Received: 7 November 2021 | Revised: 25 May 2022 | Accepted: 15 November 2022

DOI: 10.1002/nop2.1499

NursingOpen Open Access WILEY

RESEARCH ARTICLE

Mothers' perspectives of physical and psychological issues associated with caring for Ghanaian children living with tuberculosis: A qualitative study

Eric Tornu[1] | **Gladys Dzansi**[1] | **Donna M. Wilson**[2] | **Solina Richter**[3] | **Lydia Aziato**[1]

[1]Department of Adult Health, School of Nursing and Midwifery, College of Health Sciences, University of Ghana, Accra, Ghana

[2]Faculty of Nursing, University of Alberta, Edmonton, Alberta, Canada

[3]College of Nursing, University of Saskatchewan, Saskatoon, Saskatchewan, Canada

Correspondence
Gladys Dzansi, Department of Adult Health, School of Nursing and Midwifery, University of Ghana, Legon, Accra, Ghana.
Email: gdzansi@ug.edu.gh

Funding information
Queen Elizabeth II Diamond Jubilee Scholarships

Abstract

Aim: The aim of the study was to explore and describe the mothers' perspectives on issues associated with caring for Ghanaian children aged 0–14 years living with tuberculosis.

Design: Exploratory descriptive qualitative design.

Methods: Semi-structured individual interviews were conducted face to face with 15 purposively sampled mothers from two health facilities in the Greater Accra area. Transcribed data were analysed using computer-enhanced thematic analysis.

Results: Findings were grouped into (1) physical burden on the mothers and (2) psychological burden on mothers. The eight subthemes indicate that mothers of children living with tuberculosis experienced tiredness, sleeplessness, body pains, weight loss and sicknesses as they cared for their children. In addition to worrying, mothers experienced stigma and negative emotions such as sadness, guilt, fear and loneliness.

Conclusion: Mothers of children diagnosed with tuberculosis in Ghana experience physical and psychological health problems related to their caregiving roles. Nurses and other healthcare providers should identify specific problems and offer broad-based emotional and other support for these women.

KEYWORDS
care burden, caregiver, child, mother, physical, psychological, tuberculosis

1 | INTRODUCTION

Tuberculosis (TB) is an infectious airborne disease caused by the bacterium *Mycobacterium tuberculosis* (Narendran & Swaminathan, 2016). Although it is an age-old life-threatening disease, currently it is the leading cause of death among children who experience infectious diseases worldwide (UNICEF, 2020). In 2020, out of the estimated 9.9 million persons who fell ill with TB globally, children below the age of 15 years accounted for about 11% (1.1 million) (World Health Organization, 2021a, 2021b). In Ghana, 5% of all new TB case notifications in 2020 were among children below the age of 15 years (World Health Organization, 2021a). Ill children living with TB will require considerable parental or guardian care to survive. Mothers typically play the traditional role of primary caregivers for children in most settings, including Ghana (Kyu et al., 2018). As such, it is important to learn if and how the mothers' burden of care associated with their caregiver role changes when their children fall ill with TB and must be nursed back to health.

2 | BACKGROUND

The burden of care associated with caring for sick children is known to be a source of stress for caregivers (Javalkar et al., 2017). Caring for children living with chronic conditions in particular involves managing recurring symptoms, administering multiple medications and attending scheduled medical appointments while providing daily routine care such as feeding and maintenance of the child's hygiene (Javalkar et al., 2017). Caregivers who are overwhelmed by these caregiving tasks may experience impaired quality of life, poor sleep, physical strain and depression (Barros et al., 2019; Collins et al., 2020; Macedo et al., 2015; Polack et al., 2018). The factors which contribute to these caregivers' burden include their age and level of education, the child's number of medication or chronic conditions, frequency of emergency room visits and low self-efficacy of the child (Adib-Hajbaghery & Ahmadi, 2019; Barros et al., 2019; Javalkar et al., 2017). Psychosocial factors such as social support networks, family support, family functioning and well-being have also been found to influence caregiver burden (Toledano-Toledano & Domínguez-Guedea, 2019).

Providing care for children living with TB can be complicated and laborious. Children living with TB are often ill, and they miss school and suffer in other ways as a result. They must be managed on a daily combination of antituberculosis medication for 6 to 12 months as required to ensure a complete cure (Centers for Disease Control and Prevention, 2021). The Directly Observed Treatment Short-course (DOTS) system for TB management supports and encourages children to take all TB medication daily under the supervision of an adult caregiver (Seddon & Graham, 2015). Other medications such as haematinics, expectorants and antibiotics may be prescribed to support the child's treatment. Additionally, the children require nourishing meals to improve their immunity and facilitate recovery. In some cases, the child may require hospitalization for further management of complications such as immunodeficiencies, malnutrition, haemoptysis and pleural effusion (Vecchio et al., 2015). Strict adherence to routine medical reviews and antituberculosis medication refills is also required to reduce the risks of TB drug resistance or treatment failure. These intensive TB treatment measures require active support from the child's primary caregivers, who most often are their mothers.

Studies on the experiences of mothers who care for children living with TB suggest that their caregiver role puts them at risk of personal physical and psychological setbacks (Awaluddin et al., 2020a; da Silva et al., 2014; Zhang et al., 2014). A qualitative study by Zhang et al. (2014) involving 22 parents including eight mothers of children living with TB in China revealed that mothers caring for children living with TB-experienced tiredness on account of the direct care they had to provide to their ill children. The mothers remained involved in the child's direct care even when the children were hospitalized; sometimes leading to the neglect of the ill child's siblings and spouse if present. These mothers also experienced burnout, body aches and ill-health as they still needed to carry out all of their normal daily activities (Zhang et al., 2014).

Previous studies also suggest that mothers caring for children living with TB can experience psychological distress which may negatively affect their quality of life. Mothers worry about the treatment, prognosis and impact of TB on their children's education or future job prospects (Zhang et al., 2014). Mothers witness the children's deterioration of health at first-hand which may contribute to feelings of insecurity, guilt and self-blaming. This sense of guilt was especially strong when children contract TB infection from their parents (Das et al., 2021). Additionally, mothers have to live with the stigma associated with their children's TB diagnosis and isolation. Most significantly, the mothers are in constant fear of the child dying on account of TB (da Silva et al., 2014).

A few studies have explored the experiences of caregivers of children living with TB in settings such as China, Malaysia and Brazil (Awaluddin et al., 2020a; da Silva et al., 2014; Zhang et al., 2014). No studies appear to have studied the physical and psychological issues that mothers of children living with TB experience within the Ghanaian context. Unlike China, Malaysia and Brazil, Ghana is a lower-middle-income African country with a high burden of TB among its increasing population of children below 15 years (World Bank, 2022). Whereas Ghana's TB case fatality ratio for the year 2020 was 37%, treatment coverage for TB stood at 29% nationwide (World Health Organization, 2021a). It is, therefore, important to explore the experiences of mothers caring for children living with TB within the Ghanaian context because the mothers' experiences and challenges associated with providing care for children living with TB in a resource-constrained African setting such as Ghana may not be the same as other mothers' experiences in other countries. Furthermore, the differences in the socio-cultural contexts of the previous studies compared with Ghana can contribute to a difference in the mothers' care experiences, a circumstance which necessitates this study (Calderon & Tennstedt, 2021; Zarzycki et al., 2022). A study can offer healthcare providers and others insight into the challenges that mothers of children living with TB experience within the Ghanaian context, so these can be anticipated and resolved. A study was developed to explore and describe mothers' perspectives on caring for Ghanaian children living with TB.

3 | METHODS

3.1 | Research design

An exploratory descriptive qualitative research design was used to explore and describe the physical and psychological issues affecting mothers caring for children living with TB within a large metropolitan area in southern Ghana (Kim et al., 2017).

3.2 | Participants and recruitment

Participants were mothers of children (aged below 15 years) who were living with TB and receiving care in two public hospitals (a children's hospital and one regional hospital) within the metropolitan area of Accra in southern Ghana. The mothers were included in the study if they were older than 18 years and had rendered care to a child aged 0–14 years living with TB for at least 1 week. In this study, a mother was defined as the female biological parent or guardian of the child living with TB. Fifteen participants were recruited using the purposive sampling technique, to ensure that all participants met the study's inclusion criteria (Grove & Gray, 2018). The final number of participants interviewed was informed by data saturation, which is the point at which no new data which could inform the study, was obtained from participants. The participants were recruited with the assistance of two nurses who were providing healthcare services for the children living with TB through the two hospitals. The participants were included in the study irrespective of their marital status (single, cohabiting, married or widowed) and number of children they had. This measure ensured that different categories of mothers caring for children living with TB who meet the inclusion criteria are considered for inclusion in the study. All prospective participants approached provided informed consent to be part of the study. This occurred after the first author (ET) met prospective participants face to face and explained the study's purpose and procedures to them before they could choose to participate in the study.

3.3 | Setting and data collection

Data were collected through interviews with participants from January to July 2021 in the two hospitals. Both hospitals have TB units that provide inpatient and outpatient health services such as directly observed treatment and follow-up care on scheduled review dates. The two hospitals were selected for this study because they have a large population of children living with TB who seek TB health care and are accompanied by their mothers. Semi-structured individual interviews were conducted among participants using interview guides with open and closed-ended questions. Some of the interview questions that participants were asked included “How will you describe your experiences in the care of your child living with tuberculosis?” and “What difficulties do you face while caring for your child diagnosed with tuberculosis?”. The interview guide was developed by the researchers based on the study objectives and a review of literature on issues affecting mothers of children living with TB. The interview guide was pretested with two interviews, and these data were added to the later study data as no modifications were made to the interview guide. The interviewer-administered (face-to-face) interviews were conducted in each participant's preferred language (English, Twi, Ga) and venue (a private office within the participant's hospital). There were no non-participants present during the interviews. The interviews lasted between 30–60 min and were audio-recorded with participant permission. Each participant was interviewed once for the study. Field notes were kept by the interviewer to inform the data analysis.

No new information, which could inform the study, was obtained after interviewing the thirteenth participant suggesting that data saturation had been reached (Saunders et al., 2018). Two additional interviews were conducted among new participants to confirm data saturation. With data saturation, a decision was made to have no follow-up interviews. Transcripts were not returned to participants for comments or corrections. However, to ensure the trustworthiness of the study, member checking was conducted by restating and summarizing participants' responses during the interview for their confirmation of its accuracy. Furthermore, participants' audio-recorded interviews were transcribed verbatim, and findings were discussed with the co-authors for confirmation of insights drawn from the data. Participants' verbatim quotes were reported to promote the confirmability of the findings. The credibility of the study was ensured through prolonged engagement with participants which engendered a good rapport for data collection. Anonymity was ensured and none of the authors had ever met any of the participants before this study was conducted.

3.4 | Data analysis

The audio-recorded interviews were transcribed verbatim for data analysis. The interviews conducted in the local languages (Ga and Twi) were translated into the English language. The transcripts were confirmed by someone fluent in the local languages to ensure consistency in meaning. The transcripts were uploaded onto MAXQDA data analysis software (version 2020) for thematic analysis (Maguire & Delahunt, 2017). Data were coded by the lead author (ET) and confirmed by the co-authors. The researchers read the transcripts repeatedly to familiarize themselves with the data and establish the meaning of participants' responses. Similar ideas were grouped into codes, and similar codes were grouped into sub-themes. The subthemes were grouped to derive the main themes of the study findings. This measure contributed to a rich description of the participants' experiences.

3.5 | Ethical considerations

Ethical approval for the study was obtained in advance from the Ghana Health Service Ethics Review Committee (GHS-ERC 0060120). Institutional approval was obtained from the two hospitals before participants were recruited. With the aid of the study information sheet, the rationale of the study and measures to ensure participant anonymity, privacy and safety were explained to each prospective participant to ensure their voluntary participation in the study. Participant identifiers such as names and addresses were not recorded to ensure participant anonymity. Each participant willing to participate in the study signed a written informed consent form after the study procedures had been explained to their satisfaction. To secure the study data, softcopy data such as interview recordings and transcripts were saved on password-protected drives. Hardcopy documents such as signed consent forms were stored in a locked cabinet accessible only to the researchers.

4 | FINDINGS

The age range of mothers was 23–54 years, and each was providing care for one child living with TB. The participants had provided care to their children living with TB from 3 weeks to 24 months. The children were aged 1–14 years. Table 1 summarizes participants' sociodemographic characteristics including their ages, marital status, number of children and time since the child was diagnosed with TB. After an analysis of the data, we were able to group our findings into physical and psychological burdens on mothers. The two themes and eight subthemes are presented in Table 2.

4.1 | Physical burdens affecting mothers

Many problems affected the participants' physical health while caring for their children living with TB. The five (5) sub-themes identified under this theme included *tiredness*, *sleeplessness*, *body pains*, *weight loss* and *sicknesses*.

4.1.1 | Tiredness

The mothers all experienced tiredness while caring for the children living with TB. They ascribed their tiredness to combining childcare activities (such as hospital visits for TB treatment, serving TB medication, bathing and feeding the sick child) with running other errands such as caring for the rest of the family. The mothers of hospitalized children living with TB mentioned that walking around hospitals and pharmacies to conduct the children's requested laboratory investigations or buy prescribed medication also contributed to their tiredness.

> The hardship I go through is that I'm sitting at one place and the doctors call me to come and collect maybe a prescription to go and buy a drug. 'Go and do this for your child, go and do labs, go and buy medicines', that is what I would say is tiring.
>
> (P8)

4.1.2 | Sleeplessness

Several participants mentioned not having adequate sleep or rest due to their children's incessant cough, cries and inability to sleep (insomnia). Persistent thinking about the child and worry at night also contributed to participant sleeplessness. One of the participants perceived her sleepless nights as a price to pay for her child to live. Another participant used her child's recovery from TB illness and the cessation of her sleepless nights as a story to praise God.

> … the child coughs continuously in the night. It makes you the mother restless because if the child doesn't sleep, you also can't sleep. When it happens like that, she coughs so much.
>
> (P4)

> If he makes any sound, I have to be awake just so he gets well soon…We have really suffered with all his care. All the sleepless nights just for him to have life again. So I used his situation [recovery] as a testimony [story to praise God].
>
> (P12)

TABLE 1 Sociodemographic characteristics of participants

Participant identity number	Age (years)	Marital status	Number of children	Sick child's sex	Child's age	Time since tuberculosis diagnosis
P1	45	Widowed	4	Male	1 year 7 months	6 months
P2	32	Co-habiting	1	Female	3 years	3 weeks
P3	32	Single	3	Female	14 years	24 months
P4	29	Co-habiting	3	Female	1 year	3 weeks
P5	31	Single	1	Female	12 years	4 months
P6	44	Married	3	Male	8 years	6 months
P7	42	Married	6	Female	11 years	24 months
P8	24	Single	1	Female	6 years	3 months
P9	39	Married	4	Female	3 years	11 months
P10	26	Single	4	Female	1 year 9 months	14 months
P11	31	Married	2	Female	3 months	2 months
P12	54	Divorced	4	Male	1 year 3 months	5 weeks
P13	23	Co-habiting	1	Male	3 years	3 weeks
P14	28	Married	1	Female	2 years	12 months
P15	30	Married	1	Male	2 years 5 months	12 months

TABLE 2 Themes, subthemes and codes of the study

Theme	Sub-theme	Codes
Physical burdens	Tiredness	Exhausting childcare Fatigue from walking Weariness from idle waiting
	Sleeplessness	Interrupted sleep from coughing child Insomnia from worrying
	Body pains	Headaches Pains in hands, back and feet Pains after poor sleep
	Weightloss	Reduced weight from thinking Loss of weight from anorexia Loss of weight after ill-health
	Sickness	Hospitalization after caregiver strain Diagnosis with gastrointestinal ulcer Diagnosis with diabetes mellitus Anorexia
Psychological burdens	Thinking and worrying	Thinking about child's health Tuberculosis medication concerns Distressing symptoms of childhood tuberculosis Worry about treatment money
	Negative emotions	Hopelessness Guilt Sadness and crying Fear of tuberculosis medication side-effects Fear of child dying Fear of tuberculosis contagion Loneliness
	Stigma	Enacted name-calling Community members' comments Discrimination against child and mother

4.1.3 | Body pains

Participants reported feeling body pains which were physical health challenges they experienced on account of providing care to their children living with TB. Their body pain sites included their heads, backs, hands and feet. Some participants described the intensity of their body pain as not serious while others described it as severe. One participant who had severe pains in her hand had lost the ability to lift objects with her affected hand. Situations that precipitated these body pains included walking around during child care and not getting adequate sleep at night on account of waking up intermittently to care for the sick child. One participant characterized her headaches as intermittent in nature.

> I feel pains in my body… My whole body, even this hand… For now, I would say it's just this hand – if someone asks me to help them lift something, I can't lift anything to help.
>
> (P6)

> it was just my back that was aching at the time. And because I was with him and was not able to sleep, I had some headaches too.
>
> (P12)

4.1.4 | Weightloss

Most of the participants lost weight through caring for the children living with TB. Almost all the mothers attributed their weight loss to thinking or worrying either about their sick children or the money required for their children's care. The participants who had lost weight and then regained their normal weight attributed their weight gain to their children's recovery.

> Her care, and a lot of thinking. There is a lot of thinking involved… Now, she's better and some people feel I've gotten bigger, …it's not that I eat a lot or I have gotten some money, but everything is in my head, just that I don't think too much anymore.
>
> (P7)

4.1.5 | Sicknesses

Some participants mentioned that they developed various sicknesses on account of the care they were providing for their children. One of the mothers explained that she became anorexic because she was worried about her child. She later developed gastrointestinal ulcer requiring medical attention. She fell ill and had to be hospitalized because she was always carrying her child on her back.

> She's always on my back until she falls asleep and I can put her down…even recently, I fell sick and was admitted to the hospital, the polyclinic, for about a week. I just came back home this past Sunday….and because of worrying about my child, I wasn't eating. When we did the lab tests, they said I've gotten an ulcer.
>
> (P4)

Another participant reported being diagnosed with diabetes mellitus during the course of her ill child's care. She believed that her worrying and anxiety contributed to her sickness.

> when he got sick due to worrying and anxiety, I got diabetes through that because I was too anxious… I was eating alright but I had lost weight. They asked what was wrong with me and after checking, they confirmed I had gotten diabetes.
>
> (P15)

4.2 | Psychological burden on the mother

Participants had substantial varied psychological burdens while caring for their children living with TB. The theme is comprised of three subthemes: Thinking and Worrying, Negative emotions and Stigma.

4.2.1 | Thinking and worrying

Several participants revealed they were constantly thinking about and worrying over their child, and particularly when the ill child was their only child. They clarified that before the child's illness, they were not thinking as much. While some of the participants thought about how the children got infected with TB, others were worried their children may die. The recurrence of their children's health problems was a source of worry and they often thought about funds for treating their children.

> …to be taking care of a child like this and he is not getting better and everyday there's something, you worry a lot. It makes you think. You keep thinking about what you can do to make them better. If the child is not fine, you're also not fine.
>
> (P6)

Another source of thinking and worry for the participants included witnessing the distressing symptoms of TB and its associated body changes in their children. These distressing symptoms and body changes included persistent cough, inability to eat, vomiting and weight loss. Other symptoms included the children's pallor, weakness, breathing problems and body pains. One mother insisted that her previously "beautiful child" she gave birth to had changed.

> she was growing lean and she's very, very pale. She's not that fat too for her to be growing that lean… So we went to Alpha [clinic] and they gave us medicine but still she was coughing, she can't eat, any time she will eat, she will be crying, [she] says her stomach is paining her.
>
> (P3)

> …if not for how far this place is, I would have gone for my child's baby pictures and shown you. And for me to see that now my child has changed. The beautiful child I gave birth to has changed.
>
> (P1)

4.2.2 | Negative emotions

Most of the participants revealed that caring for a child living with TB was associated with negative emotions which included hopelessness, guilt, sadness and crying. Other negative emotions reported included fear and loneliness. Some participants felt hopeless immediately after their child was diagnosed with TB. One mother lost hope because she was not seeing signs of her child getting better with treatment, and she blamed herself for not believing the child's TB diagnosis and having treatment start earlier. The participants often felt unhappy at the sight of their ill children and also the clinical manifestations of TB disease.

> I haven't seen any signs of her getting better so I don't have any hope…I blame myself. I have really wronged my child. In the beginning when I was told, if I had had hope and believed what I was told, I can say that it would have been dealt with quickly so my child will escape all this.
>
> (P8)

This unhappiness sometimes made them cry. Some mothers cried because they wished they had not given birth in the first place. Others cried because of the children's hospitalization and treatment. Participants often cried at night or upon waking up. Some mothers cried at least once a day and others cried about three times each week. However, these mothers did not cry in the presence of their children to prevent the children from crying as children try to console their mothers when they cry. Whereas some of the mothers felt relief after crying, others did not.

> I used to cry but now I've seen that there's nothing good in crying…Because when I cry, the child also

> gets sad. So I was told to stop…It [crying] wasn't helping but what will you do? When I'm alone and my mother and others aren't home, I cry… The reason I cry is that I wish I hadn't given birth. It would have made me really happy.
>
> (P10)

Another negative emotion reported by participants was fear. The participants mentioned being afraid on account of their child's TB diagnosis, treatment and possible death. Other participants express fear of TB contagion to the healthy siblings and friends of the child living with TB. They experienced fear because they felt their children were too young to develop TB disease. One participant was afraid because the local name for TB disease was associated with death and a friend's mother had died on account of TB disease. She also feared that her child would experience the detrimental effects of the multiple TB medications used in her child's treatment.

> when I was young, my classmate's mother died and we were told it was that cough…they say it is 'nsamanwa' [ghost cough] and I am scared… also with her being a child and we combining about six drugs of treatment for her. I was really scared.
>
> (P11)

> At the time, I wondered if I will also get infected or the other children will get infected.
>
> (P1)

Some participants were afraid their children would die because they believed there was no treatment for TB. A participant's difficulty in securing blood for a transfusion needed by her child made her afraid of losing her child. This fear was heightened at the sight of other children dying at the hospital.

> I was afraid. If your child is sick won't you be scared? …when they said he needed blood seriously and we were finding it difficult to get some. I was scared he was going to die. Because when you are there and you see someone's own [child] die, you also get scared of yours dying.
>
> (P13)

The participants' negative emotions included loneliness. The mothers felt lonely because they were often alone at home with the sick children. Many participants felt no one cared about them and there was no one other than their sick children to console them. Several participants indicated they did not have friends. Participants with spouses who worked away from home also felt lonely at times. In some cases, the participants had access to other relatives and friends, but they were hesitant to "bother" them.

> Sometimes I feel nobody cares for me, but when I think about some things, then I shed few tears. There's nobody to console me, I forget about it… I really have nobody.
>
> (P5)

4.2.3 | Stigma

The participants revealed they and their children were being stigmatized. People in their communities talked about them and their child's TB symptoms (such as cough and weight loss) which contributed to their experience of enacted stigma. In some cases, no one would play with the children because of their illness. Other persons referred to the children living with TB as "old women", "trouble," or "dead", suggesting that the children looked weak, were a trouble to care for or would die anyway. The enacted name-calling and anticipated stigma experienced by some mothers made them hesitant to send their children outside.

> when I gave birth to [the child], there were two other girls who were also pregnant. They gave birth not long after I gave birth, but their children are walking now. And so they ask why my child is like an old woman and not walking. And because of that, I'm not free with them because when they say that, it bothers me.
>
> (P10)

The mothers also reported experiences of internalized stigma occasioned by people's uninvited instructions regarding how they should be caring for the child living with TB. According to these participants, people would often ask what was wrong with their children and they would indicate how the mothers should be providing better care for their children. These unsolicited questions and recommendations, sometimes from strangers, made mothers feel inept and were being talked about in their communities. Some mothers felt obliged to carry out the recommendations to reduce the pressure put on them.

> it's been worrying me. I don't have peace of mind… The people in our neighbourhood. The way they ask me what at all is wrong with the child, I can tell that they discuss it when they get together…people shouldn't be asking what is wrong with the child.
>
> (P6)

> They [community members] say a lot. Some say this illness [TB] is not a hospital illness. They say, "You're worrying yourself always going to the hospital, take her to a prayer camp. Take her here, take her there, go to this church, go somewhere else". I went to see our pastor.
>
> (P7)

5 | DISCUSSION

This qualitative study revealed that the mothers' well-being was negatively affected by the physical and psychological burden of being the primary caregiver of their child living with TB. The mothers' physical and psychological burden reported in this study reinforces findings from previous studies involving caregivers of children with chronic conditions in general and TB specifically (Bristow et al., 2018; da Silva et al., 2014). However, this study's results also highlight the specific challenges experienced by the mothers of children living with TB within a resource-limited African country such as Ghana. For instance, the mothers of hospitalized children living with TB in high-income countries may not be required to run the tiring medical errands described by participants of this study. Nonetheless, the results suggest that mothers of children living with TB require adequate practical support from their relatives or friends (such as spouses and siblings) so as not to be overwhelmed by their caregiving and home keeping roles (Awaluddin et al., 2020b). Furthermore, healthcare providers of the children living with TB may have to regularly assess the physical well-being of the accompanying mothers to be able to promptly identify and manage their health issues such as body pains, fatigue, insomnia and weight loss. Even though the children's care may not be the direct cause of any mothers' sicknesses (such as diabetes mellitus and gastrointestinal ulcers), the stress associated with their caregiver roles can predispose them to ill health (American Psychological Association, 2018). Consequently, when diagnosing childhood TB, the mothers of children living with TB must be encouraged to activate the social support available to them within their social networks and communities (Awaluddin et al., 2020b).

This study's results that the mothers were thinking and worried about their children living with TB is comparable to the findings of a study by Zhang et al. (2014) in China, which revealed that parents of children living with TB experienced psychological pressure and were often worried about their children's treatment and prognosis. Similar psychological challenges have been observed through previous studies involving the care of sick children in general (Collins et al., 2020; Macedo et al., 2015). For instance, Barros et al. (2019) noted a worsening in the psychological quality of life of caregivers of children with disabilities in Brazil. A study by Collins et al. (2020) in Australia also revealed that caregivers of children with life-limiting conditions generally felt psychological distress which impaired their quality of life. These psychological issues are highly probable among the mothers of children living with TB because, despite efforts to improve the treatment outcomes of children diagnosed with TB, childhood TB incidence and mortality estimates in low to middle-income countries like Ghana remain high (Dodd et al., 2017; World Health Organization, 2020). Tuberculosis is associated with death, and it is referred to as the "ghost cough" disease (*nsamanwa*) in a Ghanaian local language (Twi) (Nketiah-Amponsah et al., 2021). Understandably, a diagnosis of childhood TB contributes to a mother's fear that her child may die (Awaluddin et al., 2020a). It is therefore important that the fears, thoughts and worries of mothers about their children's diagnosis and well-being are assessed and managed adequately by healthcare providers through appropriate parental involvement, counselling and education (Aarthun et al., 2019; Choudhary & Ahmed, 2019). Such interventions have the potential to promote acceptance and address the fears and guilt mothers have regarding their children's ill health and treatment options (Awaluddin et al., 2020b; da Silva et al., 2014; Das et al., 2021).

The mothers' crying spells can be an indication of them being overwhelmed with negative emotions throughout their child's illness. This observation suggests that the initiation of treatment for children living with TB does not necessarily mark the end of their emotional challenges; especially as the mothers cried secretly so as not to distress others. These "silent tears" were noted in another study by Zhang et al. (2014). Moreover, they were evident in the participants' teary eyes and sobs during this study's interviews. Accordingly, innovative strategies (such as psychosocial support therapies) aimed at anticipating and managing caregivers' psychological and emotional issues could be offered by healthcare providers to reduce the mother's psychological burden.

The mothers' attribution of their weight gain to the children's recovery (but not food intake) further highlights the importance of psychosocial support for the mothers while their children receive treatment for TB. It was noteworthy to find in this study that even though crying did not necessarily solve the mothers' challenges, it served as a source of temporary emotional relief for some of them. Crying may be a self-soothing behaviour exhibited by the mothers who increasingly felt lonely despite having relatives who could be called on (Gračanin et al., 2014).

The absence of stigmatizing behaviours from community members towards caregivers of persons living with TB has been recorded in India (Parmar et al., 2018). Nonetheless, the intersecting stigma experienced by the mothers of children living with TB in this study extends the insight offered by da Silva et al. (2014) who identified that caregivers had to cope with stigmatizing behaviours exhibited by persons who were often prejudiced or ill-informed about TB and its current treatment (Stangl et al., 2019). This situation can delay the initiation of TB treatment and worsen the prognosis of children living with TB (Saqib et al., 2018).

The findings of this study have implications for the care provided by healthcare providers. Nurses and physicians providing care for children living with TB must recognize children living with TB and their caregiving mothers as a dyad and regularly assess both mother and child well-being. Additionally, healthcare providers should provide mothers with adequate support and counselling regarding the children's treatment and care to mitigate the worrying and negative emotional experiences associated with their burden of care.

5.1 | Limitation

A limitation of this study is that it was conducted in two health facilities within a predominantly urban setting as it took place within the Accra metropolis of Ghana. The findings may not reflect all the physical and psychological burdens experienced by mothers of children living with TB in other, more rural settings within Ghana.

6 | CONCLUSION

Mothers of children living with TB go through physical and psychological health issues occasioned by their role are the children's caregivers. The mothers require adequate physical and psychological support from their relatives and friends and also healthcare providers so as not to be overwhelmed by their caregiving roles. Nurses and other healthcare providers managing children living with TB must deliberately consider the well-being of the mothers to forestall any physical and psychological health challenges they may experience.

AUTHOR CONTRIBUTIONS

ET: conceptualization and data acquisition. ET and LA: methodology. ET, DW, GD, SR and LA: analysis of data, resources and writing (drafting, reviewing editing). LA and SR: funding acquisition.

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/recommendations/)]:

- substantial contributions to conception and design, acquisition of data or analysis and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

ACKNOWLEDGEMENTS

The authors acknowledge the support of participants and staff of the hospitals involved in this study. Special thanks go to the research assistant (Mrs Lousia Quarcoopome). The Canadian Queen Elizabeth II Diamond Jubilee Scholarships (QES) is managed through a unique partnership of Universities Canada, the Rideau Hall Foundation (RHF), Community Foundations of Canada (CFC) and Canadian universities. The QES-AS is made possible with financial support from IDRC and SSHRC. The study was funded by the QES-AS.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data available on request due to privacy and ethical reasons.

ETHICS STATEMENT

Ethical approval for the study was received from the Ghana Health Service Ethics Review Committee (GHS-ERC 0060120). The administrative heads of the health facilities provided approval for the conduct of the study in their institutions. The rationale and objectives of the study were explained to participants and their written informed consent was obtained before their participation in the study. The participants were informed that their participation in the study was voluntary and they had the right to withdraw from the study at any time without any repercussions to them. The participants were assured that confidentiality will be maintained and no personal information will be disclosed.

ORCID

Gladys Dzansi https://orcid.org/0000-0002-6036-811X

REFERENCES

Aarthun, A., Øymar, K. A., & Akerjordet, K. (2019). Parental involvement in decision-making about their child's health care at the hospital. *Nursing Open*, *6*(1), 50–58. https://doi.org/10.1002/NOP2.180

Adib-Hajbaghery, M., & Ahmadi, B. (2019). Caregiver burden and its associated factors in caregivers of children and adolescents with chronic conditions. *International Journal of Community Based Nursing & Midwifery*, *7*(4), 258–269. https://doi.org/10.30476/IJCBNM.2019.73893.0

American Psychological Association. (2018, November 1). *Stress effects on the body*. https://www.apa.org/topics/stress/body

Awaluddin, M., Ismail, N., Yasin, S. M., Zakaria, Y., Mohamed Zainudin, N., Kusnin, F., Mohd Yusoff, M. A. S., & Razali, A. (2020a). Exploring challenges faced by parents of children with tuberculosis to achieve treatment success. *Journal of Clinical and Health Sciences*, *5*(2), 46. https://doi.org/10.24191/jchs.v5i2.10114

Awaluddin, M., Ismail, N., Yasin, S. M., Zakaria, Y., Mohamed Zainudin, N., Kusnin, F., Mohd Yusoff, M. A. S., & Razali, A. (2020b). Parents' experiences and perspectives toward tuberculosis treatment success among children in Malaysia: A qualitative study. *Frontiers in Public Health*, *8*, 577407. https://doi.org/10.3389/fpubh.2020.577407

Barros, A. L. O., de Gutierrez, G. M., Barros, A. O., & Santos, M. T. B. R. (2019). Quality of life and burden of caregivers of children and adolescents with disabilities. *Special Care in Dentistry*, *39*(4), 380–388. https://doi.org/10.1111/SCD.12400

Bristow, S., Jackson, D., Shields, L., & Usher, K. (2018). The rural mother's experience of caring for a child with a chronic health condition: An integrative review. *Journal of Clinical Nursing*, *27*(13–14), 2558–2568. https://doi.org/10.1111/jocn.14360

Calderon, V., & Tennstedt, S. L. (2021). Ethnic differences in the expression of caregiver burden: Results of a qualitative study. In *Latino elders and the twenty-first century: Issues and challenges for culturally competent research and practice* (pp. 159–178). Routledge. 10.4324/9781315821382-10/ETHNIC-DIFFERENCES-EXPRESSION-CAREGIVER-BURDEN-RESULTS-QUALITATIVE-STUDY-VANESSA-CALDER

Centers for Disease Control and Prevention. (2021). *Tuberculosis (TB)– TB treatment for children*. https://www.cdc.gov/tb/topic/treatment/children.htm

Choudhary, G. N., & Ahmed, A. (2019). *Caring of tuberculosis patients: A study of psychosocial factors. February, 2415–2454.*

Collins, A., Burchell, J., Remedios, C., & Thomas, K. (2020). Describing the psychosocial profile and unmet support needs of parents caring for a child with a life-limiting condition: A cross-sectional study of caregiver-reported outcomes. *Palliative Medicine*, *34*(3), 358–366. https://doi.org/10.1177/0269216319892825

da Silva, T. d. M. V., dos Santos, M. Á., & de Almeida, F. A. (2014). Understanding the experiences of caregivers of children with tuberculosis in directly observed therapy. *Revista da Escola de Enfermagem da USP*, *48*, 39–45. https://doi.org/10.1590/s0080-623420140000800007

Das, M., Mathur, T., Ravi, S., Meneguim, A. C., Iyer, A., Mansoor, H., Kalon, S., Hossain, F. N., Acharya, S., Ferlazzo, G., Isaakidis, P., & Thakur, H. P. (2021). Challenging drug-resistant TB treatment journey for children, adolescents and their care-givers: A qualitative study. *PLoS One*, *16*, e0248408. https://doi.org/10.1371/journal.pone.0248408

Dodd, P. J., Yuen, C. M., Sismanidis, C., Seddon, J. A., & Jenkins, H. E. (2017). The global burden of tuberculosis mortality in children: A mathematical modelling study. *The Lancet Global Health*, *5*(9), e898–e906. https://doi.org/10.1016/S2214-109X(17)30289-9

Gračanin, A., Bylsma, L. M., & Vingerhoets, A. J. J. M. (2014). Is crying a self-soothing behavior? *Frontiers in Psychology*, *5*, 502. https://doi.org/10.3389/fpsyg.2014.00502

Grove, S. K., & Gray, J. R. (2018). *Understanding nursing research E-book: Building an evidence-based practice*. Elsevier Health Sciences. https://books.google.com.gh/books?id=cxNkDwAAQBAJ

Javalkar, K., Rak, E., Phillips, A., Haberman, C., Ferris, M., & Van Tilburg, M. (2017). Predictors of caregiver burden among mothers of children with chronic conditions. *Children*, *4*(5), 39. https://doi.org/10.3390/children4050039

Kim, H., Sefcik, J. S., & Bradway, C. (2017). Characteristics of qualitative descriptive studies: A systematic review. *Research in Nursing & Health*, *40*(1), 23–42. https://doi.org/10.1002/nur.21768

Kyu, H. H., Maddison, E. R., Henry, N. J., Mumford, J. E., Barber, R., Shields, C., Brown, J. C., Nguyen, G., Carter, A., Wolock, T. M., Wang, H., Liu, P. Y., Reitsma, M., Ross, J. M., Abajobir, A. A., Abate, K. H., Abbas, K., Abera, M., Abera, S. F., … Murray, C. J. (2018). The global burden of tuberculosis: Results from the global burden of disease study 2015. *The Lancet Infectious Diseases*, *18*(3), 261–284. https://doi.org/10.1016/S1473-3099(17)30703-X

Macedo, E. C., Da Silva, L. R., Paiva, M. S., & Ramos, M. N. P. (2015). Burden and quality of life of mothers of children and adolescents with chronic illnesses: An integrative review. *Revista Latino-Americana de Enfermagem*, *23*(4), 769–777. https://doi.org/10.1590/0104-1169.0196.2613

Maguire, M., & Delahunt, B. (2017). Doing a thematic analysis: A practical, step-by-step guide for learning and teaching scholars. *All Ireland Journal of Higher Education*, *9*(3), 3351. https://ojs.aishe.org/index.php/aishe-j/article/view/3354

Narendran, G., & Swaminathan, S. (2016). TB-HIV co-infection: A catastrophic comradeship. *Oral Diseases*, *22*, 46–52. https://doi.org/10.1111/odi.12389

Nketiah-Amponsah, E., Odeku, O. A., Afful-Mensah, G., Ajala, A. S., Akinsete, K., Akuffo-Henaku, P. O., Alhassan, R. K., Andoh-Adjei, F. X., Asante, F. A., & Blay, R. M. (2021). *Contemporary healthcare issues in sub-Saharan Africa: Social, economic, and cultural perspectives*. Lexington Books.

Parmar, P., Modi, A., & Godara, N. (2018). Understanding pediatric tuberculosis: Perspectives and experiences of the parents in a city of India. *International Journal of Medical Science and Public Health*, *7*(2), 1. https://doi.org/10.5455/ijmsph.2018.1232920122017

Polack, S., Adams, M., O'banion, D., Baltussen, M., Asante, S., Kerac, M., Gladstone, M., & Zuurmond, M. (2018). Children with cerebral palsy in Ghana: Malnutrition, feeding challenges, and caregiver quality of life. *Developmental Medicine and Child Neurology*, *60*(9), 914–921. https://doi.org/10.1111/DMCN.13797/ABSTRACT

Saqib, S. E., Ahmad, M. M., Amezcua-Prieto, C., & Virginia, M. R. (2018). Treatment delay among pulmonary tuberculosis patients within the Pakistan national tuberculosis control program. *American Journal of Tropical Medicine and Hygiene*, *99*(1), 143–149. https://doi.org/10.4269/ajtmh.18-0001

Saunders, B., Sim, J., Kingstone, T., Baker, S., Waterfield, J., Bartlam, B., Burroughs, H., & Jinks, C. (2018). Saturation in qualitative research: Exploring its conceptualization and operationalization. *Quality and Quantity*, *52*(4), 1893–1907. https://doi.org/10.1007/s11135-017-0574-8

Seddon, J. A., & Graham, S. M. (2015). Childhood TB: Can the end TB strategy deliver? *Transactions of the Royal Society of Tropical Medicine and Hygiene*, *110*(3), 155–157. https://doi.org/10.1093/trstmh/trw007

Stangl, A. L., Earnshaw, V. A., Logie, C. H., Van Brakel, W., Simbayi, L. C., Barré, I., & Dovidio, J. F. (2019). The health stigma and discrimination framework: A global, crosscutting framework to inform research, intervention development, and policy on health-related stigmas. *BMC Medicine*, *17*(1), 31. https://doi.org/10.1186/S12916-019-1271-3/TABLES/1

Toledano-Toledano, F., & Domínguez-Guedea, M. T. (2019). Psychosocial factors related with caregiver burden among families of children with chronic conditions. *BioPsychoSocial Medicine*, *13*(1), 6. https://doi.org/10.1186/s13030-019-0147-2

UNICEF. (2020). *Pneumonia in children statistics – UNICEF DATA*. UNICEF. https://data.unicef.org/topic/child-health/pneumonia/

Vecchio, A. L., Bocchino, M., Lancella, L., Gabiano, C., Garazzino, S., Scotto, R., Raffaldi, I., Assante, L. R., Villani, A., Esposito, S., & Guarino, A. (2015). Indications to hospital admission and isolation of children with possible or defined tuberculosis: Systematic review and proposed recommendations for pediatric patients leaving in developed countries. *Medicine*, *94*(50), e2045. https://doi.org/10.1097/MD.0000000000002045

World Bank. (2022). *Lower middle income data*. https://data.worldbank.org/income-level/lower-middle-income

World Health Organization. (2020). *Global tuberculosis report 2020*. https://apps.who.int/iris/bitstream/handle/10665/336069/9789240013131-eng.pdf?ua=1

World Health Organization. (2021a). *Ghana tuberculosis profile 2020*. https://worldhealthorg.shinyapps.io/tb_profiles/?_inputs_&entity_type=%22country%22&lan=%22EN%22&iso2=%22GH%22

World Health Organization. (2021b). *Global tuberculosis report 2021*.

Zarzycki, M., Seddon, D., Bei, E., & Morrison, V. (2022). Why do they care? A qualitative systematic review and meta-synthesis of personal and relational motivations for providing informal care. *Health Psychology Review*, *17*, 1–33. https://doi.org/10.1080/17437199.2022.2058581

Zhang, S., Ruan, W., Li, Y., Wang, X. X., & Wang, X. X. (2014). Experiences of the parents caring for their children during a tuberculosis outbreak in high school: A qualitative study. *BMC Public Health*, *14*(1), 132. https://doi.org/10.1186/1471-2458-14-132

How to cite this article: Tornu, E., Dzansi, G., Wilson, D. M., Richter, S., & Aziato, L. (2022). Mothers' perspectives of physical and psychological issues associated with caring for Ghanaian children living with tuberculosis: A qualitative study. *Nursing Open*, *00*, 1–10. https://doi.org/10.1002/nop2.1499