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COLLEGE OF HUMANITIES
SCHOOL OF SOCIAL SCIENCES

**PERCEPTIONS, BUFFERING RESOURCES, AND SELF-DETERMINATION:
AN INVESTIGATION INTO THE PSYCHOLOGICAL HEALTH OF
ADOLESCENTS LIVING WITH
CONGENITAL LIMB DEFORMITY IN GHANA**

BY

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DECLARATION

I have met the requirements and procedures and hereby present this thesis as an original piece of work I have personally undertaken in the Psychology Department, University of Ghana, and one which has never been presented in part or in full to any university or institution for the award of any degree. All references made to others have been duly acknowledged.



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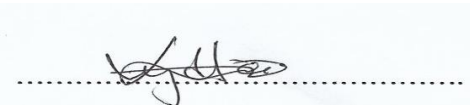


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ABSTRACT

The current study examined factors that influence the psychological health of adolescents with congenital limb deformity in Ghana. Adolescents with congenital limb deformity (AWCLD) experience a plethora of physical, psychological, and social effects of a disfiguring birth defect. Amputation, a procedure theorized to promote psychological health by increasing functional ability and minimizing disfigurement, further adds to the burden of congenital limb deformity. Body image and self-perception are usually very fragile in adolescence, which is the period between age 10 and 24, and negatively impact adolescent psychological health. Adolescents with a disfiguring disability may consequently experience more challenges affecting interpersonal relationships and participation in social activities during this transition from childhood. This study adopted a concurrent mixed-method approach to investigate predictors of psychological health outcomes of a sample of 50 adolescents, aged between 12 and 24, with congenital limb deformity in Ghana. The quantitative aspect of the study tested 5 hypotheses, and compared amputee and non-amputee participants across body image and symptoms of psychological distress. It also examined relationships between social support, coping strategies and psychological distress. The qualitative approach explored perceptions, lived experiences, and social activities of 15 AWCLD to corroborate and cross-validate the quantitative findings. Statistical analyses revealed that amputees and non-amputees had similar functional ability, similar body image, and self-esteem, as well as similar psychosocial experiences of CLD. However, there was a significant difference in their levels of distress, where non-amputees experienced more distress symptoms of depression, and interpersonal sensitivity than amputees. This finding was interpreted and attributed to the experience of stigma-related issues by non-amputee participants in the qualitative study. Social support from family, significant others and friends buffered AWCLD from the effects of CLD, and coping strategies varied among participants, with older adolescents engaging less in emotion-regulation coping. In

general, findings support the theoretical framework of the study, namely, the Broaden and Build Theory of Positive Emotions, the Buffering Effects of Social Support Theory, and the Self-Determination Theory, which underscored the buffering roles of positive emotions, social support, coping strategies, as well as self-determination, in significantly influencing psychological health outcomes, and suggests that the integration of Self-Determination Theory in disability studies may change the dominant negative narrative. Further inquiry into the role of sociocultural perceptions of deformity in fostering self-determination and self-development in the physically-disabled is recommended.

Keywords: congenital limb deformity, adolescence, psychological health, buffering resources

DEDICATION

To my family and friends. You were my source of support, coping, and positive emotions.

Thank you.

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LIST OF ABBREVIATIONS

ANOVA	Analysis of Variance
APA	American Psychological Association
AWCLD	Adolescents with Congenital Limb Deformity
BBTPE	Broaden and Build Theory of Positive Emotions
BESST	Buffering Effect of Social Support Theory
BIS	Body Image Scale
BSI	Brief Symptom Inventory
CLD	Congenital Limb Deformity
ECH	Ethics Committee of Humanities
GSI	Global Severity Index
GSPD	Ghana Society of the Physically Disabled
IPA	Interpretative Phenomenological Analysis
MSPSS	Multidimensional Scale of Perceived Social Support
NGO	Non-Governmental Organization
NOTC	Nsawam Orthopaedic Training Center
PWD	People with Disabilities
SDT	Self-Determination Theory
SPSS	Statistical Package for the Social Sciences

Psychological Health of Adolescents with CLD

UNPF

United Nations Population Fund

WHO

World Health Organisation

CHAPTER ONE

INTRODUCTION

Congenital limb deformity (CLD) is a birth defect, which results in disfigurement, disability, chronic pain, and severe fatigue over many years (Johansen, Dammann, Andersen, & Andresen, 2016). Severe forms of CLD usually lead to amputation, which is performed to improve appearance and function in individuals, although the procedure sometimes exacerbates the effects of CLD by causing more pain and distress (Adu & Annan, 2008; Durmuş et al., 2015; Heszlein-Lossius et al., 2018). Stigma-related issues are also experienced as a result of the social construction of birth defects (Adeyemo, James, & Butali, 2016; Bello, Acquah, Quartey, & Hughton, 2013; Belon & Vigoda, 2014; Munyi, 2012). By adolescence, the effects of CLD, especially disfigurement and disability, may have had a major impact on these individuals, and their overall functioning. In addition, the attitudes of family, friends, and the community may have affected their participation in, and fulfilment of social activities and roles during this transition to adulthood, ultimately affecting their psychological health (Galderisi, Heinz, Kastrup, Beezhold, & Sartorius, 2015; Jaworska & MacQueen, 2015). Inclusion in the community or society may therefore be due to the buffering resources of coping, support systems, positive emotions, and self-determination which influence the positive functioning of those “who fight against perceived injustice and inequalities...and minorities experiencing rejection and discrimination (Galderisi et al., 2015, p. 231). This study therefore examined rigorously the influence of these resources on the psychological health of adolescents with congenital limb deformity in Ghana.

1.0 Background

The World Health Organization (WHO) estimates that globally, 1 in 33, or more than 8 million babies are born each year with a defect or anomaly caused by factors present during foetal development, and infants who survive the first year suffer physical or mental disability as a result of the defects (Lu et al., 2014; WHO, 2018). A great number also face limited access to schooling, and exclusionary practices in childhood (Presler-Marshall, Jones, & Odeh, 2019).

Birth defects that result in both deformity and disability make individuals vulnerable to stigma and discriminatory behaviours (Adeyemo et al., 2016; Burçu, 2014; Mamah, 2016). As children, they may have been shielded from negative social attitudes by caregivers, and this support might have buffered the effects of stigma associated with birth defects (Bello et al., 2013). Perhaps, they might also not have been fully aware that they were different from their peers. The awareness of being physically different however, becomes more pronounced with the onset of adolescence (Gilg, 2016; de Jong et al., 2012; Xu & Liu, 2020). Consequently, as children with disfiguring birth defects move into adolescence, the most vulnerable stage of life, attitudes and behaviours of family, and the community play a significant role in the individual's self-image, and consequently their psychological health (Voelker, Reel, & Greenleaf, 2015; Xu & Liu, 2020).

During adolescence, individuals living with CLD contend, not only with the challenges of disability, disfigurement, body image, physical maturity, identity and social roles, but also performance in all areas of life (Voelker et al., 2015; Xu & Liu, 2020). Nevertheless, the lives and experiences of adolescents with CLD testify to their self-determination to survive and cope in seemingly hostile environments.

A Brief Overview of CLD

Over the last few decades, the phenomena of congenital defects have been studied extensively by diverse disciplines as far apart as anthropology (Nakano, Makishima, & Yamada, 2017; Oostra, Boer, & van der Merwe, 2016), sociology (Ajao, 2019) and zoology (Lettice, Hill, Devenney, & Hill, 2007). For instance, polydactyly, originating from the Greek ‘poly’, meaning ‘many’ and ‘dactyl’, meaning ‘finger’, refers to the condition of a limb having more than the usual number of digits or fingers, evidenced even in cats (Lettice et al., 2007). The terms congenital defect, congenital deficiency, and congenital deformity are used interchangeably to refer to anomalies present at birth. Birth registries monitor the global incidence of congenital limb defects in humans (WHO, 2018). The alarming incidence of birth defects has prompted the WHO, in partnership with a number of other organizations to promote the awareness of birth defects, research into prevention and better healthcare facilities, as well as the observance of World Birth Defects Day held every year on March 3 (WHO, 2018).

Congenital limb deformity (CLD) – prevalence, types, and treatments

Congenital limb deformities are abnormalities that occur during the development of a foetus (Lu et al., 2014), and occur in upper-limbs more than lower-limbs (Calder, Shaw, Roberts, & Eastwood, 2017; El-Sayed, Correll, & Pohlig, 2010). Growth of part, or the whole limb of the child is stunted, or there may be extra or missing phalanges (finger bones). The severe forms of CLD may be a shortage in limb length (hemimelia), missing segments of a limb (meromelia), or limbs that are missing entirely (amelia). Some children are born with appendages at the ends of their torsos that pass as arms or legs (phocomelia), while others are born with no limbs at all (Calder et al., 2017). El-Sayed et al. (2010) report that in CLD, fingers or toes might be supernumerary (polydactyly), or fused together (syndactyly). The common

forms of congenital limb deformities include club foot, pigeon toe or in-toe, and dislocated hip (Boakye, Nsiah, Thomas, & Bello, 2016; Dobbs & Gurnett, 2009). The present study however, focuses on severe forms of CLD causing visible disfigurement including hemimelia, meromelia, and phocomelia, that are classified as either transverse, or longitudinal deficiencies (Gold, Westgate, & Holmes., 2011).

The main difference between CLD and other physical disabilities is the stigma attached to it. Although in some parts of the world, amputees, polio patients and individuals who suffered injuries as babies after birth, have countless stigma-related experiences, the stigma attached to defects before birth is magnified (Bermejo-Sanchez et al., 2011). In Africa, the distress extends beyond the stigma of disability. The fear of a curse makes individuals with the deformity, and their caregivers, suffer more emotional distress as no one wants to be associated with a cursed person or family (Bonsu et al., 2018; Wachege, 2012). Consequently, it is common to find families of children with birth defects describe the defects as caused after and not before birth. Many babies with CLD from these regions are reported by their caregivers to have either suffered infantile paralysis, orthopaedic injuries (e.g femur fracture during childbirth), or iatrogenic complications during the neonatal period (Cluett, 2019; Kim, Park, & Hong, 2015).



Figure 1.1: *Vascular Malformations of the Right Upper and Lower Limbs in a Young Boy.*
Source: *Adapted from Evans & Legbo (2011).*

In Figure 1.1, the hand and foot are deformed and present as giant appendages with fused or extra-large fingers and toes, referred to as macrodactyly, or local gigantism.



Figure 1.2: *Shortage of a Lower Limb (Fibular Hemimelia).*
Source: *Adopted from Cooper & Fernandes (2016).*

In Figure 1.2, the presentation of congenital limb deformity is a shortage in one of the two lower limbs, due to a partial absence of the long bones of the fibula. This type of limb deformity may occur in both legs. In this case, only one limb is involved and the condition is referred to as singular type-II fibular hemimelia.



Figure 1.3: Radial Ray Deficiency of the Right Forearm.

Source: Adapted from [https://en.wikipedia.org/wiki/Amelia_\(birth_defect\)](https://en.wikipedia.org/wiki/Amelia_(birth_defect))

In Figure 1.3, the birth defect is characterized by the absence of a part of the arm, in this case, the hand. At the end of the limb are little appendages referred to as ‘nubbins’, where the hand was amputated during foetal development. This is referred to as meromelia.



Figure 1.4: 2A. Hoof Shaped Hand. 2B: Syndactyly Shape of a Rose Bud. 2C: Syndactyly of Feet.

Source: Adapted from Rathore & Rathore, (2017)

Figure 1.4 is a presentation of Apert syndrome, a rare congenital disorder characterized by skull and facial deformity and fusing of hands and feet, causing severe disfigurement and disability. Named after the doctor who first described the syndrome, the deformity affects males and females equally in 1 out of every 65, 000 births (Rathore & Rathore, 2017).

Overview of Amputation

Unlike the conditions presented above, CLD such as a club foot is usually treated non-surgically with prostheses or orthoses (Ponseti method) but surgery (Achilles tenotomy) is usually necessary if the club foot deformity is severe (Dobbs & Gurnett, 2009). Occasionally though, amputations (acquired) which involve the removal of the whole, or part of an arm or a leg, are performed for severe cases of deformity to increase mobility and self-reliance, usually before age 3 years, and offer better functional outcome, and higher impact activity than non-surgical procedures (Calder et al., 2017).



Figure 1.5: *Above-knee Amputation of the Right Leg.*
Source: *OTC 2019 Annual Report*

Amputation has been theorized to increase functional outcome, and wellbeing, and every year, a third of all children born with limb defects will undergo amputation to reduce disfigurement, deformity and disability, so that the child can sit, walk, dance, and perhaps live a near-normal life as possible (Adu & Annan, 2008; Calder et al., 2017; El-Sayed et al., 2010; WHO, 2010). Amputation however, is a very drastic surgical procedure as the limb will never grow back. Nevertheless, an early intervention in childhood increases the chances of a successful outcome (Adu & Annan, 2018). Typical examples of surgical procedures related to CLD include Chopart's amputation (a separation of the forefoot at the midtarsal joint) and

Psychological Health of Adolescents with CLD

Syme's disarticulation (an amputation done through the ankle joint). Surgery may also be carried out to fix an internal or external device or rod to the bone to lengthen limb shortages (Le & Scott-Wyard, 2015). According to Griffet (2016), children with congenital limb shortages, and those who acquired amputations shortly after birth usually have no sense of loss.

Global Incidence of CLD

According to a report by Bermejo-Sanchez et al. (2011), the overall total birth prevalence of CLD, from an epidemiological register of 20 surveillance programs from 1968 to 2006, and from all the continents (except Africa) was 1.41 per 100,000 births. Interestingly, Vasluiian et al. (2013) report that the birth prevalence of CLD in the Netherlands between 1981 and 2010 was 21.1 per 10,000 births with males accounting for 55% of that figure. Another finding suggested that, there were more congenital limb deformity births (amelia) in children born to mothers younger than 20 years (Bermejo-Sanchez et al., 2011). Allen, Silverman, Nosovitch, Lohnes, and Williams (2007) reports that these deformities are most often caused by fibrous bands of the amnion that constrict foetal limbs to such an extent that they fall off due to missing blood supply. Other known causes of congenital amputations and deformities include growth restrictions in the womb, genetic malformations, maternal exposure to chemicals, viruses, toxins, smoking during pregnancy, and certain drugs ingested by the mother during pregnancy (Toufaily, Westgate, Lin, & Holmes, 2018). For instance, the drug Thalidomide was implicated in the incidence of thousands of congenital limb deformities in the United Kingdom between 1958 and 1961. Kim and Scialli (2011) report that some pregnant women were prescribed the drug as treatment for morning sickness in pregnancy, or insomnia, but it was soon withdrawn from sale after babies were born with limb deformities and other disabilities. Globally, around 10,000 babies were born with the characteristic stunted arms or

leg, or missing parts, and only 50% of them survived (Kim & Scialli, 2011). In 2018, the Food and Drugs Board (FDA) in Ghana, issued a warning to women using bleaching pills to whiten the skin of their unborn children, asserting that the drugs could cause congenital limb defects and damage to foetal organs (Richards, 2018).

Prevalence of CLD in Ghana

Although there is currently no national registry of CLD births, the 2018 Annual Report of Nsawam Orthopedic Training Center (NOTC), an orthopaedic center in Nsawam in the Eastern Region of Ghana reported that prosthetic devices were provided for 319 amputees in 2018, and 14 of the amputations were treatment for CLD (OTC Annual Report, 2018). This figure accounted for 4.4% of the total number of amputees reporting to the Out-patient department, compared to 5.64% from industrial accidents. Of the amputation cases reviewed that year, 5.9% were due to CLD, compared to 5.2% from industrial accidents. Twenty-two adolescents aged 10 – 19 (7 females and 15 males) with limb deformities were also treated with medical interventions, either through prescription of prostheses, or orthoses, while 4 others were amputated for severe forms of deformity in the first 6 months of the year.

For children with CLD, the burden of disability is worsened by supernatural beliefs about birth defects that persist and fuel perceptions, attitudes, and behaviours towards such persons (Adeyemo et al., 2016; Avoke, 2002; Bello et al., 2013; de-Graft Aikins, 2012). It has been argued that a large proportion of surgical procedures for birth defects are not usually for the purpose of increasing function. For instance, Lee et al. (2007) argue that reducing the stigma of birth defects more than increasing functional ability is the reason for surgery, and further argue that, rather than a pursuit of physical perfection, some individuals may seek

surgical solutions to decrease the psychological distress that comes from being stigmatized (Lee et al., 2007).

Adolescence, CLD and Psychological Health

According to current and diverse cultural definitions of adolescence, it is the transitional period between childhood and adulthood, ranging between 10 and 19 years, and the period that raises questions about independence, social roles, friendships, recreation, sexuality, and generally, decisions about the future and careers (Dorn & Biro, 2011; Jaworska & MacQueen, 2015; WHO, 2010). The categorization of ‘youth’ according to WHO (2010), covers the age range of 15 -24, while ‘young people’ falls within the 10-24 age range. Thus, adolescence covers the categorizations of ‘young people’ and ‘youth’.

Adolescence is the time when a positive influence and support from parents is crucial in identity development, mental health, and self-esteem (Poudel, Gurung, & Khanal, 2020; Presler-Marshall et al., 2019). This is due to the shift in the parent-child relationship, when the emerging adult seeks autonomy, and the period when focus is on the self, and questions such as “who am I?” are raised (Sharma & Sharma, 2010). Self-perceptions in adolescence is usually negative, and body image which is shaped by emotions and how people think and feel about their bodies (caused by physical, physiological, and psychological changes occurring at this time), is dependent on social evaluation (Voelker et al., 2015; Xu & Liu, 2020).

The physical, psychological, as well as social or environmental effects of CLD are myriad, especially for adolescents who were amputated in childhood in order to increase functional ability, or significantly reduce the extent of disfigurement (Johansen et al., 2016). Physical effects include disability, pain, phantom limb sensations, chronic fatigue (Durmuş et al., 2015; Johansen et al., 2016; Melzack, 1997; Sinha, van den Heuvel & Arokiasamy, 2011).

The psychological effects of CLD and amputation may manifest as anxiety about the future, paranoia, interpersonal sensitivity, and suicidal ideation (Burçu, 2014; Holzer et al., 2014; LaRaia, 2010; Montesinor-Magraner, Issa-Benitez, Pagés-Bolibar & Castellano-Tejedor, 2016). A negative body image, usually associated with a negative outlook on life, has also been reported to be very high in adolescents living with some form of disabling condition or deformity (Burçu, 2014; Holzer et al., 2014; Xu & Liu, 2020). Any relationship between CLD, amputation, and psychological health may be the consequence of a fragile self and body image, and a sensitivity to peer evaluation (Voelker et al., 2015; Xu & Liu, 2020).

Negative attitudes and behaviours expressed by family and significant others at the birth of a child with a birth defect are very often internalized by the child (Bonsu et al., 2018; Fiasorgbor & Ayagiyire, 2015; Quinn & Mahat, 2019). In addition, negative emotions of fear, paranoia, depression, and anger, usually experienced by stigmatized and marginalized individuals produce narrowed thought-actions which instil flight or fight tendencies that threaten psychological health (Fredrickson, 2004). Positive emotions and a positive outlook on the other hand, have been demonstrated to reduce the effects of negative emotions (Thewissen, Bentall, Oorschot, & Myin-Germeys 2011; Tugade & Fredrickson, 2004).

Psychological distress associated with chronic conditions require the adoption and utilization of effective coping strategies, and these strategies may change in response to negative experiences, even when the stressors within the environment remain unchanged (Benson, Cobbold, Opoku Boamah, Akuako & Boateng, 2020; Pennant et al., 2019). Children and adolescents also employ various coping strategies concurrently to buffer stressors (van Schalkwyk & Wissing, 2010; Vasluian et al., 2013; Winter, Kennedy, & O'Neill, 2017; Yendork & Somhlaba, 2014). The permanency of deformity however, implies that affected adolescents' self-image may have been shaped by pain, disfigurement, stigma, and marginalization over a long period, and they may have utilized different coping strategies to

deal with these different stressors, at different stages (de Minzi & Sacchi, 2005; Pennant et al., 2019; van Schalkwyk & Wissing, 2010). Coping strategies such as reframing, disclosure, disengagement, and distraction have been reported to be effective proactive coping strategies, and beneficial for psychological health (Bos, Pryor, Reeder, & Stutterheim, 2013; de Jong et al., 2012; Morris, Simpson, Sampson, & Beesley, 2014). Nevertheless, reframing requires a tremendous reserve of positive emotions, and unfortunately, some adolescents get stuck in negativity and ultimately employ maladaptive coping strategies that usually increase psychological distress.

Social support has been reported to have psychological benefits, especially when support-seeking is a coping mechanism, thus demonstrating the integral relationship between social support and proactive coping (Bonsu et al., 2018; Pennant et al., 2019; Poudel et al., 2020; Yendork & Somhlaba, 2014). In addition, research shows that proactive coping increases positive thoughts, positive emotions and adaptive behaviour. Hence, distressed but socially-supported adolescents are less likely to engage in health-threatening behaviours like substance-abuse, or attempt suicide (Kang et al., 2017; Steers et al., 2019).

1.1 Problem Statement

Most studies on adolescents with physical disabilities from birth defects focus less on their positive emotions and more on the negative aspects of depression and anxiety (Baffoe, 2013; Burçu, 2014; Heszlein-Lossius et al., 2018; Holzer et al., 2014). Research on CLD in Ghana for instance, has also focused on the medical model of treating the problem, where amputations are usually performed to improve functional ability and appearance (Adu & Annan, 2008). The procedure has a myriad of distressing effects, physically, psychologically, and socially (Durmuş et al., 2015; Sinha et al., 2011). There is however a dearth of literature

on functional ability and aesthetic appearance after amputation translating into better psychological health and better body image of adolescents with congenital limb deformity.

Amputee and non-amputee AWCLD are a special minority, yet their voices have not been heard, as most studies have used a positivist approach to study the phenomenon of limb deformity at birth. Adolescent CLD is also usually grouped together with other adolescent physical disabilities, although in many cultures, the majority of AWCLD are perceived as accursed, and are accordingly stigmatized by their families, friends, and especially, their community, as well as the physical structures that they have to navigate, or the institutions that have actually been designed to assist them. Social support also diminishes as children grow and transition into adulthood.

Stigmatization informs the self-perception of the majority of adolescents with physical disabilities, and negative perceptions of the body are reported to have negative consequences, both emotionally and mentally. There is the need therefore for adolescents who have physical disabilities to improve their body image through psychoeducation and holistic rehabilitation. Assistive devices that improve body image, or facilitate participation in social activities, should be readily available at centers that rehabilitate AWCLDs.

Research findings indicate that the majority of physically-disabled youth in the world are aged between 10 and 24 years, the formative years of adolescence when self-image determines psychological health (Voelker et al., 2015; Xu & Liu, 2020). Although a positive outlook has been demonstrated to reduce the effects of negative emotions such as paranoia (Thewissen et al., 2011), and has also been implicated in self-determination and coping (Morris et al., 2014) there is nevertheless, a void in our knowledge about how both amputee and non-amputee AWCLD cope and maintain a positive attitude while existing in the shadow of the supernatural. Adolescents with limb deformity have been reported to experience pride and joy while pursuing their dreams, and achieving recognition in spite of social stigma and attitudes

of significant others (Coates & Vickerman, 2016). How they realise dreams and achieve goals however, has yet to be researched. It is against this backdrop that the study investigated the role of positive emotions and self-determination in psychological health of AWCLD.

1.2 Aims and Objectives of the Study

This study investigated differences in psychological health, and perceptions of body image of amputee and non-amputee AWCLD, as well as the buffering effects of coping and social support. It also aimed to explore the lived experience of CLD. The variables of amputation, body image, perceived social support, positive emotions, coping strategies, and self-determination, all play a role in the investigation of psychological health of AWCLD.

The specific objectives were to:

1. Assess psychological health of amputee and non-amputee AWCLD in Ghana.
2. Examine the coping strategies used by AWCLD in Ghana.
3. Determine the perceived social support available to AWCLD in Ghana.
4. Explore the lived experiences and social roles of AWCLD in Ghana.
5. Understand the role of positive emotions in overcoming the physical, psychological, and social effects of adolescent CLD

1.3 Relevance of the study

Birth defects such as CLD, not only affect mobility, but also have an impact on body image, and consequently, the psychological health of the individual. Disturbances in body image in adolescence have been associated with emotional problems and maladaptive coping behaviours such as isolation, aggressive behaviour, and even suicidal attempts, and suicide. To add to this, the social construction of CLD influences how adolescents living with the

phenomena respond to rehabilitation, cope with their experiences, and participate in social activities.

Rehabilitation of CLD is currently informed by the medical model of disability, and focuses on providing treatment in the form of assistive devices (prostheses, orthoses, etc.), and physiotherapy. This positivist approach deemphasizes the influence of social perceptions on the psychological health of children and adolescents after treatment. Rehabilitation must therefore be multidisciplinary in its approach, in order to provide holistic management of adolescent CLD (Mduzana, Visagie, & Mji, 2018). Psychological support would aim at helping adolescents cultivate more positive emotions, broaden their outlook, and engage as much as possible in activities that will pave the way for them to take up fulfilling social roles. This study has the potential to inform the development of culturally-sensitive psychosocial support systems that address not only the physical functioning, but also the psychosocial and emotional sequelae of CLD, as these may be the real challenges adolescents need to overcome (de Jong et al., 2012; Varni & Setoguchi, 2010). This present study thus has relevance for research, policy and also for clinical practice.

The screening of newborn babies for birth defects is a healthcare priority of some countries. In parts of Africa, the first recourse when a child is born with a deformity is to abandon or kill the child. Many Ghanaians may thus not be aware that a child with CLD can be helped with assistive devices or perhaps amputation, or have access to education and/or inclusion in sporting activities. The findings highlight the need to educate mothers in antenatal clinics about the prevalence of CLD, not to cause fear, but to create awareness of CLD as a global problem with no supernatural causation. Familiarizing ourselves with perspectives of persons living with CLD will not only enrich existing knowledge, but contribute to changing the dominant negative narrative about living with a deformity, and stimulate more research on socially constructed concepts and representations of birth defects.

CHAPTER TWO

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

2.0 Introduction

The variables of amputation, body image, social support, positive emotions, coping strategies, and self-determination, all play a role in the investigation of psychological health of AWCLD. Thus, their descriptions, roles, and rationale informing their selection are considered in this chapter. Also in this chapter, specific theories that shed light on the factors associated with the psychological health of AWCLD are discussed. These theories, the Self-Determination Theory (Ryan & Deci, 2000), the Broaden-and-Build Theory of Positive Emotions (Fredrickson, 2004), and the Buffering Effects Model of Social Support (Greenglass, 2006) are extensively examined to determine how they support the current study. These theories together underscore the need for interventions that specifically target the needs of AWCLD in Ghana.

An analysis of related empirical studies follows the theoretical review, as well as the research questions and hypotheses. The rationale for a mixed methods design and operational definitions of the key terms used are also presented in this chapter.

2.1 Theoretical Framework of the Study

2.1.1 The Broaden-and-Build Theory of Positive Emotions

Fredrickson's (2004) theory suggests that positive and negative emotions play different roles in individual processing and personal development. For instance, positive emotions broaden or expand thought-action capabilities and enable the building of personal resources such as physical, intellectual, social and psychological resources. The theory also

asserts that positive emotions can reduce or “undo” the effects of negative emotions such as depression, anxiety, suicidal ideation, and posttraumatic stress. The transformation process may begin with the experience of joy, pride, or triumph, and lead to creative ways of thinking (or problem-solving). These novel ways of thinking or dealing with problems become lasting adaptive personal resources that the individual falls on, and which ultimately lead to increased psychological health outcomes (Tugade & Fredrickson, 2004).

The Broaden and Build Theory of Positive Emotions has been used widely to demonstrate that positive emotions fuel individual differences in resilience and coping mechanisms (Poudel et al., 2020; Tugade & Fredrickson, 2004; Varas-Diaz, 2016). It has also been used to demonstrate that over time, individuals who experienced more positive emotions became more resilient to adversity (Fredrickson & Joiner, 2002). Garland et al. (2015) suggest that specific positive emotions or mindfulness increase cognitive flexibility and expand cognitive scope, which results in a deeper capacity for finding meaning and engaging with life.

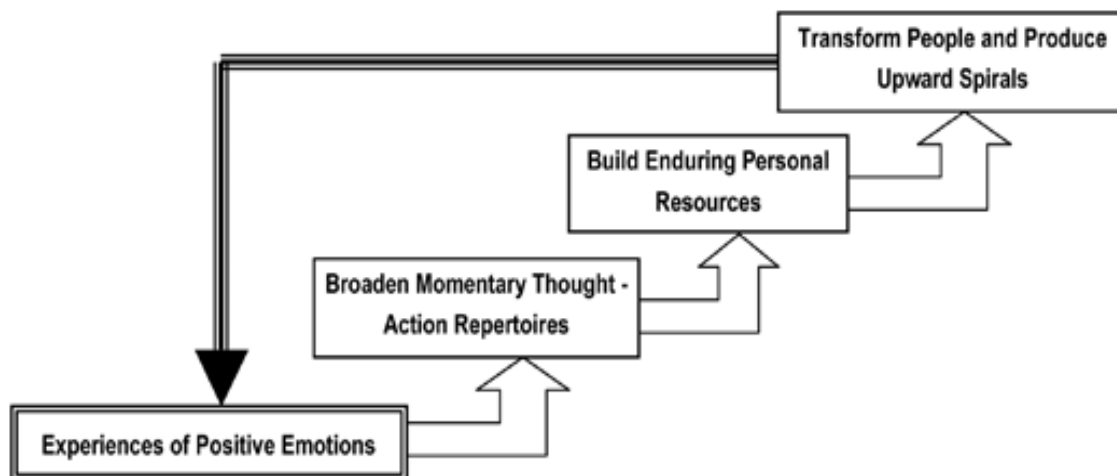


Figure 2.1: *The Broaden and Build Theory of Positive Emotions (Adapted from Han and Patterson, 2007)*

Although there appears to be a consensus that cognitive, behavioural, and nervous system changes are involved in the subjective feeling of positive emotion, critics argue that definitions of what may be considered ‘positive’ emotions vary from one culture to another (Kitayama, Mesquita & Karasawa, 2006). In addition, some researchers find the definition of emotions problematic, and argue that the term is value-laden, and recommend that future studies lay a more coherent theoretical foundation for the concept of positive emotions (Lazarus, 2003; Moors, 2009). Cavanagh and Larkin (2018) have called into question the conceptual framework and methodology used in arriving at conclusions about the ‘undoing’ power of positive emotions in optimizing wellbeing in individuals by creating more cognitive neural networks in the individual, and helping them build a variety of enduring personal resources. Other researchers have critiqued the role of personal emotions and cognitions in the formation of beliefs and attitudes (Critcher & Gilovich, 2010).

In this study, experiences of positive emotions in AWCLD, and the roles that these emotions play in self-determination, were explored to determine if experiences mirror the levels of psychological distress, body image, and coping strategies.

2.1.2 Self-determination Theory

According to Self-Determination Theory posited by Ryan and Deci (2000), there are three universal needs and urges that if met, help individuals make choices, actualize their potential, and function optimally, with a focus on self-motivation and self-determination. They identified competence, relatedness and autonomy as needs that must be nurtured by the social environment in which the individual inhabits. Competence refers to the need to be in control, and experience mastery of the outcome of one’s behaviours. Relatedness is a need to belong, to be part of, and connected to others, and experience caring and support from others, while

autonomy is described as the urge to be the causal agent of one's own life and be responsible for one's decisions and actions (Ryan & Deci, 2000). The theory also focuses on how much an individual's behaviour is motivated more intrinsically, than by external factors (Ryan & Deci, 2000).

Critics of the self-determination theory have however pointed to flaws in the theory. For instance, there have been arguments that the theory fails to explain the role played by both intrinsic and extrinsic motivational factors in academic achievement (Hosseini et al., 2016). These researchers argue that in a quantitative assessment of self-determination for instance, a student may achieve good grades in school, not because they particularly want to excel (intrinsic), but because doing so would please their parents or teachers (extrinsic). This type of determination is more in tandem with social learning theory. In contrast, critics argue that individuals do indeed rely on others to be motivated, but more often on their own perceptions, and emotions (Critchler & Gilovich, 2010; Guadagno, Lankford, Muscanell, Okdie & McCallum, 2010; Mamah, 2016).

According to Ryan and Deci (2000) however, the universal needs of competence, autonomy, and relatedness, must be carefully examined qualitatively, through phenomenological lenses to determine how they are reflected in the self-esteem of the participants, and how these components individually, or collectively, influence psychological health outcomes.

2.1.3 The Buffering Effects of Social Support Theory

The Buffering Effects of Social Support Theory (Greenglass, 2006) is the third explanatory proposition guiding this study. The theory suggests that social support functions as a buffer against stressors and helps individuals foster coping competencies that change the

threatening values of stressors in two very important ways. Firstly, it directly enhances well-being through satisfying human affiliation, affection, and safety and by strengthening feelings of self-esteem and self-efficacy, thereby ensuring that socially supported individuals experience fewer symptoms of psychological distress. Family ties, peers, and involvement in social activities can also offer a psychological buffer against stress, anxiety, and depression. There is in addition, an integral relationship between social support and proactive coping, especially the support of peers (Stanish & Temple, 2012; Stewart, Barnfather, Magill-Evans, Ray, & Letourneau, 2011).

Interestingly, peer support has been reported to have negative results, where instead of buffering against stressors, individuals have reported increased distress levels (Camara, Bacigalupe, & Padilla, 2017; Winter et al., 2017). Critics of the buffering theory also argue that peers encourage maladaptive coping strategies like substance abuse, bullying, social withdrawal, and even self-harming behaviours (Taylor & Stanton, 2007; Winter et al., 2017). Social support is sometimes too, not guaranteed in cultures that ascribe birth defects to supernatural entities. It is therefore examined in this study to determine its influence on choice of coping strategy, and how it buffers adolescents against stressors associated with CLD.

2.1.4 Summary of Theoretical Underpinnings

In summary, all three theories that underpin this study suggest that adolescents who perceive that the support they receive from family, friends, significant others, and even their communities and social networks as adequate, are buffered from the effects of disfigurement and disability caused by CLD. This in turn, fosters the cultivation of positive emotions, a positive sense of self, and proactive coping strategies which spiral into the new ways of thinking and acting that facilitate social integration, and improve psychological health.

Models and Definitions of Disability

Disability is a fact of life, and according to Degener (2016), almost everyone will, at one point in their lives, be personally affected by it. The term ‘disability’ itself has been researched and re-conceptualized by many (Chataika & Mckenzie, 2013; Degener 2016; Michailakis, 2003; Oliver, 2013), and used interchangeably with the terms ‘impairment’ or ‘handicap’. By this definition, it appears that the term itself is socialized, and puts the individual at a disadvantage in terms of membership, even within a family unit, and especially in the African context, which is the focus of this study (Chataika & McKenzie, 2013).

WHO has adopted ‘disability’ as the umbrella term for impairments, activity limitations, and participation restrictions (WHO, 2010). This revised definition now conceptualizes disability as “any condition of the body or mind” (impairment) – in other words, physical or mental limitations, “that makes it more difficult for the person to do certain activities” (activity limitation) – in other words, limited functional ability, “and interact with the world around them” (participant restrictions) – in other words, limited involvement in life situations. With this definition in mind, AWCLD may be described as being impaired by their birth defect, and handicapped by limited function, which results in them being classified as disabled and restricted in participating in social roles and activities (Kassah, 2008, 2012).

The social model of disability provides a model for understanding disability - not as a disease but rather a product of society, that is, socially constructed. By this theory, individuals are actually ‘disabled’ by the failure of society (Michailakis, 2003; Oliver, 2013). This model of disability also defines the context in which the behaviours of tolerance and intolerance of these differences occur, and deals with the issue of stereotyping and /or categorizing of individuals or groups, and which eventually becomes the reality of the whole society, regardless of facts that refute the labelling or categorization. Lately, there has been a shift from

the structural social model of disability as manifested by the Convention on the Rights of Persons with Disabilities, to an improved social model of disability that highlights the individual's human rights, and it has been suggested that the human rights model of disability certainly improves the social model of disability (Degener, 2016). This shift however, has limitations - individuals may have developed the disability from an existing medical problem.

Cross-cultural perceptions of deformity

The social constructions of birth defects and deformities usually shape the psychosocial experiences of families, and communities that these infants are born into, and the beliefs about the portent of such births usually breed fear and negativity in the community (Wachege, 2012). As a result, many such births go unreported (Bermejo-Sanchez et al., 2011). The beliefs are that these children are cursed or have been touched by the 'evil eye', or have had a spell cast on them while yet unborn, and would therefore be harbingers of bad luck if preserved alive (Avoke, 2002; Fiasorgbor & Ayagiyire, 2017). These unfortunate infants are more often than not, abandoned in forests, thrown into rivers (river-children), or destroyed immediately after birth in what a UN report terms 'mercy killing' (Adeyemo et al., 2016; Bello et al., 2013; UNPF, 2018). Children who survive usually live terrible stigmatized lives. Most often, maternal grandmothers are sources of social support to both the children and their mothers, and may take over the caregiver role in order to assist their children get on with their lives, even encouraging them to totally forget about their children (Kresak, Gallagher, & Kelley, 2014). Beliefs about deformity and disability may influence how parents and other family members relate to, and behave towards those born with a defect, and parenting behaviour has been implicated in the psychological distress experienced by children and adolescents with physical disabilities (Bonsu et al., 2018; Cero & Sifers, 2013; Kassah, 2008; Rhodes et al., 2012).

Besides parents and family, other people in the lives of AWCLD have an influence on their self-perception, and possible negative reactions or distress (de Jong et al., 2012; Wachege, 2012). The beliefs of teachers, healthcare personnel, and the communities in which they live also determine the self-perception of this target group (Wachege, 2012). Despite the increase in awareness of causation of disability, barriers continue to exist for children born with, or who acquire a physical disability.

Around the world, the majority of expectant mothers look forward to the birth of their babies with feelings of joy and thankfulness and expect the new-born to be normal in all areas of functioning (Bonsu et al., 2018). After delivery, they usually leave the hospital or midwife with thoughts of a bright future for their child, and may, even at this early stage, speculate about the career path their child would take. When a child is born with a deformity however, the first emotions experienced by the new mother are usually of shock, followed by revulsion and despair (Bonsu et al., 2018; Durowaye et al., 2011; Lemacks, Fowles, Mateus, & Thomas, 2013; Munyi, 2012; Quinn & Mahat, 2019). This was also the observation by Bonsu et al. (2018) in their study of Ghanaian mothers' first reaction to the birth a child with orofacial cleft-lip and palate.

When a child with a deformity reaches the age when he realizes that he is different from his peers because he has a missing limb, or because a wears a prosthesis, he may start to feel awkward, depending on the way he has been brought up to view his condition (Smith, 2006). By adolescence however, body image concerns may have surfaced, and he may start to suspect that his future may not turn out as bright as his peers, so he may consider career options that would not require that he display his missing limb or prosthesis (Smith, 2006). If he has not received encouragement from significant others such as parents, siblings, peers or teachers, he may not even expand his horizons (de Jong et al., 2012; Guadagno et al., 2010).

The African Concept of Disability

In most parts of Africa, children with CLD are often described as ‘cursed’, or even, evil (Munyi, 2012; Wachege, 2012). This is so, especially in sub-Saharan Africa, where knowledge about causes of birth defects is very scanty (Adeyemo et al., 2016; Bello et al., 2013). Education for expectant mothers is often negligent about problems associated with pregnancy and childbirth, and the aetiology of anomalies and deformities (WHO, 2020). The construction of social knowledge is that babies with birth defects have been touched by the ‘evil eye’ or that the pregnant mother had a spell cast on her, perhaps because she was promiscuous, or violated a social norm (Wachege, 2012; WHO, 2020). Thus, although they acknowledge that CLD is real, the interpretation is that, it is caused by supernatural forces. When a child is born under those circumstances, the belief is reinforced and passed down as fact. Studies on CLD and other birth defects and anomalies have shown that parents are often anxious to find out the cause(s) of the phenomena (Adeyemo et al., 2016; Bello et al., 2013; Bonsu et al., 2018). Although these are usually of unknown origin, the medical model of disability relieves their anxiety by pointing to some genetic or environmental factors (Adu & Annan, 2008; Calder et al., 2017; Durowaye et al., 2011). On the other hand, in Ghana, perceptions about the causes of disease and deviation coexist with the medical model (Avoke, 2002; de Graft Aikins, 2012).

Disability in the Ghanaian Context

Studies of disability in Ghana report that at one time, there were variations in perceptions of deformity and disability from one ethnic group to another (Avoke, 2002; Munyi, 2012). For example, Mamah, (2016) reports that among the Akans, a defect excluded an individual from participating in many social activities or holding certain positions. An amputation acquired through trauma or disease would even cause his destoolment as a chief.

On the other hand, among the Gas, deformed or disabled persons were held in high esteem and even revered as human representatives of the gods (Munyi, 2012). The disparity in perception of disability demonstrates the social constructions of deformity and disability in Ghana, and socio-cultural epistemologies of disability have rarely been underpinned by African theories (Avoke, 2002; Chataika & McKenzie, 2013; Munyi, 2012). Stating the case for differing worldviews of disability, Chataika and McKenzie (2013) point out the influence of theories imported from the global North as dominating and undermining indigenous theories of disabilities from different cultures, and especially African communities in ways of being and perceptions of disability (Chataika & McKenzie, 2013).

A study of perceptions of disability among the Yorogo-Yipala Community in Ghana by Fiasorgbor and Ayagiyire (2015) found that stigma and discrimination of the physically-disabled were not as widespread as they had hypothesized. Using focus group discussions, semi-structured interviews and observations in a mixed method study, the researchers examined the influence of perceptions of disability on attitudinal change towards persons living with a physical disability. The researchers discovered that although the study participants demonstrated positive perceptions about disability, the perceptions appear not to have resulted in any observable attitudinal change.

2.2 Review of Related Literature

In this section of the report, relevant literature related to the issues in this research have been synthesised and summarised.

2.2.1 Effects of Congenital Limb Deformity (CLD)

The effects of congenital limb deformity (CLD) are disability, pain, fear, depression, poverty, stigma, marginalization, low body image, low self-esteem, and a host of others (Baffoe, 2013; Burçu, 2014; de Jong et al., 2012; Gilg, 2016; Mamah, 2016; Xu & Liu, 2020).

Physical disability and functional limitations are the most common and most reported physical effects of CLD globally, and especially so when an amputation has been performed to reduce disfiguring effects, or increase mobility (Calder et al., 2017; Quinn & Mahat, 2019; Wilkins, McGrath, Finley & Katz, 2004). Even though individuals with CLD have lived with the condition from birth, and may perhaps have adapted to the shortages, amputation, and deformity, mobility or dexterity is impaired (Calder et al., 2017). These impairments interfere with speed at finishing tasks, strength, endurance, and even coordination (Quinn & Mahat, 2019). As such, functional limitations affect activities of daily living, including participation in social roles and activities (Michielsen, Wijk, & Ketelaar, 2010; Quinn & Mahat, 2019; Wilkins et al., 2004).

Individuals with physical disability may also experience somatic symptoms of chronic pain, cold sensitivity, and severe fatigue over many years, affecting functioning (Johansen et al., 2016). A report from Palestine found these symptoms to be prevalent among amputees (Heszlein-Lossius et al., 2018). In the clinical study of 254 participants in the Gaza strip, pain was the most frequent long-term complaint (in joints; 34%, back; 33% or phantom pain; 40.6%). Even though the amputations were traumatic in origin, the report highlights the physical sequelae of limb loss.

Prostheses, Orthoses, and Assistive Devices

Prostheses, which are typically fitted right away after amputation, replace parts lost by injury or missing from birth, or supplement defective body parts (Kahn, Javed, Rao, Corner, & Rosenfield, 2016). They may also be prescribed following the diagnoses of limb shortage, or a surgical procedure to correct a limb defect (Calder et al., 2017). A number of studies have investigated the role of prosthetic devices in the relationship between amputation, CLD, body image, and psychological health outcomes, and found prostheses to be very important in the overall rehabilitation of AWCLD as they usually serve to decrease body image concerns and increase self-esteem in the majority of users (Condie, McFadyen, Treweek, & Whitehead, 2011; Tamari, 2017). It has been suggested that prostheses not only restore near normal appearance and form, but also substantially reduce disability. Both amputees and non-amputees therefore benefit greatly from the prescription of prostheses to improve cosmetic appearance and function (Montesinos-Magraner et al. (2016).

Orthoses are invaluable devices used in correcting, bracing or enhancing the use of a body part that is not functioning as well as it should, especially as a result of a deformity or deficiency in those body parts (Barrios-Muriel, Romero-Sánchez, Alonso-Sánchez, & Salgado, 2020). Unlike prostheses, the defective body part is still present, dysfunctional. An adolescent with club feet may require orthotic devices like calipers to brace the feet in order to reduce pain when walking, and also to improve function (Dobbs & Gurnett, 2009).

According to Griffet (2016), children with limb differences or loss, tend to adapt remarkably well to a prosthesis, far better than adults, although there may be times when a parent thinks the child should be using a prosthesis, and the child does not want to. Research has shown that some adolescents find artificial limbs, especially upper limb prostheses cumbersome, uncomfortable, and not exactly pleasing to the eye, and would rather do without (Sims, Donovan-Hall, & Metcalf, 2020). Their bodies might also reject the device, even when

it is fitted before the age of one (Huizing, Reinders-Messelink, Maathuis, Hadders-Algra, & van der Sluis, 2010; Sims et al., 2020). Indeed, some studies have argued that prosthetic prescription is not always the best option, and findings from studies have shown that pain, which causes psychological distress, is actually exacerbated by prosthetic use, especially after the first fitting, or when surgical revisions are performed (Condie et al., 2011; Khan et al., 2016; Schaffalitzky, Gallagher, Maclachlan, & Wegener, 2012).

To gain a better understanding of how children and adolescents view upper limb prostheses in terms of activities of daily living, Sims et al. (2020) conducted a thematic analysis of data collected from 8 children and adolescents in a focus group discussion and individual interviews. The researcher reported that participants had mixed views about prostheses, but agreed that prostheses were useful in helping them interact socially with others. Participants however determined to not use them for activities of daily living, as it caused a hindrance in those activities, and also restricted their movement (Sims et al., 2020).

Phantom limb sensations have been reported by individuals who were born without limbs. Years ago, Melzack (1997) reported that 20% of children with CLD in a study experienced it, and described the sensations as being painful, suggesting that there is some form of neural pathway that is genetically determined in the body that enables the sensations to be perceived. That report has since been debunked and arguments have been made that sensations may be caused by habitual observation of other people moving their limbs, which may contribute to the conscious experience of aplastic phantoms and not by motor commands to the absent limb (Brugger et al., 2000; Reilly & Sirigu, 2011). Although rarely occurring in children under the age of ten, phantom limb sensations appear to be experienced more by adolescents (Wilkins et al., 2004). In the same Wilkins et al. (2004) study, the researchers reported that amputee participants as well as participants with CLD experienced phantom sensations.

Psychological Health of Adolescents with CLD

Durmuş et al. (2015) examined the mental health of amputees to determine the relationship between physical symptoms of pain, functional status and body image disturbances. They compared psychiatric symptoms of 50 male lower limb amputation (LLA) patients with or without neuropathic pain. The results revealed significant differences in psychological health symptoms, (especially in the neuropathic pain group) in several symptom domains including somatization, interpersonal sensitivity, depression, anxiety, anger-hostility, trait anxiety and QOL. The researchers concluded that psychiatric symptoms other than depression and anxiety may be present in amputees with neuropathic pain.

Psychological Effects of CLD

Psychological distress associated with CLD is usually expressed as depression, phobic anxiety, paranoia, low body image, and hostility towards others (Montesinos-Magraner et al., 2016). Adolescents in general, are reported to have more fragile self and body image concerns, and a sensitivity to peer evaluation than any other age group, and consequently experience more mental health problems including paranoia, depression, suicidal ideation, and low self-esteem (Lee et al., 2014; Poudel et al., 2020; Voelker et al., 2015). The suggestion therefore, that disfiguring limb defects and amputations may exacerbate already existing body image concerns, and consequently affect psychological health of adolescents has been made by Varni & Setoguchi, 2010; Xu & Liu, 2020).

To test the hypothesis that amputations would have an impact on body image and self-esteem, and that amputees might also experience a higher degree of anxiety and depression, affecting quality of life, Holzer et al. (2014), sent a 118-item survey to 298 patients (149 amputees and 149 controls) in a cross-sectional survey conducted in 3 centers. The participants responded to items on body image, self-esteem and a health survey questionnaire. Findings indicated significant positive correlations between body image and self-esteem. A significant

correlation was also found between body image and quality of life, indicating that amputation has a negative influence on an amputee's body image, self-esteem and consequently his quality of life. Phantom pain sensation was also implicated in the low self-esteem scores observed.

Sinha et al. (2011) investigated factors that affect the physical and mental health of adolescents and older amputees from a rehabilitation center, a limb-fitting center, and 4 limb-fitting camps, as well as a non-clinical adult sample in a cross-cultural study, in and around Mumbai, in India. They identified important background and amputation related factors which affect quality of life (QoL). The identified predictors of PCS and MCS in QoL were, use of an assistive device, use of a prosthesis, comorbidities, phantom-limb pain and residual stump pain, including age and time since amputation.

Gilg (2016) also studied the effects of body image on a sample of 207 adults aged 21 years and older with lower-limb amputations. Measurement of body image was carried out using the Amputee Body Image Scale. Participants differed in levels of body image, depending on the number of limbs amputated and length of time since amputation, and were more dissatisfied with their body image six to ten years after amputation.

In Africa, studies on both body image, and self-esteem of physically-disabled adolescents have replicated findings reported in other parts of the world. For instance, in a study in Nigeria involving one hundred and eighty-six disabled and non-disabled participants selected from the South-Western States, Omolayo (2009) found that self-esteem, and self-motivation were not adversely affected by disability. This finding was supported by a study from Ghana on the self-determination, motivation and coping strategies of 12 physically-disabled mothers with suicidal ideation (Acheampong & Aziato, 2018).

Social Effects of CLD

Sociocultural beliefs about birth defects such as cleft-palate, spina bifida or limb defects persist in many parts of the world, but especially in sub-Saharan Africa, and influence social attitudes, evidenced usually by unsavoury comments passed in the hearing of affected individuals (Adeyemo et al., 2016; Bannink, 2017; Quinn & Chaudoir, 2009). Stigmatization consequently has an impact on the self-perception of adolescents living with CLD. Self-perception of AWCLD determines their career choices, intimate relationships, or integration into the wider society.

Stigma refers to the devaluing and subsequent dehumanisation of a person or groups of persons, characterized by prejudice and results in widespread disapproval and discrimination. It is characterized by discontent or rejection of a person as a result of unwanted characteristics, and deals with the issue of stereotyping and /or categorizing of individuals or groups, and which eventually becomes the reality of the whole society, regardless of facts that refute the labelling, prejudice or discrimination (Avoke, 2002; Bos et al., 2013; Goffman, 1963; Mamah, 2016; Munyi, 2012). Discrimination has been reported to induce psychological distress in many disabled persons. This is because socio-cultural perceptions about amputation, stigmatization, religious and traditional beliefs that portray individuals with disabilities as ‘cursed’, reinforce the negative attitudes towards those who have lost limbs, and these perceptions are linked with anxiety, depression and suicidal thoughts in affected individuals.

While stigma can occur at individual, interpersonal and societal levels (Bos et al., 2013) public stigma, stigma by association and structural stigma are also categories of stigma that are dynamically interrelated and represent a model (Bos et al., 2013). Public stigma, which is the core of the model consists of behavioural, affective and cognitive reactions of those who stigmatize. Self-stigma reflects the social and psychological impact of possessing a stigma and

includes both the apprehension of being exposed to stigmatization and the potential internalization of the negative beliefs and feelings associated with the stigmatized condition (Scocco, Preti, Totaro, Ferrari, & Toffol, 2017).

There is also anticipated stigma, which according to Quinn and Chaudoir (2009) “refers to the degree to individuals expect that others will stigmatize them if they know about the concealable stigmatized identity” (Quinn & Chaudoir, p. 636). Some presentations of CLD may be easy to conceal, for example, a shortened leg may be concealed with a shoe adapted for the purpose, an orthosis, or a prosthesis. For some adolescents, the impact of this type of stigma, may even result in higher levels of psychological distress.

Quinn and Chaudoir (2009) reported that increased anticipated stigma, greater centrality of the stigmatized identity to the self, increased salience of the identity, and possession of a stigma that is more strongly culturally devalued would predict high levels of psychological distress. The researchers sampled 300 participants who possessed 13 different concealable stigmatized identities including mental illness, sexually related activity, previous drug use, sexual orientation, and appearance issues. Their hypotheses were supported, and demonstrated a relationship between external stigma, that is, the cultural devaluation of a person or group, self-stigma, which is internalization of those devaluing beliefs, and distress.

The findings in Africa are very similar to those reported by studies on Western populations. A study in Nigeria explored the experience of stigma of parents and individuals with cleft-lip and palate, and reported that besides the attitudinal discrimination, experienced by 22% of respondents, there were also experiences of social and structural inequalities due to sociocultural beliefs about the phenomenon of cleft-lip palate (Adeyemo et al., 2016). Stigmatization may sometimes even be expressed by family members (Adeyemo, et al., 2016).

Occasionally, more than one family member may have a CLD, reinforcing the belief of

a ‘curse’, which may ultimately lead to labelling of the entire family, and further discrimination and stigmatization (Durowaye et al., 2011). Conclusions drawn from a study in Kenya were that, the belief in curses as responsible for birth defects, and the consequences on the ‘innocent’ victim, are passed down from generation to generation, so that there is a never-ending supply of stigmatizing behaviours towards individuals living with birth defects (Wachege, 2012). Mahomed (2017) has argued, that in spite of the increase in disability discourse, the problem of stigma, attendant psychological distress, and the social disadvantage that result, become unsurmountable barriers to inclusion, preservation, and fulfilling social roles.

In Ghana, Bello et al. (2013) aimed to gain insight on the knowledge of pregnant women about birth defects in Ghana, and explored a sample of 443 pregnant women recruited from the antenatal units of the Korle-Bu Teaching Hospital, Achimota Hospital, and the Ridge Regional Hospital, in Accra. A researcher-administered questionnaire, categorized into three levels: low knowledge (0–4), moderate knowledge (5–8) and high knowledge (9–12) levels was used to collect data from the participants and their knowledge about birth defects, and analysed using percentages. The study found that almost half of the participants (48.1%) believed that birth defects were supernatural in origin. implying that knowledge about birth defects was influenced by traditional beliefs. Based on their findings, the researchers recommended that more awareness about the aetiology of birth defects be created by healthcare providers.

The lived experience of children with varying degrees of disability have been explored from the perspective of the participants in cross-cultural studies, and these same areas of stigma and discrimination have been identified (Mamah, 2016). In a study exploring the agency of 7 adolescents in Ghana, Mamah (2016) reports that, far from being burdens on their families and societies, physically-disabled adolescents have agency, and they demonstrate agency in their attitude towards life, and school, despite the restrictions placed on them by various avenues of stigmatization. Self-stigma is however identified in this study and suggests that disabled

individuals are less inclined to interact with others who are not disabled, as there is the tendency to be paranoid about offers friendship, often affecting intimate relationships (Mamah, 2016). Nevertheless, and regardless of anticipated stigma, participants demonstrated high levels of self-determination.

Mamah (2016) identifies 3 additional areas of discrimination against people living with a disability in Ghana despite the passage of the Persons with Disability Act, 2006 (Act 715). The Act, like a beacon in the night, held hope for persons with disabilities due to its promise of equality for all. Inclusion into mainstream society is listed as a right of all persons, as well as the right to a family life, the right to participate in social or recreational activities, the right to equal living conditions, the right to access to public places, and the right to freedom from exploitation, abuse, and discrimination. Disability issues in education have been highlighted in studies on the segregation of children and adolescents with special needs, by debating the inclusion of persons with disabilities in everyday activities (Mamah, 2016; Presler-Marshall et al., 2019).

Abuse of children and adolescents with deformities and disabilities by relatives and members of the community have however been reported by studies on quality of life, psychological health, satisfaction with life and self-esteem studies of physically-disabled persons (Adeyemo et al., 2016; Kassah, 2008; Kassah, Kassah, & Agbota, 2012; Omolayo, 2009; Presler-Marshall et al., 2019). Adolescents with disfiguring conditions reportedly used by their parents to earn money by doing menial jobs, or resort to begging at street corners as work (Kassah, 2008; Kassah et al., 2012). Some studies have reported that many such adolescents, especially girls are subjected to sexual abuse by people who offer them jobs or places to stay once they reach adolescence, and parents can no longer afford to take care of them (Lin, Yen, Kuo, Wu, & Lin, 2009; United Nations Population Fund, 2018). In addition,

the lack of a supportive environment for many adolescents may facilitate early sexual experiences for physically-disabled adolescent females (Somefun & Odimegwu, 2018).

According to a 2018 report by the United Nations Population Fund, about 200 million young people living with a disability are aged between 10 and 24 years. Several studies have investigated and explored the lives of these individuals, and reported harrowing accounts of discrimination and violence towards them (Lin et al., 2009; Presler-Marshall et al., 2019; Zuurmond et al, 2018). The report also determined that girls and young women with learning disabilities were 10 times more likely to experience sexual violence than boys. The UNPF report revealed that discrimination against females born with disabilities such as CLD occurs right after birth, and they are more likely than males to be destroyed at birth.

Findings from a Taiwanese study carried out between 2002 and 2007, on the treatment of individuals living with disability details the abuse experienced by these individuals. According to Lin et al. (2009), individuals with disability were 2.7 times more likely to be sexually assaulted than individuals in the general public. Another report by the United Nations Population Fund (2018) points out that many physically and intellectually disabled individuals are systematically abused, with more females than males experiencing sexual violence. This is because they are seen as less human and not deserving of protection.

In sub-Saharan Africa, there are reports of sexual activity among many adolescents who have little parental support or stable family structure. Research by Somefun and Odimegwu (2018) examined the role of family and community as protective factors in the sexual debut of male and female adolescents aged between 15 and 17 years from 12 countries in the sub-Saharan region, including Cameroun, Rwanda, Liberia, Nigeria, and Zimbabwe. Results however were significant for males but not for females, and highlighted the importance of a stable family structure in helping adolescents delay the onset of sexual activity.

The age of sexual debut in Africa however, has been argued to be much earlier than was reported by Somefun and Odimegwu (2018). Maart and Jelsma (2010) carried out a study in South Africa to compare the sexual behaviours of physically-disabled adolescents with non-disabled peers. Alarming findings from the study showed that the age of sexual debut was much earlier than expected at 12 – 17 years, and they were at equal risks of developing HIV. Shandra and Chowdhury (2012) however suggest that adolescent girls with either intellectual or physical disability engage in sexual behaviours at much the same age as their non-disabled counterparts, and the first sexual encounter is just as important, whether intended or not.

Females with birth defects are also less likely to receive an education, vocational training, or even access to prostheses or other assistive devices that would increase their functional ability and decrease any body image concerns (Presler-Marshall et al., 2019). The inaccessibility to education and training facilitates their exclusion from society, and renders them unemployable (Naami, 2012, 2015; Presler-Marshall et al., 2019; UNPF, 2018). Challenges continue to exist for individuals who find jobs, even after they have proven their ability and capability at handling specific duties, as the perception that disabilities signify inability usually persists and fuels the expression of negative attitudes (Naami, 2015).

The extant reports confirm that financial constraints, socio-cultural attitudes, caregiver burden, and affiliate stigma are identified causes of parental/caregiver neglect (Poudel et al., 2020; Presler-Marshall & Jones, 2019). In a study that sought to investigate the extent and impact of neglect on adolescents' psychological health, Presler-Marshall et al. (2019) engaged 132 adolescents with disabilities and their caregivers from Jordan and the State of Palestine. Their findings from in-depth interviews with the physically-disabled participants highlighted the fact that there was limited access to schooling, skills-building for economic empowerment, health care, and the psychosocial support or opportunities to develop the independence of adolescence, and the endorsement of their successful transition into adulthood. The

inaccessibility to education and training facilitates exclusion from society, and renders most adolescents with disabilities unemployable in later life (Presler-Marshall et al., 2019).

In a more recent study, Poudel et al. (2020) engaged 348 Nepalese early adolescents in a study to determine how self-esteem mediated the relationship between perceived social and their psychological well-being. The Rosenberg self-esteem scale, as well as the Multidimensional Scale of Perceived Social Support, and General Health Questionnaire were used to collect data, and the study reported that both adolescent males and females were more oriented towards their families than their friends for social support and those who perceived adequate social support also reported higher self-esteem, contributing to their overall psychological well-being.

WHO (2010) has reported on the devastating effects of parental self-stigma and familial neglect on children and adolescents with disabilities. Such neglect from parents and caregivers, if unheeded, often leads to severe emotional disturbances in the neglected child. Indeed, parental behaviour has been implicated in suicide-related behaviours in adolescents (Cero & Sifers, 2013). Rhodes et al., (2012) argue that neglected children are more at risk of developing suicidal ideation if neglected before age 2 years.

In Africa, females with birth defects are also less likely to receive an education (Avoke, 2002; Bonsu et al., 2018). Kassah (2008) theorized that the neglect of needy children and adolescents is more likely when parents are unemployed, and/or experiencing poverty, and suggested that many such individuals were forced into begging as work. Chataika and McKenzie (2013) also recognized the impact of poverty on disabled children and their families. These findings had implications for further research into why this occurs in families with disabling conditions. The fact that hospital stays can be very expensive and extensive, especially when a procedure to treat a condition is a complex one, putting more pressure on the

family's financial resources must also not be overlooked (Baffoe, 2013; Chataika & McKenzie, 2013).

A qualitative study in Ghana by Kassah et al., (2012) exploring the education of children with disabilities, examined various forms of abuse meted out to them. The study utilized data from 3 key informants (a parent of a child with learning disabilities, and owner of a private school for special children, an administrator at a special education unit of the Ministry of Education, and the deputy head of a school for children with disabilities) and aimed to increase awareness on the abuse experienced by disabled children.

Zuurmond et al. (2018) carried out a qualitative study in Ghana to determine if training provided to 18 caregivers of children with cerebral palsy would make a difference in the care they gave to their children. The participant from four districts, were interviewed up to three times over 14 months, to assess impact and the reasons for any changes. In assessing the impact of the training, the researchers identified factors that facilitate the neglect of children with disabilities. These included low levels of knowledge, and social isolation that caregivers endured due to the stigma attached to their children's birth defect. In addition, they identified single parenting, (the fathers usually abscond after the birth of a deformed child), and poverty.

There are educational setbacks from physical disabilities that arise from birth defects (Fiasorgbor & Ayagiyire, 2015; Mamah, 2016; Presler-Marshall et al., 2019). As many of these children have limited function, they usually start school late and miss kindergarten, so that it is not uncommon to find adolescent children with birth defects much older than their classmates (Bannink, 2017). In addition, some of the more serious birth defects occur in conjunction with other anomalies so that the children are often ill or incontinent or both (Bannink, 2017; Zuurmond, 2018). Others may require constant attention as children born

without arms (phocomelia) usually have balance issues that make them prone to falls and injuries, which may consequently undermine their psychosocial wellbeing (Griffet, 2016).

The economic effects of disability are usually felt by children and adolescents when their support systems are unable to help in the acquisition of assistive devices, or the cost of surgical interventions (Kassah et al., 2012; Mamah, 2016). The Ponseti method for treating children with idiopathic clubfoot, a very common CLD which affects almost 200,000 children a year, has been widely reported to reduce disability and improve appearance of deformity (Boakye et al., 2016; Grimes et al., 2016; Khan et al., 2016). The cost-effective Ponseti method (less than USD 200 or equivalent GHS 1100) may however remain out of the financial reach of many families with children with the condition in low-income countries, thus condemning them to a life of disfigurement and disability (Grimes et al., 2016).

In a tibial hemimelia (shortened or absent tibia), which manifests as a shortened leg with deformity in the knee and ankle (Figure. 1.3) a prosthesis fitted after amputation of the badly deformed limb is reportedly the most effective treatment (Calder et al., 2017). Weight gain, wear and tear on the device, changes in the needs of the individual (in the case of adolescents, simply outgrowing the prosthesis) however, determine the lifespan of the device, and how many times replacements will be required, although on average, replacements are needed every 3 – 5 years (Calder et al., 2017). In Ghana, replacements range between GHS 2,000 - 2,500 (USD350 - 400), which many families are unable to afford, and for these needy adolescents, the financial drain on their support system impacts satisfaction with life (Mamah, 2016; OTC, 2018). A great many children and adolescents are consequently forced to continue using prostheses that may be too small and thus do not fit properly (Khan et al., 2016; Mduzana et al., 2018).

According to Johansen et al. (2016) individuals with upper-limb deformities have a higher rate of emotional disturbance. There are in addition, a multitude of related problems, including maladaptive coping behaviours such drug and/or alcohol consumption, greater disability, poorer social functioning, and a loss of functional independence may result from difficulties in psychological adjustment. Disturbances in body image appear to be the most reported psychological adjustment issue that impacts their psychological health (de Jong et al., 2012; Waite & Freeman, 2017; Winter et al., 2017). An unhealthy body image in adolescence has also been associated with emotional problems and maladaptive coping behaviours such as substance abuse and isolation (Winter et al., 2017). The attitudes and behaviours of family, friends, and an individual's community play a significant role in determining how they cope with the condition.

Along with the identified physical, psychological, economic, and social effects of disability is the experience of psychological distress that results from the unhealthy sense of being different or 'cursed'. In his study of curses and cursing among the AKikūyū of Kenya, Wachege (2012) writes:

These category of curses run across generations being transmitted from the fore parents who are said to have done something seriously wrong or ignored with contempt some cultural or traditional taboos or norms of morality or family ethics or ancestral solidarity. Arguably, the victim members can do nothing about it. Neither can the aforesaid curses be eradicated. The rationale is such curses are not acquired but are inborn. Perhaps, the curse victims are predestined to be so cursed and (innocently) suffer the consequences. It is possible that the victims may be individually or personally not culpable, nevertheless, they are compelled to live with and die in such curses (p.2).

Wachege (2012) makes a fine distinction between the social construction of birth defects and the effects of the meanings ascribed to the phenomenon. Curses are invoked to pacify offended parties, guarantee compliance with unwritten moral codes, and more importantly, preserve the fabric of culture. Any infraction of the outlined therefore threatens the community, and a birth defect in the family responsible for the infraction absolves the community of sin. Negative attitudes towards the embodiment of disobedience, that is, children born with deformities, actually serves to placate the wronged, and maintain peace and order – somewhat similar to Azazel, the ‘scapegoat’ that bore the sins of the Israelites, and was ‘cast out’ into the desert to atone for the sins of the people (Leviticus 16:8).

2.2.2 Adolescence -The Transition Years

Adolescence is defined as the transitional period from puberty to adulthood, and traditionally believed to occur between the ages of 10 and 19 years, although there are a few cultural differences regarding the onset (Dorn & Biro, 2011; WHO, 2010). This period is divided into three age groups, namely early (10 - 14), middle (15 - 17), and late adolescence (18 - 21). These groupings presuppose that adolescents exhibit different physical, cognitive, emotional, social, and behavioural processes at each stage of development (Choudry, Blakemore, & Charman, 2006; Sawyer, Afifi, Bearinger & Patton, 2012). Some researchers have however propounded theories that challenge the conventional age groupings by basing their arguments on biological maturity where females develop much earlier than males (Casey, Duhoux, & Malter, 2010), and acquisition of social roles such as drinking alcohol, sexuality and sexual reproduction, or getting a driver’s licence. Adolescents have been reported to take on, especially in times of adversity, responsibilities and roles traditionally meant for adults, taking care of younger siblings, ailing parents, as well as manage households, in the absence of a maternal figure, or sometimes, both parents. Adolescent males, at very young ages,

reportedly work in fields, and factories, and some even engage in begging as work to feed their families (Jaworska & MacQueen, 2015; Kassa, Luck, Birru, & Riedel-Heller, 2014; Kassah, 2008).

2.2.3 Psychological Health and Distress

Psychological health is the measure of health and positive functioning with a focus on emotional wellbeing, competence, and coping. It encompasses physical, cognitive, behavioural, social, and psychological aspects of an individual, and the ability to express and modulate emotions, ability to cope with adversity, as well as function in social roles (Galderisi et al., 2015; Hattie, Myers, & Sweeney, 2004, Keyes, 2002). Although viewed as a positive attribute to possess, it is not very easy to define psychological health in general terms, as each of the components is itself conceptualized from various perspectives namely, psychological, sociological, and religious perspectives (Hattie, et al., 2004). In times of adversity, such as when dealing with disability, or disaster for example, the individual who is able to redefine the situation in order to feel good, and acts upon those feelings in a proactive way, is said to be psychologically healthy.

Psychological distress on the other hand, may be viewed as the reverse of psychological health, and is the term used generally to describe the emotional suffering generated by thoughts and behaviours, and which negatively impact an individual's ability to express and modulate emotions, cope with adversity, as well as function in social roles (Arvidsdotter, Marklund, Kylen, Taft, & Ekman, 2015). Common symptoms of distress include depression, anxiety, paranoia, obsession-compulsion, somatization, and interpersonal sensitivity. The anxious, depressed or paranoid individual can thus be described as being psychologically unhealthy (Arvidsdotter et al., 2015; Derogatis & Meliseratos, 1983).

Somatization is a psychological distress symptom that has the potential to impair functioning, and occurs when an individual's excessive psychological concerns and emotions are converted into physical symptoms (Mallorquí-Bagué, 2016). It is usually understood to be an example of the mind-body connection, such as when stress manifests as a headache, or when an anxiety attack is experienced as chest pain (Jenkins, 2020; Mallorquí-Bagué, 2016). Pain, for example, is a common complaint of individuals with physical disabilities, as well as chronic fatigue, and weakness in parts of the body (Heszlein-Lossius et al., 2018; Johansen et al., 2016). It is therefore likely, that in the event of a stigmatizing experience, or reaction to stressors within the social environment, stressed, depressed or fearful individuals may complain of pain (head, chest, stomach, joints), fatigue and/or a poor appetite, and present at a health facility for treatment of these physical symptoms (Durmuş et al., 2015; Heszlein-Lossius et al., 2018; Mallorquí-Bagué, 2016).

Depression though, results from a complex interaction of physical, psychological and social factors, and risk factors include chronic pain, low body image, stigma, low social support (Durmuş et al., 2015; Johansen et al., 2016; Ntim & Sarfo, 2015; Sentse, Lindenberg, Omvlee, Ormel, & Veenstra, 2010). It is also the single largest contributor to the global burden of mental health problems and diseases for people aged 15-19, and a risk factor of suicide and suicide ideation among that age group (Burçu, 2014; Quarshie et al., 2015).

Paranoia, in the general population, refers to a mistrust of others which is not based on actual incidents (Meisel, Garety, Stahl, & Valmaggia, 2018). Studies that examined interpersonal sensitivity and its influence on symptoms of psychological distress, as well as the association between stigma and paranoia, found that stigmatization mostly affected self and body image of targeted individuals (Meisel et al., 2018; Waite & Freeman, 2017). A negative body image, usually associated with negative self-perceptions has been reported to be highest in individuals living with some form of disabling condition or deformity, with severe forms

evidenced by adolescents with disabilities (Burçu, 2014; Varni & Setoguchi, 2010). Interpersonal sensitivity on the other hand, is the ability to read accurately others' feelings and attitudes, and this emotional state enables an individual sense covert manifestations of stigma and prejudice (Scocco et al., 2017). An oversensitivity to prejudice and stigmatization however, has been associated with paranoid ideation (Meisel et al., 2018). Derogatis and Melisaratos (1983) included these two domains in their psychological distress symptom inventory (BSI).

Waite and Freeman (2017) hypothesized that feelings of vulnerability in adolescents predict paranoid ideation, and the underlying factor in vulnerability is poor body image perceptions. To test this hypothesis, the researchers examined the cross-sectional associations between paranoia and a proxy measure of body image in epidemiologically representative cohorts, and replicated an earlier study carried out with 5515 participants in the US National Comorbidity Survey-Replication (NCS-R) with a much larger sample of 10,113 adolescent participants in the US National Comorbidity Survey-Adolescents (NCS-A). After analyses and controlling for gender, and body mass index, they reported findings which showed that negative body image and paranoia are associated in the general population, confirming their hypothesis that behind the paranoia associated with feelings of vulnerability lie body image concerns (Waite & Freeman, 2017).

In another study, and following PRISMA guidelines in a systematic review of the literature on interpersonal sensitivity and paranoia in both general population and clinical samples, Meisel et al. (2018) studied 14 articles involving a total of 12,138 participants in OVID (PsychINFO, MEDLINE) and Web of Science and discovered an association between interpersonal sensitivity and paranoia in clinical and general population samples alike, regardless of the method of assessment of both variables. Meisel et al. (2018) found evidence to support the hypothesis that personal vulnerability exacerbates early onset presentation and

maintenance of paranoia in individuals with heightened self and body image concerns. Of course, individuals with pre-existing paranoid traits, exhibited more social status concerns by evaluating themselves more negatively than others.

2.2.4 Body Image and Psychological Health

According to Cash and Pruzinsky (2002), body image is primarily concerned with the satisfaction an individual has about his or her appearance. It is a dynamic construction, subject to continual deconstruction, revision, and reconstruction in response to both internal and external stimuli. Following an experience of stigmatization or negative attitudes from significant others, the individual may go through stages of anger, paranoia, anxiety, and depression, which may cause them to revise the picture or schema of themselves that they hitherto held. Findings from studies show that adolescent body image concerns are the same around the globe (Ganesan, Ravishankar, & Ramalingam, 2018; Voelker et al., 2015).

The ideal body size and shape as dictated by peers and social media has been found to be behind eating disorders, substance-abuse, and self-harming behaviours for both male and female adolescents (Winter et al., 2017). Consequently, they experience more mental health problems such as severe paranoia, depression, low self-esteem, and suicidal ideation (Lee et al., 2014; Voelker et al., 2015).

Related to the issue of revised body image, is concern with social appearances and acceptance by others. For the majority of amputees, even when considerable success is achieved in functional restoration, there often remains some shyness about revealing the result to others (Montesinos-Magraner et al., 2016). Some amputees first face challenges adjusting to their prosthetic devices, and may give up (Khan et al., 2016) while others bear the pain as they believe they look better with it. In view of this, when Breakey constructed the Amputee

Body Image Scale (ABIS) in 1997, he included items that addressed shyness, avoidance of social situations, and perceptions of disability (Breakey, 1997).

Bailey et al. (2016) employed grounded theory to understand body image concerns in disability through the experiences of 9 individuals with spinal cords injury, and found that body image is experienced either positively or negatively. They also observed that there often remains some shyness about revealing their body to others, long after. Montesinos-Magraner et al. (2016) also studied the physical and psychosocial health outcomes of 32 adults who were born with lower limb deficiency (LLD) or had suffered amputation in infancy, as a result of a traumatic injury, or as a treatment for a congenital defect (LLA). The study had two objectives: (1) to describe the epidemiological and medical features of childhood LLA and LLD (2) to explore their relationship with subsequent physical and psychosocial functions in adulthood. In a cross-sectional survey, responses to the Locomotor Capabilities Index (LCI), and Discomfort-Engagement in Everyday Activities Involving Revealing the Body Scale (D-EEARB) were collected. After analysing the results, the researchers reported that adults who had undergone LLD and LLA amputations in childhood, showed higher scores in D-EEARB than those whose amputations had been as a result of vascular irregularity or cancer. In addition, adults with childhood LLD and LLA, seemed to perform well in all areas of functioning, although almost half of them were uncomfortable in situations where they had to expose or reveal their bodies.

Self-image is a concept that was very popular in the mid-1960s, and was defined by Rosenberg (1965) as a sense of self that is based on self-perceptions accumulated over a period of time although subject to revision. In effect, it is a component of an individual's self-concept or mental picture of his looks, strengths, weaknesses, and abilities, and more importantly, his opinions about that 'picture'. The self-perception of adolescents with CLD may be the determinant of their academic and/or career goals, and intimate relationships, and theory

behind the concept posits that children learn and develop attitudes by modelling the attitudes of significant others' and members of their communities towards them. Proponent of the theory Daryl Bem, suggests that children learn these attitudes and beliefs and internalize them. Once internalized, the beliefs and attitudes become the reality of the individual. The effects of this internalizing or self-perception may be positive or negative, depending on who they were observing. The interpretation is based on the same way a person has previously interpreted other people's attitudes and behaviour.

Body image is also a predictor of self-esteem, and psychological well-being (Orth & Robbins, 2014). Thus, an adolescent's idea of his looks, shape, size, abilities, and personality influence his attitudes, which ultimately determine his behaviours (Bem, 1972; Rosenberg 1965; Schacter, Gilbert, & Wegner, 2011). It may be inferred thus that self-image has different pathways: it may be formed by how an individual perceives himself or his reality; by observing and interpreting others' perceptions of him; or by interpreting his own opinion of himself and relating it to the ideal he would like to be. It is also the ideal self that represents hopes and wishes and which inspires and guides the individual born with a deformity. Sadly, the ideal self may not be easily achieved, or may be inconsistent with their reality (Schacter et al., 2011; Winter et al., 2017).

A positive self-image may also promote involvement in sporting activities, intimate relationships, and even careers as individuals strive to attain or maintain their goals (Crocker & Canevello, 2012). For instance, over the years, many young adults with physically-disabling birth defects have achieved success, and sometimes, international recognition for sporting achievements (Coates & Vickerman, 2016; Longman, 2007). Weightlifter Daniel Kankam, aged 19, won a gold medal for Ghana in the recent Paralympic Games in Nigeria, qualifying him for the upcoming 2020 Olympic Games in Tokyo, Japan (Tanko, 2020). Oscar Pistorius, a South African Paralympic athlete who was born with fibular hemimelia (missing fibular),

went on to win gold medals in all 3 categories (100, 200, and 400 metres) at the 2008 Summer Paralympic. In a newspaper article on Pistorious, Longman (2007) talks about the champion's sporting successes, and quotes the athlete as saying, "there's nothing I can't do that able-bodied athletes can do" (Longman, 2007, pp. A1 & A21). It seems reasonable to expect then, that like their able-bodied counterparts, adolescents living with CLD have ambitions and aspirations. Even when they are disadvantaged in terms of appearance and mobility, they usually put out conscious efforts, or overcompensate to achieve their goals, and compete with friends and schoolmates with fully-functioning limbs for the same academic or career opportunities (Coates & Vickerman, 2016; Michielsen et al., 2010).

Paradoxically though, self-image is not always a reflection of reality and may be influenced by culture, social media, and peer support (Bergagna & Tartaglia, 2018; Birkeland, Breivik, & Wold, 2014). For the majority of adolescents, their self-image is determined by family and peer acceptance or rejection. (Salzman, 2018; Sentse et al., 2010). Voelker et al. (2015) examined the role of the media on adolescent self-image, and the significance of adolescent development in shaping body image, the relationship between body image, and the consequences of having a negative body image during adolescence.

Ganesan et al. (2018) however, are of the opinion that body and self-mage among today's youth are no longer influenced by the individual's culture. To test this theory, the researchers carried out a cross-sectional study of 1200 college girls in Coimbatore, India, and reported that body image dissatisfaction was evident in 77.6% of the girls, establishing the fact that body image dissatisfaction is no longer a western concept and greatly affects Indian adolescent girls.

It appears that body image concerns are experienced more during adolescence, with girls possessing more negative body image than boys (Meland, Haugland, & Breidablik (2007).

Low body image has even been reported to be associated with increased suicide risk and self-harming behaviours in young girls with eating disorders as a direct consequence of peer and social perceptions as well as media portrayals of the ideal body shape, size, and height (Burt, Boddy, & Bridgett, 2015; Ntim & Sarfo 2015). Meland et al. (2007) examined the relationship between perceived negative health and body image in early and mid-adolescence in a sample of 5026 Norwegian pupils aged 11, 13 and 15 years. The study however, focused on age and gender differences. Data from a World Health Organization cross-national survey (Health Behaviour in School-Aged Children), was collected and analysed, and findings determined that females are more likely to report negative health than boys, which is more likely to increase with age.

Ntim and Sarfo (2015) carried out a similar study in Ghana, and discovered a positive relationship between body image and eating disorders, in 100 females sampled from a university, regardless of their educational level. These studies reflect the fact that psychological health may be compromised by excessive attempts to achieve or maintain an ideal body image through maladaptive eating habits.

Some researchers are of the view that romance and intimate relationships of physically disabled persons is a topic that has not been adequately addressed (Sellwood, Raghavendra, & Jewell, 2017). Intimacy in adolescence is a very important part of the transition into adulthood and must be addressed with sensitivity (Manoj & Suja, 2018; Wiegerink, 2010). While the sexual activity of persons with disabilities has been studied by medical and social scientists extensively, the subject rarely arises in ordinary conversations (Alexander, Courtois, Elliot, Tepper, 2017; Sellwood et al., 2017; Shandra & Chowdhury 2012). This silence reflects both the embarrassment that people feel in discussing intimacy, and the social perception that persons with disabilities are asexual (Breuner & Mattson, 2016; Kassa et al., 2014; Sellwood

et al., 2017). These researchers suggest that physical disability leads to lessened socialization, which also can hinder the desire for intimacy.

There are differences among adolescents with disability in how they experience the first sexual encounter. For the majority, disability-status makes them vulnerable to physical, or sexual abuse, and seriously influences their sexual reproductive health (Maart & Jelsma, 2010; Steinberg, 2010; UNPF, 2018). It may be concluded then that, a visible birth defect such as CLD, with the attendant disability, can negatively impact adolescents' self-image, and is undeniably, a potential risk to psychological health (Voelker et al., 2015).

2.2.5 Buffering Resources and Psychological Health

Physical, psychological, and social challenges of CLD require responses that positively impact overall psychological health and wellbeing (Stanish & Temple, 2012; Steers et al., 2019; Varas-Diaz, Neilands, Rodriguez-Madera, & Padilla, 2016). Wang (2014) conceptualizes psychosocial wellbeing as the overall emotional, mental, social, and spiritual sense of wellness. Wellbeing is also suggested to influence health, and is usually characterized by constructive coping, positive social relations, and positive emotions (Poudel et al., 2020; van Schalkwyk & Wissing, 2010). These factors, internal (coping strategies, and positive emotions) and external (social support) buffer individuals from stressors from within themselves (intrapersonal) and from their environment or social systems (interpersonal).

Coping strategies

Coping, a major predictor of psychological health, involves the conscious and unconscious efforts that individuals expend to reduce stress (Winter et al., 2017; Yendork & Somhlaba, 2014). Some studies have found that most individuals, including children and

adolescents, utilize various coping mechanisms to help them adapt to stressors and emotionally-disturbing events (Pennant et al., 2019; Poudel et al., 2020; Spirito, Stark & Williams, 1988; van Schalkwyk & Wissing, 2010; Winter et al., 2017; Yendork & Somhlaba, 2014). These strategies involve either confronting/approaching the stressors or avoiding them (Spirito et al., 1988). Proactive coping for example is an active coping style based on individual initiation, optimism, and self-determination (Chalk, 2016; Steers et al., 2019). The proactive coper takes initiative, is active when faced with stressors, and mobilizes resources (Bos et al., 2013). Avoidance coping, on the other hand, usually presents as social withdrawal, distraction or blaming others, and has been found to increase depressive symptoms (Burçu, 2014; Taylor & Stanton, 2007).

Several years ago, Compas, Connor-Smith, Saltzman, Thomsen and Wadsworth (2001) reviewed several studies on the association of coping with symptoms of psychopathology and social and academic competence. The researchers conceded that there was advancement in the conceptualization, definition, and measurement of coping, and response to stress, enough to warrant numerous associations between coping with stress and adjustment to be made. According to their report, “problem-focused and engagement coping have been found to be associated with better adjustment, whereas emotion-focused coping and disengagement coping have been found to be related to poorer adjustment” (Compas et al., 2001, p. 121).

Currently, there is an abundance of literature not only in support of the study by Compas et al. (2001), but also suggesting that individuals utilize more than one coping strategy over a period of time (Benson et al., 2020; Nemček, 2017; Omolayo, 2009; van Schalkwyk et al., 2010). For instance, they may first utilize emotion-focused coping to reduce distress levels, and later engage in problem-focused coping strategies. These coping strategies, which address the external events that the individual believes he has more control over, include being excessively confident in social situations in order to compensate for a stigmatized condition,

disclosing emotions to a specific person/group, relating with or associating with others with a similar stigmatized status, or disengagement, where the individual avoids being exposed to stigmatization (Bos et al., 2013). Emotion-focused coping strategies may include wishful thinking, positive reframing of a negative event or situation, withdrawal, distraction, as well as self-isolation. They may also include religious beliefs and practices that serve to relieve anxiety, and which foster adjustment to stressful situations (Loue, 2017; Omolayo, 2009).

In a mixed-methods study, Holen, Lervåg, Waaktaar and Ystgaard (2012) explored the associations between coping patterns for everyday stressors and mental health in young schoolchildren with the purposes of gaining a deeper understanding of the association between coping and psychological health. The study assessed the coping strategies of a young nonclinical population and sampled a total of 1324 children from 91 second-grade classes in 35 schools. Coping strategy was assessed by the Kidcope (Spirito et al., 1988) self-report checklist, which after latent-variable regression analysis indicated that both active and emotional strategies were associated with fewer mental health problems.

A question that arises however is, as individuals move from one age group to another, do their coping strategies change? To investigate the employment of coping strategies at different ages, de Minzi and Sacchi (2005) examined 153 Argentine men and women aged between 20 and 45 years in two groups for coping style. Factor analysis determined that the older age group utilized more positive emotion coping strategies such as problem-solving or cognitive redefinition (reframing), while the younger age group avoided or used evasion strategies. The conclusion drawn was that, age is what determined coping strategy and not the type of stressor (de Minzi & Sacchi, 2005)

Emotion-focused strategies to reduce negative, and occasionally, threatening emotions of fear, and depression usually experienced by children, adolescents and adults who have been

bullied, stigmatized or discriminated against, have been reported by a number of cross-cultural studies (Burçu, 2014; Morris et al., 2014; Omolayo, 2009; Xu and Liu, 2020; Yendork & Somhlaba, 2014). These studies report that emotion regulation techniques require a self-awareness and exploration of current emotional states, and identifying or naming the emotion. Many individuals who encounter stigmatizing behaviours on a regular basis learn, from an early age how to regulate their own responses (anger, sadness, fear) to these distressing encounters (Yendork & Somhlaba, 2014). Fredrickson (2004) theorizes that positive emotions have the tendency to neutralize negative emotions, when negative events are reframed as positive ones, which consequently serve to increase self-esteem (Holen et al., 2012; Nemček, 2017; Omolayo, 2009; Rosenberg, 1990). Problem-focused strategies on the other hand, involve engaging in activities with others, planning and making conscious efforts to do something about a stressor, such as seeking social support, or strengthening social networks and membership in organizations with shared activities (Camara et al., 2017; Morris et al., 2014).

Xu and Liu (2020) investigated the mediation role of coping strategy between body image evaluation and mental health and its variations among 255 Chinese university students with either physical, visual or hearing disability. All participants completed a battery of self-report questionnaires, including the Multidimensional Body-Self Relations Questionnaire Coping Style Questionnaire, and Symptom Checklist 90 (SCL-90) to find a relationship between body image evaluation, coping strategies and mental health status, in a single study. Findings from the study determined that in the group of students with physical disabilities, positive coping strategies played a role in mediating the relationship between body image evaluation and mental health.

These patterns of coping with stressors were observed in a study by Donaldson, Prinstein, Danovsky, and Spirito (2000). The study involving young children and adolescent

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boys and girls aged between 9 and 17 years old, tasked participants to complete a coping checklist in response to one of four types of stressors--school, parents/family, siblings, or peer/interpersonal. Similar patterns of coping-strategy were observed across the various stressors, with the most frequently used ones being, wishful thinking, problem-solving, and emotional regulation. The researchers noted, as observed earlier by de Minzi and Sacchi (2005) that coping strategies changed as children got older, and they were more inclined to use a wider variety of coping strategies, regardless of stressor.

The relationship between body image and risky coping behaviours such as tobacco and alcohol use was established in a study by Winter et al. (2017). They employed data from a nationally representative survey carried out on school-aged children in the United States between 2001 and 2002. Variables believed to also influence the relationship were perceptions of weight and attractiveness, and substance use (tobacco and alcohol). The researchers concluded that engaging in risky behaviours such as drinking and smoking enables adolescents cope with a negative body image.

Social Support and Psychological Health

Defined as the external social resources that persons perceive to be available, or that are actually provided to them, social support has been theorised to have two important psychological benefits (Pennant et al. 2019; Sentse et al., 2010). First of all, it directly enhances well-being through satisfying human affiliation, affection, and safety and by strengthening feelings of self-esteem and self-efficacy, thus ensuring that socially supported individuals experience fewer symptoms of psychological distress (Poudel et al., 2020; Sentse et al., 2010; Steers et al., 2019). Secondly, there is an integral relationship between social support and proactive coping, especially the support of peers (Camara et al., 2017; Steers et al., 2019). These researchers believe that it is an important protective factor for psychological distress.

During adolescence, children begin to depend less on their parents and more on their peers and friends for approval, acceptance and support (Camara et al., 2017; Carter et al., 2018; Jaworska & MacQueen, 2015). The dependence on others, occurs when individuals with practically the same or similar experiences or lifeworld, get together to share knowledge, experiences, and coping strategies. Unfortunately, social support is sometimes inadequate, or even non-existent for many adolescents born with defects. They may have had adequate support from family in the early years, but the support may have dwindled or may have been cut off, forcing many into isolation or into the streets to fend for themselves (Kassah, 2008; Taylor & Stanton, 2007). When this happens during adolescence, adolescents rely less on their parents, forcing them to ‘grow up’ or become autonomous. Autonomy comes with knowing who you are, what you are, where you are going, and how to cope with challenges on the way (Riggenbach et al., 2020). To embark on this journey of coping requires self-determination, as well as support from travellers on the same journey.

In a study on the risks and protective factors in psychological health of chronic pain sufferers, researchers examined the relationship between the satisfaction of the needs for autonomy, relatedness and competence and the resources available to adolescents suffering from chronic pain. One hundred and twenty adolescents, with an average age of 14 and half years, who were receiving treatment for chronic pain, were enrolled in the study. The findings from the study determined that higher levels of autonomy and competence satisfaction were associated with lower levels of functional disability, demonstrating the importance of individual determination to overcome challenges (Riggenbach et al., 2020).

Support from friends may encompass all the aspects of social support, that is, informational, instrumental, and emotional support (Camara et al., 2017; Greenglass, 2006; Pennant et al., 2019; Zuurmond et al., 2018), especially when an individual is in need of empathy and understanding from another who is, simply put, in the same shoes. Friendships

and social networks have also been shown to be essential aspects of an individual's support system, and tend to buffer against negative experiences and stressors. According to Camara et al. (2017), interpersonal relationships and social networks can, and do act as social support sources that buffer adolescents from stressors and help them develop and use coping strategies that safeguard them from psychological distress. That study however also suggested that interpersonal relationships can be sources of stress, and pointed to non-acceptance, and feeling judged by peers as contributing to adolescents negative emotions.

Using focus group discussions, Camara et al. (2017) engaged 80 adolescents, 43 males and 37 females aged 15 to 16, who were recruited from public and private schools in the north of Spain to determine sources of social support and coping. These support systems were perceived as familiar, mature, friendly, and trustworthy. Interpretation of participants' narratives was done inductively and revealed that although relationship with parents and peers are sources of support, they can also be sources of distress.

The concept of peer support, or support from another adolescent with a similar disability has been examined by a number of studies, with the suggestion that the single most positive experience for an amputee is communication and interaction with other amputees (Birkeland et al., 2014; Stanish & Temple, 2012; Stewart et al., 2011). For instance, 22 adolescents with physical disabilities caused by spina bifida and cerebral palsy were mentored by 5 adolescents with similar disabilities over a 6-month period in a pilot online intervention. Prior to the intervention program, the adolescents' self-perception, sense of community, sense of loneliness, social support, and coping were assessed using quantitative measures. Post testing after the period found that the adolescents had an increased sense of community, decreased loneliness, less isolation and more contact with other adolescents with disabilities, as well as increased social acceptance, and findings from interviews with the participants corroborated their accounts of peer support (Stewart et al., 2011).

Adolescents with physical or intellectual disabilities who perceive that they are supported by their peers, are treated as part of the group, and consequently, experience a sense of belonging, are reported to have high levels of self-esteem, and better psychological health (Stanish & Temple, 2012). Undeniably then, social support is beneficial not only to the individual receiving the support, but also to the provider of the support, because the self-esteem of the provider is enhanced through the knowledge that they have also been of assistance.

The role of social support in buffering psychological distress in special populations (individuals with disabilities, migrants, ethnic minorities, orphans), has been well documented (Bonsu et al., 2018; Burçu, 2014; Forouzan et al., 2013; Greenglass, 2006; Mamah, 2016; Sentse et al., 2010; Steers et al., 2019; Yendork & Somhlaba, 2014; Zuurmond, 2018). It has also been argued that this kind of support increases levels of self-confidence and esteem and is a resource that purportedly facilitates the cultivation of positive emotions, increasing coping ability even for those offering the support (Carter et al., 2018).

After examining social support as a moderator of the relationship between discrimination and overall psychological distress, as measured by the Brief Symptom Inventory (Derogatis & Melisaratos, 1983) among a community sample of 122 African-American church-going adults, Steers et al. (2019), reported that social support buffered the associations of discrimination and overall psychological distress in expected directions. Their findings highlight the importance of social support and networking in reducing symptoms of psychological distress that is usually evidenced in individuals who have experienced discrimination.

Social support as a predictor of psychological health, is further evidenced in studies on disability. Burçu's (2014) qualitative study of 9 physically-disabled young adults from 2

Turkish universities reports that respondents described feelings of worthlessness, lack of social support, isolation and unacceptance by society, promoting depression, and paranoia. Suicidal ideas were experienced by all the students in the focus group. According to the researcher, “the relationship between being young and thinking of suicide or committing suicide may be reinforced by disabling barriers, especially by an inability to resolve social problems which are further exacerbated by social loneliness caused by socio-cultural attitudes to disability” (Burçu, 2014, p.6). Inadequate social support was a major factor of their psychological health. For those who do not have adequate support, that is, a lack of emotional attachment, acceptance, reassurance or encouragement from significant others, and other behaviours theorized to buffer stressors, a great majority turn to drugs, stealing and other maladaptive behaviours to help them cope or to feed themselves (Greenglass, 2006; Winter et al., 2017).

In Africa, social support is a very important coping resource and connotes a stronger and much broader sense of belonging and inclusion, not just by the immediate and close circle of family and friends, but by the whole community (Bannink, 2017). Research from Uganda, determined the sense of belonging, as found in the African concept of ‘ubuntu’ or inclusion, or even, relatedness, buffered the stressors associated with being born with a disabling condition.

Studies in Ghana that examined and explored the role of social support in impacting the psychological health of vulnerable populations abound (Bonsu et al., 2018; Mamah, 2016; Yendork & Somhlaba, 2014; Zuurmond et al., 2018). For instance, Yendork and Somhlaba (2014) studied 100 orphans and non-orphan controls aged 7 to 17 years to determine their psychological functioning and experiences following placement in orphanages, as well as the state of orphanhood itself. The researchers hypothesized that there would be significant differences between orphanage-placed children and non-orphaned children on perceived social support, and indeed the findings determined that orphaned children perceived stronger support from friends than non-orphans. Support from family was stronger however for non-orphaned

children than orphaned children, demonstrating that peer support may sufficiently fill the emotional gap when family support is inadequate or worse still, absent in the period between childhood and adolescence.

Social support was implicated in a qualitative study that sought to explore agency in physical disability, and how children and adolescents navigated daily experiences of disability. The study reported that the young participants deplored the failure of society to give consideration to their condition, describing the lack of social support as more disabling than the actual physical limitations (Mamah, 2016). Social support was also implicated in a study by Acheampong and Aziato (2018) in a study on coping strategies of mothers living with physical disabilities in Ghana. The study found that participants' negative emotions, and any suicidal thoughts entertained, were precipitated mainly by discrimination from the community, but it also reported that instrumental, informational, and emotional support from relatives, specific coping strategies, and the determination or motivation to carry on, positively impacted psychosocial health. In agreement with this finding is a study by Bonsu et al. (2018), where emotional and informational support from spouses and health professionals buffered mothers of children with orofacial cleft palate from the initial shock and disappointment at the birth, negative emotions of sadness and anxiety, as well as stigma and discrimination from friends and the community.

Another example of how social support buffers individuals who experience social stigma on a daily basis, is evidenced in a study on the wellbeing of caregivers of children with disabling conditions. In this study, 18 caregivers of children with cerebral palsy from four different districts in Ghana, were enrolled in a training program to educate them on the children's condition, and to give them a chance to change their attitudes towards their disabled child. The researchers reported that after the training, the participants believed that their wellbeing had improved immensely as a result of the support they received from group

members, and the knowledge that they were not alone in the struggle to care for their disabled children (Zuurmond et al., 2018). This implies that the support of friends, and others sharing similar experiences can have a positive effect on psychological health by reducing the potential for stress and anxiety brought on by exclusion and isolation.

There is a reduction in social stigma when group members cultivate positive emotions and pride in their social status, according to a report by Varas-Diaz et al. (2016). Invariably, levels of psychological distress decrease to make living with disability and deformity a whole lot easier. From their studies, Varas-Diaz et al. (2016) noted that positive emotions that results from feeling valued, facilitate coping with marginalization and other effects of living with a disabling condition, while resources such as social support lead to the development of proactive coping strategies such as humour, distraction, and problem-solving lessened the effects of negative events (Steers et al., 2019).

The Role of Positive Emotions

Positive emotions optimize psychological health (Fredrickson, 2004). For example, “joy sparks the urge to play, interest sparks the urge to explore, contentment sparks the urge to savour and integrate, and love sparks a recurring cycle of each of these urges within safe, close relationships” (Fredrickson, 2004, p. 1367). Negative emotions are reported to trigger action tendencies such as flight and fight. Negative emotions also ‘narrow’ the range of urges or responses to negative or life threatening situations and produce short-term thoughts and actions. Nurturing the resources of joy, interest, and pride can, over time, broaden the individual’s action tendencies so that they begin to look for new ways for acting out their optimism to positively impact their psychological health (Garland, Farb, Goldin & Fredrickson, 2015).

In an earlier study, Fredrickson, Mancuso, Branigan, and Tugade (2000) reported that positive emotions are efficient ‘undoers’ of the effects of negative emotions. Negative emotions such as fear, anxiety, and anger, usually experienced by stigmatized and marginalized individuals threaten their psychological health and motivate individuals to engage in escape or avoidance behaviours such as social withdrawal, or aggression (Burçu, 2014; Taylor & Stanton, 2007). Positive emotions on the other hand, broaden an individual’s thinking in dealing more positively with negative events by building a variety of enduring personal resources.

Positive emotions are usually experienced by individuals with high self-esteem, mainly because self-esteem is a reflection of one’s worth or value (Holzer et al., 2014). These emotions are experienced when individuals respect, accept, believe in, and love themselves, and consequently, are motivated to do more to experience positive emotions such as pride and joy (Ryan & Deci, 2000). This process of self-esteem – positive emotions – self-esteem is reported in a study that linked emotions to physical and psychological health. Fredrickson (2004) demonstrated that when individuals build their psychological resources, such as self-esteem, positive emotions would over time, improve their emotional and physical wellbeing. The study involving 138 college students with a mean age of 20 years, intended to introduce the concept of broad-minded coping, and was repeated at 2 time points (5 weeks apart), (Fredrickson & Joiner, 2002). The study concluded that over time, individuals who experienced more positive emotions, became more resilient to adversity and experienced less distress. These new or enhanced coping skills then broadened into increased positive emotions.

Other studies have investigated the role of positive emotions in improving psychological health, and examined its influence on coping with stressors (Morris et al., 2014; Poudel et al., 2020; Varas-Diaz, 2016). Fredrickson (2004) theorized that positive emotions neutralize stressors when negative events are reframed as positive ones. Maximum effort and

self-determination however, is required in reframing the negative emotions that are likely experienced by AWCLD during these turbulent years (Morris et al., 2014).

2.2.6 Linking Self-determination and Psychological Health

Relatedness has been defined as the need to belong, to be part of, and connected to others, and experience caring and support from others, while autonomy is described as the urge to be the causal agent of one's own life and be responsible for one's decisions and actions (Higa et al., 2014; Okeke-Adeyanju et al., 2014; Ryan & Deci, 2000). This interplay of internal and external factors is what usually motivates individuals to engage in activities that enrich their lives and help them cope with adversity and uncertainties. Ryan and Deci (2000) theorized that self-determination and esteem are essential if an individual is to enjoy subjective physical well-being and sound psychological health.

Competence is the ability to do something successfully or efficiently, as well as a belief in the self to accomplish tasks (Riggenbach et al., 2020; Ryan & Deci, 2000). When an individual compares himself to others and discovers that he has competencies or abilities that put him on an equal plane with others, positive emotions invoke, and foster feelings of self-worth and esteem, which may, in turn, be expressed as positive statements. Rosenberg (1965) included statements of positive emotions, competence, and self-determination in his self-esteem scale. The statement "I can do most things as well as other people", is an example of positive emotions expressed as competence and self-worth.

Autonomy refers to the freedom to self-direct, or independence in one's thoughts or actions, and has been identified as the most important path to development in adolescence, and consequently, a relationship has been observed between autonomy, competence, satisfaction with life, and increased level of functional ability (Riggenbach et al., 2020). If an individual

with a disabling condition has been shielded from negative attitudes and behaviours, or had very little exposure to stigmatizing situations, he may never feel the autonomy or urge to push himself beyond his immediate circumstance. This truth was evidenced in a study by Sandjojo et al. (2018) on the desire of individuals with intellectual disabilities to be more independent. The study included legal representatives, support staff, and 7 individuals with intellectual disability in 2 focus group discussions. Sandjojo et al. (2018) explored barriers to their sense of autonomy or independence. Respondents stated that although they welcomed support from others, their parents had a tendency to take over, when they expressed the need to be independent and do things for themselves. They also stressed that support staff did not give them enough time to accomplish tasks. They asserted that being independent increased their self-worth, even when they were experiencing emotional distress.

Overprotected children may also lack the drive to push themselves for fear of causing themselves some injury (Sandjojo et al. 2018). On the other hand, a lack of attention from caregivers, can foster autonomy, and a desire to prove oneself capable or competent enough to stand alone (Sandjojo et al., 2018). As suggested by Birkeland et al. (2014), peers influence the development of autonomy by helping an adolescent become less reliant on parents, think more independently, and develop their own separate identity. This connection with peers has a buffering effect against negative emotions and symptoms of psychological distress such as depression, and loneliness, and it can also stabilize adolescents' self-esteem when support from family is inadequate (Birkeland et al. 2014; Greenglass, 2006). Social skills are also learned when adolescents widen their social networks, relate to, or feel accepted by peers who offer them the opportunity, or arena to cultivate positive emotions and become creative, thus buffering their psychological health (Camara et al., 2017). However, independent thinking, makes it more likely for adolescents to be influenced by peers, and/or social media, and less likely to follow parental guidelines (Morris et al., 2014; Taylor & Stanton, 2007).

The concept of relatedness refers to the sense of belonging or kinship, and synonyms include affiliation, connectedness, relationship, affinity, link, membership, association, and networking. Relatedness, or feeling that one belongs to a family, community, ethnic group or race has been researched extensively, and diverse minority groups, such as the physically and intellectually disabled, lesbians, gays, bisexuals, etc. (LGBTQs), and persons of colour (POCs) have been reported to derive pride, and psychological wellbeing from a sense of relatedness or affinity with others in the same group (Higa et al., 2014; Okeke-Adeyanju et al., 2014). Evidenced in slogans, and movements such as “I’m Black and Proud”, Gay Pride, “Don’t Dis my Ability” and Disability Pride, these positive messages of determination have been reported to correspond to increased self-esteem, and serve as a buffer against the negative impact of discrimination (Okeke-Adeyanju et al., 2014).

A similar study on the benefits of self-categorization reported that, emerging adults (adolescents) who suffered a disabling impairment but who did not identify with others of a similar status, reported lower self-esteem and perceived esteem than those with no disability (Chalk, 2016). In the study, 1353 participants were administered measures on self-esteem, perceived esteem, markers of adulthood, and disability status. The findings support another study that suggested that associating with others with a similar stigmatized status, and embracing one’s disability may offer protection against the stressful effects of a marginalized identity (Bos et al., 2013; Chalk, 2016).

A study from 4 regions in Uganda, investigated positive experiences of belonging at both family and community levels of 139 children with spina bifida (a physically disabling condition), and their families supports this finding. Bannink (2017) found that although children from the region were less likely to receive an education, more likely to perceive themselves negatively, and more likely to be subjected to discriminatory practices, the sense

of belonging, as found in the African concept of ‘ubuntu’ or inclusion, or even, relatedness, buffered the stressors associated with being born with a disabling condition.

Individuals who exhibit high levels of self-determination achieve more than they even set out to. This is because, self-determination encourages the individual to push himself beyond normal limits, usually in more than one area of life (Nemček, 2017). Physically-disabled individuals for instance, may want to pull themselves slowly up a steep hill, or move around in their home unassisted (Ryan & Deci, 2000). When asked why they did not ask for assistance, they may reply that they wanted to do it for themselves. Once success has been achieved, the individual is motivated to repeat the action that brought him a sense of achievement, joy and pride in himself. This also increases his self-esteem, and as theorised by Fredrickson (2004), the individual broadens his thought-action repertoire by looking for more ways to be autonomous and creative.

People living with a disability may decide to try out a sporting activity to increase their self-esteem, and indeed, a number of researchers argue that there are numerous benefits, both physically and psychologically in sports participation for the physically-disabled (Bragaru, Dekker, Geertzen, & Dijkstra, 2011; Dryer, Henning, Tyson, & Shaw, 2016; Nemček, 2017). Initially, they may not be so sure of themselves, perhaps because parents are hovering in the background, worrying about a possible injury, or dampening their enthusiasm to try out something new. However, once they get past the first obstacle of self-doubt, autonomy sets in, and they become self-reliant (Sandjojo et al., 2018). Adolescents with disfiguring disabilities are no different. A sense of independence allows them to feel ‘special’ as they now see themselves, even with their deformity and disability on an equal plane with others (Chalk, 2016; Omolayo, 2009).

Self-determination has an effect on self-motivation due to the fact that it allows the individual engaging in it to be motivated to continue with his actions, knowing that it will have an effect on the result. Self-motives in addition, provide both a standard and a direction for behaviour, suggesting that individuals attempt to maintain or enhance their self-esteem to some level (Nemček, 2017; Omolayo, 2009). Research from this perspective suggests that people are motivated to complete challenging tasks without help, influence, or support from others, and this has been demonstrated by individuals with disabilities (Chalk, 2016; Deci & Ryan, 1985; Omolayo, 2009; Silvia & Duval, 2004).

2.2.7 Self-esteem and Psychological Health

Although self-esteem is a concept that has been constructed differently across cultures (Salzman, 2018), its relationship with social support, and its role in psychological health outcomes, has been consistently reported by cross-cultural studies, and established by a number of research findings (Adeyemo et al., 2016; Bonsu et al., 2018; Ji, Rana, Shi, & Zhong, 2019; Omolayo, 2009; Tam, Lee, Har & Pook, 2011; Teoh & Nur Afiah, 2010). Positive self-esteem is a feature of, as well a protective factor of psychological health, in the sense that it buffers individuals against stressors and negative environmental effects (Fredrickson, 2004; Omolayo, 2009). There is no gainsaying that when self-esteem is threatened by negative events over a sustained period of time, the buffering effect diminishes, and symptoms of psychological distress are more likely to be observed, and experienced (Tam et al., 2011; Teoh & Nur Afiah, 2010).

Self-esteem is strengthened by social support and appears to be a resource that functions to maintain individual and social relationships (Tam et al., 2011; Teoh & Nur, 2010). This relationship is more readily observed in individuals with varying degrees of physical

disability, and the greater the amount of social support an individual with physical disability receives, the higher the self-esteem, leading to greater subjective well-being (SWB). Additionally, self-esteem was found to mediate between social support and perceived discrimination and inversely correlate with psychological distress (Ji et al., 2019; Tam et al., 2011).

A study that established a relationship between social support and self-esteem was carried out by Tam et al. (2011) where perceived social support was found to correlate positively with self-esteem. The study however determined that social support from peers a greater influence on the development of self-esteem in adolescents than did the support received from family members (Tam et al., 2011). Riding on the findings of Tam et al. (2011), Tahir, Inam and Raana (2015) surveyed 120 adolescent females with ages ranging from 16 to 19 years in a college in Lahore, India to determine the influence of social support on their self-esteem. A Pearson 's Product Moment correlation analysis of scores from the Rosenberg Self-esteem scale and a researchers' self-designed instrument, showed a strong correlation between the two variables. In addition, the findings determined a strong relationship between family and peer support and self-esteem. In a quantitative study on the mediation effects of self-esteem in a sample of 210 Chinese people with a physical disability, Ji et al. (2019) report that self-esteem significantly mediates the relationship between psychological outcome variables of subjective well-being (SWB) and perceived discrimination as well as social support.

Yildiz and Karadaş (2017) also studied the mediation effects of self-esteem and social support on the relationship between loneliness and life satisfaction in a study of 398 undergraduate students. Scores on self-esteem, perceived social support were analysed in a multiple regression model. The results determined however that the effects of self-esteem on the relationship was higher as a single mediator rather than when combined with social support.

Fredrickson (2004) and Omolayo (2009) theorized that as people become more proficient and realize the possibilities opening up to them, their self-esteem soars as they begin to broaden their outlook on life and begin to look forward to a productive, happy and option-filled life. When individuals reflect on their behaviour and observe that they have been maintaining a match between situational meanings and identity standards (in terms of their body image and abilities), efficacy-based self-esteem results from such successful behaviour (Nemček, 2017).

The maintenance or enhancement of self-esteem may be accomplished in several ways. Individuals may directly act in ways that increase their self-esteem when it has been lowered, they may redefine the situation to reflect more positively among themselves, or they may work to create an impression of themselves that is more positive, both in terms of worth and efficaciousness (Omolayo, 2009; Rosenberg, 1990). For example, research finds that individuals account for negative situations by attributing the cause to external factors (Hosseini et al., 2016), selectively compare themselves to those worse off, and by interacting only with those who support a positive conception of them (Sedikides & Gregg, 2008).

2.2.8 Summary and Critique of Literature Reviewed

In this section of Chapter Two, the relevant literature related to the study of psychological health of adolescents living with CLD was discussed. As mentioned at the outset of this review, there are very few studies on the psychological health, and lived experience of adolescent CLD. Currently, the approach taken by specialists and rehabilitation teams for children born with limb defects is based on the medical model, and the reviewed literature abounds with findings on amputation, treatments, and functional mobility (Adu & Annan, 2008; Calder et al., 2017; Dobbs & Gurnett, 2009; Durowaye et al., 2011; El-Sayed et al.,

2010). As a result, very little is known about whether amputation is a risk or protective factor of psychological distress in adolescent CLD.

Body image, self-esteem, social support, and coping among others have usually been examined in the positivist tradition - in surveys, with questionnaires and standardized measurements. Although these findings have informed policy, research, and healthcare, they have not expressly focused on the meanings that the participants in these studies make of their condition, or their opinions of the support systems that appear to be available to them. Montesinos-Magraner et al. (2016) on the other hand, added a qualitative aspect to their research in order to explore the physical and psychosocial health outcomes of adults who were either born with lower limb deficiencies, or had been amputated in infancy, as a result of a traumatic injury, or as a treatment for CLD. The study however, relied solely on telephone interviewing as the data-collection tool. The study was flawed in this respect, as it failed to recognise that sensitive topics that explore body image and intimacy require face-to-face interaction in order to read participants' body language, and gauge emotional feedback about concerns that may easily be disguised behind the anonymity offered by the telephone.

Studies on body image of the physically-disabled in Africa is conspicuously missing from the literature reviewed. Considering the preponderance of research on stigmatizing and discriminatory behaviours towards individuals with childhood disfiguring conditions and physical aberrations such as cleft palate, cerebral palsy, and leprosy, there are very few studies reporting findings on their body image in relation to their psychological health.

Again, although birth registries monitor the global incidence in humans, there is a conspicuous absence of data on prevalence of the phenomenon in Africa. Especially in the Ghanaian context is this absence of information more strongly felt, and existing literature has largely focused on medical treatment of the problem. Studies identified to have a bearing on

this current research have however been reviewed and reported, including those with a biomedical bent.

A reportedly disabling condition, CLD negatively impacts the lives of adolescents in four areas, namely physical psychological, economic, and social or environmental (Calder et al., 2017; WHO, 2018). There is also consensus that adolescents living with CLD are a very vulnerable and special minority from the larger population of physically-disabled adolescents, due to the cultural and traditional explanations of the aetiology of their condition. The vast majority of social research on the effects of disability has reported findings on the discrimination and stigmatization experienced by many adolescents with varying aetiologies. Several studies have also been carried out on body image of adolescent amputees. Self-perception of adolescents with CLD may be the determinant of their academic and/or career goals, and intimate relationships, yet sadly, there is a dearth of research about how AWCLD, respond and overcome challenges to reach these goals.

Amputations are performed early for babies to facilitate functional ability, and early adaptation to prosthesis. Very few life events however match the challenges of living with a disabling birth defect, and amputees often face staggering social, and financial effects, which are exacerbated by their own physical and psychological reactions to amputation. However, there is hardly data on the perceptions of adolescents born with limb defects about the prescription of amputation to improve physical and psychological health. Only one study by Montesinos-Magraner et al. (2016), was found in the review that compared CLD and amputations that were acquired in childhood, either as treatment of CLD, or traumatic injury.

Very often, the desire to be accepted results in the development of maladaptive behaviours and coping strategies. The adolescent may feel a reluctance to be involved in romantic relationships, or engage in intimacy as a result of the deformity caused by CLD. Self-

determination and self-development have been identified in studies of physical disability in children and adolescents as influencing psychosocial health. The Paralympic competitions, and the desire and determination to win exhibited by some amputees, is an example of how support, encouragement, and a positive attitude have helped some amputees adapt and make progress (Coates & Vickerman, 2016). A great many adolescents with disabilities achieve success and joy in pursuing their dreams and reaching their goals as a result of their positive outlook, self-determination and the acquisition and utilization of adaptive coping, regardless of sociocultural beliefs and attitudes of peers and significant others. Despite the positive narratives, studies have focused more on the negative emotions of depression and anxiety of adolescents with physical disabilities.

Factors identified as protective factors from the review and relevant to the study however are, positive emotions, self-determination, coping strategies, and perceived social support. Of these, positive emotions, perceived social support, and coping strategies have been reported to significantly correlate with body image, self-esteem, and symptoms of psychological distress in adolescents and young adults with disfiguring, and physically-disabling conditions. These concepts were however examined primarily via quantitative methods. As such, the experience of positive emotionality, and self-determination were not adequately captured. Additionally, in the review, the ways the related concepts of self-motivation, and self-esteem connected with positive emotions, and the components of self-determination were not addressed in-depth. This study aims to determine, and understand how all these factors influence the psychological health of AWCLD.

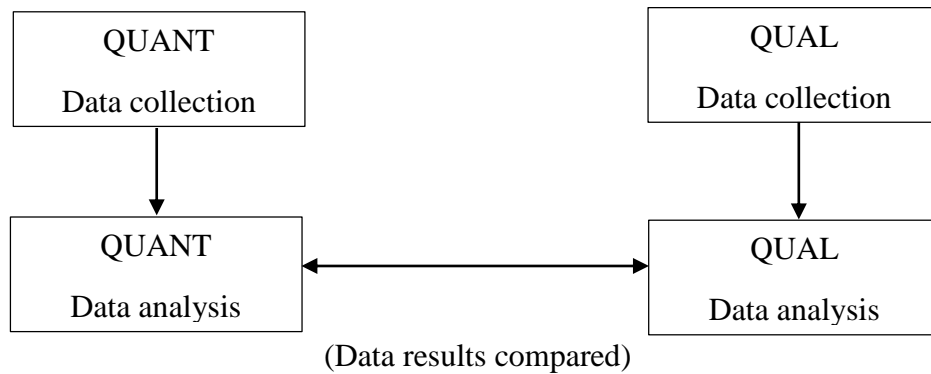


Figure 2.2: Concurrent Triangulation Design (Creswell, Plano Clark, Gutmann, & Hanson, 2003)

Figure 2.2 represents the design for this study as both quantitative and qualitative data collection was done on the same topic, at the same time, from the same group of participants, and carried same weights. Integration of the findings was carried out during the discussion.

The study therefore addressed the following research questions:

1. Is there a difference in psychological health, and perceptions of body image between amputee and non-amputee AWCLD? (quantitative).
2. From whom do AWCLD perceive available social support? (quantitative)
3. What are the physical, psychological, and social experiences of AWCLD in Ghana? (qualitative)
4. How do both amputee and non-amputee AWCLD cope with challenges? (quantitative)
5. What social roles do AWCLD fulfil? (qualitative)

2.3 Conceptual Framework for the Study

This model illustrates the influence of positive emotions in ‘undoing’ negative emotions associated with body image concerns and stigma. Positive emotions promote new ways of thinking or dealing with problems, and lead to adaptive coping resources that the individual employs, and which in turn, lead to increased psychological health outcomes (Tugade & Fredrickson, 2004).

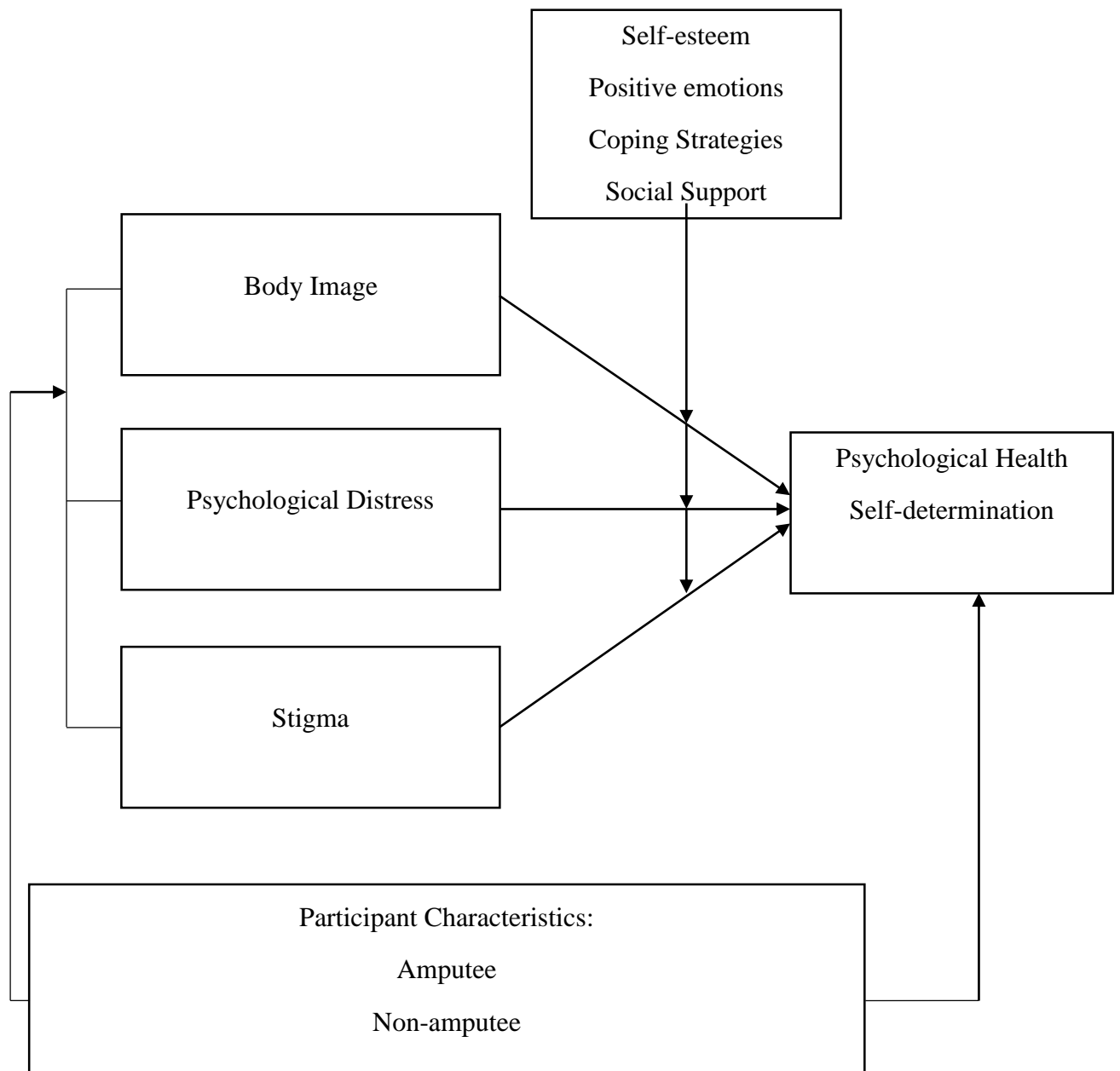


Figure 2.3: Application of the Theoretical Framework to Psychological Health Outcome of Adolescents Living with CLD in Ghana.

2.4 Rationale for the Study

A vast majority of social research on disability has reported findings on the discrimination and stigmatization experienced by many adolescents with birth defects. Several studies have also been carried out on the physical and psychological effects of amputation on adolescents. However, hardly any information exists on the perceptions of adolescents born with limb defects about the prescription of amputation as treatment.

The participants in this study are a special minority from the larger population of physically-disabled adolescents, due to the cultural and traditional explanations of the aetiology of their condition. Nevertheless, their psychosocial and psychological experiences have not been studied extensively for two main reasons. Firstly, there is no national database of CLD cases in Ghana. Secondly, CLD studies done in Ghana have focused mainly on the medical model of 'treatment' of the problem. Currently, the approach taken by specialists and rehabilitation teams is based on the medical model. As a result, very little is known about whether amputation is a risk or protective factor of psychological distress in adolescent CLD. By creating social awareness of CLD, this study hopes that more support will be given to families and individuals to enable them lead fulfilling lives.

Several studies indicate that the majority of physically-disabled youth in Ghana are aged between 10 and 24 years. Low levels of education, and employment have been recorded in this population, and neglect has been theorized to force needy children and adolescents into the streets to beg for food. Parental neglect also has an influence on the age at sexual debut of some physically-disabled adolescents, and some as young as 12 years and perhaps even younger, have been reported to engage in sexual behaviour, putting their sexual reproductive health at risk.

This study investigated CLD and psychological health from the perspective of both amputee and non-amputee adolescents using mixed methods. It examined their perceptions, and coping with a condition that is not only disfiguring, but also causes disability, their support systems and social networks. It also explored their experiences of stigma, intimate relationships, participation in social activities, and roles as they moved into adulthood.

2.5 Operational Definitions of Key Terms

Congenital limb deformity (CLD): Birth without a limb or deformity of a limb(s) at birth.

Acquired amputation: A surgical procedure that usually refers to the cutting away of the whole or part of an arm or a leg that is either causing great pain, is deformed, and/or threatens physical functioning.

Adolescence: It is the transitional period between childhood and adulthood. In this study, an adolescent refers to an individual aged between 10 – 24 years.

Non-amputee: An individual with CLD who did not undergo amputation of the deformed limb(s)

Body image: The mental picture or schema of the adolescent's body which is subject to continual deconstruction, revision, and reconstruction.

Social support: It is the perception that one is cared for or assisted by others, limited in this study to family, friends or spouse.

Social network: A support system made up of individuals who relate to each other because of their commonalities.

Coping strategies: These include mechanisms adolescents use to minimize the effects of CLD, such as isolation, problem-solving, distraction, aggression, and determination.

Psychological Health of Adolescents with CLD

Psychological health: This is the measure of health and effective functioning of AWCLD, and encompasses physical, cognitive, social, and psychological aspects of CLD.

Psychological distress level: This refers to a person's Global Severity Index (GSI) mean score of ≥ 1.0 on the Brief Symptom Inventory.

2.6 Statement of Hypotheses

H1: Psychological distress levels will differ between amputee and non-amputee AWCLD in Ghana

H2: Body image of AWCLD will be significantly related to their distress levels.

H3: Perceived support from friends will more strongly predict distress levels of AWCLD than support from friends and significant others.

H4: Coping strategies will influence distress levels of AWCLD in Ghana.

H5: There will be age group differences in coping strategies of AWCLD in Ghana.

CHAPTER THREE

METHODOLOGY AND RESULTS FOR QUANTITATIVE STUDY

3.0 Introduction

In this chapter, the determination of the research design, methods, data-collection procedures, analyses and interpretation of findings are outlined. The design of the study determines how the data will be collected and how it will be used to produce further knowledge. Of immense importance are the philosophies that determined the choice of a mixed methods design, as well as the rationale behind the choice. This study begins with a post-positivist worldview to guide measurements of variables that are quantifiable and can be generalised (Creswell & Plano Clark, 2007). These are briefly discussed, along with a description of the research settings, sample sizes and the ethical considerations underlying the study. A constructivist worldview then gives a deeper understanding of the CLD experience in context. This concurrent mixed-methods study examined amputee and non-amputee adolescents living with the condition in Ghana, and added to the existing literature by exploring their lived experience and emotions. For the purpose of this study, only amputation performed for congenital limb defects were assessed and all other forms of amputations were excluded. The study also made no distinction between upper and lower extremity deformities or amputations.

3.1 Philosophical Underpinning of the Study

This study is rooted in pragmatism. It approaches the study with the worldview that knowledge is based on several different realities and relies on an eclectic epistemology, to gain complementary insights from various theoretical perspectives into the phenomenon of adolescent congenital limb deformity. Positivism focuses on the search for cures, means of

reducing impairments, or assessments of clinical interventions in disability research, and use methods such as controlled trials, and structured questionnaires (Oliver, 2013). Amputee and non-amputee AWCLD fall within this group of physically-disabled, with impairments that require treatment. As such, this research has applied a similar methodology to test some of the working hypotheses. For example, positivists may argue that the prescription of a prosthetic device is necessary for functional ability and perhaps aesthetic appearance. Subjectivists or the social construction model of deformity may counter-argue that prostheses rather represent disability, and may thus cause a wearer to be ridiculed with derisive terms such as peg-leg and “pozo” (Mamah, 2016, p. 30; Michailakis, 2003).

Interpretative phenomenological analysis was deemed the most appropriate approach to elaborate on the present inquiry, as the study sought to understand and make meaning of the shared experiences of AWCLD. This study was undertaken with the researcher as a co-producer of the knowledge, not bracketing but reflecting on how personal attitudes, beliefs and previous knowledge may influence the research process (Sultana, 2007). Adolescents with congenital limb deformities are regarded in this clinical study as individual embodied beings who are embedded in a specific lifeworld; the expectation was that, what is embodied, the (the psychological, and physical) would be expressed through their individual voices. The inherent differences in this lifeworld informed differences in participants’ experiences, and impacted their understanding of these experiences. This new understanding was reflected in how they voiced out their experiences in the in-depth interviews. Thus, both positivist and relativist forms of knowledge acquisition were employed in this pursuit of an understanding of AWCLD.

3.2 Research Design

The approach to this study was partly due to the fact that CLD has been studied primarily as a biomedical issue in Ghana, and partly due also to the fact that there is a dearth of research to understand qualitatively the psychosocial effects of amputation in the context of congenital limb deformity.

The present study employed a concurrent triangulated mixed methods design, which is a combination of elements of qualitative and quantitative research methods, and is characterized by the collection of both quantitative and qualitative data at the same time (Creswell, 2014). Equal weights (QUAN and QUAL) were given to both sets of data, and findings from both phases were subsequently integrated and discussed. The quantitative phase involved the collection of cross-sectional survey data to explore the differences in levels of psychological distress, and body image concerns between AWCLD who had been treated by amputation, and those who had not, as well as the buffering resources and psychological health relationship. Participants' body image perceptions, symptoms of psychological distress, perceived sources of social support, and the coping strategies they most used and perceived to be most effective were assessed and analysed. The qualitative aspect involved the collection of phenomenological interview data to understand how AWCLD experienced and made meaning of disfigurement and disability. The findings from the data sets were analysed independently, and then integrated at the discussion stage. This design was adopted since the aim of the present study was to ascertain differences between amputee and non-amputee AWCLD in the areas of distress and body, especially as amputation was assumed to be the main difference between them, and to get an understanding of how and why the differences (if any) exist. The 'whys' and 'hows' may be fully ascertained if the voices of participants are heard, and the meanings that they and the researcher, as co-producers of knowledge, ascribe to the 'what' of the phenomenon of CLD are explored (Pietkiewicz & Smith, 2014). The

buffering resources of positive emotions, social support, and coping strategies were also worth investigating in order to examine the relationship between those resources and AWCLD psychological health. Thus, both quantitative and qualitative methods carried equal weights as each was to corroborate the findings of the other. A concurrent triangulation design was best suited to the overall aim of the study to help triangulate, enhance, and most of all, provide culturally-relevant and contextual explanations and illustrations of the quantitative findings.

Bryman (2012) suggests that mixed-methods research can be combined in a number of different ways depending on the purpose of the research design. This present study integrated the two datasets in three ways - by sampling, triangulation, and illustration, which invariably expanded the work. Finally, the timing of the triangulation determined that both quantitative and qualitative findings were implemented concurrently for the purpose of addressing the research questions.

The study examined amputee and non-amputee adolescents living with the condition in Ghana, and added to the existing literature by exploring their lived experience and emotions. For the purpose of this study, only amputation performed for congenital limb defects were assessed and all other forms of amputations were excluded. The study also made no distinction between upper and lower extremity deformities or amputations.

Rationale for Mixed-Method Study Design

The rationale behind the choice of a mixed-method design are the advantages that it offers a researcher. Firstly, it allows for a comparison of the data collected from qualitative and quantitative data in order to discover any contradictions (Gravetter & Wallnau, 2013). The purpose of this study design however was not only to compare the types of data collected, but

to corroborate the findings on predictors of psychological health outcomes of amputee and non-amputee AWCLD with the narratives of their lived experience of CLD.

This method also allows the respondents to have a voice, share their experience, and points of view, thereby providing richer information. This research design fosters scholarly interaction in researchers who subscribe to either method of data collection. It has also been argued that one single approach in research may be inadequate, and may not capture entirely the nuances inherent in the ontology of the participants (Breen & Darlaston-Jones, (2010). This study sought to glean the meanings that a hitherto under-researched population ascribe to the phenomenon of CLD.

Finally, taking into account the fact that the defects not only affect appearance, but also cause disability, a one-time data collection method was deemed the best fit to minimize distress to participants, as all participants lived some distance from the research setting, and the majority had to use public transportation to get to the research setting. The researcher thus sought to minimize any distress that might come from being cramped in vehicles, as well as from stares, comments, and/or any stigmatizing behaviours of fellow travellers as a result of the disfiguring birth defects.

3.3 Quantitative Research Design of Study

A cross-sectional survey design facilitates the study of relationships between variables, and provides a quantitative description of trends, attitudes, or opinions of a population by studying a sample of that population (Creswell, 2014). This research design also allows the researcher to measure the outcome and exposures in the study participants at a single moment in time, and is exceedingly helpful when there are time constraints (Smith & Davis, 2004). With these advantages in mind, a cross-sectional study of adolescents born with limb

deformities was used to evaluate, social support, positive emotions, coping, and self-esteem as internal and external factors influencing psychological health associated with CLD.

3.3.1 Rationale for Survey Method

This study collected responses, opinions and feelings about body image, coping strategies, social support, self-esteem, and symptoms of psychological distress of participants from a representative sample of the target population at a single moment in time as the researcher had a limited amount of time to carry out the study.

3.3.2 Research Setting

The main study location for the study was the Orthopedic Training Center, Nsawam. The rationale for choosing this location for the study was that it serves as the referral point for all congenital limb deformities in Ghana and as such has a database for individuals with limb deformities from every part of the country, and every ethnic background. Nsawam Orthopaedic Training Center (NOTC) was adjudged the most appropriate setting as it has been a center for referrals since the early 1960s. It was established primarily to rehabilitate physically-challenged persons in Ghana and West Africa, and enable handicapped children live independently. The center also houses a prosthetics and orthopaedic training college. Referrals from neighbouring countries visit the NOTC for physiotherapy, orthoses, and prosthetic limbs following correction procedures or amputations. The center began carrying out surgeries in the early 1990s, and twice a year, visiting surgeons assess over 6000 patients and/or perform surgeries to improve function for those with varying degrees of disability and disfigurement, referred from St. John's of God in Duayaw Nkwanta in the Brong Ahafo Region, St. Joseph's in Koforidua in the Eastern Region, and St. Anthony's in Dzodze in the Volta region between

the months of May and November. To expand the scope of the study, it was necessary to look at individuals who would have benefitted from these procedures or from assistive devices but perhaps due to poverty or some other reason were unable to access them for inclusion in the study.

The Ghana Society for the Physically Disabled, whose members include persons with all forms of physical disability (including amputees, hunchbacks, and children and adults with cerebral palsy or polio) operates at the district and zonal levels in Ghana. Although the National Secretariat is located in the capital Accra, the local executives, in their role as gatekeepers, sent messages to all districts in the country to invite them to participate in the study. The researcher exchanged telephone numbers with the district heads, and interested participants contacted the researcher and research assistants directly.

Prior to the data-collection period, participants were contacted and briefed on the nature and purpose of the study by the OPD of the primary study site. Available and consenting individuals were then contacted by the researcher from the list provide by the GSPD. Parents of adolescents below 18 years indicated their consent to the study and arranged to be at the OPD on the day of data collection.

3.3.3 Research Population

The target population included all adolescents with congenital limb deformities in Ghana. The accessible population however, comprised of AWCLD who attend the Nsawam Orthopedic Training Center (NOTC). The NOTC is the only orthopaedic center in the country that is more adequately equipped to handle limb deformities than similar facilities in Ghana. During the time of data collection, from June 2019 to January 2020, the total number of AWCLD from the outpatient records was 85 – 45 males and 40 females.

3.3.4 The Sampling Method

A combination of two non-probability sampling methods was utilized for this study, namely purposive and snowball sampling techniques, with the former being the primary technique. As an adjunct to the primary recruitment method, the snowball sampling method was used as a means of making contact with other individuals in the target group (Naderifar, Goli & Ghaljaie, 2017). Purposively recruited participants were asked to willingly provide information about peers or other adolescents they knew with CLD, after they had themselves consented to participate in the study. Participants willingly gave the researcher the contacts to other potential participants. Using this method, the researcher was able to reach AWCLD who had never been at the OPD of the research setting, and those who met the inclusion criteria were followed up and recruited for the study.

3.3.5 The Sample Size

This sample was based on the minimum sample size calculation, on the formula $n = N / (1 + N(e)^2)$ with a focus on the effect size and statistical power as well as the level of significance. (Yamane, 1967). The determination of this size was also backed by power analysis conducted in G-POWER, using an alpha of 0.05, a power of 0.80, a large effect size ($d = 0.8$), and two tails (Faul, Erdfelder, Buchner, & Lang, 2009). Based on that assumption, the desired sample size was 50.

3.3.6 Research Sample

Fifty (50) adolescents with congenital limb deformities were mostly sampled from the Nsawam Orthopedic Center in Adoagyiri. Snowball sampling was also very effective in helping the researcher identify and reach out to other AWCLD who were not outpatients of the

principal setting. Several of the respondents belonged to various groups for the physically-disabled in Ghana. Others were purposively sampled from certain identified areas in the city where many physically-disabled converged such as traffic lights, shopping malls, or churches.

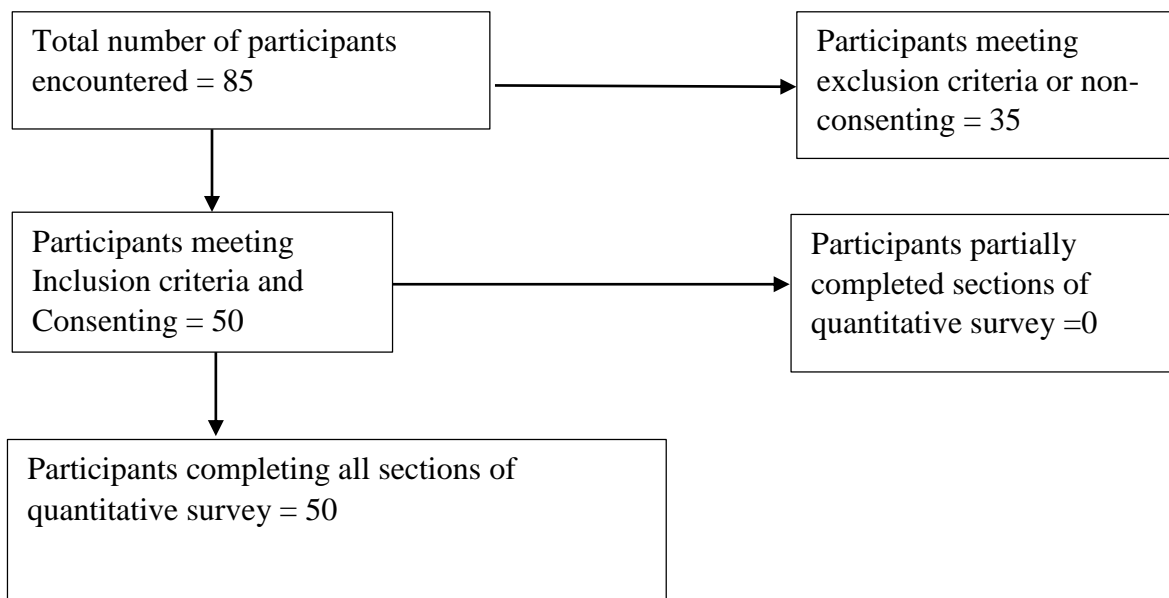


Figure 3.1: Diagrammatical Representation of Participant Recruited

Demographic Characteristics

The demographic characteristics of participants sampled for the survey are presented in Table 3.1. In this study, more non-amputees 30 (60%) than amputees 20 (40%) were sampled. The mean age of the participants was 15.9 (SD 3.9) with a minimum age of 10 years and a maximum age of 24 years. Participants aged 15-19 years (n=22; 44%) were more than those aged 10-14 years (n=20; 40%) and 20-24 years (n=8; 16%). There was an equal number of male 25 (50%) and female 25 (50%) participants. Most participants had lower-limb deformities 39 (78%). The remaining 11 (22%) had upper-limb deformities 5 (10%) and 6 (12%) had both upper and lower-limb deformities.

Table 3.1: Sociodemographic Profile of Survey Respondents

Demographic		Frequency	Percentage
Status			
	Amputee	20	40
	Non-amputee	30	60
Type of Deformity			
	Upper-limb	5	10
	Lower-limb	39	78
	Both lower and upper limb	6	12
Gender			
	Male	25	50
	Female	25	50
Age			
(early adolescence)	10-14 years	20	40
(mid adolescence)	15-19 years	22	44
(late adolescence)	20 years and above	8	16

Justification for Sample Size

The justification for using a very small sample for this study is found in the very nature of the study's participants. Congenital limb deformities are rare birth defects, and rates vary from one country to another (Vasluian et al., 2013), making sampling an exceedingly difficult procedure. In addition, the target population was adolescents aged 10 – 24. According to WHO (2010), adolescence begins at age 10 and ends at age 24. Role transitions have however extended the traditional age to 24 years (Casey et al., 2010). Thus, although a large number of

infants diagnosed with CLD were available at the research setting awaiting surgery or prosthesis fitting, they could not be included in the study.

3.3.7 Inclusion Criteria

Adolescent amputee and non-amputees with CLD who agreed to participate in the study, and met the eligibility criteria of age 10 – 24, were recruited into the study. Although the period of adolescence ranges between 10 and 19 years (WHO, 2010), emotion-regulation and cognition development continue as far as age 24 (Casey et al., 2010). In addition, the role of biological maturation, sexual debut, or the acquisition of social roles for some, begins as early as age 10 and may extend into the early 30s (Casey et al., 2010; Jaworska & MacQueen, 2015). These cut-offs have been used by Maart and Jelsma (2010), and Steinberg (2010). Thus, AWCLD were included in the study if they fell within this range covering the period of cognitive development, emotion-regulation, and biological maturity, enabling the participation in some social activities and roles.

However, participation in, and acquisition of some particular social roles may be delayed for most AWCLD as a consequence of functional limitations (Presler-Marshall et al., 2019). The study took this into account and based inclusion criteria on the expanded period of adolescence (Jaworska & MacQueen, 2015). Participants recruited through purposive sampling had their diagnosis indicated in the data received from the Orthopedic Training Center, Nsawam OPD. However, participants recruited using the snowball sampling were probed further to ascertain whether their limb deformities were congenital, and those whose diagnosis could be ascertained were included in the study. In addition, parents or guardians of adolescents below the age of 18 had to consent to their wards' participation.

3.3.8 Exclusion Criteria

The study excluded OPD database patients and individuals with CLD below the age of 10 and above the age of 24. Patients diagnosed with CLD in association with other anomalies including severe intellectual disabilities were also excluded. In addition, the study excluded participants whose questionnaires were uncompleted because the SPSS software does not work on missing data. Participants who had congenital deformities other than CLD were excluded. Participants whose limb deformities could not be confirmed as congenital defects, and intrapartum complications such as shoulder dystocia, which usually occurs when a newborn's shoulder gets caught in the birth canal during delivery, limb fractures that occurred during delivery, as well as polio were excluded from the study (Cluett, 2019; Kim et al., 2015).

3.3.9 Survey Instruments: Description and Psychometric Properties.

Primary data was collected using questionnaires that assessed perceptions of CLD, stigma, body image, coping, social support, self-esteem, and psychological health. Detailed descriptions of the instruments used as well as their psychometric properties are given below:

The Brief Symptom Inventory (Derogatis & Melisaratos, 1983)

This scale was used to measure psychological health of the participants. The purpose of the BSI is to identify self-reported clinically relevant psychological symptoms in adolescents and adults, and designed to reflect the psychological symptom patterns of psychiatric, medical and non-patients. The BSI consists of 53 items spreading over nine indications which include Somatization, Obsessive-Compulsion, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic anxiety, Paranoid ideation and Psychoticism and Positive Symptom Total. The Global Indices measures symptomatology, intensity of symptoms and number of reported

symptoms at the current or past level. The scale takes about 8-12 minutes to complete and the method of administration is either self- or interviewer-administered. In scoring this instrument, respondents rank each feeling item (e.g., “your feelings being easily hurt”) on a 5-point scale ranging from 1 (not at all) to 5 (extremely). Rankings characterize the intensity of distress during the past seven days.

1. Global Severity Index (GSI): This is calculated using the aggregates for the nine indications plus the four additional items excluded in any of the indication scores, and divided by the total number of items to which the individual responded. The GSI is the mean for all 53 items when there are no missing items.
2. Positive Symptom Total (PST): This numbers all the items with non-zero responses and shows the number of symptoms the respondent records undergoing
3. Positive Symptom Distress Index (PSDI): This is the aggregate of the value of the items recording non-zero responses divided by the PST. This index gives information on the average level of distress the respondent is reporting. The BSI manual gives a table by which data should be converted to T scores. Scores are demonstrated by comparison to age-appropriate norms. Normative data are available for both clinical and non-clinical samples of adolescents (over 13 years) and adults (Derogatis, 1993).

Cronbach’s alpha coefficient for the pilot study of 6 participants was 0.77, 0.82, 0.98, 0.78, 0.76, 0.95, 0.50, 0.45 and 0.72 for Somatization, Obsession-Compulsion, Interpersonal Sensitivity, Depression, Anxiety, Hostility, Phobic Anxiety, Paranoid Ideation and Psychoticism respectively. In this current study, Cronbach's alpha coefficient was .898 for the entire scale.

The Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988)

The scale measures perceived adequacy of support from three different sources: family, friends, and significant other. By description, the MSPSS consists of 12 items with 7-point Likert-type scales ranging from “very strongly disagree” to “very strongly agree”. In measuring perceived social support, four items are seeded from a delicate seedbed and MSPSS measures the adequacy of support from three seedbeds: family (items 3, 4, 8, 11), friends (items 6, 7, 9, 12), significant other (items 1, 2, 5, 10).

The MSPSS has been used in several studies, including one with 74 adolescents living in Europe with their families, and 605 sickle cell disease patients living in Ghana. It is self-administered. A score of 69 to 84 is indicative of high social support, 49 to 68 indicate moderate social support and 12 to 48 indicates low social support. Reliability Coefficient alphas for the subscales and scale as a whole ranged from .85 to .91 with 275 undergraduates. The MSPSS has been widely used in Africa, and particularly in Ghana (Dziwornu & Kugbey, 2015; Yendork & Somhlaba, 2016). The Cronbach’s alpha coefficient for the pilot study of 6 participants was 0.95, 0.84 and 0.90 for social support from family, support from friends and support from significant others respectively, whereas the Cronbach’s alpha coefficient for whole scale was .89. The Reliability Coefficient alpha for this study was .88.

The Rosenberg Self-Esteem Scale (Rosenberg, 1965)

The scale which measures the self-esteem of respondents, is a ten item Likert scale with items answered on a four-point scale ranging from 3= strongly agree to 0=strongly disagree. The original sample for which the scale was developed consisted of 5,024 High School juniors and seniors from 10 randomly selected schools in New York State. Items 3 (All in all, I am

inclined to feel that I am a failure), 5 (I feel I do not have much to be proud of), 8 (I wish I could have more respect for myself), 9 (I certainly feel useless at times) and 10 (At times, I think I am no good at all) are reversed scored. Scores between 15 and 25 reflect normal self-esteem, while scores that fall below 15 are indicative of low self-esteem. Partey and Yidana (2018) used the scale in a study of senior high school students in Ghana with a Cronbach's alpha of .802.

The RSES was used as a proxy measure of positive emotions and self-determination of AWCLD. There are a number of valid and reliable tools for measuring these variables individually. However, items of the RSES considerably reflect the three psychological innate needs of goal directed behaviour or, self-determination, which are largely unobservable until expressed in behaviour (Ryan & Deci, 2000). For example, positive feelings of autonomy, competence, and relatedness are expressed as "I am able to do things as most other people", or "I feel that I am a person of worth, at least on an equal plane with others" or "I certainly feel useless at times" which is reversed scored. The Cronbach's alpha coefficient for Total Self-esteem for the pilot study of 6 participants was .87. The Reliability Coefficient alpha for this study was .67.

The Kidcope (Spirito, Stark, Grace, & Stamoulis, 1991)

This scale measures children's cognitive and behavioural coping strategies. The older version (recommended for adolescents) of the Kidcope was used for all the adolescents in this study. The scale lists 11 coping strategies. These are; Distraction, Social Withdrawal, Cognitive Reframing, Self-Blame, Blaming Others, Problem Solving, Negative Emotional Regulation, Positive Emotional Regulation, Wishful Thinking, Social Support and Resignation. Each coping strategy had the frequency of usage and how efficient the strategy

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was (coping efficacy). The participants rated each of the 11 coping strategies according to whether they had used the particular item. This was scored on a scale of 0= never to 3= almost all the time, (the frequency score / how often did you do this?). Also, the participants rated how helpful they perceived this item to be on a scale of 0= not helpful at all to 4= very much, (the efficiency score/ how much did it help?).

The Kidcope has been used in Africa, and particularly in Ghana to study coping strategies in young, vulnerable populations (Yendork & Somhlaba, 2016).

The Body Image Scale (Hopwood, Fletcher, Lee & Al Ghazal, 2001)

This scale was used to assess the body image concerns of the participants for this study. The 10 test items comprised affective items (e.g. feeling feminine, feeling attractive), behavioural items, (e.g. find it hard to look at myself naked, avoid people because of appearance), and cognitive items (e.g. satisfied with appearance, or with scar). The four options for rating body image concerns were “not at all” (score 0), “a little” (score 1), “quite a bit” (score 2) and “very much” (score 3). The 10 item scores were then summed to produce overall summary score for each patient, ranging from 0 to 30. Zero scores represented no symptom/distress and higher scores represented increasing symptoms/distress. The Cronbach’s alpha coefficient for the pilot study of 6 participants was .91. The Reliability Coefficient alpha for this study was .83. Other forms of logarithmic conversion could also be applied.

3.3.10 Pilot Study

A few participants (6) were selected for a pilot study to pretest the survey questionnaire and interview guide for fit, and to ensure that the approach, participant recruitment, and

instruments were feasible to achieve the aims of the study (Creswell, 2014). The pilot study participants were AWCLD identified from the Nsawam Orthopedic Training Center OPD database, as well as two participants recruited through snowball sampling of outpatients' social networks. The researcher's observations about the pilot interviews as well as participants' feedback highlighted the need for a translation of the survey instruments as well as the interview guide into the most common local language in Ghana (Twi). The translation was carried out by a Senior High School Tutor with a Master's degree in Ghanaian languages.

3.3.11 Study Procedure

Following ethical clearance from the Ethics Committee for Humanities (ECH) at the University of Ghana, Legon, institutional clearance was sought from the Nsawam Orthopedic Training Center with certificate numbered ECH 082/18-19. Institutional clearance and permission were granted in April 2019. Data collection spanned the period of beginning June 2019 to ending of January 2020.

Two research assistants with backgrounds in psychology, and fluent in Twi, the main local Ghanaian language (Twi) received a day's orientation on the research topic and directions on how to administer the tools for data collection. A mock trial was organized for them to master the use of the tools, and a pilot study to validate the tools was conducted on 6 AWCLD, 4 of whom were outpatients of OTC, an amputee rehabilitation center in Nsawam, and the primary research setting, and 2 AWCLD, recruited through snowball sampling. Due to the sensitive nature of the topic, respondents from the general public identified through snowballing, were administered questionnaires in a private setting determined by the researcher.

From the pilot study, it was observed that some participants struggled with comprehension of some items of the questionnaire. For instance, items on the BSI (Brief Symptom Inventory) had to be literally translated into a local language to facilitate comprehension. This development prompted the researcher to translate into Twi, the most spoken local language in Ghana, all the instruments of the questionnaire, including the interview guide and the 2 vignettes used for qualitative data collection. Some participants also had difficulties in filling out the questionnaires and as a result were assisted by the researcher or research assistants to write out their responses.

3.4 Results

The aim of the present study was to evaluate the psychological health of adolescents with limb deformity (CLD) in Ghana, by examining the factors that impact their psychological health. For this purpose, the IBM Statistical Package for Social Science (SPSS) version 23.0 was used to conduct the statistical analyses of all quantitative information. The chapter thus provides tabulated and written report of the analysis of the quantitative data.

3.4.1 Preliminary Analysis

Descriptive analysis of study variables

The analysis began by inspecting the data for missing values and found none. Next descriptive analyses were conducted, where means, standard deviations, reliabilities, and normality checks (see Table 3.3) were computed for the main continuous variables. For normality, the skewness and kurtosis of the study variables were calculated to ensure that they were within the acceptable ranges of +2 and -2 (Field, 2013; Spiegel & Stephens, 2008). All study variables, except for Self-Esteem and some subscales of Brief Symptom Inventory, recorded favourable Cronbach Alpha coefficient of $\geq .70$ (Pallant, 2016). See Table 3.3 for

summary. All inferential statistics were conducted with a 0.05 margin of error and 95% confidence level.

Participant description

The final sample consisted of 50 participants: 20 (40%) amputees and 30 (60%) non-amputees. For gender 25 (50%) were males and 25 (50%) were females. Majority of the participants were schooling (92%) and only 6% were working. The youngest participant was aged 12 while the oldest was 24 years. Thus, the average age of all the participants was 15.98 ($SD = 3.92$) and all amputees had had at least one surgery. The average age of amputee participants was 15.70 ($SD = 3.96$) and non-amputee participants was 16.17 ($SD = 3.95$).

Clinical description of participants

Participants were tested on their levels of clinical symptomology as indicated on the Brief Symptom Scale. A cut-off point of 1 and above was used to compute the number of participants exhibiting clinical symptoms. Any scores below this point were treated as not exhibiting significant clinical symptoms. The findings revealed low levels of symptomatology in the majority of participants. Sixty-two (62%) of participants reported symptoms of distress that were clinically significant. For the subscale symptoms on the Brief symptom inventory, the following percentages of participants reported experiencing clinical symptoms: 26% somatization, 54% obsession-compulsion, 62% interpersonal sensitivity, 30% depression, 40% anxiety, 34% hostility, 34% phobic anxiety, 64% paranoid ideation, and 38% psychoticism.

Table 3.2: Summary of Clinical Description of Research Participants (N=50)

Brief Symptom Inventory (BSI)	Frequency	Percentage
Global Severity Index (GSI)		
Presence of clinical symptoms	19	38%
Somatization		
Presence of clinical symptoms	13	26%
Obsession-Compulsion		
Presence of clinical symptoms	27	54%
Interpersonal sensitivity		
Presence of clinical symptoms	31	62%
Depression		
Presence of clinical symptoms	15	30%
Anxiety		
Presence of clinical symptoms	20	40%
Hostility		
Presence of Clinical symptoms	17	34%
Phobic Anxiety		
Presence of Clinical symptoms	17	34%
Paranoid Ideation		
Presence of Clinical symptoms	32	64%
Psychoticism		
Presence of Clinical symptoms	19	38%

Key findings from descriptive analyses

Table 3.3: Results of Preliminary and Descriptive Analysis of Study Variables

	<i>N</i>	<i>M</i>	<i>SD</i>	Skewness	Kurtosis	α
Total Global Distress	50	.87	.44	.12	-.32	—
Somatization	50	.68	.50	.61	-.45	.45
Obsession-Compulsion	50	1.04	.71	.90	.76	.65
Interpersonal Sensitivity	50	1.25	.97	.81	.13	.65
Depression	50	.62	.59	.94	.25	.62
Anxiety	50	.82	.69	.66	-.43	.63
Hostility	50	.93	.97	1.48	1.69	.80
Phobic Anxiety	50	.84	.84	1.14	.69	.67
Paranoid Ideation	50	1.27	.65	.33	.02	.29
Psychoticism	50	.68	.61	.65	-.04	.30
Total Social Support	50	63.10	14.99	-.86	.30	.88
Support from Family	50	21.54	6.32	-.96	-.04	.89
Support from Friends	50	19.08	6.47	-.45	-.55	.82
Support from Significant others	50	22.48	5.91	-1.42	1.58	.84
Total Self-Esteem	50	22.00	4.03	-.44	.41	.67
Total Body Image Scale	50	7.34	6.12	1.02	.67	.83

α = Cronbach's Alpha

The BSI, which was the measure of psychological health in this study, defines a clinically significant score as a GSI greater than or equal to a 63. The norms for adolescent non-patients for both males and females however, are calculated from raw scores of 1.59 and 1.39 respectively, with the clinical range set at 1. From Table 3.3, participants GSI mean score ($M = .87, SD = .44$) was below 1, and thus not clinically significant. However, the mean scores

for three of the BSI domains; Obsession-Compulsion ($M = 1.04, SD = .71$), Interpersonal Sensitivity ($M = 1.25, SD = .97$) and Paranoid Ideation ($M = 1.27, SD = .65$) were above 1, which indicates the presence of psychological distress. The mean score for social support ($M = 63.10, SD = 14.99$) indicates high perceived social support. Mean scores for social support from significant others ($M = 22.48, SD = 5.91$) was higher than social support from family ($M = 21.54, SD = 6.32$) and social support from friends ($M = 19.08, SD = 6.47$). The mean score for self-esteem ($M = 22, SD = 4.03$) is indicative of high self-esteem. Participants had low body image concerns with a mean of ($M = 7.34, SD = 6.12$).

Table 3.4: Description of Responses to Stigma Statements by Amputee and Non-Amputee participants

Statements	Amputee (n = 20)	Non-amputee (n = 30)
	Frequency (%)	Frequency (%)
1. Do people view your deformity well?		
Yes	16 (80.0)	24 (80.0)
No	4 (20.0)	6 (20.0)
2. If possible, would you prefer to keep people from knowing about your problem?		
Yes	6 (30.0)	9 (30.0)
No	14 (70.0)	21 (70.0)
3. Do you think less of yourself because of this problem?		
Yes	2 (10.0)	12 (40.0)
No	18 (90.0)	18 (60.0)
4. Have you ever been made to feel ashamed or embarrassed because of your problem?		
Yes	6 (30.0)	15 (50.0)
No	14 (70.0)	15 (50.0)
5. Do you feel others have avoided you because of your problem?		

Table 3.4 continued Description of Responses to Stigma Statements by Amputee and Non-Amputee participants

Statements	Amputee (n = 20)	Non-amputee (n = 30)
Yes	7 (35.0)	14 (46.7)
No	13 (65.0)	16 (53.3)
6. Would some people refuse to visit your home because of this condition?		
Yes	5 (25.0)	7 (23.3)
No	15 (75.0)	23 (76.7)
7. If others were to find out about your problem, might it cause problems for your family?		
Yes	2 (10.0)	4 (13.3)
No	18 (90.0)	26 (86.7)
8. Would your family prefer to keep others from finding out about your condition?		
Yes	2 (10.0)	8 (26.7)
No	18 (90.0)	22 (73.3)
9. Would this problem make it more difficult for you to marry?		
Yes	2 (10.0)	12 (40.0)
No	18 (90.0)	18 (60.0)
10. Would this problem make it more difficult for someone in your family to marry?		
Yes	3 (15.0)	5 (16.7)
No	17 (85.0)	25 (83.3)

A questionnaire adopted from The International Federation of Anti-Leprosy Associations (ILEP), and adapted by Voorend et al. (2011), asked participants to respond Yes or No to items on stigma-related issues, and was administered to determine whether participants felt stigmatized, or discriminated against. The statements involved issues of stigma associated with CLD and included questions about disclosure, non-disclosure, self-

esteem, and shame. Fifty percent of non-amputees reported feeling ashamed or embarrassed about their condition, compared to 30% of amputees. Discriminatory behaviours were also experienced by 46.7% of non-amputee AWCLD who responded to the question “Do you feel others have avoided you because of your problem”? See Table 3.4.

3.4.2 Hypotheses Testing

Five hypotheses were tested in this study. The first hypothesis stated that “Psychological distress levels will differ between amputee and non-amputee AWCLD in Ghana”. This was tested using an independent t-test. The second hypothesis which stated that “Participants’ body image will be significantly related to their distress levels” was analysed using the Pearson Moment Correlation Coefficient (r). The third hypothesis which stated “Perceived support from friends will more strongly predict distress levels than other sources of social support” was analysed with Multiple regression. The fourth hypothesis which stated “Coping strategies will influence distress levels” was also tested with a Multiple regression. The last hypothesis which stated “There will be age group differences in coping strategies” was tested with A one-way ANOVA.

Hypothesis one

The independent t-test was conducted to compare the means of amputee and non-amputee participants on their scores of the GSI, selected domains, self-esteem, body image and social support. The findings revealed that there was a statistically significant difference in scores, $t(48) = -2.22, p = .03$ with non-amputee ($M = .98, SD = .40$) scoring greater than amputee ($M = .71, SD = .44$). Significant results were also recorded in one domain of the BSI namely depression ($t(48) = -2.66, p = .01$) with non-amputees ($M = .79, SD = .65$) scoring higher than

amputees ($M = 36, SD = .38$). However, to control the potential type 1 errors that usually accrue from conducting multiple t-tests on the same dependent variable, a follow-up Bonferroni correction as recommended by Armstrong (2014) was used to revise the alpha level ($\alpha_{\text{altered}} = [.05/5] = .01$). The new alpha level was subsequently tested against the p-values of GSI and selected domains of symptomatology (Somatization, Interpersonal Sensitivity, Depression, and Paranoid Ideation) and it was observed that only Depression remained significant. These results reveal that the non-amputee participants endorsed more depression than amputee participants. This finding confirms the hypothesis that distress levels will differ between amputee and non-amputee AWCLD in Ghana. See Table 3.5

Table 3.5: Summary of Independent t-test testing the study variables between Amputees and Non-amputees

Variables	Amputee (n=	Non-Amputee	<i>t</i>	<i>df</i>	<i>p</i>
	20)	(n=30)			
	<i>M (SD)</i>	<i>M (SD)</i>			
Global severity index	.71 (.44)	.98 (.40)	-2.22	48	.031
Somatization	.53 (.38)	.79 (.54)	-1.86	48	.07
Interpersonal Sensitivity	.89 (.81)	1.48 (1.02)	-2.17	48	.04
Depression	.36 (.38)	.79 (.65)	-2.66	48	.01
Paranoid Ideation	1.14 (.67)	1.36 (.64)	-1.19	48	.24
Body image	6.30 (6.36)	8.03 (5.96)	-.98	48	.33
Self-esteem	22.60 (3.49)	21.60 (4.36)	.86	48	.40
Social support	61.05 (14.80)	64.47 (15.21)	-.79	48	.44

Note. $p < .05$

Hypothesis Two

A Pearson product-moment correlation coefficient analysis was conducted to test the strength and direction of the study variables. The results of the analysis indicated two major significant relationships. Body image concerns was largely and positively correlated with

distress as measured by the Global distress, $r = .52$, $n = 50$, $p < .001$. This means that high scores on body image is related to high scores on distress. This further confirms the hypothesis that body image will be significantly related to distress levels. Self-esteem also had a small but positive relationship with social support, $r = .28$, $n = 50$, $p = .05$. The remaining and detailed results are presented in Table 3.6.

Table 3.6: Inter-correlation Matrix of Study Variables (N = 50)

Variables	1	2	3	4	5	6	7
1. Global Severity Index	—						
2. Body Image Scale	.52**	—					
3. Social Support	-.03	-.12	—				
4. Family	-.13	-.21	.77**	—			
5. Friends	-.08	-.09	.75**	.24	—		
6. Significant other	.16	.02	.89**	.62**	.55**	—	
7. Self-Esteem	.012	-.26	.28*	.23	.18	.27	—

Note. ** $p = .01$; * $p = .05$

Hypothesis Three

Multiple regression was used to assess how social support perceived from friends will predict distress level more than the other domains of perceived social support specifically from family and significant other. The results revealed that the model was statistically significant, adjusted $\Delta R^2 = .12$, $F(3, 46) = 3.12$, $p = .04$, with support perceived from family ($\beta = -.42$, $p = .02$), and significant others ($\beta = .58$, $p = .001$), contributing significantly to the model. Perceived support from significant other was the strongest unique contributor to the variance of the model. Nevertheless, support perceived from friends did not contribute significantly to the model ($\beta = -.30$, $p = .07$). This means that the hypothesis which stated that, perceived

support from friends will strongly predict distress levels than other sources of social support was not confirmed. See Table 3.7 for summary.

Table 3.7: Summary of Regression Analysis of the Types of Social Support and Distress Level

					95% C. I
Model 1	<i>B</i> (SE <i>B</i>)	β	<i>t</i>	<i>p</i>	(LB; UB)
(Constant)	.91 (.26)		3.57	.00	.40; 1.43
Social support from Family	-.03 (.01)	-.417	-2.41	.02	-.05; -.01
Social support from Friends	-.02 (.01)	-.300	-1.84	.07	-.04; .00
Social support from Significant others	.04 (.02)	.581	2.88	.01	.01; .07

Note. *B* = Unstandardized Beta; SE *B* = Standard error of the Beta; β = Standardized Beta; C.I = Confidence Level

Hypothesis Four

Multiple regression was used to assess how coping strategies frequently used by participants will predict distress. The results revealed that the model was statistically significant, adjusted $\Delta R^2 = .20$, $F(11, 38) = 2.11$, $p = .04$, with both negative emotional regulation ($\beta = .47$, $p = .003$), and social support ($\beta = -.38$, $p = .02$), contributing significantly to the model. Negative emotional regulation was the strongest unique contributor to the variance of the model. The other coping strategies included in the model did not significantly predict distress levels. This means that the hypothesis which stated that coping strategies will predict distress was confirmed. See Table 3.8 for summary.

Table 3.8: Summary of Multiple Regression Analysis for Coping Strategies Frequently used by Participants on Distress Levels

Model 1	<i>B</i> (SE <i>B</i>)	β	<i>t</i>	<i>p</i>	95% <i>C. I</i> (LB; UB)
(Constant)	.83 (.25)		3.35	.002	.33; 1.33
Distraction	-.01 (.07)	-.02	-.12	.903	-.14; .13
Social Withdrawal	.08 (.07)	.18	1.14	.261	-.06; .22
Cognitive Reframing	.00 (.07)	.00	-.00	.999	-.14; .14
Self-Blame	-.08 (.09)	-.13	-.89	.382	-.27; .11
Blaming Others	.10 (.07)	.20	1.41	.17	-.04; .24
Problem Solving	.01 (.06)	.02	.13	.90	-.12; .14
Negative Emotional Regulation	.22 (.07)	.47	3.13	.00	.08; .36
Positive Emotional Regulation	-.03 (.06)	-.08	-.54	.60	-.16; .09
Wishful Thinking	.08 (.06)	.21	1.44	.16	-.03; .20
Social Support	-.16 (.07)	-.38	-2.46	.02	-.29; -.03
Resignation	-.00 (.06)	-.01	-.03	.97	-.12; .12

Note. *B* = Unstandardized Beta; SE *B* = Standard error of the Beta; β = Standardized Beta; C.I = Confidence Level

Hypothesis Five

A one-way Analysis of Variance was conducted to explore age differences between the various coping strategies frequently used by participants. Participants were divided into three groups according to their age (Group 1: 10-14; Group 2: 15-19 & Group 3: 20+). The only statistically significant difference found was on the Problem-solving coping strategy, *F* (2, 47)

= 3.29, $p = .05$. Post-hoc comparison using the Bonferroni test indicated that, apart from the mean score for Group 3 ($M = 2.13$, $SD = .64$) being significantly higher than Group 2 ($M = 1.09$, $SD = .97$), no other significant differences were recorded. The hypothesis which stated that there will be age difference in the types of coping used by participants was therefore partially confirmed. See Table 3.9 for summary of results.

Table 3.9: One-way ANOVA for the Difference Between Frequently used Coping Strategies and Age Group of Participants

Strategies	Age Group			F	Sig.
	10-14 ($n=20$)	15-19 ($n=22$)	20+ ($n=8$)		
	<i>M (SD)</i>	<i>M (SD)</i>	<i>M (SD)</i>		
Distraction	2.00 (1.03)	1.50 (.91)	1.13 (.35)	3.151	.052
Social Withdrawal	1.00 (1.08)	1.05 (.90)	1.38 (.92)	.446	.643
Cognitive Reframing	1.98 (.95)	1.86 (.99)	2.00 (1.07)	.072	.931
Self-Blame	.30 (.66)	.55 (.80)	.25 (.46)	.858	.431
Blaming Others	.70 (1.17)	.18 (.50)	.38 (.74)	1.883	.163
Problem Solving	1.55 (1.15)	1.09 (.97)	2.13 (.64)	3.293	.046
Negative Emotional Regulation	.70 (1.08)	.50 (.91)	.50 (.76)	.258	.774
Positive Emotional Regulation	1.60 (1.05)	2.09 (.92)	2.25 (1.04)	1.815	.174
Wishful Thinking	1.40 (1.05)	1.36 (1.14)	1.63 (1.19)	.168	.845
Social Support	1.75 (1.12)	1.32 (.84)	1.13 (1.25)	1.438	.248
Resignation	1.50 (1.19)	1.41 (1.10)	1.63 (1.06)	.112	.894

3.5 Summary of Quantitative Findings

Psychological health in this study referred to a person's Global Severity Index (GSI) and psychological symptoms dimension mean score on the Brief Symptom Inventory (BSI). Psychological distress level was also defined as GSI mean score or symptom dimension score that is above, or equal to 1. Participants GSI mean score of .87 was below 1, and thus not clinically significant. However, the mean scores for three of the BSI domains; Obsession-Compulsion, Interpersonal Sensitivity, and Paranoid Ideation were above 1, which indicated the presence of psychological distress.

The survey results showed that the greater majority of participants did not experience clinical symptoms of distress (62%). The following percentages of symptomatology were however recorded in participants: 26% somatization, 54% obsession-compulsion, 62% interpersonal sensitivity, 30% depression, 40% anxiety, 34% hostility, 34% phobic anxiety, 64% paranoid ideation, and 38% psychoticism. A statistically significant difference was however recorded in distress scores between amputees and non-amputees, with non-amputees reporting more distress than amputees.

Experiences of stigma were expressed as percentages and showed that the majority of the participants (70%) did not prefer to keep people from knowing about their condition and also, did not think less of themselves (72%). However, 50% of non-amputees reported having been made to feel shame or embarrassment regarding their deformity.

In general, participants had relatively low body image concerns, indicated by the mean scores of both amputees and non-amputees. Although the instrument used to measure body image did not have a specific cut-off for concerns with body image, a score that was close to the maximum score of 30 (thirty) represented distress, and was indicative of low body image, while a score that was close to 0 (zero) represented no distress, indicating a good body image.

The hypotheses that body image concerns will be related to distress levels was significant. Particularly, a large positive relationship was found between these two variables indicating that as body image concerns increased among the participants, so did their distress levels.

Social support perceived from friends did not significantly contribute to the model in this study, and mean scores for social support from significant others was higher than social support from family and social support from friends. In fact, both amputee and non-amputee AWCLD were more oriented towards significant others for support than family and/or friends.

It was observed, when considering the predictive power of coping strategies, that negative emotional regulation and social support were the only significant predictors of distress levels with negative emotional regulation contributing most to the variance. In addition, although participants of different ages had specific strategies in common, participants in the 20+ age bracket reported more use of problem-solving coping than the other age brackets.

Finally, although no hypothesis was formulated to examine if a relationship existed between self-esteem and psychological health of participants, the variable was included and used as a proxy measure of positive emotions and self-determination. The mean score for self-esteem was indicative of high self-esteem, and any difference between amputees and non-amputees was highly insignificant. In general, both amputees and non-amputees did not feel stigmatized by their condition. In addition, they did not think less of themselves, nor believe that their disfigurement would in impact their family members negatively.

The findings from the quantitative study show that non-amputees had similar positive emotions, outlook, as well as a sense of autonomy and competence, as amputee participants. The quantitative findings thus corroborated the findings from the qualitative study.

CHAPTER FOUR

METHODOLOGY AND RESULTS FOR QUALITATIVE STUDY

4.0 Introduction

This chapter addressed the research method adopted in this study with the goal of achieving the qualitative research objectives. It discusses the research design, research setting, participants and sampling procedure, inclusion and exclusion criteria, data collection tool, and the study procedure.

4.1 Qualitative Research Design of the Study

A key aspect of any qualitative research journey is a consideration of an underlying social science philosophy. An understanding of how philosophy influences a study plays a pivotal role in determining the methodological possibilities available and influences the research process and the analysis of data. When applying phenomenological philosophies, it is expedient that the researcher states the school of thought adhered to in the study as the different viewpoints within the schools have implications for undertaking research (Davidsen, 2013). The meanings that individuals attach to their experiences also come from different realities, and little research has been undertaken to understand, for example, the nature of the lived psychosocial and cognitive experiences that adolescents with the disabling condition of CLD have faced.

The researcher recruited the services of two university graduates (a graduate nurse and a Masters student fluent in the Twi language) to assist with the interviews of participants who could only speak Twi. The research assistants received training on how to first develop rapport with study participants, and be sensitive to both covert and overt signs of emotional distress both during the survey, and in-depth interview. Training on how to administer and score the

research instruments was given, as well as how to use follow-up questions that were not explicitly stated in the interview guide to draw out participants.

4.1.1 Pilot study of Interview Guide

Six AWCLD were selected for a pilot study to pretest the survey questionnaire and interview guide for fit, and to ensure that the study could achieve its aims (Creswell, 2014). Four participants were AWCLD identified from the Nsawam Orthopedic Training Center OPD database. The remaining 2 AWCLD were recruited through snowball sampling of outpatients' social networks. The researcher's observations about the pilot interviews as well as participants' feedback highlighted the need for a translation of the survey instruments as well as the interview guide into the most common local language in Ghana (Twi). The translation was carried out by a Senior High School Tutor with a Master's degree in Ghanaian languages. Recording and transcribing telephone interviews of the pilot study also enabled the researcher gauge with a degree of certainty, the best times to call participants to avoid hassles with mobile phone networks.

4.1.2 Research Setting

The Orthopedic Training Center in Nsawam in the Eastern Region of Ghana was the main study location for the study. The rationale for choosing this location for the study was that it serves as the referral point for all congenital limb deformities in Ghana and as such has a database for individuals who have limb deformities. The gatekeepers were very helpful in granting the researcher access to the research setting and database of patients diagnosed with CLD at the Training Center, including their contact numbers for the purpose of recruitment.

4.1.2 Participants and Sampling Procedure

A combination of two non-probability sampling methods was utilized for this study, namely purposive and snowball sampling techniques, with the former being the primary technique. As an adjunct to the primary recruitment method, the snowball method was used as a means of making contact with other individuals in the target group (Naderifar et al., 2017). Participants recruited through purposive sampling had their diagnosis indicated in the data received from the Orthopaedic Training Center, Nsawam OPD. However, participants from the GSPD who were identified by their district and zonal heads, and recruited via snowball sampling, were probed further to ascertain whether their limb deformities were congenital, and those whose diagnosis could be ascertained were included in the study. A total of 15 AWCLD, 6 amputees and 9 non-amputees, participated in the qualitative data-collection.

4.1.3 Inclusion Criteria

Adolescent amputee and non-amputees with CLD who agreed to participate in the study, and met the eligibility criteria of age 10 – 24, were recruited into the study. This cut-off has been used by Steinberg (2010) in a study on adolescent risk-taking behaviours. Informed consent forms were signed and stored securely by the researcher. Also, parents or guardians of adolescents below the age of 18 were asked to sign forms consenting to their wards' participation. Younger participants however, were given the opportunity to ask any number of questions about the study, before deciding whether they wanted to participate regardless of whether their parents consented or not.

4.1.4 Exclusion Criteria

The study excluded participants who were below the age of 10 and above the age of 24 years. Although there were a considerable number of CLD patients 10 years and younger on

the Outpatient list supplied to the researcher, they were considered not suitable for the purposes of a study with a focus on adolescents. Participants who had congenital deformities other than CLD, and those who developed or acquired limb deformities after birth, such as polio patients, were excluded. Participants whose limb deformities could not be confirmed as congenital defects, either by their own report, or by the researcher's observation of their physical presentation, were also excluded from the study.

Excluded also from this study were participants who, although fell within the age range of 10 – 24 years, and had been diagnosed with limb deformities at birth, were unable to communicate verbally as a result of developmental challenges. During the recruitment process, two participants with CLD in association with impaired intellectual ability met the exclusion criteria. Although caregivers were willing to participate and provide information about their wards, the study aimed to explore participants' own accounts of their lived experiences.

4.1.5 Data Collection Tools

This study relied on semi-structured interviews and vignettes to collect qualitative data. A semi-structured interview guide (Appendix G) was developed with open-ended questions that allowed for further probing of issues. The interview guide was developed along 5 areas - perceptions and beliefs about CLD and amputation, experiences of CLD, support systems, coping strategies, as well as involvement in social activities. The use of the interview guide was to enable flexible discourse between the researcher and the participants to obtain in-depth information while serving as a guide. Some of the open-ended questions asked in the interviews were;

- What do you believe caused your deformity?
- Share with me your everyday life experiences.

- How do/did you respond to these experiences?
- In what way(s) do other people help you?

The study also employed vignettes (2) to further probe participants' views and opinions on body image, stigma, self-perception as well as self-determination. This technique was used because of the protection it provides participants in a study by placing some distance between their own experience(s) and those of the character(s) in the vignette (Bradbury-Jones, Taylor, & Herber, 2014):

- (i) There is an upcoming picnic for persons with limb deformities. There are (2) two options to the picnic. The first picnic is going to be at Aburi gardens while the second picnic is going to be at the beach. Which picnic will you prefer to go to; what are the reasons for your choice? Which one do you think other persons with limb deformities will choose; why do you think so?
- (ii) A disabled friend has to further his/her education to Senior High. Your friend has come to seek your advice on whether he/she should choose either a day school or a boarding school. Which option will you choose for your friend and why?

4.1.6 Study Procedure

The Orthopedic Training Center in Nsawam in the Eastern Region of Ghana was the main study location for the study. The rationale for choosing this location for the study was that it serves as the referral point for all congenital limb deformities in Ghana and as such has a database for individuals who have limb deformities. Gatekeepers were very helpful in granting the researcher access to the research setting and database of patients diagnosed with CLD at the Training Center, including their contact numbers for the purpose of recruitment.

The OPD clinic day at NOTC starts very early on Monday, and the researcher was advised to be there as early as 06.30am to survey as many participants as possible. Thus, over the period of gathering data, the researcher and research assistants were present at the study site at 06.00am, and ended each day at 2.00pm, to allow participants and caregivers enough time to return to their homes. There was a break of 20 minutes for participants who were selected for further inquiry in the qualitative stage, to have the snack provided by the researcher. At the end of the data-collection, all the participants were appreciated for their voluntary participation with a monetary token. Interviewees were reassured about keeping their audio recordings confidential, although a few were quite happy to have their accounts of living with CLD made public.

The researcher ensured that all interviews were conducted in a manner and environment that minimized disruptions, facilitated disclosure of negative experiences and allowed participants to freely express emotions. Both verbal and non-verbal messages were noted, and paraphrasing was done often to let participants know that they were being listened to and understood, and also to make sure that the essence of the narrative had been secured.

Data collection lasted from June 2019 to January 2020, and the total number of AWCLD from the outpatient records was 85 – 45 males and 40 females. However, contact was made with only 41 patients from the OPD patients list. To add to the numbers, the researcher carried out snowball sampling of participants' social network of AWCLD, and recruited 9 more, bringing the total number of participants to 50. One-on-one, and mostly face-to-face interviews lasted 45-60 minutes, and were conducted in English, and one major Ghanaian language, Twi (Appendix H). The interview guide was piloted on 6 AWCLD - 4 recruited from the OPD of the research setting, and 2 from snowball sampling. After conducting the pilot, the researcher discovered that for 17 participants to have a clearer understanding of the nature and purpose of the study, it was necessary to translate the survey

questionnaire and interview guide into a language more readily understood. The guide was consequently translated into Twi, the most common Ghanaian language. The translation was done by a professional with a Master's Degree in Twi, and back-translated to English to establish confirmability. Audio recordings of the interviews were made with participants' consent, and later transcribed by the researcher. Codes generated were peer reviewed by 2 clinical psychologists for credibility.

Field notes

Field notes and diaries complemented the information gleaned from conversations, as well as interactions with participants. The diaries contained personal notes to the researcher about the progress of the study, observations, as well as some codes that were generated during the note-taking, and formed an audit trail to establish confirmability of the study. Field notes were usually audio recordings the researcher made at the end of every interview, and discussion with research assistants about observations made at the research setting, as well as any peculiar information. These numbered recordings (there were 14 memos in all) were transcribed and stored until the analysis stage, when they were used to support the data from the diaries.

Interview Guide and Vignette

Besides guiding the direction of data-collection, the interview guide facilitated rapport between the researcher, research assistants, and participants, as the line of questioning was less formal than the survey instruments. Conversations with participants flowed easily, even when the vignettes explored the sensitive topic of body image, and interpersonal relationships. The responses to the vignettes were coded and themes developed for analysis, and as expected, they elicited sensitive information about perception of deformity and added depth to the research.

4.1.7 Analytic Strategy –Interpretative Phenomenological Analysis

To explore physical, psychological, and social experiences of CLD, interpretive phenomenological approach (IPA) was used to get a deeper meaning of amputee and non-amputee adolescent participants' experiences of the phenomenon. With roots in health psychology, this philosophical approach was found to be fit for exploring their lived experiences (Pietkiewicz & Smith, 2014).

In-depth interviewing and vignettes were the methods used for qualitative data-gathering. IPA was best suited for the purpose of understanding the narratives of the study participants mainly for philosophical reasons. Firstly, IPA is used to analyse interview data usually in a cultural context relevant to the participant, developing thick descriptions that gives in-depth meaning to the phenomenon under study (Fade, 2004). Secondly, it allows for an understanding of the problem from the perspective of the participant who is considered the expert or insider as far as the phenomenon is concerned (Biggerstaff & Thompson, 2008).

In IPA, coding is *posteriori* or inductive, meaning that there was no pre-existing or predetermined code before analysis of the data (Pietkiewicz & Smith, 2014). Inductive coding focuses on individuals in a study by generating codes that are based on the emerging information from participants. In this study of adolescence and the lived experience of CLD, only participants' interpretations, or the meanings they ascribed to the phenomenon were coded and analysed.

4.1.8 Methodological Rigour

Succinctly put, methodological rigour puts quality into qualitative research (Löblich, 2017). Rigour in qualitative research refers to the methods that make a study accurate and reliable, so that accurate and reliable conclusions may be drawn. It also refers to the

trustworthiness of the research findings. The study addressed emergent concerns with the trustworthiness of the interpretations of what was learned from participants. Löblich (2017) suggested four factors relating to the test of rigour, (corresponding with quality in quantitative enquiry) as credibility, fittingness, auditability, and confirmability.

Credibility

In this study, creditability was achieved by a review of the pilot interviews by the primary supervisor in order to critique the quality of the interview guide, skills and procedures. All potential and inherent biases, feelings, personal beliefs and values about the researcher were identified. For example, the researcher posed questions rigidly along the lines of the theoretical framework used. She was cautioned to avoid asking close-ended questions or questions that did not allow room for probing. Research assistants were supervised in this same exercise, so as not to influence participants' accounts.

Transferability

Transferability of findings hinges on the fit of direct quotes from participants, and description of the setting in which the phenomenon was described, to similar contexts. The setting, in this study, was the Nsawam Orthopaedic Center, as well as a few selected locations where participants' experiences would mirror or reflect the context of the phenomenon.

Auditability

Auditability is a systematic collection and documentation of the decision or audit trail that was used by the researcher. This allows an independent auditor to determine whether or not he/she will come to similar conclusions about the data (Löblich, 2017). In this study, methods of coding, categorization of data, naming of themes, as well as field and personal notes were kept and made available for scrutiny by peer reviewers to see if they would come to similar conclusions with the same data. The research assistants tried to reach consensus on coding and theme-naming as the principal researcher. In addition, the researcher enlisted the help of two Psychology PhD students as inter-raters. Consensus was reached on all five themes although ‘experiences’ was rated and coded as ‘challenges’ by one rater. Inter-rater reliability was 90%.

Confirmability

Confirmability refers to the objectivity of the data, such that two or more independent people should agree with the relevance or meaning of the data gathered (Löblich, 2017). In this study, strategies that were used to facilitate the confirmability of the study included a well-documented audit trail in addition to thesis committee members’ scrutiny of the data. The strategy included research assistant’s independent data analysis, coding, and theme naming. Memos from fieldwork, discussions between the researcher and her assistants, as well as conversations from follow-up with some participants were recorded, transcribed and carefully translated. Translated transcriptions were reviewed by a Ghanaian language professional and back-translated into English. This was done independently of the researcher.

Reflexivity

The researcher, a practising clinical psychologist who has experience with persons with physical and mental disabilities, has been involved in international non-Governmental projects with amputees and amputee support groups, and had herself used an orthosis to help with ambulation after a traumatic injury. Some of the participants were familiar with the researcher, having seeing her around a few times when she visited the center for reviews. As such they considered her as one of them, thus facilitating rapport, and disclosure of psychosocial experiences. The researcher was mindful however of the fact that this familiarity had the potential to bias the information gathered in many ways, although participants understood clearly the purpose of the study. Based on background, steps were taken to limit biases right from the recruitment phase. The advantage of this background was that having been a patient of setting of the study, the OPD staff who helped in the recruitment of the participants were co-operative and helpful in recruiting participants. Emphasis was put to these recruiters not to divulge the researcher's professional identity or pressure them to interview since this could compromise the data gathering process. The familiarity with the staff of the study setting also secured the researcher a conducive environment in which to conduct interviews

The experience of clinical practice made the task of rapport building relatively easy, however, consciously maintaining a solely researcher identity to avoid role ambiguity was not always easy and required effort. In addition, the moral and ethical dilemma of offering service to participants who needed assistance within the expertise of the researcher, and maintaining a balance between the roles of researcher and practitioner, had to be acknowledged and staved off. Knowledge of IPA data collection kept the researcher neutral to capture the participants' perspective through continual and critical enquiry (Clancy, 2013).

The researcher used vignettes to explore body image perceptions and this turned out very well in the sense that, they gave the researcher an idea of how participants felt, although this was contrary to expectation. The researcher had assumed that they might have body image concerns, hence the two scenarios were expected to elicit information about how conscious they were about their deformity. Instead, the responses were the opposite of the researcher's assumptions. Thus, even though the researcher had intended to use an inductive approach, she did go in with vignettes showing that she was expecting some particular responses. The pilot study also helped to understand that she needed to modify the questionnaire, and also helped in modifying the interview guide.

4.2. Ethical Considerations

Ethical guidelines in social research are necessary evils in any study. They ensure that the methods, design, instruments, sampling methods, and even how the findings will be used to advance science, and knowledge production remain within the boundaries of scientific enquiry. Guidelines also protect and show respect for both the researcher and the participants. Ethical clearance was obtained from the Ethics Committee for the Humanities at the Institute of Statistical, Social and Economic Research (ISSER), University of Ghana, Legon, with Certified Protocol Number ECH 082/18-19. The Nsawam Orthopaedic Center (OTC), and The Ghana Society of the Physically-Disabled (GSPD) granted permission on the basis of the ECH clearance certificate.

The aim of the study was clearly explained in the consent form, and informed consent obtained from all participants. Consent was sought for and obtained from parents or guardians of all participants below the age of consent which they indicated by either a thumbprint or signature. Prospective participants were assured that they were free to withdraw their consent

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at any time during data collection without any loss, or strings attached. Due to the sensitive nature of this study that sought to explore deep feelings about deformity and possible discrimination, provision was made for all participants to talk to a psychologist if they felt distressed in any way following their narrations.

Acknowledgement was made of any preconceived ideas and/or beliefs, and the importance of the APA's Code of Ethics.

4.3 Results for Qualitative Study

4.3.1 Characteristics of Interview participants

Table 4.1 Summary of relevant characteristics of Study 2 participants.

Table 4.1: Background Characteristics of Interview Participants

Participant ID	Age	Gender	Status	Type of CLD	Social status
Participant 1	22	Male	Amputee	Lower-limb	Student Senior High
Participant 2	16	Female	Amputee	Lower-limb	Student Senior High
Participant 3	24	Female	Amputee	Lower-limb	Student Tertiary L200/ Wife
Participant 4	18	Male	Amputee	Lower-limb	Student Junior High
Participant 5	18	Male	Amputee	Lower-limb	Student Senior High
Participant 6	21	Male	Non-Amputee	Lower-limb	Footballer
Participant 7	13	Female	Amputee	Lower-limb	Pupil Primary
Participant 8	12	Female	Non-Amputee	Lower-limb	Pupil Primary
Participant 9	24	Female	Non-Amputee	Lower-limb	Dressmaker/Wife/Mother
Participant 10	23	Female	Non-Amputee	Upper-limb	Teacher
Participant 11	15	Female	Non-Amputee	Upper-limb	Student Junior High
Participant 12	18	Female	Non-Amputee	Upper-limb	Student Senior High
Participant 13	20	Male	Non-Amputee	Both upper- and lower-limbs	Pupil Primary
Participant 14	24	Male	Non-Amputee	Lower-limb	Skateboard Footballer
Participant 15	19	Male	Non-Amputee	Lower Limb	Power Lifter

Table 4.2: Summary of Emerging Themes from Qualitative Interviews

Superordinate themes	Sub-themes
Perceptions of CLD	Retribution for violating social norms Curses and malevolence Act of God Disease-related factors Lifestyle choices
Living with CLD	Functional challenges Financial constraints Psychological distress Stigma-related experiences Abandonment and neglect Perceived as not human Exploitation by others
Response to experiences of CLD	Coping strategies Social support Positive emotions Self-determination
Outcome of response to experience of CLD	Fulfilling social roles

Four (4) major themes emerged from the data, namely “Perceptions of CLD”, “Living with CLD”, “Response to Experiences of CLD”, and “Outcome of Responses to Experiences of CLD. Sub-themes yielded more insight into participants’ experience of CLD, and the meanings they attached to the phenomenon. Quotes from participants are used in this report, and a few that lucidly articulate the perceptions and experiences of participants were carefully selected. A summary of superordinate and sub-themes that emerged are reported in Table 4.3.

Summary of Qualitative Findings

Table 4.3: Summary of Qualitative Findings

Research Questions	Themes	Basic theme/ Code	Sample Quotes
	Superordinate Theme 1: Perceptions of CLD		
What are the physical, psychological, and social experiences of congenital limb deformity of adolescents in Ghana?	Supernatural influence	Curse	<i>As a pregnant woman, you're not supposed to do certain things outside for people to see. She was cutting fish outside and a certain man was passing by and the man told her to get inside but she refused (P10, F23, Non-Amputee).</i>
		Act of God	<i>The time they gave birth to me, even one of the nurse said that I am a gift from God. That was why they named me 'Gifty' (P10, F23, Non-Amputee).</i>
	Biomedical causation	Disease-related factors	<i>They said there was a fault in my waist when I was born which doesn't allow me to sit well, so I had the operation (P9, F24, Non-Amputee)</i>
	Superordinate Theme 2: Living with CLD		
	Physical experiences	Functional Limitations	<i>I could not start school early because of my problem that is why I am now in Primary 5 (P13, M20, Non-Amputee).</i>

Table 4.3 continued: Summary of Qualitative Findings

Research Questions	Themes	Basic theme/ Code	Sample Quotes
	Psychological reactions	Suicidal ideation	<i>Sometimes I will feel like then let me end it all as in let me take my life so that if you don't see me, the memory will be there but the person will not be there (P6, M21, Non-Amputee).</i>
		Paranoia	<i>When I see people are gathered and I want to pass by, then I have this kind of feeling that everybody there will be staring at me (P6, M21, Non-Amputee)</i>
		Joy	<i>Being with my colleagues makes me active and happy because I feel like I am around people with a common problem (P6, M21, Non-Amputee)</i>
		Pride	<i>I do everything by myself. I cook by myself, I wash and when my child is about to go to school, I take care of her, give her food and dress her up for school (P9, F24, Non-Amputee)</i>

Table 4.3 continued: Summary of Qualitative Findings

Research Questions	Themes	Basic theme/ Code	Sample Quotes
		Ambition	<i>I want to inspire other disabled people and be an artist. A famous deformed artist (P8, F12, Non-Amputee).</i>
		Triumph	<i>Nobody taught me how to write. I learnt how to hold the pencil by myself (P13, M20, Non-Amputee)</i>
	Social effects	Stigma-related experiences	<i>Hmmm, actually, some people in their mind they treat me like I am, how will I say it, as if I am a spirit being or I have some bad spirit in me (P10, F23, Non-Amputee).</i>
		Sexual abuse	<i>I told him I would scream but he went behind the chair and tied my mouth and my hands and slept with me. (P11, F15, Non-Amputee)</i>
		Financial constraints	<i>My father said that he doesn't have money that is why we didn't go to any hospital to do anything (P3, F24, Amputee)</i>
		Exploitation by others	<i>I always went out to the street with my brother to beg for money. The money I earned was used to provide food for the family (P1, M22, Amputee)</i>

Table 4.3 continued: Summary of Qualitative Findings

Research Questions	Themes	Basic theme/ Code	Sample Quotes
		Neglect	<i>My mom has always made me aware she doesn't want me. She has refused to take care of me even financially (P11, F15, Non-Amputee)</i>
Superordinate Theme 3: Responses to Experiences of CLD			
What are the responses of AWCLD to the lived experience of CLD?	Coping Strategies	Praying	<i>That one, the first thing is I pray to God, that in this situation, help me God (P14, M24, Non-Amputee)</i>
		Reframing	<i>When people stare at you, don't feel shy. Stare back at them and tell yourself you are special (P1, M22, Amputee).</i>
		Aggression	<i>Me, when I get angry, I have to hit you with something because I know I cannot run and chase you (P9, F24, Non-Amputee)</i>
		Creativity	<i>I try to fix the artificial leg myself when it develops small faults (P1, M22, Amputee)</i>

Table 4.3 continued: Summary of Qualitative Findings

Research Questions	Themes	Basic theme/ Code	Sample Quotes
	Social Support	Family	<i>My relatives don't support me. (P2, F16, Amputee)</i>
		Friends	<i>My friends at boarding house fetch water for me and they dry my clothes after I am done washing. (P2, F16, Amputee)</i>
		Community	<i>A certain man in our community told my father that he wants to help me so we used to go to the Tamale Teaching Hospital, like every month. The man sponsored everything. (P3, F24, Amputee)</i>
Outcome of Response to Experience of CLD			
How do AWCLD participate and fulfil social roles?	Self-determination	Membership in groups	<i>I am part of the amputee football club. I went and played football last year and this year in UK due to the association I am in. (P6, M21, Non-Amputee)</i>
		Engagement in social activities	<i>I even train the kids in my church and school so on 31st night or Carols' Night, they have been performing, and I feel very proud (P10, F23, Non-Amputee).</i>

4.3.2 Theme 1: Perceptions of CLD

The theme “Perceptions of CLD” is the superordinate theme from which emerged two main themes “Supernatural Influence” and “Biomedical Causation” of CLD. These themes had 5 sub-themes, namely, “Retribution for violation of social norms”, “Curses and Malevolence”, “Act of God”, “Disease-related factors”, and “Lifestyle choices”, explaining the beliefs and perceptions about the aetiology of CLD.

The majority of participants in this study disclosed that the phenomenon had been attributed to supernatural forces by their families. Others said they had been told their defects had a biomedical causation, while a few blamed the lifestyle of their mothers. According to participants who perceived a supernatural aetiology, a deformity is a curse upon a parent, either as the consequence of the violation of a social or cultural norm, malevolent intent of extended family, and an invocation by an aggrieved person. Participants however, personally believed their condition as willed by God or divine intervention.

Retribution for Violation of Social Norms

A finding of this study was the belief in the ability of a supernatural power to cause CLD as retribution for violation of social values, and several studies have reported that many different cultures ascribe other congenital deviations to supernatural influence (Adeyemo et al., 2016; Bannink, 2017; Bello et al., 2013; Quinn & Chaudoir, 2009; Wachege, 2012). According to Wachege (2012) curses are invoked to pacify offended parties, guarantee compliance with unwritten moral codes, while preserving the fabric of culture. This was evident from participants’ accounts of the phenomenon:

She [mother] told me that when she was pregnant with me, she was beating a goat and a certain man came and told her that she should stop beating the goat otherwise where

she is beating the goat, the child in her stomach will suffer the same consequences because it is a curse to beat an animal when you are pregnant. She said that she did not mind him but she stopped beating the goat. Then when I was born, I was like this... Yes, my mother told me that when she gave birth to me, that is how I came out, like this. My fingers on both hands are joined together, and all the toes on both feet are also joined. You cannot even see the toes on my left foot. (P16, M20, Non-Amputee)

Curses and Malevolence

Besides the perception of CLD as retribution for violation of social norms and values, some mothers were also perceived to have been recipients of cursing and malevolence from strangers or even family members. Personal invocations of evil or curses cast upon a pregnant woman as a result of another's anger, as well as ill-will were reported:

According to my father, my mom took me to her hometown at Koforidua Mampong. He did not like the idea of my mom taking me along. It was during that visit I lost my leg. To him, my extended family are behind my amputation. They wanted to destroy my destiny and they cursed me because they knew I will become a special person in future that is why they caused this to happen to me. (P1, M22, Amputee)

Act of God

The power of supernatural forces to reward deserving ones, or punish violations and offenses, and the perception that God had foreordained their deformity, either as a blessing to their families, or as punishment for a sin they committed while yet unborn, however, was the foremost perceived cause of CLD captured under this theme.

In my family, their belief is that I am from God...because even at the hospital I learnt the time they gave birth to me, even one of the nurse too said that, this one, I am a gift from God. That was why they named me 'Gifty'. But sometimes, I will be in the room and I will be crying to God that why is it that he created me this way? So I will be questioning God (P10, F23, Non-Amputee).

Biomedical Risk Factors

Not all participants in the study believed their limb defect had a supernatural origin. According to some participants, their deformities were the result of a disease, abuse of drugs or alcohol by their mothers while pregnant, or by a malformation during their foetal development:

They said there was a fault in my waist which doesn't allow me to sit well, so I had the operation (P9, F24, Non-Amputee).

My mother said when I was born, my legs were folded, just like how Muslims sit on crossed legs. But only the right one has been amputated. The other one is stronger (P2, F16, Amputee).

Lifestyle Choices

A few participants however believed that their mothers' irresponsible behaviours and lifestyle caused their deformity, which they attributed to the intake of drugs and alcohol when they were pregnant. Taking unprescribed drugs, or ingesting concoctions purported to flush out unwanted pregnancies are not uncommon, and the devastating effects were described by a participant diagnosed with a radial ray deficiency or missing radius in the lower half of the right forearm (Figure 1.3):

My grandma told me that, when my mom found out she was pregnant with me, she started taking drugs to abort me but she wasn't successful...so I was born without the other half of my arm after my mother took the medication during her pregnancy (P11, F15, Non-Amputee).

The study noted however that, regardless of the perceptions about CLD, participants had very positive self-views and most identified themselves positively, or a par with non-disabled peers.

Like, I make friends and I always tell them not to think like because I am using artificial legs, I am different from them, so they will treat me special, no. We are equal so we all cope like that (P2, F16, Amputee).

4.3.3 Theme 2: Living with CLD

The second theme revolved around the effects of CLD, and participants detailed experiences recalled from childhood to the present. The experiences were physical, psychological, as well as social, and included experiences of neglect, financial constraints, abandonment, and exploitation.

Functional Challenges

The majority of participants experienced physical effects of CLD including disability, chronic fatigue and phantom limb sensations, which they perceived as surmountable challenges. Disability for instance, was experienced right from birth for almost all participants, and challenges in daily activities were experienced, not only in school activities, but also in the performance of activities of everyday living. Phantom limb sensations in limbs that were partially formed, or missing entirely at birth were also experienced:

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When I was born, I couldn't move around...At first I couldn't even sit on the floor, I used to drag my body on the floor using my chest. Now, the callipers help me stand.

When I remove the callipers, I can't stand on my legs (P9, F24, Non-Amputee).

I thought the leg was still there so I left the clutches. I forgot to take the crutches (P3, F24, Amputee).

Another participant, born with macrodactyly, or local gigantism (Figure 1.2) recounted her experiences of CLD and amputation:

The reason is, they wanted me to have the artificial leg so I can walk. So they did the first one (surgery) and the thing (deformed lower leg) was still too big, so they want to reduce it to a smaller size and they did the second surgery, but it was still oversized, so they cut it (P3, F24, Amputee).

Financial Constraints

Individuals living with a disabling condition, often report facing economic hardship, and a good number of studies have found poverty to be a very common consequence of disability. Financial constraints were experienced by a good number of participants, and was one reason why participants' education suffered, and others had to do without food, or assistive devices:

There was no money to get an artificial leg. My parents were very poor back then. I always go {went} out to the street with my brother to beg for money. The money I earned was what was used to provide food for the family (P1, M22, Amputee).

Psychological Reactions

The experience of CLD and its negative effects on the psychological health of participants are evident in the recollections of sadness, frustration, hostility, paranoia, and suicidal thoughts:

When I go to some place, and I see a child that wants to come to me, but the way the parents treat their children, when you see that, you will feel sorry for yourself and if you don't encourage yourself, you will start crying (P15, M19, Non-Amputee)

I get very angry and shout at my family members...My brother and sisters and my classmates all insult me and say bad things about me...It annoys me and I get very angry...Hmph!![Scowling] I just want to beat them up! (P13, M20, Non-Amputee).

Significantly, concealing CLD was one of the ways some participants attempted to reduce the psychological distress they experienced. One reason they gave was that, the stigma attached to CLD far outweighs that experienced by those whose disability is the result of an acquired amputation. For this reason, these participants concealed the truth that the disability was congenital. Hypersensitivity to negative evaluation by others or paranoia was the second reason for attempting to conceal the disfigurement:

I tell them that it is accident. I don't want long talk... someone will stop you and say this girl, what happened to your leg ... so I will just say accident. Then they will ask, what accident, motor or car. I'll say car then that is all (P3, F24, Amputee).

To this participant, the 'long talk' would involve explaining that she had been born with a defect, which was so unsightly that her limb had to be removed. This would lead to more questions as to what sin her family might have committed against God or man, which may lead to her being perceived and treated negatively. To cut all the talk short would require concealment of the truth.

Concealment was not always possible, especially if it involved a shortage in the leg such as a singular type-II fibular hemimelia (Figure 1.2). Anticipating negative reactions from others, or paranoia about being evaluated negatively was a common thread that ran through the narratives:

Maybe if I go out, a group of people are gathering and I want to pass by, then I have this kind of feeling that everybody there will be staring at me...but if I go there, maybe the thing is discouraging, I don't have to say anything and come back with my thoughts (P6, M21, Non-Amputee).

Contrary to the views expressed above, an amputee participant, did not allow others' perceptions of CLD to affect his self-views:

When I first enrolled into the school, the authorities wanted me to put on trousers so as to cover my leg. But I refused, because I didn't want to feel different around my mates (P1, M22, Amputee).

Two vignettes complemented the interviews, and were very useful in exploring and eliciting sensitive information about participants' perceptions of body image in a less menacing manner. They enabled all fifteen participants express their opinions about exposing their disfigurement, either at the beach or in shared space at a boarding school:

I prefer the beach because I like swimming...There are some people who come and look at the beach and swim. We can also do things like everybody else...it means that disability is not inability (P2, F16, Amputee).

At the day school, you'll still look down upon yourself and not wish to go out and opportunities will come and go. But with the boarding house, when opportunity comes, you know you can talk to a lot of people (P6, M21, Non-Amputee).

Stigma-related Experiences

Findings from the study showed that both amputee and non-amputee participants experienced issues of stigmatization (including self-stigma) and other discriminatory behaviours right from childhood, demonstrating similar negative social, and environmental or external experiences. A young teacher with a radial ray deficiency (Figure 1.3) said:

When I came to Accra, people told me that if I wear short sleeves, like the hand of my dress is short, they told me that it is doing their body something like it is nasty, so I should make sure I cover it anytime I walk (P10, F23, Non-Amputee)

So because of my condition my mom divorced my dad. My mom will also be polluting my dad that she doesn't know the benefits that I will bring and like I am good for nothing (P6, M21, Non-Amputee)

Self-stigma reflects the social and psychological impact of possessing a stigma and includes both the apprehension of being exposed to stigmatization and the potential internalization of the negative beliefs and feelings associated with the stigmatized condition. Narratives of participants eloquently express these experiences:

I see myself as nobody. I see myself as rejected (P15, M19, Non-Amputee).

Being discriminated against as a result of disfigurement and regardless of capability or competence, was experienced by all participants, and there were similar accounts of being shunned by both amputees and non-amputees. A few also experienced ableism. Accounts of this type of prejudice appear in these narratives:

I was in traffic light and a trotro (public transport) driver just used the truck to hit my wheelchair. People don't care about us, because when the car hit the wheelchair, and the wheelchair overturned, the driver just kept going. Also, if I am going to ask for

work, they will tell you that you can't do this because this is for able people who can do it. Yes. [shaking her head] That is very hard for me. (P15, M19, Non-Amputee)

Although social attitudes were usually experienced as exclusion from activities and discrimination from employers, some participants also experienced verbal abuse. Some participants also recalled incidents when even teachers had insulted them verbally, or used derogatory terms in describing them, and for one participant however, the abuse was sexual.

I told him I wanted to go home, but he blocked my path and pushed me back into the chair. I told him I would scream and then he went behind the chair and tied my mouth and my hands and then slept with me. (P11, F15, Non-Amputee)

Abandonment and Neglect

Cross-cultural studies on sociocultural perceptions of congenital deformity have reported that many children are abandoned or neglected by their families as a result of the shame and malevolence attached to such births. This held true for some of the participants in this study, and they experienced abandonment from the very people and environment they were supposed to feel safe in, a situation they found very difficult to comprehend.

My siblings as well, don't want me to come closer to them so whatever they are doing, they will make sure that I will be the odd one out. They always say bad things about me, that they don't know the benefits that they will get from me and they don't know where I inherited this [deformity] from. But they are blaming themselves and wish I was not part of this family...My mom told my daddy that, she cannot be with such a 'thing', that is me and she cannot stay so she's leaving (P6, M21, Non-Amputee)

Being abandoned by family or a significant other as a result of a disfiguring birth defect was the worst kind of discrimination experienced by participants. In addition, reference to

participants as “thing” was a reminder that one had been cursed before birth, or touched by the evil eye and could therefore not be described as human.

My dad left because he thinks that my mom’s family is responsible for my situation (P2, F16, Amputee).

After giving birth to me and finding out that one of my arms wasn’t fully developed, she tried to throw me away (P11, F15, Non-Amputee)

For some, the neglect did not end in childhood, as this participant’s narration shows:

Like the way she treats me, I begin to ask myself that, is she my mom? Because I have tried my best to get close to her, but the more I try, the more I get hurt (P6, M21, Non-Amputee)

Not all participants experienced stigmatization and or discrimination` in their journey from childhood to adolescence. Four participants (4) on the contrary, shared positive experiences about attitudes of family and friends. These participants celebrate their family, friends, and members of their community. Participant 12 said:

They (family and friends) always share ideas with me and they don’t neglect me. They play with me and also tell me not to tell myself I am a disabled person (P12, F18, Non-Amputee)

Perceived as not Human

This study explored how participants had been labelled by their communities and how this had impacted their psychological health. The narratives of participants express the social constructions of birth defects in cultures that perceive such children as evil, or animal-like.

When my mother gave birth to me, some people told her that, I am not a normal human being so she should throw me away. And she said she won't take it. It was the neighbouring houses that said I was not a normal human being...actually, some people in their mind they treat me like I am a spirit being or I have some bad spirit in me so some people it's like they are afraid (P10, F23, Non-Amputee).

On another occasion, on first being introduced to her boyfriend's family, this participant who was born minus her left lower arm and hand, recalled the dismissive and derogatory way that she had been described:

The mom called the grandmother and some of his family members and he told me that the mom got angry with him that why should he bring someone who is not having a hand to their family. His mom is even saying that it can be a curse in my family. (P10, F23, Non-Amputee).

Exploitation by Others

Studies on the effects of deformity and disability report that poverty or financial constraints are experienced by a significant number of individuals and their caregivers. Some participants however believed that their condition had been exploited by others:

The last time, they (disability association) gave me some money for my upkeep, ₵1000 (Old Ghana Cedis – Ghanaian currency) I gave it to my grandma to keep for me, but my mom went and deceived her and took the money. (P11, F15, Non-Amputee)

One amputee participant, and another participant who had been sexually abused by someone who offered to help her financially, had this advice to give to vulnerable young females:

I will tell the person never to do that because men will always demand for sex before they help you. Because I have learnt my lesson now. (P11, F15, Non-Amputee)

If the person tells you I like you [rolling her eyes upwards], there is something the person wants from you that is why. Maybe, it will never be true that he really loves you or likes you. He will just break your virginity or use you and after that dump you (P2, F16, Amputee).

This theme highlights the effects of CLD experienced by participants, not only as physical and/or psycho-emotional disturbances, but also as challenges within their social environment. It also highlights the experiences of abuse and exploitation of adolescents with disabilities. and determined that the experience of CLD was exacerbated by specific stressors, especially the perception of CLD as a curse or punishment. The stressors included functional challenges, financial constraints, psychological distress, and stigma-related experiences of abandonment, abuse, neglect, and exploitation by others.

4.3.4 Theme 3: Responses to the Experience of CLD

The theme “Responses to the experience of CLD” is the superordinate theme that captures participants’ thoughts, feelings, and behaviours in response to the physical, psychological, and social effects of CLD. The sub-themes included “Coping strategies”, “Social support”, “Positive emotions”, and “Self-determination”. Social support was examined as a response to CLD, due its buffering and proactive coping fostering effects.

In this section, narratives of eight (8) participants’ responses to CLD were explored.

Coping Strategies

Stress and other negative emotions experienced by AWCLD, demanded the adoption of coping strategies that were as effective as they were adaptive. Almost all of the participants admitted that they had used emotion-focused coping such as crying, praying, reframing, and isolation, and social withdrawal when they were younger, but transitioned to more proactive problem-focused strategies in older adolescence.

I used to cry but it would not help me so I threw it away. At first, I didn't go out. After school I will be in my room and cry. I will ask God, why? But if I think of it, I'll get sick so I forget about it (P12, F18, Non-Amputee).

The school kids used to laugh and tease me a lot. Also, I was slow in getting to school because of my legs and so anytime I arrived, classes had already began...So I told my aunt that I don't want to go to school anymore (P9, F24, Non-Amputee).

Cognitive reframing and emotion-regulation were however, frequently used coping strategies. Participants redefined the phenomenon of CLD to reflect more positively, or create a more positive impression of themselves, or worked hard to regulate the negative emotions that usually threatened to surface at stressful times. This was evident in the accounts of three (3) participants:

When people stare at you, don't feel shy. Stare back at them and tell yourself you are special (P1, M22, Amputee).

The only thing I tell myself is, I am special. (P8, F12, Non-Amputee)

Something has been talking to me that it is God who created me this way for people to see that he is there, he is alive (P10, F23, Non-Amputee)

The above narratives highlight the fact that these emotion –focused strategies served a purpose at the time, that is, the reduction of stress, anxiety, and symptoms of psychological distress. Facing and dealing proactively with the stressors are evident in how participants took practical steps to reduce or completely remove the stressor(s). In this narrative, a participant realized that isolation and withdrawal were not effective coping strategies:

At first, when they are going out, I don't go but I realised that I was rather not helping myself. So I started going out anytime we wanted to go outing (P12, F18, Non-Amputee).

This was also the case with Participant 2, who was ridiculed by classmates for being an amputee, and using a prosthesis. After reassessing her stigma-related experiences, she acted. In this narrative, she proudly disclosed the proactive measures she took:

So I just went to the authorities and reported them (classmates). They called them and I don't know what they (school authorities) said so they moved them from our class. So now they are in a different class (P2, F16, Amputee).

Participant 14, who has severe deformity of both lower limbs, engages in problem-solving coping, and uses his assistive device (skateboard) to work and to play:

"I use my skateboard to beg by the road, and use it to play skate soccer" (P14, M24, Non-amputee).

Social Support

Social support was a major predictor of the psychological health of participants. It was also a response to the experience of living with CLD, which served as a coping mechanism. In

this study, respondents gave glowing reports about benevolent members of their family and community. The idea however, that social support is inexhaustible, was succinctly expressed:

My mommy is the one who provides because my father is not there...she always encourages me too. My brother especially has been helping me to fetch water to bath. If my mother sends me, he wants to go with me and he tells me that because of your leg, anywhere you go, I'll follow you. This makes me very happy. (P7, F13, Amputee).

My friends at boarding house fetch water for me and they dry my clothes after I am done washing. I feel very happy when they do that (P2, F16, Amputee)

At first, people will bring you money, food and other things but they will do it up to a certain time and stop helping. So you have to improve yourself because the Bible says Heaven helps those who help themselves (P12, F18, Non-Amputee).

Positive Emotions

The findings of the study revealed that, when participants engaged in activities with abled and non-disabled peers, their competence in that activity gave them a sense of achievement, a sense of pride, thereby reinforcing the belief that they were indeed special and benevolent “Acts of God”. Their self-views also increased when they accomplished things that able-bodied persons were unable to do. Positive emotions of joy, interest, and ambition are expressed by participants, including emotions of triumph and pride in even simple accomplishments by a participant diagnosed with Apert syndrome (Figure 1.4) who has limited function in his hands:

I do not have a problem at all. I have learnt how to do everything for myself...Nobody taught me how to write. I learnt how to hold the pencil by myself (P13, M20, Non-Amputee)

Being with my colleagues makes me active and happy because I feel like I am around people with a common problem (P14, M23, Non-Amputee)

I do everything by myself. I cook by myself, I wash and when my child is about to go to school, I take care of her, give her food and dress her up for school (P9, F24, Non-Amputee)

Participations were not lacking in ambition either, despite their obvious functional challenges. They were confident in themselves and their ability to be successful, setting high goals for themselves. Some participants aimed, not only to succeed, but to be a source of inspiration to others:

I want to inspire other disabled people and be an artist. A famous deformed artist (P8, F12, Non-Amputee).

Me and my family, we have planned that after my SHS examination, I will just go to media school. But after the SHS, I will go for a fashion school for around six (6) months. And after that, I will go to the media school (P2, F16, Amputee).

Two participants achieved international recognition for their competence in sporting activities. Their response to the effects of CLD had been to engage in the social resources and activities their communities offered.

Maybe I am going to pick a car or I am going to buy something then someone will shout and call my name, I have not even seen the person before but the person will refer to me that I have heard about you, you've done this and that so is that you? Then I will be like well yeah, that's true (P6, M21, Non-Amputee).

It was the Paralympics. And I went there for the Junior Athlete powerlifting. It's not only me, yeah, we went there and we just bring three medals from Nigeria, Abuja. Yeah

I'm the first (1st) person athlete in Ghana to win a gold medal (P15, M19, Non-Amputee).

I want to show the world that, if they don't limit us or let those who are hurt by their leg or their hands or the part of their bodies, they should love us as their brothers because what they couldn't do, we, we can do better than what they think we can do or what they can't do (P15, M19, Non-Amputee)

Self-determination

The universal needs and urges of autonomy, relatedness, and competence help individuals make choices, actualize their potential, and function optimally, and are met through self-determination. All the participants narrated how they had pushed themselves from childhood to be independent by adolescence. The determination to be autonomous and competent appears to have been exercised from a very early age, and all accounts were truly remarkable and positive. For the majority, negative experiences did not dampen their determination to succeed and triumph. Below are a few narratives that eloquently express self-determination.

Sometimes, I see my life and I have been to places that people with two legs have not been to, not only once but a couple of times. I've done things that people with two legs cannot do...I see it as a plus because people with two legs cannot do it and I am doing it (P6, M21, Non-Amputee).

I'm doing my best, planning.... If I go to university. I'll learn more. And maybe because that is 1st phase, if I come back, maybe vacation then I'll go and do some work about it that will equip me...So I want to do it, I'll learn it and attach to it then I can become perfect (P4, M18, Amputee)

When I was growing up, there are certain things I tried doing. For example, cutting of okra with only one hand, and I realised that, anytime I do it, I cut my hand...I forced to do it again and again, even though I will get hurt (P10, F23, Non-Amputee)

We went for inter-zonal sports and a certain girl said that, don't I feel pity for myself and that what others are doing, I am also doing some. She also said, you a deformed person, when others are doing some of the sports, you too you go and join...I won the 3rd position and she was asking how come (P12, F18, Non-Amputee).

After sexual abuse resulted in pregnancy for one participant in this study, she experienced additional neglect and abuse, after attempts to abort the pregnancy by her mother, from whom she had expected both emotional and instrumental support, failed. Her determination to triumph despite these negative experiences is evident in this simple statement:

I won't allow anyone to adopt her, even though I am still in school. Even the woman who heads our disability group wanted to take her but I refused. I want to take care of her myself, even though I have only one hand (P11, F15, Non-Amputee).

This theme highlights the responses of adolescents to the experience of CLD. Although they all reported several negative experiences related to CLD, they acknowledged that they had broadened their outlook on life, and built on those experiences, especially when they compared themselves to able-bodied persons. Future studies should investigate further the influence of positive emotions and self-evaluation of physically-disabled adolescents on performance in diverse social activities.

4.3.5 Theme 4: Outcome of Responses to Experiences of CLD

The theme "Outcome of responses to experiences of CLD" is the superordinate theme that encapsulates the consequences of choices, and actions of participants. The sub-theme

“Fulfilling social roles” involves narratives about present social roles and activities. In the accounts, the benefits of engaging in social activities, social networks, membership in social groups and associations, as well as involvement in interpersonal relationships with the accompanying roles of marriage and parenthood are explored and shared by participants.

Fulfilling Social Roles:

Positive emotions of joy, pride, triumph, happiness were experienced by adolescents who engaged in social activities and fostered interpersonal relationships. All 15 participants narrated experiencing these emotions during such engagements with both abled and disabled people. Below are some outcomes from engagement in social activities:

I used to run at J.H.S but I never took it serious. But when I came to S.H.S, a teacher from my J.H.S told my school that I know how to run. So when it was time for inter-houses, I had to participate. That was when I was selected to join the athletes, so now I feel happy (P12, F18, Non-Amputee).

I play football, engage in swimming competition, bicycle, a lot (P5, M18, Amputee).

For the majority of participants in this study, associating with other physically-disabled members provided them with emotional, informational, and instrumental support in the form of friendships, national (and sometimes international) recognition, financial assistance, and romance:

They (social group) help me when people send things for us. They advise us. When I went there, they give me the chance to just go for the South Korea competition for para powerlifting. But when I went there, it was winter sports. Yeah, and I was the 3rd person. I won the bronze medal in skiing (P15, M19, Non-Amputee).

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After a while, we (amputees) familiarized with the others and we were able to go to town without feeling ashamed that people will look at us (P1, M22, Amputee).

We were in the wheelchair basketball team, and do the wheelchair basketball sports. So there was a time when he said he wanted to visit me. So when he came, he met my aunty and told her that he wants to marry me (P9, F24, Non-Amputee)

The narrative of one participant eloquently sums up the wholesome benefits of social and peer support, as well as membership in groups and organization:

We are different people but we see ourselves as one. Yeah, we are all one. If your right leg is not there, the left leg is there. People will tell you their stories and you will feel okay. Because yeah, it's like oh after all you are also having one leg and I am also having one leg, that's all. (P6, M21, Non-Amputee).

Marriage and parenthood were also benefits of engaging with others on a more personal and intimate level. Two female participants were married, and two were mothers. These recounted how they took up these roles despite the challenges of disfigurement and disability.

I am a wife, a mother, and a dressmaker. When my daughter sets off in the morning, I prepare food for her before she comes back...I also cook the evening meals too in addition. (P9, F24, Non-Amputee)

My husband's other wives understand that some places, I can't walk...so the husband will help me. But I do all other things wives do by myself (P3, F24, Amputee)

A female participant however, disclosed in her narrative how her deformity had impacted a budding romantic relationship as her boyfriend had been given an ultimatum by his family:

A guy proposed to me and I accepted...when I went to his place, his parents were around. And when they just saw me, the first time they were like, argh, why is it that

he brought such person to the house... the mom is even saying that it (CLD) can be a curse in my family. So the mom even told him that is either he will take me and loose the family or he will take the family and loose me (P10, F23, Non-Amputee).

This last account of involvement in interpersonal relationships demonstrates two things – the fact that some are able to overlook disfigurement in an intimate partner, while others and/or their families, are unable to get past the perception that birth defects are the result of supernatural interference.

4.4 Summary of Qualitative Findings

The qualitative results show that both amputees and non-amputees were accepting of CLD. There was no indication of amputees wishing they had maintained the original deformity nor non-amputees wishing they had had amputations, although some non-amputees hoped they could have obtained prosthesis. Both amputee and non-amputee participants had impressive functional ability, and expressed several positive emotions. It was apparent however that, participants did not take kindly to being termed ‘disabled’, especially when they perceived themselves as being just as capable or even more abled than most abled individuals.

Both amputees and non-amputees experienced varying degrees of stigmatization and/or discrimination from childhood which caused them psychological distress. Amputees and non-amputees gave accounts of stigma, prejudice, and discrimination, as well as challenges that they had overcome during the transition from childhood. Thus, the negative environmental/external experiences appear to be similar for both groups. Secondly, the emotional reactions to these negative behaviours generally changed as they moved from childhood to adulthood. That is, they seemed to be less emotionally affected, able to better

defend themselves, and able to interpret the experiences differently, often finding meaning in them (e.g., a reason to strive more) and alternative ways of doing things.

There were very few body image concerns among participants, and a complete absence of self-consciousness. The vignettes that were used to explore self-perception of CLD were effective in getting participants to freely express their views, especially as they put distance between participants and scenarios involving revealing physically-disabled and disfigured bodies at a beach, and in a boarding school. Thirteen out of fifteen participants (87%) chose to reveal their disfigurement to others, and chose a picnic at the beach over a picnic at a botanical garden. Reasons given by the participants for advising their friends with physical disabilities to choose the boarding house over day school reflected concern more for access to books and study groups than for their physical appearance.

Coping strategies varied for all participants, with the majority employing more problem-focused coping strategies in response to their experiences. Most frequently used however, were problem-focused strategies that helped participants modify the relationship between them and the stressors within their environment, and emotion-focused strategies, which they often used to regulate the negative emotions that they experienced from functional limitations, as well as from stigma-related experiences. Participants were also generally determined to achieve important life goals regardless of their conditions. Marriage and parenthood were some of the outcomes of engaging with others on a more personal and intimate level. Parenthood, even when it was unplanned, such as when sexual abuse had resulted in pregnancy, offered participants the opportunity to prove to themselves and others, how competent they could be. The findings however showed that some individuals are able to overlook disfigurement in an intimate partner, while others and/or their families, are unable to get past the perception that birth defects are the result of curses.

This study also found a preponderance of positive experiences associated with CLD, and participants revealed the benefits they accrued from being active members of social groups. Positive emotions, especially of joy, pride, and triumph, were reported by participants who engaged more in social activities and fostered interpersonal relationships. Recognition for their achievements gave them the opportunity to ‘undo’ or reduce the negative emotions they experience as a result of self- or enacted stigma, broaden their outlook, create more avenues for self-enhancement, and shore up the coping strategies that helped them overcome the odds. Inclusion in school, social activities and fulfilling social roles enabled participants to experience positive emotions and exercise their self-determination. Autonomy to participate in arenas reserved for the able-bodied gave participants the opportunity to demonstrate their competence and capabilities.

Overall, participants’ emotional experiences, and psychological states (e.g., distressed, depressed, isolated, low-esteem, suicidal thoughts vs. confident, high self-esteem, courageous, up-beat etc.) appeared to be influenced more by their self-determination, and the strength of their internal/family support systems and less by whether they were amputees or non-amputees. In particular, for those who have strong support, acceptance of their condition and of themselves as being equally worthy, or as whole individuals, (first of all from their parents and siblings and then also from other relatives, family friends, and friends), seemed to show more confidence, self-worth/esteem, self-determination, and less psychological distress. Social support from family and significant others surpassed support from friends.

CHAPTER FIVE

GENERAL DISCUSSION

5.0 Introduction

This chapter integrates the findings from the two data sets (quantitative and qualitative) that constitute the entire research work. It begins with a brief overview of the thesis and a summary of the key findings. It is followed by a triangulated discussion that gives a holistic picture of the factors impacting psychological health and lived experience of AWCLD in Ghana. The discussion links the general objectives of the study, the research questions and hypotheses and situates the findings in the theoretical framework and related literature. In this chapter, the implications of the findings to future research, clinical practice, and inclusion of AWCLD in education, and youth and sports programs, as well as healthcare policies are discussed. The chapter ends with strengths and limitations of the study, and directions for future research.

5.1 Brief Overview of the Thesis

This study aimed to investigate differences in psychological health outcomes of amputee and non-amputee AWCLD, as well as the buffering effects of coping and social support, and also, to explore their lived experience of CLD. A concurrent triangulated mixed-method design of two related studies was employed to achieve this aim. Quantitative data collection was a cross-sectional survey of 50 AWCLD (20 amputees and 30 non-amputees) who were largely outpatients of the Nsawam Orthopedic Training Center, and a few non-patients from the Ghana Society of the Physically-Disabled. Standardized questionnaires and clinical data were used to assess the association between perceptions of body image, perceived social support, coping strategies, and psychological health outcomes of AWCLD. The

quantitative addressed 3 research questions and tested 5 hypotheses. The qualitative study was a follow-up in-depth phenomenological exploration of the lived experience of CLD among 15 of the 50 survey participants using a semi-structured interview guide. Comparison tests, correlational analysis, multiple regression analysis and interpretative phenomenological analysis were used to analyse quantitative and qualitative data respectively.

5.2 Summary of Quantitative and Qualitative Key Findings

The Global Severity Index (GSI) of 50 amputee and non-amputee participants was measured in 9 symptom areas namely, somatization, obsession-compulsion, depression, anxiety, interpersonal sensitivity, phobic anxiety, paranoia, hostility, and psychoticism to determine their overall psychological health. Findings showed that on average, participants' GSI was not clinically significant, although 62% of them reported some symptoms of distress. Distress levels differed between the 2 groups, and on average, non-amputees endorsed more items of distress (depression, paranoia, obsession-compulsion, interpersonal sensitivity and hostility), and had higher levels of symptomatology than amputees. Nevertheless, the mean scores for amputees and non-amputees were both below the cut-off point for clinical distress and diverged from findings by Montesinos-Magraner et al. (2016) which reported high levels of distress in relation to CLD, and low body image among participants. In addition, the distress levels of participants in this study did not exceed levels observed by the general population of adolescents.

Body image concerns were largely and positively correlated with the Global severity index, indicating that high scores on body image were related to high scores on distress. The scores were very similar in both groups, and were below the cut-off for low body image. It may be concluded from the findings that non-amputee participants with severe deformities had little to no body image concerns, had similar functional mobility and were just as engaging in

social activities as their amputee peers. An example of functional mobility is evident in the self-determination, pride and triumph of independently achieving even the smallest victory.

In this study, social support perceived from friends was hypothesized to predict distress level more than the other domains of perceived social support specifically family and significant other. The results revealed that the model used to analyse the data was statistically significant, with support perceived from family, and significant others, contributing significantly to the model. Perceived support from significant other was the strongest unique contributor to the variance of the model.

The findings of this study demonstrate respondents' perceptions of deformity. Their concept of CLD was chiefly supernatural, as either due to curses, malevolence, or caused by God. For instance, a pregnant woman must never be seen cutting up meat, cleaning fish or harming an animal. There are consequences for flouting these cultural norms or breaking those taboos. Although amputee participants did not bear the physical mark of a curse on their bodies, (the deformity having been surgically treated in childhood, they could not entirely escape from the shadow of the supernatural. The perception therefore, that malevolent spirit forces may have orchestrated events in their lives may explain the psychological distress experienced by both amputees and non-amputees. On the other hand, 8 (53%) participants and their families believed that God had acted on their behalf, so the deformity was perceived as being a blessing. With this interpretation, the Act of God, can and does actually work both ways, where the individual may have initially believed that they were the result of a curse, but may reframe the phenomenon to look like a blessing. This is an emotion-focused coping strategy, or emotion regulation technique used to reduce psychological distress such as fear, sadness, or anger (Ong & Thompson, 2019). The parents themselves preferred to view the deformity as a form of blessing, seeing that for the majority of these deformities, there is nothing much that could have been done. These findings therefore echo studies that

investigated God's role in birth defects (Adeyemo et al., 2016; Bello et al., 2013). When a pregnant woman sinned against God, a birth defect was proof to the family and community that she was being paid back via her unborn child. This observation made by Wachege (2012), that children born under a curse have to suffer the consequences, even when they play no part in that sin, were present in our findings and echoed by 10 (67%) of participants.

It was interesting to note that almost all participants were aware of the medical explanation for birth defects yet, beliefs in the supernatural persisted, and were equally plausible. Thus, even though there was factual information by two (2) participants that their mothers had abused drugs and/or alcohol, there was still the perception that the birth defects were proof of retribution for their lifestyle choices, and/or violation of social norms – in other words, a curse, echoing findings by Opare-Henaku and Utsey (2017) that occurrences and phenomena in the spiritual realm may have dire manifestations in the physical realm. The two contradicting forms of knowledge appear to co-exist in the study participants' social environment without conflict, as typical examples of the concept of cognitive polyphasia (de-Graft Aikins, 2012). The Ghana Statistical Service (2012) estimates that 90% of Ghanaians belong to either one of the two main religions in the country (Christianity and Islam) indicating high religiosity. However, perceptions of CLD reflect a leaning less in an orthodox God, and more towards belief in malevolent spirits or ancestral forces, as capable of inflicting punishment on children yet unborn (Wachege, 2012).

This study highlighted the effects of CLD experienced by participants, not only as physical and/or psycho-emotional disturbances, but also as challenges within their social environment. Psychological distress manifested in varying forms, and at different stages along developmental trajectories of adolescent self-perception and coping behaviours. It was observed from the study that the basic difference between amputee and non-amputee AWCLD was the obvious physical presence of deformity. What the study found also converges with

other research findings that suggest that social effects of birth defects are experienced mostly as a consequence of the superstitious beliefs that certain cultures hold about the aetiology of the phenomena (Kassah, 2008; Kassah et al., 2012; Mamah, 2016; Wachege, 2012).

Findings from the study determined that various coping strategies were used extensively by participants, and also varied from one age group to another. Most frequently used however, were problem-focused strategies that helped participants modify the relationship between them and the stressors within their environment, and emotion-focused strategies, which they often used to regulate the negative emotions that they experienced from functional limitations, as well as from stigma-related experiences. These findings were similar to those of other studies that had explored coping of adolescents, both abled and disabled, in different settings (de Minzi & Sacchi, 2005; Ong & Thompson, 2019). Older participants engaged more in problem-focused strategies and proactively did something about the negative experiences that they were going through. This finding was comparable to reports by studies that explored the process of adjustment to acquired and congenital disfiguring conditions (Thompson & Broom, 2009; Waite & Freeman, 2017; Winter et al., 2017).

The researcher found that, practical strategies were more efficacious interventions that provided individuals with disfigurements the resources to deal with negative social attitudes and self-views. Emotion-focused coping strategies which include wishful thinking, cognitive reframing of a negative situation, withdrawal, self-isolation, and religious/spiritual beliefs and practices that serve to reduce psychological distress were used by almost all 15 participants as they transitioned into adolescence. Cognitively reframing the phenomenon of CLD to reflect more positively as an act of God appear to have benefited participants in this study to a very large extent.

The buffering effects of social support were found to occasionally be counterproductive in this study, and actually worked against enabling an individual develop proactive coping strategies. For instance, it was counterproductive when some adolescents reported being excluded from certain activities for fear of injury. Three (3) participants recalled occasions when teachers did not want to include them in some activity, fearing for their safety. Others recounted times when relatives did everything for them for the same reason. On the other hand, the buffering was advantageous when friends and family encouraged the individual to reach out for the stars and be the best they could be as suggested by the buffering theory underlying this study (Greenglass, 2006).

Not every physically-disabled individual gets adequate social support, and this is especially so in cultures where birth deformity is usually attributed to supernatural forces, and determines the individual's social standing (Wachege, 2012). In this study of AWCLD, a few participants told harrowing stories about negative behaviours of family and friends, on account of their disfigurement or deformity, which were similar to accounts of participants of a leprosarium in a study by Dako-Gyeke, Asampong and Oduro (2016).

In Africa, inclusion in school has been an issue for most young persons with disability. Nevertheless, in a study in Uganda, Bannink (2017) found that although children with a disability were less likely to receive an education, and more likely to be subjected to discriminatory practices, the sense of belonging, as found in the African concept of 'ubuntu' or inclusion, or even, relatedness, buffered the stressors associated with being born with a disabling condition. Inclusion in social activities is therefore essential in promoting psychological health of children and adolescents living with a disabling condition such as CLD. It may also include involvement in romantic and intimate relationships, leading to fulfilling social roles of spouse and or parent. Participants in this study included two (2) mothers and two (2) wives, clearly indicating that these areas were not exclusive to the able-bodied. Indeed,

as Shandra (2018: p.253) suggests, “nearly all people with childhood disabilities experience sexual activity by early adulthood”. A positive self-image among our participants was found to facilitate the taking up of such roles. Similarly, a positive self-image was found to promote involvement in sporting activities, and even careers, as individuals strive to attain or achieve their goals (Chalk, 2016).

The experiences and challenges of all the participants in this study bring home to bear two very important messages: First, nothing good comes easy, and second, you make lemonade with the lemons that life throws at you. Despite everything they experienced, and continue to experience, all participants displayed enormous amounts of self-determination in overcoming the odds.

5.3 Triangulated Discussion

In general, findings from both quantitative and qualitative aspects of the study concur in 4 areas, and support the theoretical underpinnings of the present study. The findings however diverge in 3 areas. Firstly, from the quantitative data, body image, social support, and coping strategies, specifically, strategies that regulate emotions were found to be very significant predictors of psychological health, and echoed the qualitative findings. Quantitative results revealed that although the majority of participants (62%) did not experience clinical symptoms of global distress, mean scores of three subscales, namely obsession-compulsion, interpersonal sensitivity, and paranoid ideation were above the cut-off points for symptomatology. These findings are convergent with findings from the qualitative study.

Secondly, participants’ responses to questions about experiences of stigma and discrimination echoed, to a large extent, the findings from the qualitative study. For instance, 50% of non-amputee participants responded that they had been made to feel ashamed of

themselves on account of their condition. Non-amputees also felt that others had avoided them because of their problem. These findings are consistent with the symptoms of interpersonal sensitivity, paranoia, depression, and obsession-compulsion that were observed from the psychological distress measure. Interpersonal sensitivity for example, is associated with high levels of psychological distress and low body image, and is also closely linked to experiences of stigma (Meisel et al., 2018; Waite & Freeman, 2017).

Non-amputee participants reported feeling stigmatized more often than their amputee peers. Interpersonal sensitivity, enabled participants sense covert manifestations of stigma and prejudice. A few non-amputees also admitted to occasionally feeling paranoid, and experiencing felt or self-stigma. Amputee participants on the other hand, experienced less stigma, and less shame or felt-stigma. They had no visible manifestation of a supernatural interference with their birth, and their missing limbs generally invoked pity rather than fear in their social interactions. A point of convergence with other studies was the finding that prosthetic devices also served a cosmetic purpose, and shielded amputee participants from negative reactions to their limb loss (de Jong et al., 2012). Another finding from participants' narratives of positive experiences support findings from previous studies that suggest that disclosing positive emotional experiences such as joy, triumph, or pride, produce better or improved psychological health outcomes (Bos et al., 2013; Tugade and Fredrickson, 2004). In all the accounts, there were both positive and negative experiences, influenced by behaviours within participants' social environment. This finding also supports the findings by de Jong et al. (2012).

In the second instance, a large positive relationship was found between body image and psychological distress, indicating that as body image concerns increased among the participants, so did their distress levels. The study found that participants possessed both a positive self-image, and a sense of independence that allowed them to feel 'special', a finding

very similar to findings of several studies (Omolayo, 2009; Xu & Liu, 2020). Even with a deformity and disability, they viewed themselves as being on an equal plane with others, especially when they embraced their disability status.

On the issue of stigma, the survey results determined that the majority of amputees (90%) did not believe their condition would negatively impact theirs, nor family members' chances of marriage. This finding did not corroborate those of Kassah (2008, 2012), and diverged also from findings of Naami et al. (2012), who reported that most people would actively avoid marrying a PWD, as they are viewed as not deserving of respect. Nevertheless, a female participant with a very noticeable arm deficiency, lost out on love and marriage, when her boyfriend was asked to choose between her and his family.

Despite social perceptions of CLD, and regardless of stigma-related issues, participants had few body image concerns. A young participant with a shortened leg or fibular hemimelia (Figure 1.2) wished to be in the spotlight so that she could shine, saying... "there will be a lot of people there, then they will see how special I am. And after too, the movie will be on television and many people will see how special I am".

Both sets of results corroborate findings of several studies on the buffering effects of social support, and the feeling of belonging that it fosters (Camara et al., 2017; Greenglass, 2006; Sentse et al., 2010; Steers et al., 2019; Fredrickson et al., 2000; Yendork & Somhlaba, 2014). Associating with other physically-disabled members provided emotional, informational, and instrumental support in the form of friendships, national (and sometimes international) recognition, financial assistance, and romance. Social support enabled autonomy and competence, and encouraged participants cultivate positive emotions of pride and triumph, which in turn, helped them cope with the negative effects of CLD. Thus, social support led to the development of better positive emotion-regulation and problem-solving coping strategies

(Steers, et al., 2019). In both studies, participants who perceived high social support, and who in addition, perceived themselves as being special, unique, or blessed, also reported higher self-esteem, had better coping skills, and better psychological health.

Inclusion in school, social activities and fulfilling social roles enabled participants in this study to experience positive emotions and exercise their self-determination, and the autonomy to participate in arenas reserved for the able-bodied also gave participants the opportunity to demonstrate their competence and capabilities. For instance, in this study, some participants realized their potential in athletic sports only after they were included in sporting activities and encouraged to compete with able-bodied schoolmates. They were granted unsolicited permission to be autonomous, that is, to direct and decide for themselves where their paths in life should go. These findings are consistent with research suggesting that academic, and sporting achievements serve as sources of self-esteem and positive sense of self, especially for adolescents (Bragaru et al., 2011; Dryer et al., 2016).

Although it was observed from the quantitative findings that majority of participants reported positive self-views, the qualitative findings suggest that there were some attempts at concealing the deformity, or at least, the etiology of the deformity, contradicting earlier responses. For example, one participant reported waiting until everybody had left the classroom before leaving. Another participant had referred to the explanation of the cause of her disfigurement as “long talk”. To cut all the talk short would require concealment of the truth, and to this end, would simply say that her amputation was a result of a road traffic accident. People were more inclined to sympathize with her that way than if she admitted that it was due to a birth defect. Other participants however, made conscious efforts to not react to other people’s behaviors, and since the behavior was expected, it did not cause as much distress. These findings are similar to findings on adjustment to disfiguring conditions (Thompson & Broom, 2009).

The finding about self-views also highlights the role of amputation in reducing stigma-related experiences. In the survey, amputee participants' responses revealed that they self-stigmatized less than non-amputees. For instance, in response to the question "Would this problem make it more difficult for you to marry?", 40% of non-amputees said that it would, compared to only 10% of amputees. Non-amputees appeared to be more self-conscious about their bodies compared to amputees, and therefore experienced more interpersonal sensitivity, thereby anticipating that their obvious disfigurement might be a barrier to being perceived as desirable marriage partners. This finding is also consistent with studies that found a relationship between body image and stigmatization (Bos et al., 2013; Chalk, 2016; Meisel et al., 2018; Waite & Freeman, 2017). However, when asked whether CLD would make it more difficult for family members to find marriage partners, both amputee and non-amputee participants responded in the negative. This finding diverges from similar studies that reported that individuals with a family history of disability usually do not get marriage partners due to the belief in disability as a curse on a family (Kassah, 2008; Naami et al., 2012)

In exploring perceived social support in this study, most of the participants talked about the psychological benefits they derived from friends, as well as from being members of social networks and groups, echoing findings of other studies on the buffering effects of social support (Birkeland et al. 2014; Camara et al., 2017; Greenglass, 2006; Sentse et al., 2010; Zuurmond et al., 2018). Participants attributed their positive self-views to how others had supported them and put faith in their ability to succeed in their endeavours, whether academic, sports-related, vocational, or romantic. This finding is important as it strongly suggests that the social systems that fuel the negative experiences of CLD are actually the same systems that buffer and help undo the negative emotions that individuals experience. Social support perceived from friends however, did not significantly contribute to the model as observed, and support from family and significant others surpassed support from friends, diverging from participants' narratives

from the qualitative data findings. The finding was also contrary to a report by Chalk (2016) that found peer support to be higher among adolescents with disabilities. Findings were also not consistent with findings by Winter et al. (2017), where peer support was found to produce negative results, and instead of buffering against stressors, individuals reported increased distress levels.

5.4 Revised Model of the Study

Figure 5.1 is a graphic revision of the model for the study. It elucidates the role of the factors that significantly influence participants' psychological health outcome. The model underscores the significance of positive emotions in fostering self-determination, and the desire to participate in social activities. More importantly, it highlights the buffering nature of social support and coping strategies in reducing the effects of stigma-related stressors, and promoting psychological health, evidenced in feelings of autonomy, competence, a sense of belonging, and positive statements.

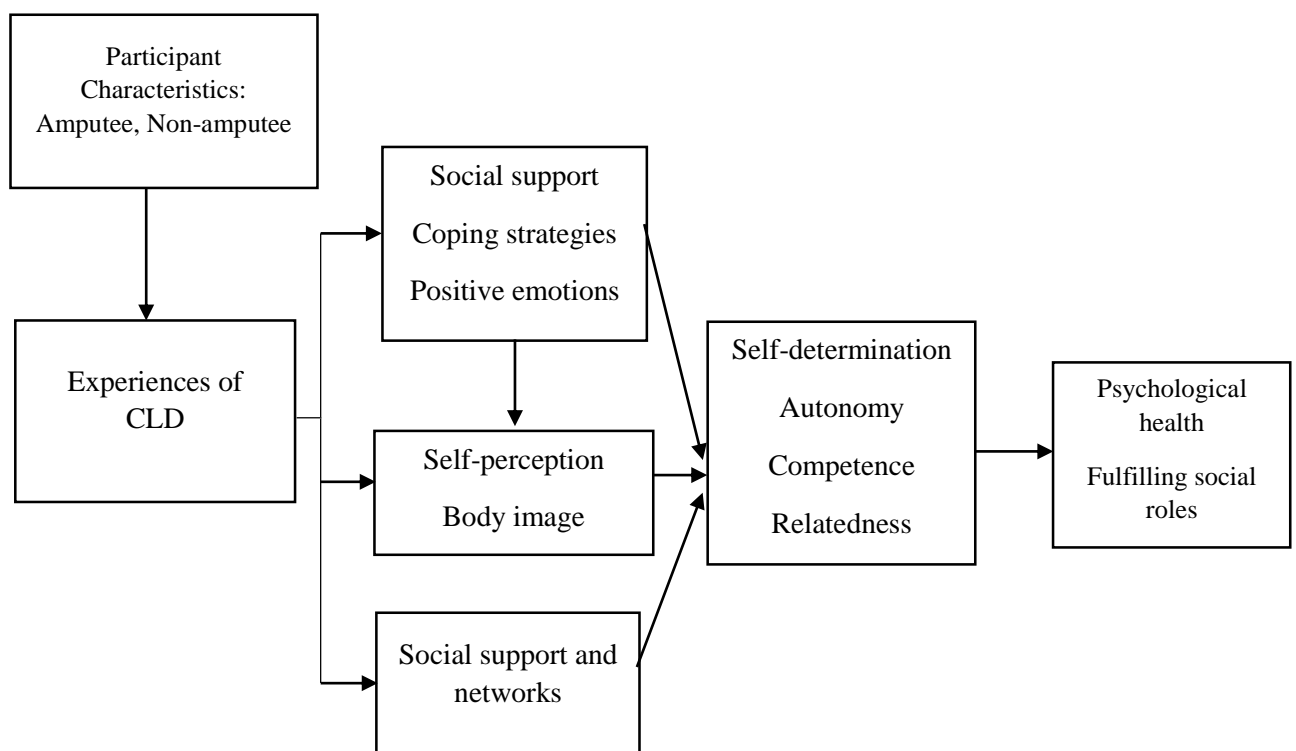


Figure 5.1: Revised Model Depicting the Relationship Between Buffering Resources, and the Outcomes of Psychological Health and Fulfilling Social Roles.

Findings from this study buttress the theoretical framework (BBTPE, BESST, and SDT), and demonstrate the broadening effect of positive emotions on experiences of CLD. It shows the development of self-determination, which enables and promotes participation in social activities and the fulfilment of social roles. It also illustrates the relationship between the buffering resources of social support and coping in psychological health outcome of AWCLDs in Ghana.

5.5 Original Contributions of the Study

This investigation into perceptions and psychological health concerns associated with congenital limb defects began with the questions, “How does CLD impact the psychological health of adolescents in their transition to adulthood, especially since their self-perception is very fragile?” “Does amputation really increase functional ability, and translate into better psychological health and fewer body image concerns of AWCLD?”

The original contribution of this study is the finding that amputation does not necessarily improve the psychological health of AWCLD in Ghana as amputee and non-amputee AWCLD had similar functional ability and body image. This mixed-method study however, demonstrated that AWCLD in Ghana continue to live in the shadow of supernatural beliefs about CLD, and experience the social effects of the phenomenon, more so than the physical and psychological. In this regard, amputation served, not to improve functional ability, as all participants demonstrated similar autonomy and competence, but to disperse the shadow of supernatural influence, and preserve the fabric of culture. Yet, despite the beliefs, disfigurement and disability, non-amputee AWCLD had positive self-views and ambitions, and were determined to be included in, and to participate in all social activities and roles.

In addition, the study makes a case that the social systems that effectuate negative experiences of AWCLD, are the very ones that buffer against psychological distress by enabling inclusion in fulfilling social roles, participation in social activities, and the cultivation of positive emotions. Thus, although it replicates prior studies on the role played by social constructions of deformity on psychological health outcomes, it changes the dominant narrative from a negative to a more positive and vibrant adolescent perspective, while highlighting the ambitions and triumphs of AWCLD. The study has consequently made key contributions to knowledge, practice, and research.

It also draws attention to the effects of exclusion from participatory sports and other social activities that AWCLD demonstrate competence in. No research, to the best of the researcher's knowledge, has highlighted the effects of exclusion, nor the determination and efforts individuals with disfiguring conditions put in to fulfil social roles and become active members of society.

More importantly, the study fills a gap in the literature with novel knowledge about the very fervent desire of individuals born with limb defects to escape from the malevolent shadow of social perceptions or interpretation(s) of the phenomena, and align themselves with the benevolence of God ("Act of God"). It reports on the choice of most AWCLDs in Ghana of poliomyelitis or postnatal mismanagement, which although causing extreme disfigurement and/or disability, is a more acceptable explanation for the deformity, both for the individual, and his community.

This study also highlighted the association between emotions and cognitions involved in perceptions of disability, and demonstrated how these influence the choice of coping strategies that sustain the individual in the pursuit of autonomy. It therefore introduced a novel methodology for approaching studies on self-determination. A self-esteem scale was used as a

proxy measure of positive emotions, autonomy, and competence in AWCLD. Although there are a number of valid and reliable tools for measuring these variables individually, it was expedient to utilize an indirect measure of self-esteem (strongly correlated to positive emotions) to measure the unobservable positive emotions inherent in self-determination.

5.6 Practical Implications of the Study

This study has implications for policy in four key areas: clinical practice, education, youth programs and finally, a multidisciplinary approach to rehabilitation of AWCLD.

5.6.1 Implications for Clinical Psychology Practice in Ghana

There are implications for Clinical Psychology, which is the integration of science, theory and clinical knowledge for the purpose of relieving distress and promoting personal development. There is, first and foremost, a need for collaboration with rehabilitation services that offer assistance to children and adolescents with CLD. This is especially important as many individuals are unaware of the existence of orthopedic rehabilitation centers that treat children born with limb deformity, or associations and disability groups ready and willing to help these children make it through life. As a result, the first recourse for families is to abandon or kill the child. Psychological support would therefore be tailored in a way to help caregivers adjust to the birth of a child with CLD, and also cope with the condition. Support for AWCLD would encompass interventions for psychosocial adjustment to deformity such as cognitive behaviour therapy (CBT), since body image is significantly related with depression, lower levels of self-esteem, and poor psychological health. In addition, counselling would aim at helping adolescents cultivate more positive emotions, broaden their outlook, and engage as much as possible in activities that will pave the way for them to take up fulfilling social roles. Assessment of body image would have to be made an integral part of the rehabilitation

program. Body-image workshops, peer support with positive AWCLD role models, as well as individual psychotherapy when necessary, would need to be factored in all programs.

5.6.2 Implications for Newborn Screening and National Birth Defects Surveillance

Newborn Screening programs need to educate all mothers attending antenatal clinics on the role of genetic and environmental factors in increasing the chances of giving birth to a child with a limb deformity, in the same manner that education about the effects of drug and alcohol abuse and the consequences of certain life styles is disseminated. Maternity homes and hospitals would also have to share motivating but practical life stories about the social roles and activities that persons living with birth defects participate in, and excel. The idea that such children could also be blessings from God may be well accepted in advance by families, even before these births occur. This study would also task traditional birthing attendants in rural areas to adequately inform families about congenital limb deformities, available treatment, and rehabilitation services. In the likelihood that they assist in the delivery of such births, they would be able to provide both emotional and informational support to the families.

There are implications also for the accountability of children and adolescents with birth defects, and the need for a national registry as well as a surveillance of birth defects across the continent and in the sub-Saharan region. The importance of a surveillance especially those recorded by traditional birth attendants in order to provide adequate informational, instrumental, and emotional support to families living with CLD is highlighted.

5.6.3 Implications for Rehabilitation of CLD

The study also brought to light the inadequacy of OPD databases at orthopaedic centers and rehabilitation facilities in monitoring paediatric CLD cases that are treated surgically or with assistive devices. Children who undergo amputation to improve function usually receive their last review by age 12. Many of those using assistive devices, and child amputees would have had several surgical revisions by then, and their self-perception would have been influenced by their physical, and psychological challenges, as well as their social interactions. Despite the use of prosthesis, dissatisfaction concerning the perception of body image occasionally remains an issue for users. Its prompt recognition and evaluation are crucial during rehabilitation. This study will equip rehabilitation teams with insight on social representations of the phenomena of congenital limb deformity and amputation for the purpose of optimum rehabilitation. It would benefit institutions that have dedicated themselves to helping youths with challenges, such as the research setting in Nsawam, access the much-needed assistive devices to enable them carry out holistic management of individuals who are born with a congenital birth defect, and their families. These facilities would need to be well resourced in order to help patients understand the concept of such cases; its aetiology, surgery and other interventions, psychological support in dealing with deformities in both the short and the long term

5.6.4 Implications for Inclusive Education, Youth and Sports Programs

There are implications for inclusionary practices in school for children and AWCLD and other physically-disabling conditions. The study found that inclusionary practices in school, social activities and fulfilling social roles, enabled participants to experience positive emotions and exercise their self-determination, and the autonomy to participate in arenas

reserved for the able-bodied also gave participants the opportunity to demonstrate their competence and capabilities.

5.7 Limitations and Strengths of the Study

Despite the contributions of this study in adding depth to our understanding of the psychological health of AWCLD, there were some issues that if addressed, could have made the study more generalizable, and resulted in a more vigorous outcome. These issues are understandably limitations, and address weaknesses of the study.

First and foremost, there is no surveillance data of CLD births in Africa in general and in Ghana in particular. There are cases that have been recorded in the teaching hospitals but they do not represent the actual figure of CLD births in the country. To compound the problem is the fact that many children are also destroyed at birth so that even at birthing centers with the traditional midwives, there is no record of children who are born with limb deformities. This affected the study because cases that were seen and attended to at NOTC, were patients who had presented over 15 -20 years ago. Treatment is usually initiated as early as age 1, especially for those who get amputated, with most amputations occurring by the age of two (2). Once they have adapted to their assistive devices, or prosthesis usually by age ten (10) they would have had all surgeries required for the fitting of prosthesis. Once many leave the center, there are no follow-up reviews, and usually, no data on their whereabouts. This limitation was also observed in the actual data that was provided to the researcher. The center had lost track of many of the patients although records were kept for as long as four to five years. As they could not update their records, the bio-data they gave of a patients were inaccurate. Contact information was also a problem because the phone numbers that they had were also wrong, or most of the phone numbers were no more in use, making it difficult to track the adolescents or to track the patients who had been treated at the center in order to get their narratives.

The sample size was limited again by the same issues. Some statistical analyses require equal and adequate group sizes when carrying out ANOVA for instance, or when running regression analyses, however, when group sizes are too small, as happens when studying ‘scarce’ populations such as individuals with specific congenital defects, internal validity may be compromised (Saunders, Lewis, & Thornhill, 2015). In terms of getting participants, the study was limited in the number that could be contacted and was forced to rely on others who were not on the center’s OPD list, and as such, had not been accessed. Proper diagnoses had also not been made about their deformities. The rest of the sample had to be recruited through snowball sampling. The researcher encountered a problem with ascertaining what type of deformity the individuals had been born with. To limit the study even further, almost all those who agreed to participate preferred to describe their deformities as a result of injections or polio or some other cause, other than by birth, further limiting the size of the sample. A national registry of congenital abnormalities would have provided the study with the data it required to investigate the psychological health of adolescents with the condition.

Recall bias was encountered by the researcher especially in the cases where there were amputations. As mentioned earlier, the amputations are carried out very early by age 2. Some participants had had revision amputations. Some had even had as many as 15 amputations over a short period. But for the majority, once they had had the amputations at age 2, there were no further revisions. So recounting experiences prior to the amputation and even in the early years following amputation was limited and flawed. The self-report was therefore subject to retrospection bias or recall bias which affected the quality of both the quantitative and qualitative study.

The strength of this study however, lies in its potential to inform the development of culturally-sensitive psychosocial support systems that address not only physical functioning, but also the psychosocial and emotional sequelae of CLD. This is due to the fact that severe

forms of the defect usually lead to amputation, a procedure with a number of negative effects. This fact begs the question as to whether functional ability and aesthetic appearance after amputation translate into better psychological health and better body image of AWCLD. Research on CLD in Ghana has focused on the medical model of treating the problem, thus the approach used to research the phenomenon in this study captured, not only respondents' objective survey report, but also their subjective experience of the phenomenon of CLD.

A major strength also of this study was the choice of the research setting, as it is the referral point for all congenital limb deformities in Ghana and as such, has a database for individuals with limb deformities from every part of the country, and every ethnic background. This study is therefore a synopsis of the experiences of AWCLD in Ghana, and other countries with similar cultural beliefs about birth defects. It challenges the dominance of the medical paradigm of disability in determining functional outcomes of AWCLD, and investigates congenital limb deformity from the perspective of the individual.

The approach taken to investigate this scantily researched area however adds depth to our current understanding of the phenomenon, and facilitates generalizing of the findings. There are several implications in a study such as this, with the potential to inform policy in research, health, clinical practice, and inclusionary practices in education, youth and sports.

5.8 Direction for Future Research

A follow-up study on AWCLD to determine whether self-perceptions of non-amputees would change should they undergo amputation at any time, and/or whether amputation would mediate the social effects of stigma is recommended. This recommendation is based on the qualitative findings, showing that the physical manifestation of deformity influenced stigmatizing behaviours towards participants at both family and community levels, and even,

at the individual level. The study did not investigate also the influence of gender on body image and coping strategies in relation to psychological distress experienced by AWCLD. It is proposed that future studies take this sociodemographic variable into account, in predicting psychological health outcomes and participation in social roles and activities.

The study also makes recommendations for future research to include focused groups in order to get the group opinion of what constitutes psychological health in adolescent limb deformity. The study carried out fifteen (15) in-depth interviews besides a survey, in order to gain understanding of the experiences. However, focused group discussions have been known to bring out varying and various views on the same topic at the same time in order to get a richer understanding of how a phenomenon cuts across a number of people.

Finally, the influence of culture in the development of autonomy, and decision-making were observed during the analysis of qualitative data. More focus on the role of culture in fostering self-determination is recommended in future studies. Future studies should investigate further the influence of positive emotions and self-evaluation of physically-disabled adolescents on performance in diverse social activities.

5.9 Conclusion

This study sought to investigate and understand how AWCLD perceive, respond, and cope with the phenomenon of CLD. It also aimed to examine differences in distress levels and body image, as well as sources of social support, and coping strategies, between adolescent amputees and non-amputees. To achieve this, the study set out specific objectives which were to assess participants for symptoms of distress; examine perceptions of body image, determine sources of social support, and explore the lived experience of CLD. Consequently, the study investigated 50 adolescents aged between 10 and 24 years who were born with limb defects,

and who were amputated as treatment of the birth defect, in an explanatory mixed methods research design. Data was collected from a cross-section of adolescent amputee and non-amputee outpatients of Nsawam OTC, an orthopaedic rehabilitation center, as well as a few members of the Ghana Society for the Physically-Disabled who met the inclusion criteria. The aim as well as the objectives of the study were achieved, and analyses of both sets of data (quantitative and qualitative). Difference tests, and regression analyses determined that support from family and significant others but not friends significantly predicted distress level. Nevertheless, social support from the community played a role in buffering against stressors that were generated within the same environment. The buffering effects were observed when participants were allowed to engage in, and take up positions in social roles and the institutions of education, marriage, business, and sports. Inclusion in school, social activities and fulfilling social roles enabled participants in this study experience positive emotions and exercise self-determination. In addition, the autonomy to participate in arenas reserved for the able-bodied also gave participants the opportunity to demonstrate their competence and capabilities. The study thus shed light on how participants remain positive despite deformity and disability, and the support systems that significantly influence psychological health outcomes.

This study's interest was also in AWCLD's turbulent transition period, when they tend to focus on every little aspect of themselves, and believe that others are focused on these as well. Self- image and appearance therefore take on a greater importance as they try hard to project themselves favourably to peers and budding intimate relationships. Very often, adolescent perceptions reflect those of the community and are exaggerated and flawed, posing a threat to psychological health. In order to explain the qualitative findings further, a phenomenological study of the lived experiences of 15 of the survey participants was conducted with the help of a semi-structured interview guide. Interpretative phenomenological analysis (IPA) was used to analyse the data collected. Four major themes emerged from the

data, and involved their perceptions of CLD, their lived experience and response to those experiences, as well as the outcome of the response, which added meaning to the survey's findings.

The study found that participants had to work hard to move away from, and beyond the perceptions about birth defects, and consequently found joy, and pride in being able to do things for themselves from a very early age. They found satisfaction in being autonomous, making decisions for themselves that helped them cope with the challenges associated with CLD. The phenomenon of CLD was investigated from the perspective of both amputee and non-amputee adolescents who have lived with the effects of disfigurement and disability since birth, focusing on the medical theory that amputation improves function and appearance of the individual. The research consequently compared these adolescents on levels of psychological distress, and body image concerns. It focused on their positive emotions and the determination to move past the challenges, and looked at how participants were able to widen their social networks, achieve goals in education, careers, and other areas of interest, and even take up social roles of marriage, and parenthood. It also explored the challenges they encountered along the way and also how, and if at all, they were able to overcome those challenges. The emotional reactions to negative experiences however appear to change as they move from childhood to adulthood. Participants seemed less emotionally affected, able to better defend themselves, and able to interpret the experiences differently, often finding meaning in them (e.g., a reason to strive more) and alternative ways of doing things. Coping strategies used by adolescents in this study changed as they transitioned into adulthood, although the stressors associated with CLD remain unchanged. Adolescents in the study used all kinds of coping strategies, whether problem-focused or emotion-regulating. Their coping strategies, whether emotion-focused, or problem solving, played a role in their levels of psychological health. In general, participants' positive emotions facilitated coping with stigmatization and other effects of living with a disabling condition.

Participants in this study demonstrated the effectiveness of being proactive in stress reduction and increasing feelings of worth. They took active steps to reduce stressors by joining organizations for the physically-disabled, expanding their social networks, and actively participating in competitive sports and other recreational activities. Although previous studies have suggested that academic, and sporting achievements may serve as sources of self-esteem and positive sense of self, this study found that, a positive outlook and self-determination were the most significant determinants of psychological health of AWCLD.

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APPENDICES

Appendix A: Quantitative Questionnaire (English)

Please answer all questions as honestly as possible. You may write your full name or just your first name. Your responses will not be shared with anyone else without your consent.

Date.....

Name.....

1. Age.....
2. Sex.....
3. Where do you live?
4. Who do you live with?
5. Which region do you come from? (a) Greater Accra (b) Volta (c) Eastern
(d) Western (f) Central (g) Upper East (h) Upper West
(i) Northern (j) Brong Ahafo (k) Ashanti
6. Do you go to school? Yes..... No.....
7. Most recent level of Education: (a) Tertiary; (b) Senior High School; (c) Junior High School; (d) Primary Schooling
8. Do you work? Yes..... No.....
9. Are you an amputee? Yes..... No.... (Please tick). If Yes, at which age were you first amputated? (a) Less than 1 year old (b) 2 to 5 years old
(c) 6 to 10 years old (d) 11 to 15 years old (e) 16 and above years old.
10. How many surgeries have you had? (a) 0 (b) 1 (c) 2 (d) 3
(e) 4 (f) 5 (g) more than 5
11. What do you think caused your deformity? Tick which is true. You may choose more than one.
 - a. Disease
 - b. Injury
 - c. Curse/witchcraft
 - d. Punishment from God
 - e. Punishment from gods/ancestors
 - f. Mother's drugs/ medicine
 - g. Inherited problem.....
 - h. Blessing from God.....
 - i. Other cause(s)

Stigma Statements

Below are (10) ten statements that you may agree or disagree with. Indicate your agreement with each item by placing YES or NO on the line preceding that item. Please be open and honest in your responding.

	STATEMENT	YES	NO
1	People view my deformity very well.		
2	If possible, I would prefer to keep people from knowing about this problem.		
3	I think less of myself because of this problem.		
4	I have been made to feel ashamed or embarrassed (loss of face) because of my problem.		
5	I feel others have avoided me because of my problem.		
6	Some people refuse to visit my home because of this condition.		
7	If others were to find out about my problem, it might cause problems for my family.		
8	My family would prefer to keep others from finding out about my condition.		
9	(If you are unmarried) If people know about it, this problem might make it more difficult to marry. (If you are married) This condition might cause problems in my marriage.		
10	This problem could make it more difficult for someone in my family to marry		

Body Image Scale (BIS)

NO	QUESTION	Not at all	A little	Quite a bit	Very much
1	Have you been feeling self-conscious about your appearance?				
2	Have you felt less physically attractive as a result of your disease or treatment?				
3	Have you been dissatisfied with your appearance when dressed?				
4	Have you been feeling less feminine/masculine as a result of your disease or treatment?				
5	Did you find it difficult to look at yourself naked?				
6	Have you been feeling less sexually attractive as a result of your disease or treatment?				
7	Did you avoid people because of the way you felt about your appearance?				
8	Have you been feeling the treatment has left your body less whole?				
9	Have you felt dissatisfied with your body?				
10	Have you been dissatisfied with the appearance of your scar?				

Multidimensional Scale of Perceived Social Support (MSPSS)

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how much you agree or disagree to each statement. Use the following answers:

1= Very strongly Disagree; 2= Strongly Disagree; 3= Mildly Disagree; 4= Neutral; 5= Mildly Agree; 6= Strongly Agree; 7= Very strongly Agree

		1	2	3	4	5	6	7
1	There is a special person who is around when I am in need							
2	There is a special person with whom I can share my joys and sorrow							
3	My family really tries to help me							
4	I get the emotional help and support I need from my family.							
5	I have a special person who is a real source of comfort to me							
6	My friends really try to help me.							
7	I can count on my friends when things go wrong.							
8	I can talk about my problems with my family							
9	I have friends with whom I can share my joys and sorrows.							
10	There is a special person in my life who cares							
11	My family is willing to help me make decisions.							
12	I can talk about my problem with friends.							

Brief Symptom Inventory (BSI)

	Here is a list of problems people sometimes have. I want you to indicate how much that problem has distressed or bothered you during the past 7 days including today. On the right side are the answers I want you to use.	Not at all	A little bit	Moderately	Quite a bit	Extremely
1	Nervousness or shakiness inside	0	1	2	3	4
2	Faintness or dizziness	0	1	2	3	4
3	The idea that someone else can control your thoughts	0	1	2	3	4
4	Feeling others are to blame for most of your troubles	0	1	2	3	4
5	Trouble remembering things	0	1	2	3	4
6	Feeling easily annoyed or irritated	0	1	2	3	4
7	Pains in heart or chest	0	1	2	3	4
8	Feeling afraid in open space or in the streets	0	1	2	3	4
9	Thoughts of ending your life	0	1	2	3	4
10	Feeling that most people cannot be trusted	0	1	2	3	4
11	Poor appetite	0	1	2	3	4
12	Suddenly scared or afraid for no reason	0	1	2	3	4
13	Temper outbursts that you could not control	0	1	2	3	4
14	Feeling lonely even when you are with people	0	1	2	3	4
15	Feeling blocked in getting things done	0	1	2	3	4
16	Feeling lonely	0	1	2	3	4
17	Feeling blue/depressed or sad	0	1	2	3	4
18	Feeling no interest in things	0	1	2	3	4
19	Feeling fearful	0	1	2	3	4
20	Your feeling being easily hurt	0	1	2	3	4

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21	Feeling that people are unfriendly or dislike you	0	1	2	3	4
22	Feeling inferior to others (compared to others, you feel less important)	0	1	2	3	4
23	Nausea or upset stomach; you feel like vomiting	0	1	2	3	4
24	Feeling that you are watched or talked about by others	0	1	2	3	4
25	Trouble falling asleep	0	1	2	3	4
26	Having to check and double check what you do	0	1	2	3	4
27	Difficulty making decision	0	1	2	3	4
28	Feeling afraid to travel on buses or trains	0	1	2	3	4
29	Trouble getting your breath or you have difficulty breathing	0	1	2	3	4
30	Hot or cold spells; you feel hot and cold at short time intervals	0	1	2	3	4
31	Having to avoid certain things, places, or activities because they frighten you	0	1	2	3	4
32	Your mind going blank; your mind becoming empty and you can't remember anything	0	1	2	3	4
33	Numbness or tingling in parts of your body ("ananse" feelings)	0	1	2	3	4
34	The idea that you should be punished for your sins	0	1	2	3	4
35	Feeling hopeless about the future	0	1	2	3	4
36	Trouble concentrating	0	1	2	3	4
37	Feeling weak in parts of your body	0	1	2	3	4
38	Feeling tense or keyed up	0	1	2	3	4
39	Thoughts of death or dying	0	1	2	3	4
40	Having urges to beat, injure, or harm someone	0	1	2	3	4

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41	Having urges to break or smash things	0	1	2	3	4
42	Feeling very self-conscious with others	0	1	2	3	4
43	Feeling uneasy in crowds (among many people), such as shopping or at a movie	0	1	2	3	4
44	Never feeling close to another person	0	1	2	3	4
45	Spells of terror or panic	0	1	2	3	4
46	Getting into frequent arguments	0	1	2	3	4
47	Feeling nervous when you are left alone	0	1	2	3	4
48	Others not giving you credit for your achievements	0	1	2	3	4
49	Feeling so restless you couldn't sit still (feeling so uncomfortable you couldn't sit at one place)	0	1	2	3	4
50	Feeling worthlessness; that you have no value	0	1	2	3	4
51	Feeling that people will take advantage of you if you let them	0	1	2	3	4
52	Feeling of guilt	0	1	2	3	4
53	The idea that something is wrong with your mind	0	1	2	3	4

KIDCOPE—OLDER CHILDREN

INSTRUCTIONS: Please read each item and circle which phrase applies (if any). Then, answer both questions to the right of each item, circling the best answer.

Did It Help?		How Often Did You Do This?					How Much				
		Not at all	Som e times	A lot of the time	Almo st All the Time		Not at all	A littl e	Som e what	Prett y muc h	Very muc h
		0	1	2	3		0	1	2	3	4
1	I thought about something else; tried to forget it; and/or went and did something like watch TV or play a game to get it off my mind.										
2	I stayed away from people; kept my feelings to myself; and just handled the situation on my own.										
3	I tried to see the good side of things and/or concentrated on something good that could come out of the situation.										
4	I realized I brought the problem on myself and blamed myself for causing it.										
5	I realized that someone else caused the problem and blamed them for making me go through this.										
6	I thought of ways to solve the problem; talked to others to get more facts and information about the problem and/or tried to actually solve the problem.										
7	I talked about how I was feeling; yelled, screamed, or hit something.										
8	I tried to calm myself by talking to myself, praying, taking a walk, or just trying to relax										
9	I kept thinking and wishing this had never happened; and/or that I could change what had happened.										
10	I turned to my family, friends, or other adults to help me feel better.										
11	I just accepted the problem because I knew I couldn't do anything about it.										

Self-Esteem Scale (SES)

Below is a list of statements dealing with your general feelings about yourself. If you STRONGLY AGREE, circle SA. If you AGREE with the statement, circle A. if you DISAGREE, circle D. If you STRONGLY DISAGREE, circle SD.

	STATEMENT	Strongly Agree	Agree	Disagree	Strongly Disagree
1	I feel that I am a person of worth, at least on an equal plane with others	SA	A	D	SD
2	I feel that I have a number of good qualities	SA	A	D	SD
3	All in all, I am inclined to feel that I am a failure	SA	A	D	SD
4	I am able to do things as most other people	SA	A	D	SD
5	I feel I do not have much to be proud of	SA	A	D	SD
6	I take a positive attitude toward myself	SA	A	D	SD
7	On the whole, I am satisfied with myself	SA	A	D	SD
8	I wish I could have more respect for myself	SA	A	D	SD
9	I certainly feel useless at times	SA	A	D	SD
10	At times, I think I am no good at all	SA	A	D	SD

Appendix B: Quantitative Questionnaire (Twi)

Yesre wo bua nsemmsisa ahorow yi nokwarem. Wobetumi akyerew wo din nyinaa anaa wo din a edi kan pe. Yemfa wo ho nsem mma obaira gye se wopene so.

Eɔda.....

Edin.....

1. Wo mfe.....
2. Woye ɔbaa/ɔbarima.....
3. Ehe na wote?.....
4. Hena na wo ne no te?.....
5. Ehenfa na wofi?.....
6. Wokɔ sukuu anaa?.....
7. Se woakɔ sukuu da, wokɔ duu he?.....
8. Woye adwuma?.....
9. Wadi dem anaa?.....

Se wadi dem a, bere ben na wodii dem?

 - a. Bere a midii afe baako
 - b. 2-5
 - c. 6-10
 - d. 11-15
 - e. 16 anaa nea eboro saa
10. Operahyin sen na woaye?
 - a. 0
 - b. 1
 - c. 2

- d. 3
- e. 4
- f. 5
- g. Nea eboro 5

11. Wosusu sɛ dɛn na ɛmaa wodii dem?

Paw nea ɛɛ nokware wɔ mu

- a. Yare
- b. Akwanhyia
- c. Duabɔ
- d. Asotwe a efi Nyankopɔn
- e. Asotwe a efi Nananom fa w'awo ho
- f. Me maame faa adurow bi
- g. Wɔde woo me
- h. Nyankopɔn nhyira
- i. Anaa biribi foforo

Stigma Statements

Dee edidi soɔ yi ye nsem dua (10)a ese se wokyerɛ se wogyɛ tom anaa wonnye ntom. Wode Aane ne Daabi na ebekyerɛ wɔ nsensanee a edi anim no so. Ma nokwardedi nna adi wɔ wo mmuaee no mu.

		Aane	Daabi
1	Afoforo hu me yare no yie		
2	Sɛ ebeyɛ yie a, mempe sɛ afoforo hu me yare ho asem		
3	Mebu me ho abomfia mehaw no nti		
4	Me tebea no nti, eye a na m'ani awu		
5	Mete nka sɛ afoforo mmen me, me haw no nti		
6	Nnipa binom mpe sɛ wɔba me fie me tebea no nti		
7	Sɛ afoforo hu me tebea ho asem a, ebɛhaw m'abusua		
8	M'abusua bepe sɛ wɔde me haw ho nsem besie		
9	Sɛ wo nware a, ebetumi ama w'aware ho aye den. (Sɛ w'aware) ede nsensem beba aware no mu.		
10	Me nti ebeye den ama m'abusuani sɛ obeware		

Body Image Scale (BIS)

Fa nsem ahorow yi bua nea edidi so yi.

NO		Daab i	Kakraa	Eye kakra a	Aane
1	Ɛye a, wode w'adwene si senea wo nnipadua te no so?				
2	Wo tebea no nti, wohu wo ho se wo ho nye fe?				
3	Se wosiesie wo ho a wo hu wo ho sen?				
4	Woyare no nti wo nhu wo ho yiye se obarima anaa o _{baa} yiye?				
5	Ɛye wo den se wobehwe wo ho bere a wonhye ataade?				
6	Wosusuw se wo ho nye akonno wo haw no nti?				
7	Wotwe wo ho fi nnipa ho anaa?				
8	W'ayaresa no nti wote nka se wo nnipadua no nni mu?				
9	W'ani nnye senea wo nnipadua no aye anaa?				
10	Okwan ben so na wo ho etwa a ewo wo ho no emma wo kuma nto wo yam?				

Multidimensional Scale of Perceived Social Support (MSPSS)

Kyere eyinom nea efa wo ho pa ara

		1 Menny e ntom da	2 Menny e ntom koraa	3 Menny e ntom	4 M'adw ene nsii pi	5 Megye to mu	6 Megye to mu yiye	7 Megye to mu pa ara
1	Onipa soronko bi wɔ me nkyen bere biara a mehiammoa							
2	Onipa soronko bi wɔ hɔ a me ne no kye m'anigye ne m'awerehosɛm							
3	M'abusua bɔ mmɔden boame							
4	Menya mmoa ne anigye a mehia wɔ m'abusuafo hɔ							
5	Mewɔ onipa soronko bi a ɔkyekye me were yiye							
6	Me nnamfonom bɔ wɔn ho mmɔden boame							
7	Mɛtumi de me ho ato me nnamfonom so wɔ ahohiahia bere mu/wɔ bere a emu ye den mu							
8	Mene m'abusua tumi din nkɔmɔ fa me haw ho							
9	Mewɔ nnamfo a me ne wɔn kye m'anigyesɛm ne me haw nyinaa							
10	Onipa soronko bi wɔ m'abrabɔ mu a m'apɔwmuden ho nsem ye n'asenhia							
11	M'abusua boame mami gyinae							
12	Me ne me nnamfonom kasa fa me haw ho							

Brief Symptom Inventory (BSI)

	Nea edidi so ye ohaw a nnipa binom hyia. Fa nsempo ahorow no kyere senea ohaw no haw wo fae. ewo dapen a atwam yi a nne ka ho.	Daabi	Kakra	Bebree	Papaapa	Bebree pa ara
1	Ayamhyehye anaa ahowosow	0	1	2	3	4
2	Anisobiri	0	1	2	3	4
3	Mete nka se obi wo me nsusuw so tumi	0	1	2	3	4
4	Mete nka se afoforo hye me haw akyi	0	1	2	3	4
5	Mentumi nkae nneama yie	0	1	2	3	4
6	Me bo fuw ntemtem	0	1	2	3	4
7	Akoma mu anaa ebo so yaw	0	1	2	3	4
8	Me yaw sore bere a mapue anaa mewo nnipadom mu	0	1	2	3	4
9	Menya adwene bi se menku me ho	0	1	2	3	4
10	Mete nka se mentumi mfa me ho nto afoforo so	0	1	2	3	4
11	Mentumi nnidi	0	1	2	3	4
12	Metaa bo birimbirim	0	1	2	3	4
13	Abufuw a mentumi nhye so	0	1	2	3	4
14	Mete nka se mentumi nye hwee	0	1	2	3	4
15	Meye ankonam	0	1	2	3	4
16	Anigyina tumi ka me	0	1	2	3	4
17	Eye a na dadwen ne awerhow ahye me so	0	1	2	3	4
18	Mennya atenka wo biribiara mu	0	1	2	3	4
19	Ehu ne suro kyekyere me	0	1	2	3	4
20	Nneama nketekete tumi hye me so pa ara	0	1	2	3	4
21	Mete nka se afoforo mpe m'asem	0	1	2	3	4
22	Eye a mete nka se me mfata wo afoforo ani so	0	1	2	3	4

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23	Mebo fono me anaa menya ayamkeka	0	1	2	3	4
24	Mete nka se afoforo hwe me, ka me ho nsem	0	1	2	3	4
25	Mentumi nna	0	1	2	3	4
26	Menni ahotoso wo me mu	0	1	2	3	4
27	Gyinaesi ye me den	0	1	2	3	4
28	Mesuro se metu kwan wo boso anaa keteke mu	0	1	2	3	4
29	Mehome tumi te	0	1	2	3	4
30	Me honam mu ye me basaa beretia mu	0	1	2	3	4
31	Metwe me ho fi nneama ne mmeae ahorow a ema meye basaa anaa ebetumi apira me	0	1	2	3	4
32	M'adwene tu fra na menkae hwee	0	1	2	3	4
33	M'akwa no baabi ye me titirii/titiritii	0	1	2	3	4
34	Menya adwene se ese se wotwe m'aso wo me bone ho	0	1	2	3	4
35	Eye me se anidaso biara nni ho	0	1	2	3	4
36	Mentumi mfa m'adwene nsi ade biako so	0	1	2	3	4
37	Mete nka se me honam akwaa no bi dodow me	0	1	2	3	4
38	Mete nka se biribi hwe me so	0	1	2	3	4
39	Medwen me wu ho	0	1	2	3	4
40	Mete nka se me mpira obi	0	1	2	3	4
41	Mete nka se mensee nneama a atwa me ho ahyie	0	1	2	3	4
42	Mehwe me ho so yie wo afoforo ho	0	1	2	3	4
43	Me ho teete me bere a mewo nnipadom mu te se guaso	0	1	2	3	4
44	Mente nka se meben afoforo	0	1	2	3	4
45	Mete nka se obi rebedi me awu anaa me yam hyehye me	0	1	2	3	4

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46	Metaa ne afoforo nya akasakasa	0	1	2	3	4
47	Ehu ne osuro hye me so bere a aka me nko ara	0	1	2	3	4
48	Afoforo nhu adwuma pa a meye	0	1	2	3	4
49	Eye me se mewo nneema bebree ye a mentumi ntena faako mpo	0	1	2	3	4
50	Mete nka se mense hwee	0	1	2	3	4
51	Mete nka se me tebea no nti afoforo sisi me	0	1	2	3	4
52	Mebu me ho fo se maye bone	0	1	2	3	4
53	Eye a mesusu se m'adwenem wo haw	0	1	2	3	4

KIDCOPE

Akwankyerɛ: Kenkan nea edidi so no yie, na fa bua nsemmisa mmeinuu a edidi so yi.

		So woyee saa no eboa wo?					Mpen dodow sen na woye saa?				
		Daa bi	Ebi wo ho a	Mpe n pii	Bere nyina a		Daa bi	Ka kra	Ebi wo ho a	Mpe n pii	Bere nyin aa
		0	1	2	3		0	1	2	3	4
1	Medwen bribi foforo ho, mebo mmoden se mema me were afi, eye a medi agori, hwe TV senea ebeye a mayi afi m'adwene mu										
2	Metwe me ho fi afoforo ho, di me hwa ho dwuma a menka ho asem nkyere obiara										
3	Mede m'adwene si nneama papa a ewo asem no ho. Se ebia bribi papa befi mu aba.										
4	Mehuu se me ara na mede ohaw no aba me so, enti mebuu me ho fo.										
5	Mebuu se obi foforo na ohye me haw no akyi, na me mmom na merehu ho haw.										
6	Meboo me ho mmoden se medime haw no ho dwuma, bisaa afoforo ho mmoa nso.										
7	Meka me haw ho asem abufuw so.										
8	Meboo mmoden se medwodwo me ho. Eye a mene me ho kasa na mebo mpaee nante nante de dwodwo me ho.										
9	Eye a me dwen ho se anka saa asem yi ansi. Na eye a mesusuw se metumi asesa nea ato me no										
10	Meko me nnamfo ne abusuafu ho hwehwe mmoa										
11	Megye nea ato me no tom esiane se mentumi nsesa nea asi no.										

Self-Esteem Scale (SES)

Nea edidi so ye nsemmissa a w'ani begye ho anaa w'ani rennye ho. Fa nsem a edidi so yi bua nsemmissa no

		Megye tom pa ara	Megye tom	Mennye ntom	Mennye ntom koraa
1	Mehu me ho se onipa titirw, na mewo hokwan se meye nea afoforo tumi ye.				
2	Mete nka se mewo suban pa ahorow bi wo me mu.				
3	Ne nyinaa mu no mete nka se me so nni mfaso.				
4	Metumi ye nneama a afoforo ye no bi.				
5	Mete nka se minni nea mede hoahoa me ho.				
6	Mewo adwene pa wo me ho.				
7	Nokarem no, senea mete no ye ma me.				
8	Meye se menya obu kese ma me ho.				
9	Eye a mete nka se me so nni mfaso.				
10	Eye a mete nka se me so nni mfaso anaa meye adeso.				

Appendix C: Ethical Clearance Certificate – ECH, University of Ghana



UNIVERSITY OF GHANA
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)

P. O. Box LG 571, Legon, Accra, Ghana

My Ref. No.....

11th March, 2019

Ms. May Cullen Wulff-Cesar
Department of Psychology
University of Ghana
Legon, Accra

Dear Ms. Wulff-Cesar,

**ECH 082/18-19: ASSESSING BELIEFS, SOCIAL SUPPORT, AND PSYCHOLOGICAL WELL-BEING
IN ADOLESCENTS WITH CONGENITAL LIMB DEFORMITY IN GHANA.**

This is to advise you that the above reference study has been presented to the Ethics Committee for the Humanities for a full board review and the following actions taken subject to the conditions and explanation provided below:

Expiry Date:	11/03/20
On Agenda for:	Initial submission
Date of Submission:	16/01/19
ECH Action:	Approved
Reporting:	Annually



Please accept my congratulations.

Yours Sincerely,

Prof. C. Charles Mate-Kole
ECH Vice Chair

Cc: Dr. Benjamin Amponsah, Department of Psychology, UG.

Appendix D: IRB Clearance – Orthopedic Training Center Nsawam



NATIONAL CATHOLIC HEALTH SERVICE

Tel: 03421-22031
024-4214907
020-8136234

(Diocese of Koforidua)

E-mail: liznewman3121@gmail.com
Web site: www.otcghana.org

Orthopedic Training Centre
P.O. Box 306
Adoagyiri-Nsawam
Eastern region
Ghana, West Africa



29th April, 2019

Ms. May Cullen Wulff-Caesar,
Department of Psychology,
University of Ghana,
Legon.

Dear Madam,

APPROVAL TO CONDUCT RESEARCH AT NSAWAM OTC

We are writing in response to your letter requesting permission to conduct research at the Orthopedic Training Centre, Nsawam. This is in support of your study, with the title:

“Assessing beliefs, support & psychosocial well-being of adolescents with congenital limb deformities in Ghana”.

We are happy to grant you approval to use our institution as your research setting, and hope our centre can provide you with the information you require to help your research.

This approval is for a period of one year, and data gathered for the research should be used for the approved purposes only.

Thank you.

Yours faithfully,

Sister Elizabeth Newman SSND
Director

7/8/20

Asante Kissi Eleazer
Public Relation Officer

Appendix E: Informed Consent

UNIVERSITY OF GHANA



Official Use only
Protocol number

Ethics Committee for Humanities (ECH)

PROTOCOL CONSENT FORM

Section A- BACKGROUND INFORMATION

Title of Study:	Experiences of Adolescents with Congenital Limb Deformities in Ghana
Principal Investigator:	May Cullen Wulff-Caesar
Certified Protocol Number	

Section B- CONSENT TO PARTICIPATE IN RESEARCH

General Information about Research

This study aims to understand how young people (adolescents) who were born with deformed arms and legs (congenital limb deformity) view themselves (self-perception), and how their lives have been affected by how other people view and treat them. Although these individuals with these problems are special, their lived experiences of deformity have not been studied extensively to find out if they face any psychological challenges or distress. This is because studies in Ghana have focused mainly on medical treatment of the deformities. The study therefore purposes to explore how these adolescents with CLD view themselves and give meaning to their experiences, and also to investigate symptoms of psychological distress.

The study will require that you answer in either English, Ga or Twi, questions about how you see yourself, what your life has been like, and the people who have helped you up till now. The interviews will be recorded and what you say will be later written down. Afterwards, you will have the opportunity to listen to what you said to be sure.

You will also answer some questions about psychological problems you may be experiencing, and how much they affect you. It will take you about one hour to answer all the questions. One week after you have done the interview and answered the questions, you will be asked to join other people who have similar arm and leg problems in a discussion about your experiences. There will be 2 groups, one for young people aged 12 -15 years, and one for young people aged 16 - 25 years.

Transportation to and from the research setting in Nsawam Orthopedic Training Center (Eastern Region) will be arranged and paid for you. The study will cover the period November 2018 – May 2019.

Risks of the study

There are no risks associated with this study. As such, all that is required of you is your availability and patience for your responses. However, as the study will involve young people with leg or arm deformities, you may meet other people with very serious deformities which might disturb you. Your voluntary participation in the study will not only add to knowledge but will also help in intervention and policy with regards to providing physical and psychological support for people living with CLD.

Benefits of the study

The benefit of the study is the support and new friendships you may form with other people like yourself. You will also be able to talk to people trained to help you take part in activities that you find interesting, and get access to braces or arm and leg supports.

Confidentiality

You are highly assured that your responses will be kept confidential. You are also assured that your real name will not be used and any identifying characteristics will be disguised. Only the research assistants will know your real identity. In line with this, although this study is meant for academic purposes, your consent (whether by signature or thumbprint) implies making the findings available to the general public and academia especially.

Compensation

In appreciation of your participation and commitment to this study, you will receive an amount of GH 20.00 (Twenty Ghana Cedis). This token of our appreciation will be given to you at the end of the group discussions.

Withdrawal from Study

Although we acknowledge with respect and gratitude your contribution to this study, it is important for you to know that your participation in this study is entirely voluntary. As a prospective participant, you are free to take part or withdraw your consent during any part of data collection without any loss or strings attached. You can also refuse to answer any questions that you are uncomfortable with, and any legal representative you have will be informed of any information you give that may be damaging to you when findings are made available to the public.

Contact for Additional Information

You can contact the following for any answers to any questions about the research, or if you suffer any injuries while participating in the study.

May Cullen Wulff-Caesar, P.O. Box SK 238. Phone Nos: 0244444594, email: mawulff-caesar@st.ug.edu.gh; Also, if you have any questions about your rights as a research participant in this study you may contact the Administrator of the Ethics Committee for Humanities, ISSER, University of Ghana at ech@isser.edu.gh / ech@ug.edu.gh or 00233- 303-933-866.

Section C- PARTICIPANT AGREEMENT

"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and I am willing to give consent for me, my child/ward to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."

Name of Participant

Signature or mark of Participant

Date

If participant cannot read and or understand the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Name of witness

Signature of witness / Mark

Date

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Name of Person Who Obtained Consent

Signature of Person Who Obtained Consent

Date

Appendix F: Guardian Informed Consent

UNIVERSITY OF GHANA



Official Use only
Protocol number

Ethics Committee for Humanities (ECH)

GUARDIAN/PARENTAL PROTOCOL CONSENT FORM

Section A- BACKGROUND INFORMATION

Title of Study:	Assessing Beliefs, Support and Psychosocial Wellbeing of Adolescents with Congenital Limb Deformities in Ghana
Principal Investigator:	May Cullen Wulff-Caesar
Certified Protocol Number	ECH 082/18-19

Section B- CONSENT TO PARTICIPATE IN RESEARCH

General Information about Research

This study aims to understand how young people (adolescents) who were born with deformed arms and legs (congenital limb deformity) view themselves, and how their lives have been affected by how other people treat them. It also aims to find out whether amputation of the deformed limb changes how they as well as other people in their communities view them. Adolescents with this problem have not been studied extensively to find out if they face any psychological challenges. Studies in Ghana have focused mainly on medical treatment of the deformities. The study therefore purposes to understand how these adolescents make meaning of their experience of CLD, assess support systems, psychological distress and coping. The study also seeks to determine if age and gender influence how adolescents with CLD perceive, and cope with the problem.

The study will require that your ward answers, in either English, Ga or Twi, questions about how he/she sees him/herself, what life has been like, and the people who have helped him/her cope up till now. The interviews will be recorded and what he/she says will be later written down. Afterwards, he/she will have the opportunity to listen to what he/she said to be sure. No one else in the family or community will hear what he/she says.

Your ward will be asked to join other people who have similar arm and leg problems in a discussion about his/her experiences. There will be 2 groups, one for those who have been amputated, and one for those who have not been amputated. After the group discussions, your ward will be interviewed alone, and asked questions about his/her life. It will take about one hour to answer all the questions.

If necessary, transportation to and from the research setting will be paid for your ward. The study will cover the period January 2019 – June 2019.

Risks of the study

There are no risks to your ward in this study. However, he/she may experience some degree of psychological distress when he/she encounters some extreme form of deformity. In the event of that happening, your ward will receive the necessary psychological support.

Benefits of the study

The benefits of your ward's participation in this study include support from adolescents with similar problems, new relationships and networks, and increased psychological wellbeing. Your ward's participation in the study will not only add to knowledge but will also help in intervention and policy with regards to providing physical and psychological support for young people living with CLD.

Confidentiality

You are highly assured that your ward's responses will be kept confidential. You are also assured that your ward's real name will not be used and any identifying characteristics will be disguised. Only the research assistants will know your ward's real identity. In line with this, although this study is meant for academic purposes, your guardian/parental consent (whether by signature or thumbprint) implies making the findings available to the general public and academia especially.

Compensation

In appreciation of your ward's participation and commitment to this study, he/she will receive an amount of GH 20.00 (Twenty Ghana Cedis). This token of our appreciation will be given to your ward at the end of his/her interview. Your ward will receive this token of our appreciation even if he/she decides not to participate further or is unable to complete the questionnaire.

Withdrawal from Study

Although we acknowledge with respect and gratitude your contribution to this study, it is important for you to know that your consent for your ward to participate in this study is entirely voluntary. As the guardian/parent of a prospective participant, you are free to take part or withdraw your consent during any part of data collection without any loss or strings attached. Your ward can also refuse to answer any questions that he/she is uncomfortable with, and any legal representative you have will be informed of any information your ward gives that may be damaging to him/her when findings are made available to the public.

Contact for Additional Information

You can contact the following for any answers to any questions about the research, or if your ward suffers any injuries while participating in the study.

May Cullen Wulff-Caesar, P.O. Box SK 238. Phone Nos: 0244444594, email: mcwulff-caesar@st.ug.edu.gh; Also, if you have any questions about your rights as a research participant in this study you may contact the Administrator of the Ethics Committee for Humanities, ISSER, University of Ghana at ech@isser.edu.gh / ech@ug.edu.gh or 00233- 303-933-866.

Section C- PARTICIPANT AGREEMENT

"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and I am willing to give consent for me, my child/ward to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."

Name of Participant

Signature or mark of Participant

Date

If participant cannot read and or understand the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Name of witness

Signature of witness / Mark

Date

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Name of Person Who Obtained Consent

Psychological Health of Adolescents with CLD

Signature of Person Who Obtained Consent

Date

Appendix G: Qualitative Interview Guide (English)

Qualitative Interview Guide

Thank you for agreeing to participate in this study. We shall be discussing your perceptions and experience of CLD, how you view yourself, and any challenges you have faced. We would also like you to share with us how your family and members of your community have helped. In addition, we would be happy to hear how you respond(ed) to the experiences, and challenges. We would also like you to tell us about your relationship with other people, involvement in intimate relationships, participation in social activities, as well as your future plans. Please feel free to express your feelings, and do not answer questions that you are not comfortable with. You are also free to stop the interview at any time.

Background and relevant information

- What is your age, and ethnic background?
- How did you get your deformity?
- Kindly describe your deformity.
 - When were you amputated?
 - How do you feel about not having a leg/arm/foot etc
 - How many surgeries have you had since then?
 - How do you get around?

Experiences of deformity, and social stigma

- How has CLD affected you?
- Share with me your daily activities.
- Share with me your everyday life experiences.
- What challenges have you faced since childhood?
- Share with me your memorable experiences.

Support systems

- How do your family members view your deformity?
- Share with me the things your friends do to support you.
- How have other people helped you?

Coping Strategies

- How did you respond to how people viewed you?
- Tell me about the times you said and did things that you regretted.
- Share with me the things you did which made you feel good.

Interpersonal relationships and social activities

Psychological Health of Adolescents with CLD

- Please describe your relationship with people in your community
- What social activities do you engage in?
- Tell me about any particular person(s) in your life.
 - (a) Why are they special?
- Share with me your plans for the future?

Is there anything else you would like to share? Thank you for talking to me.

Vignette

- (i) There is an upcoming get-together for persons with physical disabilities at two different locations, simultaneously. One party will take place at Aburi Gardens while the second gathering is at the beach. However, you have to make a choice about which one to go to. Which one will you prefer to attend; what are the reasons for your choice?
- (ii) A physically-disabled friend has to further his/her education at a Senior High School. He/she has come to seek your advice on whether they should choose a day school or a boarding school. Which option will you choose for your friend and why?

Appendix H: Qualitative Interview Guide (Twi)

Yɛda wo ase sɛ woapene so sɛ yɛne wo nyɛ dwumade yi. Yɛbɛsusuw w'adwene kyere, ne wo suahu ahorow a woahyia, wo haw no nti. Yɛpɛ sɛ yɛhu senea w'abusuafo, wo fiefo, anaa mpɔtemfo aboa wo. Bio nso, yɛpɛ sɛ yɛhu senea wodii wo haw ahorow so. Afei nso, yɛpɛ sɛ, woka senea wone afoforo ntam abusuabɔ te, ne senea wode wo ho fra afoforo wɔ nnipa dɔm mu, ne senea wohu wo daakye. Fi wopɛ mu bua nsemmissa ahorow yi a erenhaw wo wɔ ɔkwan biara so.

Background and Relevant Information

- Wadi mfe sɛn, na ehe na wofi?
- Ebaa no sɛn na woahyia saa haw yi?
- Ka wo haw ho asem kyere me.
 - (a) Bere ben na saa asem no sii?
 - (b) Wo haw no maa wotee nka sɛn bere a wotwaa wo nan anaa wo nsa?
 - (c) Operahyin sɛn na woayɛ?
 - (d) Woyɛ dɛn di akɔ-ne-aba?

Experiences of deformity and social stigma

- ɔkwan ben so na wo dem no ahaw wo?
- Ka wo da biara da dwumadi ho asem kyere me
- Ka wo da biara da suahu ho asem kyere me
- ɔhaw ahorow ben na woahyia fi wo mmofrase
- Ka wo suahu atitiriw ho asem kyere me

Support systems

- W'abusua hu wo haw no sɛn?
- ɔkwan ben so na wo nnamfo aboa wo?
- ɔkwan ben so na nnipa afoforo nso aboa wo?

Coping Strategies

- Woyɛ woade sɛn wɔ senea afoforo hu wo?
- Nneama a wayɛ a ama woanu wo ho no, ka bi kyere me
- Nea woyɛ a ɛma w'ani gye no ka ho asem kyere me

Interpersonal Relationships and Social Activities

- Wone wo fiefo ntam abusuabɔ te sɛn?
- Agodi anaa nnipa dɔm dwumadi ben na wode wo ho hyɛ mu?
- Ka nnipa tititriw a wɔwɔ w'asetena mu asem kyere me. Na aden nti na wope won asem?
- Den na wope sɛ woyɛ daakye?
- Briɓi foforo biara wɔ ho a wope sɛ woka ho asem kyere me?

Vignette

Wode dwumadi bi rehyehye so ama won a won adi dem wɔ mmeae mmienu bere biako mu. Wobeyɛ biako wɔ mpoano anaa biako nso wɔ Aburi Gardens. Nea ewɔ he na wobekɔ na aden ntia?

W'adamfo a wadi dem rebekɔ Senior High School (Ntoaso Sukuu) wobehye no nkuran ma wakɔ Boarding (sukuu a wɔdahɔ) anaa Day (sukuu a wɔkɔ-ne-aba) sukuu na aden ntia?

Appendix I: Coding Scheme for Thematic Analysis

Themes	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15
Perception of CLD															
Retribution for violating social norms										*			*		
Curses and Malevolence	*					*									
Act of God									*	*			*		
Biomedical causation		*	*						*						
Lifestyle choices						*					*				
Experience of CLD															
Physical challenges	*	*						*	*	*	*		*	*	
Financial constraints	*		*			*	*		*	*	*		*	*	*
Negative emotions	*		*			*			*				*		*
Stigma-related issues		*				*			*	*	*		*		*
Exploitation	*	*									*				
Response to experience of CLD															
Coping strategies	*	*	*	*		*		*	*	*	*	*		*	**
Social support	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
Positive emotions	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
Self-determination	*	*	*	*	*	*	*	*	*	*	*	*	*	*	*
Outcome of response to experience of CLD															
Fulfilling social roles	*		*		*	*			*	*		*			*

Appendix J: SPSS Output

T-Test

	Group Statistics				
	AMPUTEE/NON-AMPUTEE	N	Mean	Std. Deviation	Std. Error Mean
Total Global Severity Index	AMPUTEE	20	.7068868	.44281375	.09901616
	NON-AMPUTEE	30	.9766981	.40663136	.07424039
Total Body Image Scale	AMPUTEE	20	6.30	6.359	1.422
	NON-AMPUTEE	30	8.03	5.962	1.089
Total Social Support	AMPUTEE	20	61.05	14.802	3.310
	NON-AMPUTEE	30	64.47	15.211	2.777
Total Self-Esteem	AMPUTEE	20	22.60	3.485	.779
	NON-AMPUTEE	30	21.60	4.360	.796
Somatization	AMPUTEE	20	.5264286	.38297552	.08563593
	NON-AMPUTEE	30	.7859524	.54071828	.09872120
Interpersonal Sensitivity	AMPUTEE	20	.8925000	.80489865	.17998081
	NON-AMPUTEE	30	1.4800000	1.01571701	.18544371
Depression	AMPUTEE	20	.3633333	.38340960	.08573299
	NON-AMPUTEE	30	.7938889	.65057200	.11877765
Paranoid Ideation	AMPUTEE	20	1.1350000	.67207456	.15028044
	NON-AMPUTEE	30	1.3583333	.63611609	.11613838

		Independent Samples Test								
		Levene's Test for Equality of Variances			t-test for Equality of Means					
		F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference	
									Lower	Upper
Total Global Severity Index	Equal variances assumed	.591	.446	-2.218	48	.031	-.26981132	.12162613	-.51435704	-.02526560
	Equal variances not assumed			-2.180	38.413	.035	-.26981132	.12375717	-.52025610	-.01936654

Psychological Health of Adolescents with CLD

Total Body Image Scale	Equal variances assumed	.369	.546	-.981	48	.332	-1.733	1.767	-5.287	1.820
	Equal variances not assumed			-.968	39.019	.339	-1.733	1.791	-5.355	1.889
Total Social Support	Equal variances assumed	.278	.600	-.786	48	.435	-3.417	4.345	-12.152	5.319
	Equal variances not assumed			-.791	41.645	.434	-3.417	4.321	-12.138	5.305
Total Self-Esteem	Equal variances assumed	.458	.502	.858	48	.395	1.000	1.165	-1.343	3.343
	Equal variances not assumed			.898	46.303	.374	1.000	1.114	-1.242	3.242
Somatization	Equal variances assumed	3.152	.082	-1.856	48	.070	-.25952381	.13985140	-.54071389	.02166627
	Equal variances not assumed			-1.986	47.775	.053	-.25952381	.13068813	-.52232185	.00327423
Interpersonal Sensitivity	Equal variances assumed	1.428	.238	-2.170	48	.035	-.58750000	.27076321	-1.13190593	-.04309407
	Equal variances not assumed			-2.273	46.454	.028	-.58750000	.25842303	-1.10754149	-.06745851

Psychological Health of Adolescents with CLD

Depression	Equal variance assumed	6.100	.017	-2.662	48	.011	-.4305556	.16173500	-.75574557	-.10536554
	Equal variance not assumed			-2.939	47.436	.005	-.4305556	.14648644	-.72517670	-.13593441
Paranoid Ideation	Equal variance assumed	.016	.900	-1.189	48	.240	-.2233333	.18780839	-.60094741	.15428074
	Equal variance not assumed			-1.176	39.290	.247	-.2233333	.18992718	-.60740660	.16073994

Correlations

Descriptive Statistics

	Mean	Std. Deviation	N
Total Global Severity Index	.8687736	.43785882	50
Total Body Image Scale	7.34	6.120	50
Total Social Support	63.10	14.991	50
Social support from Family	21.54	6.319	50
Social support from Friends	19.08	6.474	50
Social support from Significant others	22.48	5.912	50
Total Self-Esteem	22.00	4.025	50

Correlations

		Total Global Severity Index	Total Body Image Scale	Total Social Support	Social support from Family	Social support from Friends	Social support from Significant others	Total Self-Esteem
Total Global Severity Index	Pearson Correlation	1	.515**	-.026	-.129	-.078	.158	.012

Psychological Health of Adolescents with CLD

	Sig. (2-tailed)		.000	.858	.370	.591	.274	.934
	N	50	50	50	50	50	50	50
Total Body Image Scale	Pearson Correlation	.515**	1	-.115	-.207	-.086	.024	-.259
	Sig. (2-tailed)	.000		.427	.149	.554	.871	.069
	N	50	50	50	50	50	50	50
Total Social Support	Pearson Correlation	-.026	-.115	1	.768**	.750**	.894**	.281*
	Sig. (2-tailed)	.858	.427		.000	.000	.000	.048
	N	50	50	50	50	50	50	50
Social support from Family	Pearson Correlation	-.129	-.207	.768**	1	.238	.618**	.234
	Sig. (2-tailed)	.370	.149	.000		.096	.000	.102
	N	50	50	50	50	50	50	50
Social support from Friends	Pearson Correlation	-.078	-.086	.750**	.238	1	.553**	.181
	Sig. (2-tailed)	.591	.554	.000	.096		.000	.209
	N	50	50	50	50	50	50	50
Social support from Significant others	Pearson Correlation	.158	.024	.894**	.618**	.553**	1	.265
	Sig. (2-tailed)	.274	.871	.000	.000	.000		.063
	N	50	50	50	50	50	50	50
Total Self-Esteem	Pearson Correlation	.012	-.259	.281*	.234	.181	.265	1
	Sig. (2-tailed)	.934	.069	.048	.102	.209	.063	
	N	50	50	50	50	50	50	50

** . Correlation is significant at the 0.01 level (2-tailed).

* . Correlation is significant at the 0.05 level (2-tailed).

Regression

Descriptive Statistics

Psychological Health of Adolescents with CLD

	Mean	Std. Deviation	N
Total Global Severity Index	.8687736	.43785882	50
Social support from Family	21.54	6.319	50
Social support from Friends	19.08	6.474	50
Social support from Significant others	22.48	5.912	50

Model Summary^b

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	Change Statistics				Sig. F Change	Durbin-Watson
					R Square Change	F Change	df1	df2		
1	.411 ^a	.169	.115	.41196003	.169	3.118	3	46	.035	1.664

a. Predictors: (Constant), Social support from Significant others, Social support from Friends, Social support from Family

b. Dependent Variable: Total Global Severity Index

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	1.588	3	.529	3.118	.035 ^b
	Residual	7.807	46	.170		
	Total	9.394	49			

a. Dependent Variable: Total Global Severity Index

b. Predictors: (Constant), Social support from Significant others, Social support from Friends, Social support from Family

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients Beta	t	Sig.	95.0% Confidence Interval for B		Correlations		
		B	Std. Error				Lower Bound	Upper Bound	Zero-order	Partial	Part
1	(Constant)	.911	.255		3.570	.001	.397	1.425			
	Social support from Family	-.029	.012	-.417	-2.410	.020	-.053	-.005	-.129	-.335	-.324
	Social support from Friends	-.020	.011	-.300	-1.837	.073	-.043	.002	-.078	-.261	-.247

Psychological Health of Adolescents with CLD

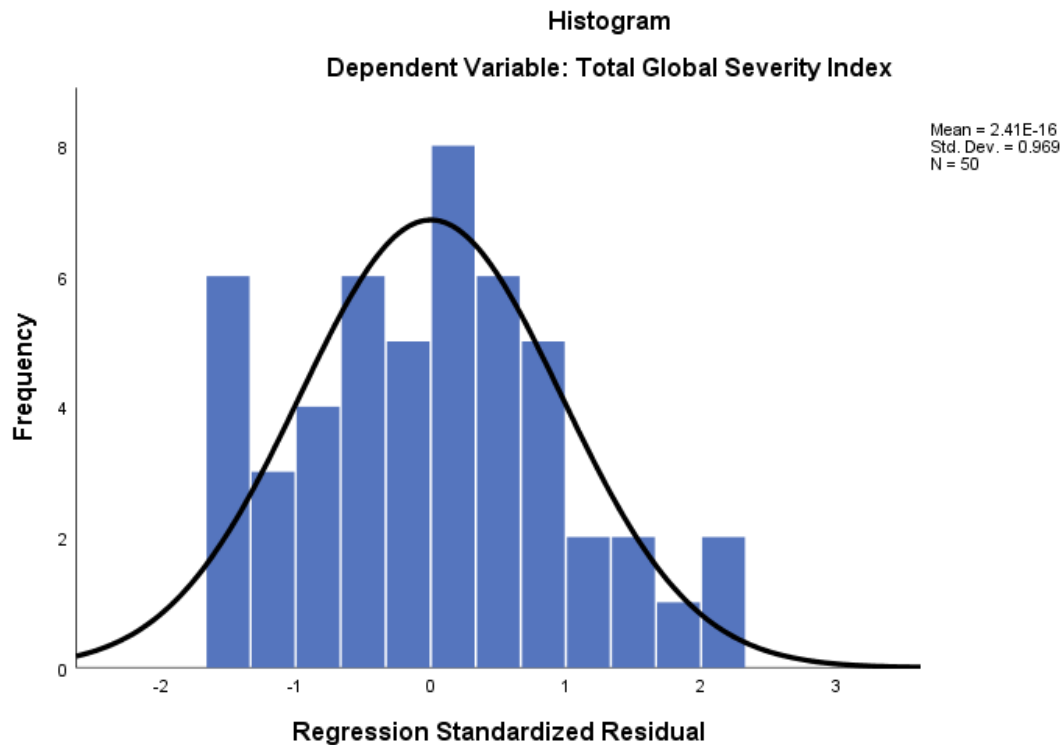
Social support from Significant others	.043	.015	.581	2.880	.006	.013	.073	.158	.391	.387
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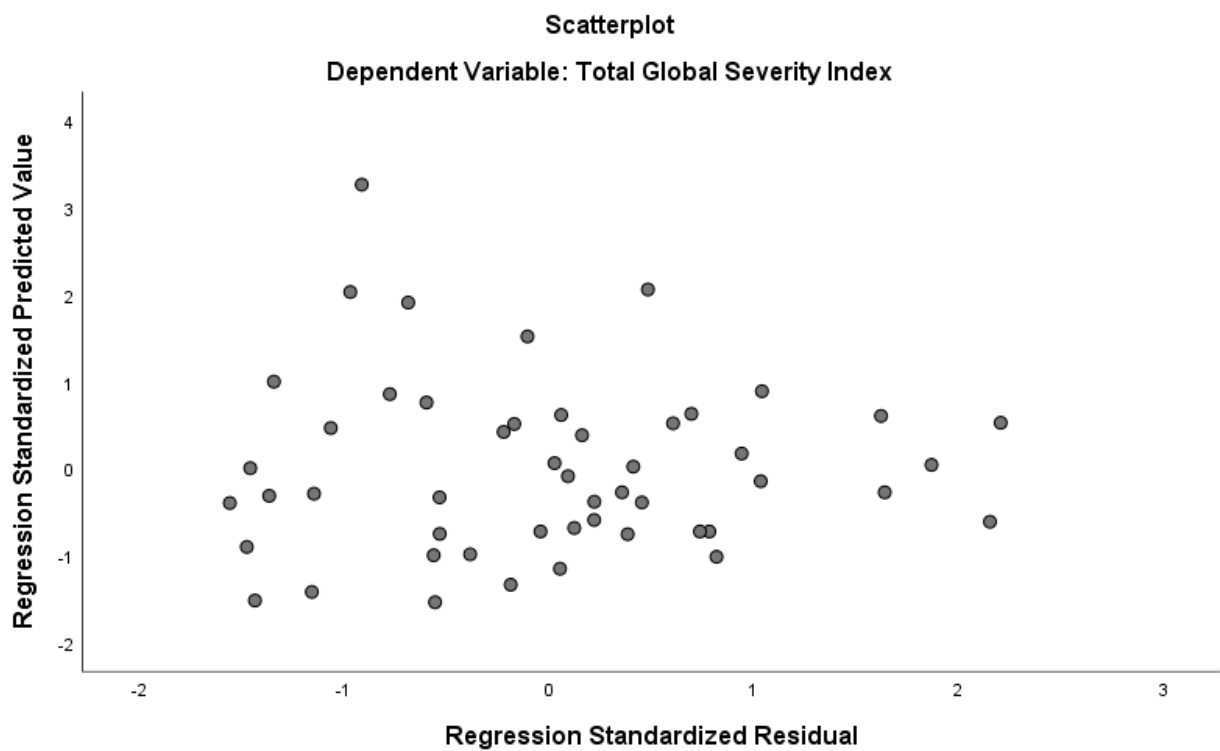
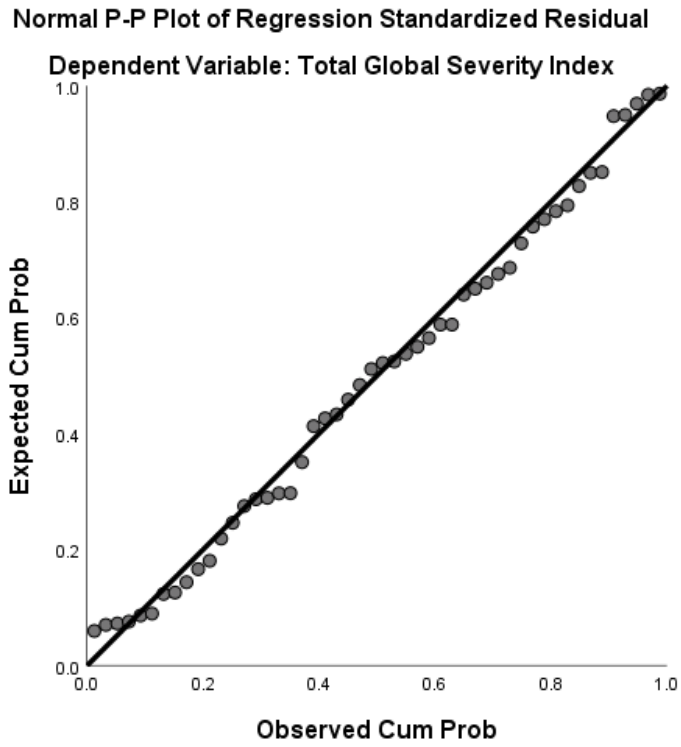
a. Dependent Variable: Total Global Severity Index

Residuals Statistics ^a					
	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	.5921573	1.4565798	.8687736	.17999931	50
Residual	-.64172816	.90919399	.00000000	.39914984	50
Std. Predicted Value	-1.537	3.266	.000	1.000	50
Std. Residual	-1.558	2.207	.000	.969	50

a. Dependent Variable: Total Global Severity Index

Charts





Regression

Descriptive Statistics

	Mean	Std. Deviation	N
Total Global Severity Index	.8687736	.43785882	50
Distraction Frequency	1.64	.942	50
Social Withdrawal Frequency	1.08	.966	50
Cognitive Reframing Frequency	1.92	.966	50
Self Blame Frequency	.40	.700	50
Blaming Others Frequency	.42	.883	50
Problem Solving Frequency	1.44	1.053	50
Negative Emotional Regulation Frequency	.58	.950	50
Positive Emotional Regulation Frequency	1.92	1.007	50
Wishful Thinking Frequency	1.42	1.090	50
Social Support Frequency	1.46	1.034	50
Resignation Frequency	1.48	1.111	50

Model Summary^b

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change	Change Statistics			Sig. F Change	Durbin-Watson
						F Change	df1	df2		
1	.616 ^a	.380	.200	.39165862	.380	2.113	11	38	.043	1.064

a. Predictors: (Constant), Resignation Frequency, Distraction Frequency, Cognitive Reframing Frequency, Social Withdrawal Frequency, Negative Emotional Regulation Frequency, Positive Emotional Regulation Frequency, Blaming Others Frequency, Self Blame Frequency, Wishful Thinking Frequency, Problem Solving Frequency, Social Support Frequency

b. Dependent Variable: Total Global Severity Index

ANOVA^a

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	3.565	11	.324	2.113	.043 ^b
	Residual	5.829	38	.153		
	Total	9.394	49			

a. Dependent Variable: Total Global Severity Index

Psychological Health of Adolescents with CLD

b. Predictors: (Constant), Resignation Frequency, Distraction Frequency, Cognitive Reframing Frequency, Social Withdrawal Frequency , Negative Emotional Regulation Frequency, Positive Emotional Regulation Frequency, Blaming Others Frequency, Self Blame Frequency, Wishful Thinking Frequency, Problem Solving Frequency, Social Support Frequency

		Coefficients ^a									
		Unstandardized Coefficients		Standardized Coefficients		95.0% Confidence Interval for B		Correlations			
Model		B	Std. Error	Beta	t	Sig.	Lower Bound	Upper Bound	Zero-order	Partial	Part
1	(Constant)	.830	.248		3.350	.002	.329	1.332			
	Distraction Frequency	-.008	.065	-.017	-.122	.903	-.141	.125	.083	-.020	-.016
	Social Withdrawal Frequency	.079	.070	.175	1.142	.261	-.061	.220	.210	.182	.146
	Cognitive Reframing Frequency	.000	.067	.000	-.002	.999	-.135	.135	.016	.000	.000
	Self Blame Frequency	-.082	.093	-.131	-.885	.382	-.270	.106	.016	-.142	-.113
	Blaming Others Frequency	.099	.070	.200	1.413	.166	-.043	.242	.107	.223	.181
	Problem Solving Frequency	.008	.063	.020	.131	.897	-.119	.136	.073	.021	.017
	Negative Emotional Regulation Frequency	.216	.069	.469	3.130	.003	.076	.356	.361	.453	.400
	Positive Emotional Regulation Frequency	-.033	.062	-.077	-.535	.596	-.160	.093	-.064	-.086	-.068
	Wishful Thinking Frequency	.084	.059	.209	1.436	.159	-.034	.203	.198	.227	.184

Psychological Health of Adolescents with CLD

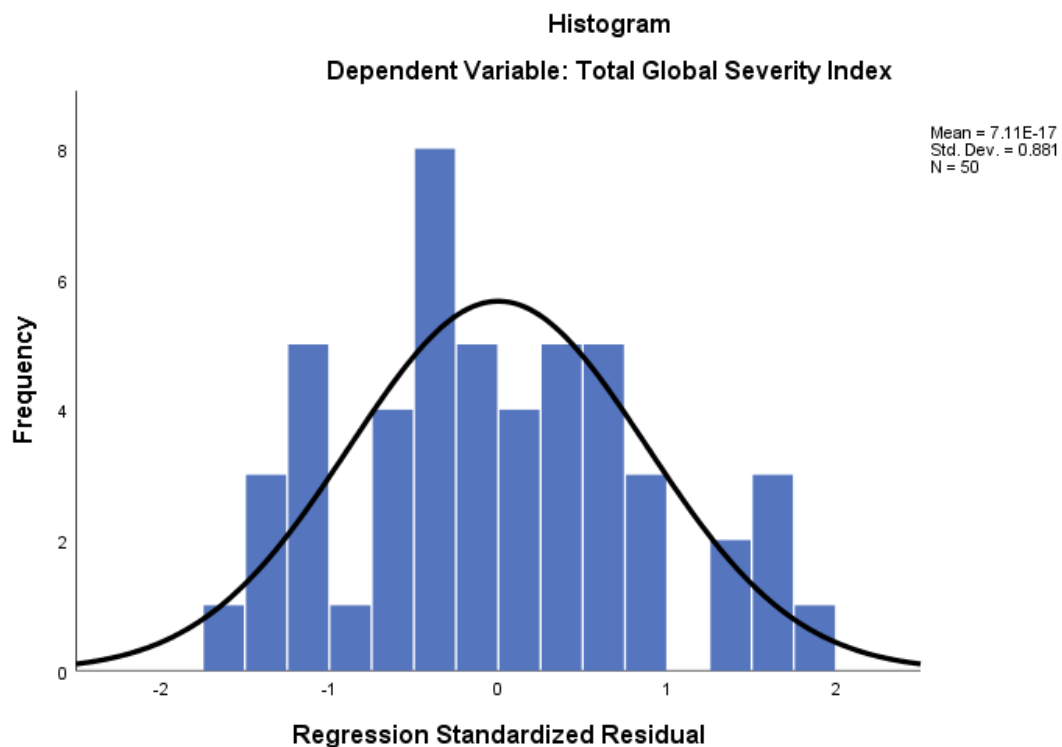
Social Support	-.159	.065	-.376	-	.019	-.290	-.028	-.286	-.370	-.314
Frequency				2.456						
Resignition	-.002	.059	-.005	-.033	.974	-.121	.117	-.032	-.005	-.004
Frequency										

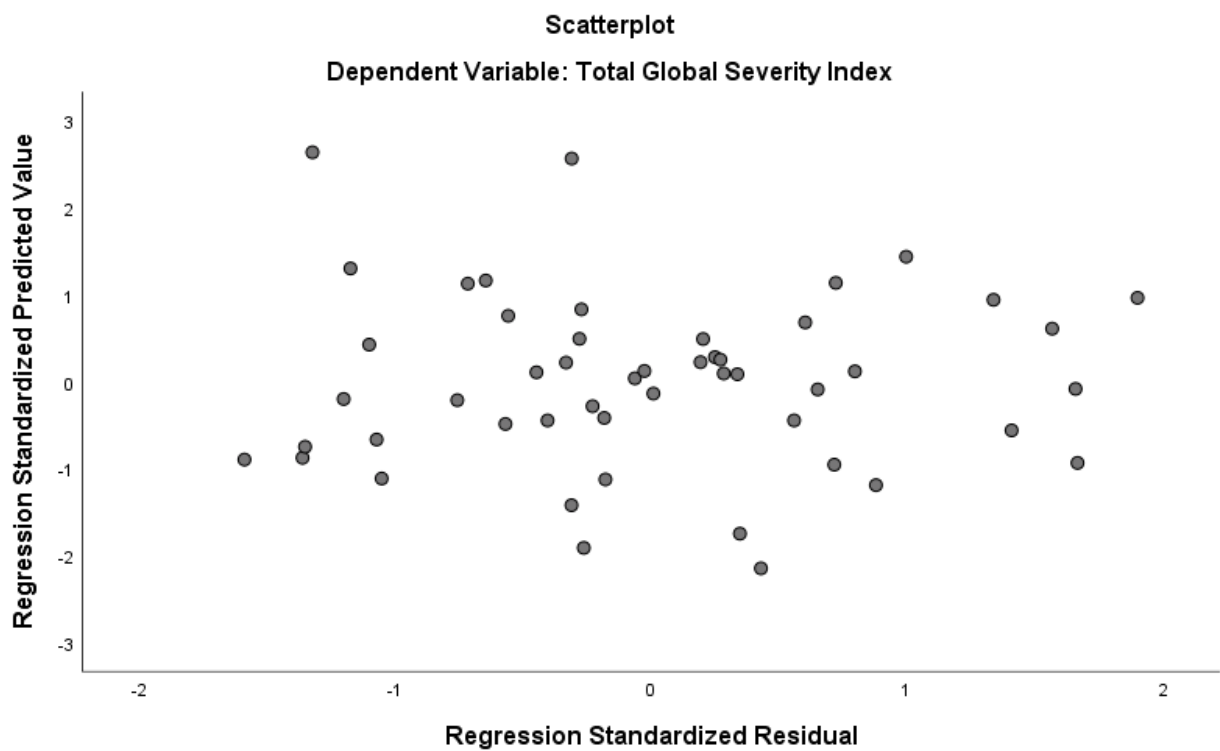
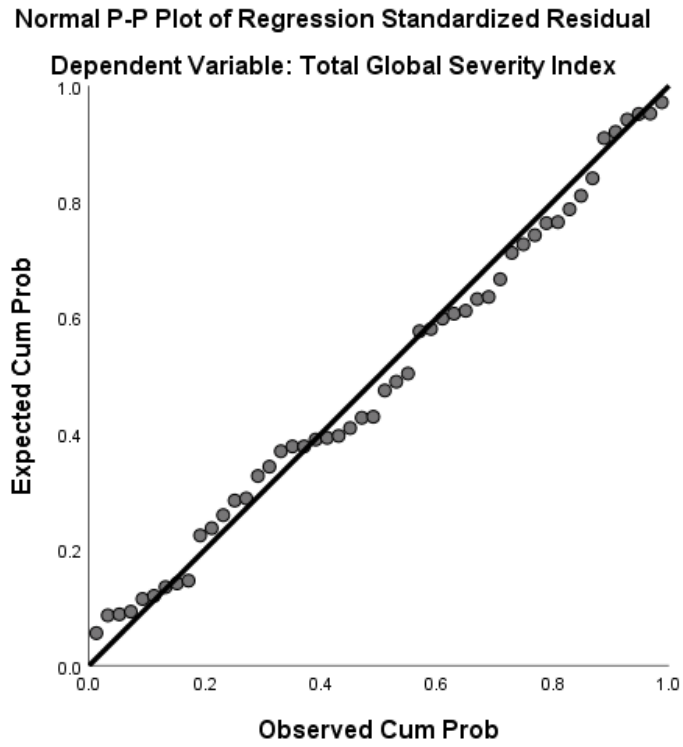
a. Dependent Variable: Total Global Severity Index

	Minimum	Maximum	Mean	Std. Deviation	N
Predicted Value	.2896824	1.5798361	.8687736	.26974027	50
Residual	-.62225217	.74409837	.00000000	.34490656	50
Std. Predicted Value	-2.147	2.636	.000	1.000	50
Std. Residual	-1.589	1.900	.000	.881	50

a. Dependent Variable: Total Global Severity Index

Charts





T-Test

Group Statistics					
	Age_group1	N	Mean	Std. Deviation	Std. Error Mean
Distraction Frequency	10-16	32	1.94	.982	.174
	17-24	18	1.11	.583	.137
Social Withdrawal Frequency	10-16	32	.97	.933	.165
	17-24	18	1.28	1.018	.240
Cognitive Reframing Frequency	10-16	32	1.88	.942	.166
	17-24	18	2.00	1.029	.243
Self Blame Frequency	10-16	32	.47	.803	.142
	17-24	18	.28	.461	.109
Blaming Others Frequency	10-16	32	.47	.983	.174
	17-24	18	.33	.686	.162
Problem Solving Frequency	10-16	32	1.31	1.030	.182
	17-24	18	1.67	1.085	.256
Negative Emotional Regulation Frequency	10-16	32	.69	.998	.176
	17-24	18	.39	.850	.200
Positive Emotional Regulation Frequency	10-16	32	1.69	.931	.165
	17-24	18	2.33	1.029	.243
Wishful Thinking Frequency	10-16	32	1.47	1.047	.185
	17-24	18	1.33	1.188	.280
Social Support Frequency	10-16	32	1.63	1.008	.178
	17-24	18	1.17	1.043	.246
Resignation Frequency	10-16	32	1.38	1.070	.189
	17-24	18	1.67	1.188	.280

Independent Samples Test									
Levene's Test for Equality of Variances				t-test for Equality of Means					
F	Sig.	t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference		
							Lower	Upper	

Psychological Health of Adolescents with CLD

Distraction Frequency	Equal variances assumed	8.074	.007	3.255	48	.002	.826	.254	.316	1.337
	Equal variances not assumed			3.733	47.797	.001	.826	.221	.381	1.271
Social Withdrawal Frequency	Equal variances assumed	.664	.419	-1.088	48	.282	-.309	.284	-.880	.262
	Equal variances not assumed			-1.062	32.836	.296	-.309	.291	-.901	.283
Cognitive Reframing Frequency	Equal variances assumed	.000	.983	-.436	48	.665	-.125	.287	-.702	.452
	Equal variances not assumed			-.425	32.804	.674	-.125	.294	-.724	.474
Self Blame Frequency	Equal variances assumed	4.430	.041	.925	48	.360	.191	.207	-.224	.606
	Equal variances not assumed			1.069	47.950	.291	.191	.179	-.168	.550
Blaming Others Frequency	Equal variances assumed	1.585	.214	.517	48	.608	.135	.262	-.391	.662
	Equal variances not assumed			.570	45.599	.571	.135	.237	-.343	.613
Problem Solving Frequency	Equal variances assumed	.126	.724	-1.145	48	.258	-.354	.309	-.976	.268
	Equal variances not assumed			-1.128	33.839	.267	-.354	.314	-.992	.284

Psychological Health of Adolescents with CLD

Negative Emotional Regulation Frequency	Equal variances assumed	2.768	.103	1.069	48	.290	.299	.279	-.263	.860
	Equal variances not assumed			1.119	40.304	.270	.299	.267	-.241	.838
Positive Emotional Regulation Frequency	Equal variances assumed	.094	.760	- 2.267	48	.028	-.646	.285	-1.219	-.073
	Equal variances not assumed			- 2.203	32.486	.035	-.646	.293	-1.243	-.049
Wishful Thinking Frequency	Equal variances assumed	.799	.376	.418	48	.678	.135	.324	-.516	.786
	Equal variances not assumed			.403	31.764	.689	.135	.336	-.549	.819
Social Support Frequency	Equal variances assumed	.029	.866	1.524	48	.134	.458	.301	-.146	1.063
	Equal variances not assumed			1.509	34.351	.140	.458	.304	-.159	1.075
Resignation Frequency	Equal variances assumed	.682	.413	-.889	48	.378	-.292	.328	-.951	.368
	Equal variances not assumed			-.863	32.358	.394	-.292	.338	-.980	.396