Exploring the Lived Experiences of Mothers of Children With Intellectual Disability in Ghana

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Abstract
This study explored the experiences of mothers of children with intellectual disability in Ghana. Specifically, the study sought to determine the challenges and coping strategies associated with raising a child with intellectual disability. Using the phenomenological approach, 11 mothers were purposively selected from mothers whose children attended a “special” school. Semistructured interviews were used to collect data on the experiences of mothers of children with intellectual disability. Data were analyzed and interpreted into six themes including emotional reactions, caregiving challenges, societal reactions, knowledge of the condition, perceived cause of the condition, and coping strategies. The findings of the study demonstrate that being a mother of a child with intellectual disability is beset with several negative experiences of stress; however, mothers recounted the valuable nature of their coping strategies including spiritual beliefs, support, and hope in raising their children with intellectual disability. This study highlighted the challenging nature of having a child with intellectual disability and the beneficial roles of coping strategies in helping mothers traverse the caregiving journey with their children. This study provides relevant information for mental health practice, policy, and research, and serves as a guide in developing intervention programs for parents of children with intellectual disability in Ghana.

Keywords
mothers, intellectual disability, stress, coping, spiritual beliefs, support

Introduction
The prevalence rates of intellectual disability (ID) are estimated at 1% to 3% of the global population (Maulik, Mascarenhas, Mathers, Dua, & Saxena, 2011). Higher prevalence rates exist in developing countries (Maulik et al., 2011; World Health Organization [WHO], 2001) and Ghana is not an exception. In Ghana, the report on the 2010 population census indicated that about 737,743 persons live with disability and this represents 3% of the country’s total population. In addition, 15.2% of the 3% have intellectual malfunctioning (Ghana Statistical Service [GSS], 2012). ID is characterized by significant limitations in intellectual functioning and in adaptive behavior, and occur before age 18 (American Association on Intellectual and Developmental Disabilities [AAIDD], 2009).

ID has emerged as the preferred term for what was referred to as “mental retardation” due to the negative and derogatory attributes associated with “mental retardation” (AAIDD, 2006). There are three different classifications of ID, and these are associated with significant impairment in three main areas of intellectual development. First, a person should have significant impairment in intellectual functioning. Second, a person should have approximate scores of two standard deviations below average which could occur in about 2.5% of the population or scores below 70 and this is determined by standardized and culturally appropriate IQ tests. Third, a person with ID should have limitations in adaptive functioning including living independently, communicating with others, and being responsible for oneself (American Psychiatric Association [APA], 2013). In the current study, ID refers to a disability with significant limitations in intellectual, communication, and adaptive functioning.

Raising children with ID creates enormous psychological challenges often expressed as depression, anxiety, and somatic symptoms for parents (Cramm & Nieboer, 2011; Norlin & Broberg, 2013). Several studies have found that having a child with ID is unequivocally associated with personal and financial adjustments, and adaptation to the new role of meeting the unique needs of the child (Olsson & Hwang, 2008; Pisula, 2007). Families also have to deal with...
daily demands of caregiving including feeding, bathing, dressing the child, toilet training, and child behavioral problems (Plant & Sanders, 2007; Tomanik, Harris, & Hawkins, 2004). Most parents also express concern about how their children will function independently or who will take care of the child when they are no more (Altiere & von Kluge, 2009; Pisula, 2007). Ultimately, these fears and anxieties can be further linked to the stigma, isolation, and shame of having a child with ID (Ambikile & Outwater, 2012; Green, 2003; McNally & Mannan, 2013).

Persons with disabilities and their families are treated differently from all other persons in many countries including Ghana (Ambikile & Outwater, 2012; Avoke, 2002; McNally & Mannan, 2013). Studies have reported that many cultures in Ghana view ID as a spiritual condition whereby families into which persons with ID are born are regarded as being punished by the gods (Avoke, 2002). This means that a family can give no reason for having a child with ID except that the family is being punished for some sin they may have committed against the gods of the land. There are also reports that some rich parents of children with ID have such children because they have used them for rituals, and this is referred to as “juju” in the local Akan parlance in Ghana (Inclusion Ghana, 2011). In Ghana, these beliefs are so deep-seated that even the introduction of Christianity and Islam could not entirely eradicate the interpretation of ID in spiritual terms (Andin, 2008). Specifically, people belonging to both Christian and Islamic faiths perceive ID in spiritual terms (Andin, 2008; Hervie, 2013; Jegatheesan, Miller, & Fowler, 2010). However, studies have shown that people in Ghana and other Asian countries hold both biomedical and theological beliefs about the causes of ID (Andin, 2008; Kaur, 2011).

The negative traditional beliefs associated with disability have been found to initiate discrimination, stigmatization, and isolation of disabled children and their parents (Aldersey, 2012; Avoke, 2002). These behaviors propel some families to abandon their children at river banks to be taken up by the river or even get them killed at birth (Aldersey, 2012; Ghana News Agency cited in Anum, 2011). In Ghana, persons with disabilities are viewed as nonhumans and experience physical, emotional, and social abuses (Kassah, 2012). They are also restricted from participating in social activities (Hervie, 2013; Kassah, 2012), and hardly achieve social and political positions in society (Sackey, 2015). Eventually, these beliefs exacerbate the social exclusion and emotional burden experienced by families of children with ID from family members and the larger society (Avoke, 2002; Bafoe, 2013; Green, 2003). In the face of these challenges, governmental and nongovernmental agencies are making enduring efforts to support people with disabilities in Ghana. For instance, the enactment of the Persons With Disability (PWD) law (2006) which focuses, among others, on promoting access to education, health care, housing, employment, and other social activities for persons with disability. However, persons with disabilities in Ghana continue to face social exclusion which creates barriers to adequate health care, education, housing, and employment opportunities (Hervie, 2013; Inclusion Ghana, 2011).

Although considerable research on children with ID and the negative effects on parents have dominated literature for decades (Leung & Li-Tsang, 2003; Olsson & Hwang, 2008; Trute & Hiebert-Murphy, 2002), some studies have found some parents cope well and remain emotionally strong (Bayat, 2007; Hastings, Allen, McDermott, &Still, 2002). Current literature asserts that some mothers of children with ID generally rely on coping resources including social support (Ha, Greenberg, & Seltzer, 2011; White & Hastings, 2004), hope (Heiman, 2002; Kausar, Jevne, & Sobsey, 2003; Kearney & Griffin, 2001), and spirituality (Durà-Vilà, Dein, & Hodes, 2010; Gray, 2006) that affect positively on mothers’ experiences.

Family and social support have been found to protect parents from psychological distress (Paster, Brandwein, & Walsh, 2009; White & Hastings, 2004). In addition, parents’ spirituality, which often includes a belief in God or attending church, serves as an important coping strategy to assuage their distress (Marshall et al., 2003; Poston & Turnbull, 2004). Among people of African descent, including families of children with ID, spirituality and family support systems are frequently relied on as coping strategies in times of adversity (Allen & Marshall, 2010; Ha et al., 2011; Utsey, Adams, & Bolden, 2000).

Among families of children with ID in Dares Salaam, Tanzania, Aldersey (2012) found that families felt stigmatized and lacked both formal (i.e., support from religious organizations, government, and nongovernment agencies) and informal support (i.e., family support). However, families exhibited variety of strengths in the form of their spiritual beliefs (e.g., “It is God’s will”). According to Durà-Vilà et al. (2010) and O’Hara and Bouras (2007), parents perceive their children with ID as beneficial as they ascribe a sacred meaning to having a child with ID. In addition, Allen and Marshall (2010) asserted that parents of children with chronic illness often turned to their faith in God as a form of coping strategy for raising their children.

These findings corroborate other studies (Luong, Yoder, & Canham, 2009; McNally & Mannan, 2013) which have shown that though parents reported psychological distress associated with caring for their children with disability, they also reported some positive experiences associated with their cultural beliefs of spirituality and social support. Many parents in these studies relied on their extended families for support. However, support was found to be inadequate as some of the parents indicated that they could not rely on others for support. Other studies acknowledge that despite the positive effects of the extended family system which is distinctive of collectivist cultures, the stigma associated with ID is so pervasive that support from the family and society is limited (Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010; Gupta, Mehrotra, & Mehrotra, 2012).
Existing research in other cultures irradiate the strengths in cultural values of social support, rewards of caregiving, and spirituality in coping among parents raising children with ID (Allen & Marshall, 2010; Edwardraj et al., 2010; Ha et al., 2011). The current study had two purposes. First, sparse literature exists on the challenges and coping strategies associated with parenting a child with ID in the Ghanaian context; thus, this exploratory study sought to illuminate how Ghanaian mothers of children with ID cope with the related stress of raising their children. Second, the present study sought to add onto the few studies (e.g., Anum, 2011; Hervie, 2013) which have reported on the spirituality and family support systems as essential to the experiences of mothers of children with ID in Ghana. As mothers serve as the primary caregivers in many households (Lutz, Patterson, & Klein, 2012), it is important to have an informed knowledge of their stress and coping experiences to address them adequately. A relevant research question of this study is as follows:

**Research Question 1:** What are the lived experiences of mothers raising children with ID?

This broad question dealt with the emotional reactions of mothers raising children with ID, their daily caregiving challenges, societal reactions, and the coping strategies they employ.

**Method**

The qualitative approach was considered appropriate for this study because it provides an in-depth understanding and a rich description of the experiences of participants (Creswell, 2007). The research method for this study was based on the phenomenological approach which ensured a detailed description of the phenomenon under study (Smith & Osborn, 2003).

**Participants**

Participants for the study comprised of 11 mothers of children with ID purposively selected from the New Horizon Special School in an urban society, Accra, Ghana. This school provides education and advocacy for mothers and their children with ID. All 11 participants were mothers of children with ID. Inclusion criteria for the study were (a) mothers who self-identified as caring for a child with ID, (b) mothers involved in the day-to-day care of the child with ID, (c) mothers of children with ID between the ages of 5 and 12 years. This age range of 5 to 12 years was settled to narrow the focus of the study and to decrease the variance that is likely to occur with a wide age range, (d) mothers who consented to be interviewed with audiotape and could speak and understand English or Akan languages. The age range of participants was from 38 to 63 years, with an average age of 47 years. The age range of the children was from 5 to 12 years, with an average age of 6 years. The majority of the participants were married (N = 7), employed (N = 7), and their religious affiliation was Christianity (N = 11). Largely, the recruitment strategies were directed at selecting persons who were directly involved in the care of children with ID. Demographic characteristics of participants are presented in Table 1.

**Semistructured Interview Schedule**

Semistructured interview schedule was used to elicit information on the stress and coping experiences of mothers of children with ID. The interview included questions that focused on different areas such as demographic information, experiences of having a child with ID, and how they coped. Some of the questions included were as follows: How did you feel when you first found out the condition of your child? How do people in society react to you and your child? What strategies do you use in dealing with stress associated with caring for your child? Probing questions were asked where necessary to obtain information, clarify a point, or expand on ideas. Field notes on the experiences of mothers were also made during each interview to serve as an audit trail.

**Procedure**

Participants were informed of the study through the school administrators. After the initial contacts were made, 11

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**Table 1. Demographic Characteristics of Participants.**

| No. | Namea | Gender | Age  | Marital status | Employment status | Religious affiliation | Gender of child | Age of child |
|-----|-------|--------|------|---------------|-------------------|----------------------|----------------|-------------|
| 1   | Adessa| Female | 40   | Married       | Self-employed     | Christian           | Female         | 12          |
| 2   | Gessie| Female | 45   | Widow         | Formal            | Christian           | Male           | 10          |
| 3   | Meryl | Female | 47   | Married       | Formal            | Christian           | Male           | 10          |
| 4   | Adjo  | Female | 53   | Married       | Formal            | Christian           | Male           | 6           |
| 5   | Alice | Female | 40   | Married       | Self-employed     | Christian           | Female         | 10          |
| 6   | Eve   | Female | 45   | Divorced      | Formal            | Christian           | Female         | 12          |
| 7   | Enoma | Female | 38   | Married       | Unemployed        | Christian           | Male           | 8           |
| 8   | Obenewa| Female | 53   | Married       | Self-employed     | Christian           | Male           | 9           |
| 9   | Samuela| Female | 55   | Divorced      | Formal            | Christian           | Female         | 12          |
| 10  | Grandma| Female | 63   | Widow         | Unemployed        | Christian           | Male           | 12          |
| 11  | Leslie| Female | 42   | Married       | Self-employed.    | Christian           | Male           | 5           |

*aPseudonyms were used throughout the study.*
participants agreed voluntarily to participate in the study. Participants were contacted by the researcher via a telephone call with the aid of the school administration to schedule a meeting at their own time and convenience. Although some participants preferred to be interviewed on the school premises, others preferred their homes. During the interviews, mothers were requested to give a detailed description of their experiences. Data collection spanned over a 3-month period. All 11 interviews were conducted in English and Akan languages, digitally recorded, and lasted for 30 min to 50 min.

**Ethical Consideration**

Ethical approval for the study was granted from the Institutional Review Board (IRB) of the Nuguchi Memorial Institute, University of Ghana, Accra, Ghana. Participants were requested to sign a consent form prior to the interview sessions. The consent form provided a description of the nature of the study. The consent form clearly indicated the voluntary nature of the study to participants, and their right to withdraw from the study at anytime without any consequence. To ensure confidentiality and anonymity, the researcher created pseudonyms for participants and this was used throughout the study. Moreover, permission was sought and obtained for the interviews to be audiotaped. Participants were given learning materials, but no other compensation as appreciation for participating in the study.

**Analysis**

All tape-recorded interviews were transcribed using the Microsoft Word’s word processing program. However, recordings in the Akan language were translated into the English language before they were transcribed. Two doctoral students with experience in qualitative research assisted in transcribing the tapes. The transcribed data were also reviewed by the researcher to ensure that all the details of the interview were captured accurately. Analysis was done using the principles of Interpretive phenomenological Analysis (IPA) which basically deals with examining how people make sense of their experiences (Smith & Osborn, 2003). This study is phenomenological because it sought to gain a deeper understanding of the experiences of mothers caring for their children with ID uniquely understood by themselves and within their cultural context.

The following four steps involved in IPA were followed: (a) familiarization with the data, (b) generating initial codes and searching for themes, (c) reviewing themes, and (d) defining and naming themes. First, each transcript was read and reread to get familiar with it and to identify important quotes and phrases within each transcript. The researcher proceeded to make notes from the transcripts documenting similar quotes and phrases. These notes represented a description of the participants’ experiences and the researchers’ interpretation of the transcripts. Second, codes and themes were generated by examining the transcripts for identifiable themes in the mothers’ narrative. Third, themes were reviewed by comparing the themes across the 11 transcripts, identifying connections between preliminary themes and editing the themes. At the fourth and final stage of the analysis, the themes were named and a thematic network was developed to summarize all the superordinate themes and their subthemes.

Trustworthiness was enhanced using peer debriefing. Emergent themes were discussed with two peers with much experience in qualitative analysis. According to Creswell and Miller (2000), having multiple reviewers ensures reduction in biases as well as reliability in understanding the data. Member checking was done by contacting participants after the transcription and analysis to authenticate the identified themes (Lincoln & Guba, 2000).

**Results**

Analysis of the interview transcripts yielded six major themes that best captured the total experience of raising a child with ID. The themes were presented in line with answering the research question on experiences of mothers of children with ID. Themes were categorized into major and subthemes. Each major and subtheme was described and supported by direct quotes from the interviews. The six major themes were as follows: (a) emotional reactions, (b) caregiving challenges, (c) societal reactions, (d) knowledge of condition, (e) perceived cause of condition, and (f) coping strategies. The major themes and subthemes are illustrated in Table 2.

**Theme 1: Emotional Reactions**

Mothers of children with ID unanimously expressed sadness, worry about the child’s future, and stress associated with raising a child with ID.

| Table 2. Major Themes and Subthemes. |
|--------------------------------------|
| Major themes | Subthemes |
| Emotional reactions | Sadness, Worry about future, Stress |
| Caregiving challenges | Employment issues, Demands of caregiving |
| Societal reactions | Stigma, Isolation |
| Knowledge of condition | Medical/psychological assessment, Teacher information, Personal knowledge |
| Perceived cause of disability | Spiritual beliefs, Medical |
| Coping strategies | Spiritual beliefs, Hope, Support |
Sadness
All mothers unanimously described the knowledge of their child’s condition propelled an emotional reaction of sadness. This is illustrated by statements from some mothers:

That day I found out “I cried.” I wasn’t happy at all because, I have two children and the first is a girl and even that I wanted a boy as my first child and so when I had this boy I was so excited because that is what I wanted but when they told me about this situation, I didn’t like it, I cried a lot. (Gessie)

It was very painful and I cried. After her birth I decided not to give birth again and so it was really painful that my last child had to have such a condition. (Eve)

Worry About the Future
All mothers in this study articulated their uncertainty and worry about their child’s present and future condition, especially their inability to achieve the developmental milestones and how to be independent in the future. Two parents described how they were worried about their child’s achievement of developmental milestones and future life. This is illustrated with the words of these mothers:

If you look at him now that he is almost eight years but there are so many things he cannot do for himself, he is not walking, talking, and not able to do anything and so I worry about his future. (Enoma)

I am very worried about his future because as at now he can’t talk, think or do anything for himself and so if God does not help him to get well and I die and leave him what will he do. Who will take care of him? I used to have house helps but they were all not treating him well in my absence so I decided to stop working and concentrate on his care so his future keeps me very worried, who will get such time for him. (Grandma)

Stress
Mothers also described the stressful nature of caring for a child with ID. One mother expressed herself as follows:

I think every parent gets stressed in parenting children but the stress associated with parenting a child with autism is very intense. She is always running up and down and always shouting and you need to control her, it can be very stressful. Thinking of all the sacrifices you have to make for her development and how to get her through the daily activities, getting the other disciplines to understand the situation, financing her education which is more expensive than regular school. It’s a whole lot of trouble. (Adessa)

Theme 2: Caregiving Challenges
Mothers created the awareness of the challenges involved in raising their children with ID. These challenges were described in terms of demands of caregiving, employment, and financial issues.

Demands of Caregiving
The need to assist the child to perform all routine daily activities such as eating, brushing teeth, bathing, dressing, and using the toilet were described by a mother as follows:

I go through a lot on a normal day. In the morning when we wake up, I wake him up and brush the teeth . . . brushing his teeth is difficult. I have to sing and crack jokes for him to laugh so that when he opens the mouth then I can brush. I have to bathe him, dress him, feed him and virtually do everything for him. The issue is that he cannot do anything for himself so I have to help him out every time. After all these I have to take him to school myself. (Enoma)

Employment and Financial Issues
Mothers in this study pointed out that they had difficulties getting and sustaining a job, and financial difficulties as a result of having children with ID. Two mothers described their experiences as follows:

Growing up I had plans of working and having a fabulous career, but because of my daughter I had to come to terms with the fact that I will be a caregiver all my life. I cannot work like other women do. I made a decision to stop working as I could not work and also take care of my daughter. (Adessa)

I had problems with my employers because I had to leave work in the afternoon to pick my son from school, they would not allow me to do that every afternoon and I had no help, so I had to give up my work and this affected my finances significantly. (Obenewa)

Theme 3: Societal Reactions
Throughout the interviews, all mothers reported that having a child with ID was a transition into a new and often unwelcome identity in society. Mothers demonstrated their awareness of societal attitudes which made them feel stigmatized and isolated. This is illustrated in the following narratives by different mothers:

Stigma
It has been a real experience and a very difficult journey of having a child with special needs. In this society, it is a taboo to have and people often say that you have a child with intellectual disability because of something bad you have done. One day a certain woman in our area insulted me that I have given birth to a dog because of my sins. (Leslie)

Isolation
Mothers also reported feeling isolated from the rest of society because of their children. A mother described her situation as follows:
I cannot take my son out to any social program as I do not like the way other people would look at him. Instead of asking what is wrong with her they stare at her and I feel bad so I stay with her in the house when others are attending social programs we could be part of. (Samuela)

**Theme 4: Knowledge of Condition**

This theme described the various ways through which mothers got to know of their children’s condition. Mothers alluded to knowing of their children’s condition from three sources including their personal knowledge in observing physical features of the child, medical/psychological consultation, and teacher information.

**Personal Knowledge**

About 30% of the mothers in this study indicated their suspicion of something wrong with their children’s development. This was based on the physical features of their children and also the delays in development, especially toilet training abilities. One mother, Adjo, said,

I think some months after birth I realised that my child has a problem . . . I know their features and their pace of development, he was not growing as the sister at 6 months. He had features of Down syndrome like the round face, slanting eyes, I knew something was wrong. (Adjo)

There is still no speech but he cried a lot, he was just staring and quiet, and I didn’t know if he was hungry or wet. I knew there was something wrong. (Enoma)

**Medical/Psychological Consultation**

A total of 50% of the mothers in this study reported on their uncertainty surrounding delays in the development of their children. In seeking to understand what was going on, mothers indicated that they sought medical attention:

Because of his development delay I took him to the hospital, and the doctor (Paediatrician) conducted several tests on him . . . the conclusions were that my son has brain damage and that is preventing him from developing normally. (Obenewa)

**Teacher Information**

A total of 20% of the mothers reported knowledge of their children from their teachers. Children were not performing as other children in the school:

Her teacher started complaining that when she teaches the child she does not get it and in the words of one teacher, “when I ask your child a question, she just stares at me. She does not say anything.” (Eve)

**Theme 5: Perceived Cause of Disability**

The majority of mothers, about 80%, recounted what they were told by doctors and nurses regarding the cause of the children’s condition. However, all mothers reported being aware of the spiritual nature of having a child with ID in Ghana. From their responses, the causes of ID were categorized into medical and spiritual. A statement is illustrated below:

**Medical**

After we were discharged from the hospital we went for review after two weeks and I met a white doctor who said because I was over 40 years, that could be a contributing factor to my child having Down syndrome. So it was there that I knew it. (Samuela)

**Spiritual**

Although many of the mothers in this study, about 80%, claimed they did not believe in the existing spiritual and evil connotation people ascribe to ID in Ghana, all the mothers in this study placed emphasis on attributing having a child with ID to the will of God than to the traditional beliefs of curse and punishment from the gods. This is illustrated in a statement from one of mothers:

We are in Africa and so sometimes I hear a lot of things concerning spirituality in terms of children with intellectual disability being children of the rivers or what and also you hear people say that they are going to “escort them” and then they leave them to their fate at river banks. But as I said I am a strong believer in God so I do not think that my child is a river child. The only thing I know is that God gave her to us and He knows why He gave her to us. (Adessa)

**Theme 6: Coping Strategies**

Despite the problems that mothers encountered with raising their children with ID, mothers possessed coping strategies for managing their problems. Coping strategies such as their spiritual beliefs, hope, family, and community support were recounted by mothers as providing meaning and purpose for their lives, and helped them to adapt to their new life.

**Spiritual Beliefs**

About 95% of the mothers emphasized the role of their spiritual beliefs in coping with their children with ID. These beliefs made them interpret why God gave them the child and surrendered everything to God through prayers. This is illustrated by statements from some mothers:

I am a strong believer in God so the only thing I know is that God gave her to us and He knows why He gave her to us. I believe I was chosen by God to have a child with a disability. My daughter had to come to the world but through me. Sometimes I ask God, “Why me” and a friend once said “why not you?” I believe God wanted this child to come into the world and he had to choose me. I believe it is a calling. (Adessa)
Meryl believed that she had to totally surrender her situation to God to help her go through the challenges. This is illustrated by a statement:

Sometimes I feel like I am in charge and can carry all the burdens alone . . . But there comes a point where you realise that it is only by the grace of God that you can survive. (Meryl)

I usually do prayers and understanding and knowing the Lord you serve, knowing what He can do for me encourages me . . . I mostly pray for direction and I always go to the church programmes in order to feel relieved. The prayers do help but most often though we pray and all but just the thought of being in this state is a great worry, I think in every situation things happen to us and you ask God “why me?” but I think the first thing to do is to accept it so you know how to handle it. (Samuela)

On the contrary, 5% of the mothers felt frustrated by their own spirituality because they felt they had not been treated fairly by God who had given them such a child. The extract below highlights this dichotomy and is illustrated by a statement from one mother:

I am not able to pray because the moment I open my mouth I start crying. I ask “oh God why me? Why should this happen to me? What have I done to deserve this? Why do I have to go through this problem?” (Leslie)

Hope

Although about 80% of the mothers in this study were very conscious of the limitations of their children, they were also hopeful of better days ahead for their children. This was stated in the words of two mothers:

I know God will make him become somebody in the future. I will not give up because there is hope. (Samuela)

There is hope for the future because since she started school she has really improved and I’m so thankful to God that we did not abandon her. (Adessa)

Support

All the mothers in this study reported on how the availability or lack of support from others helped them to cope. About 70% of the mothers reported they had support from their husbands, family members, friends, church, and health care professionals, and this was central in sustaining their mental health. Some of the reports of support from husbands and family are found in the statements below:

My husband helps a lot, days when I’m not able to take her to school, he does it and even at home he helps with taking care of the home. He is very supportive. (Adessa)

Another mother, Samuela, also described the support she receives from her friends:

I have a good friend in Kumasi whom I usually call when I’m stressed. For the family, they always come in to help especially when I have to go for a course abroad. At church too, there is one Sunday school teacher who supports us, helps my daughter to fit into her class at church and protects her from children who might be rude to her. (Samuela)

In another instance, mothers, for example, Grandma, made reference to getting support from her church. They also reported that attending church relieved them of their stress as they met people who were willing to help them. The extract below illustrates these responses:

My church members and pastor are a very strong source of support; they visit us and also give us some financial support whenever they can. I really appreciate this. (Grandma)

All mothers who participated in this study reported on the support they received from their children’s school and how it helped them to cope. This is illustrated by a statement from one of the mothers:

The school also helps a lot because they organise programmes for us on how to handle our children and how to cope. They encourage us anytime we are sad that everything will be well. (Enoma)

However, about 30% of the mothers also reported on the limitations in the support they got from family, friends, church, and health professionals. These are found in statements below:

Gessie specifically stated the problems she is experiencing because of the death of her husband. She said,

The family is not helping. My husband has passed on and the sister once said that “we know about your situation but . . . we also have children to take care of.” Unfortunately my parents have also passed so I really do not have anybody who is providing support for us. (Gessie)

With regard to support from the church, mothers asserted that the church did not always serve as a haven of refuge for the sick and vulnerable.

Grandma stated that

One day at church he urinated on himself and one woman said, “an old boy like you why should you urinate on yourself?” but I got bored about it and told her that the child has a problem. There is also a woman at church who tells everybody who comes to the church for the first time about my grandson’s condition but one day I confronted her and told her that instead of telling people about the child she should pray for him. (Grandma)
Some mothers, about 60%, also raised issues on being mistreated by health professionals. Adessa described how she was disappointed with a health professional when she sent her daughter for medical care. She described it as follows:

She urinated on herself one time and a nurse shouted at her “how can a big girl like you urinate on yourself?” I think that was extreme coming from a health professional. (Adessa)

Discussion

The purpose of this study was to explore the experiences of mothers raising children with ID in Ghana. Findings revealed varied experiences of mothers of children with ID. For instance, spiritual beliefs in the form of prayer and organized religious activities served as coping mechanisms for some mothers but not for others. Generally, this study revealed mothers experience enormous challenges as they made efforts to care for their children with ID. These challenges were related to their emotional reactions on knowing their child’s condition, caregiving challenges, societal reactions, perceived cause of disability, and the coping strategies they adopt to deal with their prevailing situation.

The emotional reactions reported by mothers in this study resonates with research that mothers of children with ID are often emotionally burdened by their child’s condition (Cramm & Nieboer, 2011; Norlin & Broberg, 2013). Mothers expressed ambivalence about their children’s future with regard to living independently like typically developing children of their age and this contributed to their distress (Altire & von Kluge, 2009; Pisula, 2007). However, some mothers in this study also expressed hope of their children’s abilities in the future with the help of God.

Mothers also reported being sad either after getting a diagnosis from a medical or psychological source or gaining knowledge on their child’s condition through teachers and personal information. With regard to personal knowledge, studies have reported that parents of children with disabilities often become concerned about their children’s early abnormalities in their developmental process confirmed by their child’s abnormal physical features, delayed speech, inability to walk, inability to be toilet-trained, and perform other tasks that children of their age could perform suggesting the presence of an ID before professionals become aware and make a diagnosis (Ahern, 2000). With regard to responses from mothers in this study, there is an indication that just about 30% of the mothers noticed delays in the child’s development before seeking for help. This means that the Ghanaian society needs to be better educated on the signs of ID so that parents will be able to seek intervention early.

Moreover, the nature of the daily caregiving activities, employment, and financial challenges, which they are often not prepared for, overwhelmed the mothers in this study (Pisula, 2007; Plant & Sanders, 2007). Existing research indicates that having a child with ID often interferes with a mother’s ability to get employed and also puts pressure on their finances (Ambikile & Outwater, 2012; Olsson & Hwang, 2008). The significance of their finances to the care of their children and the need for financial support was evident in their response to any other information they wanted to share after the interview. Most mothers mentioned the need for financial support from family, society, government, and nongovernmental agencies to traverse the difficult situation they find themselves.

Mothers in this study reported being stigmatized in society as have been happening in other societies (Ambikile & Outwater, 2012; McNally & Mannan, 2013). Moreover, mothers narrated feeling isolated from society because of negative comments and stares from people. Green (2003) found that mothers of children with disabilities experience high levels of stigma from society. These negative attitudes are possibly due to the cultural and spiritual beliefs associated with disability in Ghana (Avoke, 2002). Mothers raised their children under the influence of powerful traditional beliefs that devalue people with disabilities (Avoke, 2002; Baffoe, 2013).

The spiritual interpretation of disability in the African, and particularly the Ghanaian, context may have also influenced mothers’ interpretation of their children’s condition. Although mothers reported on the medical basis for their children’s condition, often related to their age at pregnancy or the presence of convulsions in the child, majority of the mothers knew of the spiritual interpretations of having children with ID. They did not debunk the possibilities of these spiritual connotations even though they created the impression that they did not believe in evil interpretations society associated with their children’s condition. Mashego (2005) asserted that Black mothers of children with behavioral problems could not tell the cause of their children’s condition due to their external locus of control of attributing their children’s situation to supernatural causes. Clearly, the findings of this study showed that mothers’ experiences are situated in the context of how they believe society views and treat their children (Avoke, 2002; Baffoe, 2013; Hervie, 2013). However, research has shown that in Africa, health beliefs have been described as holistic, where many families and communities hold multiple beliefs, consisting of medical and African traditional and supernatural belief system explanations and treatment of diseases (Andin, 2008; White, 2015).

Regardless of the challenges that mothers encountered with raising a child with ID, they also reported a variety of effective coping strategies in managing the challenges in parent- ing their child. Generally, mothers highlighted their spiritual beliefs, family/community supports, and hope as vital to their coping experiences. For many of the mothers, the faith they reposed in God strengthened them (Aldersey, 2012; Durà-Vilà et al., 2010). In a qualitative study on the family’s perceptions of caring for children with disabilities among 14 families in Moshi, Tanzania, McNally and Mannan (2013) found that participants emphasized their belief in God and His power to carry them through their experiences of raising a child with disabilities.
Research has shown that parents may use these beliefs to interpret their children’s disability as a special gift from God and also assuage the distress associated with caring for their children (Durà-Vilà et al., 2010; O’Hara & Bouras, 2007). Moreover, mothers in this study who were all Christians highlighted the beneficial nature of the support from their church leadership and congregation. This resonates with existing literature which indicates that support provided by religious organizations improves the psychological health of parents of children with ID (Pillay, Girdler, Collins, & Leonard, 2012; Poston & Turnbull, 2004). Although some mothers felt not fairly treated by God, and questioned God, others were also not happy with the absence of support from the church (Speraw, 2006). One intriguing aspect of the interview was that some mothers did not consider their spirituality, especially prayer, as an effective coping strategy. Indeed one mother indicated that she did not pray because anytime she attempted to pray, she ended up crying and questioned God for her predicament.

The need to have great support from family and society to successfully raise their children was a concern for mothers in this study. Mothers with strong support from their spouses, siblings, grandparents, and their children’s school reported improved psychological health. Extensive research emphasizes the important role of support from family, friends, church, and professionals in alleviating stress and facilitating positive coping ability among parents of children with ID (Aldersey, 2012; Ha et al., 2011; McNally & Mannan, 2013). However, it was also obvious that some mothers were not satisfied with the support from family, friends, and the society. According to some mothers in this study, the fact that they had children with ID caused them to be perceived as outcasts in their family and society.

Considerable research have reported that mothers of children with ID experience enormous burden as a result of the limited support they receive from their family and the community (Aldersey, 2012; Edwardraj et al., 2010; Gupta et al., 2012). The communal nature of the African family which provides support for families in times of stress (Boyd-Franklin, 2003; Gyekye, 2003) seems to be eroding as many community and extended family members no longer share in the problems of other members and, therefore, may not provide adequate support for parents and their children with ID. Mothers need to be supported emotionally and financially by families, friends, society, health professional, governmental, and nongovernmental agencies concerned with improving the lives of mothers and their children with ID.

Hope, as a coping resource, possessed by mothers in the current study is an indication of how mothers navigated their emotional burden in anticipation of a positive future for their children. Mothers were happy with the improvement in the little achievements their children made and this made them stronger (Heiman, 2002; Kausar et al., 2003; Kearney & Griffin, 2001). This finding corroborates previous research of Kausar et al. (2003), where hope was found to influence parents’ interpretation of their children’s condition and provided them with strength to cope with their challenges.

As evidenced from the narratives of mothers, the coping strategies they adopted contributed significantly to their psychological functioning. One revealing condition about the coping strategies utilized by mothers in this study was their association with the cultural values of spirituality and family support systems of the Ghanaian people (Gyekye, 2003). This reiterates the point raised by researchers that many people of African descent prefer coping strategies associated with their worldview which has spirituality and family support as its main tenets (Belgrave & Allison, 2006; Gyekye, 2003; Utsey et al., 2000). In the present study, mothers did not focus entirely on their negative experiences, but also focused on the brighter side of their lives. This is consistent with emerging literature that having a child with ID is not an entirely gloomy situation but also a source of encouragement and strength (Bayat, 2007; Hastings et al., 2002; Kausar et al., 2003).

Study Limitations

This study was not without limitations. First, findings from this study cannot be generalized to all mothers of children with ID in Ghana. The present study focused on mothers living in urban areas; therefore, it remains unknown whether mothers living in rural Ghana differ in their lived experience. Second, the participants of this study were relatively homogeneous as they have their children attending special schools. Thus, the findings cannot be generalized to mothers whose children are not attending special schools. Third, although this study focused on maternal experiences, it does not seek to belittle the role and experiences of fathers in relation to their children. Future studies into the experiences of fathers may provide a rich understanding into the dynamics of raising a child with ID. Nevertheless, findings from this study provide a suitable guide for future research into the experiences of parents and may lead to an improvement in their well-being.

Implications for Interventions and Policies

Emphasis should be placed on empowering families with coping strategies associated with their cultural values to help them traverse the challenges associated with raising children with ID. Mental health professionals should support mothers in considering the positive aspects of their experiences, offer them hope, assist them to make efforts in reframing their situation, and make meaning of the experience of having a child with ID. Findings of this study could inform the design of culturally sensitive programs and policy on children with ID.

Moreover, inclusive disability policies that require the appropriate agencies such as the Social Welfare Department
and the Ministry of Gender, Children, and Social Protection to provide mental health assessment to families of children with ID should be implemented. Advocacy and support groups such as the Parents of Children With Intellectual Disability (PACID-Ghana) should be involved in embarking on antistigma programs to educate the public on the causes of IDs, experiences of family members, and the need to show love and concern for families of children with ID. Health professionals should provide a warm reception in their interaction with parents and their children. Financial support from government and other corporate organizations for mothers to educate their children and support themselves should be provided.

Conclusion

This study explored the experiences of mothers raising children with ID. Findings from this study highlighted the distress of having children with ID. However, mothers reported on their reliance on faith, hope, and support to cope with the challenges associated with raising their children. Understanding the role of these coping strategies would enable their incorporation into designing therapeutic interventions for mothers and their children with ID. Finally, this study enhances our knowledge on the experiences of mothers of children with ID in the Ghanaian context.

Author’s Note

The author is responsible for the content and writing of the article.

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