# Coping Strategies of Jordanian Adolescents With Cancer: An Interpretive Phenomenological Analysis Study

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## Abstract

Interpretive phenomenological analysis methodology was used to explore coping strategies used by hospitalized Jordanian adolescents with cancer. In-depth face-to-face interviews were conducted with 10 Jordanian adolescents, aged 13 to18 years, who were receiving chemotherapy for cancer. During treatment, participants were confronted with physical, psychosocial, and emotional distresses resulting from the disease process, the treatment, and its associated side-effects. To cope with the impact of their illness, participants utilized 4 coping strategies: “Strengthening spiritual convictions,” “Being optimistic and rebuilding hope,” “Enhancing appearance,” and “Finding self again.” The findings of this study can assist health team members to promote positive psychological care to Arab Muslim adolescents with cancer in a supportive and therapeutic treatment environment.

## Keywords

adolescents, coping, interpretive phenomenological analysis

## Introduction

Cancer is one of the leading causes of death among adolescents worldwide (Bleyer, O’Leary, Barr, & Ries, 2006; National Cancer Institute, 2014; World Health Organization, 2014). In Jordan, the incidence of cancer in adolescents is 159 new cases per 100 000, of which 15% die within 1 year of diagnosis (Tarawneh, Nimri, Arkoob, & Zaghal, 2009). While advances in cancer treatment continue, many adolescents with cancer continue to have a poor prognosis. They continue to undergo complex medical treatment that affects their physical and psychosocial well-being and experience prolonged periods of hospitalization that separate them from their family and friends (Nadége et al., 2002; Pizzo & Poplack, 2006; Whelan, 2003; Woodgate, 2005; Woodgate & Degner, 2005).

Adolescents with cancer face many physical and psychological challenges throughout their treatment and beyond (Woodgate, 2005; Woodgate & Degner, 2004). Their illness alters their physical appearance, places limitations on their capabilities, and affects their social and psychological well-being. For example, adolescents may suffer loneliness and feeling of isolation due to frequent and prolonged absences from school and separation from their healthy counterparts. They may have limited physical ability due to treatment, uncertainty about the future, and doubts about their sexuality (Bleyer et al., 2006; Collins et al., 2000; Gibson et al., 2005; Hedström, Haglund, Skolin, & von Essen, 2003; Hinds et al., 1999; Kameny & Bearison, 2002). As a result, they can become tense, anxious (Enskar, Carlsson, Golsater, & Hamrin, 1997; Ishibashi, 2001; Neville, 1998; Woodgate, 2006) or depressed, experience changes in their self-esteem (Prouty, Ward-Smith, & Hutto, 2006), and develop feelings of low self-worth (Hicks, Bartholomew, & Ward-Smith, 2003; Parry & Chesler, 2005; Pendley, Dahlquist, & Dreyer, 1997). All of these reactions may alter normal developmental processes. Health team members need to help adolescents develop positive coping styles and help them adjust to the changes that are occurring.

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Coping can be defined as the methods that human beings follow to challenge and overcome the negative experiences they face (Zastrow & Kirst-Ashman, 2013). Adolescents with cancer use cognitive or behavioral techniques to cope with the physical and psychological challenges they are experiencing (Franks & Roesch, 2006; Kyngäs et al., 2001; Wu, Chin, Haase, & Chen, 2009). A Finnish study conducted to explore the coping mechanisms of adolescents aged 16 to 22 years found that the major coping techniques used were social support and getting back to normal life as soon as possible (Kyngäs et al., 2001).

Several other studies emphasized the importance of social support in the process of coping (Hinds, 2000; Parry & Chesler, 2005; Woodgate, 1999, 2006). Positive thinking and belief in their own power were also effective coping techniques used by adolescents in a Swedish study (Enskar et al., 1997).

Other researchers reported hope as a positive coping technique (Haase & Phillips, 2004; Hendricks-Ferguson, 2008; Hinds, 2004; Hinds et al., 1999; Hinds & Martin, 1988; Kyngäs et al., 2001). Building hope increases adolescents' self-esteem (Hinds, 2000), self-worth (Snyder et al., 1997), feelings of control (Hinds, 2000), and quality of life. Other positive coping techniques that some adolescents use are adherence to religious rituals (Hendricks-Ferguson, 2006, 2008; Kyngäs et al., 2001; Prouty et al., 2006), seeking information, positive expectations/optimism, and seeking guidance/support (Franks & Roesch, 2006; Wu et al., 2009).

The related literature in this area of study is based on research conducted in Western societies, which have a different cultural context compared to Arab countries, such as Jordan, where the majority of adolescents are Muslim and Arab. The present research aims at describing the experiences of the Muslim Arab adolescents with cancer.

## Methodology

Qualitative research and interpretive phenomenological analysis (IPA) methodology were used as they are particularly useful when little information is available on the phenomena under study (Witt & Ploeg, 2006). The primary objective of IPA is to obtain a detailed description of the individuals' lived experiences in their natural context (Speziale & Carpenter, 2007).

### *Ethical Approval*

The ethical approval for this study was obtained from Jerash University Ethical Committee and the Jordanian Ministry of Health Human Research Ethics Committee to conduct the study at Al-Bashir Hospital. Al-Bashir Hospital is one of the largest and busiest referral hospitals in Amman, the capital of Jordan.

### *Sample and Setting*

Ten adolescents were recruited for the present study based on the following criteria: (*a*) aged between 12 and 18 years, (*b*) aware of their cancer diagnosis, and (*c*) have the ability to speak and understand the Arabic language.

A snowballing technique was used to recruit participants. At the beginning, researchers posted flyers about the study on notice boards in the Haematology Unit asking adolescents who were willing to participate to call one of the researchers. When they contacted the researcher their eligibility to be part of the study was assessed, and if they met the criteria, an information sheet and consent form was left in a sealed envelope at the nursing desk in the Haematology Unit for them to collect. They were asked to contact the researcher again after they discussed the study with their parents if they wanted to proceed to participate in the research or if they or their parents had further questions they wanted to discuss with the researchers. In accordance with Jordanian Ministry of Health laws, any adolescent aged less than 18 years is required to have their father's consent to participate in this study. Hence, consent was obtained from adolescents and their fathers.

### *Interview Process*

One of the researchers, who has long experience in interviewing patients and has counselling experience, conducted face-to-face, in-depth interviews with the participants in a mutually agreed upon place. Written consents were obtained from the participants and from the fathers of adolescents aged less than 18 years. Each interview lasted between 50 and 90 minutes. Participants were asked to tell their story of living with cancer from the moment they were diagnosed until the day of the interview. Participants were also given the chance to reflect on the interview and document their own notes and send them to the researcher after the interview. They were informed that they could withdraw from the interview at any time without any consequences. In addition, they were assured of their confidentiality in any reports or publications resulting from the research.

### *Data Collection and Analysis*

Interviews were USB recorded and transcribed verbatim by researchers into Microsoft Word Office to facilitate its entry to QSR© NVivo8 software. The QSR NVivo8 software facilitated the management and the coding of the transcribed data, easing the extrapolation, emergence, and identification of the themes. Data analysis involved adhering to the 6 phases described by Smith, Flowers, and Larkin (2009). Descriptions were read several times and substantial notes were generated and summarized. From these initial and substantial notes, subthemes emerged. Further collapsing occurred in the next step by searching for connections across the subthemes to generate the main theme. The procedure was repeated with each participant. The last phase brought themes together and established connections among them.

### *Trustworthiness*

Two different researchers analyzed the data independently, and the similarities and differences were discussed until a consensus concerning the themes and the subthemes was achieved. Furthermore, all the researchers audited data to ensure the rigor of the interpretation and the description of the findings. The researchers saved all the papers and the records of the research to allow for audit trails to further increase the credibility of the research findings.

## Results

Five male and 5 female participants, who received chemotherapy, took part in this study. Of these participants, 3 were aged 13 years, 2 were 15 years, 4 were 17 years, and 1 participant was 18 years. Participants were diagnosed with leukemia (n = 4; 40%), Hodgkin’s (n = 3; 30%) and non-Hodgkin’s lymphoma (n = 3; 30%). All participants were diagnosed within 9 months of the data collection period and were receiving chemotherapy treatment. Four themes emerged: “Strengthening spiritual convictions,” “Being optimistic and rebuilding hope,” “Enhancing appearance,” and “Finding self again.”

### *Strengthening Spiritual Convictions*

Almost all participants strengthened their spiritual beliefs and relied on their religion. All the participants in this study were Muslims; hence, they made use of their Islamic rituals to adapt to life with cancer. However, the participants followed the Islamic rituals in varied ways according to their understanding of faith. Some were actively looking for a supernatural power that would be able to cure them. This power helped them enhance the quality of their life and could help them defer the bad consequences of cancer. In many occasions, the patients believed that such a power could directly treat the disease. According to Muslim beliefs, Allah [God] can resuscitate people after death, which makes it very easy for Him to help cure a person suffering from cancer. For instance, Participant 1 believed that medical treatment and Allah’s will together were the basic requirement for his health improvement, and without Allah’s will, a medical treatment, like chemotherapy, would not be of any help. Therefore, he strengthened his belief in Allah as shown in the following part of the dialogue with him:

> I’ll be cured. [Researcher: What is the thing that will help you to be cured?]. The wish of Allah, then medicine [is what is helpful]. I mean there is a long time for curing but under the wish of Allah, I’m 95% confident that I’ll be cured. (Participant 1, male, 13 years old)

Muslims believe that Allah tests their beliefs and the strength of their faith at various occasions. They also believe that Allah always chooses the best for his people. Participant 2 was not scared of having cancer and she saw it as a test from Allah. She viewed her cancer as the right thing from Allah for her at the time, because, from an Islamic perspective, one should be satisfied with his/her lot as things could have been worse. Based on such a belief, she accepted her cancer as a test from Allah and she decided to fight and defeat it. This is demonstrated in the following part of the interview with her:

> No, this is [cancer] something from Allah and anything from Allah should not be scary. [Researcher: why?] Because Allah is the most merciful. Because it is a test from Allah and I should succeed in it. (Participant 2, female, 17 years old)

Muslims also believe that the Holy Qur’an is a miraculous way of treatment. Reading the Qur’an comforts exhausted souls and cures ill people. For example, Participant 10 read the Qur’an when he was tired and tense to help him relax:

> [Researcher: What did you do to stop sadness?] My family encouraged me to read Qur’an whenever I felt tense and/or was tired. I have been reading the Qur’an every day for long hours and I feel much better. (Participant 10, male, 13 years old)

Given the ubiquitous presence of Islam in participants’ lives, they depended on Islamic rituals to cope with their illness. Performing some Islamic rituals helped in bringing peace to the participants’ souls and in giving them hope for the future. On the one hand, Islam answered their unsolved questions, such as “why me?” On the other, Islamic rituals gave participants hope for the future as, from their perspective, Allah is capable of curing their disease.

### *Being Optimistic and Rebuilding Hope*

Most of the adolescents were optimistic and in the process of rebuilding hope by being positive regarding their cancer diagnosis. They believed that their type of cancer was not dangerous and their chemotherapy treatment was simple; they also felt that they would become well soon. Such optimistic views were further strengthened by real, positive, and successful stories of other adolescents who had survived their cancer diagnosis. Participant 9 believed that her diagnosis was made early when her cancer was in its simplest form and earliest stages. Therefore, the possibility of a successful treatment was very high, so she was not worried about it:

> I complain of leukemia. This type of cancer is not serious. In addition, it's still in the early stages and the percentage of getting cured is very high compared with other types of cancer. (Participant 9, female, 13 years old)

Participant 8 witnessed many positive and successful stories of patients surviving and adapting well to their cancer. Therefore, cancer was not a scary illness for him:

> When I was at the hospital the first time I saw many people diagnosed with cancer too long ago. One lived with cancer for the last five years and he is still alive. He went to school every day. Seeing such examples gives us hope in future [Researcher: could you please explain more?] witnessing such examples reminds us that cancer is not a serious illness and we can live with it. (Participant 8, male, 17 years old)

Talking about cancer in such a simple manner, participants were trying to trivialize its severity. This allowed them to maintain their hope in the future and increase their cure possibilities.

## *Enhancing Appearance*

Participants tried to hide the physical changes they were experiencing; such changes were the side effects of the chemotherapy they were receiving. They began wearing Hijab (a head cover) and wigs as well as using cosmetics to hide their hair loss. Participant 5 used wigs at the beginning and then she chose to wear Hijab to cover her head. Wearing the Hijab protected her from unnecessary negative censure that she might have otherwise encountered:

> There is no hair and I'm putting on wigs. Mom bought hats and scarves to me to cover my head so that nobody would know if there was hair or not, it's normal, because it is covered. . . . Wearing Hijab will save my face in front of others and I will avoid any awkward situations. (Participant 5, female, 15 years old)

Participant 2 did not wait for her hair to fall out; she rather prepared herself for such an experience in advance. She cut it short like a boy and she got her eyebrows cut as well. She also covered her pale face by using make-up:

> When I lose my hair completely I will cover my head by wearing Hijab. My face look pale now and I am exhausted because of my disease. This is not a problem, I will put some cosmetics and hide all these signs and no one can discover what is hidden. (Participant 2, female, 17 years old)

Male participants did not feel that losing hair was as problematic as their female counterparts did. They cut their hair very short as it was fashionable. Participant 6 usually had a very short haircut. Therefore, there was no change in his appearance after the chemotherapy. When asked if he was losing his hair, he said: "Yes, I am losing it. [Researcher: Is this bothering you?] No (he stressed 'No') because I always cut it very short" (Participant 6, male, 18 years old).

Participants tried to enhance their physical appearance in order to maintain their sense of normality and to avoid embarrassment in front of their friends. However, they did this on their own and without any help and support from the health team members as none of participants mentioned anything concerning the role of health team members in this regard.

## *Finding Self Again*

The prolonged hospitalization, frequent absenteeism from school, side effects of the treatment, and frequent prolonged bouts of pain kept the participants away from their friends and families. This occurred because they felt inferior to their healthy counterparts. To cope with the situation, participants tried to find new ways to express and/or find themselves. Playing electronic games and making new friends in a safe environment were among the coping techniques they used to avoid stigma from those they knew. These activities boosted their self-esteem and made them regain trust and belief in themselves. For example, Participant 4 explained that she spent most of her time playing play station games. She described herself by using the term "winner." These games distracted her from thinking about the disease and provided her with a sense of control, worthiness, and satisfaction. She said,

> I surf the net and I play [on the] play station, it entertains me. I like Resident Evil [a name of a game]. I spend too many hours playing this game. I like it as it does not need too much effort but it needs minds. . . . I keep winning. . . . I keep winning. (Participant 4, female, 17 years old)

Participant 5 found herself again through making new friends from all over the world using the Internet chat rooms. This helped her overcome the limited physical boundaries that surrounded her and her sense of isolation;

she could establish a new social support system through new friendships:

> I spent most of my time surfing the Internet. . . . In particular, I spent my time chit chat with new friends using Pal talk and Facebook. I enjoyed playing Hay Day [a name of a game]. Every day I made new friends from all over the world. (Participant 5, female, 15 years old)

Participant 7 found herself teaching and taking care of young girls who had been then hospitalized due to a cancer diagnosis. It seems that her engagement with others and supporting other cancer girl-patients helped her to feel normal again. She was happy and felt self-worth as this was clearly reflected in her everyday demeanor. She reflected on that by saying,

> In the rest lounge, I found other girls who were younger than I and recently diagnosed. We chit chat together about our illness. She asked me too many questions. . . . I try to help her. (Participant 7, female, 15 years old)

Participants also involved themselves in practicing their hobbies to forget about their cancer, and to establish a sense of self-worth. Cancer drained their physical energy, and as they became less physically active they looked inside themselves to discover their strength. Their intellectual activities, such as playing chess and writing stories and poems, helped them recover and value themselves more. For instance, Participant 3 read stories and wrote poems. He enjoyed such activities, particularly reading stories. He stated,

> I like to read. When I start reading, I forget everything around myself [researcher: everything!] yes everything I even forget my pain and I forget the hospital. Sometimes I write poems as well. (Participant 3, male, 17 years old)

These activities eliminated, or at least reduced, some of the pain and helped adolescents in regaining some of their normal activity within the boundaries of their illness.

## Discussion

Participants reported using different coping techniques. Religion was one major technique. Given the ubiquitous presence of Islam in participants' lives, they relied on their religious belief to empower themselves and cope with their illness. They increased the use of invocations and prayers to overcome their sorrows; this is similar to the findings of Hart and Schneider (1997). This coping mechanism is not limited to Jordanian adolescents; many other studies found that people across different cultures and religions turn to their God in difficult situations (Barrera, D'Agostino, Gammon, Spencer, & Baruchel, 2005; Forgeron, Finley, & Arnaout, 2006; Hendricks-Ferguson, 2008; Ritchie, 2001a, 2000b; Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006).

Adolescents during the early stages of their illness often rely on their spiritual convictions to cope with their crises (Hendricks-Ferguson, 2008). Spirituality, in the present study as well as in other previous studies, buffers the stress of patients with cancer and maintains their thread of hope (Holt et al., 2009; Siegel, Anderman, & Schrimshaw, 2001). People, at times of difficulties, generally return to supreme powers and Gods. Since cancer is a lethal disease and, therefore, death is believed to be its ultimate end, Muslims find Allah as the only resort (Al Omari & Wynaden, 2014). This fatalistic belief is magnified as a result of the significant death rate existing in this age group (Tarawneh et al., 2009). The lack of appropriate communication among adolescents with cancer and with health team members and parents is another contributing factor doubting the quality of the health services provided to them (Al Omari & Wynaden, 2013). The aforementioned reasons provided cancer adolescents with a sense of uncontrollability (Holt et al., 2009), which awakens the need for a supreme power that surpasses the human's abilities; for Muslims, life is the power of Allah. The fatalistic belief of the participants played an important role in empowering them. Therefore, it is important for health team members to rely more on and use such beliefs as essential elements in their teaching and psychosocial plans. There is growing evidence on the importance of integrating religion into medical practice because of the value and meaning it can add to adolescents' lives (Balboni et al., 2007; McCord et al., 2004; Smith, 2009). Thus, Jordanian health team members need to integrate religion in teaching and in psychosocial plans.

Participants in the present study tried to enhance their appearance by using wigs, scarfs, Hijab, and cosmetics to cope with their new distorted appearance. Adolescents in previous studies did the same (Larouche & Chin-Peuckert, 2006; Wallace, Harcourt, Rumsey, & Foot, 2007). There is a significant negative association between the body image and the psychological status (Larouche & Chin-Peuckert, 2006). Participants who looked ill with alopecia were found to be more vulnerable and were easily stressed compared with those who believed that the chemotherapy and cancer did not affect their body image (Price, 2009; Wallace et al., 2007). Furthermore, altered appearances led adolescents, at some certain occasions, to become socially isolated and fearful of public places (Williamson, Harcourt, Halliwell, Frith, & Wallace, 2010; Williamson & Wallace, 2012). Moreover, the alteration in adolescents' appearances caused depression and decreased self-esteem (Novakovic et al., 1996). To avoid these complications, adolescents, in the present study and in previous literature, responded by trying to hide the changes in their physical appearance in order to improve their psychological status (Larouche & Chin-Peuckert, 2006; Wallace et al., 2007). However, the participants in the present study discovered these techniques on their own. Nurses need to be educated about these techniques that should be adopted by health teams and nurses in their everyday support system.

Maintaining hope as well as being positive regarding cancer and all the stressors during illness was another coping mechanism adolescents used to deal with cancer (Enskär & von Essen, 2007; Wu et al., 2009). Participants in the present study refocused on their inner strengths and relied on their personal skills to overcome their limited physical abilities. For instance, participants started to read and write stories and poems, made new friendships, played video games, and helped other patients with the same illness to help them enhance their self-worth and make them feel that they were winners. Adolescents in previous studies used similar methods (Griffiths, Schweitzer, & Yates, 2011; Wu et al., 2009). Some hospitals in Jordan have their own "playing rooms" to encourage adolescents to practice their hobbies; yet many other hospitals do not have them. Hence, there is a need to promote this idea so that all hospitals would adopt it to support adolescents with cancer.

Surfing the Internet to make new friendships with anonymous people was another important technique the participants used. A relatively new technique, still, it helped the participants to overcome their new limited physical abilities. Additionally, participants used such a technique to receive peer support, which they failed to receive from people around them due of their poor physical condition, frequent absenteeism from school, and the social stigma they faced in real life (Al Omari, 2011).

Friendship is another important contributing factor in helping adolescents to cope with their illness that is not mentioned by adolescents in the current study. This is related to the social stigma connected with this disease (Al Omari, 2011). The social stigma caused by this disease needs further research to better understand its nature and how it can be best addressed within the cultural context. What may compensate for the lack of friends' support in the Jordanian context is establishing a significant collaboration between the family members, which in turn supports the well-being of the affected person, especially at an early stage of the diagnosis (Al Omari, 2011). However, in previous research, adolescents relied on their friends' support; they tested their new abilities in front of their friends to receive direct feedback about their level of improvement and to know whether the type of coping mechanism they used was appropriate or not (Enskar et al., 1997; Larouche & Chin-Peuckert, 2006). Friends played major roles in providing adolescents with emotional support compared with their parents as the parents' emotional support is often limited due to the parents' classical role as primary caregivers (La Greca et al., 1995). Having a friend also provides the adolescent with a sense of acceptability among his/her healthy counterparts, which might positively reflect on their psychological and mental well-being (Kyngäs et al., 2001).

Previous studies identified other coping styles used by cancer patients who were diagnosed with cancer for a long period of time. Those patients tried to help the patients who were newly diagnosed with the disease (Kyngäs et al., 2001; Stegenga & Ward-Smith, 2009). They felt that they were paying back others by helping new cancer patients. They, therefore, felt happy and satisfied with this new role (Stegenga & Ward-Smith, 2009). However, this is not practiced at Jordanian hospitals. There is a need to activate this trend in Jordanian families and establish support groups consisting of adolescents with cancer, their parents, and the health team members. Such people usually have long term experience with cancer, giving them the ability to play an important role in helping the newly cancer-diagnosed adolescents.

Finally, there is a need to keep reminding adolescents with cancer and their families of the old saying: "Cancer is a word, not a sentence."

## *Implications for Nursing*

Health team members require education in the area of psychosocial interventions that can be used with adolescents coping with cancer. A more supportive structured approach to supporting the development of effective coping skills in this group of patients would provide greater support to adolescents and their families and also facilitate their ability to cope with the physical changes resulting from their illness and treatment. While the findings of this study show that Jordanian adolescents used various coping mechanisms that were similar to those used by adolescent with cancer in Western countries, they used these without any planned support from health team members. There is also a need for family education to provide families with strategies that they can use to provide effective support to their family member.

Participants in this study relied on new technology, such as the Internet, to communicate with their peers and to make new friendships to overcome problems concerning the confined physical space during their periods of hospitalization and their limited physical abilities due to their illness. Participants reported that this method of communication was helpful to them and hospitals could initiate more formal chat groups to encourage adolescents with cancer to get involved in community life. By doing so, adolescents with cancer will likely be able to retain an important part of their everyday life routine, which may eventually reduce the level of their stress and pain.

## Limitations of the Study

This study is one of the preliminary studies conducted in Jordan with a small sample collected from one setting. Therefore, there is a need for further studies with larger sample sizes, recruiting participants from different settings in Jordan. Furthermore, because some of interviewees were females, the interviewer, who was male, faced some challenges during the first stages of the interviews. Due to cultural issues, female participants did not feel at ease and hesitated about communicating their personal experiences and concerns to a male interviewer, who, with much effort, could successfully break the ice and establish a harmonious accord with them, and thus could come up with a rich detailed description of the phenomenon under study.

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