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Exploring Coping Strategies among Caregivers of Children who have Survived Pediatric Cancer in Jordan

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CAREGIVER COPING AFTER PEDIATRIC CANCER

**Exploring Coping Strategies among Caregivers of Children who have Survived Pediatric
Cancer in Jordan**Taleb Ismael¹, Noor Ismael¹, Ala'a Jaber², Somaya Malkawi³, & Sherin Al Awady⁴**Authors' Note**

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Statement of Contributor ship

TI and NI researched literature and conceived the study. All authors were involved in protocol development. TI, NI and AJ were involved in gaining ethical approval, patient recruitment, and data analysis. TI and NI wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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Data Availability Statement

Authors can share the data of this study upon reasonable request.

Conflict of Interest Statement

The authors of this study have no conflict of interest.

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Research Ethics

Institutional Review Board of King Hussein Cancer Center approved the study (Research # 17 KHCC 121).

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**Exploring Coping Strategies among Caregivers of Children who have Survived Pediatric
Cancer in Jordan**

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Abstract

Objective: To explore the coping strategies of caregivers of children who have survived pediatric cancer in Jordan. *Materials and Methods:* This study utilized a cross-sectional survey design, and convenient sampling. The sample included 102 caregivers of children who have survived cancer, and outcome measures included the Arabic-translated Brief COPE, and caregiver and child demographic and condition questionnaire. Data analyses included descriptive statistics, analysis of frequencies, and Spearman-rank order correlations. *Results:* Caregivers most frequently utilized religion coping (M= 6.42, SD= 1.85), followed by acceptance (M= 5.95, SD= 1.96) and planning (M= 5.05, SD= 1.94). The least utilized coping strategies were humor (M= 2.98, SD= 1.24) and behavioral dis-engagement as coping strategies (M= 3.01, SD= 1.42). *Conclusion:* Caregivers of children who have survived cancer in Jordan frequently utilize passive coping strategies like religion and acceptance coping to overcome daily life stressors. Caregivers might benefit from psychosocial occupational therapy interventions to support their engagement in more active or problem-focused coping strategies.

Keywords: cancer, neoplasms, child, caregivers, psychology, mental health

1 **Exploring Coping Strategies among Caregivers of Children who have Survived Pediatric** 2 **Cancer in Jordan**

3 According to the American Cancer Society (2020), cancer is the second leading cause of
4 death in children ages one to fourteen years, after accidents. Cancer is a serious medical
5 condition that affects not only people who have this condition, but also their surrounded families
6 and friends (Im Song, Shin, Choi, Kang, Baik, Mo, & Kim, 2011). After surviving the cancer
7 condition, many children and caregivers deal with residual physical (Ness, et al., 2009),
8 cognitive (Bonner, Hardy, Willard, & Gururangan, 2009) and/or psychosocial challenges that
9 may affect their daily life functioning (Li, Lopez, Chung, Ho, & Chiu, 2013). A number of
10 studies have investigated caregiver coping during pediatric cancer treatments (e.g., Gage-
11 Bouchard, Devine, & Heckler, 2013; Kohlsdorf, & Costa Junior, 2011). However, limited
12 evidence investigated how caregivers cope after surviving the cancer condition. To authors'
13 knowledge, there were no studies in this area in Jordan or the Arab world. Therefore, this study
14 aimed to explore the coping strategies of caregivers of children who have survived cancer in
15 Jordan.

16 **Literature Review**

17 Caregivers of children who have cancer experience elevated stress levels as compared to
18 other medical and/or educational childhood conditions (Pinquart, 2018). There are several
19 cancer-related factors that contribute to caregivers' stress including disruption in everyday
20 routine changes, and participation restrictions while being on the cancer treatment (Litzelman,
21 Catrine, Gangnon, & Witt, 2011). The nature of the cancer condition, and invasive procedures
22 (e.g., lumbar punctures, bone marrow aspirations) associated with cancer treatments also
23 contribute to caregiver stress and poor quality of life (Vrettos, et al., 2012). While stress is

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1 greater in caregivers of recently diagnosed individuals, it continues to affect caregivers during
2 treatment and even after cancer recovery (Üzar-Özçetin, & Dursun, 2020). There is accumulating
3 evidence that looked at caregivers' negative psychological states like stress, anxiety, or
4 depression (e.g., Fladeboe, et. al., 2018; Pierce, Hocking, Schwartz, Alderfer, Kazak, & Barakat,
5 2017); however, there is little evidence on how caregivers' of children with or who have
6 survived cancer cope with these states. Ways of coping influence people's adaptations to various
7 conditions (Biggs, Brough, & Drummond, 2017), and contribute to their health and wellbeing
8 (Kirby, et. al., 2021).

9 Coping refers to the thoughts and actions people use to manage stressful situations
10 (Carver & Connor-Smith, 2010). Coping strategies are highly individualized because of people's
11 differences in resources, experiences, motivation, preferences, and skills for coping. The early
12 work of Carver and Scheier (1989) characterized people's coping into several different coping
13 strategies, including planning, use of emotional support, and denial. Researchers differ in how
14 they classify different coping strategies, like problem-focused or emotion-focused (Lazarus &
15 Folkman, 1984); and adaptive or maladaptive coping (O'Brien, & Moorey, 2010). Engaging in
16 adaptive or problem-focused coping strategies like planning or active coping contribute to better
17 caregiver psychosocial and physical health, and quality of life (Mayordomo, Viguier, Sales,
18 Satorres, & Meléndez, 2016). On the other hand, mal-adaptive coping strategies like substance
19 use negatively affect the health and quality of life of caregivers and surrounding family members
20 (Knowles, Apputhurai, O'Brien, Ski, Thompson, & Castle, 2020).

21 Unlike stress in caregivers of children with cancer, caregivers' coping strategies were
22 scarcely studied in the literature. A study in 2013 by Gage-Bouchard, Devine and Heckler,
23 investigated caregiver coping strategies in families of children with cancer, and found

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1 associations between caregiver coping and a number of socio-demographical factors. For
2 example, Mothers utilized active coping, instrumental support, religious coping, and emotional
3 support, more than fathers. Also, gender and educational levels were linked to certain
4 maladaptive coping strategies like substance use (Gage-Bouchard, 2013). While this later study
5 investigated potential factors that affect caregiver coping during pediatric cancer, evidence on
6 caregiver coping after surviving pediatric cancer remains understood. A relatively recent study of
7 caregivers of lung and colorectal cancer survivors (Litzelman, Kent, & Rowland, 2018), found
8 that caregivers engaged in emotion-focused coping (i.e., religion, acceptance, positive re-
9 framing, and emotional support) more than problem focused coping. Care recipients in this study
10 were adult cancer survivors not children.

11 Research in this area is needed to build on the evidence about caregivers coping during
12 and after surviving pediatric cancer. The novelty in this study is to investigate what coping
13 strategies caregivers of children who have survived cancer utilized to overcome daily life
14 challenges. Up to authors' knowledge, there were no studies about caregivers' coping in Jordan.
15 We hypothesized –since children have survived the cancer condition- that caregivers will utilize
16 more problem-focused coping strategies to overcome daily life challenges. Characterizing
17 caregiver coping strategies is important to investigate intervention strategies that promote the
18 selection of adaptive or problem-focused coping strategies, and therefore, enhance caregivers'
19 psychosocial health.

20 **Materials and Methods**

21 **Design**

22 This study utilized a cross-sectional survey design to explore the coping strategies of
23 caregivers of children who have survived pediatric cancer.

1 **Participants and Settings**

2 The study recruited caregivers of children who have survived cancer through the pediatric
3 quality of life clinic at XXX in Jordan. Care-providers in this clinic (pediatric oncologist and
4 specialized oncology nurses) follow-up yearly with children and their caregivers in relation to
5 child and family health and quality of life after surviving the cancer condition. Eligibility criteria
6 for caregivers to participate in this study included: (a) Caregivers of children who have survived
7 cancer, (b) children were clients in the pediatric survivors' clinic at XXX, (c) children were off
8 cancer treatment for at least two years, and (d) caregiver who can read and write in Arabic in
9 order to complete the study survey. The study excluded caregivers who did not meet the
10 inclusion criteria mentioned above.

11 One hundred and two caregivers participated in this study and completed the study
12 survey. Around 63% of the caregivers were mothers, 83% were married, only 18 % had a
13 Bachelor degree, and almost half of them were un-employed (see Table 1 for demographic
14 characteristics of the caregivers and their children). Around half of the children who have
15 survived cancer were males, (43%) survived Leukemia, 35% had current health problems, and
16 56% did not receive rehabilitative services (occupational therapy, physical therapy, special
17 education, and\ or speech and language services) (see Table 2 for cancer diagnoses).

18 **Instruments**

19 ***The Brief COPE (Carver et al., 1989)***

20 It is a shorter version of the COPE Inventory, and measures individuals' ways of coping
21 in different life situations. The Brief COPE consists of fourteen coping sub-scales with two items
22 in each (28 items in total): *Self-distraction* (e.g., I've been turning to work or other activities to
23 take my mind off things); *Active coping* (e.g., I've been concentrating my efforts on doing

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1 something about the situation I'm in); *Denial* (e.g. I've been saying to myself "this isn't real);
2 *Substance use* (e.g., I've been using alcohol or other drugs to make myself feel better); *Use of*
3 *emotional support* (e.g., I've been getting emotional support from others); *Use of instrumental*
4 *support* (e.g., I've been getting help and advice from other people); *Behavioral disengagement*
5 (e.g., I've been giving up trying to deal with it), *Venting* (e.g., I've been giving up trying to deal
6 with it); *Positive reframing* (e.g., I've been trying to see it in a different light, to make it seem
7 more positive); *Planning* (e.g., I've been trying to come up with a strategy about what to do);
8 *Humor* (e.g., I've been making jokes about it), *Acceptance* (e.g., I've been accepting the reality of
9 the fact that it has happened); *Religion* (e.g., I've been trying to find comfort in my religion or
10 spiritual beliefs); and *Self-blame* (I've been criticizing myself).

11 Subscales' scores are generated by summing items for each sub-scale. Higher sub-scale
12 scores indicate a respondent's tendency to engage in a particular coping strategy (Greer, 2007).
13 Several studies explored the psychometric properties of Brief COPE. For example, Hagan et al.
14 (2016), which sampled individuals newly diagnosed with incurable lung and gastrointestinal
15 cancers and suggested that the Brief COPE had good psychometric properties among this
16 population. Also, Nunes et al. (2021) found that the Brief COPE is a psychometrically sound
17 instrument that shows measurement invariance across samples and good reliability.

18 Researchers in this study performed the forward-backward translation of the original
19 English Brief COPE into the Arabic language (after obtaining permission from the primary
20 COPE author Dr. Carver by e-mail) according to World Health Organization's recommendations
21 for forward-backward translations of assessment tools (WHO; accessed October 2021). The
22 second author (who knows Arabic and English very well, is a health-care professional, an expert
23 in the terms of the Brief COPE, and studied PhD in the United States) performed the forward

1 translation of the Brief COPE from English into Arabic. An Expert panel (second and third
2 authors) reviewed the Arabic translated Brief COPE terminology, discussed any conflicts, and
3 agreed on the pre-final Arabic version. This expert panel took into consideration cultural
4 adaptation, common language use, and conceptual equivalence of the scale. Then, a bilingual
5 health-care professional (occupational therapist, had a master's degree in rehabilitation, and
6 expert in the language of the Brief COPE), performed the backward translation of the Arabic-
7 translated Brief COPE into English. An expert panel (second and third authors) reviewed the
8 backward translated version, discussed conflicts in wordings, changed, and agreed on the final
9 Arabic version.

10 *The Demographic and Condition Questionnaire*

11 Researchers in this study designed this questionnaire to collect child and caregiver
12 demographic and condition information, like child age, gender, diagnosis, medical and
13 educational services, and caregiver education and social status.

14 **Procedures**

15 The internal review board at XXX approved this study (approval number XXX).
16 Researchers prepared the study survey, which consisted of the Child and Caregiver Demographic
17 and Condition Questionnaire and the Arabic version of the Brief COPE. A registered nurse at the
18 pediatric survivors' clinic at XXX. (Last author) initiated contact with caregivers who were
19 waiting for their appointment and invited them to participate in this study. The nurse explained
20 the study to caregivers, and assured them that their participation is voluntary, and that they can
21 quit the study at any time. Caregivers who agreed to participate provided informed consent and
22 completed the study survey. Data collection took place only at the pediatric survivors' clinic at
23 XXX. All completed survey papers are kept in a secure place at XXX.

1 Data Analyses

2 All data analyses procedures utilized the Statistical Package for Social Science (SPSS 23;
3 IBM, 2015). After data cleaning, normality and homogeneity of variance was inspected. Then
4 Brief COPE sub-scales were calculated by summing items for each subscale. Considering the
5 Likert scale used in the Brief COPE (1= Never to 4= Always), the minimum scores a participant
6 can obtain is 2 while the maximum score is 8. Therefore, sub-scales' scores from 6-8 reflect
7 greater coping strategy utilization (Ismael, Mische Lawson, Little, & Muqbel, 2018). Data
8 analyses included calculating descriptive statistics (mean, median, range, and standard deviation)
9 and analysis of frequencies of child and caregiver demographics, and the Brief COPE sub-scale
10 scores. Spearman-Rank Order Correlation was used to explore if there were relationships
11 between child and caregiver demographics, and caregiver utilization of certain coping strategies.
12 This study referred to Akoglu (2018) in classifying the strengths of correlations as follows:
13 Negligible (0 to .09), Weak (.1 to .19), Moderate (.2 to .29), Strong (.3 to .59), Very strong (.6 to
14 .89), and Perfect (.9-1). Then Linear Regression analysis explored how significant correlates
15 affect caregiver coping strategy utilization. The significance level was set at .05 for the
16 correlations and regression analyses.

17 Results

18 Analysis of frequencies showed that 63.7% of caregivers of children who have survived
19 cancer in this study were mothers, 83.3% were married, only 18.6% had a bachelor's degree,
20 almost half of them were un-employed, and 60.8% had a monthly income under 500 JD. The
21 most common cancer condition was acute Leukemia 43.1%, followed by Rhabdomyosarcoma
22 (11.8%), bone tumors (10.8%), and Wilms (8.8%). Around half of the children who have
23 survived cancer were males, and 34.3% were in elementary school grades 1-6. Around 60% of

1 the children had between three to five siblings, and 22.5% were first in order among their
2 siblings (see Tables 1 and 2 for additional demographic and condition-related characteristics).
3 Caregivers in this study mostly utilized religious coping ($M= 6.42$, $SD= 1.85$), followed by
4 acceptance ($M= 5.95$, $SD= 1.96$) and planning ($M= 5.05$, $SD= 1.94$) (see Table 3). Caregivers
5 rarely utilized humor ($M= 2.98$, $SD= 1.24$) and behavioral dis-engagement as coping strategies
6 ($M= 3.01$, $SD= 1.42$). Out of the 102, four caregivers almost always utilize substance use as a
7 coping strategy (see Figure 1).

8 A number caregiver and child demographics were correlated with utilizing different
9 coping strategies. For example, caregiver educational levels were associated with self-distraction
10 ($r_s = -.273$, $p = .006$), use of instrumental support ($r_s = -.268$, $p = .007$), and self-blame ($r_s = -.217$,
11 $p = .031$). In specific, elementary school education (a lower level of education) was associated
12 with utilizing more self-distraction ($r_s = .227$, $p = .022$) and more self-blame ($r_s = .248$, $p =$
13 $.012$), while having a bachelor's degree (a higher level of education) was associated with less
14 self-distraction ($r_s = -.206$, $p = .038$). Also, having a graduate degree was associated with less use
15 of instrumental support ($r_s = -.249$, $p = .012$). Besides caregiver education, having a female child
16 was associated with utilizing more self-distraction ($r_s = .284$, $p = .004$), use of emotional support
17 ($r_s = .201$, $p = .043$), and use of instrumental support ($r_s = .205$, $p = .038$). Also, having current
18 health or educational problems in children who have survived cancer was associated with more
19 caregiver substance use utilization ($r_s = .245$, $p = .015$) (see Table 4 for additional significant
20 correlations). Linear regression showed that having a female child predicted more self-distraction
21 utilization ($\beta = .265$, $p = .007$).

22 Discussion

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1 This study explored coping strategies among caregivers of children who have survived
2 cancer in Jordan and analyzed potential associations between caregiver and child demographics
3 and the utilization of different coping strategies. More than half of the caregivers were mothers,
4 and half of them were un-employed. Only a small percentage of the caregivers in this study had a
5 bachelor's or a graduate educational degree. Demographical characteristics in this study will help
6 in discussing caregiver utilization of different coping strategies in the following paragraphs.

7 Findings from this study showed that caregivers mostly utilized religious coping to
8 overcome everyday stressors. Considering cancer as a very serious and life-threatening condition
9 (Lee & Cho, 2017), individuals with cancer and/or their caregivers might view cancer as a
10 hopeless condition that has no effective treatment (Rafferty, 2015). Therefore, caregivers might
11 turn to spiritual and religious coping mechanisms as more powerful and alleviating treatment
12 options (Lagman, Yoo, Levine, Donnell, & Lim, 2014). This finding is aligned with much
13 previous research on individuals with cancer in the Eastern (e.g., Ahmadi, Hussin, &
14 Mohammad, 2019; Elsheshtawy, Abo-Elez, Ashour, Farouk, & zaafarany, 2014) and Western
15 countries (Thuné-Boyle, Stygall, Keshtgar, Davidson, & Newman, 2011). Religious coping,
16 especially in the early stages of cancer treatment, may help caregivers in redefining potential
17 stressors as beneficial (Ahmadi, et al., 2019), and accepting the condition and its consequences
18 (Haghighi, 2013).

19 The novel finding from this study is that caregivers may continue to utilize religion
20 coping even after their children's survival from the cancer condition. Closely looking at the
21 characteristics of caregivers who frequently utilized religion, most of them were mothers and had
22 only a school degree (66% for both). Also, almost all of them were unemployed. Given that
23 religious coping does not involve scheduling appointments, planning treatments, and paying for

1 treatments, caregivers in this study might find it a suitable and comfortable way to overcome
2 stress. In addition, caregivers in this study might feel thankful for their children's survival and
3 continued their spiritual practices seeking help for residual health problems. It is important to
4 mention here that religious coping, even if it involves engaging in spiritual activities, does not
5 solve the actual stressor and its consequences. Therefore, there is contradicting evidence about
6 the effect of engaging in religious coping on individuals' health and quality of life (i.e.,
7 Haghghi, 2013; Ng, Mohamed, Sulaiman, & Zainal, 2017)

8 While not as frequent as religion, caregivers in this study also engaged in acceptance and
9 planning coping. Considering that this study was after cancer survival, and a significant amount
10 of time was spent dealing with cancer, utilizing acceptance coping might seem typical for this
11 population. Acceptance is showed as a common way of coping in individuals with terminal
12 illness, and can improve individuals' quality of life (Nipp, et al., 2016). Acceptance is also
13 viewed as the step after denial (Kübler-Ross, & Kessler, 2009), and before searching for
14 treatment options, and solving any related stressors. However, when individuals engage in
15 acceptance coping, they are not actively solving their problem (Norberg, Lindblad, & Boman,
16 2005). Therefore, it might be considered as a passive way of coping and should be utilized with
17 more active ways like planning and active coping. Caregivers also utilized planning, but this
18 study did not investigate if planning complemented acceptance coping. It is worth studying in the
19 future what coping strategies do caregiver combine to form their coping profile.

20 The least utilized coping strategies by caregivers in this study were humor and behavioral
21 dis-engagement. In looking at the definition of humor as making jokes or fun of the situation,
22 and the definition of behavioral dis-engagement as giving up coping, it is obvious that these
23 coping mechanisms might be more relevant to early stages of the cancer experience. After

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1 battling a significant and serious disease with their beloved children, caregivers may turn into
2 more mature and strong individuals for their children and families. Therefore, caregivers in this
3 study might not find it appropriate to engage in humor, nor withdraw from this children's
4 condition. Instead, caregivers in this study were clients in the health and wellness clinic after
5 cancer and continued to be part of the condition with their children. In some research, humor and
6 behavioral dis-engagement along with substance use were considered as maladaptive and
7 dysfunctional ways of managing stressors (Costas-Muñiz, 2012; Parekh, et al., 2017). In other
8 studies, humor was viewed as a comforting and relaxing mechanism that promotes caregivers'
9 health (Tan, & Schneider, 2009; Christie, & Moore, 2005). It is worth further investigating if
10 promoting the use of humor in caregivers of children who have survived cancer can alleviate
11 caregivers' psychosocial health and improve the quality of life of caregivers and their families.

12 This study found that having a girl child cancer survivor predicted caregivers' utilization
13 of more self-distraction as a coping strategy. Caregivers' active engagement in activities other
14 than thinking about current health problems of their girls might be a mechanism to forget the
15 problem and its consequences. There is a strong cultural belief in the Arab world that girls' role
16 in the community comes from their ability to form families, and born and raise children (Douki,
17 Ben Zineb, Nacef, & Halbreich, 2007). Caregivers in this study who were mostly mothers, might
18 engage in self-distraction in a medium amount to stop thinking about their daughters' abilities to
19 be future wives and mothers. The invasive treatments and their side effects might impose many
20 physical disabilities, and change body appearance and function.

21 Although correlation analyses yielded low to medium associations, these were worth
22 mentioning and discuss to contribute to the limited evidence in this area. Having the lowest level
23 of education (elementary) was associated with utilizing more self-blame and self-distraction,

1 while having the highest level of education (graduate) was associated with utilizing more
2 instrumental support. Having higher forms of education might help caregivers to move from
3 passive to active ways of coping. Instrumental use of support, which is utilizing help and advice
4 from other people that might be professionals in supporting caregivers, was minimally studied in
5 the literature. (Hill, 2016) showed that emotional social support seeking predicted better
6 individual and family psychosocial functioning while instrumental social support seeking did
7 not.

8 In another association, having current medical and/or educational problems was
9 associated with more substance use. While substance use was not a frequent coping mechanism
10 by caregivers in this study, almost half of the caregivers responded “2 = I've been doing this a
11 little bit” to one of the two items that for the substance use sub-scale. These two items involve
12 utilizing alcohol and/or drugs to overcome problems. Substance use affects the health and quality
13 of life of individuals and their families (Belizaire, & Fuertes, 2011). Almost half the caregivers,
14 who had some degree of engagement in substance use in this study, had between 3-5 children,
15 and almost half of them had a relatively low family income. These results suggested the need to
16 promote caregivers' limited time and financial resources toward solving their families' medical
17 and educational needs.

18 In summary, caregivers of children who have survived cancer in this study utilized
19 mostly religion coping. This study didn't investigate the reasons why caregivers didn't
20 frequently use other ways of coping that are defined in the literature as problem-focused like
21 active coping, or that involve other professionals or family members like use of emotional and
22 instrumental support coping. Given that coping is a highly individualized process, there might be
23 factors, like the cultural and social contexts, that characterize this process and are still under-

1 investigated. Further investigation of potential factors that affect caregiver coping will inform
2 care-providers on how to support caregivers' utilization of adaptive and active ways of coping
3 that promote caregivers' and families' health and well-being.

4 **Strengths and Limitations**

5 This study was novel in investigating coping of caregivers of children who have survived
6 cancer in Jordan. While the study utilized a convenient sample of caregivers from XXX, this
7 later setting is the primary cancer center in Jordan and serves clients from different Jordanian
8 cities. The utilization of the Brief COPE was helpful in investigating a wide variety of
9 caregivers' coping styles. While this study performed the forward and backward translation of
10 the Brief COPE into Arabic, and a committee discussed the words and phrases in both languages
11 before agreeing on the final Arabic version, it did not investigate the psychometric properties of
12 the Arabic Brief COPE. There were missing data related caregivers and child demographics (as
13 reported in the tables), especially those related to age, and therefore, were not included in the
14 analyses. Finally, this cross-sectional study did not investigate whether caregivers' utilization of
15 different coping strategies change from the diagnosis, during treatment, and after surviving
16 cancer.

17 **Conclusions**

18 Caregivers of children who have survived cancer in Jordan utilized mostly passive coping
19 strategies like religious coping and acceptance. Also, having a girl cancer survivor predicted
20 caregivers' utilization of more self-distraction coping. Psychosocial interventions to support
21 caregivers' utilization of active coping strategies like active coping, and use of emotional and
22 instrumental support is important to promote caregivers' and families' psychosocial health and
23 quality of life.

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Key Findings

1. Caregivers of children who have survived cancer mostly utilize religious and acceptance coping when dealing with everyday stressors.
2. Having a girl child cancer survivor predicted caregivers' utilization of more self-distraction coping strategy.

What the Study Has Added

Caregivers of children who have survived cancer utilize passive coping strategies that may affect their families' health and wellbeing. Occupational therapy psychosocial interventions to support caregivers' engagement in active coping strategies are needed.

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1 Table 1
2 Demographic Characteristics of Caregivers and Children N= 102
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Caregiver Demographics			Child Demographics		
Relationship to child	Mother	65(63.7%)	Child gender	Male	53(52%)
	Father	31(30.4%)		Female	45(44.1%)
	Others	4(3.9%)		Prefer not to report	4(3.9%)
	Prefer not to report	2(2%)			
Social status	Married	85(83.3%)	Child School Grade	Elementary	35(34.3%)
	Divorced	1(1%)		Middle	35(34.3%)
	Other	14(13.7)		High	16(15.7%)
	Prefer not to report	2(2%)	Number of Siblings	<3	28(27.5%)
Educational status	Elementary	22(21.6%)		3-5	61(59.8%)
	High school	45(44.1%)		>5	12(11.8%)
	Diploma	13(12.7%)	Order of child	1st	23(22.5%)
	Bachelors	16(15.7%)		2nd	28(27.5%)
	Graduate	3(2.9%)		3rd	21(20.6%)
Prefer not to report	3(2.9%)	4rth-7th		29(28.4%)	
Employment status	Full-time	30(29.4%)	Total family members	Prefer not to report	1
	Part-time	9(8.8%)		<5	12(11.8%)
	Un-employed	50(49%)		>5	86(84.3%)
	Prefer not to report	13(12.7%)	Prefer not to report	4(3.9%)	
Monthly income	<500	62(60.8%)	Residence type	House	30(29.4%)
	500-1000	27(26.5%)		Apartment	71(69.6%)
	>1000	5(4.9%)		Prefer not to report	1(1%)
	Prefer not to report	6(5.9%)			

4 Notes: N= Total sample number, n (%)= Number and percent of participants

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Table 2
Condition-Related Characteristics of Children N= 102

Cancer diagnosis n (%)	Acute leukemia	44(43.1%)
	Rhabdomyosarcoma	15(14.7%)
	Bone tumors	11(10.8%)
	Wilms	9(8.8%)
	Lymphoma	5(4.9%)
	Neuroblastoma	2(2%)
	Germ-cell tumors	2(2%)
	Brain tumors	1(1%)
	Nasopharyngeal cancer	1(1%)
	Optic pathway glioma	1(1%)
	Prefer not to report	11(10.8%)

Notes: N= Total sample number, n (%)= Number and percent of participants

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Table 3*Descriptive Statistics of the Brief COPE Sub-Scale Scores N= 102*

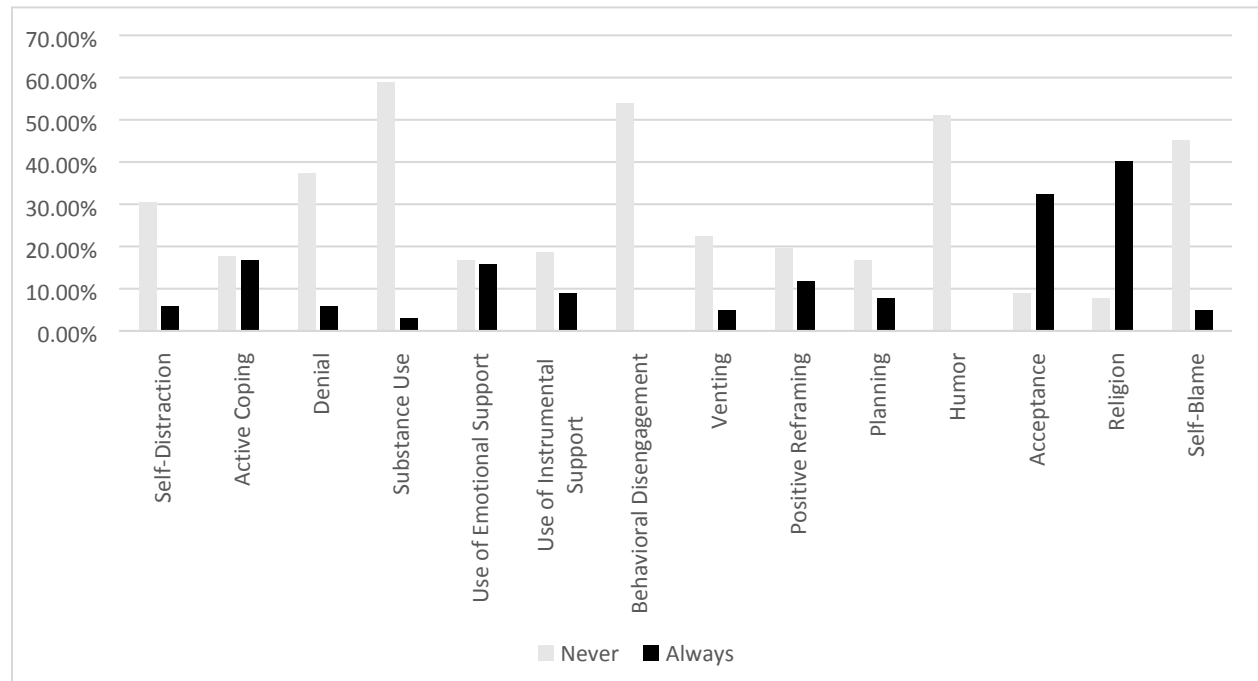
Brief COPE Subscales	Mean	Median	Range	Min	Max
Religion	6.42	7.00	6.00	2.00	8.00
Acceptance	5.95	6.00	6.00	2.00	8.00
Planning	5.10	5.00	6.00	2.00	8.00
Active Coping	5.01	5.00	6.00	2.00	8.00
Positive Re-framing	4.96	5.00	6.00	2.00	8.00
Use of Emotional Support	4.89	5.00	6.00	2.00	8.00
Use of Instrumental Support	4.83	5.00	6.00	2.00	8.00
Venting	4.30	4.00	6.00	2.00	8.00
Self-Distraction	4.10	4.00	6.00	2.00	8.00
Denial	3.69	3.00	6.00	2.00	8.00
Self-Blame	3.52	3.00	6.00	2.00	8.00
Substance Use	3.11	2.00	6.00	2.00	8.00
Behavioral Dis-engagement	3.09	2.00	5.00	2.00	7.00
Humor	2.98	2.00	5.00	2.00	7.00

Notes: N= Total sample size, Min= Minimum subscale score, Max= Maximum subscale score

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Figure 1
Caregivers' Utilization of Different Coping Strategies



Notes: Responses 1= Never and 4= Always were used in this figure.

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Table 4*Correlations between Caregiver Characteristics and Coping Strategies*

	Relationship to Child	Educational Level	Employment Status	Child Gender	Current Health Problems	Child order	Number of Siblings
Self-Distraction		-.273**	.216*	.297**			
Substance Use		.006	.042	.003	.255*		
Use of Emotional Support				.201*	.011		
Use of Instrumental Support		-.268**		.211*		-.226*	
Venting	-.213*						-.203*
	.034						.042
Self-Blame	-.236*	-.217*					
	.018	.031					

Notes: * indicates $p < .05$, ** indicates $p < .01$

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Exploring Coping Strategies among Caregivers of Children who have Survived Pediatric Cancer in Jordan

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Keywords:	Caregivers, Psychology

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Exploring Coping Strategies among Caregivers of Children who have Survived Pediatric Cancer in Jordan

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Statement of Contributor ship

NI and TI researched literature and conceived the study. All authors were involved in protocol development. NI, TI and AJ were involved in gaining ethical approval, patient recruitment, and data analysis. NI and TI wrote the first draft of the manuscript. All authors reviewed and edited the manuscript and approved the final version of the manuscript.

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Data Availability Statement

Authors can share the data of this study upon reasonable request.

Conflict of Interest Statement

The authors of this study have no conflict of interest.

Funding Statement

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Research Ethics

Institutional Review Board of King Hussein Cancer Center approved the study (Research # 17 KHCC 121).

Abstract

Objective: To explore the coping strategies of caregivers of children who have survived pediatric cancer in Jordan. *Materials and Methods:* This study utilized a cross-sectional survey design, and convenient sampling. The sample included 102 caregivers of children who have survived cancer, and outcome measures included the Arabic-translated Brief COPE, and caregiver and child demographic and condition questionnaire. Data analyses included descriptive statistics, analysis of frequencies, Spearman-rank order correlations, and linear regression. *Results:* Caregivers most frequently utilized religion coping (mean= 6.42, SD= 1.85), followed by acceptance (mean = 5.95, SD= 1.96) and planning (mean = 5.05, SD= 1.94). The least utilized coping strategies were humor (mean = 2.98, SD= 1.24) and behavioral dis-engagement as coping strategies (mean = 3.01, SD= 1.42). Having a female child predicted more self-distraction utilization ($\beta = .265$, $p = .007$). *Conclusion:* Caregivers of children who have survived cancer in Jordan frequently utilize passive coping strategies like religion and acceptance coping to overcome daily life stressors. Caregivers might benefit from psychosocial occupational therapy interventions to support their engagement in more active or problem-focused coping strategies.

Keywords: cancer, neoplasms, child, caregivers, psychology, mental health

What is already known on this topic

Caregivers of adults' cancer survivors engage in emotion-focused coping more than problem focused coping. Caregivers' coping strategies in families of children who have cancer is associated to certain demographic factors like gender and educational levels. Caregiver coping after surviving cancer is poorly understood.

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What this study adds

Caregivers of children who have survived cancer mostly utilize religious and acceptance coping when dealing with everyday stressors. Also, having a girl child cancer survivor predicted caregivers’ utilization of more self-distraction coping strategy.

How this study might affect research, practice or policy

Future research should investigate if caregivers’ coping change between having the cancer diagnosis and after surviving the cancer condition. Care-providers should evaluate caregiver coping and provide psychosocial interventions to support caregivers’ engagement in active coping strategies.

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1 **Exploring Coping Strategies among Caregivers of Children who have Survived Pediatric** 2 **Cancer in Jordan**

3 According to the American Cancer Society, cancer is the second leading cause of death in
4 children ages one to fourteen years, after accidents.[1] Cancer is a serious medical condition that
5 affects not only people who have this condition, but also their surrounded families and
6 friends.[2] After surviving the cancer condition, many children and caregivers deal with residual
7 physical,[3] cognitive[4] and/or psychosocial challenges that may affect their daily life
8 functioning.[5] A number of studies have investigated caregiver coping during pediatric cancer
9 treatments.[6,7] However, limited evidence investigated how caregivers cope after surviving the
10 cancer condition. To authors' knowledge, there were no studies in this area in Jordan or the Arab
11 world. Therefore, this study aimed to explore the coping strategies of caregivers of children who
12 have survived cancer in Jordan.

13 **Literature Review**

14 Caregivers of children who have cancer experience elevated stress levels as compared to
15 other medical and/or educational childhood conditions.[8] There are several cancer-related
16 factors that contribute to caregivers' stress including disruption in everyday routine changes, and
17 participation restrictions while being on the cancer treatment.[9] The nature of the cancer
18 condition, and invasive procedures (e.g., lumbar punctures, bone marrow aspirations) associated
19 with cancer treatments also contribute to caregiver stress and poor quality of life.[10] While
20 stress is greater in caregivers of recently diagnosed individuals, it continues to affect caregivers
21 during treatment and even after cancer recovery.[11] There is accumulating evidence that looked
22 at caregivers' negative psychological states like stress, anxiety, or depression;[12,13] however,
23 there is little evidence on how caregivers' of children with or who have survived cancer cope

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1 with these states. Ways of coping influence people's adaptations to various conditions,[14] and
2 contribute to their health and wellbeing.[15]

3 Coping refers to the thoughts and actions people use to manage stressful situations.[16]

4 Coping strategies are highly individualized because of people's differences in resources,
5 experiences, motivation, preferences, and skills for coping. The early work of Carver and Scheier
6 characterized people's coping into several different coping strategies, including planning, use of
7 emotional support, and denial.[17] Researchers differ in how they classify different coping
8 strategies, like problem-focused or emotion-focused;[18] and adaptive or maladaptive
9 coping.[19] Engaging in adaptive or problem-focused coping strategies like planning or active
10 coping contribute to better caregiver psychosocial and physical health, and quality of life.[20] On
11 the other hand, mal-adaptive coping strategies like substance use negatively affect the health and
12 quality of life of caregivers and surrounding family members.[21]

13 Unlike stress in caregivers of children with cancer, caregivers' coping strategies were
14 scarcely studied in the literature. A study by Gage-Bouchard et al investigated caregiver coping
15 strategies in families of children with cancer, and found associations between caregiver coping
16 and a number of socio-demographical factors.[6] For example, Mothers utilized active coping,
17 instrumental support, religious coping, and emotional support, more than fathers. Also, gender
18 and educational levels were linked to certain maladaptive coping strategies like substance use.[6]
19 While this later study investigated potential factors that affect caregiver coping during pediatric
20 cancer, evidence on caregiver coping after surviving pediatric cancer remains poorly understood.
21 A relatively recent study of caregivers of lung and colorectal cancer survivors, found that
22 caregivers engaged in emotion-focused coping (i.e., religion, acceptance, positive re-framing,

1 and emotional support) more than problem focused coping.[9] Care recipients in this study were
2 adult cancer survivors not children.

3 Research in this area is needed to build on the evidence about caregivers coping during
4 and after surviving pediatric cancer. The novelty in this study is to investigate what coping
5 strategies caregivers of children who have survived cancer utilized to overcome daily life
6 challenges. Up to authors' knowledge, there were no studies about caregivers' coping in Jordan.
7 We hypothesized –since children have survived the cancer condition- that caregivers will utilize
8 more problem-focused coping strategies to overcome daily life challenges. Characterizing
9 caregiver coping strategies is important to investigate intervention strategies that promote the
10 selection of adaptive or problem-focused coping strategies, and therefore, enhance caregivers'
11 psychosocial health. Therefore, this study aimed to explore the coping strategies of caregivers of
12 children who have survived cancer.

13 **Materials and Methods**

14 **Design**

15 This study utilized a cross-sectional survey design to explore the coping strategies of
16 caregivers of children who have survived pediatric cancer.

17 **Participants and Settings**

18 The study recruited caregivers of children who have survived cancer through the pediatric
19 quality of life clinic at King Hussein Cancer Center (KHCC) in Jordan. Care-providers in this
20 clinic (pediatric oncologist and specialized oncology nurses) follow-up yearly with children and
21 their caregivers in relation to child and family health and quality of life after surviving the cancer
22 condition. Eligibility criteria for caregivers to participate in this study included: (a) Caregivers of
23 children who have survived cancer, (b) children were clients in the pediatric survivors' clinic at

1 KHCC, (c) children were off cancer treatment for at least two years, and (d) caregiver who can
2 read and write in Arabic in order to complete the study survey. The study excluded caregivers
3 who did not meet the inclusion criteria mentioned above.

4 **Instruments**

5 ***The Brief COPE[17]***

6 It is a shorter version of the COPE Inventory, and measures individuals' ways of coping
7 in different life situations. The Brief COPE consists of fourteen coping sub-scales with two items
8 in each (28 items in total): *Self-distraction* (e.g., I've been turning to work or other activities to
9 take my mind off things); *Active coping* (e.g., I've been concentrating my efforts on doing
10 something about the situation I'm in); *Denial* (e.g. I've been saying to myself "this isn't real);
11 *Substance use* (e.g., I've been using alcohol or other drugs to make myself feel better); *Use of*
12 *emotional support* (e.g., I've been getting emotional support from others); *Use of instrumental*
13 *support* (e.g., I've been getting help and advice from other people); *Behavioral disengagement*
14 (e.g., I've been giving up trying to deal with it), *Venting* (e.g., I've been giving up trying to deal
15 with it); *Positive reframing* (e.g., I've been trying to see it in a different light, to make it seem
16 more positive); *Planning* (e.g., I've been trying to come up with a strategy about what to do);
17 *Humor* (e.g., I've been making jokes about it), *Acceptance* (e.g., I've been accepting the reality of
18 the fact that it has happened); *Religion* (e.g., I've been trying to find comfort in my religion or
19 spiritual beliefs); and *Self-blame* (I've been criticizing myself).

20 Subscales' scores are generated by summing items for each sub-scale. Higher sub-scale
21 scores indicate a respondent's tendency to engage in a particular coping strategy.[22] Several
22 studies explored the psychometric properties of Brief COPE. For example, Hagan et al, which
23 sampled individuals newly diagnosed with incurable lung and gastrointestinal cancers and

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1 suggested that the Brief COPE had good psychometric properties among this population.[23]

2 Also, Nunes et al found that the Brief COPE is a psychometrically sound instrument that shows
3 measurement invariance across samples and good reliability.[24]

4 Researchers in this study performed the forward-backward translation of the original
5 English Brief COPE into the Arabic language (after obtaining permission from the primary
6 COPE author Dr. Carver by e-mail) according to World Health Organization's recommendations
7 for forward-backward translations of assessment tools.[25] The first author (who knows Arabic
8 and English very well, is a health-care professional, and an expert in the terms of the Brief
9 COPE) performed the forward translation of the Brief COPE from English into Arabic. An
10 Expert panel (first and third authors) reviewed the Arabic translated Brief COPE terminology,
11 discussed any conflicts, and agreed on the pre-final Arabic version. This expert panel took into
12 consideration cultural adaptation, common language use, and conceptual equivalence of the
13 scale. Then, a bilingual health-care professional (occupational therapist, had a master's degree in
14 rehabilitation, and expert in the language of the Brief COPE), performed the backward
15 translation of the Arabic-translated Brief COPE into English. An expert panel (first and third
16 authors) reviewed the backward translated version, discussed conflicts in wordings, changed, and
17 agreed on the final Arabic version.

18 *The Demographic and Condition Questionnaire*

19 Researchers in this study designed this questionnaire to collect child and caregiver
20 demographic and condition information, like child age, gender, diagnosis, medical and
21 educational services, and caregiver education and social status.

22 **Procedures**

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1 The internal review board at KHCC approved this study (Research # 17 KHCC 121).
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1 The internal review board at KHCC approved this study (Research # 17 KHCC 121).
2 Researchers prepared the study survey, which consisted of the Child and Caregiver Demographic
3 and Condition Questionnaire and the Arabic version of the Brief COPE. A registered nurse at the
4 pediatric survivors' clinic at KHCC. (fourth author) initiated contact with caregivers who were
5 waiting for their appointment and invited them to participate in this study. The nurse explained
6 the study to caregivers, and assured them that their participation is voluntary, and that they can
7 quit the study at any time. Caregivers who agreed to participate provided informed consent and
8 completed the study survey. Data collection took place only at the pediatric survivors' clinic at
9 KHCC. All completed survey papers are kept in a secure place at Jordan University of Science
10 and Technology.

Data Analyses

12 All data analyses procedures utilized the Statistical Package for Social Science.[26] After
13 data cleaning, normality and homogeneity of variance was inspected. Then Brief COPE sub-
14 scales were calculated by summing items for each subscale. Considering the Likert scale used in
15 the Brief COPE (1= Never to 4= Always), the minimum scores a participant can obtain is 2
16 while the maximum score is 8. Therefore, sub-scales' scores from 6-8 reflect greater coping
17 strategy utilization.[27] Data analyses included calculating descriptive statistics (mean, median,
18 range, and standard deviation) and analysis of frequencies of child and caregiver demographics,
19 and the Brief COPE sub-scale scores. Spearman-Rank Order Correlation was used to explore if
20 there were relationships between child and caregiver demographics, and caregiver utilization of
21 certain coping strategies. This study referred to Akoglu (2018) in classifying the strengths of
22 correlations as follows: Negligible (0 to .09), Weak (.1 to .19), Moderate (.2 to .29), Strong (.3 to
23 .59), Very strong (.6 to .89), and Perfect (.9-1).[28] Then, Linear Regression analysis explored

1 how significant correlates affect caregiver coping strategy utilization. The significance level was
2 set at .05 for the correlations and regression analyses.

3 Results

4 One hundred and two caregivers participated in this study and completed the study
5 survey. Around 66% of the caregivers were mothers, 83% were married, only 18 % had a
6 Bachelor degree, and almost half of them were un-employed. Around half of the children who
7 have survived cancer were males, and 34.3% were in elementary school grades 1-6. Around 60%
8 of the children had between three to five siblings, and 22.5% were first in order among their
9 siblings. The most common cancer condition was acute Leukemia 43.1%, followed by
10 Rhabdomyosarcoma (11.8%), bone tumors (10.8%), and Wilms (8.8%). Thirty-five percent had
11 current health problems, and 56% did not receive rehabilitative services (occupational therapy,
12 physical therapy, special education, and\ or speech and language services) (see Tables 1 and 2
13 for additional demographic and condition-related characteristics).

14 Caregivers in this study mostly utilized religious coping ($M= 6.42$, $SD= 1.85$), followed
15 by acceptance ($M= 5.95$, $SD= 1.96$) and planning ($M= 5.05$, $SD= 1.94$) (see Table 3). Caregivers
16 rarely utilized humor ($M= 2.98$, $SD= 1.24$) and behavioral dis-engagement as coping strategies
17 ($M= 3.01$, $SD= 1.42$). Out of the 102, four caregivers almost always utilize substance use as a
18 coping strategy (see Figure 1).

19 A number of caregiver and child demographics were correlated with utilizing different
20 coping strategies. For example, caregiver educational levels were negatively associated with self-
21 distraction ($r_s= -.273$, $p= .006$), use of instrumental support ($r_s = -.268$, $p = .007$), and self-blame
22 ($r_s = -.217$, $p = .031$). In specific, elementary school education (a lower level of education) was
23 positively associated with utilizing more self-distraction ($r_s = .227$, $p = .022$) and more self-

1 blame ($r_s = .248, p = .012$), while having a bachelor's degree (a higher level of education) was
2 associated with less self-distraction ($r_s = -.206, p = .038$). Also, having a graduate degree was
3 associated with more use of instrumental support ($r_s = .249, p = .012$). Besides caregiver
4 education, having a female child was positively associated with utilizing more self-distraction (r_s
5 = $.284, p = .004$), use of emotional support ($r_s = .201, p = .043$), and use of instrumental support
6 ($r_s = .205, p = .038$). Also, having current health or educational problems in children who have
7 survived cancer was positively associated with more caregiver substance use utilization ($r_s =$
8 $.245, p = .015$) (see Table 4 for additional significant correlations). Linear regression showed that
9 having a female child predicted more self-distraction utilization ($\beta = .265, p = .007$).

10 Discussion

11 This study explored coping strategies among caregivers of children who have survived
12 cancer in Jordan and analyzed potential associations between caregiver and child demographics
13 and the utilization of different coping strategies. Caregivers most frequently utilized religion
14 coping, followed by acceptance and planning. The least utilized coping strategies were humor
15 and behavioral dis-engagement as coping strategies. More than half of the caregivers were
16 mothers, and half of them were un-employed. Only a small percentage of the caregivers in this
17 study had a bachelor's or a graduate educational degree. Demographical characteristics in this
18 study will help in discussing caregiver utilization of different coping strategies in the following
19 paragraphs.

20 Findings from this study showed that caregivers mostly utilized religious coping to
21 overcome everyday stressors. Considering cancer as a very serious and life-threatening
22 condition,[29] individuals with cancer and/or their caregivers might view cancer as a hopeless
23 condition that has no effective treatment.[30] Therefore, caregivers might turn to spiritual and

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1 religious coping mechanisms as more powerful and alleviating treatment options.[31] This
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3 finding is aligned with much previous research on individuals with cancer in the Eastern;[32,33]
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5 and Western countries.[34] Religious coping, especially in the early stages of cancer treatment,
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7 may help caregivers in redefining potential stressors as beneficial,[32] and accepting the
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9 condition and its consequences.[35]
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15 The novel finding from this study is that caregivers may continue to utilize religion
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17 coping even after their children's survival from the cancer condition. Closely looking at the
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19 characteristics of caregivers who frequently utilized religion, most of them were mothers and had
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21 only a school degree (66% for both). Also, almost all of them were unemployed. Given that
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23 religious coping does not involve scheduling appointments, planning treatments, and paying for
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25 treatments, caregivers in this study might find it a suitable and comfortable way to overcome
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27 stress. In addition, caregivers in this study might feel thankful for their children's survival and
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29 continued their spiritual practices seeking help for residual health problems. It is important to
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31 mention here that religious coping, even if it involves engaging in spiritual activities, does not
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33 solve the actual stressor and its consequences. Therefore, there is contradicting evidence about
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35 the effect of engaging in religious coping on individuals' health and quality of life.[35,36]
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40 While not as frequent as religion, caregivers in this study also engaged in acceptance and
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42 planning coping. Considering that this study was after cancer survival, and a significant amount
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44 of time was spent dealing with cancer, utilizing acceptance coping might seem typical for this
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46 population. Acceptance is showed as a common way of coping in individuals with terminal
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48 illness, and can improve individuals' quality of life.[37] Acceptance is also viewed as the step
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50 after denial,[38] and before searching for treatment options, and solving any related stressors.
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54 However, when individuals engage in acceptance coping, they are not actively solving their
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1 problem.[39] Therefore, it might be considered as a passive way of coping and should be utilized
2 with more active ways like planning and active coping. Caregivers also utilized planning, but this
3 study did not investigate if planning complemented acceptance coping. It is worth studying in the
4 future what coping strategies do caregiver combine to form their coping profile.

5 The least utilized coping strategies by caregivers in this study were humor and behavioral
6 dis-engagement. In looking at the definition of humor as making jokes or fun of the situation,
7 and the definition of behavioral dis-engagement as giving up coping, it is obvious that these
8 coping mechanisms might be more relevant to early stages of the cancer experience. After
9 battling a significant and serious disease with their beloved children, caregivers may turn into
10 more mature and strong individuals for their children and families. Therefore, caregivers in this
11 study might not find it appropriate to engage in humor, nor withdraw from their children's
12 condition. Instead, caregivers in this study were clients in the health and wellness clinic after
13 cancer and continued to be part of the condition with their children. In some research, humor and
14 behavioral dis-engagement along with substance use were considered as maladaptive and
15 dysfunctional ways of managing stressors.[40,41] In other studies, humor was viewed as a
16 comforting and relaxing mechanism that promotes caregivers' health.[42,43] It is worth further
17 investigating if promoting the use of humor in caregivers of children who have survived cancer
18 can alleviate caregivers' psychosocial health and improve the quality of life of caregivers and
19 their families.

20 This study found that having a girl child cancer survivor predicted caregivers' utilization
21 of more self-distraction as a coping strategy. Caregivers' active engagement in activities other
22 than thinking about current health problems of their girls might be a mechanism to forget the
23 problem and its consequences. There is a strong cultural belief in the Arab world that girls' role

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1 in the community comes from their ability to form families, and born and raise children.[44]
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1 in the community comes from their ability to form families, and born and raise children.[44]
2 Caregivers in this study who were mostly mothers, might engage in self-distraction in a medium
3 amount to stop thinking about their daughters' abilities to be future wives and mothers. The
4 invasive treatments and their side effects might impose many physical disabilities, and change
5 body appearance and function.

6 Although correlation analyses yielded low to medium associations, these were worth
7 mentioning and discuss to contribute to the limited evidence in this area. Having the lowest level
8 of education (elementary) was associated with utilizing more self-blame and self-distraction,
9 while having the highest level of education (graduate) was associated with utilizing more
10 instrumental support. Having higher forms of education might help caregivers to move from
11 passive to active ways of coping. Instrumental use of support, which is utilizing help and advice
12 from other people that might be professionals in supporting caregivers, was minimally studies in
13 the literature. One study showed that emotional social support seeking predicted better individual
14 and family psychosocial functioning while instrumental social support seeking did not.[45]

15 In another association, having current medical and/or educational problems was
16 associated with more substance use. While substance use was not a frequent coping mechanism
17 by caregivers in this study, almost half of the caregivers responded "2 = I've been doing this a
18 little bit" to one of the two items that for the substance use sub-scale. These two items involve
19 utilizing alcohol and/or drugs to overcome problems. Substance use affects the health and quality
20 of life of individuals and their families.[46] Almost half the caregivers, who had some degree of
21 engagement in substance use in this study, had between 3-5 children, and almost half of them
22 had a relatively low family income. These results suggested the need to promote caregivers'

1 limited time and financial resources toward solving their families' medical and educational
2 needs.

3 In summary, caregivers of children who have survived cancer in this study utilized
4 mostly religion coping. This study didn't investigate the reasons why caregivers didn't
5 frequently use other ways of coping that are defined in the literature as problem-focused like
6 active coping, or that involve other professionals or family members like use of emotional and
7 instrumental support coping. Given that coping is a highly individualized process, there might be
8 factors, like the cultural and social contexts, that characterize this process and are still under-
9 investigated. Further investigation of potential factors that affect caregiver coping will inform
10 care-providers on how to support caregivers' utilization of adaptive and active ways of coping
11 that promote caregivers' and families' health and well-being.

12 **Strengths and Limitations**

13 This study was novel in investigating coping of caregivers of children who have survived
14 cancer in Jordan. While the study utilized a convenient sample of caregivers from KHCC, this
15 later setting is the primary cancer center in Jordan and serves clients from different Jordanian
16 cities. The utilization of the Brief COPE was helpful in investigating a wide variety of
17 caregivers' coping styles. While this study performed the forward and backward translation of
18 the Brief COPE into Arabic, and a committee discussed the words and phrases in both languages
19 before agreeing on the final Arabic version, it did not investigate the psychometric properties of
20 the Arabic Brief COPE. There were missing data related caregivers and child demographics (as
21 reported in the tables), especially those related to age, and therefore, were not included in the
22 analyses. Finally, this cross-sectional study did not investigate whether caregivers' utilization of

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3 1 different coping strategies change from the diagnosis, during treatment, and after surviving
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5 2 cancer.

3 **Conclusions**

4 Caregivers of children who have survived cancer in Jordan utilized mostly passive coping
5 strategies like religious coping and acceptance. Also, having a girl cancer survivor predicted
6 caregivers' utilization of more self-distraction coping. Psychosocial interventions to support
7 caregivers' utilization of active coping strategies like active coping, and use of emotional and
8 instrumental support is important to promote caregivers' and families' psychosocial health and
9 quality of life.

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CAREGIVER COPING AFTER PEDIATRIC CANCER

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CAREGIVER COPING AFTER PEDIATRIC CANCER

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1 Table 1
2 Demographic Characteristics of Caregivers and Children N= 102
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Caregiver Demographics			Child Demographics		
Relationship to child	Mother	65(63.7%)	Child gender	Male	53(52%)
	Father	31(30.4%)		Female	45(44.1%)
	Others	4(3.9%)		Prefer not to report	4(3.9%)
	Prefer not to report	2(2%)			
Social status	Married	85(83.3%)	Child School Grade	Elementary	35(34.3%)
	Divorced	1(1%)		Middle	35(34.3%)
	Other	14(13.7)		High	16(15.7%)
	Prefer not to report	2(2%)	Number of Siblings	<3	28(27.5%)
Educational status	Elementary	22(21.6%)		3-5	61(59.8%)
				>5	12(11.8%)
			Order of child	1st	23(22.5%)
				2nd	28(27.5%)
				3rd	21(20.6%)
4rth-7th	29(28.4%)				
Prefer not to report	1				
Employment status	Full-time	30(29.4%)	Total family members	<5	12(11.8%)
				>5	86(84.3%)
				Part-time	9(8.8%)
				Un-employed	50(49%)
Monthly income	<500	62(60.8%)	Residence type	House	30(29.4%)
				Apartment	71(69.6%)
				>1000	5(4.9%)
				Prefer not to report	6(5.9%)
Prefer not to report	13(12.7%)	Prefer not to report	4(3.9%)		

4 Notes: N= Total sample number, n (%)= Number and percent of participants

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Table 2*Condition-Related Characteristics of Children N= 102*

Cancer diagnosis n (%)	Acute leukemia	44(43.1%)
	Rhabdomyosarcoma	15(14.7%)
	Bone tumors	11(10.8%)
	Wilms	9(8.8%)
	Lymphoma	5(4.9%)
	Neuroblastoma	2(2%)
	Germ-cell tumors	2(2%)
	Brain tumors	1(1%)
	Nasopharyngeal cancer	1(1%)
	Optic pathway glioma	1(1%)
	Prefer not to report	11(10.8%)

Notes: N= Total sample number, n (%)= Number and percent of participants

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Table 3
 Descriptive Statistics of the Brief COPE Sub-Scale Scores N= 102

Brief COPE Subscales	Mean	Median	Range	Min	Max
Religion	6.42	7.00	6.00	2.00	8.00
Acceptance	5.95	6.00	6.00	2.00	8.00
Planning	5.10	5.00	6.00	2.00	8.00
Active Coping	5.01	5.00	6.00	2.00	8.00
Positive Re-framing	4.96	5.00	6.00	2.00	8.00
Use of Emotional Support	4.89	5.00	6.00	2.00	8.00
Use of Instrumental Support	4.83	5.00	6.00	2.00	8.00
Venting	4.30	4.00	6.00	2.00	8.00
Self-Distraction	4.10	4.00	6.00	2.00	8.00
Denial	3.69	3.00	6.00	2.00	8.00
Self-Blame	3.52	3.00	6.00	2.00	8.00
Substance Use	3.11	2.00	6.00	2.00	8.00
Behavioral Dis-engagement	3.09	2.00	5.00	2.00	7.00
Humor	2.98	2.00	5.00	2.00	7.00

Notes: N= Total sample size, Min= Minimum subscale score, Max= Maximum subscale score

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Table 4*Correlations between Caregiver Characteristics and Coping Strategies*

	Relationship to Child	Educational Level	Employment Status	Child Gender	Current Health Problems	Child order	Number of Siblings
Self-Distraction		-.273**	.216*	.297**			
Substance Use		.006	.042	.003	.255*		
Use of Emotional Support				.201*	.011		
Use of Instrumental Support		-.268**		.211*		-.226*	
Venting	-.213*						-.203*
	.034						.042
Self-Blame	-.236*	-.217*					
	.018	.031					

Notes: * indicates $p < .05$, ** indicates $p < .01$

Figure 1 Legend

Caregivers' utilization of different coping strategies. Responses 1= Never and 4= Always were used in this figure. Religion and acceptance coping were mostly utilized by caregivers of children who have survived pediatric cancer, while humor and behavioral disengagement were the least utilized coping strategies.

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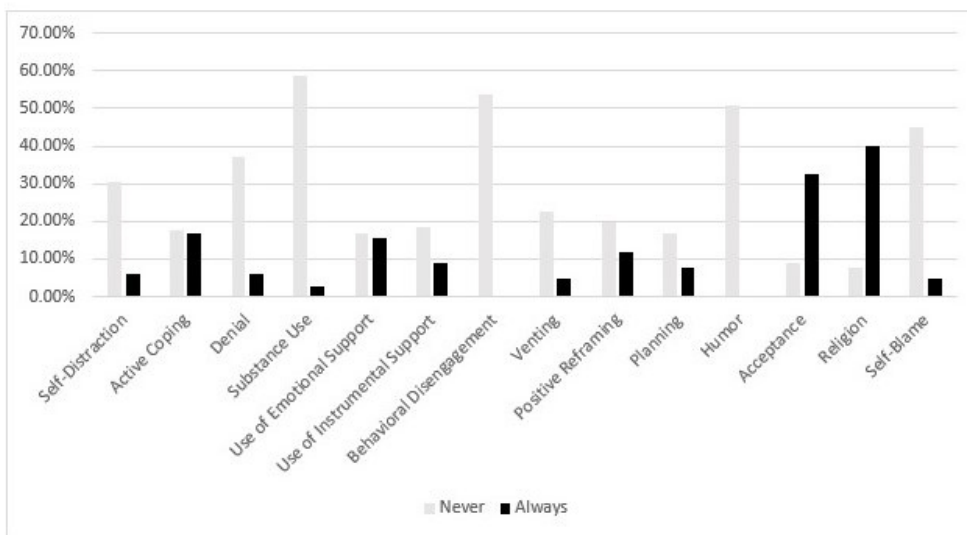


Figure 1 Legend

Caregivers' utilization of different coping strategies. Responses 1= Never and 4= Always were used in this figure. Religion and acceptance coping were mostly utilized by caregivers of children who have survived pediatric cancer, while humor and behavioral disengagement were the least utilized coping strategies.

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