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# Coping strategies adapted by parents caring for children with cancer: a qualitative exploratory study in Ghana

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**Abstract**

**Background** Caring for children with cancer by parents in Ghana is associated with diverse psychological and emotional burdens. However, such parents utilize coping strategies to adjust to their distressing situations. There is dearth of literature on the coping strategies of parents of children diagnosed with cancer in Ghana. Therefore, this study sought to explore the coping strategies adapted by parents of children with cancer.

**Methods** A qualitative exploratory descriptive design was employed to conduct the study. Purposive sampling method was used to recruit seventeen parents of children with cancer. Semi-structured interview guide was used to conduct in-depth data collection. Data was analysed using content analysis approach.

**Results and discussion** Parents reported that emotional and spiritual support enhanced parental coping to the ordeal associated with caring for children with cancer. The parents shared that counselling, self-motivation and inspiration from family and health professionals immensely assisted them to cope. Spiritual support through personal belief in God, religious activities and support from their priests and church members were other strategies parents employed to cope with the traumatising experience associated with caring for children with cancer.

**Conclusion** This study concludes that parents of children with cancer are better able to cope with the distress encountered in their children's care journey through emotional and spiritual support.

**Keywords** Childhood cancer · Coping strategies · Emotional burden · Counselling · Self-motivation

## 1 Introduction

The International Agency for Research of the World Health Organisation reported that worldwide, nearly 280,000 children and adolescents between ages 0–19 years were diagnosed with cancer and 110,000 children died from cancer in 2020 [43]. The global incidence and prevalence of childhood cancer particularly among children under five in 2019 was also recorded as 8,774,979 and 8,956,583.8 respectively [75]. Considering the global gender variations, the incidence and prevalence of childhood cancer cases in 2020 was high among girls than boys [75]. In South Asia and Sub-Saharan Africa, 43% of all childhood cancer cases remain undetected.

Chances of survival from childhood cancer in low-and middle-income countries are 20%, compared to 80% in high-income countries [85]. The incidence and prevalence of childhood cancer in Ghana between 2015 and 2019 was 1073

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cases as recorded at the two main paediatric cancer referral centers in Ghana; Korle Bu Teaching Hospital (KBTH) and Komfo Anokye Teaching Hospital (KATH). The incident rates expressed as age-specific rates (ASRs) was 9.36 per 100,000 person-years. It was higher in male children (2.10 per 100,000 person-years). The highest ASR was seen in children from 0 to 4 years (0.27 per 100,000 person-years). The highest incidence was recorded in the Greater Accra region of Ghana (ASR 4.17 per 100,000 person-years) [63].

Annually, an average of one hundred and seventy (170) new diagnoses of paediatric cancer are treated in the Paediatric Cancer Unit of the Korle Bu Teaching Hospital of Ghana [76]. However, few of these children treated in Ghana recover from the condition [62]. Access to treatment of childhood cancer in Ghana account for the low recovery rate among children treated with cancer. Boateng and colleagues postulated that in Ghana, only 47 of essential childhood cancer drugs (CCD) are on its National Essential Medicines List (EML). 88% of essential Drugs procured inefficiently were more susceptible to stock-outs. These impinge on access to drug affordability, availability and quality [18]. According to the authors, priority interventions to improve drug access in Ghana include nationally-coordinated procurement strategy for CCD, public financing for childhood cancer care and policies to control drug costs [18].

Another bottleneck to the effective childhood cancer care in Ghana are late diagnosis and initiation of prompt treatment. These are attributed to inability of parents to identify early warning signs, financial constraints to facilitate referral of suspected cases as well as limited affordability of diagnostic investigations. Religious and cultural factors could also impact health-seeking behaviours among parents. These factors create a barrier to effective referral of a child with cancer to the referral centres [34]. Nonetheless, Bhakta and colleagues stipulated that with advanced treatment and supportive care from stakeholders, about 80% of childhood cancers can be treated [16].

Generally, parents of children with cancer face myriad of devastating experiences when their children are diagnosed with cancer which affect their emotional and psychological well-being [20]. Findings from a systematic review to assess standards of psychosocial care for parents of children with cancer espoused that post-traumatic stress symptoms are heightened around the period when a child is diagnosed with cancer [44]. Most parents around this time, become extremely devastated and exhibit low levels of coping as a result of their children's condition [37, 97]. Evidence from literature showed that mothers from lower socioeconomic and educational backgrounds are susceptible to psychological distress and less able to cope effectively [5, 71, 77]. It has also been found that when parents hear about the diagnosis of their children with cancer, they feel guilty, express doubt and displace their anger on God, themselves, the doctors, and their partners [37].

In Ghana, the socioeconomic and physical burdens associated with caring for a child with cancer is undoubtedly of great concern). Caregivers are bedevilled with high cost of childhood cancer care stemming from direct cost [26]. Meanwhile, in the course of caring for a child with cancer, most parents lose their economic livelihood and face huge financial burden hence are unable to meet the high cost of childhood cancer treatment [3, 55]. Out-of-pocket payment for treatment of childhood cancer which leads to treatment abandonment [64], negatively affects parental coping. Others encounter interactions in their social life, family relationships as well as a strain on their quality of life as they traverse their care trajectory [26].

Findings from a study by Bekui et al. [14] to explore the psychological and spiritual wellbeing of family caregivers of children with cancer at a teaching hospital in Ghana, espoused that parents mainly mothers' as caregivers of a sick child with cancer encounter caregiving challenges such as fear and anxiety, distress and sadness, blame, confusion and helplessness. The authors believed that such psychological struggles parents in Ghana face were linked to breaking the news of child's diagnosis, uncertainties with treatment and prognosis of childhood cancer, limited extended family support in child care so that parents who work in the formal could continue working to support financially [14].

In the midst of the aforementioned challenges parents encounter during the care of a child with cancer, most parents are able to exhibit resilience and high adaptability amid the crisis []. Parents have adapted several coping strategies to deal with their distressing experiences of caring for children with cancer which leads to improved general well-being [53, 88]. Sharma and others stipulated that among such coping strategies adapted by parents of children with malignancy were distancing, self-control, finding social support, escape avoidance and problem-solving [82]. Psychological counselling has also been reported to assist parents of children with cancer deal with the emotional and psychological strain on their family lives [74, 94]. Studies have shown that the mental health behaviour in parents of children with cancer was significantly improved after they were subjected to psychological therapy [12, 30, 48]. Emotional and psychological support for parents of children living with cancer have been identified to build parental resilience and optimize coping [32, 44, 45, 56, 57, 68].

Findings from a qualitative study to explore the factors facilitating and hindering coping methods of Lebanese parents with a child with cancer, espoused that family support are some parental coping strategies adapted to face the

emotional and intense psychological stressors involved with caring for a child with cancer [28]. It has further been echoed by another study that family bond, a positive self-image, and the ability to strategize for the future are some other positive coping strategies that contribute to the psychological well-being of the mother in particular during the child with cancer's disease trajectory [32]. Furthermore, parental acceptance of the situation leads to a positive impact on parents' adjustment [50, 91]. Conversely, some caregivers cope with their children's illness by self-distancing, as they reflected their deepest thoughts and feelings during treatment or any diagnostic procedures related to their children's illness [69, 82].

Studies have illuminated that during such troubling moments such as dealing with cancer, patients and their caregivers place their hope and faith in the existence of the supreme being to cope with the experience [1, 24, 27, 46, 49, 54, 80]. Family and friends of parents also provide spiritual support through prayer [72].

The Ghanaian cultural views and beliefs significantly shapes the coping abilities and care experience of caregivers of advanced cancer patients [2] of which childhood cancer is of no exception. The Ghanaian community or society and family cohesiveness contribute to their meaning in life [96]. The sociocultural setting and family values also promote interdependence and social well-being respectively [95]. This is reflected in way people within a given community in Ghana become each other's keeper in the midst of crises. The communal living among the people of Ghana strengthens family cohesiveness, community and social support [2, 55]. Community members, the family and neighbours offer social support through regular visits to the parent and the sick child at home and at the hospital. Sometimes, during their visits, they offer all kinds of advice to parents of the sick child to such as suggesting alternative and herbal care for the sick child. This is notably minimal in modernized societies in Ghana where people live solitary lives such as in the cities.

Additionally, until modernization and urbanization, the family system in Ghana was closely knit whereby the family compound housing system was common [25]. In such environments the extended family members and neighbours come in to provide child care support to relieve the burden off the parents. Family of child with cancer develop resilience from the psychological well-being derived from such family strength [90].

In Ghana, anecdotal evidence shows that, people associate chronic conditions such as childhood cancer to evil or spiritual forces and bad omen therefore some dissociates themselves from people affected. Such misconceptions attached to childhood cancer in Ghana like other lower income countries lead to stigmatization and prejudices [22]. Hence, parents cope by shunning away from the support of the community and extended family members who should have been their pillar of hope. Social isolation among parents of children with cancer has been reported as a social burden [55].

Spirituality and religiosity become heightened when a child is stricken by a chronic condition [10], as parents strive to cope with the rejection and humiliation meted out by the society due to their child's condition. Caregivers tend to fully rely on God for Divine healing and hope through participating in religious activities [10]. Others reach out to their pastors, imams, traditional priests and deities in their quest for spiritual intervention. In their vulnerable state, they are subjected to all forms of rituals and exorcisms in the name of spiritual healing. As a result of the cultural and religious beliefs about illnesses among some Ghanaian parents, they fail to take practical steps to seek early medical care for their sick children [34] hence report to the hospital at the terminal stage. But there seem to be paucity of literature in the coping strategies of parents caring for children with cancer in Ghana. Therefore, this study explores coping strategies of parents of children with cancer in the Greater Accra Region of Ghana.

## 2 Methods

### 2.1 Design

Qualitative exploratory descriptive design was employed to conduct the study. This approach allowed detailed descriptions of the perspectives of parents caring for children with cancer with regards to their coping strategies [39].

### 2.2 Research setting

The Paediatric Oncology Unit of the Korle-Bu Teaching Hospital was the setting for the study. Korle-Bu Teaching Hospital is the most prestigious tertiary referral facility in Ghana, Accra serving as the key referral facility for all health care centres across the country. The Paediatric Oncology Unit (POU) comprises the inpatient paediatric oncology ward, an outpatient paediatric oncology unit and the day care unit where children receiving outpatient chemotherapy and follow-up clients are received.

### 2.3 Population

Parents of children with cancer who were receiving treatment at the Korle-Bu Teaching Hospital's Paediatric Oncology Unit for at least 2 months were the target population for the study. Majority of the children of the target population were receiving chemotherapy whiles others were on radiotherapy. This allowed the researchers to explore the diverse coping experiences of parents whose children were on different treatments. The parents were the caregivers of their children. Parents paid for their children's cancer treatment out-of-pocket, and through philanthropic donations. Inability to pay for the high cost of treatment led to treatment abandonment [64]. The National Health Insurance Authority (NHIA) of Ghana in June, 2022 included childhood cancer diagnosis and treatment of four childhood cancers namely Acute Lymphoblastic Leukaemia, Burkitt Lymphoma, Wilms Tumours and Retinoblastoma to the National Insurance Scheme (NHIS) Benefit Package. Nonetheless, there are some challenges with the childhood cancer policy [61]. The Authority seeks to develop capacity to absorb all the costs of coverage for the above cancers with the hope to remove the financial barriers and burden on parents and families [61].

### 2.4 Sampling and data collection procedures

Purposive sampling was used to recruit participants for the study because the participants had the characteristics of interest to the researcher to explore the given phenomena [67]. Permission was sought by the researcher at the Paediatric Oncology Unit. The support of the nurses on the ward to assist in recruiting the participants who met the inclusion criteria was sought. The inclusion criteria were parents of children diagnosed with cancer and receiving treatment within at least two (2) months of diagnosis. Participants' consent were sought before data collection. A semi structured interview guide was used to collect data. Each interviewer conducted face-to-face interviews at designated consulting rooms and audios were recorded with the permission of the participants. Probing of responses were further done for clarity. Data saturation was reached on the seventeenth participant. Although data saturation determined the number of participants involved in the study, the researchers invited twenty-three (23) participants out of which five declined to take part in the study. In all, three (3) male participants and fourteen (14) female participants were recruited for the study. Each interview lasted between 30 min and an hour.

### 2.5 Data analysis

Data analysis was done through inductive content analysis [52]. This was done through verbatim transcription of data from the audiotapes and immediately analysed. Researchers thoroughly read through the transcribed data to make meaning of the data or become familiar with the data. The data was then coded by creating and assigning codes to categorise data extracts. Coding was done by recognizing a set of codes to decrease volumes of verbal information into more controllable data forms, from which the researcher recognised patterns to derive insight [66]. Similar codes from the data were put together to form sub-themes. Sub-themes were aggregated for major themes to emerge. The emerging themes and sub-themes were analysed by the researchers to ensure that, it mirrored the exact interpretation of participants' perspectives.

### 2.6 Rigour

The validity of findings and interpretations were achieved through member checking. This was done by contacting participants to clarify ambiguous responses and repeating some of the responses given by them to reiterate the idea and to affirm what was said during the interview. Triangulation was achieved by comparing field notes and transcripts to precisely depict what participants said. To confirm the appropriateness of the study, the researchers recruited participants who met the inclusion criteria of the study. Concurrent data collection and transcription allowed the collection of both verbal and nonverbal clues to ensure reality.

Dependability was ensured when researchers involved an impartial auditor to examine the researchers' operations. Bracketing was done by separating our own experiences from what was being studied to avoid biases and prejudices. Confirmability was ensured by the researchers by reading thoroughly through the transcripts before interpretation. Raw data was kept, analysis notes and field diary, and proper recording ensured audit trail.

### 2.7 Ethical consideration

Ethical approval was sought from the Korle-Bu Teaching Hospital Scientific and Technical Committee as well as the Institutional Review Board to recruit participants for the study. Copies of approval letters from the hospital's institutional review board and an introductory letter were sent to the Head of Nursing Services of the Paediatric Oncology Unit to seek authorisation to recruit participants. Voluntary participation was encouraged. Participants were told that they could withdraw from taking part in the study at any time without any consequences such as withdrawal of care or intimidation. Consent forms were signed by participants who voluntarily opted to take part in the study. The interview was recorded with participants' permission. The interviews were conducted in a quiet room and privacy was ensured to promote free expression of participants' views. Codes were assigned to the participants to ensure anonymity and consent forms were not stored together with the transcripts to prevent any link of the transcripts with the participant.

## 3 Results

### 3.1 Participants' demographic characteristics

In all, seventeen participants took part in the study. The ages of the participants ranged between 21 and 70 years. Biological parents to the children were 13 whereas four (4) were grandmothers taking care of the children with cancer. The participants were all from different parts of Ghana. The educational backgrounds of the participants were primary school, junior high school, secondary, middle school, vocational school and tertiary education. Two (2) of the participants had had no form of formal education.

Two (2) of the male participants were accountant and teacher respectively, and one (1) female participant was a receptionist. Six (6) of the participants were traders. The other participants were engaged in other occupations such as farming, trading, dressmaking, hairdressing, and food vending. A female participant was without a job and was fully reliant on her elder brother. All the 17 participants had more than one child. Three (3) of the participants were widows, nine (9) of them were married, three (3) were divorced and two (2) were not married. Selection of participants from different demographics in terms of their marital status allowed the researchers to delve into how a cancer stricken child's caregiver's marital status influenced their coping strategies as they navigated their care journey.

### 3.2 Themes and sub-themes

Two broad themes emerged after content analysis. These were emotional support and spiritual support. Sub-themes which emerged under emotional support included; inspiration from family and health professionals, counselling and self-motivation. On the other hand, personal belief in God, religious activities and faith group were generated under the theme spiritual support. The themes and sub-themes have been presented in Table 1.

**Table 1** Themes and sub-themes. Source: transcribed data

| Themes | Sub-themes |
|---|---|
| Emotional support | • Inspiration from family and health providers |
| | • Counselling |
| | • Self-motivation |
| Spiritual support | • Personal belief in God |
| | • Religious activities |
| | • Faith group |

### 3.3 Emotional support

This theme describes the emotional support parents of children with cancer received as they navigated their children's illness journey which contributed to their ability to cope with their predicament. Participants narrated that the inspiration from others such us family members and health professionals helped them to cope with their situation. Also, counselling and self-motivation gave them a glimmer of hope as they cared for their children. It was uncovered from the narrations of the male participants that the inspiration from family members could swiftly empower them to be brave and resilient in the midst of their family adversity. This resilient ability shown by fathers involved in the care of a child with cancer could be attributed to the fact that in Ghana, the sociocultural norms and socialization dictates that men are not supposed to show weakness or cry but rather, they are supposed to be the emotionally strong one in the midst of family crises.

### 3.4 Inspiration from family and health professionals

Other participants reported that some of their family members showed that they cared and understood their emotional and psychological predicaments through their words of reassurance and encouragement.

*"Oh, because some of the family members encourage us to be brave and we also have that bravery, so we can face it very well. We can say that we have been steadfast. We sometimes even laugh with him (the child) and converse very well. It shows that we haven't been affected badly".* **P5 (Male participant)**
*"Whenever I think, I cry but my mummy had told me not to cry again, because it might have effects on the child so I should rather take care of the child and that God will make a way".* **P13**

Some participants also disclosed that they were able to cope with the stress of caring for their children with cancer as a result of the reassurance and encouragement from their doctors and nurses.

*"…the doctors and the nurses have always been encouraging us."* **P1**
*"I will say that if it had not been for the support of the doctors and nurses I met here, I believe I would have been dead by now, leaving my son behind because I could hide and cry my heart out because I didn't understand it. So, if it had not been the way they comforted and encouraged me, I wouldn't have known what would have happened to me…".* **P2**

### 3.5 Counselling

Participants narrated that counselling sessions held for them at the Paediatric Oncology Unit supported them to cope.

*"The hospital staff here called us and counselled us to stop crying and leave everything to God and pray because it is only God who can do all things for us so we should not continue to cry but put our hope in God"* **P10**
*"Mmm…most of the time the health team hold counselling sessions for us" P5*
*"The health care workers counsel us that the condition will not last forever and that we should be courageous and put our hope in God because God will fight the battle for us for the child to be healed. These are the words of encouragement that they give us, and we also accept it that God has done it all"* **P9**

Most participants indicated that counselling sessions conducted by the nurses and doctors granted them the stability and hope to care for their children with cancer.

*"The counselling sessions have helped me. When I came here at first, I used to be very stressed out but the pieces of advice I have received from the doctors and nurses have been very supportive. They always counsel me to compare my child's condition with others and take inspiration that my child's condition is even better …I have been worried about my son's condition but the counselling has helped me cope".* **P2**
*"They (nurses and doctors) counsel us to take heart because the child will get better so I hope that my grandson will get better. We have accepted this and have taken inspiration from it because they have realized that we think so much".* **P8**

Some of the participants also indicated that they were counselled to watch television to divert their attention from the difficulties of caring for children with cancer.

*"One of the staff counselled me that there was a TV on the ward so I should be watching it. Sometimes too when I watch the TV, I forget my problems and laugh whiles watching because if I don't do that, I would probably worsen my situation. So sometimes I think about it and other times my mind diverts from everything that is happening".* **P12**

On the other hand, a participant indicated that she had not received any form of counselling from the health experts on the ward and therefore advocated for one.

*"Since I came, I haven't received any counselling from the health team. I need some counselling".* **P16**

### 3.6 Self-motivation

Most of the parents disclosed that they had to build inner strength and resilience to face the difficult situations that confronted them in the course of their children's diagnosis and treatment. According to some of the parents, amid the mishaps, they had to be strong and cheerful for the sake of their children and exude positive energy into them.

*"I am strong what will I do (she laughed). If I do not become strong, what will I do? So, you as a parent should not always look sad because when you look sad, your child will also look sad hence you should always be happy. It is not easy oo… but in Ghana and Africa, when you can't even breathe and you are asked, you should say I am fine".* **P1**
*"I cheer myself up with that and chat with other people as well and all that helps me forget about my situation for a while and cheer up. I cannot say I do not feel any emotional pain but just that sometimes too I'm able to cheer myself up. So, the feelings keep changing all the time; from a sorrowful one to a cheerful one and that is my situation right now".* **P12**

Other participants were of the opinion that seeing other children who had survived cancer gave them the inner fulfilment that their children would equally recover from the cancer.

*"When I see the children, who have survived the cancer, I really become very happy…It is a delight to see them. When they finish with the cancer treatment too, they become very beautiful and handsome such that it becomes difficult to believe that they had once been diagnosed of cancer".* **P2**
*"…again, one of my husband's cousins' children was also admitted here. He was also diagnosed of cancer, but he was managed well here and now he has recovered. So, when she even came to meet us her, she said, "oh the people here will take good care of him" because of the way my child's situation was. So, I get some hope from what the child experienced and today, the child has even gone back to school".* **P3**

### 3.7 Spiritual support

In this theme, participants expressed that they coped with the predicament of caring for a child with cancer through their personal belief in God which they exhibited through their faith, hope, and commitment to God. Participants also relied on religious activities such as prayers, fasting, singing, reading the Bible and Quran to cope. Some of the participants received spiritual support from their faith members such as priests and church members which contributed greatly to their coping abilities. Both male and female parents involved in the study did not vary in their spiritual coping abilities because they all expressed their dire reliance on God in such troubling times through participating in religious activities and getting close to their faith leaders. Perhaps, parents believe that, a condition such as cancer has a spiritual basis hence as they seek medical attention, they need to intensify their spiritual life by getting close to God for His divine intervention.

### 3.8 Personal belief in God

Participants expressed that they believed God was their source of strength and as a result of His divine intervention, they were hopeful that their children would recover from cancer successfully.

*"Since I have God, everything will be fine. I always have the belief that God is there and everything will be fine. It's just a little challenge because even Jesus Christ Himself went through difficulties and so everything will be fine. My child will successfully recover…she laughed".* **P1**
*"God is my source of strength…because of God's help…, everything will be fine and my child will come out of the condition successfully".* **P3**
*So, we get a lot of hope and we strongly believe in God that our child will recover for us to go home and give glory and honour to God".* **P5 (Male participant)**

### 3.9 Religious activities

Most of the participants, irrespective of their religious backgrounds, recounted that they resorted to religious activities such as prayers and fasting in their difficult moments. According to them, they prayed diligently together with their children and implored God's healing power over the sick children's life because He was their only helper.

*"I fasted and prayed to God to heal my child from this ailment. Since I came here, anytime I am going to bed, I pray to God and at times too my child tells me we should pray then we pray together. I tell God, I have no helper and that he is my helper so he should heal my child for when he speaks, it's final".* **P16**
*"Yes, we do fast and pray often. When I wake up, I pray with my child for us to overcome this problem".* **P17**

Some other participants narrated that, singing gospel songs gave them inspiration and consolation that God was capable of healing their children of cancer. According to them, singing these songs also offered them happiness and hope in life.

*"As for spiritual strength, I love music, so when I sing gospel songs, I use it to cheer myself up. It makes me know that God is in control…it makes me happy. So, for me, music is my inspiration".* **P3**
*"Sometimes we sing gospel songs…that God should listen to our plea and heal our child…"* **P5 (Male participant)**
*"I consoled myself through…singing. It gives me hope that my child would be cured because I used to think a lot".* **P7 (Male participant)**

Many of the participants shared that, words from their religious books such as the Bible and the Quran encouraged and strengthened them spiritually to cope with the issues of caring for a child.

*"I encouraged myself with the Qur'an saying God doesn't give one a burden he or she can't carry but when he puts a burden on you it means one can carry such burden. Then if it's God who loaded me with the burden then, He should show his powers because He knows I can carry the burden that's why He has given it to me."* **P14**
*"… reading the bible and sharing the word is what I do to strengthen myself spiritually...".* **P1**
*"I use God's words from the Bible and His messages to overcome all the fear I have concerning my child's condition".* **P11**

### 3.10 Faith group

According to some of the participants, their Pastors demonstrated that they cared for their sick children by calling them on phone to motivate them to be strong. According to them, these Pastors were very instrumental in their lives and they were appreciative of their diverse contributions.

*"…The Pastor of Deeper Life Church has encouraged me to have faith, and that has changed my mind, so I will start going to church again. The Pastor calls me every two days to have a conversation that has given me faith to go to church, when I leave the hospital, I will be the first person in church".* **P7 (Male participant)**
*"I receive calls from my Priest encouraging me that they have been praying for me and my child and wish me well. In addition to my Priest and everybody who prays and encourage help us to cope".* **P1**

Other participants recounted that their church members also spiritually cared for them by supporting them in prayers when their children were diagnosed with cancer.

*"It was really difficult for me and I was always crying but my church members also supported us with prayers. On Wednesdays, we hold women association prayers. My Pastor's wife also sought prayers from congregants and it helped me. They did a great job by praying for us from the beginning to when we were discharged".* **P3**
*"I receive calls from my church members encouraging me that they have been praying for me and my child and wishing me well"* **P1**

## 4 Discussion

The findings of the study uncovered that emotional care, counselling, and self-motivation propelled parents of children with cancer to cope with the difficult situation they faced. Literature echoed that emotional and psychological care and interventions empower parents of children with cancer to cope with their distressing experiences [21, 74].

Words of encouragement said to them by their families and friends during their most difficult moments was beneficial. This finding is in line with literature that quality support from friends of parents of children with cancer enable parents of children with cancer to build resilience and develop better health behaviours [13, 94]. Counselling was one of the interventions parents of the study benefitted from their health care providers which improved their coping. These counselling sessions were periodically offered to these vulnerable parents to motivate them to have a glimmer of hope and resilience about their children's illness. Empirical evidence from a quantitative study conducted in Iran concluded that psychological counselling eliminates anxiety and depressive symptoms of parents of children with cancer, hence, mental health is improved [74]. Parental counselling also presents an opportunity for counsellors to stress the need for parents to comply with their children's treatment which prevents abruptly curtailing the treatment [6, 7, 81]. However, it was problematic that some health professionals counselled the parents to stop crying and rely on God which seem to suggest that health professionals did not pay attention to the psychological ramification of their feeling. Even though believing in God during distressing moment is important, suggesting that family members should rely on God and ignore the feelings they experience is not good enough. Contrary views of some of the parents of this study were that they did not participate in any form of counselling. They however expressed that they would appreciate the benefit from counselling. This finding reinforces that counselling is a prerequisite to provide coping skills to individuals in times of need [40]. Counselling provides a crucial support for parents of children with cancer for the reason that they face diverse anxiety disorders, depression and post-traumatic stress disorders due to their children's devastating health status [23, 78]. The study further disclosed that the parents exhibited self-motivation that they would not give up on themselves and their sick children. They developed inner strength, resilience, stayed focused and positive. They exhibited such attributes to be a source of motivation to their sick children. A study by Sharp et al. [42], stipulated that the ability of parents to stay strong and consistently reassure their youthful children living with cancer, is a catalyst for instilling resilience in them [42]. The self-motivation other parents in this present study displayed emanated from the joy of seeing that their sick children were responding to the treatment regimen. This inner drive of the parents to see their children succeed in their treatment prevented them from shedding any more tears and became focused on the brighter side of their children's condition amid its traumatising impact. This is similar to a qualitative study conducted in the Netherlands that espoused that, parents of children with malignant or non-malignant diseases, receiving palliative care, psyched themselves up and behaved more positively. They did that by focusing on the present, kept their hopes alive, and became extremely optimistic amid the challenges that confronted them [91]. This hope and positivity the parents developed, according to Conway et al. [24], was so strong that they were not perturbed by any distraction [24]. Parents stood a higher chance of developing positive well-being as a result of good personality traits and consciously developing better-coping styles to be emotionally stable [19]. On the contrary, the unknown outcome of the child's condition and apprehension could contribute immensely to parental post-traumatic stress disorder (PSTD) manifestations months after discharge. PSTD can result when parents fail to utilise positive coping skills but rather stay in denial, self-blame, and vent [35]. Furthermore, parents were personally convinced that once other children had survived childhood cancer, their children would equally make it [84]. Conversely, Toledano-Toledano and de la Rubia [89] postulated that the confidence of parents to control their motivation and be optimistic is not associated with their anxiety levels [89]. Parents were perhaps self-motivated against all odds in their care experiences since they saw the need to be strong for themselves, their sick children, and family throughout their child's disease trajectory. Parents of children with cancer are able to cope better with emotional support due to the fact that caring for children with cancer could be emotionally and psychologically daunting which may affect their entire quality of life hence, emotional support propels such parents to face the situation squarely without breaking down. Therefore, emotional support through regular visits by families and friends must be encouraged by implementing a flexible visiting hour policy at the hospital. It is evident that regular visits from family and friends during hospitalisation promote coping [15]. Instituting such a policy will build confidence and morale in the parents [11]. Therefore, the current findings suggest that there must be adequate professional counsellors and clinical psychologists to carry out a continuous assessment of emotional and psychological health needs of the parents and access to suitable psychological interventions [44]. The nurses and doctors at the unit should be trained to attain the requisite knowledge and skills for counselling to efficiently counsel the parents in times of distress. Parents should for that matter be encouraged by their health care personnel to persistently utilise the attitudes of self-motivation to cope better with their distressing issues. They must be commended for staying focused and empowered for their children. Also, parents must be encouraged to surround themselves with positive people who acknowledge their strengths and weaknesses and inspire them to forge ahead until their children are successful with their treatment cycles.

### 4.1 Spiritual support

The majority of the parents caring for children with cancer had a strong belief in the divine existence of God in times of crisis. They had so much conviction in God to intervene in their difficult situation. When parents demonstrate such strong beliefs in God, it enables them to develop a fulfilling relationship with Him [29]. The belief in the supernatural power of God becomes extensive at the time of a child's diagnosis when stress levels, especially among mothers, are profound [41]. In this current study, personal belief in the supernatural higher power gave the parents a sense of hope, meaning to live, spiritual support, and strength. Others also derived hope and faith of healing from God irrespective of the phase of the child's condition. Several studies corroborate this current finding [58, 59, 70, 93]. Spiritual faith, according to Wiener et al. [94], was amplified in both single and married parents at the time of their child's diagnosis [94]. Exercising spiritual belief in God allows the parents to recognise that they are powerless to protect their children from adverse effects of the condition. This belief parents have in God fosters their reliance on Him for recovery amidst a child's ailment [86]. During a child's disease trajectory, the faith and hope parents show in God determine their treatment initiation decision-making and life-supporting treatment for their child with life-threatening conditions [86]. Parental spiritual belief in God gave them the peace of mind to cope with their challenging circumstances [87]. Believing in God in times of crisis also reassure parents that God was the only one they had to trust to provide them comfort, hence, they committed all their burden to him. Sociocultural influences and belief system on health are a major concern in most cultures around the world [8, 33, 51]. The indigenous Ghanaian is also very spiritual, hence, during an illness such as cancer, they find it strange and a bad omen so develop a heightened belief in God whom they trust to deliver them from any such catastrophes and also heal their children. Parents must therefore be supported to continue believing in the healing power of their God to satisfy their spiritual needs when they are going through such predicaments. However, there must be sensitisation to the general public that scientific medical interventions and health technology are far advanced. Hence parents and other family members must cooperate with their health care team while they exercise their hope and faith in God for divine healing. This will lead to the advancement in paediatric oncology care.

The parents of the study also resorted to prayer and fasting as part of their religious activities. They diligently prayed together with their sick children for God to intervene and heal the children of their ailments. It has been reported that among the Greek families with a child with cancer, prayers are used as complementary treatment therapy [73]. Other parents were of the view that, anytime they combined prayers with fasting, they became positive that their prayers had been answered by God. The notion that their prayers had been answered resulted in a better coping outcome. The singing of gospel songs gave Christian parents some inspiration in God. In addition to the above-enumerated activities parents engaged in, a couple of the parents also dedicated themselves to reading their Bibles and deriving some spiritual strength in the face of their adversities. Islamic believers also derived their inspiration from reading their Qurans [46].

Parental religious activities during such tough moments imply that people naturally become extremely religious when in distress [38] so that they can connect with their supernatural being to endow them with optimism to cope with their challenges. Effective religious coping in caregivers alleviates some depressive symptoms they develop from the care burden [9, 92]. These reasons substantiate some parents' decisions to support themselves with religious activities [17]. Findings from a qualitative study in Iran concluded that psychological issues are factors that drive parents of children with cancer to seek spiritual attention in order to develop a sense of peace and adapt to the distressing situation [83]. Likewise, a cross-sectional study deduced that individuals in the palliative phase of cancer enjoy a high quality of life when they cope better with religious and spiritual activities []. On the other hand, a quantitative study postulated that positive religious coping does not correlate to caregiver burdens and for that matter their depressive states [47]. Notwithstanding, nurses and other health professionals must respect and support patients to participate in any form of religious activities they practice as far as it may not be detrimental to other parents on the ward. Health care providers must be trained in transcultural nursing care [31, 36, 65]. Training in transcultural nursing will equip them with the knowledge and skills to support the parents with culturally competent care to meet parents spiritual needs [4]. Spiritual health needs assessment during this difficult time is significant for the right interventions to be given them [79].

Furthermore, Pastors of the parents in this present study showed so much spiritual care to the parents and their sick children as they went through the distasteful experience. The Pastors regularly called on their phones to check up on them and exhorted them with the word of God. The parents narrated that their church members also became a network of support during their difficult moment. Nicholas and colleagues posited that the support which parents of children with cancer derived from their faith community endow them to cope spiritually [60].

The spiritual support the parents of children with cancer at the oncology unit received from their faith group members, may perhaps be due to the fact that most people run to their religious leaders and members of their faith in times of distress because they perceive them as resources of hope and spiritually equipped to draw them closer to God. Hence, their prayers and support were seen as satisfying and revered. It is therefore recommended that the spiritual leaders and the church reach out to parents of children with cancer and consistently support them in kind and cash in addition to the prayer support. This will project a sense of hope in them that their "spiritual family" cares for them [98].

## 5 Limitation of the study

The main limitation of the study was the challenge of sustaining interviews for participants who did not have someone to support them with child care. Also, another limitation was recruiting participants who could read and understand the information sheet and consent form.

## 6 Potential of the study, why it is important and how it can be used and its practical application

1. The study finding highlight the coping abilities parents of children with cancer built from emotional support from family as they navigated child cancer journey. This finding may promote the implementation of flexible visiting hour policy at the hospital to enable family members spend more time with the parents.
2. Inspiration from health professionals was an avenue for parent to cope with their psychological distress. This may prompt practical interventions by health authorities to train health professionals on therapeutic communication so that health professionals will learn effective communication skills to explore the feelings of their clients and family and provide the best of care**.**
3. Counselling benefitted the parents to cope. Therefore, the Ministry of Health of Ghana may acknowledge the need to employ adequate professional counsellors and clinical psychologists to provide counselling services to support the parents of children with cancer.
4. Establishment of parental support groups by Head of the Paediatric Oncology Unit may encourage the parents to share their unique experiences and derive strength from one another.
5. Parent adapted spirituality/religiosity to cope with their situation. Policy makers may learn from this finding to inculcate spiritual care training into the nursing curriculum and training programmes to improve the competency of nurses to support patients and caregivers spiritually.
6. Reliance on religion for hope was captured in the findings. This may enhance sensitisation of the general public that as they exercise their hope and faith in God for Divine healing for children with cancer, they must also seek medical care early to avoid complications.

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**Data availability** The datasets for the analysis of this current study can be obtained from the corresponding author on reasonable request.

## Declarations

**Ethics approval and consent to participate** Since this study involved humans, all methods were conducted in accordance with relevant guidelines and regulations as specified by the Declaration of Helsinki. Informed consent was obtained from all study participants. Ethical clearance was obtained from the Scientific and Technical Committee as well as the Institutional Review Board (KBTH-IRB/000128/2020 of Korle-Bu Teaching Hospital, Ghana). Informed consent was obtained from participants.

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**Competing interests** The authors declare that, they have no competing interests.



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