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## Stories of restitution: Family experiences of diagnosis and help-seeking for a child with cerebral palsy

Emmanuel Asante<sup>a,\*</sup>, Joanne S. Lymn<sup>b</sup>, Claire Diver<sup>b</sup>

<sup>a</sup> Faculty of Health, Psychology and Social Care, University of Derby, School of Health Sciences, University of Nottingham, United Kingdom

<sup>b</sup> School of Health Sciences, University of Nottingham, Nottingham, United Kingdom

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### ABSTRACT

**Background:** The experience of living with children with CP is dominated by the voice of the mother while others are rarely reported. Incorporation of the voices of other family members is important for a holistic understanding. **Methods:** Drawing on the philosophical perspectives of pragmatism, generic qualitative methodology, and Frank's narratives, this article highlights how restitution was constructed by 30 family members.

**Findings:** They constructed restitution by hoping for a cure through either biomedical and/or alternative models of treatment, followed by intransitive and transcendent restitution.

**Discussion:** This appears to be the first time that restitution has been extended to families living with children with chronic illnesses.

**Application to practice:** This would mean that paediatric nursing professionals and other health professionals dealing with family members living with children with CP could attend to their stories in an open and focused manner to honour and validate their stories as well as their experiences.

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### Background

Cerebral palsy (CP) is a group of movement or motor function disorders that occur in the early stages of childhood development (Browne & Miller, 2005; Gulati & Sondhi, 2018). It is primarily caused by a brain development anomaly or damage to the parts of the brain involved in movement production; this can occur during pregnancy, childbirth, or shortly after childbirth (Gulati & Sondhi, 2018; Miller, 2005).

Population-based study reports from around the world have estimated that cerebral palsy prevalence ranges from 1 to nearly 4 per thousand lives births (Durkin et al., 2016). The cause of CP is complex and multifactorial. Multiple risk factors and aetiologies frequently interact, giving rise to the term "causal pathway" to describe this complicated process (Gulati & Sondhi, 2018; Vitrikas et al., 2020). Prematurity and low birth weight are two of the most important recognised risk factors for cerebral palsy, with the risk of CP increasing with decreasing gestational age and birth weight (Vitrikas et al., 2020).

**Abbreviations:** AIDS, Acquired Immune Deficiency Syndrome; CFS/ME, Chronic Fatigue Syndrome/Myalgic Encephalomyelitis; CP, Cerebral Palsy; KATH, Komfo Anokye Teaching Hospital.

\* Corresponding author.

E-mail addresses: [e.asante@derby.ac.uk](mailto:e.asante@derby.ac.uk) (E. Asante), [joanne.lymn@nottingham.ac.uk](mailto:joanne.lymn@nottingham.ac.uk) (J.S. Lymn), [claire.diver@nottingham.ac.uk](mailto:claire.diver@nottingham.ac.uk) (C. Diver).

Severe hyperbilirubinemia, neonatal seizures, birth asphyxia, irregular menstrual cycle, preterm birth, and neonatal sepsis are the most common risk factors for CP in Ghana (Adei-Atiemo et al., 2015).

The goal of managing children with CP is to improve functionality and capabilities, minimise progressive deformity, maintain health in terms of locomotion, cognitive development, social interaction, and independence, and manage associated problems (Monbaliu et al., 2017; Nahm et al., 2018; Smith & Kurian, 2012). Early and intensive management yields the best clinical outcomes, necessitating a multidisciplinary team approach involving paediatricians, physical therapists, orthopaedic surgeons, dieticians, and occupational therapists (Monbaliu et al., 2017; Nahm et al., 2018; Smith & Kurian, 2012).

Qualitative studies conducted on the experiences of families living with children with CP have found that this causes *emotional distress*, (de Aguiar Lélis & Cardoso, 2014; Dehghan et al., 2015; Fernández-Alcántara et al., 2015; Huang et al., 2010; Kruijzen-Terpstra et al., 2016; Milbrath et al., 2008), *changes in family priorities* (Baltor & Dupas, 2013; Dantas et al., 2012; Dehghan et al., 2015; Fernández-Alcántara et al., 2013; Milbrath et al., 2008), *Mistrust in Healthcare Professionals*, (Hayles et al., 2015; Huang et al., 2010; Iversen et al., 2013; Kruijzen-Terpstra et al., 2016; Whittingham et al., 2011), *Negative societal attitudes*, (Alaee et al., 2015; Baltor & Dupas, 2013; Dehghan et al., 2015; Huang et al., 2012) and an *increased need for family support*. However, these studies have mostly focused on the voices of mothers and that of other family members are rarely reported. The child with

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CP is considered a valuable member of the Ghanaian family and caring for such a child is deemed the responsibility of both the nuclear and the extended family. It is therefore important that the voices of other family members are reflected in research. This study considers the experiences of living with children with cerebral palsy from a multi-participant family perspective; it explores the diagnosis and help-seeking period for the child's condition, using insight from the restitution narrative of Frank's illness narratives (Frank, 1995a, 1995b).

### Theoretical framework

The restitution narrative of Frank's illness narratives (Frank, 1995a, 1995b) was used as the underpinning theoretical framework for this study. This narrative reflects a natural desire to get well and stay well (Frank, 2013). The restitution plotline is characterised by "Yesterday I was healthy, today I'm sick but tomorrow I'll be healthy again (Frank, 1995a, 1995b, p.77). Frank stressed that the desire of the ill person to get well is also compounded by others' expectations to hear restitution stories (Frank, 2013); the plotlines are dominated by medical assessments, investigations, and treatments with the aim of achieving a 'cure' He further proposed three ways in which restitution stories could be told: prospectively, retrospectively and institutionally. According to Frank (2013) institutionalised restitution narratives model how illness stories are to be told. They adopt the biomedical perspectives of getting ill and the possible outcome of getting well. Retrospective restitution stories describe the past, through the lens of biomedicine and recount actions taken to aid the occurrence of restitution. Prospective restitution stories look into the future, assimilating various illness outcomes and hopes for restitution to occur based on biomedical perspectives (Frank, 2013, p. 106). The use of the restitution narrative in this research is unique, as it provides novel insights into chronic illness and the help-seeking behaviour of family members living with children with cerebral palsy.

### Methodology and methods

This research study employed a generic qualitative research design underpinned by the philosophical perspectives of pragmatism. The pragmatist philosophy provides an epistemological justification for bringing together multiple sources of knowledge with the aim of gaining a greater understanding of people and the world in which we live, practice, and solve individual problems as well as social ones (Pavlis & Gkiosos, 2017). This supports the purpose of this study; understanding the reality of living with a child with CP from multiple family members' perspectives.

#### *The research context /study setting*

The study was conducted at the child health department of the Komfo Anokye teaching hospital (KATH), located in Kumasi, the capital city of the Ashanti region of Ghana. At the time of the study, the department was providing services to nearly 11,276 children as in-patients and 20,239 children as out-patients among which about 5000 children had a diagnosis of CP.

#### *Sampling strategy*

Purposeful sampling (Patton, 2002) was used to select participants for this study who were family members living with a child with CP. Posters advertising the study were displayed in patient waiting areas at the department. The study was introduced to mothers by the lead researcher at the monthly meeting of physiotherapists and family members. Contact information, of mothers who expressed an interest in the study, was taken by the researcher who was also present at the meeting. Those interested were then contacted by telephone to arrange

an appointment to meet and discuss the study in more detail. Mothers who consented to take part in the study were recruited into the study; they were also asked to act as gatekeepers and identify additional family members for the study. Arrangements were made through the mothers for an opportunity to meet other family members to talk to them about the study; those who expressed interest were formally recruited.

#### *Inclusion criteria/exclusion criteria*

For the purpose of this study, the term family means those individuals who are considered significant in the life of the child in either the nuclear or extended family of the child with CP. In terms of the inclusion criteria, family members who had children with cerebral palsy that came to the Child Health department were considered potential participants for this study. Family members of children with CP from ages 5–17 were considered for the study. It was expected that from age 5 years and above, the family member would have lived with the child long enough to be able to talk about experiences during diagnosis and the growing milestones of the child. Again, the cut-off age for Children with CP was 17 because in Ghana, it is considered that a person above age 17 is no longer a child (Constitution of Ghana, 1992).

Regarding the exclusion criteria, family members with children with CP below age 5 or above age 17 were excluded. Furthermore, those family members who did not come to the Komfo Anokye teaching hospital with their children were excluded.

#### *Data collection: semi-structured interviews*

Semistructured face-to-face interviews were used to explore the experiences of study participants. An interview guide was developed from existing literature on living with children with CP (Baltor & Dupas, 2013; Dantas et al., 2012; Dehghan et al., 2015; Fernández-Alcantara et al., 2013; Milbrath et al., 2008) and from the researcher's own clinical experience.

Interviews lasted between 60 min and 120 min. Interviews were conducted individually in the comfort of participant homes. Questions were formulated to capture the period when the child was diagnosed with cerebral palsy and the experiences around this period, followed by prompts which enabled the lead researcher to probe more into the experiences shared by participants. All interviews were conducted in Twi, audio-recorded, transcribed, and translated to English by the lead researcher. The translated interviews were then back-translated to Twi by local professional translation services to ensure that meaning had not been lost.

#### *Data analysis: narrative thematic analysis*

Thematic analysis was done inductively in NVivo, underpinned by Braun and Clarke's thematic analysis steps (Braun & Clarke, 2006). These steps included familiarising with data (listening to the audio data, transcription, reading and reading of transcripts), generating initial codes, searching for themes and reviewing themes, defining and naming themes. Themes were then deductively reorganised using the lens of the restitution narrative of Frank's illness typologies (Frank, 1995a). The lead investigator conducted the data analysis and the co-investigators compared the findings with the data, ensuring that they were data-driven.

#### *Demographics*

Thirty family members were recruited: 10 mothers, 6 fathers 6 siblings, and 8 extended family members whose ages ranged from 18 to 73 years. All participants lived with one child with severe CP in the family.

The majority (25) were Christians, 4 were Muslims and 1 participant practised the traditional religion.

### Ethics

This research was carried under the auspices of both the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee and that of the Komfo Anokye Teaching hospital in Ghana. Voluntary informed written consent was obtained from participants before interviews were conducted and participants were given the opportunity to decline or withdraw from the study at any time. To comply with the ethical principle of anonymity, all names of participants as shown in the findings section are fictitious.

### Study findings

Participants told both retrospective and prospective restitution stories. The retrospective restitution narrative was influenced by how they sought to resolve the children's condition in the past. Within the prospective restitution stories, participants expressed the desire, hope or a wish, for a time when the children would be returned to a "normal state of health again"; this meant that the desire for restitution never went away.

#### The restitution narrative

Participants desired restitution to happen for their children by whatever means possible. Their narratives were characterised by family members suspecting something was wrong with their child, seeking treatment for their child and the expectation that their child would be restored to health, consistent with the restitution narrative that to every illness there is a cure (Diver et al., 2013a; Frank, 2013). The restitution narrative was enacted by all groups of participants, but it was dominated by parents and in particular the participants' journey of seeking possible remedies for the children's condition. The restitution narrative was underpinned by two themes: *Help-seeking Behaviour* and *Hope for a cure*. The *Hope for cure* theme was underpinned by two sub-themes: *Intransitive hope for cure* and *Transcendent hope for cure*.

#### Help-seeking behaviour

Help-seeking behaviour characterised a major part of the restitution narrative. The journey of seeking help for their children began with noticing that "something was wrong"; this was mostly in relation to the delay in achieving developmental milestones evident in behaviours or physical skills, e.g., delay in rolling over, sitting up, crawling, head control, etc. This was typified by statements made by Margaret (grandmother).

*"We (family members) realised it when she was above 4 months. I know that from 2 months a child should start to sit and she should have mastered sitting when she is above 4 months and can, therefore, sit on her own but her situation was different. We tried sitting her, but she found it difficult doing it.".... Margaret (grandmother).*

Families sought healthcare interventions for the child as, like any other illness, they thought this would mean resolution. Decisions were made in the family to seek appropriate help or treatment and this action evidenced the "to-every-illness-there-is-a-remedy" plotline of the restitution narrative (Frank, 1995a).

The delay in the developmental milestone of the child was perceived as "something was wrong"; This led most participants to seek an explanation or solution within the medical model of healthcare, further enacting the restitution narrative. Health professionals dominated this

part of the narrative as they conducted a variety of tests to determine the reason for the presenting complaints, creating expectations of explanations that would reveal what was wrong with the children, re-enacting the restitution narrative in turn.

*"They referred me to the x-ray department to have a picture of her neck. They told me they would send the x-ray results to me on my phone when the results were in" .... Betty (mother).*

Participants were given a diagnostic label and biomedical explanations as to the cause of cerebral palsy as noted through the extracts below:

*"The doctors said it would take a long time before her neck would become stable. They also said her sitting, crawling, walking and talking would delay and these are also obvious on the child" ...Kennedy (father).*

After diagnosis, the children were scheduled to attend routine physiotherapy treatments. Mostly twice a week at the initial stages, decreased to once a week or once a month based on the expert opinions of professionals. Participants thought the child would "get well soon" although health professionals had not assured them of this.

*"We followed their treatment regimen because we wanted the child to get well soon so we continued going to the hospital for the exercises" .... Mary (grandmother).*

Participants had expected biomedical treatment to have brought some improvements in the developmental milestones or provided a remedy for the children's situation, but their expectations were not met. They expressed how they felt when treatment didn't bring about the expected improvements.

*"We have been going for physiotherapy till now but still we have not seen any improvement. There have been many times that we don't send him for treatment because we don't see an improvement. Sometimes we feel like stopping this physiotherapy treatment thing altogether" ... Natasha (Grandmother).*

Failure of treatment to meet the expectations of participants was significant and led participants to consider alternative means of treatment to augment the chances of their child getting better. They appeared to still be trying to fulfil the "tomorrow I will get better" restitution plotline. The different groups of participants sought alternative help for the child by accessing complementary medicine (mainly herbal medicine).

*"Mmm, yes, I remember we took her to one woman herbalist who is also a pastor. That woman through her herbs was able to make the child sit on her own. I guess if we had gone to the woman earlier, the child would be walking by now. So it is that woman that made the child sit on her own. Yea...Emelia (Grandmother).*

However, participants described not disclosing their use of alternative medicine to any of the healthcare professionals involved in the childcare as they discouraged them from seeking alternative help.

*"Most of the time, we the parents who have children with this condition go behind the health professionals to seek help from other people as they discourage seeking alternative help. You often meet people who would tell you, 'I have encountered someone who had a child with this same condition and directed him to a man who helped him. I think if you go to see that man, he will be able to help your child as well'. So, we go*

*behind health professionals to see herbalists for help very often” .... Arthur (Father).*

With both biomedical and alternative treatments now being used, improvements still often did not materialise; this resulted in frustration and disappointment:

*“We gave him to some herbalist to take care of the child and cure his condition but whatever the herbalist tried brought no results. Many herbalists have taken huge amounts of money from us and gave us assurances that the child would be cured but they couldn't restore the child to health” .... Peter (Grandfather).*

However, some participants acknowledged some appreciable improvements in the children's condition and in their hope of still achieving restitution for their children. It appeared they felt combining these two approaches of treatment could bring the desired outcome they hoped for and that both biomedical and alternative approaches must be used complementarily and not in competition with each other.

*“I am convinced that the herbalists have their part to play and the trained doctors in the various hospitals also have their part. You can be passed through various screening and scanning machines at the hospital for them to know what exactly is happening in your body, but the native doctors do not do these scanning and screenings. So, I believe taking herbs and going to the hospital walk hand in hand and this means that whiles visiting the native herbalists for herbs or leaves you must also visit the hospital as well.” ...Samson (grandfather).*

None of the participants reported the cure they hoped for and came to acknowledge the long-term nature of CP. Though participants described how both biomedical and alternative medicine had failed to provide cure, the restitution narrative was not completely abandoned; the hope of a cure was never lost.

#### *Hope for cure and the restitution narrative*

With Biomedical and alternative approaches failing to provide the desired cure, participants' hope for restitution continued to be evident and they looked forward to this in the future. However, this prospective hope or desire for restitution to occur was not based on either biomedical intervention or alternative (traditional treatment). Their longing for cure at this time became intransitive (Hope for a cure that has “no specified object or direction”, Frank, 2013, p.232) and transcendent (Hope for cure based on God's intervention influenced by religious beliefs. The hope for cure appears to reinforce passive restitution, as participants seem to shift from actively engaging restitution, i.e., through treatment, to becoming passive, hoping for restitution to occur intransitively and transcendentally.

#### *Intransitive hope for cure*

The Intransitive hope for cure was based on the notion that cure might happen eventually, without treatment, as their children continued to grow. In constructing this hope of restitution, they left the future open for the possibility of the children getting well. This was solely the narrative of mothers and siblings but not fathers and extended family members. It appeared it was strongest at instances where efforts to mobilise were made by the children with CP; this made them maintain that their children would eventually get well with time.

*“He is very active. Whenever I lay him down on a mat to exercise him, he makes some appreciable efforts to get up on his own. This gives me the hope that he will soon walk and be independent. The child will walk no*

*matter his circumstances” .... Fanny (sibling).*

For some mothers in the study, it appeared this intransitive hope for cure continued to be maintained despite the realisation that this hope was unlikely to be fulfilled but the mobility efforts made by their children would make them continually cling to this hope.

*“Though I have been told [by health professionals] my child would not walk again but I still believe in my heart that he will walk one day. Sometimes in the night, you would see him lifting his arms and feet whiles stretching himself at the same time on his mat. I would be stealing glances at him at such times, and it would make me feel that the child will rise one day and walk. I know he is going to walk one day” .... Nancy (mother).*

It also appeared the hope of cure was co-constructed through opinions of non-family members reinforcing their belief that their children would eventually get well.

*They [other people] always encourage me to continue taking care of the child and that he is going to get well. They think the child will get well so they continue to encourage me .... Florence (mother).*

#### *Transcendent hope for cure*

The transcendent hope for cure, describes a hope that was beyond the range of physical human experience; it was a re-storying of their hopes of restitution underpinned or influenced by their religious beliefs, i.e., the belief that God could cure their children. It appeared participants had acknowledged the limitations of conventional and alternative treatments and endeavoured to replace these with hope in God. It appeared in the latter stage of the stories, of all groups of participants, that religious beliefs replaced their biomedical ones. All participants had affiliations with a formal or institutionalised religion and were active participants in religious activities at the time of the study and this belief was not associated with only one faith. They appeared to have the opinion that God has time for everything including the time that he would heal the children; all they could do was wait.

*“God also knows when this child will get well. So, everything is in the hands of God now. We know that with time, God would be able to heal him, and our brother might improve and eventually walk” .... Leah (sibling).*

Within the narratives of all participants was the realisation that all possibilities for cure or healing had been exhausted and the only final means for cure would be from God.

*“Now I have also come to know that there is no humanly possible cure for cerebral palsy, so I always ask God in my prayers to heal my son. I pray every day, petitioning God to change my son's condition and restore him to proper health” .... Arthur (father).*

Though the child was still in continuance of physiotherapy treatment, this statement demonstrates an absence of hope in even the therapy his child was receiving.

Transcendent hope appeared to mostly stem from religious readings. For instance, the practising Christians related this to instances in the Bible, where some persons with disability were healed miraculously.

*“The book of Mark in the Bible, chapter 10 verse 46 says that Bartimaeus was blind. When one day Jesus was passing by, he used his mouth to*

*shout for help from Jesus. People tried to shut him up but he continued shouting. He kept on shouting until Jesus heard and healed him. Like Bartimaeus we know our child would be well with the help of God" .....Kennedy (father).*

Some of the participants believed that being healed by God would also be a testimony that would convert people to religion.

*"I tell him that God loves him and that his life is going to be a testimony to the whole world. I tell him to keep in mind that God loves him deeply. I tell him to keep in mind that he will one day testify of what he went through as a child but was healed by God in front of a huge crowd and his testimony will draw many people to God. Ernestina (mother).*

Participants engaged in continuous personal or contingent religious rituals [prayers in Christianity and "Salah" in Islam] through which they bargained with God for improvement and cure for their children's condition.

*"We organise some prayer camps in the church I attend so when the times are due, I send him there to be prayed for. So gradually, God has listened to our prayers and the child is able to walk and talk a little" .... Abraham (father).*

A transcendent hope for cure was also reinforced by the opinions of others and in particular the religious leaders in their communities.

*"I have been taking him for prayers [at different churches] till now. They tell us at such places that he would walk and talk. These are men of God and they are spiritual people, so when they tell you things like this, you cannot doubt it". Mary (grandmother).*

The transcendent hope for cure that participants expressed never waned and they were sure this would happen in the future.

## Discussion

Having its narrative plotline as "yesterday I was healthy, today I am sick but tomorrow I will be better", the restitution narrative has been framed as the most common narrative among people with recent illness but may be less evident among the chronically ill (Frank, 1995b; Frank, 2013; Whitehead, 2006). The restitution narrative demonstrates a movement away from an optimal state of health, coming back again to the optimum and explores the experiences encountered within health investigations and treatments. The desire for restitution to occur is compounded by other people's expectations to hear restitution stories. It is suggested that the institutional stories of illness have affected people's expectations of how stories of illness should be told (Frank, 2013).

In this study, the restitution narrative was evidenced at the pre-diagnosis stage, after diagnosis, seeking treatment and when participants came to the realisation that both biomedical and traditional treatment had failed and therefore resorted to religious beliefs for cure. Restitution in the current study was therefore underpinned by help-seeking behaviour and belief in transcendence for a desired cure.

The current study has demonstrated that restitution first emerged at the pre-diagnosis stage when study participants perceived that "something was wrong" with the children. This is consistent with the narratives of parents having children with cancer (Bally et al., 2014) where participants did not initially consider the children's condition to be long-term as they believed the condition could be resolved within the biomedical model like any other acute illness. However, this differs from the reports of chronically ill people themselves where inconsistencies in the emergence of the restitution narrative have been

detected. In a report of people with Fibromyalgia Syndrome (Diver et al., 2013b), it was observed that all participants began with the restitution narrative at the onset of their symptoms during the pre-diagnosis stage. However, this was not the case for people suffering from cancer (Thomas-Maclean, 2004) or HIV (Ezzy, 2000).

Furthermore, the actions of all participants in this study also reflected the tenets of the medical model of disability in which disability is conceptualised as a biological or medical problem (Marks, 1997), which needed to be corrected; hence their ongoing endeavour to seek a cure.

The failure of biomedical treatment in providing the desired restitution led participants to consider an alternative means of seeking restitution for the children. Herbalism was engaged to complement biomedical treatment, with the hope that in lieu of biomedical treatment, alternative or the traditional approach to treatment could bring restitution into effect. This action further deepened the participant's desire for restitution to happen. Participants did not disclose the alternative source of help they sought to health professionals.

The use of herbalism as an alternative treatment in this current study, and the hope participants had it would provide a cure has contextual explanation. Previous research has demonstrated that in developing countries especially Africa, herbal remedies, often called traditional medicines are often preferred over treatments recommended by cosmopolitan or western medicine (Abdullahi, 2011; Amoah et al., 2014). This is because of accessibility to these treatments and their associated low prices or cost. In addition, there is the general perception that traditional treatments are harmless and are guaranteed to bring favourable result. It has been estimated empirically that in Ghana, around 70% of healthcare is provided by traditional healers who have no formal training and that "there is an estimated one traditional healer for every 400 inhabitants and one physician with conventional medical training for every 12,100 inhabitants" (Abdullahi, 2011; Amoah et al., 2014). In Ghana, traditional medicines are created by ordinary people and form part of their way of life (Abdullahi, 2011; Yeboah, 2000). The media have also helped in the promotion of traditional medicines because their practitioners and purveyors are allowed to advertise their products for a small fee. Many times, in a bid to reinforce the potency of their plant-based medicines, herbalists would bring some people who they would portray as their past patients, to testify about their products and how the products have helped with their healing. This practice in the Ghanaian setting seems to reinforce Frank's (1995) view that the media helps in the propagation of the restitution narrative. These traditional healers or herbalists have no formal training in the use of traditional medicines yet people trust in their expertise for healing. Therefore, healthcare practitioners advise against consultations with traditional healers and frequently warn patients and their carers that traditional healers may exacerbate medical conditions as opposed to cure or managing cure. However, the current study reveals that family members still seek alternative help from herbalists irrespective of any advice that may have been given. This could therefore suggest that family members may defer to alternative treatment in future.

This also portrays a lack of knowledge about chronic conditions and their long-term nature. Previous research that relates to the enactment of the restitution narrative by ill persons, provides further evidence on how chronically ill persons demonstrated an alternative help-seeking behaviour within the restitution narrative which reflects the current finding (Whitehead, 2006). For those with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME), the use of alternative therapies was widespread after the establishment of diagnosis. All participants tried a form of complementary/alternative treatment and several therapies (Whitehead, 2006). However, while the current study demonstrated that herbalism was the main form of alternative treatment for participants, Whitehead (2006) discovered that diets in the form of wheat-free, sugar-free, no meat, no dairy products and a high potassium diet, were the most common form of alternative treatment for those with CFS/ME.

There exists published research (Bannister, 2015; Barrett, 2005; Village, 2005) in the practice of religious beliefs and rituals believed by some people to elicit the intervention of that which is divine causing spiritual and physical healing, especially in Christian practice. This is reflected in the findings of the current study when both biomedical and alternative sources had failed to provide the cure participants had expected. There is the assertion by believers that by religious faith through prayer and/or other rituals such as laying on of hands, a divine presence and power could be stimulated to bring about the healing of disease and disability (Village, 2005, pp. 51–53). Furthermore, there have been popular claims that numerous religious rituals such as prayer, intervention from the divine, or an individual healer's ministrations can bring about healing or cure illness (Barrett, 2005). According to the American Cancer Society (Bannister, 2015), many people have expressed claims that faith and prayer can cure chronic conditions such as multiple sclerosis, blindness, deafness, defective speech, cancer, many developmental disorders, Acquired Immune Deficiency Syndrome (AIDS), etc. Recovery from these conditions has been attributed to many religious techniques which have been classified commonly as faith healing (Bannister, 2015). Faith healing can involve a strong belief in a higher power or a supreme being for cure, prayer or a visit to a religious shrine to perform some rituals (Bannister, 2015). The New Testament of the Bible has been interpreted by many Christians as a canon that teaches a belief in and practice of faith healing. A study among some Americans found that participants believed praying to God can cure the ill person regardless of the claims of medical science that the condition is incurable (Gansler et al., 2008; Kalb, 2003). Muslims also claim that through a ritual called *ruqyah* in which the right hand is placed on the forehead or at the site of illness and certain words from the Quran classified as *Sura Al-Fatiha* are then recited, illness can be cured (Haokip, 2007). The present study has demonstrated that as both biomedical and traditional medicine failed in bringing about the expected cure, participants felt they had exhausted all avenues for healing and felt there was nothing they could do in their power to bring about restitution. From thenceforth, it emerged that participants had begun trusting in a supreme being or in a higher power for cure. It appeared they had lost hope in any human intervention and expressed a belief in transcendence for cure, a cure that was beyond the normal physical human experience.

### Implications for practice

This study has implications for paediatric nursing specifically and health practice in general. Paediatric nursing professionals and other health professionals dealing with family members living with children having cerebral palsy could attend to their stories in an open and focused manner to honour and validate their stories as well as their experiences. The recognition of restitution stories by health professionals could lead to more focused assessments, care and interventions for ill persons and their families. Family members who may tell the restitution stories could be supported to come to the realisation that cerebral palsy cannot be cured but rather managed. Health professionals could then lead them to understand and practice the various ways of managing cerebral palsy and preparing well for the uncertain future of the children.

### Recommendations for further research

As this is the first study to consider the experiences of family members surrounding the chronically ill child with the use of Frank's narratives, more research is needed to validate the repeatability of these findings in other settings. Further research may also be needed to explore the narratives of family members living with adult children (from 18 years of age) to find out if their narratives would differ or would remain the same and whether or not these narratives would even be enacted at all.

### Strengths and limitations of the study

A major strength of this study is that it is the first study which has employed Frank's illness narrative typology as a framework to study the experiences of persons around the chronically ill child by employing multiple participant perspectives from the family. Furthermore, study outcomes were grounded in data and the framework also provided an in-depth explanation of findings which have helped improve the understanding of living with a child having cerebral palsy in the family.

As a limitation, the researchers have no way of knowing, empirically, to what extent the results would be similar or different in another study setting given the small sample size and the specific nature of the study. Furthermore, this study may demonstrate a potential for selection bias as the first step to gain access to participants was in a healthcare institution. This meant that only the family members of mostly mothers who came to the selected regional hospital with their children for routine physiotherapy treatment were included in the study. Again, the lead researcher's professional background as a person who works with persons with disability and their families and who wanted to elucidate their experiences might have influenced the way study findings were interpreted. Finally, the local language used for data collection and the study setting may also impact the study's applicability to other settings, that notwithstanding, the study may provide a global insight into living with chronic illness as far as less developed settings are concerned.

### Conclusion

This is the first study that has employed Frank's illness narrative typologies as a framework to study the experiences of persons around the chronically ill child by employing multiple participant perspectives from the family and has found the existence of dominant typologies of restitution, Chaos and Quest in their narratives. Study outcomes were grounded in data and the framework also provided an in-depth explanation of findings which have helped improve the understanding of living with a child having cerebral palsy in the family. Findings from the current study have provided new theoretical insight into the experiences of having a child with cerebral palsy in the family. The use of the restitution narrative (Frank, 1995b) has provided a novel, holistic, and a more comprehensive understanding of familial experiences of living with a child with cerebral palsy.

### Credit author statement

- 1. Conceptualisation:** The research Ideas and formulation of research goals were done by the Principal author: Dr. Emmanuel Asante
- 2. Methodology:** The methodology was developed and written by Dr. Emmanuel Asante with guidance from Prof. Joanne Lymn and Dr. Claire Diver
- 3. Data analysis:** Dr. Emmanuel Asante conducted the data analysis
- 4. Supervision:** Prof. Joanne Lymn and Dr. Claire Diver supervised the research and related write-ups
- 5. Validation:** all validation processes were done by Prof. Joanne Lymn and Dr. Claire Diver as Thesis supervisors
- 6. Resources:** library resources and online databases were made accessible by the University of Nottingham with recommendations from Prof. Joanne Lymn and Dr. Claire Diver as Supervisors
- 7. Writing-Original Draft:** Dr. Emmanuel Asante wrote the original draft
- 8. Writing-Review and Editing:** Prof. Joanne Lymn and Dr. Claire Diver reviewed and edited the article

### Declaration of Competing Interest

None.

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## References

- Abdullahi, A. A. (2011). Trends and challenges of traditional medicine in Africa. *African Journal of Traditional, Complementary, and Alternative Medicines*, 8(55).
- Adei-Atiemo, E., Rodrigues, O., & Badoe, E. (2015). *Classification and Risk Factors for Cerebral Palsy in the Korle Bu Teaching Hospital, Accra\_A Case-Control Study*. Pediatrics. American Academy of Paediatrics.
- de Aguiar Lélis, A. L. P., & Cardoso, M. V. L. M. L. (2014). Mothers'/caregivers' experience facing regarding the pain of the children with cerebral palsy. *Cienc Cuid Saude*, 13(4), 730–738.
- Alaee, N., Shahboulaghi, F. M., Khankeh, H., & Kermanshahi, S. M. K. (2015). Psychosocial challenges for parents of children with cerebral palsy: A qualitative study. *Journal of Child and Family Studies*, 24(7), 2147–2154.
- Amoah, S. K., Sandjo, L. P., Bazzo, M. L., Leite, S. N., & Biavatti, M. W. (2014). Herbalists, traditional healers and pharmacists: A view of the tuberculosis in Ghana. *Revista Brasileira de Farmacognosia*, 24(1), 89–95.
- Bally, J. M., Holtslander, L., Duggleby, W., Wright, K., Thomas, R., Spurr, S., & Mpofu, C. (2014). Understanding parental experiences through their narratives of restitution, chaos, and quest: Improving care for families experiencing childhood cancer. *Journal of Family Nursing*, 20(3), 287–312.
- Baltor, M. R. R., & Dupas, G. (2013). Experiences from families of children with cerebral paralysis in context of social vulnerability. *Revista Latino-Americana de Enfermagem*, 21(4), 956–963.
- Bannister, J. W. (2015). *Exploring narratives in supernatural healing at Grace Church of God*. Brooklyn NY: Drew University.
- Barrett, S. (2005). Some thoughts about faith healing. *J une*, 1(5), 2.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Browne, E., & Miller, F. (2005). *Cerebral palsy*. New York: Springer. <https://books.google.co.uk/books?id=THpol5rQ8qQC>
- Constitution of Ghana (1992). *The 1992 constitution of Ghana*.
- Dantas, M. S. D. A., Pontes, J. F., Assis, W. D. D., & Collet, N. (2012). Family's abilities and difficulties in caring for children with cerebral palsy. *Revista Gaúcha de Enfermagem*, 33(3), 73–80.
- Dehghan, L., Dalvandi, A., Rassafiani, M., Hosseini, S. A., Dalvand, H., & Baptiste, S. (2015). Social participation experiences of mothers of children with cerebral palsy in an Iranian context. *Australian Occupational Therapy Journal*, 62(6), 410–419.
- Diver, C., Avis, M., & Gupta, A. (2013a). Quest, chaos and restitution: The illness narratives of individuals diagnosed with fibromyalgia syndrome. *Chronicity, care and complexity* (pp. 25–40).
- Diver, C., Avis, M., & Gupta, A. (2013b). Quest, chaos and restitution: The illness narratives of individuals diagnosed with fibromyalgia syndrome. *Chronicity: care and complexity* (pp. 25–40). Brill.
- Durkin, M. S., Benedict, R. E., Christensen, D., Dubois, L. A., Fitzgerald, R. T., Kirby, R. S., ... Yeargin-Allsopp, M. (2016). Prevalence of cerebral palsy among 8-year-old children in 2010 and preliminary evidence of trends in its relationship to low birthweight. *Paediatric and Perinatal Epidemiology*, 30(5), 496–510.
- Ezzy, D. (2000). Illness narratives: time, hope and HIV. *Social science & medicine*, 50(5), 605–617.
- Fernández-Alcántara, M., García-Caro, M. P., Berrocal-Castellano, M., Benítez, A., Robles-Vizcaino, C., & Laynez-Rubio, C. (2013 January). Experiences and changes in parents of children with infant cerebral palsy: a qualitative study. *In Anales del Sistema Sanitario de Navarra*, 36(1), 9–20.
- Fernández-Alcántara, M., García-Caro, M. P., Laynez-Rubio, C., Pérez-Marfil, M. N., Martí-García, C., Benítez-Feliponi, Á., ... Cruz-Quintana, F. (2015). Feelings of loss in parents of children with infantile cerebral palsy. *Disability and Health Journal*, 8(1), 93–101.
- Frank, A. (1995a). *The wounded storyteller: body, illness. Ethics*.
- Frank, A. (1995b). *The wounded storyteller: Body, illness*.
- Frank, A. W. (2013). *The wounded storyteller: Body, illness, and ethics*. University of Chicago Press.
- Gansler, T., Kaw, C., Crammer, C., & Smith, T. (2008). A population-based study of prevalence of complementary methods use by cancer survivors: A report from the American Cancer Society's studies of cancer survivors. *Cancer*, 113(5), 1048–1057.
- Gulati, S., & Sondhi, V. (2018). Cerebral palsy: An overview. *The Indian Journal of Pediatrics*, 85(11), 1006–1016.
- Haokip, K. H. (2007). *Increasing knowledge about divine healing within the leadership of an immigrant Asian Baptist church*. Oral Roberts University.
- Hayles, E., Harvey, D., Plummer, D., & Jones, A. (2015). Parents' experiences of health care for their children with cerebral palsy. *Qualitative Health Research*, 25(8), 1139–1154.
- Huang, Y. P., Kellett, U., & St John, W. (2012). Being concerned: Caregiving for Taiwanese mothers of a child with cerebral palsy. *Journal of Clinical Nursing*, 21(1–2), 189–197.
- Huang, Y. P., Kellett, U. M., & St John, W. (2010). Cerebral palsy: Experiences of mothers after learning their child's diagnosis. *Journal of Advanced Nursing*, 66(6), 1213–1221.
- Iversen, A. S., Graue, M., & Råheim, M. (2013). At the edge of vulnerability—Lived experience of parents of children with cerebral palsy going through surgery. *International Journal of Qualitative Studies on Health and Well-Being*, 8(1), 20007.
- Kalb, C. (2003). Can religion improve health? *Newsweek*, 142(19), 44–56.
- Kruijssen-Terpstra, A. J., Verschuren, O., Ketelaar, M., Riedijk, L., Gorter, J. W., Jongmans, M. J., ... Group, L. M.-S (2016). Parents' experiences and needs regarding physical and occupational therapy for their young children with cerebral palsy. *Research in Developmental Disabilities*, 53, 314–322.
- Marks, D. (1997). Models of disability. *Disability and Rehabilitation*, 19(3), 85–91.
- Milbrath, V. M., Cecagno, D., Soares, D. C., Amestoy, S. C., Siqueira, H. C. H., & d. (2008). Being a woman, mother to a child with cerebral palsy. *Acta Paulista de Enfermagem*, 21(3), 427–431.
- Miller, F. (2005). *Cerebral palsy*. Springer. [https://books.google.co.uk/books?id=V\\_p50E-Up7IC](https://books.google.co.uk/books?id=V_p50E-Up7IC)
- Monbaliu, E., Himmelmann, K., Lin, J. -P., Ortibus, E., Bonouvié, L., Feys, H., ... Dan, B. (2017). Clinical presentation and management of dyskinetic cerebral palsy. *The Lancet Neurology*, 16(9), 741–749.
- Nahm, N. J., Graham, H. K., Gormley, M. E., Jr., & Georgiadis, A. G. (2018). Management of hypertonia in cerebral palsy. *Current Opinion in Pediatrics*, 30(1), 57–64.
- Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work*, 1(3), 261–283.
- Pavlis, D., & Gkiosos, J. (2017). John Dewey, from philosophy of pragmatism to progressive education. *Journal of Arts and Humanities*, 6(9), 23–30.
- Smith, M., & Kurian, M. A. (2012). The medical management of cerebral palsy. *Paediatrics and Child Health*, 22(9), 372–376.
- Thomas-MacLean, R. (2004). Understanding breast cancer stories via Frank's narrative types. *Social science & medicine*, 58(9), 1647–1657.
- Village, A. (2005). Dimensions of belief about miraculous healing. *Mental Health, Religion and Culture*, 8(2), 97–107.
- Vitrikas, K., Dalton, H., & Breish, D. (2020). Cerebral palsy: An overview. *American Family Physician*, 101(4), 213–220.
- Whitehead, L. C. (2006). Quest, chaos and restitution: Living with chronic fatigue syndrome/myalgic encephalomyelitis. *Social Science & Medicine*, 62(9), 2236–2245.
- Whittingham, K., Wee, D., Sanders, M., & Boyd, R. (2011). Responding to the challenges of parenting a child with cerebral palsy: A focus group. *Disability and Rehabilitation*, 33(17–18), 1557–1567.
- Yeboah, T. (2000). Improving the provision of traditional health knowledge for rural communities in Ghana. *Health Libraries Review*, 17(4), 203–208.