Caring for People with Intellectual Disability: Experiences

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Abstract: This paper reports findings on the challenges and sources of resilience of carers of Persons with Intellectually Disabilities (PwIDs) in Ghana. Semi-structured interviews were used to gather data from ten (10) institutional carers (House Mothers), and five (5) teachers at three different institutions for PwIDs in the Kumasi metropolis of Ghana. The challenges carers face is because of socio-cultural perceptions regarding PwIDs as well as work related constraints. Even though this research confirmed the fear, apprehension and negative comments by family, friends and the public to care work, it also revealed that this could be due to ignorance, lack of understanding and unfamiliarity of the public with PwIDs. Despite the challenges involved with care work such as aggressive behaviour from PwIDs for instance, carers indicated that PwIDs were 'interesting' and 'funny', making the work enjoyable. The study revealed that religion and the expectation of a future blessing from God were a major source of resilience for carers. Since increased social integration has been suggested to reduce stigma against PwIDs, this study recommends that Ghanaian social workers actively engage in discussions regarding the integration of PwIDs in day-to-day social processes. Furthermore, while it is important to build the resilience of carers, it is equally relevant for Ghanaian social workers to address the source of challenge (in this case stigma and discrimination) that necessitates this resilience in the first place.

Keywords: Persons with Intellectual Disability, Care Work and Resilience, Social Integration, Cultural Beliefs and Disabilities

1. Introduction

According to the study [28], 1 out of 7 persons in the world are persons living with a disability, 80% of whom live in abject poverty within developing countries. Persons living with disability suffer discrimination in various forms including discrimination in terms of access to health, employment and general social engagement [1]. Among persons living with disabilities, Persons living with Intellectual Disabilities (PwIDs) may be the most marginalized [24]. This is because parents and families are sometimes reluctant to seek adequate healthcare for PwIDs or do not pay sufficient attention to the health needs of PwIDs. Some health professionals on the other hand, are ill equipped and less prepared to work and communicate with PwIDs who come to their facilities [24]. Promoting the independence and social inclusion of PwIDs has thus,

become one of the most important aspects of social work with this special population [11]. In fact, much emphasis has been placed on PwIDs' medical needs and daily upkeep [5], to the extent that other areas such as education, employment, transport and social relationships has been given less attention [26].

One way of improving the livelihood of PwIDs, according to some researchers and professionals [9, 34], is to provide institutional care and special schools for PwIDs. These care institutions and special schools were prominent in developed countries in the West [34]. One of the main ideas behind the establishment of special schools and care institutions for PwIDs was to provide a safe, non-discriminatory environment for PwIDs and subsequently enhance their independence and social inclusion. However, the study [34] points out that despite the noble intentions, these institutions were built because of societal stigma against PwIDs and that their true aim was to protect society from some special populations, including PwIDs. This

emerging perspective on institutional care drives an on-going campaign for deinstitutionalisation of PwIDs and the integration of PwIDs into everyday schools (inclusive education) [26]. Professionals and researchers are increasingly advocating for societies to implement a social model (where PwIDs can live full inclusive lives within communities) rather than institutional care and special education in special schools. Social workers and other stakeholders argue that such a social model would help eliminate the social stigma and the perception of the 'other' that was created through institutional care and special schools [26]. Despite increasing calls for inclusive education and care across Africa, institutional care and special schools remain one of the main approaches for caring for PwIDs on the continent. In Africa, some of the challenges that PwIDs face emerge from the socio-cultural norms of the people. Some African beliefs portray PwIDs as undesired people, persons born out of the effect of witchcraft, curses, or the actions of the gods and ancestors. This brings about a lot of stigma against PwIDs [6, 21, 24, 28] leading to their exclusion from social processes [24, 28].

In Ghana specifically, approximately 10% of the population are persons living with some disability. According to a report by the Ghana Statistical Service (GSS) on disability in Ghana, PwIDs constitute about 15% of all persons with disabilities [15]. Despite the availability of local and international conventions aimed at protecting the rights of persons with disability, widespread instances of discrimination persist [29]. Research reports indicate for instance that most Ghanaians discriminate against and stigmatize PwIDs in their attempt to access healthcare, education and employment [19]. Religious beliefs continue to be a source of discriminatory attitudes and practices against PwIDs in Ghanaian societies [17, 27, 28]; this, despite modernization and the increasing levels of formal education among the populace [33]. Thus, although PwIDs in Ghana are "no longer killed physically, they seem to be killed emotionally through dehumanizing names which makes them victims of mockery" [17]. The challenges faced by PwIDs in Ghana, as discussed above, make the support of international and research institutions as well as carers, both formal and informal, crucial to the well-being of PwIDs. In caring for PwIDs however, carers face challenges that can have negative implications for the quality of services they provide [26]. This research investigated how carers in special schools for PwIDs in Ghana, within the context of exclusion, experience care work and their source of motivation to work with PwIDs. Specifically, this research set out to: a) explore the reaction and perception of carers' family, friends and the public to their work with PwIDs; b) examine the challenges carers face on the job and the strategies they adopt to overcome these challenges; and c) investigate carers' source of resilience to work-related challenges.

2. Theoretical Framework

Care work in general can take a toll on caregivers' health, quality of life and interrupt family patterns [35, 36]. It is therefore necessary to understand how caregivers manage the difficulties associated with their work. The theory of resilience provides a good theoretical framework for exploring such a phenomenon. Some researchers define resilience in terms of positive adaptation when significant hardship is encountered [36]. Other researchers also define resilience as comprising of skills employed when faced with a difficult situation including a range of positive thoughts, feelings and behaviours [32]. While the definition by the study [36] focuses on behaviours, the study [32] add another perspective, which has more to do with thoughts and feelings. Thus, resilience does not only include behaviours but also has to do with positive reflection and thought. Characteristics of resilience are self-esteem, strong coping skills, hardiness, coherence, self-efficacy, optimism, strong social resources, adaptability, risk-taking, determination, perseverance and high tolerance of uncertainty [22, 37].

According to the study [14], resilience is determined by both risk and protective factors. The risk factors comprise those factors that threaten the caregiver's wellbeing including stigma, isolation and occupational restrictions [36]. The protective factors on the other hand facilitate and strengthen the response of the caregiver to stress [36]. According to [10] these protective factors can be termed as promotive factors, and according to them, these factors can be grouped into two (assets and resources). Assets are the attitudes inherent in an individual such as self-esteem and perceptions of self-efficacy. Resources are the various support systems available to help the individual caregiver, such as family and social support. The protective factors bring about positive outcomes and healthy personality characteristics despite unfavorable life circumstances. Emotional management skills, intrapersonal reflective skills, academic and job skills, ability to restore self-esteem, planning skills, life skills and problem solving skills are protective factors identified by other authors [22, 37]. In addition to the above, the study [30] also introduced the challenge model of resilience. This model posits that a risk factor can enhance a person's adaptation (if the risk is not extreme), by preparing the individual to face future challenges [22, 37].

Caregiver resilience results from the deployment of protective factors to manage challenges and emerge not just stronger, but flourishing [3]. This notwithstanding, one of the main challenges of using resilience is the diversity of definitions that exist concerning key concepts [12, 13]. As emphasised by the study [25] this challenge makes it difficult to assess the extent, effectiveness and relevance of resilience based intervention approaches. Furthermore, differences in the definition of concepts make it difficult to compare the findings of different resilience based studies. Questions remain as to whether resilience is a trait, a process or an outcome [12]. Furthermore, the study [12] allude to persisting inconsistencies and questions regarding the meaning and scientific relevance of adversity and positive adaptation, both of which are key concepts in resilience. One significant limitation concerning current knowledge of resilience is the lack of a culturally and contextually sensitive

definition of resilience, separate from dominant Western conceptualisations [12]. This research attempts to address this limitation by focusing on the sources and forms of resilience among carers within a sub-Saharan African context. In addition, there is little research on how to assess the extent, effectiveness and relevance of resilience based intervention approaches for specific client groups [25]. Even though some practice frameworks have been developed, it is important for African practitioners to explore their setting and identify which factors of resilience exist and how these should inform culturally relevant practice approaches [25]. This study will contribute by creating and building this culturally relevant knowledge base, in order to inform teaching and practice of social work in local Ghanaian contexts.

3. Methods

3.1. Area of Study

The study was conducted in Kumasi, Ghana's second largest city and capital of the Ashanti region. Ashanti region has the highest percentage of persons living with disability in Ghana (16.9%). The capital Accra has a percentage of 14.1% while the Eastern and Volta regions have 12.8% and 12.4% respectively [15]. The 2010 population census indicated that approximately 42,060 of the population in Kumasi are living with some form of disability, of which an estimated 14.4% are persons living with intellectual, speech and hearing disabilities. The Social Welfare Department is responsible for the provision of social welfare services. However, the department is constrained in its work by financial, infrastructural and logistic challenges [4]. In addition to the Department of Social Welfare, other stakeholders, including Non-Governmental Organisations, Civil Society Organizations, Faith Based Organizations and other private institutions and agencies [4] play important roles in the provision of social welfare services to the people of Kumasi. According to [20], there are two main special schools for PwIDs in Kumasi. These are Garden City Special School (GCSS) and Community Special Vocational School (CSVS). In addition to these institutions, the Kumasi Children's Home, the Cheshire Home and other private institutions provide some care for PwIDs.

3.2. Data Collection

Data reported in this study was collected from 15 participants (housemothers and teachers) in the two main special schools in Kumasi (GCSS and CSVS) as well as the Kumasi Children's Home. The housemothers and teachers were of particular interest for this study because they stay in close contact with PwIDs and interact frequently with them during the time they spend in school. Given the focus of this research (the experiences of carers), this frequency of interaction and familiarity with PwIDs was an important determinant in choosing participants for this study. The GCSS has 169 students in boarding facilities. There are 21 teachers and 4 housemothers who take care of the students after school. The CSVS has 74 students. There are seven teachers and four housemothers. The Kumasi Children's Home, the main facility for orphaned, neglected and abandoned children in Kumasi, also houses approximately 25 PwIDs, with two housemothers. Purposive sampling techniques were used to collect data from all housemothers (8) in both schools, as well as the two house mothers at the children's home. In addition to the housemothers, 5 teachers, 2 from CSVS and 3 from GCSS were selected. The teachers were selected based mainly on convenience sampling (availability and willingness to participate) considering the nature of their work. Thus, the findings presented in this study are mainly from the housemothers (10) and teachers (5).

The study collected data through semi-structured qualitative interviews. Participants were asked whether they actively sought to work with special populations; the initial and continuing reaction of family and friends to their work and how they are able to maintain themselves and overcome the persisting societal stigma while performing their duties as carers. The interviews with the housemothers were conducted in the local language (Twi) and later translated into English during transcription. As indicated by [31], authors faced the challenge of finding the accurate word in English to represent specific words and phrases in the local language during transcription. However, authors' (all of whom are native speakers) contextual understanding of the local language and words used allowed this problem to be overcome. Furthermore, in the course of the interview, reflective paraphrases and summaries were used by authors as a way of clarifying from participants if the interpretation of authors were in line with participant's intended message. Where difficulties persisted in this regard, the local word was directly reported and then immediately translated into the English language as suggested by [31]. The interview with the teachers was conducted in the English language. Each interview lasted for approximately 40 minutes and took place at the place of work of participants.

3.3. Data Analysis

The audios were transcribed ad-verbatim. After the transcription, the main research objectives were used as a basis to re-organize the transcripts. Thus, under each objective, all transcribed responses relevant to that objective were copied and pasted, maintaining the participant's identity in the process. Responses under each objective were further read to make the researcher familiar with these organized responses, in preparation for the process of coding and theming. Subsequently, a more in-depth reading was conducted in which words and phrases (codes) were used to represent major ideas and experiences from participants. Similar codes were put together to form a theme for presentation and discussion. Thus, initial organization of the transcripts was determined mainly by the key objectives that informed the study. The subsequent codes and themes emerged directly from the data and were also informed by the key assumptions underlying the theory used.

3.4. Ethical Consideration

A letter of introduction was taken from the Department of Sociology and Social Work at the Kwame Nkrumah University of Science and Technology to the various institutions for data collection. Approval was sought from the Regional office of the Department of Social Welfare since the various institutions are under the jurisdiction of the Department. Individual carers and teachers were informed of the nature of the research, the questions to be asked; the time it would take and what was expected of them. All participants gave their consent, verbally to participate. At the beginning of each interview, researchers made participants aware of their right to withdraw from the interview or refuse to answer a particular question, without fear or favour or without harm to their person, reputation and esteem. The real names of participants have been replaced with pseudonyms (HM for housemothers and T for teachers) in the presentation of findings.

4. Results

4.1. Brief Background of Participants

The carers were between the ages of 30-60 years. They had worked for a minimum of 1 year and a maximum 15 years at their current places of employment. Only two participants indicated that they actively sought special education as an occupation. The other participants revealed that they ended up working with PwIDs after they had been introduced to the job by their social network (either family/ family friend).

4.2. Presentation of Findings

The findings are presented narratively under the three broad objectives that informed this study. a) To explore the reaction and perception of family, friends and the public to care work with PwIDs; b) to examine the challenges carers face on the job and the strategies they adopt to overcome these challenges; and c) to investigate carers' source of resilience to work-related challenges. Sub themes are developed under each of these objectives to enhance the presentation of the findings.

4.2.1. Reaction of Carer's Family, Friends and Neighbours

Participants revealed mixed reactions from family and members of the public regarding the work they do. It is important to emphasise that all participants, with the exception of one, received support from their spouses for their chosen field of work. Predominantly, two main themes emerged from the analysis regarding the reaction of family, friends and neighbours to care work. These themes 1) lack of understanding and ignorance of PwIDs and 2) fear and apprehension for carers; are discussed in the following sections.

i. Lack of understanding and ignorance of PwIDs

For some participants, friends and members of the public often ask questions about their work, questions that demonstrate persisting public ignorance of PwIDs. T1 reveals that as soon as people get to know the work she does: "their facial expressions alone changes, then they ask …you work with those people... how are they… are they… do they… they will be asking you a lot of questions that indicate that they want to understand" (T1, Teacher). T1 explains that resistance to her work from family and friends began during her school days when she offered special education: "Yes my family, especially my mum and my sisters…errhmm… it's like they asked; why will you go and work with those gyimi gyimi (morons)" (T1, Teacher). T2 reveals that her friends and neighbours often asked "don't they hurt you...don't they use something to hit you?" (T2, Teacher). This lack of understanding appears in the following narrative:

> People always ask us if we are able to stay with these PwIDs and I reply that Yes', they are just like you and me,—all that you need to do is to draw them closer to yourself then you would study their likes and dislikes. People really do not understand the nature of these PwIDs, after conversing with them (friends and the public); they come to understand certain things about our job. (HM4, Housemother)

Even though the above depicts inherent negative perception of PwIDs, they also show a persisting lack of public understanding and ignorance of PwIDs. This finding is important for social work efforts in Ghana. In order to eliminate discrimination and exclusion for all, it is crucial that social workers and other actors within the social welfare sphere work to improve public understanding of PwIDs. Thus, the perception of "otherness" which appears to be inherent in the assumptions of the public need to be eliminated through concerted educational and public awareness programmes.

ii. Fear and apprehension for carers

The public's lack of understanding, discussed above, creates some form of apprehension and fear among other members of the public, especially concerning the wellbeing of carers. For HM1 for instance, the reaction of family and friends were mostly that of fear and apprehension as well as shock: "Most of them were frightened. They kept asking me if I could handle these children that society term as insane. Some warned they could hurt you, don't you know that? And those children have their mouths drooling with saliva" (HM1, housemother). HM1 goes further to explain how the reaction of members of the public is often that of shock and surprise at her work: "people are mostly shocked when they hear that. Even yesterday, when I went to the salon, they asked me what I do. When I told them I take care of PwIDs, they were like: huh, those sick children?" (HM1, Housemother). For HM3 however, when her mother did not know the details of her work, she supported her. However, things changed when she explained the true nature of her work:

> At the beginning my mother felt hurt, because after I explained the children I was working with, that these were not deaf and dumb, but some of these could even get convulsion, she even got scared, because she had never seen such before. (HM3, Housemother)

For some participants, even though they experienced no

negative reaction from family, mainly because other family members had worked with PwIDs before, friends resisted and expressed negative emotions and feelings. Most of the negative reactions revolved around fear of possible violence from PwIDs towards carers as well as perceived unhygienic and unsanitary nature of PwIDs. HM4 elaborates:

> My family was okay when I took it upon myself to work with PwIDs but my friends were against the idea. They made me aware of how young I was and the possibility that, because of my work with PwIDs, I will give birth to a PwID…they kept telling me that some of the PwIDs are witches; they fly and do all sorts of weird stuff. (HM4, Housemother)

In further exploring this challenge, HM5 indicate how these negative comments could serve as a demotivating factor for carers: "The reaction of people I met at social gathering when I introduce myself and the kind of work I do is sometimes discouraging" (HM5, Housemother). Similarly, HM3, almost gave up her work because of her mother's negative reaction: "so after some time, I wished to leave this place" (HM3, Housemother). Evidently, the negative reaction of family to HM3's work forced her to reconsider and look for other options.

Only one participant, HM6, indicated positive reaction from friends and members of the public to her work:

> During social gathering, I take the kids with me and I feel proud with even walking with these children. I receive cheers … applauds from people with the kind of good work I have taken upon myself. I hardly receive any negative comments from society. (HM6, Housemother)

The participant who indicated positive reaction from family members revealed prior family experience with PwIDs.

The findings above indicate how family and friends, who can otherwise be important sources of social support for carers, tend to have certain misconceptions about PwIDs. These misconceptions, even though embedded in socio-cultural beliefs; also emanate from a general lack of familiarity and association within community settings. In other words, persons living with intellectual disabilities are still not included in social processes, extremely marginalised and are not 'seen' operating within communities and occupational settings, hence this persisting assumption of 'otherness'.

4.2.2. Challenges Carers Face on the Job

In examining the challenges carers face on the job three main themes are presented. The first and second themes presented (aggression from PwIDs and limited ability of PwIDs for self-maintenance) are challenges directly related to some actions and inactions of PwIDs. The third theme presented (lack of resources) present challenges related to the existence of an institutional barrier or the lack of some essential resource needed for effective care work.

i. Aggression from PwIDs

One of the challenges that both teachers and mothers alluded to was the occasional aggressive and sometimes violent behaviour of PwIDs. T2 argues: "…the problem is our classroom is not enclosed so if they want to go out and you try to prevent them, if you don't take care, they will push you out of the way." HM1 also reveals how aggression could become potentially harmful: "mostly with the autistic children, they occasionally become very violent…they would go round throwing objects, use their mucus or even throw their saliva on you" (HM1, Housemother). To effectively undertake their mandates as teachers and housemothers, participants explain how they adopt a non-aggressive stance as a strategy for overcoming the aggression from PwIDs. HM6 explains: "we have a way of mostly holding them. We put them on our laps and gently hold the backs of their neck till we realise they have calmed down" (HM6, Housemother). HM1 and HM4 re-emphasise the use of a similar strategy:

> With a situation like that, you would have to show them love. Therefore, when you approach, we embrace them and they will stop. As a result, we always keep them by our side but if you leave them alone; that is when they start acting aggressive… these children just seek attention. (HM1, Housemother)

> We have nothing to do than to draw close to them. The only strategy we use is to embrace them. So when we get closer to them they start laughing. All we do is to sit beside them and then pamper them...they need attention, pampering and conversations. (HM4 Housemother)

In addition to the strategies for overcoming aggression, described above, other housemothers discuss how they rely on non-verbal cues to help communicate with PwIDs. HM2 for instance states "oh! For that they do not worry me...sometimes if I see anyone misbehaving, I have a way of looking at them which makes them stop misbehaving. Sometimes they even call out my name and apologise" (HM2, Housemother).

This finding from participants, especially on how they handle aggression gives credence to the fact that understanding PwIDs largely can enhance meaningful and respectful social relationship with other members of the public.

ii. Limited ability of PwIDs for self-maintenance

For most of the housemothers, the nature of their work itself was challenging as they revealed that they work under unhygienic conditions and keep several sleepless nights. "We don't close; we neither go for weekends nor holidays till it is vacation" (HM3, housemother). Here, HM3 reveals how the nature of the work demands the time and attention of mothers. As a housemother, HM3 is in charge of 22 boys, most of who, according to her, cannot take care of their basic needs: "when you see a grown-up who cannot take his bath unless you do it for him, it becomes difficult…they can't even wear their footwear, wearing them in the opposite direction" (HM3, Housemother). This inability of PwIDs to take care of their basic needs and the need for carers to do so for them has health implications for carers as illustrated below:

> Some of these children have toilet inconsistencies… At times, some children mess up their bed and the ground with faeces. We have no option than to clean it up. So after

cleaning everything, you would even end up losing appetite for the whole day. (HM1, Housemother)

Some of the housemothers in charge of girls indicated how they have to change menstrual pad of girls without the help of necessary resources:

The ladies even don't know how to use a pad during menstruation and I have to do it for them…I ensure that they are not soiled during their menstrual period, unless it is the first day of their cycle which I might not know. (HM2, Housemother)

The above findings are interesting, given the fact that teachers and housemothers also have a responsibility to assist their service users to become increasingly independent and socially capable. As emphasised in the literature on resilience and social work practice, if practitioners are to make a difference in their practice with service users, then they must be aware of the concepts of resilience and must be able to incorporate strategies that enhance resilience in the services they provide for their service users [25]. Child centred practice models that are based on resilience emphasises a sense of belongingness and self-esteem [25].

iii. Lack of Resources

In addition to their aggression, most of the teachers expressed the lack of teaching resources and the teacher-student ratio as another challenge careers face in their work. T1 laments the lack of facilities and resources to properly engage the students, including facilities like "seesaw swing, merry go round, basketball court and volley ball" (T1, Teacher). Without these facilities, T1 laments how difficult it is to get PwIDs to be attentive. This lack of resources can sometimes serve as a source of discouragement for the teachers: "when you come here and you start work, sometimes you feel discouraged though because you are a human being, I want to do this. But how… the way… is…hmm, it is very discouraging" (T2, Teacher).

This finding is not surprising since social welfare officers in Ghana generally practice within a context of limited resources.

4.2.3. Carers' Source of Resilience to Negative Comments and Job Related Challenges

The challenges outlined above notwithstanding, carers continue to work with PwIDs. This section presents responses on carers' source of resilience to work related challenges. The responses are presented under three main themes: 1) inherent passion for care work with PwIDs; 2) spirituality and religion; 3) defiance and reasoning with stigma.

i. Inherent passion for care work with PwIDs

T1 and T2 explain that an inherent passion for special education and working with special populations drove them to and sustains them in their work. T2 emphasises that in order to work with PwIDs, you must have "a divine calling and an inherent desire for the work in the sense that if you don't have that passion, that love for PwIDs, you can't work with them" (T2, Teacher). She goes further to argue that having the inner passion makes one resilient to negative comments and perceptions from the public, enabling the worker to sustain him/herself in the profession: "Because if you have the passion, no matter what people will say, no matter what people will say, you will still do the work" (T2, Teacher). T1 explains how her inner passion made her resilient: "…some of my colleagues, after meeting with PwIDs in school, they changed their specialty to hearing or visual disabilities. They shift to visual and hearing who were neater than this group…for me it's a passion" (T1, Teacher). Here, T1 demonstrates how her passion for PwIDs enabled her to stay further, unlike her colleagues.

ii. Spirituality and religion

For the other participants, the promise of God's blessing serves as a major source of motivation and resilience in their work. In responding to the initial challenges she faced on the job, HM3 explains:

In the course of time, God strengthened me for the job…It is the grace of God. You know the Bible says for whatever assignment God gives us, we are going to account for it. So you will have to do it wholeheartedly so that after you have received a good reward here on earth, you'll go to heaven to continue. (HM3, Housemother)

Clearly, the expectation of a future blessing from God, both on earth and in heaven serves as a source of resilience for some carers. HM4 explains how her experience with PwIDs and the blessings she gets keeps her going:

So looking at the kind of blessings and returns it brought to our family, I decided to take up this position…One thing about PwIDs is that when you draw them close to you, you get a lot of blessings. Even though we had a recent accident, no one died, and I believe all this was because of working with these children… considering the love for PwIDs, whatever you ask God you receive it, even if you sleep without praying, you would be protected, that is why I enjoy this work. We do not even get sick or tired of being with PwIDs. Therefore, it is through this work that God blesses our descendants and us. (HM4, Housemother)

Here, HM4 clearly demonstrates how her belief in God and potential blessings drive her on in her work. Interestingly, her belief in the spiritual benefits is not only limited to her as an individual, but also her descendants as well. On her part, HM2 indicates clearly that:

I couldn't do it without the strength of God, so anytime I prayed, I used to ask God to grant me the strength to do this work because it wasn't easy…So even when I faced times that were tough for me, I used to pray to God to strengthen me since I believe He called me for this job. (HM2, Housemother)

Here, HM2 appears to give credence to the earlier argument that carers believe that to be successful, you must have an inner passion (to be called) for the job. Our observations during the period of data collection revealed that caregivers, together with PwIDs under their care, say prayers before the beginning of each day. This religious ritual was observed on different occasions (including when the schools received donations from voluntary organizations),

and during different times of the day (including before lunch). Thus, the religious nature of the caregivers has become a model for which the students look up to.

iii. Defiance and reasoning with stigma

Concerning the negative comments from members of the public and family, participants revealed how they overcame such negativity. For instance, HM1 states: "But for me, I told them that I would do it, so far as I have taken it upon myself, I would live with them" (HM1, Housemother). Other participants attempt to explain to the public or try to make the public understand that there is nothing mythical about PwIDs. T1 demonstrates this strategy in the following narrative: "Me, I often say to them that the condition of the children is the fault of their mothers or something that happened during pregnancy and childbirth. So the children should not suffer for it" (T1, Teacher). Similarly, HM1 indicates how she tries to explain to the public: "so I patiently explain to them that they are not sick but rather they have low intellect" (HM1, Housemother). For HM4, family history and familiarity with PwIDs serve as a source of motivation: "with how I saw my mother and uncle work with these children, I never paid heed to my friends" (HM4, Housemother) When this was not sufficient, the alternative for HM4 was to ignore the comments.

5. Discussion

This study has revealed how carers of PwIDs in Ghana often receive negative comments from friends, family members and the public in response to their work. We argue that the negative perceptions of family and friends, combined with the challenging conditions under which they work serve as risk factors, conditions that can threaten the carer's ability to sustain him/herself on the job. This is because, family and friends are important sources of social support and their perception regarding life choices; personalities and jobs can have significant implications for the self-esteem and wellbeing of individuals [18]. Furthermore, societal 'alienation' and 'demoralisation' can be a source of risk and affect the resilience of both carers and service users; since the availability or lack of social support has implications for resilience [13]. Thus, carers in Ghana often have to deal with negative comments, resistance and perception from family and friends, while working within a context of limited resources. This context of limited resources and the peculiar challenges with working with PwIDs create the risk factors, which affect the carer's ability to cope.

The above notwithstanding, carers in this study have revealed important protective factors, factors which enhance their ability to be resilient and deal with the risk factors. The protective factors they possess are assets, as defined by [10]. For carers in this study, the same religious beliefs that serve as sources of exclusion for PwIDs serve also as important inherent factors in promoting resilience. These religious beliefs allow carers to survive, even within a context of limited resources and negative perception. This is not surprising since religion is a core part of the Ghanaian society,

shaping individual identities and relationships and creating the medium through which Ghanaians understand their world [17]. According to the study [17] religion defines the Ghanaian and religion informs the thoughts and actions of the Ghanaian. The Ghanaian can therefore not be separated from his or her religion. Here, religion and religious beliefs can be seen as providing positive thoughts and reflections for carers, serving thus as an important source of resilience for carers. These religious beliefs and convictions make it possible for carers to possess some of the key characteristics of resilience, including optimism, determination and perseverance [22, 37]. Participants' reliance on religious and spiritual factors reflects hardiness, as explained by the study [23] as another important determinant of resilience. Here, participants used religion as a means of finding 'meaningful' purpose for their work. Through religious beliefs, carers in this study explained that their work was actually the work of God, an interpretation that enhanced their resilience at the work place.

The challenge model of resilience is evident in the responses of other carers. Here, some carers indicated how prior family experience and exposure to PwIDs helped to strengthen their resolve and make them resilient in the face of challenges. According to the study [30], the challenge model is evident when carers develop the resolve to stay with service users because of their prior exposure to similar service users and situations. This type of resilience is observed in the narrative of those carers who indicated that some of their family members had worked with PwIDs in the past; making them aware of the challenges involved in the work before their employment. This prior awareness and exposure served, to some extent as a form of motivation and resilience against job-related challenges.

Carer's illustration of how they deal with aggression (by making PwIDs feel accepted and loved) is another demonstration of their resilience. As the study [23] point out, acceptance, including tolerance for the client and their condition is another key determinant of resilience among carers. This approach also reflects the current knowledge in literature. Aggression is a common challenge for carers who work with PwIDs [7]. The aggressive behaviour of PwIDs result from, among other factors, the lack of attention they receive from people they love, and communication difficulties [2, 16]. Thus, by drawing PwIDs closer and showing signs of acceptance and care, carers in Ghana are not only showing resilience but also demonstrating aspects of good practice in working with PwIDs. They demonstrate professional competence and an inherent understanding of the condition of their service users, which paves the way for acceptance in day-to-day care work.

When faced with challenging situations, a person's support networks can help in maintaining a sense of self and adequate functioning. They serve as a source of hope, guidance and an avenue for managing distress through reassurances and affirmation [18]. Given the important role that social support networks play, it becomes critical, when a person faced with challenging situations cannot fall back on such forms of

support. The alternative is for carers to rely on either problem-focused coping (by addressing environmental challenges) or emotion focused coping (by modifying the meaning of the stressful event for one's self) [18]. It appears that in order to continue working within this context of exclusion and discrimination, carers in Ghana cannot rely much on social support networks as a way of coping; neither do they have the ability, individually, to eliminate the environmental barriers. This research has revealed how emotion-focused coping is a major strategy for carers in working and building resilience within such a context of exclusion.

6. Limitations of Study

This study's focus on institutional carers means that relational carers (parents, siblings and other relatives) were excluded. This clearly limits the applicability of the study's findings, since relational carers may present different challenges and sources of resilience.

7. Conclusions

Carers of PwIDs in Ghana face many challenges, both on and off the job. This is because of socio-cultural perceptions regarding PwIDs as well as work related constraints. Sources of resilience are therefore crucial to care work with PwIDs, given the external pressure and internal challenges faced by carers. Even though this research confirmed the fear, apprehension and negative comments by the public, it also revealed that this could be due to ignorance, lack of understanding and unfamiliarity of the public with PwIDs. The approach that care workers adopt in handling aggression further emphasises the view that the public's lack of understanding of, and familiarity with, PwIDs enforces the sense of 'otherness', 'insanity' and 'deviance' of PwIDs. The inherent frustration and helplessness that emerged in the narrative of housemothers regarding the limited abilities of their service users (regarding sanitation and personal care needs), perhaps point to a greater need/challenge for social work educators in Ghana. There is a need for students and future practitioners to be taught how to enhance the inherent capacity and independence of their service users (in this case PwIDs). This is important since the basic principle of empowerment requires social workers to enhance the capacities and strengths of their service users; and to enhance progressive social inclusion and meaningful relationships. Since resilience theory has been used as a basis for developing service user relevant intervention approaches [13]; understanding the sources of resilience of carers in Ghana can serve as a basis for promoting either practitioner or service user resilience, while informing new practice strategies. Practitioners within educational settings in Ghana must therefore incorporate resilience as part of their educational programmes. This will ensure that practitioners are equipped to promote the independence, and ultimately the social inclusion of service users.

This research also revealed persisting stigma and discrimination against PwIDs. While it is important to build the resilience of carers, it is equally relevant to address the source of challenge (in this case stigma and discrimination) that necessitates this resilience. It is important that Ghanaian social workers actively engage in discussions regarding the integration of PwIDs in day-to-day social processes. The challenges that carers of PwIDs face on or off the job is indicative that constraints associated with institutional care of PwIDs has not changed. Therefore, the call for promoting independence and social integration of PwIDs need to be supported by a reform of existing social policies concerning care of PwIDs. The whole concept of institutional care and education, and its contribution to the persisting prejudice and discrimination that PwIDs and their carers face should be critically re-examined by Ghanaian social work educators and practitioners. This is relevant since the more integrated PwIDs are in the Ghanaian society, the more people will come to understand them. This will eliminate, to some extent, the perception of 'otherness' and some of the negative perceptions held by the public about PwIDs.

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