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The 3-Phase Process in the Cancer Experience of Adolescents and Young Adults

KEY WORDS

Adolescents and young adults
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Background: When confronted with cancer, adolescents and young adults (AYAs) enter a psychosocial trajectory. Previous research has acknowledged the importance of care adjusted to the specific needs of AYAs. To develop AYA-focused care, in-depth knowledge about the experiences of AYAs with cancer is necessary. **Objective:** The purposes of this study were to discover the psychosocial experiences of and their meanings for AYAs enduring cancer, as well as its treatment and follow-up, and to capture the basic social psychological process that shaped these experiences.

Methods: This was a qualitative study in which individual semistructured interviews were conducted with 23 participants aged 15 to 25 years. **Results:** A 3-phase process was identified, which demonstrated alterations in the AYAs' experiences and their underlying meanings: (1) maintaining normal life was essential, (2) normal life was slipping away, and (3) evolving toward a new normal life after treatment. Certain core dynamics were present in these 3 phases. Throughout the cancer trajectory, the AYAs attempted to maintain control, redefine the self, and incorporate their cancer experience to the long-term course of life and had varying expectations of their social networks. **Conclusions:** Understanding the process that AYAs with cancer go through and taking into account their experiences can facilitate better psychosocial care for this emotionally vulnerable population. **Implications for Practice:** Healthcare professionals need to take a patient-centered approach, with a focus on communication, to meet the needs of AYAs throughout the cancer trajectory.

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All young people face a series of major developmental tasks in adolescence, leading them from childhood toward the next phase in life, adulthood. The developmental tasks that adolescents and young adults (AYAs) face are related to cognitive and emotional growth, such as forming identity, developing body image, initiating (intimate) relationships, separating from parents, and decision making to establish goals about future education, profession, or family planning.^{1,2} In general, these developmental concerns can be distressing for AYAs. When, at the same time, an AYA is given a diagnosis of cancer, the significant transition between childhood and adulthood is jeopardized.^{3–5} These AYAs experience life-threatening illness⁶ and additional stressors such as increased dependence on their parents, changes in their physical appearance, isolation, and loss social life.⁷ The compromise between developmental needs for autonomy and independence and the demands of their illness such as dependence, vulnerability, and isolation is challenging.⁸

Previous research has highlighted the importance of psychosocial support for this patient population, by determining the particular needs of AYAs in their cancer trajectory^{9,10} and demonstrating that high levels of unmet service needs in this population were associated with poorer health-related quality of life.¹¹

Coping with cancer may include negative and positive experiences and outcomes,^{6,12,13} but in general, a cancer experience remains primarily distressing with ubiquitous challenges.^{2,14} To what extent AYAs feel burdened by the cancer experience depends on how each one copes with the disease and treatment and is therefore partially individually defined. Although AYAs represent a group with disparate physical, emotional, and social needs,^{15,16} Grinyer^{17(p153)} states that “there is more that unites young adults than divides them.” Despite their differences, AYAs share mutual experiences and have specific age-related needs.

Previous research on cancer in AYAs has categorized the negative experiences of AYAs as distress, related to physical concerns,³ an altered appearance,^{6,18} or fear of dying.⁶ Positive experiences include emotional support of family,¹⁹ increased personal strength,²⁰ or posttraumatic growth.²¹ However, few qualitative studies have focused on AYAs’ self-reported perceptions of their cancer experiences through individual interviews. Some studies have investigated support needs,²² healthcare needs,²³ appearance-related concerns,²⁰ or information needs²⁴ of AYAs, but there is still a lack of empirical research that studies the times across the continuum of cancer care that support is needed.² To improve psychosocial outcomes, the health-illness transitions of 1 phase in the illness to the next should be taken into account.²⁵ Furthermore, there is increasing consensus that the psychosocial care of AYAs should be age appropriate²⁶ and meet their specific developmental needs.^{27,28} The development of such tailored psychosocial care should be informed by evidence as to how AYAs experience their cancer trajectory. Yet, this kind of comprehensive research is rare.

The purposes of this qualitative study were to discover the psychosocial experiences of AYAs experiencing cancer, its treatment and follow-up, and the meanings they attributed to these experiences and to capture the processes that shaped their experiences.

■ Methods

Design

A qualitative research study, based on the principles of grounded theory,²⁹ was undertaken to gain holistic insight in the experiences of AYAs with cancer. This article focuses on the basic social psychological process³⁰ that AYAs underwent during the cancer experience and the meanings they attributed to this process. The AYAs’ psychosocial cancer experiences and their meanings are described in the study of Belpame et al.³¹

Sample and Recruitment

For a period of 1 year, 23 participants, recently given a diagnosis of cancer (in the first month since diagnosis), in active treatment or during follow-up (after the end of the treatment), were recruited on 4 different wards in 1 university hospital—pediatrics, medical oncology, hematology, and orthopedics—because these were the settings where almost all AYAs with cancer are treated. Examples of diagnoses of AYAs treated on these wards include leukemia, osteosarcoma, testicular cancer, brain tumor, and Ewing sarcoma.

The following inclusion criteria were applied: male and female AYAs were required to be between 15 and 25 years old, 15 years or older when given a diagnosis of cancer, and no longer than 5 years in follow-up. After an event-free period of 5 years, one can be regarded as a cancer survivor, which possibly generates a distinct and different perception that is not relevant to this study. A 5-year event-free survival criterion has been used previously in several studies.^{32–35}

Excluded from recruitment were nonnative Dutch-speaking participants, AYAs in palliative care (ie, whose treatment was not aimed at recovery), and participants with nonmalignant or benign tumors.

The initial purposeful sampling intended to achieve situational diversity by means of variation in age, gender, diagnosis, social context, education, and time since diagnosis. As the analytical process progressed, sampling was based on the preliminary findings (theoretical sampling). For example, the data revealed that friends represented an important part of the support network for AYAs. To increase insight into the value and meaning of friendship for AYAs, the study aimed to explore friendship in different situations, such as at school and work. Consequently, the participants recruited after preliminary results were assessed varied in professional and educational status. These participants were recruited on the same 4 wards.

Ethical Review

The study was approved by the ethics review committee of the Ghent University Hospital (Belgian registration number B67020096417). Participation in the study was voluntary. All participants signed an informed consent. For those younger than 18 years, parents gave their signed permission as well.

Because of ethical considerations, the hospital staff member who contacted potential participants, who matched inclusion

criteria, gave only age, diagnosis, and telephone number of the AYA to the researcher. Additional information was provided by the participant during the interview. The researcher did not review each participant's medical record.

Data Procedure

Eligible participants in active treatment were asked in the hospital by a member of the multidisciplinary team whether an independent researcher could contact them within the context of a study. Eligible participants in follow-up were telephoned by a member of the multidisciplinary team with the same question. During the period of recruitment, all newly diagnosed AYAs were invited to participate. The member of the multidisciplinary team who approached the AYA only passed on to the researcher if the AYA was "newly diagnosed," "in active treatment," or in "follow-up." Detailed information on how far the AYA was into the cancer trajectory was not given.

All potential participants received an information letter about the study, and if they volunteered, the researcher contacted them with more detailed information about the interview structure and the study in general. The interviews were scheduled at the hospital or at home, depending on the participant's preference.

Data Collection

Three interviewers conducted an individual 1-time semi-structured interview with each participant, with 1 exception: 1 interview was conducted with 2 participants together, at their request. On average, the interviews lasted 95 minutes (range, 26–185 minutes). All the interviews were audio-recorded and transcribed verbatim.

The initial interview guide included open-ended questions to stimulate the participants to respond in their own words, as well as elicit extensive answers and thick descriptions. The interview guide was developed by the researchers, in accordance with the objectives of the study. Questions from the initial interview guide were as follows: What does it mean to you to have cancer? How have you experienced your illness and treatment until now? Can you tell me more about what it means to be treated in the hospital? What have you experienced as helpful? The first interviews were based on the input of the participants themselves. The interview guide evolved throughout the research process, based on the analysis of earlier interviews. This resulted in more focused interviews; however, they always began with an open start, such as the following questions: What does it mean to you to be alone in the hospital? How do you experience the physical consequences of your illness and its treatment? How do you cope with the information provided? As the analysis progressed, different topics on psychosocial experiences were discussed: impact of the diagnosis, perceptions of the disease on daily life, experiences in treatment and hospitalization, the meaning of consequences of the disease and treatment, ways of coping, experiences with healthcare professionals, expectations of care, psychosocial needs in the cancer experience, and vision of future life. These topics were deepened as the data collection progressed and concepts emerged through data analysis.

Data Analysis

To start, the interviewers read 3 interview transcripts and coded them together, line by line, using open codes.³⁶ This coding was discussed in a meeting with the entire research group, which consisted of the 3 interviewers and 6 other researchers with different disciplinary backgrounds. The interviewers then coded 3 new interviews, using open codes, but this time individually. They compared and discussed each other's coding. After this, they together coded the 6 interviews again, using axial codes. This was followed by a discussion on the coding with the entire research group. As the data were further collected and analyzed in the group in a cyclic process, the method of constant comparison was used to examine the new data, and codes were reviewed, refined, and made more specific, which resulted in the construction of meaningful categories (selective coding). As this iterative process progressed, the entire research group discussed and reflected on the applied codes and categories and worked toward major concepts extracted from the data. In this manner, data saturation was reached.

Through this process of data analysis, second-order concepts were obtained, and theories were developed. These findings transcended individual experiences³⁷ because the experiences of the participants were described on a more theoretical level. Data and coding were managed by using the qualitative analysis program NVivo 8 (QSR International, Victoria, Australia).

Quality

In this study, quality was ensured by executing an audit trail, peer review, and researcher triangulation. Contextual notes regarding the interviews, methodological decisions in the research process, analytical reflections on the data, and personal responses and thoughts were noted in an audit trail. The strategy of peer review was applied as the 3 interviewers reanalyzed all the other data, working toward consensus. During the entire research process, there was researcher triangulation. Using their scientific, practical, or methodological expertise, the researchers discussed the study design, formulation of the research question, interview guide, sampling, and data analysis. The varied backgrounds of the researchers (nursing and social work) contributed to the value of triangulation. In addition, a research committee consisting of different healthcare professionals (physicians, nurses, clinical nurse specialists, social workers, and psychologists) supervised the research process. They critically followed all steps in the research process and formulated their opinion on the findings and, in a later stage, on the AYA box. Participants gave their permission for all researchers to have access to their data.

■ Results

A total of 22 semistructured interviews were conducted with 23 AYAs who were each interviewed once. Nine men and 14 women participated; 4 had been recently given a diagnosis of cancer, 6 were still in treatment, and 13 were in follow-up (Table).

✱ **Table • Demographic Characteristics of the Participants (N=23)**

Stage of Cancer Trajectory	Recently Diagnosed	On Treatment	In Follow-Up	Total
No. interviewees	4	6	13	23
Age, y				
15–19	2	1	7	10
20–25	2	5	6	13
Gender				
Female	2	3	9	14
Male	2	3	4	9
Relationship				
Yes (female AYA)	2	3	4	9
No (female)			5	5
Yes (male AYA)		2	2	4
No (male AYA)	2	1	2	5
Studies/profession				
Secondary school	1	1	4	6
High school		1	5	6
University		2	2	4
Employed	2	1	1	4
Unemployed	1	1	1	3
Wards of recruitment				
Pediatrics	1		5	6
Medical oncology	1	2	3	6
Hematology	2	4	1	7
Orthopedics			4	4

The data analysis revealed that AYAs go through a specific process in the cancer trajectory, starting with the phase of diagnosis moving into the phase of active treatment until the phase of follow-up (Figure 1). Although this process was seen in every AYA, individual experiences were also needed for this to be understood. All AYAs went through this process in their own way, defined by their personal characteristics, specific diagnosis and treatment, and the particular informal networks surrounding them.

In the process, 3 phases were identified: (1) one in which maintaining normal life was obvious and essential for the AYA, followed by (2) a phase wherein the AYA felt that normal life was slipping away ineluctably, and finally, (3) the phase during which the AYA focused on evolving toward a new normal life. These phases should not be seen as delineated phases and as

fixed periods determined in time. The transition of 1 phase to another was primarily induced by challenges the AYA needed to cope with, related to the disease and its treatment, instead of a specific moment in time.

As the cancer experience progressed and the AYA's endurance was tested, the AYA developed different views on the cancer experience and faced new challenges. Thus, throughout the 3 phases, certain dynamics were shaped, which demonstrated alteration in the AYA's experiences and the underlying meanings. As a consequence, the AYA experienced different psychosocial needs at the beginning of this trajectory compared with during it or at the end. The data revealed certain expectations that the AYAs had of their informal and professional networks, in which they were situated. These are described within every phase. From this point, the AYA is referred to in the masculine form to facilitate reading.

The 3 Phases in the Process of AYAs Experiencing Cancer

PHASE 1: "MAINTAINING NORMAL LIFE"

As demonstrated in the data, living his endless life to the fullest, the AYA experienced the cancer diagnosis like a bomb going off. Seldom devoid of indication of symptoms and without any logic, the cancer struck the AYA suddenly, leaving him deprived of all his senses. To cope with this verdict, the AYA put it in a temporary perspective that understood his illness as a transient occurrence, after which everything would go back to the way it was before. As 1 AYA said, "As my treatment will be finished at the end of the summer, I will restart my life, and I will go back to school and start my studies. That is totally achievable." Because everything happened quickly in this phase of the cancer trajectory, perceiving the cancer experience as a transient occurrence, limited in time, made it manageable and gave the AYA a sense of control. As a first expectation, the AYA needed everything outside the cancer experience to remain normal. As 1 AYA stated, "A friend of mine sent me a text message: 'I didn't pass my exam' but 10 minutes later, she sent: 'That's not important, what you are facing is worse.' But the fact that she sends normal things to me makes me happy because she just acts normal with me."

During hospitalization, the AYA wanted to continue his own way of living (eg, diet, sleeping habits, use of Internet, etc).

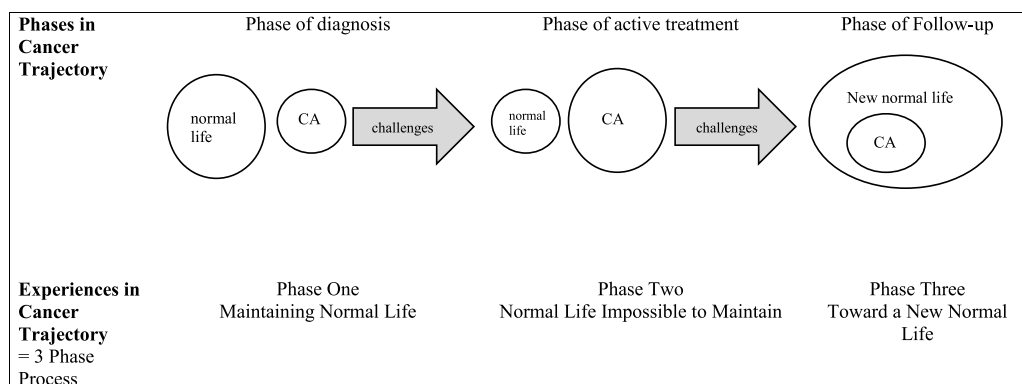


Figure ■ A 3-phase process in the cancer experiences of AYAs.

Maintaining a normal life was as obvious as essential for the AYA because it did not occur to him that his life beyond the cancer experience could change. The conviction that the disease was a temporary condition without far reaching consequences strengthened the assumption that the AYA did not need to adapt to cancer. Cancer befell him without a particular reason so the AYA wanted to spend only the energy needed for a cure and found it important that his way of living remained the same. Therefore, he appreciated it if family and friends behaved normally as well. Having fun, being updated about all occurrences in daily life by his friends, was essential for the AYA. Thus, as a second expectation, the AYA needed everyone to behave normally and to treat him no differently than before. An AYA said, "I don't want to be wrapped in cotton wool. I prefer not to be reminded of it [the cancer], I prefer that everybody behaves like I am just a normal person." To cope with the cancer experience, a positive attitude was essential for the AYAs. The presence of friends encouraged them to maintain positive thoughts. The presence of parents prevented them from feeling alone so the AYAs wanted their parents with them at all times. At least 1 parent (mostly the mother) was practically permanently present or immediately reachable for the AYA, who considered this essential. Seeing the cancer experience as a bounded period encouraged the AYA to hold on to a positive attitude. To safeguard this, the AYA avoided challenging situations and confrontations.

Another expectation derived from the data was that the AYA did not want to get involved with other AYAs with cancer. In the interviews, many AYAs declared that support of family and friends was sufficient. One AYA explained, "I did not want to go on a holiday with other cancer patients, I rather go with my scouts. Activities, I want to do them with the people I know, with normal people. To have fun together and not to be confronted with diseases and so on."

MAJOR CHALLENGE

In this initial phase, it appeared that it was extremely difficult for AYAs to cope with alterations in appearance, as a result of the disease and treatment. Physical consequences like alopecia or weight loss made the disease apparent and violated the identity of the AYA by demonstrating to him, as well as others, that there was something wrong. A changing appearance undermined the AYA's state of mind completely. A deviant appearance emphasized the abnormal and the unknown which challenged the positive attitude of the AYA. An AYA said "I could not bear looking in the mirror, having no hair, wearing a scarf. I looked ill."

PHASE 2: "NORMAL LIFE SLIPS AWAY"

This second phase was characterized by the supremacy of the cancer over the AYA's ability to maintain a normal life; the AYA could no longer evade the comprehensive impact of the disease and its treatment. He had to endure invasive therapies and surgical interventions, which left him with pain, sickness, and physical limitations. In this phase, the AYA focused on managing the illness and its treatment to get cured. Maintaining a normal life was no longer a priority. Besides, even if he wanted

to, attempts to maintain a normal life were seldom successful; for example, studying was impossible when the AYA experienced chemotherapy adverse effects. Often, it was not until this phase that the AYA truly understood the life-threatening character of the disease. An AYA explained, "It was only then, after my first chemos, when I started to feel the pain, that I realized everything. That was the hardest time for me, then I felt really downhearted."

At the same time, the AYA had less contact with friends. The AYA received a lot of visits, telephone calls, or messages in the beginning of his trajectory, but now, the AYA reported that he got to know his "real friends." An AYA said, "Once you're ill, then you see who your true friends are. I truly experienced this.... Some friends that I've expected to visit me just didn't come. People you really could expect to visit me." The AYA found that friends were afraid to contact him because they did not know how they should react or because they felt insecure about what they could do for the AYA.

With the decreasing frequency of visits and contacts with friends, the AYA was cut off from his normal life. The connection that the AYA used to feel with his friends was jeopardized because the normal lives of friends continued, whereas his life was frozen by the cancer experience. An AYA said, "There was a time that I did not want to see sunlight. If you are hospitalized in summer and you see everybody out there, while you are trapped inside.... For sure, my curtains remained closed!" Some AYAs who felt like outsiders became interested in meeting other AYAs with cancer, in search of recognition or social acceptance.

An important finding was that the AYA wanted to direct the support he received. The AYA managed his remaining informal network so that friends were there for him, but only when he needed them. For instance, when the AYA experienced nausea or when he endured severe pain, he did not feel like having a lot of people around him. One AYA explained, "I indicated them (friends) that I rather preferred them not to visit me because when I was sick, I hardly could talk anymore. I just wanted to sleep and just...yeah, they had to leave me alone." Real friends were those who supported the AYA in the way he preferred to be supported.

MAJOR CHALLENGE

In comparison with the initial phase, physical alterations such as alopecia were put in perspective. An AYA declared, "At first, I found it so terrible that my hair needed to be cut because it was so long. But now...That's just something that really doesn't matter if you have such a disease. It comes along with it and it will grow back. I definitely don't upset myself about it anymore." More challenging in this phase was the experience of overall loss and distress. The AYA lost control as cancer determined everything; he was bereft of personal freedom and autonomy because he became dependent (again) on others for personal care, financial aid, or practical support, both in and out of the hospital. An AYA reported, "The worst thing is that I lose my independence. It looks like I need to move back to my parent's place. If it's not necessary, I won't do that. I'm really not looking forward to this!"

PHASE 3: "TOWARD A NEW NORMAL LIFE"

This phase began at the end of the treatment trajectory. The AYA was released from the hospital, the treatments were finished, and contact with healthcare professionals reduced. This was the moment the AYA had anticipated. Nevertheless, in contrast with his initial belief, the AYA declared that picking up the threads of his life was difficult. The world around him did not feel the same anymore; everything from his former world kept on evolving while his life was frozen during the entire cancer trajectory. This complicated the (re)connection with family and friends. An AYA said, "I had to go to this wedding and you know it's going to be hard but still you want to do that. And then, you see your friends, still having fun and then you think 'Why not me? Why can't I just be normal, like all my friends... just dancing?' That is the hardest thing for me."

Although the AYA's life was put on hold, the development of his identity was not. All AYAs declared that, throughout the disease and its treatment, they had become different people. The AYAs felt that the cancer experience was not a temporary occurrence, as a first thought, but an experience that they would carry for the rest of their lives. An AYA said, "Cancer is something that is with me, every day. Not that I necessarily talk a lot about it but inside, I carry it with me, like in a backpack." Besides possible permanent limitations (eg, an amputation), the cancer experience seemed to have had a significant impact on their identities.

The AYAs declared that they had developed a new view on life, which could be positive or rather negative. Some AYAs perceived the cancer experience as a distinct lesson in life, saying that the confrontation made them more mature or that it taught them to appreciate simple things. As 1 AYA said, "I'm not going to say that I have defeated death but it is something in the back of my head... It's like, I know I was lucky and now I am truly going to make something out of my life."

MAJOR CHALLENGE

In this phase, many AYAs felt alienated and did not know how to manage all the challenges after treatment had ended. The AYAs stated that they struggled with finding a new direction in life, for instance, concerning studies or employment. They had to deal with a lot of insecurities or fears, such as fear of relapse, fear that others would appreciate them less because of their cancer histories, or the insecurity of not finding a partner. An AYA said, "I have the feeling that I am now, after the treatment, more at a loss to know what to do, than during treatment, especially psychologically it's difficult." Some AYAs explicitly expressed the need for professional guidance for the psychosocial challenges they faced.

The Dynamics in Transitioning the 3 Phases

Underpinning the 3 phases, the following core dynamics could be distinguished. These dynamics could not be attributed to specific moments in time.

FROM "HAVING THE WORLD IN OWN HANDS" TOWARD "REALIZING THE INABILITY TO HAVE EVERYTHING UNDER CONTROL"

Before the diagnosis of cancer, the AYA felt quasi-invincible and, as he was becoming more independent from his parents, experienced

a growth in control over his own life. When he was subjected to an unpredictable disease and its treatment, the AYA lost this sense of mastering life and became more aware of his own vulnerability. This feeling of vulnerability was affirmed by the permanent physical limitations and the psychological changes due to the disease and treatment and the fear of relapse. An AYA explained, "Recently I had a sore throat and I felt a swollen gland. I became crazy! I called my physician immediately who took a blood sample. Fortunately, it was all okay, a weight off my shoulders, really. I think this fear will stay forever."

From "Having A Familiar Identity" Toward "The Quest For A New Identity"

During active treatment, the AYA lost the identity he had created before the diagnosis. The physical alterations changed his self-image and influenced the AYA's feelings of personal freedom and independence. Things the AYA used to take for granted in life, such as finding a partner, having a family of his own, or entering a good profession, became uncertain. As 1 AYA said, "I'm afraid that in the future, a possible employer will choose someone else instead of me. Imagine that I become a very good educator and that an employer would prefer someone not that good as me just because this person does not have physical limitations... I really ask myself how this will turn out for me in the future." The AYA felt forced to redefine his self and his capabilities.

FROM "SEEING CANCER AS SOMETHING FAR AWAY" TOWARD "LIVING WITH CANCER IN A BACKPACK"

Before they became ill, most AYAs considered cancer as a disease of elderly people. The data demonstrated that they perceived cancer as something far away. At diagnosis, they perceived cancer as a temporary occurrence, in the here and now. In follow-up, some AYAs started to wonder what the impact of their cancer trajectory would be in the course of life. They realized that this experience would remain present somehow and that they would take it along with them forever. An AYA told, "It is a part of my life and it will stay a part of my life."

FROM "LIVING A NORMAL LIFE" TOWARD "CREATING A NEW NORMAL LIFE"

Throughout the process, the normal life of the AYA crumbled away. Initially, he tried to maintain this normal life because he still saw cancer as a temporary, passing experience, but as time passed, he realized that this was not possible. When the treatment ended, the AYAs needed to construct a new normal life, which was challenging for many of them. An AYA stated, "I lost a part of my life and I found this really difficult. Every week, I trained [cycling], for hours. I lost all of this. Now, I need to find something to fill this gap."

From "Having A Familiar Network" Toward "Identifying Renewd Meaningful Relationships"

Initially, the AYAs were not interested in meeting other AYAs with cancer. They declared that the friends they had were all they needed. This changed throughout the illness trajectory. Because

a considerable number of AYAs found that former friendships changed or faded away, they needed to find “new” connections and acceptance with peers. At that point, many of them wanted to contact other AYAs with cancer, because as 1 AYA explained, “If I talk to others who had cancer, I feel less of an outsider.”

The AYAs who had a partner before they became ill reported changed dynamics in their relationships. Some relationships came to an end. An AYA told, “My boyfriend became jealous and started to check me out. I had the feeling that he had lost control because he used to feel responsible about me. He took care of me but then, this wasn’t the case anymore. I felt him having difficulty with this. In the long run, he forbade me to see my friends any longer. That was the final straw.” One AYA, still together with her boyfriend, stated, “When we used to be together every day, I didn’t realize anymore how much I loved him. But now I see him like one or two hours a day, now I know again how it feels to miss him. Now I realize that I truly love him.”

The AYAs stated in the interviews that the cancer also had an impact on the relationship they had with their parents. Many AYAs declared that the relationship became more intense. The AYAs experienced an increased need for support from parents because it became too difficult to deal with the cancer experience alone. Often, AYAs stated that their parents had become more protective, which was sometimes difficult to handle once they needed to regain their independence in life after treatment ended. As 1 AYA said, “Towards my parents, it is more difficult. They are very well organized and well-structured and I prefer to do whatever I want now. If I want to travel to Africa, I will do that.... I try to avoid stress as much as possible. I want to take it easy. Sometimes, my parents do not understand this. I have changed as a consequence of my experience.”

■ Discussion

Adolescents and young adults with cancer go through a distinct biopsychosocial process during their illness trajectory. This dynamic 3-phase process offers understanding in how AYAs, throughout the cancer trajectory, attempt to maintain in control, how they redefine the self, what their experiences add to their long-term course in life, and how their expectations of their social networks change.

Having a sense of control is of great importance for the AYA. When cancer has taken over the life of the AYA, regaining a sense of control is crucial for his recovery process.² The formation of a new identity and a new normal life in the process allows the AYA to regain control.³ This can be facilitated by empowering the AYA to make his own decisions during treatment,²⁷ which demands a certain flexibility from healthcare professionals.³⁸ To meet the changing needs of an AYA, it is crucial that the AYA’s development is considered^{39,40} and that psychosocial interventions are offered across the total disease trajectory.⁴¹ For instance, Zebrack et al⁵ suggest that giving the AYA the opportunity to define how much information he wants and when should be a constant throughout the continuum of care.⁵ They also found that AYAs ranked opportunities to meet other AYAs with cancer significantly higher later in the trajectory. This is similar to our

finding that the need of AYAs for peer support increased as they went through the different phases.

Previous research indicated that, depending on the phase of the illness, certain views or expectations may differ.^{20,27,42} The findings in this study emphasize the variation in the AYAs’ needs throughout the cancer experience. What an AYA finds essential today may not be a priority tomorrow. For instance, an AYA can be very preoccupied with hair loss initially, which prompts wearing a wig or learning beauty techniques. However, this concern may assume less importance when the AYA needs to cope with a limb amputation. Our findings support Millar et al⁴³ who argued that the needs of AYAs are phase sensitive, for example, on treatment, and that the needs for age-appropriate hospital care, food, and activities are often unmet. After treatment has ended, emotional and psychological needs, such as support in coping with identity changes and a new direction in life, become primary. Because cancer not only determines the life of AYAs during diagnosis and treatment but has a profound impact on their future lives as well, psychosocial interventions should be implemented across the entire disease trajectory and even into long-term survival.^{41,44,45}

The demonstrated importance of normality, as well as its changing nature, from losing the “old normal life” toward the creation of a “new normal life,” confirms previous research.^{17,20,42,46} In this process, adjustment to the disease is an essential phase, which can consist of negative and positive aspects. Similar to our findings, in a study by Mattsson et al,¹² AYAs reported positive aspects, such as developing a more mature view on life, as well as negative aspects, including worries about relapse. How an AYA adjusts to the cancer experience translates into the development of a new identity. This is affirmed by Park et al⁴⁷ who stated that the identification of the AYA with a “survivor” or with a “person who has had cancer” influences their well-being. As our findings show, after treatment ends, many AYAs feel alienated and somewhat confused about how to go on with life. This is similar to studies of Cantrell and Conte⁴⁸ and Thompson et al¹ who pointed out that AYAs are often unprepared as they move out of an intense healthcare regimen toward follow-up care. For many AYAs, it is not until the follow-up phase that they start to process all the things that they have experienced.⁴⁹

It was clear in this study that AYAs had close relationships with their parents. The AYAs needed their parents “being there,”⁵⁰ which is also identified as a parental need in pediatric oncology.^{51–53} The AYAs considered the need for their unconditional presence and support to be self-evident. They found it essential to manage the support they would receive from them. Evidence is growing that psychosocial care from informal networks, as well as from healthcare professionals, is equally, if not more, important after than during treatment.⁵⁴ Psychosocial support should be made available as part of transitional services in a multidisciplinary approach.⁵⁵

Implications for Practice

By highlighting an underlying process, which includes 3 different transitional phases, this study demonstrates the importance of holistic care and patient-centered interventions throughout the

cancer trajectory. Examples of these interventions may be multidisciplinary consultations during treatment and in follow-up, network meetings,⁵⁶ promoting peer support in follow-up, and coaching parents in the process of balancing protection and facilitating independence for AYAs. Healthcare professionals are challenged to help AYAs in responding to the different challenges and needs they experience. Understanding the process the AYAs undergo can be the necessary first step. In a culture of increased development of clinical pathways and standardized care, the self-reported experiences of AYAs emphasize that an individual approach is still of value. Different from younger children, AYAs are growing into independence, which can be demonstrated in changing preferences or nonconforming behavior. Therefore, an open attitude and a willingness to communicate by healthcare professionals can improve patient outcomes.

Healthcare professionals should pay special attention to the dynamics underpinning the 3-phase process because these demonstrate how AYAs' experiences and needs change during the cancer trajectory. Thus, our theory highlights the importance for healthcare professionals to strive for individualized and flexible care. This requires an open approach in which healthcare professionals are willing to start a dialogue with AYAs to discover their needs and wants.

Following our theory on the 3-phase process, the "AYA box" was developed, which was based on the experiences and needs of the AYAs with cancer that were revealed in this investigation. This patient-centered box was developed to meet the AYA's specific needs and to enhance the communication between the AYAs, their informal networks, and professional caregivers. The box and its contents were attractively designed and youth based. The box includes several tools, addressed to the AYAs, which can be of value throughout the 3 phases of the cancer experience. It contains a booklet with meaningful stories of AYAs' experiences. We developed cards that express the AYA's preferences in phase 1, to continue his own, normal way of living during hospitalization. Other postcards aim at creating more openness in communication with the AYA's network. These resources meet the AYAs' needs to direct their own care and have a voice in decision making, which is of value in phase 2. For instance, there is a postcard on which the AYA can mark expectations of healthcare professionals: a "Code for Good Practice." With this tool, the AYA can inform his physician that he prefers to receive all medical information in the presence of a loved one. A brief symptom scale is available on which the AYA can score his psychosocial concerns, such as loneliness, feelings of guilt, or tension. Other postcards can be used to let friends and parents know how the AYA feels about them. Inside the box, there is a unique AYA tag, the meaning of which is known only to other AYAs with cancer. With this tag, the AYA can mark his door during his stay at the hospital. In this subtle way, the AYA lets other AYAs with cancer know that he is there and willing to meet them. In addition, special stickers were developed to express feelings or concerns. These tools are in line with the AYAs' psychosocial challenges that are faced in phase 3. Cards with information or instructions, for example, about how to deal with physical alterations or about where to find trustworthy advice on the Internet, are included in the box as well. We also

designed cards that help the AYA to reflect on past experiences and encourage him to describe expectations for the future. This may help the AYAs express what kind of professional guidance they may need after the end of the treatment. Adolescents and young adults given a diagnosis of cancer receive this box and are often encouraged by healthcare professionals to use the tools. These tools can also be used by healthcare professionals in their counseling. The box was brought before several AYAs with cancer to elicit their opinions. On the basis of the first positive evaluations, it has been introduced into practice in several hospitals and will be evaluated in future research.

Strengths and Limitations

In this study, valid findings were obtained, and data saturation was achieved. Some limitations can be noted.

All participants were recruited in 1 setting. This may have consequences for external validity.⁵⁷ In addition, sampling was in the beginning heterogeneous and was later followed by more theoretical sampling,⁵⁸ common in a grounded theory approach. Core concepts of meaning for all participants were identified, irrespective of the sampling. However, if the aim was to further deepen a specific theme, for example, physical alterations, then the sampling method could have been too variable. In that case, it would have been advisable to sample more homogeneously on diagnosis or pathology, resulting in more insight in, for instance, the difference in meaning of physical alterations for an AYA with leukemia and for one with an osteosarcoma.

This study focused on the experiences of AYAs in curative cancer treatment. The findings cannot be generalized to AYAs who are in a palliative phase.

At the end of their cancer trajectory, AYAs have reached a different perspective on the disease and its impact than in the beginning. Moreover, the cancer experience has touched every aspect of their self, leaving traces on all domains of life. As mentioned previously,^{46,59} not all these changes can be attributed solely to the cancer experience. Adolescence is a distinct period, in which several life events change the ways maturing AYAs feel and think. It cannot be determined whether certain developmental aspects are related only to the cancer experience or are part of the "normal" development of adolescence.

Implications for Future Research

It may be that the cancer experience for an AYA who knows that he is in a palliative phase has other meanings than for the AYAs who were included in this study. This would be an interesting focus in future research.

Future research can also focus on support for AYAs and their parents during transition from active treatment into follow-up. Developing and evaluating psychosocial interventions that respond to the process that AYAs go through during this phase are needed to optimize care for AYAs.

Conclusions

This article reveals the dynamics in the experiences of AYAs with cancer. In this process, 3 phases are described: "maintaining a

normal life,” “normal life slips away,” and “toward a new normal life.” In these phases, AYAs develop different views on the impact of the disease in their lives, and their identities are reformed. Furthermore, the process demonstrates distinct needs and expectations of AYAs toward their informal and professional networks throughout the cancer experience. Understanding and taking this into account can facilitate the development of psychosocial interventions for this distinct population. Healthcare professionals are specifically encouraged to take a patient-centered approach with a focus on open communication to explore the varying needs throughout the cancer trajectory.

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