2021; 3(1): 60-72
PublishedOnline:01/10/2021
(https://journals.unza.zm/index.php?journal=medicine)
DOI: 10.21617/jprm2021.321

ISSN: 2415-038X (Print)

ORIGINAL ARTICLE Open Access

Experiences of Adults Living with Cerebral Palsy in Accra Ghana

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Abstract

To cite: Tonugble C, Nyante G, Kwakye SK, Quartey J,. Experiences of Adults Living with Cerebral Palsy in Accra Ghana. JPRM 2021, 3(1): 60-72. doi: 10.21617/jprm2021.321

Background: Cerebral palsy is a neurologic condition resulting from brain injury that occurs before cerebral development is complete. The life expectancy of children with cerebral palsy is increasing rapidly and most live into adulthood. The transition to adulthood, together with the change in roles and responsibilities, have been identified as challenges for young adults with cerebral palsy. These include health care, education, employment, independent living, and community engagement. However, there is a gap in understanding the experiences, perceptions, and needs of individuals with cerebral palsy as they transition toward adulthood. This studyTo explore the life experiences of adults living with cerebral palsy.

Methods: A phenomenological qualitative study was carried out involving 6 participants recruited from the La Nkwantanang Madina Municipal District, Osu Klottey and La Dade Kotopon Municipal District in the Accra Metropolis. Semi – structured interviews were conducted with each participant, after which the interviews were transcribed and analysed using the Colaizzi method.

Results: Two main themes emerged: the ‘realisation of self’ and ‘developing coping strategies to deal with living with cerebral palsy. Under the first theme, four sub-themes emerged: making sense of the condition, feeling of belongingness, self-pity and constraints from people because of the condition. The second theme generated two sub-themes: internal coping mechanisms or behaviour and external coping mechanisms.

Conclusion: Adults living with cerebral palsy face different problems compared to children living with the same condition. Adults with cerebral palsy are aware and have more understanding of their condition. They have a good perception of societal attitudes towards them and also are able to develop their peculiar means of dealing with it. The study suggests the necessity to enhance support of adults living with cerebral palsy and enhance their integration into the community-based adult care from paediatric care.

Keywords: *life expectancy, cerebral palsy, phenomenological, adulthood, colaizzi method.*

Received: *27 November 2020* ***Accepted:*** *04 December 2020* ***Published:*** *10 January 2021*

INTRODUCTION

Cerebral palsy (CP) is a neurologic condition resulting from brain injury that occurs before cerebral development is complete [1]. It is reported as occurring in approximately 2-2.5 of 1000 live births globally [2] affecting males more than females [3]. In recent times, the advances in technologies for neonatal care has increased survival for neonates who would have otherwise died, allowing more infants to live with the disability [4]. Unfortunately, however, public attitudes towards disability in Africa are frequently unpleasant, based on fear, misunderstanding and stereotyping individuals with disabilities [5]. This results in caregivers of children living with CP contemplating infanticide, while others have already done so due to the belief in the 'spirit child' phenomenon (commonest in the northern parts of Ghana), which names some childhood illnesses as the potential cause of misfortune in the family [6]. In view of this, there are hardly any adults living with CP. Several studies have been done in other parts of the world but there is very scanty data within the African context especially in Ghana [7]. There is a need for more knowledge about living with CP in communities where there is poor understanding of the public regarding disability.

According to Strauss and colleagues [8], CP is a lifelong disease with over 90% of individuals living past age 18. Although CP is known as a non-progressive disorder, in terms of its core deficits, many of its secondary impairments can progressively worsen over the lifespan of affected persons [9]. The transition to adulthood, together with the change in roles and responsibilities, have been identified as challenges for young adults with CP [10]. These include health care, education, employment, independent living and community engagement [11]. There is a gap however, in understanding the experiences, perceptions, and needs of individuals with cerebral palsy as they transition toward adulthood [12].

Adults with CP face different challenges as compared to children with the same condition, for example, experiencing more pain, fatigue, imbalance, and weakness [13]. These impairments affect self-image, and produce new thoughts about being different [14]. Some adults with CP receive emotional and social support, especially from family, which enables them to cope with the challenges of living with this condition [15]. For others negative attitudes serve as a strategy for dealing with lack of autonomy and living with a lifelong disability [16]. Mobility and self-care problems still prevail in young adults with CP and during the transition into adulthood, and can cause problems with domestic life and work [17]. The same study reported that, approximately 70% of adults living with CP in southwest Netherlands experienced problems in daily life; self-care, productivity, and leisure activities (in descending order of most difficult to perform) [17]. Although much has been written about the concerns in adults ageing with CP, few studies have addressed psychosocial aspects. A study using secondary data analysis identified the need for social support, self-acceptance and acceptance by others; the need for accommodations in the workplace and the environment; and sense of coherence (SOC) as being the main psychosocial challenges of adults ageing with CP [18].

In a phenomenological study [19] of the lived bodily experience of 10 adults with CP concluded that the self-awareness of the individuals' bodies and their ability to adapt to continue to participate in various aspects of their lives were the most prominent findings. In this study, some participants were found to use strategies such as adapting or restricting activity and building in rest breaks, to deal with their pain or fatigue [19], while other participants did not have the knowledge or understanding of their bodies to recognize signs of fatigue and/or how to adapt their activities to cope. On the contrary, in a cross-sectional study [20] comparing 335 adults with CP and their able-bodied counterparts found that adults with CP can have good psychological health as there was no association between psychological well-being and variables related to body structure and gross motor function in young adults with CP.

For persons living with CP, the transition from paediatric to adult health care is important and part of a larger theoretical framework for transition affecting all youth, young adults, and families, as outlined by Meleis [21]. This study therefore explored adults living with cerebral palsy's perceptions or understandings of the condition and investigated the coping mechanisms of adults living with the condition.

METHODS AND MATERIALS

Design

The study was a phenomenological qualitative study conducted within the Accra metropolis of Ghana. Phenomenological approach offers an in-depth description of the lived experience of the participants on the phenomenon being studied free from researchers' personal biases [22]. The principal idea is the researcher authentically listening and reporting the participants' understanding of the phenomenon by reflecting on the assumptions they bring to gain an understanding of how individuals experience life and the meaning they attribute to their experiences, to describe the essence of the experience for more general understanding and to gain an in-depth understanding of often sensitive and complex topics about which little is known

The study involved 6 purposively sampled participants, from La Nkwantanang Madina Municipal District, Osu Klottey and La Dade Kotopon Municipal District in the Accra Metropolis who were above 19 years and affected by CP. Many authorities in descriptive phenomenological studies recommend that researchers recruit at least three participants [23, 24 & 25] for this kind of study. Hence Englander [24] affirmed that, in conducting phenomenological study: "one seeks knowledge of the content of the experience, often in depth, to seek the meaning of a phenomenon, not "how many" people who experienced such phenomenon", hence the number arrived at for this study.

People living with CP with intellectual disability and communication deficits were excluded from this study. This was to eliminate the influence of a comorbidity on the experience of CP which may alter the findings. The strength of this study was hinged on the strong qualitative research background possessed by GN in conjunction with research experiences obtained by CT, JQ and SK in this area. The reflexivity of the researchers were problems that relate to dysfunction of the body structures of adults with CP, the deficiencies in the health systems in Ghana in general and rehabilitation in specific. In addition, the researchers had a preconception that some Ghanaians associate CP with superstition. On the other hand, the lead researcher's knowledge of the ICF concept was a valuable tool for data collection and analysis.

Two pilot interviews from two participants who were not part of the main study were conducted with the aim of developing relevant lines of questions and modification of the interview guide. Interviews were transcribed, read to the participants for them to add further questions. A revised interview guide was developed incorporating the suggested questions, and issues identified during the lead researchers' reflection, suggestions from the second and third authors on the pilot interview process and the field notes. A third pilot interview was conducted with the aim of confirming the improved quality of the interview guide.

Purposive sampling is a technique widely used in qualitative studies for identifying and selecting information-rich cases related to the topic of interest. It is the intentional selection of informants to elucidate a particular theme [26]

Interview process

During the interview, participants were asked questions on the interview guide by the researcher and participants were requested to answer as they understood them. Most often the responses given by the participants probe further discussion between the researcher and the participant. All interviews and discussions were in English. Every discussion was recorded with a Galaxy Grand Prime+ audio recorder (android version 6.0.1) and an Infinix note-3 audio recorder (android version 6.0). There were six questions on the interview guide and each question was asked and discussed. The interview was conducted within a period of three weeks, by interviewing two participants every week on different days tailored to suit the convenience of participants.

Procedure for data collection

Six participants were recruited by the snowball technique. Some physiotherapists and colleagues were involved in recommending eligible participants. Participants recruited were contacted by the researchers and were given printed documents which spelt out the purpose of the study as well as consent forms to sign before the interviews were conducted. Bracketing was conducted to eliminate researcher bias. In-depth face-to-face interviews were conducted and recorded in suitable or comfortable environment chosen and agreed on by participants. The lead researcher (CT) who works at the paediatric unit of the Ghana's premier teaching hospital has a long-time friend with cerebral palsy, hence has developed her own perceptions, assumptions and preconceptions about the phenomenon (living with CP). To assist with critical reflection, CT was engaged in two bracketing interviews [27] to bring into reality her own perceptions and personal experiences.

CT kept a reflexive diary, made field notes and engaged in critical discussion with GN and JQ throughout the research process. During each stage of the study the lead researcher (CT) tried to analyse how her perceptions had influenced the study [28]. From the phenomenologist point of view bracketing is used as a further step in terms of addressing reflexivity issues.

All participants chose their homes for the interview. The interviews took the form of semi structured interviews with the aid of an interview guide. Interviews which lasted for an hour on the average were conducted in English by one of the researchers (CT) after which all researchers participated in transcription of the interviews verbatim into text.

Data analysis

Data collected were categorized into themes using the Colaizzi method [29 & 30]. The following steps represent the Colaizzi process for the phenomenological data analysis.

1. Familiarisation: Each transcript is read several times to obtain a general sense about the whole content.
2. Identifying significant statements: For each transcript, significant statements that pertain to the phenomenon under study should be extracted.
3. Formulating meanings: Meanings should be formulated from these significant statements after careful consideration. The researcher must reflexively “bracket” his or her perceptions to stick closely to the phenomenon as experienced
4. Clustering themes: The formulated meanings should be sorted into categories, clusters of themes and themes.
5. Developing an exhaustive description: The researcher should write a full and inclusive description of the phenomenon, incorporating all previously identified themes.
6. Producing the fundamental structure: The researcher summarises the exhaustive description down to a short statements that capture essential aspects for structure of the phenomenon.
7. Seeking verification of the fundamental structure: The validation of the findings should be sought from the research participants to compare the researcher’s descriptive results with their experiences. The researcher may go back and modify earlier steps in the analysis in the light of this feedback.

In this study, four steps were used: generation of transcripts, formulation of meanings, categorizations and clustering.

RESULTS

Socio-demographic characteristics of the participants

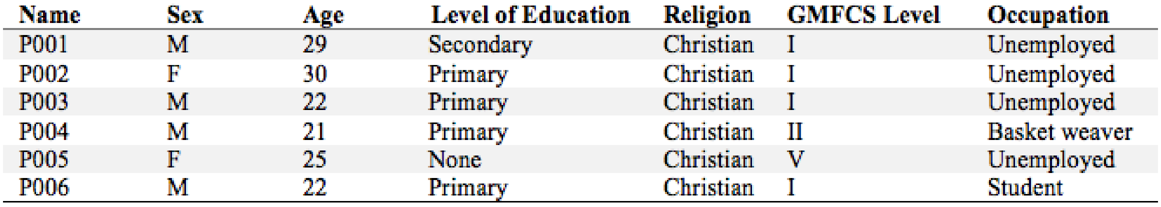
There were eight volunteers, however, two of them were ineligible for the study. One had been diagnosed of intellectual disability and the other lived outside the study site (Accra Metropolis). A total of six adults therefore were eligible and consented to participate in the study. Table 1 represents the socio – demographic characteristics of the participants. Four participants were males with age range of 21 to 30 years, mean (standard deviation) of 24.8 ± 3.5 years. Four participants had only primary school education and were all Christians.

Four participants were on level I of the GMFCS while the other two were on levels II and V. Four of them were unemployed, one was a basket weaver and the other a primary school pupil. All participants lived with their families in low-income areas of urban Accra except one, who lived in a social welfare home. They all had family support, including the participant who lived in the support facility, which was structured to have a family system. For example, they had caregivers they referred to as “mothers".

Overview of major themes

Two themes emerged: realisation of self and developing coping strategy to deal with living with CP. Table 2 shows the categorization of themes, sub-themes and theme clusters.

Table 1: Socio – demographic characteristics of participants



Name	Sex	Age	Level of Education	Religion	GMFCS Level	Occupation
P001	M	29	Secondary	Christian	I	Unemployed
P002	F	30	Primary	Christian	I	Unemployed
P003	M	22	Primary	Christian	I	Unemployed
P004	M	21	Primary	Christian	II	Basket weaver
P005	F	25	None	Christian	V	Unemployed
P006	M	22	Primary	Christian	I	Student

Table 2: Categorization of themes, sub-themes and theme clusters

Main Theme	Sub Theme	Theme Clusters
Realization of self	1. Making sense of the condition	Acceptance of condition By self and others Difficulty in performing activities Self-sufficiency and insufficiency
	2. Feeling of belongingness	Support from family
	3. Self-pity	Suicidal Tendencies Dependence on others
	4. Constraint from people because of the condition	Feeling of rejection from society Displeasure towards rejection Adherence to societal pressure Resistance to societal pressure
Coping strategy to deal with living with CP	1 .Internal coping mechanisms /Behaviour	Withdrawal Indifference Misconduct
	2 .External coping mechanisms	Religion as coping strategy Family support system and coping with stress

Theme 1: Realisation of self

A very important theme that emerged was the realisation of self. Under this theme, four sub- themes emerged as shown in Table 2.

Sub – theme 1: Making sense of the condition.

Participants expressed different ways by which they made sense of cerebral palsy. These included acceptance of condition by self and others. One participant commented as following when asked how CP affected his work:

> "*My boss let me close early because of my condition. He said I should close early and go and relax because of the way I am. I accepted it"* (P001)

Participants acknowledged the condition, agreed that they were different and admitted having difficulty in performing activities. Despite requiring more effort and taking longer to master activities than their peers however, participants were usually able to perform activities with a similar degree of independence, albeit not necessarily to the same standard. This was as a result of some impairment (mostly pain) and fatigue and hence the need to improvise in performing some activities as explained by P002

> *"...because if I'm sweeping then I'll be tired' and (P005) 'my hands are weak so I cannot use it to do any activity, but 'I'm able to manipulate the remote control with my foot."*
>
> *"...I find it difficult to walk faster but I can walk". (P004)*
>
> *P002 recounts" I'm writing then I feel pains in my hand, so I have to stop"*
>
> *In response to "what is a typical day like?" P004 responded ... we play football. I used to be the goalkeeper. I used to play at first but now I have stopped. When I kick, my leg start to pain me. So when I catch I will ask one of my players to kick the ball for me."*
>
> *"I just want to have something to do. I've washed the dishes once. My mother didn't use to allow me to wash because of the mess I'll make in the process" (P005)*
>
> *"...like I can't write my name and I also can't write exam.....my hand will be shaking, if I'm writing I can't write it well. " P003 admitted to how CP affected his schoolwork of the way I am. I accepted it"* (P001)

Although there is obvious limitation in performing activity, some participants expressed self-sufficiency and pleasure in performing activities of daily living. There was a sense of pride in being able to accomplish something they thought was "normal". This made them feel somewhat independent. P004 in stating his rewards feels accomplished for being able to do "normal", things. He said;

"My rewards? Maybe if somebody sees me weeding, he'll say this boy is a very good boy. Look at the way he is weeding. Maybe because it's not every normal person who can weed."

'I like to work on a lot of things' I sometimes cook and wash my own clothes, though it is sometimes difficult I manage to do it and I become happy and forget about my sickness (P002).

On the contrary, others expressed self-insufficiency and dependence on others as elaborated by one participant:

'I can't say that I am adult because I am under training. My mother gives me advice, gives me food, she even buys my clothes for me. To me when I start working, I can now call myself an adult' (P004).

The feeling of insufficiency was not pleasant for these individuals as they would like to have total independence and autonomy. Participants feel that they can be "controlled" by the people they are dependent on.

P005 laments "*I don't like to be ordered around about what to do. Like bathing……My older brother is too overprotective. I don't want him to control what I do. He doesn't want me to go anywhere.*"

Sub – theme 3: Self pity

Self-pity was revealed in participants as they showed displeasure in having to be dependent on others. Their dependence on others make them feel like a burden on their friends and family, which may not be the case.

'I always feel bad asking them for money. I always feel bad…because you have come to a certain stage whereby you don't have to keep asking mummy and daddy. For me, I'm 29. I just turned 29, 8th March and it's really weird for me. It's just weird' (P001).

In relation to how CP affects work, P001 said. When you don't have anything (job) to do it's stressful because it's like you have to find something to do to earn something, but you don't get it because just you're cerebral palsy." (P001)

"It is difficult for me to make a friend….when I want to make friends, unless my friends tell the person" (P004)

Sub – theme 4: Constraint from people because of the condition

All participants communicated some form of resistance and constraint from others in society because of their condition. Participants perceived that teachers and classmates' limited awareness and understanding of their diagnosis limited their access to strategies that would enable their school performance. Many participants felt frustrated, in that the support available was not appropriate for their needs and felt disadvantaged by school systems that made life more difficult for people with cerebral palsy.

'School has been really tough because actually the kids are afraid to get close to you because they feel you look like a snake or worm or anything. And the teachers too don't have time for you. They feel you're being a burden to waste time, it is sometimes annoying' (P001).

'You see, here in Ghana when people see me they run away from me, thinking I am a bad person, that I am coming to harm them or something.' (P004)

All participants shared feelings of displeasure. When asked what his challenges were P004 responded that;

> *'In fact, last week I was walking then I met some people. In fact, they see me as a beggar. So, when I go there, they say "You should leave here. We don't have money". Which I was like "Ah I'm not coming to beg but I'm here to ask you some questions". I feel bad. It's not the first time. They are always talking but I just ignore them and move on.'*

Most were therefore forced to adhere to the voice of society and hence did not live to their full potential.

> *'My mother made the plans for me .When I was in IPMC, one of my friends told me that Citi FM is looking for graphic designers, so we can send our CVs. I came to talk to my mother. She said no. (P004).'*
> *'I discussed it (job hunting) with my mother but my mother said I should wait…But when I am going to look for a job, the management when they see me, they will reject me.' (P004).*

P004 in describing how CP affected schooling-

> *"…(when walking to school) they (neighbours) will be like I am tired so I should sit in a car and me I don't like that I will sit in a car going from here to here."*
> *And*
> *"I didn't go to SHS (secondary school). My teacher gave my mother advice that SHS, when you are going to boarding (school) they (other students) will maltreat (me) "*

P006 remembers his primary school days

> *"They (teachers) said my handwriting was fine …so I tried to stay in the school. And my friends said that because of my mind, the cerebral palsy, I can't read "*

In spite of the societal restrictions, some participants were able to break forth. P002 proudly states her steadfastness when asked about her challenges:

> *'They don't mingle with us. Outside if you go to some people, they will drive you away. But for me if you drive me away thousand times I'll come because I like you as a friend'*

Theme 2: Developing coping strategy to deal with living with CP

Another very important theme that emerged was the development of coping strategy to deal with living with cerebral palsy. Under this theme, two sub- themes emerged: Internal coping mechanisms/behaviour and external coping mechanisms.

Sub – theme 1: Internal coping mechanisms

Participants identified a range of strategies and activities that helped them to manage their emotions. All participants had their own inherent ways of dealing with living with CP. This included withdrawal:

> *'One time my father took me to his place but he said I was being stubborn there that's why I don't want to go there again' (P003).*
> *'If I approach you and you don't have patience, next time I see you, I will just pass by. I won't even greet you. I will just pass' (P004).*

Indifference was also highlighted as a coping mechanism. In response to what his challenges were, P004, highlighted indifference as his coping strategy

> *'One day I was in a car. We were going to Nungua. Me alone. And when I sat inside the car, when the person (passenger) saw me he was like 'I don't sit beside disabled people'. In fact, the thing really pained me. It pained me serious…I just keep quiet and go my way. I think that it is not necessary to talk (P004).*

One participant in response to how CP affected school:

> *'In secondary school, I didn't allow them (fellow students) to intimidate me I just didn't allow them. Like if I see there's trouble, you'll see me there…and cause trouble so you'll know that this guy is someone you should know' (P001).*

P005 says

> *"I don't like it when people stare at me. It bothers me. I get upset and insult them "*

This comes across as misconduct to deal with the stress of living with CP. They adopt withdrawal and indifference as coping strategies to prevent themselves from the hurt of stereotyping and discrimination from the society. This shields them from having to deal with these negative attitudes head-on. Aggression or misconduct in some adults with CP's opinion also builds an impenetrable wall around them, because they are seen by potential discriminators as intimidating. Unfortunately, they believe that when the tables are turned, they cannot be looked down on.

Sub – theme 2: External coping mechanisms

Aside the intrinsic coping mechanisms, participants also mentioned external factors that help them cope. All participants mentioned religion and their belief in God and His providence as ways of reducing the stress of living with CP. P002 in talking about how a typical day is, said:

> *'It's not easy for me to sweep here but I take it like it's God's work… Because if I'm sweeping then I'll be tired …I'll do it. I'll sacrifice and do it.'*
> *'Sometimes when I sit down quietly then negative thoughts come that I should go and kill myself or drink a medicine and die…and so sometimes I pray that God will remove the negative thoughts' (P004) when narrating his challenges.*

Family support was also highlighted as a major source of encouragement for these adults:

> *'So, when I am not happy my father will see it so he will always come around giving me encouragement.' 'I see my friends and family members. It makes me happy'. (P004)*
> *I make myself happy with, let me say if I have a friend around me to make me happy (P002)*

Apart from participants finding their own inherent ways of dealing with living with CP, they depend largely on external influences. The most motivating factor for these individuals is their belief in a supreme being.

Root cause analysis of living with cerebral palsy

Living with cerebral palsy (CP) undoubtedly has its challenges. Adults in this study living with CP agree that acknowledging their condition went a long way in helping them deal with living with the condition.

There was realization of 'self' which meant that the participants understood the diagnosis, their abilities and disabilities, as shown in Figure 1. Participants accept that they are different rather than living in denial. The story is the same for their family and friends. Participants of this study expressed pleasure in their ability to perform some activities of daily living (ADL). Limitations in performing other complex tasks was frustrating to say the least but some participants were able to improvise to perform them while others had caregivers who cater for those needs. Such situations made them pity themselves because of the inability to perform seemingly easy tasks. Some also felt that they were burdens to their family although it was never insinuated.

Figure 1 shows that, participants of this study also attested to the fact that family was very important to them since they got support, encouragement care, love and pleasure in times of gloom as well as a sense of belongingness from such family members. When faced with the unpleasant treatment from society, participants knew they could count on their families on any day for solace.

It was rather unfortunate that they did not feel the same support from the society. Rather, there was stigmatization, discrimination and in some cases, unintentional constraints from participation in activities. Although this was from a place of genuine concern, it did more harm than good by preventing these participants from living up to their full potential. Adults living with CP appreciate efforts to support them however, they would rather have the over protection of these ‘good Samaritans’ reduced so that they can live as independently as they possibly could.

The study also showed that each participant had either an intrinsic or extrinsic way of coping with the pressure of living with CP as depicted in Figure 1. To deal with the problems of living with CP, some participants withdrew from activities they had some difficulty doing and people with negative attitudes toward them altogether. Some approached instances of discrimination with indifference, to help them keep their sanity and avoid getting hurt by negative societal sentiments, which included keeping calm, ignoring unsavoury comments and not responding to them. The belief in God, his omniscience and providence helped participants to deal with living with CP (Figure 1). Most of them agreed that partaking in religious activities especially prayer, enabled them deal with the everyday problems associated with CP. Although some admitted that they initially questioned the reason why they had CP, they were comforted in knowing that God was in control.

Hence, adults living with CP by their experience seem to have understood the meaning of living with a lifelong condition and have thus developed different strategies to deal with them.

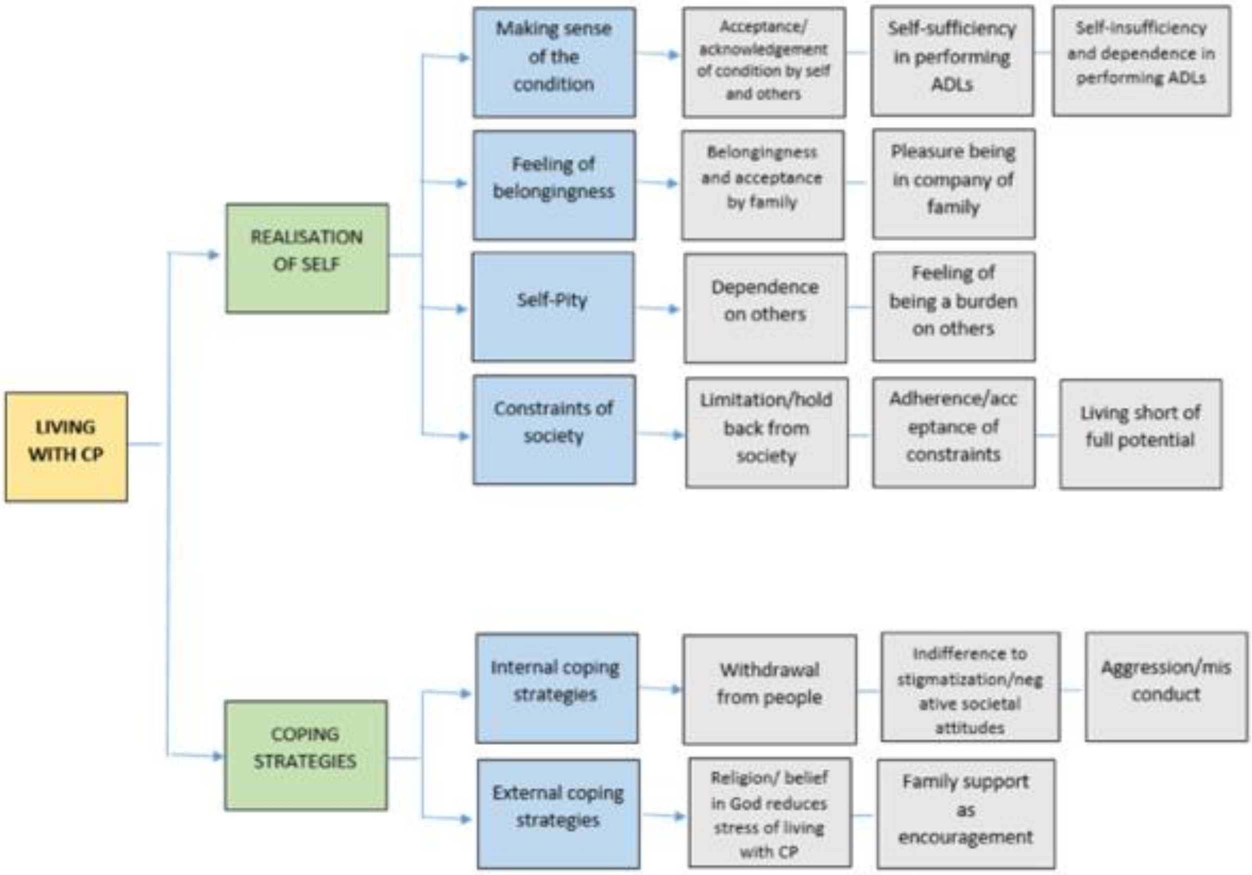


Figure 1: Living with cerebral palsy root cause analysis diagram

DISCUSSION

Six (6) adults living with CP were recruited for this study within the Accra Metropolis. The Accra Metropolis is an urban community, with majority of the population living in low – income areas. Most participants were males owing to the increased incidence of CP in males [3]. Majority of the participants had 12 or more years of schooling, which corroborates the study of Mesterman and colleagues [11] who reported that majority of people with CP complete at least 12 years of schooling. The lower levels of the GMFCS correspond with milder forms of CP, while the higher levels indicate increasing severity and hence translates to higher risk of multi morbidity [31]. Most participants had mild CP whereas only one had severe CP and was wheelchair bound. None of the participants were receiving therapy at the time the study was conducted. Four participants were unemployed, one was a student and the other a basket weaver. Of the unemployed, one participant was functionally unable to work, being highly dependent in performing ADLs. Another participant was catered for by a special home and thus was not required to earn a living. The other two participants were unemployed due to experiences of discrimination on the part of employers. This is a global problem and buttresses the outcomes of some studies that indicate discrimination against people with disabilities in employment [9]. The discrimination is worse in females [32]. All the participants lived with their family except one, who lived in a community social welfare home for people with disabilities and orphans. None of the participants required home modification or special equipment except one participant who was wheelchair bound. No participant had special assistance or grants.

Considering that CP is a lifelong condition, most participants attempted to understand their current state in terms of difficulty in performing activities and self-sufficiency and insufficiency. They also put emphasis on acceptance of the condition of both themselves and others. Living with a lifelong condition comes with the feeling of being different from others, which can be experienced in relation to activity limitations, the attitudes or treatment from other people and lack of autonomy. This is as a result of the deterioration of motor function in individuals in their adulthood. This deterioration is associated with musculoskeletal problems including pain and limited range of motion and fatigue [14].

In spite of these deteriorations, many individuals are still able to manage and maintain the performance of activities of daily living, sometimes through improvisation to solve the problem, because they are aware of their bodies, capabilities and incapability [19]. Knowledge about their condition may be attributed to living in an urban community where there is generally more awareness and advocacy for people with disabilities in comparison to rural areas.

Participants' experience of having to dedicate more time and effort to master simple skills however, made them question their ability to master complex skills that they regarded as important for their future independence. Their concerns are supported by submissions of a study [33] which reported that adults with poor coordination described learning complex motor skills, such as those required as part of a new job, as stressful and time-consuming. In addition, many of the participants emphasized the importance of being accepted and treated equally by others which appears similar to findings by Törnbom, Törnbom & Sunnerhagen [10]. For these reasons, there is discrimination and lack of confidence in their abilities, especially in the education and work environment as indicated by another study [18]. Public attitudes towards disability in Africa is often based on fear, misunderstandings and stereotyping individuals with disabilities and thus allows prejudice, discrimination and the denial of rights and resources that are due them [5].

This study showed that there is a general sense of belongingness for people living with CP [15]. This is as a result of family support and being in familiar environments. The family forms the primary socialization of an individual and people born into families are shown love by the provision of needs and caregiving which includes support. It is therefore a natural phenomenon that these individuals take solace in family support and have a sense of belongingness among people they are comfortable around. Findings from a similar study [34] showed that the participation of children in social roles was directly linked to the social support at home which is believed could be translated into adulthood. The findings of this study also affirm the social model of disability, which according to Colver *et al* [34] is the physical, social and attitudinal environment of people with disabilities that influences their participation in daily activities and social roles.

Very few of the participants expressed extreme displeasure concerning their condition and consequently, their experience of unpleasant physical, emotional and psychological problems. This could be attributed to the feeling of difference and inability to perform activities, or to do so with limitations. Self-pity led to extreme depression and suicidal tendencies in very few of the participants. This contrast findings by Jiang et al. [20] who indicated that individuals living with CP can still have good psychosocial health in spite of their disability. Majority of the participants showed sadness for themselves because of their dependence (functional and financial) on others.

Conventionally, individuals within the ages of 15 and 60 are recognized as the working class and are expected by society to be financially independent. However, due to the disability accompanying CP, there is dependence on others, of individuals, who ideally, should have been independent. This feeling of self- disappointment in the long run resorts to self-pity as reported by Bagatell *et al.* [12] that the transition from childhood to adulthood and the change in roles and responsibilities of people living with CP, specifically independent living, have been identified as challenges for young adults with CP. Engagement in physical activity is a basic human right and has numerous benefits including mental well-being. Persons with disabilities are often denied this right due to a number of barriers existing on physiological, psychological and structural levels. Aside the personal factors limiting activity and restricting participation of people with disabilities, adults living with CP have lower participation levels as compared to their counterparts without disabilities. The feeling of rejection from the society causes poor mental well-being, particularly poor self-esteem and shying away of adults living with CP from social interaction or social isolation.

Individuals may assume various behaviours in order to cope with the stress and problems of living with CP. A study [16] reported that negative attitudes serve as strategy for dealing with lack of autonomy and living with a lifelong disability in general. These negative attitudes may include aggression and misconduct. Withdrawal is also listed as a behavioural coping strategy. The individual assumes this state to prevent hurt from the rejection or stigmatization of the society [35]. Like young adults interviewed by Missiuna *et al.* [33], some participants in this study were able to cope by avoiding or withdrawing from complex motor activities and emotional demands that they felt were beyond their capabilities.

Aside behavioural strategies, people with disabilities also tend to depend on other factors to cope with their condition. According to Wachholtz & Pearce [13], many patients with chronic pain use religious or spiritual forms of coping, such as prayer and spiritual support, to cope with their pain as revealed in this study. This may either be as a result of thoughts that their problems are beyond human intervention or their inherent culture of seeking God imbibed in them from their infancy. Furthermore, most participants in this study received emotional support, especially from family which helped them cope with the condition. This finding corroborates findings by Moos [15].

LIMITATION

The qualitative nature of this study appears to be limitation as the findings cannot be widely generalized. There was also some difficulty in hearing the participants while transcribing because of the slurred speech, which made the transcription process tedious and time consuming.

CONCLUSION

Generally, adults living with CP face different problems compared to children living with the same condition. Adults with CP are aware and have more understanding of their condition. They have a good perception of societal attitudes towards them and are also able to develop their peculiar means of dealing or coping with the condition. Some adults with CP tend to isolate themselves from society due to stigmatization. Some also feel disadvantaged in school due the lack of the availability of appropriate support systems. The deterioration in abilities of adults with CP was not only a loss in activities but also influenced autonomy, with reduced ability to control one's own daily life

There is a need for similar studies to be conducted nation-wide and in other middle and low-income countries to allow for more powerful conclusions to be drawn about the lived experiences of adults living with CP in such countries. Future studies may employ a larger sample size whose results can be more generalized.

DECLARATION

Contributors CT, GN and JQ contributed to the study design, data analysis and wrote the manuscript. JQ and SK conducted literature searches. CT, conducted all the interviews. CT, GN, SK and JQ contributed towards data transcription and reviewed the manuscript for important intellectual content. CT, GN, SK and JQ revised the draft and approved the final version of the manuscript for submission.

Acknowledgement The researchers would like to acknowledge all clients who participated in this study. The researchers would also like to thank physiotherapists who helped to identify and recruit participants for all their support.

Competing interests There were no competing interests from all authors in this study.

Ethics approval Ethics approval (SBAHS-PT/10566535/SA/2018-2019) for the study was sought and obtained from the Ethics and Protocol Review Committee, School of Biomedical and Allied Health Sciences, University of Ghana. The rationale of the study was explained to the participants recruited including information about their right to refuse to answer questions they were uncomfortable with, provided with consent forms and consent obtained before they were interviewed.

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