The experience of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services: A qualitative study

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Abstract
Aim: This study aims to explore the experiences of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services.

Background: Cerebral palsy is the most common chronic disability from childhood, which needs lifelong rehabilitation. Most of the population living in rural communities in Ghana have virtually no form of rehabilitation services for their chronic disabling conditions. Caring for children with disability are known to be challenging especially when coupled with environmental challenges in rural communities.

Results: Purposive and snowball techniques were used to recruit 12 carers, age 22 to 68 years, of children with cerebral palsy aged 7 to 15 years. Two main themes, developing personal beliefs to support the caregiving role and the demands that shape the experience of caring, emerged from six subthemes and 25 theme clusters of the narratives of the carers. The essential structure of the phenomenon demonstrated the complex interaction of personal and environmental factors in harmony with the actual demands to influence the experiences of participants positively or negatively. Positively, carers achieved coping, committed to caring, hoped for the future, and accepted the condition. However, negatively, carers described the triggering factors of feeling of despair and sorrow as frustration and lack of understanding of the condition, felt stigmatized, and perceived the child was going through pain and suffering.

Conclusions: Carers derived strength from their religious and spiritual beliefs to balance the demands of caregiving. Findings could be used as basis for developing interventions to support carers and inform new strategies for rehabilitation service and sensitization of community members about inclusion of children with disabilities.

KEYWORDS
caregiving, cerebral palsy, Ghana, rehabilitation, qualitative, rural

1 INTRODUCTION

Cerebral palsy (CP) has been identified as the most common, chronic childhood disability (Rosenbaum, 2003); however, the prevalence in rural Ghana is unknown. In Ghana, since 1999, Community Health Planning and Services (CHPS) have delivered primary care to rural communities by Community Health Nurses (CHNs). CHNs offer public health outreach, clinical services, and serve as the first point of contact and referrals. However, the services do not include rehabilitation, and there is a clear need for interventions for childhood disabilities (Nyonator, Awoonor-Williams, Phillips, Jones, & Miller, 2005; Zuurmond et al., 2018). In addition, in Ghana, there is a shortage of
health professionals particularly in rehabilitation and rural communities face other challenges, for example, no provision of potable water, no electricity, and no access to a good road network (Ghana Statistical Service, 2014).

In rural areas of Ghana, where 26% of the nation’s population reside, children are important for the economic productivity of the family (Ghana Statistical Service, 2014). As a result, children with severe disability may be perceived as a misfortune by parents. This perception may affect the quality of caregiving, the value attributed to the child, and the psychological stress associated with caregiving. Zuurmond et al. (2019) reported that traditional beliefs in Ghana contributed to the feelings of stigma and shame experienced by families of children with disability. Other authors (Huang, Kellett, & St John, 2011; Kuo & Lach, 2012; Uldall, 2012) investigating how cultural and traditional beliefs influence how families perceive caring and interpret the diagnosis of CP have reported similar findings.

Milbrath, Cecagno, Soares, Amestoy, and Heckler de Siquiera (2008) found that giving birth to a child with CP was contrary to societal perceptions of a “successful woman.” Women experienced overt stigmatization, little support, and often discrimination and rejection by family members (McNally & Mannan, 2013). Community beliefs and superstitions frame disability as a form of punishment from God or the child as a spiritual entity (Gona, Xiong, Muhit, Newton, & Hartley, 2010).

A systematic review (Pousada et al., 2013) of the impact of caring for a child with CP on parents showed high levels of stress, depression, and lower quality of life than experienced by parents of nondisabled children. Challenging and difficult issues that dominated caregivers’ lives focused on managing personal care, lifting, and positioning frequently without access to assistive devices and concerns about aging. Often the caregiver’s role included meeting the child’s educational and recreational needs, leaving little or no time for their other commitments (Burkhard, 2013; Dalvand, Dehghan, Rassafiani, & Hosseini, 2018; Geere et al., 2012).

Most studies reviewed focused on caregiving in an urban context, and no studies exploring the caregiving role in rural areas of Ghana were found. The purpose of this study was to explore the experiences and perceptions of primary caregivers of children with CP living in rural communities in Ghana who had not received any rehabilitation services.

2 | ETHICS

Ethical approval for the study was obtained from the Ghana Health Service Ethical Review Committee and Coventry University Research Ethics Committee.

3 | METHODS

Descriptive phenomenology (Dowling, 2007) was chosen to guide the study design. The central tenet of this methodological approach is the ability of researchers to authentically listen to participants’ understanding of the phenomenon of interest and to critically reflect on

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Example interview questions</th>
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<tbody>
<tr>
<td>• How did you get to know about this condition?</td>
<td></td>
</tr>
<tr>
<td>• How would you describe the condition to someone who doesn’t know [child’s name]?</td>
<td></td>
</tr>
<tr>
<td>• How would you explain the problems you feel [child’s name] has?</td>
<td></td>
</tr>
<tr>
<td>• What do you think you, as a caregiver of a child with this condition, needs to know in order to care for them as well as possible?</td>
<td></td>
</tr>
<tr>
<td>Questions derived from the literature</td>
<td></td>
</tr>
<tr>
<td>• Spirituality: How important are your spiritual beliefs in helping you care for [child’s name]?</td>
<td></td>
</tr>
<tr>
<td>• How do they help you?</td>
<td></td>
</tr>
<tr>
<td>• Taking care of self: How do you take care of yourself?</td>
<td></td>
</tr>
<tr>
<td>• Resourcefulness: What have you found to be useful in taking care of [child’s name]?</td>
<td></td>
</tr>
<tr>
<td>• Stressors: Can you describe your experiences of stress and how they impact on your ability to care for [child’s name]?</td>
<td></td>
</tr>
<tr>
<td>• Role conflict: How has caring for [child’s name] affected your other roles and responsibilities?</td>
<td></td>
</tr>
<tr>
<td>• Isolation: How has caring for [child’s name] affected your social participation?</td>
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</tbody>
</table>

the beliefs and assumptions they bring to the research process (Jootun, McGhee, & Marland, 2009). The primary researcher (G. N.) is a paediatric physiotherapist, educator, and mother. In order to facilitate critical reflection, she participated in two bracketing interviews (Hamill & Sinclair, 2010), kept a reflective journal, made field notes, and engaged in critical discussion with the second author (C. C.) throughout the study process.

3.1 | Participant recruitment

A combination of purposive and snowball sampling approaches were used to guide the participant recruitment process. The participants
were primary caregivers of children with CP, had not received any rehabilitation, had been a resident in a rural community for the previous six months, and were fluent in one of the Akan languages.

The study was conducted in Shia Osudoku district, the largest in Greater Accra Region of Ghana. It has 13 CHPS zones. CHNs in five CHPS zones assisted in recruiting participants. They distributed the study invitations—verbally and by flyers—to caregivers and identified those who were interested in participating. Rural households within each community are located long distances apart and do not have numbered addresses. There is no systematic record of their locations, and the road networks are underdeveloped. Consequently, the CHNs had to accompany the primary researcher (G. N.) on her first visits. The primary researcher met each participant twice. During the first visit, the participants were fully informed about the study, and consent was obtained by signature or thumbprint, and a second visit was scheduled for the interview. Recruitment ended when we considered that data saturation had been achieved. Data saturation is presumed to have occurred when little or no new information about the topic of interest is being acquired. It is broadly associated with sample size decisions in qualitative research. However, it depends on a number of factors including the scope of the research question, the quality of data collection methods, the ability of participants to reflect on their experiences, and other sources of information (Carpenter & Suto, 2008).

### 3.2 Data collection

Semistructured interviews, congruent with descriptive phenomenology, were chosen as the data collection method. G. N. translated the interview guide of broad open-ended questions (see Table 1) from English to Akan, and the interview process was piloted with two volunteer caregivers. One in-depth interview was conducted in Akan by G. N. with each participant. Each interview was audio-recorded and lasted between 90 and 120 min. Field notes were written after each interview, documenting details about the interview context and process. The audio recordings were translated into English and transcribed by G. N.. A bilingual Akan–English colleague reviewed the transcripts to ensure there was no discrepancy between the written record and the interview audio recording.

### 3.3 Data analysis

Colaizzi’s (1978) phenomenological method was used to guide the data analysis process. This method consisted of seven interconnected stages that are summarised in Table 2. The second author was involved as peer reviewer in Stages 2–5. The description of the two final themes was forward and back-translated to Akan by G. N., and the Akan version was audio-taped because only two of the participants could read. The participants reviewed the final description and provided feedback to GN.

### Table 2: Stages of data analysis

<table>
<thead>
<tr>
<th>Stages</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Reading and rereading each transcript to make general sense on the whole</td>
</tr>
<tr>
<td>2</td>
<td>Highlighting and extracting significant statements that are related to the experience of caregiving</td>
</tr>
<tr>
<td>3</td>
<td>Formulating the meaning of each statement in the researcher’s own words</td>
</tr>
<tr>
<td>4</td>
<td>Grouping the formulated meanings initially into clusters, then into subthemes and finally into themes which represent the essential structure of the phenomenon being studied</td>
</tr>
<tr>
<td>5</td>
<td>Producing an exhaustive description of the experience of caring for children with CP in rural Ghana</td>
</tr>
<tr>
<td>6</td>
<td>Removing all misplaced, redundant and overestimated description</td>
</tr>
<tr>
<td>7</td>
<td>Return to the participants for feedback</td>
</tr>
</tbody>
</table>

### Table 3: Participant profile

<table>
<thead>
<tr>
<th>Name</th>
<th>Gender</th>
<th>Age</th>
<th>Marital status</th>
<th>Education</th>
<th>Occupation</th>
<th>Relationship with child</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kofi</td>
<td>M</td>
<td>46</td>
<td>Married</td>
<td>None</td>
<td>Farmer</td>
<td>Cousin</td>
</tr>
<tr>
<td>Doreen</td>
<td>F</td>
<td>39</td>
<td>Married</td>
<td>Primary</td>
<td>Trader</td>
<td>Mother</td>
</tr>
<tr>
<td>Kwame</td>
<td>M</td>
<td>44</td>
<td>Married</td>
<td>None</td>
<td>Unemployed</td>
<td>Father</td>
</tr>
<tr>
<td>Becky</td>
<td>F</td>
<td>35</td>
<td>Married</td>
<td>None</td>
<td>Unemployed</td>
<td>Mother</td>
</tr>
<tr>
<td>Rose</td>
<td>F</td>
<td>28</td>
<td>Single</td>
<td>Primary</td>
<td>Unemployed</td>
<td>Mother</td>
</tr>
<tr>
<td>Gloria</td>
<td>F</td>
<td>33</td>
<td>Married</td>
<td>None</td>
<td>Trader</td>
<td>Mother</td>
</tr>
<tr>
<td>Rash</td>
<td>F</td>
<td>48</td>
<td>Married</td>
<td>None</td>
<td>Trader</td>
<td>Mother</td>
</tr>
<tr>
<td>Vida</td>
<td>F</td>
<td>31</td>
<td>Married</td>
<td>First degree</td>
<td>Midwife</td>
<td>Mother</td>
</tr>
<tr>
<td>Edwina</td>
<td>F</td>
<td>68</td>
<td>Married</td>
<td>None</td>
<td>Unemployed</td>
<td>Grandmother</td>
</tr>
<tr>
<td>Harriet</td>
<td>F</td>
<td>22</td>
<td>Single</td>
<td>None</td>
<td>Unemployed</td>
<td>Mother</td>
</tr>
<tr>
<td>Annie</td>
<td>F</td>
<td>23</td>
<td>Single</td>
<td>Secondary</td>
<td>Unemployed</td>
<td>Mother</td>
</tr>
<tr>
<td>Mary</td>
<td>F</td>
<td>60+</td>
<td>Married</td>
<td>None</td>
<td>Unemployed</td>
<td>Grandmother</td>
</tr>
</tbody>
</table>

Abbreviations: F, female; M, male.
### RESULTS

Twelve participants comprising two males and 10 females whose ages ranged from 22–68 years were recruited (Table 3). Pseudonyms were chosen by each participant to ensure anonymity. Eleven were Christians and one was Muslim. Three husbands had left home without informing the mothers, and one husband provided direct care. Six participants lived in rented accommodation within a compound occupied by 7–15 other families. Four participants did not have a kitchen and cooked on the porch or under a shelter in the compound, one used a stove for cooking, and the others, coal-burning pots. Three participants had piped water in their homes. Six had to buy water from a neighbour, and three had to depend on hand-dug wells. Nine participants had toilets in their homes, two used a nearby public toilet for a fee, and the other had to walk for about 3 min to a free toilet facility. The children, five girls and seven boys, ranged in age from 2 years to 14 years.

Two themes, developing personal beliefs to support the caregiving role and the demands that shape the experience of caring, represent the study findings. These were constructed based on the reduction of the formulated meanings into 26 clusters and subsequently into six subthemes. These are outlined in Table 4 and the six subthemes are highlighted (in italics) in the following theme descriptions.

#### Theme 1: Developing personal beliefs to support the caregiving role

In describing experiences of caring for a child with CP, participants frequently interpreted the condition through the lenses of their spiritual and religious beliefs. They found obtaining accurate information about the diagnosis either very difficult or impossible. As a result, as Doreen describes, the child's condition was commonly attributed to a spiritual cause:

> The doctors kept telling me that she would be okay. I did not understand, her sister was talking, walking, and had even started going to school but she was just lying down, she could not even sit, nor talk. I figured it could not be treated at the hospital and must be spiritual.

Others sought spiritual intervention from influential community members, for example, church or traditional healers in their efforts to seek help for their child. They frequently combined spiritual and religious beliefs in order to make meaning of their child's condition. They theorized that their child's condition “came from God” and supported these theories by recounting stories of people who had been healed by God. The participants commonly stated their belief that with

<table>
<thead>
<tr>
<th>Main themes</th>
<th>Subthemes</th>
<th>Theme clusters</th>
</tr>
</thead>
</table>
| Developing personal beliefs to support the caregiving role | Interpretation of the child's condition through religious and spiritual beliefs | • Perceived cause of condition is spiritual
• Committed to caring because of benefits an blessings from God
• Hope for the future because of religious belief
• Acceptance of condition because of the belief that it is given by God
• Coping supported by religious belief
• Beliefs in spiritual intervention |
| The demands that shape the experience of caring | Physical demands | • Difficulty in handling child causes exhaustion
• Managing other responsibility
• Lack of assistive devices for transfers and mobility
• Lack of physical support
• Cost of caring
• Give up work to look after child
• Lack of money for basics
• Lack of financial support from spouse and family |
| Financial demands | • Informational conformity
• Attitude of others
• Social support |
| Social influence | Feeling despair and sorrow | • Acknowledging the child's developmental delay
• Lack of understanding of condition resulted in hopelessness and profound sadness
• Perception that child is experiencing pain and suffering
• Frustration
• Feeling stigmatized |
| Perceived standard of caregiving | • The nature of caring
• Strategies to improve condition
• Protecting child
• Estimation of recovery |
God’s help, their children would achieve developmental milestones and be healed. These beliefs sustained their hope for the child’s future, and several participants were convinced that their children were destined to become prominent persons in society. This view was frequently reinforced by pastors as Kwame described:

“Since all the pastors we’ve seen have reassured me that my son will be someone important in future, I want to do everything I can for this child because they all confirm that my son will be great in the future.”

The standard of caregiving they achieved was perceived as a way of serving God, and anticipation of God’s blessing supported their commitment to caring for their child. As Becky described,

“I understand it (caring) in the sense that the Bible has told us that when we give birth and we do not cater for the child it is a curse, that being responsible for the child’s needs attracts God’s blessings.”

The participants were concerned that their vulnerable children would be abused—physically and spiritually—by other people. They consistently tried to protect their children by limiting access to certain people and not discussing the child’s condition in their presence. As Rose explained,

“Some people [family members] say this illness is from the devil, that he [her child] is a snake, and I should send him to the forest then cook and leave the food for him. Then the fetish priest will shoot him and the child will turn into a snake and vanish into the bush. I refused to do that to my child. I do not believe in all these things because I got pregnant and delivered my child so I do not need anyone to tell me he is an animal. I know I gave birth to a human being.”

For many participants, their child’s “recovery” was linked with their ability to walk, which they associated with happiness, quality of life, and independence. Their child’s continual inability to walk caused them considerable anxiety, for example, Edwina said

“Sometimes I ask myself, if this child [her granddaughter] is not able to walk, what will she do? She will be a burden. Even if she could at least take some steps, which are not like normal steps, I will be happy because our difficulties will be over.”

Ignorance about CP, and their growing understanding of the reality of living with CP, contributed to the feelings of despair and sorrow they experienced as the child grew older. These feelings were made more poignant by comparison with nondisabled children in the family. Those participants who were biological mothers spoke of the sense of humiliation, shame, and personal failure they felt for not delivering a “healthy” baby. They felt responsible for the child’s condition and saw it as punishment for a sin they had committed against God. As Kwame said, “I will not deceive you, from the beginning I was shaking, I kept on thinking what sin have I committed?”

### 4.2 Theme 2: The demands that shape the experience of caring

Caring was frequently associated with words like “suffering,” “hardship,” “tiring,” “relentless,” “unbearable,” “difficult,” and “sacrifice.” All the participants faced increasingly difficult physical demands and challenges in assisting their children as they grew older. These challenges were compounded by the neurological, primarily spasticity, and musculoskeletal complications associated with CP. Activities, such as bathing, changing diapers, and soiled linen, were identified as some of the most difficult and exhausting. As Doreen said,

“Sometimes she [13-year-old daughter] will soil herself with urine and faeces, so I have to get her clean. It is not an easy task bathing her because she is now heavy and tall. I sometimes struggle with her for more than an hour trying to clean her.”

Some participants were no longer strong enough to manage their children but had no one to assist them. None of the participants had received any professional “manual handling” advice and consequently risked injury to themselves and their child. Rash’s account represents these risks:

“Sometimes when I am bathing her, she would be struggling with me. She is now stronger than I am. If she is doing something and I tell her not to do it, she can struggle with me until we both fall.”

They were concerned about staying physically strong in order to maintain their standard of care. None of them had access to assistive devices or equipment. Development of contractures affected the children particularly those who were able to stand and/or walk. Participants had no access to appropriate seating or wheelchairs and adapted old car seats or wooden boxes for their children to sit in. They clearly understood that these were uncomfortable and caused poor posture and skin problems. As Doreen explained,

“I used to put her in an old car seat and bring her outside, but she is now older and she does not sit in the seat quietly, she will stretch herself till she’s on the floor.”

Caring for a child with CP made significant financial demands on the participants and most lived in very basic conditions. They often spent their limited financial resources on spiritual interventions they hoped would improve their child’s condition, for example, prayer camp and herbal preparations that had little effect. Vida’s account reflects how desperately participants’ wanted to find a “cure” for their children, the lengths they were prepared to go, and how vulnerable they were to exploitation:

“The physician assistant prescribed another drug for him [her son], it was expensive—150 cedis (35 dollars)—to be taken for 2 weeks. We had no choice but to buy it for him, we were just seeking any drug that could heal him so a lot of money was used in vain.”

In addition, money was needed to transport their children to appointments, which was problematic because public transport was
not an option. Most participants had insufficient money to provide basic needs for their family or pay their bills, and they often relied on the occasional charity of friends and family members. As Kofi explained, this reinforced their concerns that they were failing as caregivers:

I do not have money, I try my best to get it if she [his cousin], needs something but I am often not in the position to provide it, it worries me a lot.

Participants were influenced by their social context. They frequently complied with, and acted on, advice and recommendations given to them by their community even when these conflicted with their own personal beliefs and values. Their compliance served to align them with societal expectations, to maintain their identity within the community, and to offset the stigma they experienced. Children with CP were frequently labelled as animals, for example, snakes, or as a rock or special being, for example, spirit child. Some participants were aware that uncritically acceding to others’ opinions was detrimental to them and their children. As Vida said, "If you are not careful, you will not have any meaningful life. All your life will be dos and don'ts from others." Most distressing were suggestions that they should end their child’s life. As Rose explained,

People try to discourage you. Some will tell you to poison the child, others will tell you to go and abandon her somewhere and some even advice that we bury her.

The participants felt blamed for their child’s condition and discriminated against by family and community members. As a result, the participants tended not to reveal their child’s disability. As Rose described,

I don’t mingle with people ... someone might poison her.
They think she is not a human being and should not live. Initially, I used to carry her with me when I went to sell, but they refused to buy from me when they saw her. It even brought some quarrel between me and some adults because they said children like this do not need to be brought to where people gather.

These attitudes affected their lives in a variety of ways, for example, Rose had to resign from her position as class attendant at a nursery school. A condition of her employment was that she reside on the premises but the head teacher would not allow her daughter to live with her.

Social support was very important to the participants, and the unsupportive attitude of their extended families was a source of sadness and disappointment. In many cases, they relied upon siblings, who were often minors or a specific family member, for example a “grand auntie.” Church members most often supplied support by visiting, sitting with the child to give the caregiver a break, and offering prayers for the child’s recovery.

5 | DISCUSSION

It is estimated that worldwide there are between 2 and 3 children per 1,000 born with CP (Pousada et al., 2013); however, it is not known how many children live with CP in rural areas (Zuurmond et al., 2018). This study is the first to explore the experience of caregivers in rural areas in Ghana whose children with CP have not received rehabilitation services. The credibility of the study was ensured by peer review at all stages of the process: data collection and analysis, pilot test of the interview process, translation of transcripts and member checking, and a thorough examination of the researcher’s critical stance. To date, most of the research on caring for children with CP has been conducted in a diversity of developed and developing countries and in primarily urban regions where some form of health care and rehabilitation services are available. This has made it difficult to compare study findings or transfer the new knowledge to different contexts.

The significance of personal and environmental factors were evident in the findings of our study. Caregiving challenges were related to personal care, manual handling, progressive neurological changes, and aging. Similar issues were identified in other studies conducted in different countries (Borg, Lindstrom, & Larsson, 2009; Burkhard, 2013; Dalvand et al., 2018; Geere et al., 2012).

In our study, the caregivers’ sense of empowerment was compromised by inaccurate and inconsistent information about CP and their inability to consult medical and rehabilitation professionals. As a result, they felt their child was vulnerable to “spiritual sickness” and in need of spiritual protection. This led them to simultaneously access multiple interventions from ethnomedicine and local faith healers (Nyante, Carpenter, & Igo, 2017). In Denham, Adongo, Freydberg, and Hodgson’s (2010) mixed methods study, participants (community and family members, health nurses, and spiritualists) in Northern Ghana consistently identified children with disability as “spirit children,” which they defined as “bush spirits born into a family in human forms so that they can access the good things and destroy them” (p.611). These traditional and uninformed views of CP are reflected in the findings of other studies (Gona et al., 2010; McNally & Mannan, 2013; Olawale, Deih, & Yaadar, 2013). The prevalence of these misconceptions in rural settings in African countries is alarming, as they have negative implications for the caregiving process and decrease the efficacy of rehabilitation programmes when these are available (Nyante et al., 2017).

Not surprisingly, poverty and financial hardship were identified as main concerns in a number of studies involving caregivers of children with CP, especially those conducted in an African context Gona et al., 2010; McNally & Mannan, 2013). As in this study, the caregivers wished to work and earn an income to support their families but had to give up these opportunities because of difficulties in combining the different roles. Wrigley-Asante (2008) investigated gendered poverty and survival strategies in rural Dangme West District of Ghana. This study revealed the high rate of male outmigration and that women left behind to take care of the children was bound by traditional responsibilities.

A diversity of environmental factors were identified in our study and in others (Hartley et al., 2005; McNally & Mannan, 2013). The negative attitudes of community members towards children with CP contributed to participants’ experiences of social rejection,
stigmatization, discrimination, abuse, and fears of being insulted and pitied and subsequent feelings of loneliness and isolation. The feelings of humiliation, shame, guilt, and personal failure experienced by mothers in our study who had given birth to a disabled child did not appear to be easy to reconcile.

The participants in our study described caregiving as “a hard task” that required them to demonstrate commitment, patience, unconditional love and attention, and to pray and to protect their children. The Taiwanese participants in Kuo and Lach’s (2012) study similarly attributed meaning to their caregiving role through “interpretation” (their ability to understand the feelings and intentions of their children with CP), “protection” (a determination to protect their disabled child from bullying and teasing), and “sacrifice” (associated with loss of a “normal” life for themselves). In our study, the participants felt strongly the lack of family, community, and health professional support. This was not identified in studies conducted in developed countries (Burkhard, 2013; Magill-Evans, Darrah, & Galambos, 2011). These differences can perhaps be attributed to the different medical systems and cultural influences in Western countries.

6 | RECOMMENDATIONS

When caregivers are informed, they better understand their children’s rights and needs, make appropriate decisions for, and with, their children, and rely less on traditional interventions. Also given accurate information, they can positively influence societal attitudes at a local level. However, there are many barriers in undeveloped countries that have not been addressed (Eysenbach & Jadad, 2001). As a result of this study, a support and education “Getting to Know Cerebral Palsy” programme, involving a physiotherapist and a nurse, has been offered in each of the eight districts in the Greater Accra Region of Ghana. Each group of 8–10 caregivers met monthly for an average of 4 hr. After the conclusion of our study, we offered this opportunity to the participants and subsequently they all participated in the programme. The programme has been evaluated (Zuurmond et al., 2018) with positive results and may serve as a model for other African countries. This evaluative research involved collaboration between community and university researchers and provides contextualized evidence for this type of educational initiative.

Late diagnosis of CP and inaccurate and inconsistent information about CP in most countries in Africa is largely due to a lack of knowledgeable trained personnel (Donald, Kakooza, Wammanda, Mallewa, & Samia, 2015). The provision of basic education interventions that target front-line health personnel must be a priority. Such interventions will enable them to identify CP, monitor a child’s situation, and provide information in a way that is understandable to poorly educated individuals. In addition, it must be recognized that alongside the biomedical system in Ghana, there is a well-established African traditional ethno-medicine system in rural areas which needs to be acknowledged and better understood. By adopting a purely biomedical approach to educational programmes, the opportunity to change societal attitudes towards disability and to capitalize on local knowledge and resources may be lost (Simmons, 2011). Similarly, community education initiatives need to be developed in traditional ways, for example, in Ghana, most public health education takes place at "community durbars” (Nyonator et al., 2005, p. 27). These have been effective in promoting open discussion of CHPS activities in the past (Nyonator et al., 2005).

Ghana was the first African country to endorse the United Nations Convention on the Rights of the Child in 1990, but it still faces challenges in implementing these policies to make a difference in the lives of disabled children (Appiah, 2006). The Under Five Child Health Policy (2007–2015) developed by Ghana’s Ministry of Health (2007) states that "The Child Health Programme will advocate for collection and use of appropriate data in planning interventions to address the management of children with existing long term mental and physical disabilities from malformations, birth trauma and other factors needs improvement” (Point 8 p. 15). However, children with CP in the rural communities in Ghana have still not benefited from the implementation of this policy and, based on the study findings, implementation and increased community services funding and resources are strongly recommended.

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