer diagnosis poses existential questions to AYA patients regarding their future, encompassing premature confrontation with mortality; changes in physical appearance; increased dependence on parents; potential loss of reproductive capacity; and disruptions in social life, education, and employment due to treatment. These factors may have a negative impact on health-related quality of life (HRQOL).<sup>4</sup>

Empowerment is a factor that may be associated with HRQOL and has become a topical issue in cancer survivorship over recent years.<sup>5-10</sup> With its roots in community psychology, empowerment originally was defined as “the mechanism

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by which people, organizations, and communities gain mastery over their lives.”<sup>11</sup> 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.<sup>12</sup> For example, empowerment can be viewed as a process versus an outcome, and on an individual versus collective level.<sup>12-14</sup> For the current study, we used the construct of psychological empowerment of Zimmerman<sup>15</sup> 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.”<sup>15</sup> In accordance with a recent review on measuring and defining empowerment in patients with cancer,<sup>16</sup> Zimmerman states that empowerment reflects a broad construct and comprehends intrapersonal, interactional, and behavioral components.<sup>15</sup> The intrapersonal component refers to how people think about themselves and includes perceived control, self-efficacy, and 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 (eg, active coping and participation in decision making).<sup>14,15</sup>

Empowered AYA patients with cancer 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.<sup>5,6</sup> In view of this knowledge, it is important to evaluate which sociodemographic (eg, sex), clinical (eg, treatment intent), and psychological (eg, loss of autonomy, coping difficulties, high levels of psychological distress, and unmet social support needs) factors are associated with low levels of empowerment among AYA patients with cancer. This also may help us to identify those patients who might benefit from additional support or interventions.

The objectives of the current study were to assess the: 1) levels and associated factors (demographic, clinical, and psychological) of empowerment; and 2) the association between empowerment and HRQOL among AYA patients.

## MATERIALS AND METHODS

### *Participants*

Patients aged 18 to 35 years at the time of cancer diagnosis and who had been seen by at least 1 of the members of the AYA team of the Radboud University Medical Center in

The Netherlands were invited to participate in the current 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, who are diagnosed with a relatively advanced stage of disease and are undergoing intensive treatments, and who are reporting more difficulties with coping. Patients with lower stage disease (eg, cervical cancer or melanoma) who are treated solely by surgery are not often seen by the AYA team.

For the current study, AYA patients with cancer 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 a combination), or the number of AYA team visits (some patients only had 1 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 patients with cancer who are 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. Patients who were willing to participate had to actively opt-in to the study by providing written informed consent by E-mail to a member of the AYA team. Participants were then sent a single set of questionnaires by E-mail that could be completed online. The study was deemed exempt from full review and approval by a research ethics committee (CMO Regio Arnhem-Nijmegen).

### *Measures*

#### **Empowerment**

The Cancer Empowerment Questionnaire (CEQ) is based on Zimmerman’s theory of psychological empowerment and to the best of our knowledge is one of first empowerment questionnaires validated in patients with cancer.<sup>8,15,16</sup> Validation in survivors of breast cancer provided a 4-factor structure representing the intrapersonal and interpersonal strengths of patients with cancer.<sup>8</sup> The CEQ consists of 40 items with 4 subscales: Personal Strength (19 items [range, 19-95];  $\alpha = .90$ ), Social

Support (9 items [range, 9-45];  $\alpha = .76$ ), Community (6 items [range, 6-30];  $\alpha = .81$ ), and Health Care (6 items [range, 6-30];  $\alpha = .78$ ). Personal Strength encompasses intrapersonal aspects of empowerment regarding self-efficacy, self-esteem, optimism, and personal competence. The remaining 3 subscales represent the interpersonal aspects of empowerment with items of perceived support from individuals 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: "I think I am worthwhile" (Personal Strength), "The people around me accept me" (Social Support), "The society respects my rights as a citizen" (Community), and "My health care professionals are there when I need them" (Health Care). 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.<sup>8</sup> Baseline internal consistency was good (Cronbach  $\alpha$ , .93).

#### Health-related quality of life

The Quality of Life-Cancer Survivors (QoL-CS) questionnaire measures the HRQOL of patients with cancer. 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.<sup>17</sup>

#### Associated Factors

##### Sociodemographic and clinical characteristics

Demographic data, including age, sex, 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 the initial diagnosis were extracted from the patients' medical records by 2 of the researchers (S.E.J.K. and S.v.D.).

##### Autonomy-connectedness

The Autonomy-Connectedness Scale (ACS-30) questionnaire measures individual differences in autonomy-

connectedness (ie, the capacity for self-governance, including in social relationships). It consists of 30 items divided into 3 subscales: Self-Awareness (7 items [eg, "I often do not know what my opinion is"]), Sensitivity to Others (17 items [eg, "I often wonder what other people think of me"]), and Capacity for Managing New Situations (6 items [eg, "I quickly feel at ease in new situations"]). All items are measured with 5-point scales ranging from disagree to agree.<sup>18,19</sup> Internal consistency in this study was good, with  $\alpha$  values of .81, .82, and .80, respectively.

#### Psychological distress

Psychological distress was assessed with the Hospital Anxiety and Depression Scale (HADS), with 7 items each for assessing symptoms of anxiety and depression. All items were scored on a 0-point to 3-point scale, with higher scores indicating more symptoms. A total score was calculated, with higher scores indicating more distress.<sup>20</sup>

#### 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 QoL-CS questionnaire.<sup>17</sup> The question regarding the amount of social support was: "Was the amount of support you received 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 the coping subscale indicates more coping difficulties.

#### Statistical Analysis

Analyses were performed using SPSS statistical software (version 22; IBM Corporation, Armonk, NY) and 2-sided  $P$  values  $< .05$  were considered statistically significant. Descriptive statistics and frequencies concerning sociodemographic and clinical data, levels of empowerment, and correlates were calculated. Pearson and Phi correlations were calculated to examine associations between 2 continuous variables and continuous and dichotomous variables, respectively. This first was performed for correlates of levels of empowerment and thereafter was performed 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 those 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 patients with cancer who were visiting 1 of the members of the AYA team. A total of 89 patients, comprising 57% of those who opted to take part in the study (155 patients) and 29% of those invited (309 patients) completed the online questionnaire. Six patients were excluded due to age criteria: 4 were diagnosed with cancer at age <18 years and 2 were aged >35 years at the time of diagnosis. Table 1 shows sociodemographic, disease, and treatment-related characteristics of the final sample (83 patients). The mean age at the time of diagnosis was 27.5 years (standard deviation [SD], 4.6 years) with a range of 18 to 35 years and a median age at diagnosis of 27 years. Three patients (3.6%) were aged 18 and 19

**TABLE 1.** Characteristics of the AYA Patient Study Sample

Characteristic	Total = 83 (%)
Sex	
Male	43 (52%)
Female	40 (48%)
Mean age at diagnosis (SD), y	27.5 (4.6)
Mean age at survey (SD), y	29.6 (4.8)
Mean time since cancer diagnosis (SD), y	2.1 (2.6)
Cancer diagnosis	
Testicular cancer	28 (34%)
Sarcoma	16 (19%)
Breast cancer	10 (12%)
Lymphoma/leukemia	10 (12%)
Gynecological cancer	9 (11%)
Melanoma	3 (4%)
Other <sup>a</sup>	7 (8%)
AJCC TNM staging system stage of disease	
NA	9 (11%)
I	11 (13%)
II	25 (30%)
III	13 (16%)
IV	18 (22%)
Unknown	7 (8%)
Treatment intention	
Curative	71 (86%)
Palliative	12 (14%)
Treatment status	
Active	22 (26%)
Completed	61 (74%)
Treatment type (yes)	
Surgery	70 (84%)
Chemotherapy	72 (87%)
Radiotherapy	24 (29%)
Immunotherapy/targeted therapy	13 (16%)
Hormonal therapy	7 (8%)
Systemic therapy other	13 (16%)
Partner	
Yes	58 (70%)
No	24 (29%)

**TABLE 1.** Continued

Characteristic	Total = 83 (%)
Children	
Yes	27 (33%)
No	55 (66%)
Living situation	
With parents	14 (17%)
On own	24 (29%)
With partner	44 (53%)
Highest completed education <sup>b</sup>	
Low/intermediate	38 (46%)
High	44 (53%)
Employed/studying	
Yes	68 (82%)
No	15 (18%)
Received social support meeting needs, mean (SD) <sup>c</sup>	8.1 (1.8)
Coping with effects of cancer and its treatment, mean (SD) <sup>d</sup>	4.1 (2.6)
Psychological distress, mean (SD) <sup>e</sup>	11.0 (6.6)
Autonomy connectedness, mean (SD)	
Self-awareness <sup>f</sup>	25.9 (6.1)
Sensitivity to others <sup>g</sup>	57.2 (10)
Handle new situations <sup>h</sup>	19.2 (5.5)

Abbreviations: AYA, adolescent and young adult; NA, not applicable; SD, standard deviation.

Not all numbers add up to 83 because of missing data.

<sup>a</sup>Brain tumor in 1 patient, sigmoid carcinoma in 1 patient, oropharyngeal cancer in 1 patient, neuroendocrine tumor in 1 patient, salivary gland cancer in 1 patient, adrenal carcinoma in 1 patient, and lung cancer in 1 patient.

<sup>b</sup>0 indicates low/intermediate vocational education or less and 1 indicates high-level vocational education/university.

<sup>c</sup>Score ranges from 0 to 10, with a higher score indicating more social support.

<sup>d</sup>Score ranges from 0 to 10, with a higher score indicating more coping difficulties.

<sup>e</sup>Score ranges from 0 to 42, with a higher score indicating more distress.

<sup>f</sup>Score ranges from 7 to 35, with a higher score indicating more self-awareness.

<sup>g</sup>Score ranges from 17 to 85, with a higher score indicating more sensitivity to others.

<sup>h</sup>Score ranges from 6 to 30, with a higher score indicating ease at handling new situations.

years. The average time since diagnosis was 2.1 years (SD, 2.6 years) and 86% of patients received curative treatment. Of the participants, 52% were male. The most commonly diagnosed cancers were testicular cancer (34%) and sarcoma (19%).

**Levels of Empowerment**

The mean empowerment level was 154.1 (SD, 17.8), with a range of 114 to 200. The mean scores for each domain were 74 (SD, 9.8) for Personal Strength, 36.5 (SD, 4.1) for Social Support, 19.7 (SD, 4.6) for Community, and 23.9 (SD, 3.4) for Health Care.

**Associated Factors of Empowerment**

Factors associated with total empowerment and the 4 empowerment subscales are presented in Table 2. Female



**TABLE 2.** Associated Factors of Empowerment

	Personal Strength	Social Support	Community	Health Care	Total
Sociodemographic and clinical factors					
Age at diagnosis, y	-0.05	-0.10	-0.01	-0.16	-0.08
Gender: 0 for male and 1 for female	-0.26 <sup>a</sup>	-0.21	-0.28 <sup>a</sup>	-0.31 <sup>b</sup>	-0.32 <sup>b</sup>
Partner: 0 for yes and 1 for no	-0.21	-0.12	-0.13	-0.06	-0.19
Educational level <sup>c</sup>	0.20	0.09	-0.04	0.05	0.13
Living status <sup>d</sup>	-0.05	-0.03	-0.08	-0.09	-0.07
Work/school: 0 for no and 1 for yes	0.22 <sup>a</sup>	-0.03	-0.13	-0.02	0.07
Children: 0 for no and 1 for yes	0.04	-0.01	-0.03	-0.09	-0.01
Time since diagnosis, y	0.07	-0.03	-0.18	0.03	-0.01
Disease stage <sup>e</sup>	-0.12	0.26 <sup>a</sup>	0.11	0.17	0.01
Treatment status <sup>f</sup>	0.03	-0.12	-0.09	0.06	-0.02
Treatment intent <sup>g</sup>	-0.23 <sup>a</sup>	-0.10	0.01	-0.08	-0.16
Chemotherapy: 0 for no and 1 for yes	0.13	0.09	0.03	0.09	0.12
Autonomy connectedness					
Self-awareness	0.55 <sup>b</sup>	0.47 <sup>b</sup>	0.19	0.27 <sup>a</sup>	0.51 <sup>a</sup>
Sensitivity to others	-0.21	-0.14	-0.24 <sup>a</sup>	-0.07	-0.22 <sup>a</sup>
Capacity for new situations	0.51 <sup>b</sup>	0.42 <sup>b</sup>	0.23 <sup>a</sup>	0.27 <sup>a</sup>	0.48 <sup>b</sup>
Other					
Amount of social support meeting needs	0.34 <sup>b</sup>	0.46 <sup>b</sup>	0.39 <sup>b</sup>	0.46 <sup>b</sup>	0.48 <sup>b</sup>
Coping difficulties	-0.47 <sup>b</sup>	-0.23 <sup>a</sup>	-0.11	-0.25 <sup>a</sup>	-0.38 <sup>b</sup>
Psychological distress	-0.66 <sup>b</sup>	-0.48 <sup>b</sup>	-0.16	-0.37 <sup>b</sup>	-0.58 <sup>b</sup>

<sup>a</sup>  $P < .05$ .<sup>b</sup>  $P < .01$ .<sup>c</sup> 0 indicates low/intermediate vocational education or less and 1 indicates high-level vocational education/university.<sup>d</sup> 0 indicates with parent and 1 indicates independent/together with partner (children) or friends.<sup>e</sup> 0 indicates stages I and II and 1 indicates stages III and IV.<sup>f</sup> 0 indicates receiving treatment and 1 indicates completed treatment.<sup>g</sup> 0 indicates curative and 1 indicates palliative.

sex was found to be negatively associated with total empowerment and all empowerment subscales except Social Support. Employment and education were found to be positively associated with the empowerment subscale of Personal Strength. Higher stage of disease was positively associated with the subscale of Social Support. Palliative treatment intent was found to be negatively associated with Personal Strength. With regard to 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 found to be negatively associated with total empowerment and the empowerment Community subscale. Perception of social support demonstrated 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 univariately significant correlates (except for psychological distress, which was highly correlated with coping [correlation coefficient of

>0.8]), the results remained significant for self-awareness ( $\beta = .35$ ;  $P < .01$ ), new situations ( $\beta = .19$ ;  $P = .05$ ), coping difficulties ( $\beta = -.19$ ;  $P = .04$ ), and social support ( $\beta = .35$ ;  $P < .01$ ), but not sex ( $\beta = -.14$ ;  $P = .11$ ) or sensitivity to others ( $\beta = .08$ ;  $P = .38$ ).

### Associations Between Empowerment and HRQOL Among AYA Patients

Bivariate correlations demonstrated 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 also were found to be significantly associated with HRQOL (Table 3).

Female sex 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 of Self-Awareness was found to be positively associated with total and social HRQOL. The autonomy subscale demonstrated that

**TABLE 3.** Correlations Between Empowerment, Other Covariates, and HRQOL

	Physical	Psychological	Social	Religious	Total HRQOL
Empowerment					
Personal strength	0.45 <sup>a</sup>	0.63 <sup>a</sup>	0.42 <sup>a</sup>	0.29 <sup>a</sup>	0.65 <sup>a</sup>
Social support	0.26 <sup>b</sup>	0.43 <sup>a</sup>	0.40 <sup>a</sup>	0.22 <sup>b</sup>	0.46 <sup>a</sup>
Community	0.21	0.21	0.22 <sup>b</sup>	0.24 <sup>b</sup>	0.28 <sup>b</sup>
Health care	0.41 <sup>a</sup>	0.42 <sup>a</sup>	0.45 <sup>a</sup>	0.27 <sup>b</sup>	0.52 <sup>a</sup>
Total	0.44 <sup>a</sup>	0.58 <sup>a</sup>	0.47 <sup>a</sup>	0.32 <sup>a</sup>	0.63 <sup>a</sup>
Sociodemographic and clinical					
Age at diagnosis, y	-0.18	-0.11	0.01	-0.05	-0.12
Age at survey, y	-0.13	-0.05	0.10	-0.05	-0.05
Sex: 0 for male and 1 for female	-0.35 <sup>a</sup>	-0.39 <sup>a</sup>	-0.35 <sup>a</sup>	-0.16	-0.43 <sup>a</sup>
Partner: 0 for yes and 1 for no	-0.11	-0.09	0.05	-0.15	-0.09
Educational level <sup>c</sup>	0.15	0.01	-0.18	0.15	0.03
Living status <sup>d</sup>	-0.01	-0.07	0.02	0.01	-0.03
Work/school: 0 for no and 1 for yes	0.22 <sup>b</sup>	0.17	-0.09	0.37 <sup>a</sup>	0.20
Children: 0 for no and 1 for yes	0.11	-0.04	0.04	-0.01	0.02
Time since diagnosis, y	0.04	0.03	0.11	0.02	0.06
Disease stage <sup>e</sup>	-0.11	-0.17	-0.04	-0.23	-0.19
Treatment status <sup>f</sup>	0.27 <sup>b</sup>	0.16	0.04	0.10	0.18
Treatment intent <sup>g</sup>	-0.27 <sup>b</sup>	-0.31 <sup>a</sup>	-0.13	-0.30 <sup>a</sup>	-0.35 <sup>a</sup>
Chemotherapy: 0 for no and 1 for yes	0.14	0.18	0.10	-0.05	0.16
Autonomy-connectedness					
Self-awareness	0.14	0.20	0.25 <sup>b</sup>	0.12	0.25 <sup>b</sup>
Sensitivity to others	-0.01	-0.31 <sup>a</sup>	-0.32 <sup>a</sup>	0.07	-0.24 <sup>b</sup>
Capacity for new situations	0.31 <sup>a</sup>	0.36 <sup>a</sup>	0.25 <sup>b</sup>	0.20	0.40 <sup>a</sup>

Abbreviation: HRQOL, health-related quality of life.

<sup>a</sup> $P < .01$ .

<sup>b</sup> $P < .05$ .

<sup>c</sup>0 indicates low/intermediate vocational education or less and 1 indicates high-level vocational education/university.

<sup>d</sup>0 indicates with parent and 1 indicates independent/together with partner (children) or friends.

<sup>e</sup>0 indicates stages I and II and 1 indicates stages III and IV.

<sup>f</sup>0 indicates receiving treatment and 1 indicates completed treatment.

<sup>g</sup>0 indicates curative and 1 indicates palliative.

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.

To assess the independent association of empowerment with the 5 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 ( $\beta = .31$ ;  $P < .01$ ), psychological ( $\beta = .50$ ;  $P < .01$ ), social ( $\beta = .39$ ;  $P < .01$ ), religious ( $\beta = .33$ ;  $P < .01$ ), and total HRQOL ( $\beta = .52$ ;  $P < .01$ ).

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

## DISCUSSION

The results of the current study indicate that AYA patients with cancer who were 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 the current study were comparable to those in a previous study in patients with breast cancer; however, this study only included female patients who were older than patients in the current study sample.<sup>21</sup> The results of the current study demonstrated that the most important factors associated with empowerment in AYA patients were autonomy, sex, social support and coping. This provides beneficial insight into groups that may benefit from support interventions that aim to empower AYA patients. AYA patients with higher levels of empowerment were more likely to be male, have higher autonomy scores, and to receive more social support. These patients also reported fewer difficulties in coping and lower levels of psychological distress. The current study data have demonstrated the importance of high levels of empowerment because this was found to be 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.<sup>22</sup> Although many AYA

patients have developed decision-making skills regarding their own health or life goals,<sup>22</sup> 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.<sup>23</sup> Health-related information should be delivered in a manner that is appropriate to the age of the patient because this is critical in helping AYA individuals learn to cope with their disease and navigate the health care system.<sup>24</sup> The capacity to handle new situations is closely related to the concept of coping. In their relatively short lives, the majority of AYA patients have not encountered many major life events. AYA patients may require more support because they have not had the opportunity to develop skills that 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 that demonstrated 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.<sup>25</sup> Additional support for female AYA patients may be warranted; however, we should not assume that all male AYA patients will require less social support.

Although AYA patients often feel isolated, perceived social support from family and friends contributes to high levels of empowerment.<sup>7</sup> A cancer diagnosis and its treatment lead 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.<sup>26</sup> Not unexpectedly, studies have shown that support from other AYA patients with cancer is incredibly important for this age group in helping them to cope with their disease.<sup>27</sup> In addition, AYA patients want to provide support to their own family and friends 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.<sup>28</sup> Those with high levels of sensitivity toward others, more commonly women, have greater difficulty accepting this realization and therefore feel less empowered.<sup>25</sup> As the results of the current study demonstrate, 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 and the absence of self-worth and appropriate coping skills may all have a negative effect on psychological distress, which itself is a strong negative correlate of empowerment. Last, the results of the current study demonstrate that treatment intent (curative vs palliative) also

contributes to the levels of personal strength. The needs of AYA patients with advanced cancer intensify as they near the end of their lives.<sup>29</sup> The physical changes associated with advanced disease result in a loss of capacity to manage activities of daily living and aspects of medical regimens.<sup>5</sup> 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 to allow patients to maintain a level of autonomy is very important in this phase.<sup>5</sup>

Given the strong correlation between empowerment and HRQOL found in the current study and others,<sup>30</sup> and the relatively high levels of empowerment measured in this AYA sample, strategies to reinforce empowerment in AYA patients should be explored. Interventions could focus on 1 or all 4 domains of empowerment. First, the sense of personal strength can be positively influenced by self-management (ie, 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).<sup>31</sup> Self-management will help patients to manage the medical aspects of cancer by managing life roles (including changes in roles brought by cancer) and managing the psychosocial consequences of cancer.<sup>32</sup> Such a self-management intervention might include cognitive behavioral therapy components such as psychoeducation, cognitive reframing, goal planning, and process evaluation.<sup>33</sup> Second, social support can be enhanced by offering real-life and digital platforms for AYA patients in which they can virtually meet and share information and feelings with peers (unpublished data). For example, online peer support groups and age-specific information portals for AYA patients have been shown to significantly reduce feelings of social isolation, and improve knowledge, self-efficacy, problem-solving skills, and effective interpersonal interactions.<sup>34</sup> With regard to the third empowerment dimension, community, attention should be paid to reframing the perception of AYA patients as a burden to society. The fourth empowerment dimension, health care, can be improved by creating inpatient and outpatient dedicated multifunctional spaces to suit the needs of AYA patients, training AYA-dedicated professional caregivers, and establishing educational programs for health care 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.



The current study has several limitations. First, all participants were treated in a single center and received multidisciplinary care by a dedicated AYA team. Therefore, it could be that the empowerment levels of the current study sample are higher than those of AYA patients treated in other centers in the Netherlands without age-specific care. However, the patients in the current study sample were diagnosed with a relatively advanced stage of disease and were treated intensively, mostly with >1 treatment modality. This might be an overestimation in disease severity of the entire AYA cancer population, in which lower stage disease (cervical cancer, melanoma, thyroid cancer, and brain tumor) treated solely by surgery is more common. Both factors limit the generalizability of the results of the current study. A second limitation of the current study is the low response rate, which is not unusual in studies in young patients with cancer but was even lower than in previous questionnaire studies<sup>35,36</sup> among AYA patients (29% response rate in the current study sample vs 43% and 52% in previous studies). Unfortunately, we do not have information regarding the reasons for no participation. Because demographic data were not collected from the nonresponders, we could not rule out selection bias. Third, empowerment is rarely formally assessed as outcome and to our knowledge a few validated questionnaires exist, particularly for the cancer setting,<sup>6</sup> therefore making it difficult to compare the results of the current study with those from other groups of patients with cancer. Fourth, the cross-sectional design of the current study 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 patients 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 1 member of the multidisciplinary AYA team, or by the psychometric properties of the empowerment questionnaire. Although the CEQ has demonstrated good psychometric properties, to the best of our knowledge the sensitivity and specificity of this instrument have not been tested and there is no validated cutoff point in the cancer setting.

Empowerment is an important factor related to HRQOL in late adolescence and young adulthood. Empowerment levels as measured in the current study were quite high in AYA patients with cancer who were treated in a specialized care center. Low levels of empowerment were associated with low levels of autonomy and social support, female sex, and coping difficulties. Future

research should explore the best ways to increase empowerment in identified risk groups.

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