

**A Case Study of the Social Coping Experiences of an Adolescent with
Arthrogryposis Multiplex Congenita**

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KEYWORDS

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ABSTRACT

A CASE STUDY OF THE SOCIAL COPING EXPERIENCES OF AN ADOLESCENT WITH ARTHROGRYPOSIS MULTIPLEX CONGENITA

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Arthrogryposis multiplex congenita or A.M.C. is a disorder, which is characterized by multiple contractures of the joints. The disorder presents with varied grades of severity. Despite the physical deformities, intelligence is intact. The aim of this research was to explore the social coping experiences of an adolescent living with Arthrogryposis. This research was a qualitative study. The research design was a case study. Phenomenology was the theoretical framework used. The data collection was done by using one sample, an adolescent living with Arthrogryposis who shared her social coping experiences. Thematic analysis was used to analyse the data. This research was a personal journey for the researcher because he too lives with Arthrogryposis. Objectivity was maintained. After securing the participant's consent, I emphasized anonymity, confidentiality and the voluntary nature of the study to her. The significance of this research was to develop an understanding of and support for people living with Arthrogryposis and for the disabled in general. The major issues, which arose from this research was the role of transport, social relationships, communication with the non-disabled, the role of the community, making friends, the role of the parent in socialization and others' perceptions of Arthrogryposis. There were limitations to the study, which included interviews, which were partially inaudible, the absence of the participants' father, the shyness of the participant, the social inexperience of the participant, lack of other participants and complications with transportation.

DECLARATION

I.....declare that *A Case Study of the Social Coping Experiences of An Adolescent with Arthrogryposis Multiplex Congenita* is my own work, that has not been submitted before any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.



ACKNOWLEDGEMENTS

First and foremost I wish to thank my Heavenly Father and Lord for guiding me and giving me the strength to persevere until the end of this journey. I want to express my sincerest gratitude towards the participants for their willingness to participate in this study. I also would like to thank my family and friends for their ongoing support during the writing of this thesis.



DEDICATION

I want to dedicate this thesis to my mother, Sophia whose love, strength and support ran like a golden thread throughout my study career.



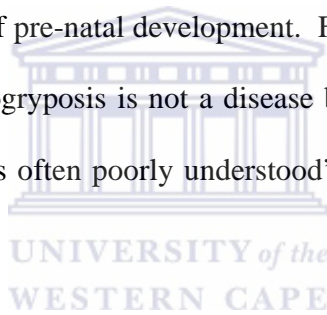
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Chapter 1.

Introduction

As a term, Arthrogyrosis Multiplex Congenita is not familiar to most people. Mostly those living with the condition and medical professionals are familiar with this rare condition. According to Shrouf (1994) the limbs of a person with Arthrogyrosis are fixed in any position and all or some of the joints are involved. This means that the limbs involved might be turned inwards which makes functionality of the limbs difficult. Arthrogyrosis according to O'Flaherty (2001), was initially classified as a disease, however it was later classified as a syndrome affecting the neuro-muscular systems of babies during the fetal stages of pre-natal development. From O'Flaherty's point of view it is therefore clear that Arthrogyrosis is not a disease but a syndrome. Arthrogyrosis therefore "is a condition that is often poorly understood" in terms of its cause" (Fixen, 1999, p.183).



Arthrogyrosis occurs once in 3000 live births. However, the diagnosis needs to be confirmed by a person familiar with Arthrogyrosis (Sells, Jaffe & Hill, 1996). The most common form of Arthrogyrosis, according to Sells, Jaffe & Hill (1996), is Amyoplasia. Important to note is the fact that this condition affects the family and immediate community as well as the person living with the condition. The reason for this is because of the grades of severity of the people affected by this syndrome. According to Fixen (1999), for those living with Arthrogyrosis the condition could be a taxing one. This is not only true for those living with the condition but for those who are responsible for taking care of such individuals as well. This is indicative of the fact that to live with the

condition and to care for those living with it could be challenging. Being part of a mostly non-disabled community could yield its own challenges especially if the intention is to assist the non-disabled community to understand how to deal with Arthrogyrosis. Having social interaction and being amongst non-disabled people could be a challenge in attempting to explain this rare condition to the community especially during the adolescent phase of development.

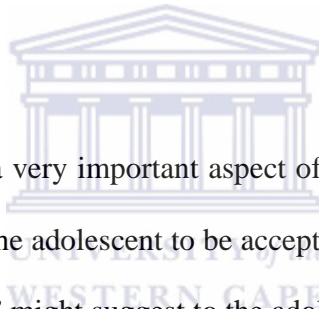
According to Kimmel and Weiner (1995) “adolescence refers to the period of life between childhood and adulthood-roughly corresponding to the teenage years”, (p. 2). Michael Jaffe (1998) defines adolescence by saying that adolescence mean “to grow into adulthood” (p. 19). Relating to Kimmel and Weiner it is therefore evident that a person in the adolescent phase of life is not an adult yet, because they are still in the process of forming an own identity. Gouws, Kruger and Burger (2000) mention that adolescents are still in the process of developing a self in society. It is during this phase where adolescents are probing into who they are. Another aspect of adolescence is the fact that they seek out each other in order to form social relationships. It is therefore important to notice that friendships play an integral part of the development of the adolescent into adulthood. Kimmel and Weiner (1995) use the words “intimate, supportive, loyalty, faithfulness, competition and sharing” to describe what the concept of friendship entails (p. 153). They hereby point out that forming friendships is important for social development to take place. Acceptance and approval are integral parts of the development of the adolescent into adulthood. Gouws, Kruger and Burger (2000)

concede, “acceptance is an important component of love” (p. 69). This illustrates that acceptance of the individual means that the peer group loves her or him.

According to Gouws, Kruger & Burger (2000) it is important for adolescents to form relationships with each other because this enhances the growth of “self-concept and self-actualization” (p. 75) By identifying with others in the same developmental phase, the adolescent is given the opportunity for personal development with others of his or her peer group. Failure to achieve close relationships with peer groups might result in frustration. This might also mean that such adolescents are isolated from peer groups. If this is the case it makes one wonder how adolescents keep track of what they are feeling. According to Sieffge-Krenke (1995) diaries used by adolescents are important because in them, adolescents express feelings and problems that they (adolescents) might harbor. However, these diaries are also used to illustrate the function of friends in addressing these issues. Therefore diary writing could be viewed as an important tool for adolescents to express concerns and issues they might be grappling with.

Being part of a peer or “in-group” is an enhancement of the self-image of adolescents. “As adolescents navigate their social world, close peer relationships offer many protective benefits. Adolescents formulate group alliances to provide psychological support and a sense of belonging. They desire confidants with whom they talk about their personal lives and challenges,” (Hall-Lande, et al., 2007, p. 266). Therefore validation of the individual plays an integral part of the interaction of adolescents with each other as illustrated by Hall-Lande (2007). Adams, Gullotta and Markstrom-Adams (1994) suggest

that the sense of self is viewed as a strong motive. For some adolescents life might not be that simple. Social isolation might be a trigger to exclusion from peer groups. Not having a social life during adolescence could be very hurtful (Hall-Lande, et al., 2007). This in turn could be a precursor to states such as depression. Adams, Gullotta and Markstrom-Adams (1994) mention that if adolescents do not have the personal support from peers it might lead to depression. Therefore it is important to note that adolescents might have profound effects on each others' self-esteem. From a broader perspective it is evident that adolescent peer groups depend on each other for the emotional need of acceptance and support. The above literature suggests that without these constructs adolescents' self-image could suffer.



Social interaction therefore is a very important aspect of the adolescents' life. As earlier mentioned it is imperative for the adolescent to be accepted by his/her peers. Coping with not being part of the "in-group" might suggest to the adolescent that he or she is not good enough to be included in these groups. Coping and the manner in which stressors are handled are important to the adolescent. To cope many adolescents depend on the social relations that they have with others of the same age. This brings to the fore the role of coping and its importance to adolescents. According to Snyder and Mann Pulvers (2001) in Snyder (2001) "coping reflects thinking, feeling, or acting so as to preserve a satisfied psychological state when it is threatened," (p. 4). Therefore it is important to note that modern day stressors encountered by adolescents are combated by the interaction with each other.

Having social interaction is an important aspect in the life of the adolescent. It is a way of connecting with others who are in the same developmental phase as themselves. Sharing their experiences with each other is a way of making a social connection. Another consideration are the influences peer groups have on attitudes, values and behavior (Hopkins, 1983). It is possible or likely that having Arthrogyryposis can change the experience.

1.1 Aim of Research

As a result of the nature of the condition, those living with Arthrogyryposis will present with different grades of severities. The assumption could therefore be made that not all who live with the condition would have the same social experiences, as the grade of severities of the condition differ from one person to another.

This study aims to explore the social coping experience of an adolescent with Arthrogyryposis Multiplex Congenita. It seeks to create awareness about Arthrogyryposis because it is a rare condition. This study will be significant to those who are living with Arthrogyryposis. It is a personal journey, because I, the researcher, am living with the same condition. It will be of benefit to me, as this research will allow others to share their experiences with me. My own (social) experiences might differ from others of the same condition because I am not severely affected by this condition. The other significance of this research is to develop an understanding and social support for the individual with Arthrogyryposis and for the disabled as a whole.

Chapter 2.

Literature Review

The literature in this study is dated and the reason this is so is because no recent studies had been conducted on Arthrogyrosis. The following vignette is an extract from Marjory, Major, Meyer, Peter & People (1994) about an adolescent named Bong Delrossario who is affected by Arthrogyrosis:

“Hormones raging and pick-up lines compete as the two dudes inspect the school girls on Baltimore’s Roling Road. Like many other kids his age, Bong Delrosario, 17, wears the requisite badges of coolness-two small earrings in his left ear, and a Guess? Wristwatch with silver band. And like many of the local teens, he spends his free time at the Owings Mill Mall with his best pal, Donnell Green, also 17. There is a never-ending competition. ‘We can’t even count the arguments we’ve been in over girls’, says Bong. Concedes Donnell: ‘He’s not shy. I’m shy. He’d go up to girls and come back with phone numbers’. Bong had been crippled and virtually paralyzed by Arthrogyrosis, a condition that freezes the joints”, (Marjory, et al., 1994, p. 66). Bong is unable to walk and is therefore dependant on his motorized wheelchair.

Bong’s story is a reflection of an adolescent who displays the behavior of that of any other adolescent. The only difference between Bong and other adolescents is the fact that he is physically handicapped and lives with the rare condition Arthrogyrosis. Like others of his peer group, he likes spending time in the local mall with his friend. His disability does not prevent him from the pleasure of enjoying social interaction. The girls

that he encounters seem to enjoy his company and are willing to exchange telephone numbers with him.

From Bongs' story, it is evident that he is unable to walk by himself and is therefore dependent on his motorized wheelchair. Judging from the above vignette, it is clear that Bong is severely affected by this rare condition.

2.1 Personality

The concept of personality especially in the psychological sense has been written about many times. Many psychologists explained the concept and there exist much literature about it. The concept of personality tells us who we are and where we stand in the world and amongst our peers. Bongs' story illustrates that personality plays an integral part of the way in which adolescents function with each other. He displays self-confidence and comfort with who he is. The mere fact that he is able to obtain the telephone numbers of the girls at the mall bears testimony to his good sense of self.

Personality plays an important role in the success of adolescents in their social environment. Mischel (1993) defines personality as, "the distinct patterns of behavior (including thoughts and emotions) that characterizes each individual's adaptation to the situations of his or her life", (p. 5). The definition by Mischel illustrates that personality plays an integral role in the way individuals come to terms with their world. It is therefore important to note that adolescents are no different. According to Mischel (1993), "the organism in the course of actualizing itself engages in a valuing process" (p. 238). Therefore one could argue that adolescents are in the process of coming to terms

with who they are. They might also ask questions like, ‘who am I?’, and ‘what is my role in this life?’. These questions might influence the self-regard (Mischel, 1993) of the individual either positively or negatively.

Adolescents, as mentioned earlier, rely on the feedback that they receive from their peers. Mischel (1993) concedes that the need for positive regard “develops as the awareness of the self emerges and leads the person to desire acceptance and love from the important people in his life” (p. 240). The above statement by Mischel, illustrates that adolescents have the need to feel accepted by their peers. Acceptance by others of the same age group plays an important role in how individuals view themselves. Therefore the tendency to measure up to others becomes important to some adolescents because this will become a yardstick to how they ‘weigh up’ to their peers. Meuller (1994) admits that the adolescent phase is a difficult one. He also suggests that to try and be like other adolescents and act as other do is one of the difficulties of being an adolescent. This pressure referred to by Meuller is not an uncommon phenomenon in life.

Peer pressure could have a negative or positive effect on an adolescent. Because of the physical difficulties and nature of Arthrogryposis, the seriously affected adolescent might not be able to engage for example in activities suggested by peers and will therefore not succumb to peer pressure. What then will happen with the adolescent whose isolation stems from rejection by his/her peer group? Mischel (1993) mentioned that adjustment which might be critical to the development of the personality.

Being withdrawn from others in the same peer group, might lead to loneliness and isolation. In addition to the physical challenges of social interaction, being shy could have a negative effect on the social interaction of the adolescent with Arthrogyrosis. According to Kimmel and Weiner (1995), “shyness is defined by a pattern of social anxiety and interpersonal inhibition arising in situations that raise the prospect of being evaluated by others”, (p. 318). Anxiety about being evaluated by others might be a catalyst for isolation from adolescent social activities. The adolescent with Arthrogyrosis could be developing a shy personality, in order to protect him/herself against the evaluation by others. It is important to note that disabled adolescents may isolate themselves because of the attitudes displayed towards them by their peers. Thomas (1982) mentions that attitude means the way people think about others. According to Shrout (1994), some parents keep their (disabled) children from venturing into the outside world to protect them from emotional (and perhaps physical) harm by other children. This protection against other children might be a factor in the development of the personality of the adolescent with Arthrogyrosis.

One could also argue that the personality of the adolescent may be influenced by pre-conceived ideas about what others in their peer groups *might* be thinking about them. According to Nichols, Haworth and Hopkins (1981) support for engaging in social interaction with peers is of vital importance for non-disabled adolescents to get to know those adolescents with Arthrogyrosis. Ham, Aldersea and Porter (1998) suggest in their research with wheelchair users that an individuals’ personality could affect other peoples’ reaction to their disability and could subsequently hamper social interactions. The above-

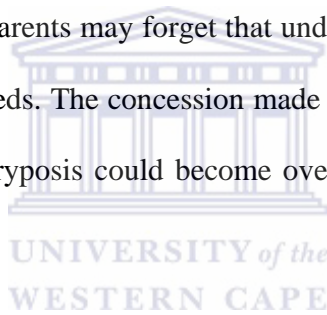
mentioned researchers also concede that disabled people react differently to their disabilities. Therefore the adolescent with Arthrogyrosis may or may not view the severity of his/her condition as an obstacle to have social contact with peers.

2.2 Parental Roles

The parents of adolescents play a very important role in the social development of their children. Palmer (1993) mentions that parents are “providers of direct physical care” as well as “comforters and supporters” in their role of looking after their sick children (p.187). Parents of adolescents living with Arthrogyrosis are no different. According to Read (2000), mothers find it difficult to go out into the outside world with their disabled children. There are many challenges that face such parents, and the rearing of adolescents living with Arthrogyrosis could be quite taxing. Oliver and Sapey (2006) concede that assisting in the practical aspects of rearing a disabled child is more important than the ‘emotional reactions’ to their child’s disability (p. 96). It is assumed that by then the parents have learned what the physical need(s) of their adolescent children are. The importance about social needs becomes critical. It is during the period of adolescence that parental guidance is vital. Encouragement by the parents of adolescents with A.M.C., to have social interaction with other adolescents, is important.

Parents of adolescents with Arthrogyrosis play an integral part in the formation of the self-concept of such adolescents. Parental influence could either sway self-concept in a negative or positive direction. Often the parents of adolescents with Arthrogyrosis could be over protective of their children. As mentioned earlier, some parents may be

concerned that their adolescent children may be judged by their peers. Parents of the affected adolescent keep an “eye on their adolescent” as other non-disabled children are not aware of the complexities of the condition. The general assumption is that non-disabled children do not know for example that some children with Arthrogyrosis need walking aids to walk, because important muscle groups, which would help them to walk, did not develop properly. Another example is that non-disabled children might not understand that children with Arthrogyrosis might get injured when knocked down because reflexes which would prevent them from falling did not develop either, hence the parents’ over protectiveness. David Luterman (1987) concedes that by being overprotective, a deaf child’s parents may forget that underneath the disability there is an individual with his/her own needs. The concession made by Luterman, is that the parents of an adolescent with Arthrogyrosis could become over protective with regards to the social side of their child’s life.



Over protection could become problematic for the adolescent with Arthrogyrosis in his or her social life. This in turn could precipitate frustration of the adolescent towards his or her parents because of their (the parents’) interference. By being over involved the adolescent with Arthrogyrosis might feel that his or her parents are jeopardizing their sense of independence. However, it needs to be taken into consideration that the severities of Arthrogyrosis differ and not every adolescent with Arthrogyrosis will have the same experiences.

As the child with Arthrogyriposis reaches adolescence, he or she might express the wish to have social interaction with peer groups, without the assistance of his/her parents. It is evident that parenting and in particular the way thereof is very important. According to Bern (1997) being a parent means more than just looking after the physical well being of the child. Therefore parents are responsible for the psychological well being of their children and as well. According to Bern (1997) "parenting styles are usually described in terms of major dimensions or degrees: authoritative (democratic), authoritarian (parent-centered), or permissive (child-centered); warm versus hostile; and demanding-controlling versus accepting-responsive," (p. 152). The parenting styles identified by Bern could have an effect on the social coping experience of the adolescent with Arthrogyriposis. If the parent is too authoritarian, the adolescent with Arthrogyriposis could find it difficult to be socially active with peer groups. The reason for such parenting might be anxiety that something might happen to the adolescent while in the company of peers. This is not only so for non-disabled children and adolescents, but for those with Arthrogyriposis as well. According to Berns (1997) it could be a very difficult task for parents when deciding how they are going to rear their children. This could not be truer than for the parents of an adolescent with Arthrogyriposis. This is because of the fact that adolescents with Arthrogyriposis have such diverse needs- therefore their physical needs vary. It would even be more difficult to parent an adolescent with Arthrogyriposis in the case of a single parent home.

As mentioned earlier, the severity of Arthrogyriposis might vary from person to person. According to Sells, et al. (1996) adolescents with Arthrogyriposis are living at home

because they (the patients with Arthrogyrosis) still need assistance with daily activities. Through their encouragement, the parent(s) of an adolescent with Arthrogyrosis could lay a good foundation for positive social experiences with peer groups. Therefore encouragement could have a major influence on the social independence of the adolescent with Arthrogyrosis.

2.3 Public Perception

Public perception about Arthrogyrosis is another factor, which may or may not impede the social interaction of the affected adolescent. As a result of the nature of the syndrome, the person living with Arthrogyrosis may presents with hands, which are in flexion. This means that the affected person's hands are in a fixed position - bent either inwards or outwards. Because of this, it is complex for the non-disabled person to comprehend the nature of the syndrome and would prompt questions such as, 'why are your hands like that?' or 'what happened to your hands?' These types of questions indicate the fact that the non-disabled adolescent is curious about the condition, however does not want to appear insensitive in posing such direct questions and in so-doing cause emotional harm to the affected adolescent.

Morgan (1987) argues that children with disabilities are perceived as "different" in the community (p. 15). When other non-disabled members of society perceive adolescents with Arthrogyrosis as "different", it could become problematic for the affected adolescent to socialize. Because adolescents with Arthrogyrosis are perceived as "different" the risk is that such adolescents might be socially excluded (Casas, 2007).

Through “social exclusion” (Casas, 2007) it might suggest to adolescents with Arthrogyrosis that other non-disabled peers don’t view them as good enough to interact with socially (p.463).

In her book, ‘Abuse and Neglect of Handicapped Children’ Sharon Morgan (1987) gives utilitarianism as one of the reasons why children with disabilities were abused and murdered in ancient societies. According to Morgan (1987) “utilitarianism was based totally on a societal group’s practical needs and ability to survive. If children were born with conditions so disabling that they required life-long care by somebody in the group, then those children were seen as a liability to the society,” (p. 16).

The above quotation from Morgan’s (1987) book is an illustration of the perception that society had about what disability meant. Diamond and Huang (2005) for example mentioned, “children’s ideas about peers with disabilities are related to their parent’s beliefs about people with disabilities” (p. 40). Therefore parents of non-disabled children could either teach their children healthy virtues about people with disabilities, or they could install negative stereotypes about the disabled. Of course society is not as harsh with disabled children today, however there are members of the non-disabled society who have distorted perceptions about what it means to have a disability. This could not be truer with regards to these people’s perceptions of those adolescents living with Arthrogyrosis. Stephanie Takemoto in Hans and Patri (2003) relates to her own struggle to make friends and relationships because of the fact that she has spinal arthritis. She explains that because of her disability she was afraid that men, for example would judge her on the grounds of her disability and not on who she was. Therefore her rejecting

personality made it impossible for her to create relationships and in doing so dispel the myths that the disabled are incapable of socializing. Perhaps as a result of their ignorance about disability in general, members of the non-disabled community may also link physical disability with mental disability even though the intelligence of the adolescent living with Arthrogyrosis is in tact.

According to Morgan (1987) normality is a concept, meaning that it does not deviate from the norm. Therefore often people with disabilities, those with Arthrogyrosis included are deemed 'abnormal', because of public perceptions about the condition. However, Morgan (1987) is adamant that disabilities and deformities are phenomena, which exist since time immemorial.

Morris (1993) mentioned the concept of "community care" and the question of whether the disabled should be encouraged to live independently or should be 'looked after by their respective communities, i.e. the concept of independence plays a role (p. 5). However, Mark Drinkwater (2009) warns that through their attitudes the community might also affect the progress of the disabled. The main onus therefore is on the concept of independence and the ability to care for oneself. According to Morris (1993) to be independent means to have the ability to address ones own needs thereby effectively taking care of one-self.

Being independent in the sense Morris has described could vary from person to person affected by Arthrogryposis. There are those who are more severely affected by the condition than others. This means that physical dependence would differ because of the fact that the physical needs of those affected are different. This is true for the disabled community at large. As a result, some members of the non-disabled society perceive the disabled members of society as having a chronic need for help.

Assistance is one concept that evokes different responses from the non-disabled public. The question centers on whether to help, or not to help. Giving assistance to the disabled might reinforce the perception that the disabled, including those with Arthrogryposis are unable to sustain an independent way of living. Morris (1993) mentioned that while some disabled people would not want to be assisted even by those closest to them, other disabled people would welcome assistance. These attitudes may stem from the sense that assistance will infringe on the adolescents' sense of independence. Some might feel that their own capabilities are sufficient to help in daily activities or socialization, while others would welcome assistance from the non-disabled members of society.

Social exclusion is one factor that is a very real prospect for the adolescent with Arthrogryposis. Read (2000) says that words such as 'degrade', 'depreciation' and 'omission' could have a major effect on the social relations of those adolescents affected by Arthrogryposis. By being excluded the adolescent with Arthrogryposis might experience a devaluation of his or her self-worth as well as the ability to have social interaction. The above mentioned constructs could have an adverse effect on how the

adolescent with Arthrogyrosis (and other physical disabilities) weigh themselves up to those who are not disabled. It might also foster the notion that the social views of the disabled are not important. “One problem about such misunderstandings is that because non-disabled people are generally to be found formally and informally in stronger positions of power than their disabled peers, they are often well-placed to impose their views and make them stick” (Read, 2000, p. 101). The issue that comes to the fore is whether the abovementioned misunderstandings are rectifiable. For the broader public to get an insight into the world of the adolescent with Arthrogyrosis, education about the syndrome, and the needs of those adolescents affected by it, is necessary.

2.4 Self-Reliance and Independence

Being dependent and reliant upon the self is not only the aim of the non-disabled adolescent, but that of the adolescent with Arthrogyrosis as well. Of course the degree of self-reliance depends upon the degree of severity of Arthrogyrosis that the adolescent is affected with. What then does it mean to be independent? According to Morris (1993) to be independent means the ability to be self-sufficient, to have the ability to assist one-self in addressing one’s own needs.

For those who are not affected by Arthrogyrosis, independence will have different meanings to those who are affected with it. Some would be able to live fairly ‘normal’ lives without the assistance of other (non-disabled) people, while others who are more seriously affected might need special attention. This might also affect the way in which the affected socialize with other non-disabled peers. “Personal autonomy” (Dartington,

Miller & Gwynne, 1981) is a very important aspect in the personal and social development of the adolescent with Arthrogyriposis (p. 73). A lack thereof could be strenuous to the social development of the adolescent with Arthrogyriposis.

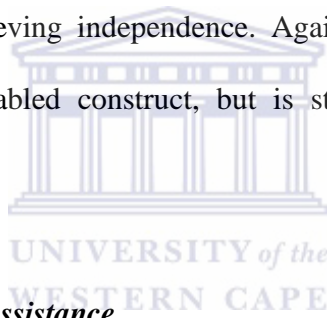
According to Morris (1993) one of the assumptions of living independently, is that even if some people are psychologically or bodily distressed, they still have the last say over their dignity as people. This might also be true for those adolescents affected by Arthrogyriposis, unless those who are more affected might choose to be cared for by family members. Prilleltensky (2004) is of the notion that in order to facilitate good emotional and physical growth, it is important that parents allow their children to express themselves, and this would yield positive effects on a social level. The ability to be assertive is an important aspect of the social growth of the adolescent with Arthrogyriposis as well. This will allow the adolescent to express wants and needs pertaining to his or her physical capabilities. Prilleltensky (2004) for example makes mention of a disabled mother in a wheelchair who derived satisfaction out of the fact that although in a wheelchair she did not need assistance from others if she took her children out. The above example illustrates that disability does not necessarily mean confinement to the home and also illustrates the sense of independence. The mother in the abovementioned example displays the confidence of going out in public despite her condition. Therefore the mother believed in her own abilities of venturing in the outside world unaided.

Adapting to surroundings is another factor that needs to be taken into consideration when the adolescent with Arthrogyrosis is socializing (Millard, 1984). Accessibility might be a concern with the adolescent with Arthrogyrosis and specifically with regards to rough terrain. Hewitt-Taylor (2008) for example, mentioned “children with complex health needs find it more difficult to play than it is for their peers” (p.23). Therefore, the adolescent with Arthrogyrosis might have difficulties coping with rough terrain. This might be of concern as not all those affected by Arthrogyrosis is able to, for example, ascend flights of steps (Millard, 1984) to get to a non-disabled friends’ house or apartment. Therefore, mobility plays a key role in the quest for being self-reliant and independent.

There is a tendency among the broader community to assume that the disabled are innately ‘dependent’ on others in all spheres of their lives at all times. In some cases this might be true, however some adolescents with Arthrogyrosis are very capable of looking after their own physical needs and do not need the help of others. Although independence is an ideal for most adolescents, unfortunately not all are able to achieve it. Nicolausson (1982) noted the importance of the adolescent moving away from the family and adopting their own identity. Therefore one could ask whether the adolescents’ identity allows him - or herself to believe he or she is capable of being independent, despite the severity of Arthrogyrosis that affects him/her. Referring back to Bongs’ story, it illustrates that despite the fact that he is severely affected by Arthrogyrosis, he still enjoys having social interaction with others. It also brings the personality into perspective, as a big factor in the concept of being independent. For some adolescents with Arthrogyrosis the mere thought of not having help “on tap” is too daunting a

prospect to consider because of their dependence on others for their daily living and assistance.

To many adolescents with Arthrogyriposis physical aids such as leg braces and wheel chairs, as seen in the case of Bong, might be of help to their cause of being independent and self-reliant. The standard of living as described by Davis and Madden in Davis (2006) is paramount to whether the adolescent with Arthrogyriposis would be satisfied with his or her sense of independence or not. According to Madden and Davis in Davis (2006) the standard of living is paramount to the person and consequently it is an important stride towards achieving independence. Again being independent and self-reliant is not only a non-disabled construct, but is strived for by adolescents with Arthrogyriposis as well.



2.5 Others' Responsibility of Assistance

Others' acceptance of the condition and responsibility of personal assistance is another key aspect in the social contact of the affected adolescent with Arthrogyriposis. Oliver and Barnes (1998) explain that the onus rests on the family to support and assist the disabled if the state is not doing so. According to Oliver and Barnes (1998) mostly woman are given the responsibility to take care of disabled relatives. Again it needs to be noted that not all adolescents affected by Arthrogyriposis will need the same amount of assistance from the non-disabled members of society. Some are more severely affected and will need assistance in a social situation, while others require no assistance and would favor doing everything by themselves (Shrout, 1994). However, the question of whether to help

or not is a complex one for the non - disabled. To many adolescents the need for personal assistance has been translated into the need for ‘care’ in the sense that they need to be looked after (Morris, 1993).

“Tricia, a single woman in her fifties, spent some time looking after her parents. Disabled from birth, she was in her late thirties by the time she felt ready to leave home but ‘that was about the time my parents started to depend on me, both emotionally and physically. I think they wanted to be needed. They got much more protective of me as they got older. Because they had let me do things before, that was how I got on really, but the older they got they seemed to live through me. My father would be outside looking for me if I was late home. It was awful.” (Morris, 1993, pp. 96-97). Having a child with a disability may require that the parents give their full attention to their disabled child. This is especially true in the beginning when such a child is still small and vulnerable. This is no different for an adolescent born with Arthrogyriposis. As seen in the extract though, it is clear that ‘Tricia’ felt that she was under pressure to see to the well being of her parents, as they did the same for her in the years of growing up. However they seem to have become over protective even though she was an adult. The issue of assistance in this case could become overbearing as ‘Tricia’ explained. Tricia’s story is also an indication of the negative side of assistance to those with a disability.

The above story reflects to what lengths parents would go to assist their handicapped children. According to Thomas (1982) “the most obvious form of caregiving is that from parent to child” that the parental role “requires little or no explanation: it exists

unquestioned and the structure and purpose of the role are equally clear: to guard, nurture and encourage the unfolding of the child's potential to be both unique and at the same time a member of his society" (p. 71). Thomas re-iterates the fact that the relationship between a mother and her child or children should not be underestimated and that it is probably the most important partnership in the initial phases of a child's life. This relationship could be even more protective in nature if the child is born with a disability. However, some disabled would resist this over protectiveness. The reason for that is that they are confident that they are capable of doing things for themselves and that assistance from others would compromise their sense of independence.

Assistance however, is not exclusively the responsibility of the parents. In the social realm assistance plays an integral part in the quality of social interaction of the adolescent with Arthrogyrosis. Limaye in Hans and Patri (2003) explained in her paper that being deaf is one of the most serious forms of disability as being deaf affects the communication aspect of a person with this disability. Communication in itself is important to relate with others, but even more so – it is important for non – disabled community to understand the needs of the disabled. Thomas (1982) mentions the words, "pro-social behavior" with regards to the "giving of care, aid and comfort" (p. 71). Furthermore he suggests "pro-social behavior offers psychological theories of human behavior which has emphasized the significance of struggle, domination and self-enhancement as the prime motives of conduct" (p. 72). Therefore being one's own source of help is of the utmost importance with regards to the social interaction of the individual with his or her peers. Concern (Thomas, 1982) for the well being of others including the

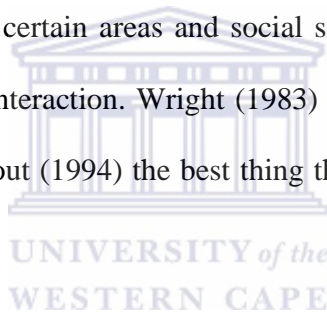
disabled, might be a prerequisite if the adolescent with Arthrogyrosis is to be assisted by members of the non-disabled community. It is difficult though, to offer assistance to the adolescent with Arthrogyrosis if the non-disabled friend does not know what the limitations of the adolescent friend with Arthrogyrosis are. One can assume that not all non-disabled adolescents would be forthcoming to those adolescents with Arthrogyrosis, because they choose not to become involved, or because they are unaware of the physical difficulties and limitations of the adolescent's friend with Arthrogyrosis.

Acceptance of those with disabilities, especially in the adolescent phase, is paramount to the success of the adolescent with Arthrogyrosis on a social level. Consider the following from a father with a handicapped son- "I feel that society, at least the people that I know, is becoming very accepting of children who have special problems. My son goes to a regular elementary school. There are special classes for him, but also activities where all the kids do things together. I think people are changing" (Healy, Keese & Smith, 1989, p. 89). The above extract illustrates that it is possible for the disabled adolescent to cope on a social level, if the non-disabled friends are made aware of the condition first, and they are educated about what the particular limitations are with regards to the adolescent with Arthrogyrosis.

Another aspect that came to the fore in the abstract is the fact that the young boy was exposed to other non-disabled children at an early stage. The positivism of the exposure of this young boy to non-disabled peers is twofold. First it will enhance the relationship between himself and his non-disabled friends, and second it will teach them (the non-

disabled friends) about how to interact with him in a social situation. The fact that the children in class are aware of the physical limitations of the disabled classmate, might give rise to deeper friendships because they understand their roles in the assisting process.

Responsibility of assistance by peer groups of the adolescent with Arthrogyriposis is a concept that needs to be thought through with regards to social interaction. Here it depends on the group(s) whether they want to take the responsibility in helping their friend with Arthrogyriposis. Therefore communication (Ham, Aldersea & Porter, 1998) with peers about assistance in certain areas and social situations is important as it may enhance the quality of social interaction. Wright (1983) views help as part of the social relationship. According to Shrouf (1994) the best thing that non-disabled peers can do if they want to assist is to ask.



In summary, for the purpose of this study, five aspects came to the fore with regards to the social coping of an adolescent with Arthrogyriposis. The first is the role of the personality and how it might influence social coping. Another aspect identified is the influence of the parents in the life of an adolescent with Arthrogyriposis. Public perception might also influence how an adolescent with Arthrogyriposis copes in his/her social environment. Another aspect that came to the fore in the literature is the issue of self-reliance and independence and how these aspects might have an effect on the social coping of the adolescent affected by Arthrogyriposis. Finally the literature sites the role of others' responsibility for assistance and how other non-disabled members of the

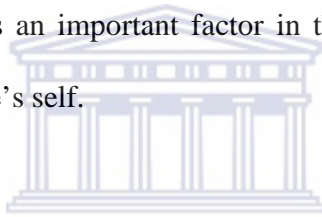
community respond to assisting the disabled specifically an adolescent with Arthrogyryposis.

3. Theoretical Framework

Because this study is about the social coping experiences of an adolescent with Arthrogyryposis, the chosen theoretical framework is phenomenology. Donald Vandenberg (1997) describes phenomenology as “this kind of description of phenomena in the lived world, or description of the movements of consciousness that enables one to become aware of phenomena, or both these together” (p. 10). He then goes on to say that, “it describes how an adult is conscious about things” (Vandenberg, 1997, p. 10). One can thus assume that the point that Vandenberg wants to bring across is the fact that an adult has the ability to verbalize his/her thoughts and therefore it would be easy for an adult to describe what he/she is experiencing. Not only is this factor relevant to adults but for adolescents as well, because adolescents are in a stage where they have the ability to think on an abstract level.

Phenomenology will assist in the process of explaining what the adolescent with Arthrogyryposis is experiencing on a social level. Therefore the adolescent with Arthrogyryposis will give an insiders’ view on what strategies are employed in order to cope on a social level.

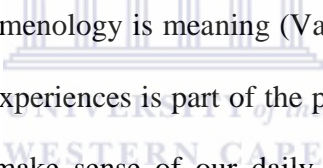
According to Carr (1986) “the life of consciousness is composed, then, in the phenomenological view, as a sequence of more or less distinguishable experiences” (p. 27). For the adolescent with Arthrogyriposis social interaction and how he/she experiences it, might yield different results, either negative or positive. Surely as people we cannot make judgments on experiences unless we have experienced them ourselves. Only then are we in a position to express that which we feel about the experience(s) that we had. Others are contributing to our experiences in this lived world. As a result we might judge ourselves by way of our feelings towards others with whom we had experiences. This could not be truer for the adolescent with Arthrogyriposis. The interaction with peer groups is an important factor in the formation of opinions about social interaction and about one’s self.



Previous experiences (Carr, 1986) may contribute and/or may influence the quality of social interaction of the adolescent with Arthrogyriposis. In the past such an adolescent might have been rejected from peer group activities as a result of his/ her condition. Conversely peers might have accepted them in the past, because others took the responsibility of integrating such adolescents in social activities and interactions. Whatever the results, it is evident that the conscious experience is at the core of the concept of phenomenology.

Thomas (1982) mentioned many times that the definitions parents have of their handicapped child are (often) shaped by the responses they (the parents) get when they are in public with their handicapped child. Assume that the parents do not rectify the

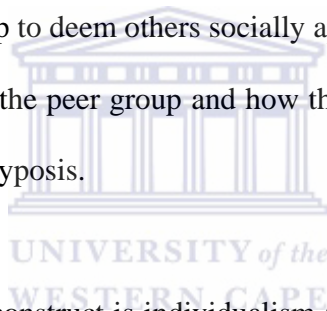
misconception that other non-disabled members of society have about the handicapped. This might have a negative impact when the child reaches adolescence on how he/she perceives the social sphere. Phenomenologically speaking then such adolescent may view the concept of social interaction as he/she had been “taught” at an earlier stage. Van Manen in Vandenberg (1997) mentions, phenomenology simply illustrates the different realms of human experience that are achievable. Therefore as people we are going to have many different experiences with others like us. However we might not all interpret our experiences the same. This might well be true for the adolescent with Arthrogyrosis. Whereas other adolescents with Arthrogyrosis might have difficulties socializing, others might have positive experiences with other non-disabled peers.



Another aspect linked to phenomenology is meaning (Van Manen in Vandenberg, 1997) and how making sense of our experiences is part of the phenomenological framework. It is important to note that we make sense of our daily lives through our experiences. Making sense of our social world is how we understand what we are encountering when we are with others. Others form part of our phenomenological experiences. The premise here falls on social influence (Turner, 1991). He defines social influence as the following: “it comprises the process whereby people directly and indirectly influence the thoughts, feelings and actions of others” (Turner, 1991, p. 1). Therefore the adolescent with Arthrogyrosis might be influenced negatively or positively by the parents, with regards to socialization with peers. Vander Zanden (1988) defines socialization “as a lifetime process of social interaction by which people acquire those behaviors essential for effective participation in society” (p. 161). Through this process the adolescent with

Arthrogyrosis might learn how other members of the same peer group think about socialization with the disabled. This might become a motivating factor in that it might foster a positive attitude towards social interaction or it might have a negative influence in the perceptions of such adolescents in the social sphere.

Another aspect in the phenomenological process is that of conformity, or conforming to the social norm (Turner, 1988). The question that comes to the fore is ‘how difficult would it be for the adolescent with Arthrogyrosis to conform to the social norm?’ According to Turner (1988) conformity is linked to the dependence of the individual to the group, in order for the group to deem others socially appropriate. Therefore success or failure to conform depends on the peer group and how they view the social participation of the adolescent with Arthrogyrosis.



Part of the phenomenological construct is individualism (Pinkard, 1996). Pinkard (1996) mentioned that people need not search for the ability to assert themselves in their world(s), but they are born with the ability to do so. Furthermore he mentions that social interaction should be performed based on individuality. The social circumstances of the adolescent with Arthrogyrosis will illustrate whether such an adolescent demonstrates his/ her individuality with regards to establishing his or her role in the social sphere. The social circumstances might illustrate perceptions of social interaction, but will be a reflection of peer group attitudes as well. Perceptions of the peer groups will then shape the social reality of such an adolescent (Collin, 1997). For some adolescents with Arthrogyrosis their social reality is an established social fact (Collin, 1997). They are

either included in the social sphere and experience contentment with it, or are excluded and harbor feelings of social inadequacy, loneliness and social isolation.

It is also important to note that such adolescents might be socially excluded as a result of the severity of their Arthrogyrosis, which makes it difficult for them to socialize. It may also be the result of the over protectiveness of the parents. Conversely, the adolescent might be content with the quality of socialization experienced because he or she might not be severely impaired by Arthrogyrosis, making it easier for such adolescents to be amongst peers.

Phenomenology gives insight into the conditions and circumstances of the affected adolescent with Arthrogyrosis and how he or she perceives the social world of contemporaries. Often body image plays a major role in the adolescent phase. This factor could have either negative or positive connotations for the adolescent with Arthrogyrosis. Because the severities of this syndrome differ, some adolescents might have difficulties in the socialization process while others will have no problem with their body because they are not severely affected. However early socialization at home and the particular role of the parents in the shaping of socialization is very important to the later interactions and relations with others in the peer group. Like other adolescents, socialization with other non-disabled peers will be a manner by which their identities are formed and confirmed. Phenomenology as a concept shed light into the possible complexities of the social interpretation(s) of not only non-disabled adolescents, but those with Arthrogyrosis.

In summary, phenomenology as a theoretical framework will assist in analyzing how the adolescent with Arthrogryposis copes on a social level. The central theme of phenomenology is that of meaning. This will give insights into how the adolescent with Arthrogryposis makes sense of his/her social experiences and indeed his/her social world. Phenomenology could also shed light on how the adolescent with Arthrogryposis conform attempts to conform to the social norms imposed by society.



Chapter 3.

Methodology

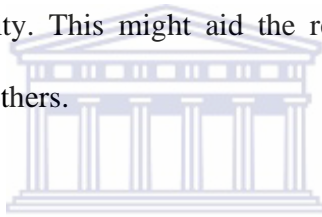
This study was conducted by making use of the qualitative research method. “There are five main methods employed by qualitative researchers, namely observation, interviewing, ethnographic fieldwork, discourse analysis and textual analysis (Travers, 2001, p. 2). Here, Travers gives some insight to what the qualitative researcher will need to gather data and make sense of it. Banister et al. (1994) explains that qualitative research aims to give insight into the underlying issues, those issues and uncover the meaning of those issues in question.

Interviewing plays an integral part in the investigation into the research question. This requires of the researcher to ask questions, whether direct or indirect, to individuals or groups (Travers, 2001). Furthermore Travers (2001) explains that when the researcher does his or her ethnographic fieldwork, he or she spends much time observing the way of life of the people he or she is interested in. Silverman (1997) is adamant that the phenomena studied, require pragmatic examination. Therefore, one needs to understand that it is important that the researcher see the behaviour of a particular population if he or she is to make assertions regarding the observed people.

There are certain requirements to which the qualitative researcher needs to adhere. According to Silverman (1997) “the fieldworker must remain open in order to discover the elements making up the markers of the tools that the people mobilize in their actions

with others and, more generally, with the world” (p. 9). The emphasis thus falls on the objectivity of the researcher without his or her own bias jeopardizing the investigation.

What value is attached to the decision to use qualitative research? Travers (2001) gives many reasons why qualitative research holds such value. He explains that qualitative research assists in the quests of students and academics to find meaning in their own experiences to that of the broader social context (Travers, 2001). Therefore students and academics want to know whether their thoughts on morality, politics and the like are congruent with the rest of society (Travers, 2001). Qualitative research holds the key to get to answers such as these. Asking people about life and perhaps their lives gives the researcher insight into humanity. This might aid the researcher in attempting to find meaning in the observation of others.



Travers (2001) mentions that learning about people, is the same as learning about the spoken word of people. Gaining an understanding of the language of the people studied is to gain an understanding of what it means to be human and subsequently the human condition. It is therefore evident that qualitative research differs from the quantitative inquiry, which uses numbers (Seale, et al., 2004). Seale et al. (2004) mentions “the association of qualitative research with words rather than numbers is simplistic and is closely related to the issue of meaning, the logic of enquiry and the question of generalizability” (p. 313). The above statement by Seale (2004) and associates makes it clear that central to the qualitative enquiry is the making sense of what is researched and the logic that is needed.

Travers (2001) speaks of the practical value of research and in particular mentioning the Dearing Report, which “emphasizes the acquisition of transferable skills, rather than research being abstract” (p. 12). This notion mentioned by Travers (2001) makes sense as it advocates skills that could be used by other researchers to conduct their own research. “Such research might also be of benefit to the assistance of a country economically, and could also contribute to the effectiveness of a company, whether it be in the private or public sector” (Travers, 2001, p. 12).

3.1 Research Design

The design of this study is that of a case study. “In a case study a particular individual, program, or event is studied in depth for a defined time” (Leedy & Ormrod, 2001, p. 149).

The premise of the case study is in depth studying, i.e. the researcher selects a person who he or she would like to study more intensely than would be the case for example in a focus group interview. For the purpose of this study focusing on the experience(s) of an adolescent with Arthrogryposis, the case study method is a fitting tribute to the social prowess of such adolescent. The data collected in a case study is invaluable, as this will supply the researcher with a true reflection of the social experiences of the particular adolescent.

According to Yin (1984) “case studies are the preferred strategy when ‘when’ and ‘how’ questions are being posed, when the investigator has little control over events, and when

the focus is on a contemporary phenomenon within some real-life context” (p. 13). The above extract from Yin reflects the purpose of the utilization of the case study as a means of research. The purpose of this research is to gain some understanding of the social experiences of an adolescent with Arthrogyriposis.

Case studies are very effective in gaining an understanding about a certain phenomena. According to Yin (1984) the case study method and in particular the single case, represents a serious situation. In the case of this research, the phenomena under the magnifying glass, is the rare syndrome - Arthrogyriposis and the social coping experiences of an adolescent affected with this rare condition.

Goodwin (1995) mentioned about the flexibility of the case study method saying that not only are single people investigated through this method but for example people of different religious convictions. The subject of this research is an adolescent who is affected with this condition. Therefore the involved adolescent will disclose some of the aspects of socializing with other adolescents who are not disabled. Yin (1984) also mentions that by using the case study method, the subject will reveal to the researcher the true situation of his or her (the subjects’) life.

The case study allows the researcher to gain in depth insight(s) into the phenomena, which is being investigated. According to Vadum and Rankin (1998), case studies help in understanding “rare conditions” and in this case the adolescent with Arthrogyriposis (p. 51). To gain full understanding of what the adolescent with Arthrogyriposis is

experiencing the case study method allows the researcher the opportunity to look at the social coping experiences of the adolescent with Arthrogyriposis. According to de Vaus (2001) “a well-designed case study will avoid examining just some of the constituent elements” and “it will build up a picture of the case by taking into account information gained from many levels” (p. 221). One could thus assume that the case study of the social coping experiences of the adolescent with Arthrogyriposis might also reveal the role of not only socializing with non-disabled peers, but could also provide the researcher with insight(s) of the adolescents’ social interaction with other members of the community. Ely et al. (1991) mentions that “learning to see through the eyes of others in order to understand and accurately describe their experience is a complex task” (p. 122). This means that whenever the case study is used to describe a certain phenomena, it is difficult to view the aspects of the studied phenomena, unless the subject gives an accurate description of the phenomena therefore giving the researcher an idea of what he or she is ‘seeing’.

Coolican (1999) mentions that the case study method has the potential to state the opposite of what a theory would. This means that a case study could prove that a situation differs from what the theory presupposes. Therefore the adolescent with Arthrogyriposis will give insight to her social situation that would either support the theory of her social coping or not.

On the other hand the case study method also has the potential to carefully support a psychological theory (Shaughnessy & Zechmeister, 1997). In such a case the case study

would not be taken at face value by all in the scientific world and would need further investigation in order to make sure that the results of such research could be believed (Shaughnessy & Zechmeister, 1997). Thus it means that another researcher might challenge the current research done on the adolescent with Arthrogyrosis to prove or disprove the psychological assumption about her social coping.

3.2 Data Collection

3.2.1 Procedures

The method of data collection for the purpose of this study consisted of one sample- an adolescent with Arthrogyrosis. This participant was recruited from a school for the physically disabled in Cape Town. The adolescent who participated in this study is an only child and lives with her mother and stepfather on the Cape Flats. She is seriously affected by Arthrogyrosis. She has difficulties in using her hands because they are curved inwards. She also has difficulty walking upright and walks leaning forward. She is a very shy individual and would not initiate a conversation. The interviews were conducted at the Department of Psychology at the University of the Western Cape.

Before scheduling a date for the interviews I first established a good rapport with the mother of the participant. Because I live with the same condition as the participant the parent found it very easy to bond with me as the researcher. This rapport was established through constant telephone conversations. The initial idea was to schedule a meeting with the mother of the participant, however the lack of transport for both myself, the participant and her mother created difficulty. Hence the use of the telephone as means of

communication. Because the participant was still fifteen years of age, her mother gave consent on behalf of her daughter to participate in this study.

The interview sessions took approximately forty-five minutes to an hour to complete. The intention was to schedule one interview only. However, after the initial interview it emerged that the information obtained was not sufficient to come to any conclusions. This prompted another interview, at the Psychology Department as well. An interview guide with open-ended questions was used to conduct the interview and was relevant to the research question and aim of the study. The interviews were conducted in English and were recorded and transcribed. I was the facilitator of these sessions.

3.3.2 Data Analysis

This is a qualitative study and therefore the data analysis for this study was done by making use of thematic analysis. “Thematic analysis is a search for themes that emerged as being important to the description of the phenomena” (Dally, Kallehear & Gliksman in Fereday & Muir-Cochrane, 2006, p. 3). These sessions were recorded and transcribed after completion of the interview sessions. Because thematic analysis is used for this study, the themes, which emerged from this study, were put under the appropriate headings and are discussed.

4. Reflexivity

The research that was conducted was of significance to me. The reason why this study was significant was because I live with the same condition as the participant. This research project was a personal journey with myself and was a test to see whether the lives and social experiences of those with the same condition mirror that of my own. I therefore construed this research as a journey of discovery not only of myself but also those who live with this rare but very interesting condition, which is Arthrogyrosis. As the researcher I attempted to remain objective in conducting this study. Very rarely did I relate to personal experiences.

5. Ethical Statement

The participant in this study had been informed about the purpose of this research. Much emphasis was placed on anonymity and that the participants could withdraw from the study if they so chose. Under no circumstances was any participant forced to partake in the study if they did not wish to do so. Confidentiality was of the utmost importance and was stressed prior to the commencement of (all) the interviews. Participation in this study was voluntary and the consent of the mother and daughter had been secured.

6. Significance of the Study

This study is significant, as it will serve the following purposes:

- a. It will introduce Arthrogyrosis to those who are not aware of this relatively rare condition;

- b. It will assist in the development of understanding that those who live with the condition are affected not only physically but could be affected on a social level as well.

In summary, the method for conducting this research was done by means of the qualitative research method. This study was done in the form of the case study method. The reason for using the case study method was because case studies allow for the study of a phenomenon and it also provides in depth insight. The case study method also has the potential to either challenge a theory or it could carefully support it. The procedures for data collection consisted of an interview with one sample. The interview took place at the Department of Psychology, University of the Western Cape. The data analysis for this study was done by making use of thematic analysis. Therefore the emerging themes were put under headings and discussed. The research being done was a personal journey because the researcher lives with the same condition. Participation in the study was voluntarily. The consent for participation was secured prior to the commencement of the study. This study was significant because it will be introducing the condition as well as informing those who are not aware of it as well. It will also assist in developing an understanding for those affected by the condition socially and physically.

Chapter four will discuss the results of the interview done with the adolescent with Arthrogyryposis.

Chapter 4

Results and Discussion

As indicated earlier, the research conducted centers around the social coping experiences of an adolescent with Arthrogyrosis. This adolescent was interviewed and the questions asked pertained to the concept of social interaction and the effect of Arthrogyrosis on social interaction. No prior research has been done on this topic. Therefore it would be the first time that such research has been conducted.

This research was conducted by means of a case study. Only one person was interviewed for the purpose of gaining insight about the social coping experiences of an adolescent affected by Arthrogyrosis. Because this condition is so rare, it was difficult to find other adolescents living with this condition. A school for the physically disabled in Cape Town was very helpful in that they assisted me in finding an appropriate candidate who could participate in this research.

4.1 The Participant

First Interview

The participant interviewed was a 15-year-old girl from the Cape Flats named Angie (not her real name). She attended a school for the physically disabled in Cape Town. Initially she was very tentative and very shy to participate in this research. Her mother who did most of the talking in the initial interview accompanied her. It was therefore difficult to get her to share her thoughts with me. Her mother was very interested in the research, because she wanted to share the story of how her daughter copes with her condition as

well as how she socializes with the people around her. Although I welcomed her mothers' comments, the girls' comments would have been better as it would have given some insight as to what she felt about interacting socially. I was a little disappointed in not getting the information that I was looking for.

Second Interview

Because the first interview did not yield the desired results, a second interview was scheduled. I decided that I was going to allow both mother and daughter to share their views on Angie's social interaction and how Arthrogyrosis affects her social life. This time the interview with Angie was done in a very relaxed atmosphere and therefore it was easy to ascertain what she was feeling pertaining to being amongst others in the social sense. Her mother made comments but this time Angie was participating in the interview.

As mentioned- the second interview was done in a more relaxed manner. The speculation is that Angie felt more comfortable in the second interview, because she was now aware that the interviewer/researcher was also affected by Arthrogyrosis and that she need not be afraid of the interview.

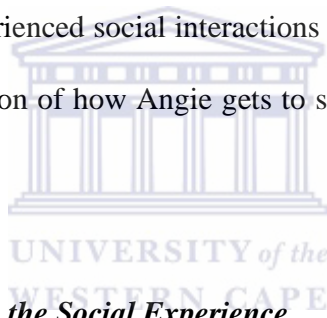
Although Angie was more relaxed during this interview, there were instances when Angie would be shy, but then her mother would encourage her to speak about her social experiences. She would then be able to talk about her experiences as she saw and felt about them. I would then turn to her mother, who would add to what Angie already

mentioned. This would add some substance to the issues, which were brought up by Angie.

The venue for the follow-up interview might have had an influence on the interview because it was a very small room and had an intimate feel to it. We sat close to each other, which might have made it easier for Angie to share her experiences and how she and her mother felt about it.

4.2 Discussions and Analysis

A variety of themes emerged from the interview done with Angie. These themes are indications of how Angie experienced social interactions with others around her or in her social environment. The question of how Angie gets to socialize with others arise where the analysis starts.



4.2.1 The Role of Transport in the Social Experience

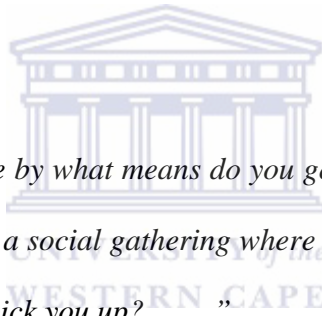
Transport emerged as a very important aspect in the social life of Angie. For her ‘getting there’ and the question of how, plays an integral part of how Angie spends time amongst others. Because of her condition, it is important that the mode of transport is sufficient and comfortable for Angie to use. Public transport is of concern because some of the taxis do not make provision for disabled commuters who have difficulties straightening their legs and so forth, as the next extract will illustrate:

Mom: “Mostly public transport that she has a problem with.....”

Morne: “.....ok”

Mom: “When they have to left, sometimes taxis are not convenient inside.....(inaudible).....for her legs to.....there’s no space to.....the one is.....like straight and the one can’t bend. The one is bending and the other one is straight. So I always have to be(inaudible).....comfortable for her to sit.....(inaudible)..... That is why we do not make use of too much public transport. I would ask someone to take me (and Angie) to where I want to be. It makes it more difficult.....”

The above extract testifies to the fact that public transport is not an option when it comes to going to places. However, Angie does have a means of getting to social gatherings. As she mentions in this exert.



Morne: “Okay. Can you tell me by what means do you get to attend social gatherings, in other words, how do you get to a social gathering where other people are? Do you travel by car or do people come and pick you up?.....”

Angie: “If I wanna go out....?”

Morne: “Yes....”

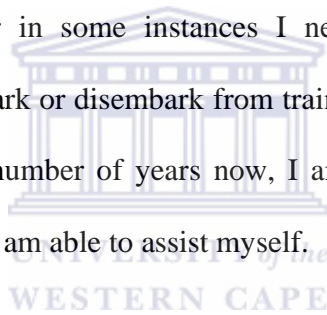
Angie: “They come and pick me up”

Morne: “So, they come and pick you up. Okay, so do they come pick you up by private vehicle or do they come and pick you up by special bus, or.....”

Angie: “By special bus”

Morne: “By special bus, okay.....”

In the above extract Angie confirms that she makes use of a ‘special bus’ to get her to social gatherings. The fact that the bus is ‘special’ indicates that the bus is a specially adapted bus suited for the transportation of people with special needs. Therefore the adapted bus makes it easier for Angie to attend social gatherings. This also illustrates the point made by Madden and Davis in Davis (2006) about the importance of the “quality of life” and in Angie’s case the quality of transport to and from social gatherings (p. 17). Casas (2007) mentioned in the literature review that without the appropriate transport, such adolescents might be socially excluded. From my own experiences, even though I am less seriously affected by Arthrogryposis, I was flexible enough to get into certain vehicles by myself. However in some instances I needed the assistance of others especially when I have to embark or disembark from trains. Because I have been making use of public transport for a number of years now, I am aware of when I needed the assistance of others and when I am able to assist myself.



From the above extract, one also senses that Angie is content with the help from those who provide the special transport for her. Therefore phenomenologically, the special transport provided for Angie will enhance a positive outlook on her social experiences.

4.2.2 Social Relationships

Another interesting theme, which emerged from the interview, was that of Angie’s social relationships. The next thought that arises from the interview centers on the question of with whom Angie is socializing. It emerged that the people with whom Angie has a social relationship are other disabled people her age, as the following extract will illustrate.

Morne: “Okay....okay. Your friends- and I’m specifically referring to your non-disabled friends- you do have non-disabled friends.....?”

Angie: “No!”

Morne: “Are all your friends disabled?”

Angie: (Nodding, confirming)

Morne: “Okay. So, do they make you feel part of the social group if you go there?”

Angie: (Nodding, confirming)

Morne: “They do. So you feel confident and part of the group?”

Angie: “Yes.....”

From the above extract it is evident that Angie only socializes with peers who are also disabled. The reason for socializing with disabled peers only might be a reflection of the fact that she might not be comfortable with non-disabled peers and might also be afraid of being judged by non – disabled peers. Takemoto in Hans and Patri (2003) mentioned in the literature review that she was afraid to be judged by others because of her disability. Therefore for Angie, being with peers who are also disabled might create a sense of familiarity and comfort, and that disabled peers would be the most likely to understand Angie’s condition. However, further on in the interview Angie mentioned that she had been socializing with non-disabled peers as well. The following exert is an illustration of socialization with non-disabled peers:

Morne: “Okay. So, have you ever been to a gathering where there are non-disabled peers?”

Angie: “Yes”

Morne: “Can you tell me about it?”

Angie: “I went out with a group.....(inaudible).....so we mixed with other children....”

Morne: “So, they were mixing with you freely?”

Angie: (speaking inaudibly)

Morne: “So, it’s okay with them?”

Angie: (She confirms)

The above exert illustrates that Angie does socialize with peers who are not disabled. By doing so, Angie might use it as an opportunity to educate those (peers) who are not disabled about her condition. Personally I had very good relationships with disabled and non-disabled friends alike. During adolescence I derived a sense of confidence from the fact that I was fairly mobile and could therefore go and socialize with friends without the assistance of others. However having said that, I chose to socialize only with those friends who lived close to my home, as safety was a concern for me if I would visit a friend who lived far from my home. Therefore phenomenologically, Angie might give non-disabled peers insight into what life is like on a social level living with Arthrogryposis, through her own social relationships with them.

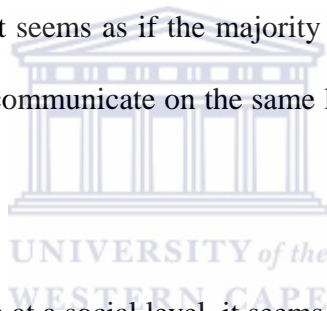
Morne: “So what do you do, actually you are educating others about your condition.....”

Angie: “Yes.....”

The above mentioned exert indicates the fact that being amongst non-disabled peers might have positive consequences as it will give rise to the opportunity to educate others about Arthrogyriposis. She might be asked about Arthrogyriposis. The request for help might also be an opportunity to explain what the condition is. This then brings the role of communication with non-disabled peers into focus.

4.2.3 Communication with the Non-Disabled

Communication plays a very important role in the social process. For those who have a lot in common it would be easier to express thoughts and feelings that others could relate to. Therefore in Angie's case it seems as if the majority of her friends are disabled who would make it easy for her to communicate on the same level as they have their physical disabilities in common.



With regards to communication at a social level, it seems as if expressing herself depends on the (social) situation and whether mom is present. The following extracts are illustrations of that:

Morne: "Tell me something. Do you have difficulty in communicating with people who are non-disabled?"

Angie: "No..."

Morne: "Okay. So you say what you want?"

(Mumbling by mom and daughter)

Mom: (Inaudible)

Morne: "So, you're not used to asking? Why is that?"

Angie: "Because I can do it by myself. Because you can do it by yourself"

And

Morne: ".....Tell me something. If you had to go out to a gathering, to a social gathering where there are disabled and non-disabled people does your condition makes it difficult for you to socialize?"

Angie: "Yes"

Morne: "How so?"

Angie: "It's like my mommy is not there. Now there's like a bottle standing, a bottle of juice and that. I can't pour myself or dish my own food.....(inaudible)....."

Morne: "So, do ask people to help you?....."

Angie: "No....."

Morne: "You don't ask"

Angie: "No"

Morne: "Okay. So, you just say you're not hungry or you're not thirsty.....?"

Angie: "Yes"

From the above extracts it is evident that assertiveness is the core concept in certain situations. It is certainly evident that the level of assertiveness varies in some situations. She would display self-efficacy in certain areas in which she feels that she is able to do things for herself, whereas in other situations she is not as confident in her (physical)

abilities yet she does not ask for help. In the literature review, Limaye in Hans and Patri (2003) mentioned the importance of communication and that the lack thereof could pose difficulties when the disabled person needs to relate to the non – disabled members of society. Angie seemed to have difficulties with communication with the non – disabled as illustrated in the extract. This reverts back to self-reliance and independence. In this case it illustrates that in some situations Angie depends on her own abilities to ‘get things done’ while in other situations she would require assistance from other (non-disabled) peers, however she lacks assertiveness in order to alert people to the fact that she needs help. She might also feel embarrassed or ashamed that she is different. Asking for help would draw attention to those differences. Personally, I had difficulties in “speaking up” when it would have been to my advantage. Therefore the emphasis falls on assertiveness and my lack thereof, which had a subsequent influence on my self-esteem. However as I reached adulthood, I started to become aware of this, and the fact that I needed to work on becoming more assertive in my interactions with the non-disabled community.

4.2.4 The Role of the Community

The community and the role that it plays in the shaping of Angie’s view on social interaction should not be underestimated. From the interview I learned that Angie comes from a community on the Cape Flats, which is socio-economically very underdeveloped. Gangsterism is rife and situations could become very dangerous at times. I was very interested to know what impact the community has on her social ability and coping.

Going out into the community she risks being hurt when the situation becomes dangerous. This certainly impacts negatively on relationships that she might want to strengthen with others in her community. However, I was surprised to learn that even the gangsters were concerned for her safety, as the following insert will illustrate:

Mom: “When’s she’s outside- it’s just sometimes that I don’t allow her to go outside. The environment is not so okay there by us. I don’t allow her to go outside. She’s got to stay inside.”

Angie: “Like (inaudible) also. I ran and I fell. Now, they were shooting and I was the only one outside.....”

Mom: “.....the only one outside.....”

Angie: “.....the one gangster picked me up and said, ‘run in’.....”

Mom: “.....you were standing outside.....”

Angie: “But they just lived in our road. They picked me up and said, ‘run in’.”

As illustrated above- the environment in which Angie lives has a negative impact on social interaction. The situation in her community makes it difficult for her to move freely and therefore hampers her social relationships with peers whether, disabled or non-disabled. During adolescence, I had a lot of support from the community in which I lived. Even though the community did not fully understand my rare condition, they, especially the elders in the community recognize the fact that I had a disability and they therefore assisted me where I needed it. Through their parents, the non-disabled adolescents that I grew up with, became aware of my condition, and followed their parents’ example.

However the surprising twist to the interview with Angie is the fact that the gangsters are aware of her condition and therefore they are concerned for her safety in the dangerous situations. Ironically the gangster provided (the) 'aid' and 'comfort' mentioned by Thomas (1982) and illustrated the notion of others' responsibility for assistance as mentioned in the literature review.

The situation in her community does not always remain dangerous all the time though. There are instances during the social contact with other members of her non-disabled community in which she is assisted in her everyday life. The following insert will be an illustration of that:

Mom: "Like she said- it is like that. And then the people in our road too, they know how to go to the shop.....(inaudible).....how to handle her....."

Morne: "Sure....."

Mom: ".....how to hand her money to her, put stuff in her bag or whatever. They take care of her"

It seems therefore that the assistance that she receives from the community enhances her ability to successfully socialize with the majority of non-disabled members and peers in her community. It seems as if she appreciates the fact that other members of the community are keen to assist her in any way possible. While Angie told me about the fact that others want to help her I got a sense of contentness about what the community is willing to do for her.

Phenomenologically speaking, the fact that the community is willing to help would be an enhancement of her view of her social condition and how she fits into the social sphere, especially with relation to her peers.

At times people might not be as understanding about Angie's condition. She confessed that not everybody in the community is as helpful as desired. This is what she said:

Angie: "I fell on my bum.....".(giggles)

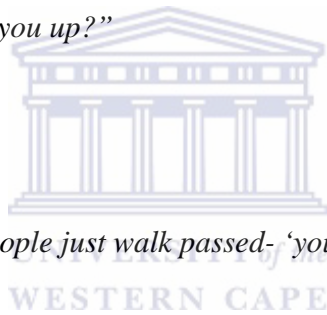
(Angie fell and a couple of boys in her street came out to assist her)

Morne: "Okay. So, tell me more about it. How did you feel when the boys came running out and helped you and picked you up?"

Angie: (Giggling)

Morne: "How did you feel?"

Angie: "Its okay. Sometimes people just walk passed- 'you get up yourself'"



The above insert illustrates that some members of the community are reluctant to offer any assistance to Angie. This could also have a negative impact on Angie's ability to socialize with the non-disabled members and peers in her community. The reluctance of some members of the community to assist Angie might be because of their own inability to understand the concept of disability or they might not want to become 'involved' in assisting such a person. The behavior of those 'walking by' might give Angie the sense that she is not socially appropriate to warrant assistance from them. I also got the sense that Angie is not very assertive in asking for assistance from other members of the

community and is willing to wait until assistance arrives from those who want to help, as illustrated by the boys who assisted her when she fell.

4.2.5 Making Friends

Friendships play an integral part of the socialization process and the basic need for companionship is one, which is very important for people to make sense of life. Association with others of like-mindedness makes it easier for people to adapt to the social environment. This is no different for the disabled as well.

During my interview with Angie I got the sense that she waits for others' response to her (and her condition). Once she has established rapport with a person, she would feel comfortable to socialize. This was evident in the following extract:

Morne: "So did you, tell me something. Did you.....(silence).....have you ask for help?" (from someone other than your mom)

Angie: "Yes....."

Morne: "You have.....Can you tell me more about it?"

Angie: "A girl from another school. We had something on. We ate with our hands. But she dished my food and she nicely took out a spoon out of the salad. She took it out and gave it to me"

Morne: "So, she helped you to....."

Angie: "Yes! She said, 'here, eat with the spoon'"

Morne: "And how did you feel about it?"

Angie: "Good"

Morne: "You felt good about it. Was that the only time that you asked for help?"(from her)

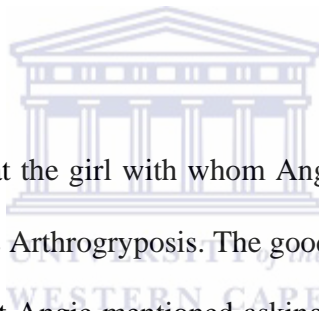
Angie: "I only ask her....."

Morne: "You only ask her"

Angie: "Yes"

Morne: "Can I ask what it is about her that makes it okay to ask (her) help?"

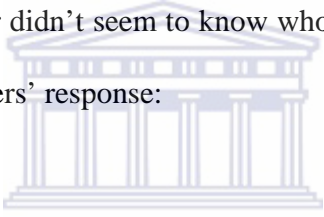
Angie: "If you ask something, she'll do it. If I come late then, she'll take my bag and take my stuff out and yes."



The above extract indicates that the girl with whom Angie associates herself with is not fazed by the fact that Angie has Arthrogyriposis. The good rapport between Angie and her friend is evident in the fact that Angie mentioned asking only this friend to assist her. It also comes across that the friend does not mind assisting Angie in whatever she needs assistance with. Thomas (1982) speaks of "pro-social" behavior which is what Angie's friend displays (p. 71). This display of solidarity by her friend will have a positive impact on how Angie views her role in the social sphere. Even though Hewitt-Taylor (2008) mentioned the difficulties of "children with complex health needs", Angie's friend has clearly learned to adapt to her friends' needs and disability (p. 23). As an adolescent, I was fortunate to have both disabled and non-disabled friends. My disabled friends all attended the same school for the physically disabled. Because I was more mobile than my (disabled) friends they sometimes requested my assistance in performing some day-to-

day tasks, which I was happy to oblige. Through those experiences I gained valuable insights into the value of true friendship and that strengthen the bond of friendship amongst my disabled friends and me.

Perhaps one could argue that Angie might learn from her friend that it is fine to request the assistance of others if the need arises. I also got the sense that Angie is somewhat selective about who she wants assistance from. In this case the friend who assisted her at the function. She might feel that her friend is the 'only one who understands her needs' and therefore bonded very easily with her. I wanted to know whether Angie's mother knows the friend, as the mother didn't seem to know who the girl Angie was referring to was and this was Angie's mothers' response:



Mom: "I don't actually know her actually....the girl....but, um, she obviously help.....(inaudible)..... You can always ask her what's happening"

Angie: (Inaudible).....also helps me"

Mom: "She walks home with her too. Carry her bag, wait for her and they walk together"

Morne: "So, she's quite a good friend?"

Mom: "Ja. She don't come there by our house. Her parents don't allow her to walk around....."

Angie: "Her parents like me"

Mom: "And she can go to their house, ja"

Angie: "But no-one else"

Mom: "But no-one else can"

Morne: "So, you do have, like I understand it, social contact with her?"

Angie: "Ja"

Morne: "And she's non-disabled?"

Angie: "Yes"

Morne: "So, it seems as if you are comfortable with her than most other times that you are with other non-disabled, because she understands you better than other non-disabled people do?" (Angie confirms by nodding)

The above extract illustrates the fact that Angie is only social with non-disabled peers if they are comfortable with her. One could understand the fact that the parents of Angie's friend are not too keen for her to walk around the neighborhood. This might be a result of the volatile situation there. There was no mention of how far Angie's friend lives from her. One could therefore assume that Angie's friend lives within walking distance and therefore no transport is needed. There was also an indication that the girl accompanies Angie whenever they go home from school, assisting Angie with her bag and so forth. The fact that Angie is willing to go to the friends' house to socialize is indicative of the fact that she needs and appreciates social contact with others just as much as any adolescent her age, whether disabled or non-disabled.

It emerges from this extract that Angie's mother does not know her daughters' friend very well. However, she does seem to make conversation with the girl although on a small scale. She admitted to asking her daughters' friend, 'what's happening'. This

indicates that Angie's mother is interested in the relationship of her daughter with the girl. The warmth with which Angie is greeted at her friends' house may create a feeling of social appropriateness with Angie. This might also encourage her to seek more social opportunities with other non-disabled peers.

Reverting back to Bong Delrosarios' story (Marjory, et al., 1994) it is evident that because he initiated contact with the girls at the mall, they responded positively to his request for their phone numbers. His personality played a pivotal role in his apparent social success. He came across as being very outgoing and independent. Angie appeared not to be very outgoing but rather dependent on her mom for assistance. Her personality might impact her view of herself and how she views her role in the social realm. Personality therefore plays a very important role in the socialization process as it will determine how socially successful a person would be. As in Bongs' case he was an adolescent who sought out those who were around the same age. In his vignette it was mentioned that he and his friend 'argued a lot' about who was getting the most girlfriends. That is an indication of his good self worth and his appropriateness at a social level, hence his outgoing personality. Angie's personality might also be an indicator of how she conducts herself when having social contact with non-disabled others.

As indicated by Angie, her personality differs from social situation to social situation. When she is with friends who are also disabled, she came across as being very comfortable because they have a commonality with regards to their disabilities. However, when she is in the company of non-disabled friends she seems to be uncomfortable. This

may be because she might feel that she is at 'the wrong place' in the sense that the non-disabled peers would not be as understanding of her disability as her disabled friends would be.

4.2.6 Parental Role in Socialization

From my interview with Angie it seemed as if her mother had a very big impact on her socialization. It is also important to understand that Angie's mother is still the primary care giver and sees to it that Angie is very well taken care of. I also got the sense that Angie's mother was/is very over protective of her daughter. This is understandable because Angie has Arthrogyrosis. It needs to be understood that Angie is seriously affected by her condition and needs assistance performing some tasks. Consequently, Angie's mother is very involved with her daughters' daily living.

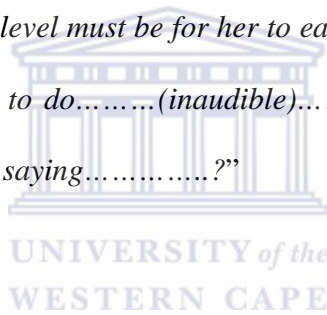
Having the same condition as Angie, I have experienced the over protectiveness of a parent. However, during adolescence, I was encouraged by my mother to engage in social activities with non-disabled friends. She also played an important role in that she gave advice on social issues, for example how to engage in conversations with girls. Therefore the concern of parents of disabled adolescents might not be bad, however being over concerned about their disabled children, could be overwhelming. This over protectiveness might have a serious impact on the growth of independence in their children. Being dependent on the self might enhance Angie's notion that she is appropriate on a social level.

From what I gathered during my interview with Angie and her mother, I got the sense that Angie's mom was very concerned for her daughters' safety especially if she (the mother) was not around. One exception was when Angie was in school, where she is well taken care of. It emerged from the interview that Angie's mother did not want others to take care of Angie, as noted in the following extract:

Mom: "They do it, but for me, as a mother it feels I don't want to put a burden on someone else to do things for my child, cause I'm used to do it for my child. Now someone else need to do it for her. And I know how to handle her- I know how to put the food down, and... and how the level must be for her to eat off the table and whatever and I thought I know exactly what to do.....(inaudible).....to push a bench here and a table there, you know what I'm saying.....?"

Morne: "Absolutely....."

Mom: "So she knows...."



In the above exert the mother explained that she knows what her daughter needs. It is evident that Angie's mother knows, for example, how high the level of the table should be in order for her daughter to eat off it properly.

Another aspect of Angie's mothers' involvement in her life is the fact the mother does not feel comfortable about leaving Angie with other people. As she put it, "I don't want to put a burden onto someone else". It comes across as if Angie's mom is often overwhelmed with concerns for her daughter's safety, i.e. the emotional aspect, rather

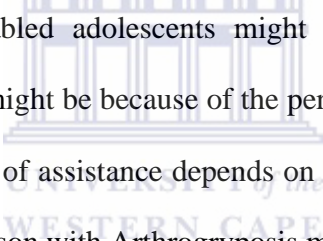
than offering practical solutions to her daughter on how to become more independent as suggested by Oliver and Sapey (2006) in the literature review. Because she did all the care giving throughout Angie's life, she feels that it is her responsibility as the mother to care for Angie. This might impact the social aspects of Angie's life. Palmer (1993) mentioned the words "comforter" and "supporter" and summed up how Angie's mother feel about her role towards her daughter (p.187). Helping might be taxing for others especially with regards to transport. Assisting a child with a disability could be taxing and intimidating even for the parents of such children.

In social situations the over protective parent may be overwhelming to an adolescent with Arthrogyrosis. However it must be understood that it depends on the severity of the condition. Because this condition is so rare, the features of it could be intimidating to others who do not understand it. In Angie's case the 'others' might refer to other non-disabled adolescents with whom she is socializing or with whom she has social contact. As mentioned earlier- all or some of the joints may be involved. Therefore, if the adolescent with Arthrogyrosis is severely affected by the condition, it is understandable that parents of such adolescents would be overprotective. In Angie's case, she is badly affected by Arthrogyrosis hence her mothers' over protectiveness.

4.2.7 Others' Perception about Arthrogyrosis

Because Arthrogyrosis is a rare condition, which occurs once in 3000 live births, it is a disability, which is not regularly seen. As also mentioned earlier, the features of Arthrogyrosis might be intimidating, especially to those who are not aware of the

condition. Because people with Arthrogyrosis are affected differently, adolescents with Arthrogyrosis might have difficulties in socializing with other non-disabled adolescents. Depending on the severity the adolescents with Arthrogyrosis might have physical difficulties participating in social activities. In addition, the non-disabled adolescent might have no interest in social interaction with such adolescents, again because of the fact that many do not understand the condition. I found that even some doctors have either never heard about Arthrogyrosis or they know very little about it. It was through my own knowledge (and later further research) that I could educate non-disabled friends and other non-disabled adolescents about this condition.



Another reason why non-disabled adolescents might be reluctant to socialize with someone with Arthrogyrosis might be because of the perception that disability translates into having to help. The extent of assistance depends on the severity of the condition. In some cases the hands of the person with Arthrogyrosis might be in flexion, which means that the hands are in a fixed position being bend either inwards or outwards. If that were the case, such a person would need the help of others to perform certain tasks. This in itself could create uncomfortable situations for both the adolescent with Arthrogyrosis and the non-disabled adolescent, because some adolescents might not understand the reason for the condition and/or what assistance is needed to make the situation comfortable for both parties. Angie indicated in the interview that she educates others about Arthrogyrosis. However, it also emerged that Angie would not want to impose her self on to others who do not want to socialize with her. This was Angie's response:

Morne: “So, what do you do, you actually educate people about your condition.....?”

Angie: “Yes....”

Morne: “And they respond positively to it.....? Tell me something. Uhm, when you are.....okay when you were at a social gathering, were there non-disabled peers who ignored you?”

Angie: “No....”

Morne: “So all of them talked to you and mingled with you?”

(Angie confirms by nodding)

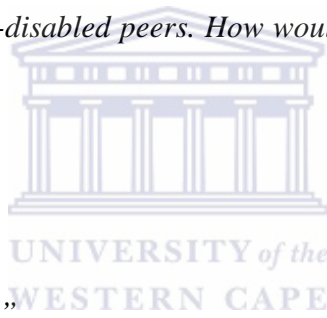
Morne: “Tell me something. How would you, say for instance you would go to a social gathering where there are non-disabled peers. How would you handle it if some of them would ignore you?”

(silence)

Angie: “I’d rather go home”

Morne: “You’d rather go home”

Angie: “Yes”



The above extract illustrates that Angie does educate others about her condition, however, she did not respond to my question of whether others, especially adolescents her own age respond positively (or negatively) to Arthrogyriposis. One could conclude that perhaps other adolescents are not interested in what she has to say about Arthrogyriposis or she selects those whom she feels comfortable to talk to about her condition.

Another interesting facet about the above extract was my question about what she would do if some non-disabled adolescents ignored her. Her response was that she'd 'rather go home'. I specifically used the words 'some adolescents' to assess how she would react to that question. The basic premise of that question put the emphasis on rejection. In this case one could call it social rejection. Judging from her response it comes across that she does not handle rejection very well and chooses to retreat to the comfort of her home where there is a sense of familiarity and acceptance from her parents. At such a social gathering there would probably be others that would welcome her company and would be happy to have her around. It is evident that she is not assertive enough to seek the attention of the other adolescents at the gathering. Therefore she would not seek out the company of more accepting adolescents and choose rather to go home.

From the above extract it could be construed that social isolation is a reality, because Angie indicated that she would rather go home if ignored by some. Her lack of assertiveness could also be construed by other non-disabled adolescents that Angie is not interested in having social contact. Therefore other non-disabled adolescents may not want to include her in their social activities, hence her preference to socialize with disabled friends. It is important to note that communication plays a pivotal role in being social. Throughout the interview I got the sense that she does not communicate her feelings with others well. For example she said that she is reluctant to say when she needs help with opening a bottle and therefore would say that she is not thirsty, or that she would say that she is not hungry in the case where she is struggling to dish her own food. This demonstrates a lack of assertiveness.

Phenomenologically speaking, it is important to understand that because she is not assertive in social meetings, this might lead her to have misconceptions about other adolescents and having success on a social level. It might lead her, for example, to believe that, in general, she is not appropriate at social gatherings where there are non-disabled adolescents. The above extract also pointed out that it is unlikely that Angie would contest the rejection that she could be subjected to. Therefore, instead of being assertive in saying what she wants, she would rather keep to herself and not say anything and retreat to the comfort of her home.

The interview with Angie revealed that there were many aspects which had an influence in her social interaction with the people around her. The aspects impacting her social coping included: the role of transport and how Angie experienced difficulties in traveling. Her social relationships with the people in her community, communication with the non-disabled, the role of her community in her social coping, how she makes friends and how that impacts on her social coping, the role of her parent in how she sees herself in relation to being socially competent and how others view Arthrogyrosis and its impact on Angie's social coping experiences.

Chapter 5

Conclusions and Recommendations

The above results of the interview brought forward some insight into the social world of a young adolescent girl dubbed 'Angie'. She allowed me, the researcher, to have a look-in to what she experiences in her day-to-day social contact with others. The 'others' referred to in this case, are not only non-disabled or disabled adolescents but also the community as a whole. There were factors, which have an influence in her daily social contact with others.

Transport is a factor that obviously has an influence on her social contact. It was evident that public transport does not suit someone with the grade of severity of Arthrogryposis as she has. If she makes use of public transport she has difficulties adjusting herself in order to make herself comfortable. She is unable to bend both legs to become comfortable. It therefore emerged that if she was to go to a social function, a special bus picks her up. It is important to understand that these types of busses that Angie refers to are specially built to accommodate disabled individuals with special needs. For Angie and her mother these busses offer a safe and comfortable manner to travel. The issue of transport for Angie is also an indication that she make use of it if she has to travel to locations which are far from her home. It is important to note that for her mother it is important that Angie is safe when traveling with any mode of transport.

It is evident that the special bus that she uses to transport her to social gatherings works well. It therefore also seems that she feels comfortable with the idea of traveling with the special bus because it accommodates her.

Referring to the literature review, transportation issues are central to the point made by Dartington, Miller & Gwynne (1981) about being self-sufficient, especially for people with a disability. One important aspect to note is that those responsible for the transport service for the differently abled are delivering a service. This is an indication that others are willing to take responsibility for assisting Angie, for the self-reliance and independence could be enhanced by traveling on her own. She may gain confidence in the idea that she will be fine if allowed to travel alone. The recommendation would be that Angie makes use of this service as it benefits her transport needs and her independence. There are also other transportation services available which she could make use of, example a transport service exclusively for the disabled.

Social relationships were another factor, which came to the fore during this investigation into the social experiences of Angie. It came to light that Angie does have social relationships with both disabled and non-disabled adolescents her age. It seems from her own account that she is more comfortable in the presence of other disabled adolescents than with non-disabled adolescents. It might be that being with disabled adolescents creates a feeling of comfort in the knowledge that there are others who are in a similar situation as she is. She also made it clear that her core friendship circle consists of disabled adolescents.

She did mention that she has had social contact with non-disabled adolescents on occasions, however she feels most comfortable in the presence of those who understand her physical limitations.

The above mentioned might be an illustration of a possible misconception that other non-disabled adolescents would not be as understanding of her condition or disability as a whole. In the literature review Morgan (1987) used the word “different” (p. 15), which might be a reason why non-disabled adolescents are often hesitant to have contact with differently abled adolescents. This could also be a reason why Angie would only be comfortable amongst other disabled adolescents. Her personality might also be a factor because it came across that Angie did not have an outgoing personality and therefore does not draw other non-disabled adolescents to her as in the case of Bong Delrosario (Marjory, et al., 1994). Therefore she is more comfortable forging friendships with other disabled adolescents than with non-disabled adolescents. The recommendation in this case would be that Angie be exposed to events in her community where there are other non-disabled adolescents. In so doing she could educate them about Arthrogyrosis as well as her physical needs. It is also understandable that not all non-disabled adolescents would be open to education about her disability. Angie should therefore make an attempt to educate those who want to learn about this condition.

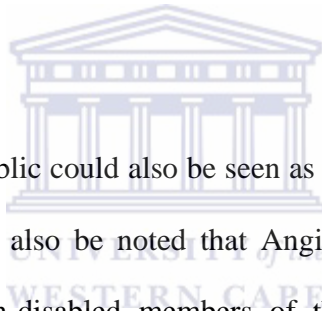
Being amongst other non-disabled adolescents would introduce Angie to others. This would be an opportunity for her to boost her self-confidence (with the emphasis on

ultimately building her self-esteem) and the sense that she is socially appropriate in any situation whether with disabled or non-disabled adolescents.

Communication, especially with other non-disabled adolescents, was another factor that came to the fore in conducting this research. It emerged that Angie is not very assertive in her communication with other non-disabled adolescents. It was apparent that requesting assistance depended on the situation. At some stage during the interview she mentioned that she has difficulty in requesting assistance if her mother is not present at a social function with her. She mentioned that she has the ability to perform some tasks on her own. However there was a point during the interview that she mentioned that without her mother at her side at the social occasion it would be difficult to request assistance.

Thinking about her experiences at social gatherings brings the idea to the fore that perhaps there are people at some of the social gatherings who are not only aware that there would be disabled adolescents who would need their assistance, but who had been assigned to assist them. An example of this would be adults who know the disabled individual who will be attending the social gathering. Therefore one gets the sense that there is assistance at some gatherings while at others there might not be. In such a scenario there are others who will be taking the responsibility for assisting Angie and others like her.

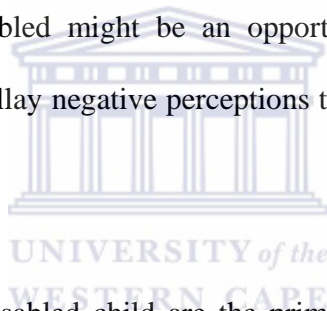
The community and the role that it is playing in Angie's social world illustrated how various situations that she finds herself in prompted different actions to be taken to ensure that she is safe. It emerged from Angie's personal accounts that in some instances the community comes to her aid if the need arises. This is evident when she goes to the local shop. There are those who assist her in putting her items in the bag for example. In another example she related how a boy from the community assisted her. The boy helped her get up when she could not do so herself. This behavior from the community might enhance the sense that she is worthy of assistance from non-disabled community members. It may also strengthen others' responsibility for assistance of those who are differently abled.



The helping behavior of the public could also be seen as an opportunity for them to learn about her condition. It should also be noted that Angie should initiate conversations, which would allow other non-disabled members of the community, including non-disabled adolescents to learn about Arthrogyrosis and perhaps the disability as a whole.

Making friends was one of the issues connected to Angie's social contact in the community. From what I could gather in the interviews it seems as if most of Angie's friends do not live near her. This would possibly explain why she would need transport to travel to social gatherings. It also seems as if she only socializes with those who are at school with her. It came to the fore that Angie comes across as a very inhibited individual and she does not have a very outgoing personality that would draw other non-disabled adolescents to her. If this would had not been the case she could have a more satisfying

social life, however she proved to be someone who is not very assertive and because of this, other non-disabled adolescents might view her as being anti-social. She did however mention a girl in her community whom she befriended. This friend helps her with her bag and walks home with her and whom she visits on occasion. This illustrates that she, as mentioned, is not very outgoing and does not have many friends in the community other than those in her school. The difficulty with this scenario is that although she has social support from her friends at school as well as at home it would be beneficial for her to reach out to other non-disabled adolescents. Doing so would enhance her social support structure and would help her broaden her social horizon. Reaching out to other adolescents who are not disabled might be an opportunity for them to learn about Arthrogyrosis and may also allay negative perceptions that the public might have about the physically disabled.

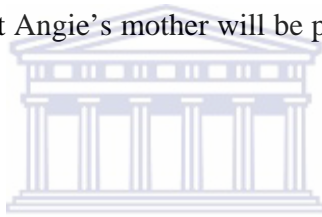


In general, the parents of a disabled child are the primary caregivers. Angie's mother plays a prominent role in her life. In both the interviews that I conducted with Angie and her mother, Angie's mother would intervene if she (Angie) could not answer a question. Angie's mother was very protective over her daughter, which is understandable. Throughout the interviews the theme of protectiveness and in a sense, control was tangible. The mother communicated that there were few things that she would approve Angie doing without her knowing or that she would not assist with.

As mentioned, Angie's mother is very actively involved in her daughters' life. Angie's mother admitted on some occasions that she was the only person who knew how to

handle her daughter. It also emerged during the interviews that Angie's mother knew the complexities of the condition and therefore she knew what her daughters' needs are.

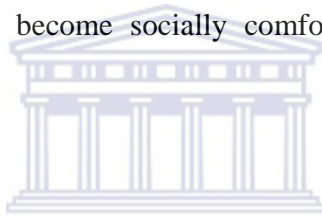
The fact that Angie was only fifteen years old at the time of the interviews is another factor that must be considered as a reason why Angie's mother was overprotective of her daughter. The fact that Angie was only an adolescent warranted the over protectiveness of her mother. Therefore the over protectiveness might not only be a result of the fact that Angie has Arthrogyrosis, but could be a result that she was still under age. One gets the sense though that the over protectiveness of Angie's mother would not stop when Angie is an adult. It is my opinion that Angie's mother will be protective over her for the rest of her life.



It is understandable that parents would be concerned for their children especially if the children are still under age. Angie's mother is certainly no different from any other parent. However the concern is that over parenting might cause the parent to lose sight of the fact that children in the adolescent phase need that space to develop their own identity. From the interviews with Angie and her mother, I was concerned that Angie's mother might be so over protective that her daughter would not be able to develop the important skill of coping in the social world. Angie's mother might come across as being over protective which could have an affect her on her daughters' social interaction.

It was evident that Angie cannot function without the aid of her mother. In some instances during my interviews with the adolescent and her mother I got the sense that

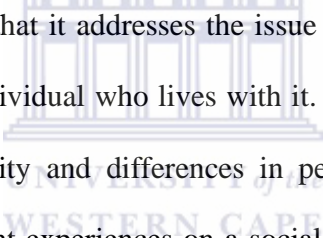
Angie's mother would become anxious if she (Angie) is not home at a designated time. It is understandable because Angie needs assistance with the performance of some tasks whether it is at home, school or at a social gathering. However the concern is that Angie might not develop the sense of self-efficacy, which will give rise to the ability to do things for herself that are within her capacity. The recommendation in this regard would be that Angie should be allowed by her mother to spend some more time with other adolescents her age. This may allow Angie to develop a more assertive personality and therefore adapt to social environments. This step might address her mothers' anxiety over the safety of Angie if she is with other non-disabled adolescents in a social situation. This step will help her in turn to become socially comfortable with other non-disabled adolescents.



As mentioned, Arthrogyrosis is a condition that is very rare and is not well known by many people. During this investigation it was apparent that Angie's condition is not well understood by non-disabled adolescents. In the interview she mentioned that at times she had to educate other non-disabled adolescents about her condition. This was an indication that, as mentioned, many do not understand the condition. The fact that she was willing to share her knowledge about her condition with others is a step in the right direction because this is an indication that she is educating others about Arthrogyrosis. Educating others about Arthrogyrosis could be viewed as a way for Angie to come to terms with her condition, as this would also teach her about herself. Understanding the condition would be a personal journey in understanding the complexities of the condition and why it presents the way that it does. Angie should view this as self-educational and this might

be done by finding material on Arthrogryposis, which would help Angie understand the complexities of the condition.

During the interviews Angie did not give me any sense as to how much she knows about Arthrogryposis. Therefore I got the sense that she does not have factual knowledge in order to properly explain to others what Arthrogryposis is. In order for her to obtain factual knowledge about Arthrogryposis, another recommendation would be that Angie equips herself with such knowledge by requesting reading material from medical experts, or to consult literature on disabilities in her local library or the internet.



The relevance of this study is that it addresses the issue of the effect that this condition has on the social life of the individual who lives with it. Because this condition presents with different grades of severity and differences in personality and parenting styles, individuals would have different experiences on a social level. However Arthrogryposis will have an effect on the social life of the individual who lives with it, however small. By conducting this study the hope is expressed that it be used to understand how this condition affects those with Arthrogryposis psychologically. In this case the onus fell on the psychological processes that gave rise to the thinking about the coping of this individual not only on a social level but also with her condition. This study therefore seeks to create awareness of the complexities of this condition on having a satisfying social experience wherein others could be taught about Arthrogryposis and how it affects the individual who lives with it.

5.1 Limitations of the Study

There were several limitations in conducting this study. These were the factors, which came to the fore:

- a) Much of the interview with Angie and her mother were inaudible. This meant that much information, which could have been used, was lost.
- b) The absence of the participants' biological father or stepfather was another limitation to this study. Because of the fathers' absence I could not get input as to how their behavior towards their daughter might have an influence on her social coping. Their input could have provided the study with more insight into how their daughter could improve her social situation.
- c) The participant was very shy and inhibited during the first interview. As the researcher, I assume the reason for this could be because I was (a) male and she might have shared more experiences if a female conducted this study. As a result of this, I had to schedule another interview. In order to give me more information I allowed the mother to give some input in the interview.
- d) The participant was socially inexperienced and did not provide me with much information about her coping mechanisms in social situations. She was also very over protected and because of this her mother provided me with much of

information.

- e) Another limitation to this study is the fact that I had difficulties in getting hold of other possible participants for this study. At one stage another adolescent agreed to participate in the study, however she and her family relocated to another town without leaving contact details of where to reach her. That prompted me to start the search for other candidates.

- f) Transport was another limiting factor in the sense that, if available, it would have allowed me to go to the home of the adolescent to meet her, her mother and her father or stepfather first hand. If I would have had transport at my disposal I could have made the process easier for both the adolescent and her family because they would have gotten to see the fact that I too live with Arthrogyrosis and therefore telephone conversations would not have been necessary to develop rapport. To get to the venue (it seemed as if it) was a very tiring process as it is very difficult for the adolescent to travel by public transport because her condition does not allow her to do so. Unfortunately, the only mode of transport that was available to Angie and her mother was public transport.

The limitations to this study therefore were: some of the information may have been lost because the interview was inaudible at some stages. The absence of the biological/step father was a limitation because their input could have provided me with much more

information. The adolescent in this study was very shy and was reluctant to participate in the study. Another limitation to this study was the difficulties in finding participants to participate in this research. Transport and the lack thereof limited me in the sense that I could not meet the participant and her parent(s) at home initially. The participant had difficulties in traveling to campus where I had scheduled an interview with them.



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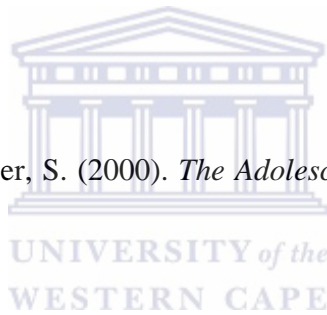
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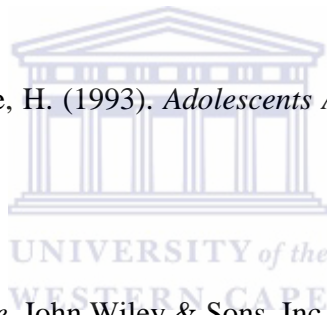
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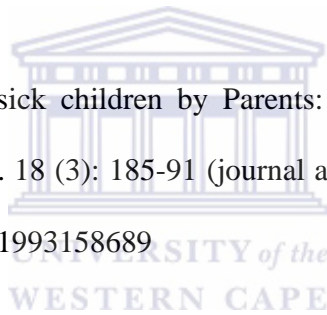
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Appendix A

The Social Coping Experiences of an Adolescent with Arthrogryposis Multiplex Congenita

Interview Guide

1. By what means do you attend social gatherings?
2. Do your friends/peers make you feel part of the group at social gatherings?
3. Do you have difficulty in communicating with the non-disabled?
4. How do you handle a situation at a social gathering where you are ignored by non-disabled guests?
5. Does your condition make it difficult for you to socialize? If so, in what way?
6. How has A.M.C. impacted on your life?
7. In social settings, do you educate others about your condition if asked?



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CONSENT FORM

Title of Research Project:

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

Participant's name.....

Participant's signature.....

Date.....



Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator:

Study Coordinator's Name:

University of the Western Cape

Private Bag X17, Belville 7535

Telephone: (021)959-

Cell:

Fax: (021)959-

Email:

Appendix B

A transcript of the interview with Angie, the adolescent with Arthrogryposis Multiplex Congenita.

Morné: “Okay. This is the interview with Angie and this with regards to the thesis on The Social Coping Experiences of an Adolescent with Arthrogryposis Multiplex Congenita.....”

(Pause while getting ready for the interview)

Morné: “Okay. Can you tell me, by what means do you attend social gatherings, in other words – how do you get to a social gathering where other people are? Do you travel by car, or do people come and pick you up?”

Angie: “If I wanna go out?”

Morné: “Yes.....”

Angie: “They come pick me up.....” (Silence)

Morné: “So, they come and pick you up. Okay..... So, do they come pick you up by private vehicle or do they come pick you up by special bus, or.....”

Morne: “By special bus, okay.....”

Angie: “Mommy.....” (Asking mom to help answering the question)

Mom: “Should I now..... Ja, they come and pick her up by special bus when they out the whole day.....”

Morne: “When they go out the whole day.....”

Mom: “Yes.....”

Morne: “Tell me something. Do you have difficulties with private vehicles, or.....?”

Angie: “No.....”

Morne: “No....”

Angie: “Yes, yes, yes.....” (Laughing)

Morne: “Okay. Can you tell me more about it? (Silence) Can you tell me more about the difficulties?”

Angie: “When we are in taxi, it is awkward.....”

Morne: “So public transport. You have difficulties with public transport

Angie: “Yes.” (Answering matter-of-factly) (Silence)

Morne: “Anything you wanna say, mom with regards to public transport?”

Mom: “Mostly public transport that she has a problem with.....”

Morne: “.....okay”

Mom: “When they have to left, sometimes taxis are not convenient inside (inaudible).... For her legs to..... There’s no space to.....the one is.....like straight and the one can’t bend. The one is bending and the one is straight. So, I always have to be...(inaudible)...comfortable for her to sit.....(inaudible)....That is why we don’t use too much public transport. I would ask someone to take me where I want to be. It makes it more difficult.....”

Morne: “Okay. So, you have to, uhm, if you wanna use public transport, sorry private transport, you need to ask someone.....(yes – mom)...to come and pick her up.....”

Mom: “.....pick both of us up and I have to pay that person and take me to that place and bring me back again”

Morne: “Okay. So I assume it is someone that knows about her condition.....”

Mom: “Yes, yes”

Morne: “.....okay”

Morne: “Okay. So you’re comfortable with that?” (Directing question at Angie)

Angie: “Yes”

Morne: “It’s someone that you know and that can help you. So, you travel by, if you wanna go out, you travel by special bus.....?”

Angie: “Yes”

Morne: “So, did you ever, um, travel by public transport, other than a bus, if you wanna go to say, for instance an occasion. Can you tell me more about it?”

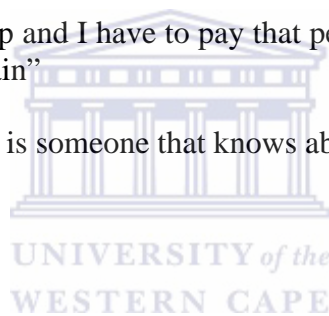
Angie: (Nodding)

Morne: “When was that?”

(Silence)

Angie: “Can’t remember”

Morne: “Can’t remember....”



Morne: “Okay. Okay, your friends, and I’m specifically refers to your non – disabled friends – you have non – disabled friends.....”

Angie: “No!”

Morne: “Are all your friends disabled?”

Angie: (Nodding affirmatively)

Morne: “Okay. So do they make you feel part of the social group if you go there?”

Angie: (Nodding)

Morne: “They do. So, you feel confident and part of the group?”

Angie: “Yes”

Morne: “Were there times when she would perhaps come back and say that she didn’t feel good about.....(directing question at mom)

Mom: “Then again she would always enjoy herself with the group that she went out with”

Morne: “Okay. So you feel comfortable with them each and every time you are bonding with them, you feel comfortable and you feel confident and that.....”

Angie: “Yes...”

Morne: “Okay. Tell me something. Do you have difficulties in communicating with people who are non – disabled?”

Angie: “No...”

Morne: “Okay. So, do you say what you want? Do you say if you want something?”

(Mumbling by mom and daughter)

Mom: (Inaudible)

Morne: “So, you’re used to asking. Okay, so why is that?”

Angie: “Because I can do it myself. Because you can do it by yourself”

Morne: “So, when you tell them that you can’t, and they say that you should do it by yourself and that kinda stuff. So does that make you feel like going back.....(inaudible)....Mom? How do you feel about communication with people who doesn’t have a disability?”

Mom: “Well, she do communicate with, uh um, well they don’t notice that she has a handicap at first, due to her face or whatever, they don’t notice. And when she

ask for something then they say, 'no, she can go fetch it', and I say, 'no, she can't'. And then they wanna know why she can't go fetch that thing. Then they as, 'go fetch me a glass of water'. Then I say, 'no she can't'. Then they wanna know why she can't because she looks normal. Then I say, 'no, she is handicapped' – haven't you noticed anything?' But, um, the non – disabled, they do adapt. They do adapt to, um, um, her condition and knowing that she can't do this and she can't do that. So, um.....(silence). She's quite content with them, but sometimes they can be very....(silence)....especially the youngsters, and 'you can go do that, don't ask me'...."

Morne: "Uh-huh"

Mom: ".....I just, uh...."

Morne: "So, it seem to me as if they, um, they have no insight into....."

Mom: "Uhm...."

Morne: ".....her condition and they don't understand"

Mom: "Yes they don't understand....."

Morne: "Ja, so they, they have this perception that she can....."

Mom: "She can do that, ja"

Morne: "They don't really understand why she cannot do it....."

(Mom confirms)

Mom: "It's not the time to explain what is wrong with her or whatever. But, um, she'll tell you one day, what's actually wrong with her. She doesn't like it.... When she was young, when she was growing up, she didn't like people looking at her.....(inaudible).....don't look at her, staring at her. She would shout at you or..... And I'd say, 'don't shout at him', 'but, they're looking at me!'. Why you're looking at me?' (Emulating Angie). Then she wanna know why you looking at her. Due to her handicap maybe. They're just looking. Some people are arrogant, some people don't.....you know God made people like this and just, leave it....."

Morne: "Absolutely...."

Mom: "They will grow to accept you after all, so..... And gradually they will learn to accept it. A lot of children know that she is like that and some can be very, uh – um, should I say mocking her or whatever – making fun of her. She comes in and she cries or whatever. I say, 'just leave it'. Sometimes I have to go out and have to do something. She's so angry but she's angry at me....."

Morne: ".....Uh-hum"

Mom: “.....I can’t go hit that child saying you don’t do this, you don’t do that. I go the child’s parents and tell them, ‘you speak to your child’ and tell him his not the only child in this world. There are other children too. Then the mother can sort him out. And then she’s satisfied. But, I’ve told her she must try defend herself. She had to. I’m not gonna do it for her. She had to. She had to defend herself. Always come running, crying just because that one said..... Its more than....(inaudible).... That’s not why I’m not saying anything(mom speaking to Angie)

Morne: “It seems to me as if the overwhelming theme that comes through is the fact that, um, people are, especially children

Mom: “Ja..”

Morne: “.....have no insight into disability in other words. So, they don’t, can’t understand.....”

Mom: “Ja...”

Morne: “.....why people are disabled”

Mom: “Yes... That is a good point, I think because,..... like children when they grow up they see other children, then the must go research or whatever and their parents should tell them too. We have a lot of children here, but that one has God made, that one like that and that one like that. So you can’t go mocking that one and this one.....”

Morne: “.....absolutely....”

Mom: “.....you see?”

Morne: “So they need to understand that there are differences between children.....”

Mom: “.....between children, yes”

Mom: “The thing is she is at (school’s name). So (school’s name) is just a school for physically disabled children. Now you go to (school’s name). (School’s name) is a school for the physically and mentally disabled.....”

Morne: “.....uh-huh....”

Mom: “You see, its on both on that side again, you see....”

Morne: “Absolutely....”

Mom: “Now, now the difference there is the one child is gonna mock the other one, because the one child makes that kinda sounds and the other one makes that kinda sound. That is a whole – that’s what’s been happening in there. That is why her. That is why her paritive of getting in at (school’s name). She’s going to mock the other children making sounds. She saw that baby making, uh, uh,

that sound. That baby is mentally disabled. And I should start doing the same thing, you see. Now she's older, now someone else's who is normal is mocking her now. And now she's crying"

Morne: "Were you at (school's name)?" (Directing question at Angie)

Angie: "No!"

Morne: "Okay..."

Mom: "They wanted to put her there and they said no, her therapist said no..."

Morne: "Okay. So have you ever been to a gathering where there are non – disabled peers?"

Angie: "Yes"

Morne: "Can you tell me about it?"

Angie: "I went out with a group.....(inaudible)..... So, we mixed with other children..."

Morne: "So they were mixing with you freely....?"

Angie: (Speaking inaudibly)

Morne: "So its okay with them.....?"

(Angie confirms)

Morne: "So, what do you do, you are actually educating others about your condition....."

Angie: "Yes, yes"

Morne: "And they respond positively to it?"

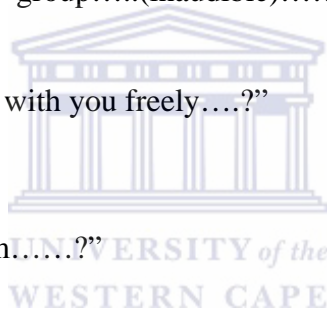
Morne: "Tell me something. How would you say for instance you would go to a social gathering, um, were there non – disabled children who ignored you?"

Angie: "No"

Morne: "So all of the talked with you and mingled with you?"

(Angie confirms)

Morne: "Tell me something. How would you, say for instance you would go to a social gathering where there are non – disabled peers – um, how would you handle it if some of them ignored you?"



(Silence)

Angie: "I'd rather go home"

Morne: "You'd rather go home"

Angie: "Yes"

Morne: "Okay"

Mom: "She's the type of child who wouldn't talk easily, to make friends, but if they talk to her, then she will talk too. And, um, if she don't feel comfortable, um in the conversation or whatever, then she tells me, then we go home. 'Take me home. I don't feel like being around anymore' (emulating Angie)..."

Morne: "So, she would talk to you about it and....."

Mom: ".....and tell me about it. She wouldn't tell someone else. If she's looking uncomfortable, she will come to me and tell me"

Morne: "It seems to me, it comes across to me that you spend a lot of time together....."

Mom: ".....uh-huh..."

Morne: "Is that.....?"

Mom: "Yes. The only time I allow her to go out and stuff. The only time I allow her to go out, is.....(inaudible)..... They go away for the weekend. They go to a hotel and they're gathering with the mothers of children having talks over HIV and Aids and anything they can talk about. They must just like, give their input – what they think of the disease and all that and they have a nice weekend, but I do, I let this weekend but she must come back at the end of it and Angie is fine and everything, because Angie wouldn't tell you to help her....."

Morne: ".....uh-huh..."

Mom: ".....because she will try and do that thing on her own even though she knows she can't do it....."

Morne: ".....absolutely...."

Mom: ".....but she will try to do it. She will try to undress herself instead of asking this lady to undress her, and uhm, that's the only time she goes out alone. But where ever I go or whatever, to functions or whatever, 'cause normally I'd go out alone before, but now I don't because I always think about her. I couldn't go out and leave her with something else. I always think about her. Can people handle her or whatever.....(inaudible).... I don't even allow her to go on holiday, school holidays are alright, because being over protective in a sense

or will people be able to handle her. Will she be able to tell this and will she be able to..... for me I two days it's enough for Angie to be away and then she must come home. If she's gone for a week, and its time, cause I know she's coming back on a Sunday. But alone? No...."

Morne: "So you are.....if you are not with her, you are very, very concerned about her well being....."

Mom: ".....yes, yes"

Morne: ".....and whether other people can handle her like....."

Mom: ".....yes, yes..."

Morne: ".....you do.."

Mom: "Yes I am. Even if she tells my sister-in-law also.....(inaudible).....can they help her. If she goes to the toilet, can they clean her properly like I do....."

Angie: ".....they do it....."

Mom: "They do it. But for me as a mother it feels I don't want to put a burden on someone else to do things for my child 'cause I'm use to doing things for her. And I know how to handle her, I know how to put the food down, and, how the level must be for her to eat off the table and whatever and I thought 'I know exactly what to do.....(inaudible).....to push a bench here and a table there, you know what I'm saying?"

Morne: "Absolutely"

Mom: "So, she knows"

Morne: "Its sounds to me as if she, the fact that she wants to undress herself"

Mom: ".....uh-huh...."

Morne: ".....um sounds to me like she has the confidence within herself that she can do it. She's able to do things for herself."

Angie: "But I can do it"

Morne: "You can do it"

Mom: "She can do it"

Morne: "Absolutely"

Mom: "She believes she can do it. Then I just leave her. There are times that I tell her that I'm going to the centre. I lock the door - throw the key through the window. So, whoever phones - don't pick up the phone. Whoever knocks on

the door – you don't even look through the window. You don't give adds – nothing. You just sit inside and that's it – wait until I come back.....(inaudible).... When I come back, you've just been bathed. She, um, sort herself out.....

Morne: “Okay.....”

Mom: “The only thing is that she cannot, like, um, um, make coffee and.....and that. So I never allow her to do that – to put on the kettle, or to pour water out, but she can, if she wants to make her bread, then she can do it. Although she'd struggle with it, I'll leave. I'll let it be – well she must learn”

Morne: “Absolutely.....”

Mom: “I told her that she must learn to do something. But then for me, I see it's so difficult, because of the way she handles the stuff. I'm gonna do it for you. I take it out of her hands and I do it, which, is also wrong. But the thing is also this, I can't see her struggling with something – that's the main point.....”

Morne: “Uh-hum.....”

Mom: “That's why I'm doing everything for her”

Morne: “So it's difficult for you to see her not being able to do things.....”

Mom: “Uh-hum”

Morne: “You know the interesting thing about what I just heard is the fact that you can make your own bed.....”

Angie: “Yes, yes...!”

Morne: “.....that you can make your own bed”

Angie: “Yes, yes and my mommy's.....!”

Morne: “And your mommy's?”

Angie: “And when I'm finished with bed I go wash up.....”

Morne: “Okay. The kitchen?”

Angie: “Yes and when my mom's finished and she comes in the house is clean.”

Morne: “Okay, okay. So you have the ability to do the dishes as well?.....(silence)...That's very interesting. So you are, I can see you are very over protective.....”

Mom: “Yes, I am”

Morne: “Tell me something. If you had to go to a gathering a social gathering where there are disabled people and non – disabled people, does your condition make it difficult for you to socialize?”

Angie: “Yes”

Morne: “How so?”

Angie: “It’s like my mommy is not there. Now, there’s like a bottle standing, a bottle of juice and that. I can’t pour myself or dish my own food.....(Inaudible)....”

Morne: “So, do you ask people to help you?”

Angie: “No..”

Morne: “You don’t ask....”

Angie: “No...”

Morne: “Okay. So, you’re not hungry and you’re not thirsty.....”

Angie: “Yes..”

Morne: “Okay....”

Mom: “She....(inaudible).....when I’m not around. She feels that she’s going to be a burden to the next person if she asks for something – ‘Angie, have you eaten yet? No, I’m not hungry..... (emulating Angie). That’s how she do things. I don’t know why she does it. She’s used to me doing everything for her – putting her to bed or whatever. That’s why she....(inaudible)..... and when she comes back, I’d ask, ‘did you eat?’ No, and now she’s hungry because she never ate. They were all eating and now she was just sitting – she’s not hungry, she’s not hungry. She would starve herself. She couldn’t ask for someone jut to give you something, no.....”

Morne: “So did you..... Tell me something. Did you.....(silence).....have you ever ask someone for help?”

Angie: “Yes”

Morne: “You have? Can you tell me more about it?”

Angie: “A girl from another school. We had something on. We ate with our hands. But she dished my food and she nicely took out a spoon out of the salad – she took it out and give it to me.”

Morne: “So, she helped you to.....”

Angie: “Yes. She said, ‘here, eat with the spoon’”

Morne: “And how did you feel about it?”

Angie: “Good”

Morne: “You felt good about it. Was that the only time that you’ve asked or help?”

Angie: “I only ask her....”

Morne: “You only ask her”

Angie: “Yes”

Morne: “Can I ask. What is it about her that makes it okay to ask for help?”

Angie: “If you ask something, she’ll do it. If I come late then, she’ll take my bag and take out my stuff out and yes.”

Morne: “So, she helps you whenever you guys are in the vicinity.....”

Angie: “Yes”

Morne: “Mom, do you know her?”

Mom: “I don’t actually know her actually, the girl, but, um, she obviously help.....(inaudible).... You can always ask her what’s happening.....”

Angie: “(inaudible).....also helps me”

Mom: “She walks home with her too. Carry her bag, wait for her and they walk together.”

Morne: “So, she’s quite a good friend.”

Mom: “Ja, she don’t come by our house. Her parents also don’t allow her to walk around....”

Angie: “Her parents like me.”

Mom: “And she can go to their house, ja”

Angie: “But no-one else”

Mom: “But no-one else can”

Morne: “So, you do have, like I understand it, social contact with her?”

Angie: “Ja”

Morne: “And she’s non-disabled?”

Angie: “Yes.”

Morne: “So, it seems to me that as if you are more comfortable with her than most other times that you have been with other non-disabled, because she understands you better than other non-disabled people do?”

(Angie confirms)

Morne: “Okay...”

Angie: “There in my road also....”

Morne: “In your?”

Angie: “In my road.....”

Morne: “Okay. Other people in your road....”

Angie: “Ja.”

Morne: “Okay. What about you, mom?”

Mom: “Like she said. It’s like that. And then people in our road too – they know how to go to the shop....(inaudible).....how to handle her.....”

Morne: “Sure.”

Mom: “.....how to hand her money to her, put stuff in her bag, or whatever, they take care of her.”

Angie: “If they see my mommy they run.....”

Morne: “So, um, it seems to me as if they know about your condition - about your inability to pick your money up. So they come running and.....”

Mom: “The one time also – she slipped. I was inside.....”

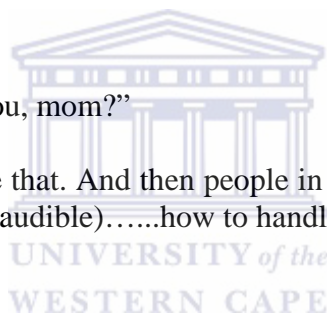
Angie: “.....and a boy.....”

Mom: “.....and a boy just came running and picked her up and the neighbour on the opposite side picked her up.”

Morne: “.....yeah...”

Mom: “.....because she can’t get up by herself.....”

Angie: “I fell on my bum.”



(Giggles)

Morne: “Okay. So, tell me more about it. How did you feel when the boys came running out and helped you and picked you up?”

(Angie giggles)

Morne: “How did that feel?”

Angie: “Its okay. Sometimes people just walk passed – ‘you get up yourself’. Its actually just the boys that helps, not girls”

Morne: “You think its because, um, the boys go to you not them.....”

(Angie giggles)

Morne: “.....and not the other girls – something like that. So mom are you okay with your neighbours?”

Mom: “Ja...”

Morne: “.....if they are around then you know that she’s going to be okay”

Mom: “When she’s outside – its just sometimes that I don’t allow her to outside. The environment is not so okay by us. I don’t allow her to go outside – she’s got to stay inside”

Angie: “Like.....(inaudible).....also. I ran and I fell. Now they were shooting and I was the only one outside.....”

Mom: “.....the only one outside”

Angie: “.....the one gangster picked me up and said, ‘run in’”

Mom: “.....you were standing outside...”

Angie: “But they just live in our road. They just picked me up and said, ‘run in’.”

Morne: “Okay. So they were quite aware of you.....”

Mom: “Uh-huh.....(inaudible).....They are aware of her, yes. Don’t allow her to be outside when they are busy with their activities.....”

Angie: “They warn me, ‘go in’”

Mom: “They do. When she’s outside they see her outside they say, ‘we’re gonna start now’”

Angie: “And then they warn me before the others”

Morne: “Okay. So they are quite concerned for your safety – more than the others”

(Mom confirms)

Mom: “Cause they are playing outside”

Morne: “Okay. We spoke about, um, how A.M.C. impacts, how your condition makes it difficult for you to socialize. And you were saying – mom can you remember – regarding the gangsters.....”

Mom: “.....to go inside.....”

Morne: “.....to go inside”

Mom: “It was, um, if they do start, whatever, fusion that they have whatever outside.....”

Morne: “.....uh-huh....”

Mom: “.....they always tell her. You cannot inside. Because then they start, i was panicking – now I was thinking, ‘where is she now?’ Because everybody was running and no-one has seen her - where’s she. Eventually she came in and I asked her, ‘where were you now?’ She said, ‘no, she fell and one of them picked her up and then they told her to go inside. Because they just gave a sign, when they are gonna start shooting. And that’s why I don’t allow her to go outside. Its like, ‘go outside, finish your food first”

Angie: “Like one also. I was in when they started shooting and my mom was looking for me. They said I’m in the house.....”

Morne: “So they asked from outside that you’re.....”

(Angie confirms)

Morne: “.....in the house. Ja..... So it seems to me that even the gangsters have immense respect for you and for your safety. And I’m just, you know, it’s just a little ironic, because I just wish that they could’ve had this concern for other citizens as well....”

(Mom confirms)

Angie: “Or they warn the other gangsters when I’m around – if I see anyone of you I shoot.....”

Mom: “And then they come tell”

Angie: “Then they come tell we must stay inside.”

Mom: “You mustn’t walk around and all that”

Angie: “(Inaudible).....They see anyone they shoot”

Mom: “What about the children?” (Directing question at Angie)

Angie: “They must just stay indoors. Well, they said they’re just starting now because our road is nice and quiet”

Mom: “It’s always like going into the Festive season and it’s like, they must do something now”

Morne: “So do you feel that you are being held hostage by your circumstances, um, outside of your control? So now you have to like sit indoors, you’re not allowed to go outside?” (Directing question at Angie)

Angie: “Yes”

Morne: “So, its difficult to just..... But in any case. So the overwhelming theme here is the concern for your safety first and foremost. And I see there are two parties here – you mom’s concern for you and even the gangsters’ concern for you. Wow, that’s quite special”

Mom: “The one that is part of the gangsterism is..... (inaudible).....and he is still with his activities, but if he do see her, he would tell her, ‘look its going now, we are gonna do this now. And they pushing him around like mad thing – up and down the road.....”

Angie: “They pushing around, ja...(giggles)...just take him in with us.....”

Mom: “....uh –huh..”

Angie: “.....because he’s gonna get more shot up...”

Mom: “They’re pushing him around and chasing this one and he’s chasing and that, the side of the wheelchair hitting and that, but if he sees her outside, then he tells her, ‘you must go in now – we’re gonna be outside’.....”

Morne: “Okay. So is he the one who always warn you to go outside?”

Angie: “....or the others...”

Morne: “Or the others.....”

(Mom confirms)

Morne: “Okay. It comes across as if they know what it is like to be disabled and because they have a disabled gang member.....”

Mom: “Uh – huh”

Morne: “.....and so they try to hid her.....”

Mom: “Yes....”

Angie: “He’s not disabled – they shot him like that”

Morne: “They shot him like that?”

Mom: “They shot him, yes. He’s disabled cause he can’t help himself”

Angie: “And the other one’s getting mad” (Giggles)

Morne: “Okay. It is so interesting, because I’ve never heard about, you know, gangsters’ concern for the safety of others.....”

Mom: “Ja...”

Morne: “So even he doesn’t allow his disability to get in his way of his gangster activities”

(Mom confirms)

(Angie speaks inaudibly)

Morne: “You know, Ive heard stories about, um, some disabled guy in Strand, um, He, um, he had this leg.....”

Mom: “Uh – huh”

Morne: “.....that he used to drag and I remember in the early 90’s when there still gang activities going on, um, he was the king pin.....”

Mom: “.....uh – huh...”

Morne: “Now, he was the one who hang in the front of the guys and, you know, standing with two knives and that kinda stuff. So, you know, this guy reminded me so of the other king pin guy I used to know.”

Mom: “I don’t know why this, I mean, he’s in a wheelchair. Now what, what can that do for you? Because they just come and give you a big smack and you, which I already did to him.....”

Angie: “.....and out of the wheelchair.....”

Mom: “.....out of the wheelchair”

Angie: “And the ladies skel here, ‘jy kan kom, jy kommie met jou gun na my toe nie – jy kan kom na my toe met jou hande.....”



(Giggles)

Morne: “But tell me something. Does he, um, does he like use a firearm?”

Angie: “No. He uses pellet guns”

Morne: “He uses pellet guns?”

Angie: “Yes.....”

(Mom confirms)

Angie: “.....They said, they tell me, he doesn't have a real gun. He has a pallet gun just to make them scared”

Morne: “Okay. So he doesn't use the real deal.....”

(Giggles)

Mom: “They feel macho or whatever.....”

Morne: “.....Okay....”

Mom: “.....because they told him already when I went out, ‘you are having your feud with whoever, but if anything happen to my child when she's outside then you gonna see what I'm gonna do. Then tehuy somme say I'm gonna go piemp or I'm gonna do this and that. But the fact is this – it is my child. If she's outside and you starting whatever, it's over..”

Angie: “My daddy also said if something happen to me, then he's gonna take it out on him also...”

Morne: “So your dad's gonna take it out on him?”

Mom: “Yes. If anything happen to her if she's outside, and like just going out to the shop and anything is happening in between, that time, then they're gonna.....(inaudible)”

Morne: “Then would I be right in saying that the reason why your dad is going o be hard on him, is because he knew about your condition, and yet.....”

Mom: “.....yes. He started it!”

Morne: “Absolutely, yes...yes. And he didn't take it into consideration”

Mom: “Yes, yes. That's what he said last night, because they started it. You have to an dothers.....(inaudible).....other peoples' driveway just to go out”

Morne: “So, it disrupted your normal.....”

Mom: “Yes”

Angie: “or they stand in the other road and they shoot over, OR they stand on the roofs”

Morne: “Sounds like a war zone”

Mom: “If they start, it’s a war zone”

Angie: “You can’t stand near your window, you can’t go to the bathroom. You can go no-where. You must just sit in the dining room, bent down”

Morne: “Okay. But I think if I can say that the positive that comes out of this story is the fact that they are, first and foremost concerned for your safety and whether you are safe at the end of the day, and I think that is a good thing.....”

Mom: “Uh – huh”

Morne: “Okay. Um, just in a general sense – how does A.M.C. impacts on your life or how did it impact on your life?”

(Angie speaks inaudibly)

Morne: “Just in a general sense”

Angie: “I don’t understand”

Morne: “You don’t understand. Okay. What I mean is, um, does it have negative effects on you? If so, what are they? What are the positive impacts that it has on your life?”

(Silence)

Morne: “Say for instance you, um, something like, ‘because of A.M.C. I cannot swim, or because of A.M.C. um, I cannot embark or disembark from trains or taxis or that stuff.....”

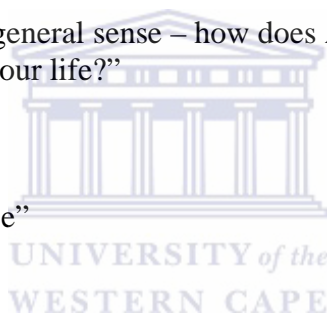
Angie: “Yes.....(inaudible).....I can do nothing with my disability. I can’t do what other people do. So.....”

Morne: “So, just give a general sense. What can you do and what can you not do?”

Angie: “I can wash myself...(mom and daughter mumbling).....I can wash up, and I can climb stairs, I can lift a glass with my teeth.....”

Morne: “With your teeth?”

Angie: “I can’t use my hands”



(Silence)

Morne: “Okay. So, ja. Earlier you told me that if you are at a social gathering then you wouldn’t ask someone to pick the glass up for you and that you just leave it.....”

Angie: “Yes”

Morne: “Okay. Is that, um, does that perhaps have, um, an inhibiting effecton your social life?”

Angie: “Yes”

Morne: “Okay, so it inhibits you to go out and.....”

Angie: “Yes”

Morne: “.....be social. Okay..... Is that the only difficulty that you have?”

Angie: “Yes”

Morne: “So, it’s only the handling of, um, stuff like cutlery and glasses? Tell me something. Um, how do you, um, say for instance you have to go to the movies, the movie houses, are they accessible to.....”

Angie: “Yes”

Morne: “So, you can – you don’t have difficulties going there, sitting down and watching a movie.....”

Angie: “No...”

Morne: “Tell me about the.....(inaudible).....positive aspects of A.M.C. What do you think? What are the positives that you can take from your condition?”

(Silence)

Morne: “Is it difficult to think about it now?”

(Giggles)

Morne: “Say for instance, um, something like, um, you always have people around you, or like I just heard now that even the gangsters are concerned about your safety. Okay, what other advantages?”

(Mumbling by mom and daughter)

Morne: “Mom, what are your thoughts? What do you think, um, are the positives that you can take out, for instance? Just off the top of your head.”

Mom: "A lot."

Morne: "A lot. How do you feel with regards to her condition? Are you positive that she'll be able to, one day runs her own home, because there definitely are some things she can do for herself....."

Mom: "She always tells me if she can handle herself. She's gonna make her own food, she's gonna drive her own car and she's gonna do things or herself. That is how she thinks positively. For me its..... I think, 'how are you gonna do that?' 'How can you chop the onions? How are you gonna peel the potatoes?' then she tells me, 'there's a machine that can do that, and there's a machine for that'.....(inaudible).....and she's gonna drive her own car. How you gonna drive your own car? Everything's gonna work with my hands. If she's gonna do that thing, then she will be able to do that thing. So, I just say, 'we'll see when it comes to that'"

Angie: "My dream car is actually a Ferrari....."

Morne: "A Ferrari?"

(Angie confirms)

Morne: "So, what is it about a Ferrari that is so....."

Angie: "The doors can go up. Easy for me than this one"

(Pause)

Morne: "Do you feel that um, cars are made for non-disabled people only, or not?"

Angie: "No"

Morne: "No"

Angie: "It's for everybody"

Morne: "Okay. So would you be able to climb into a convertible car where the doors open up like this and not like this?"

Angie: "Yes, but a person must close it for me"

Morne: "Okay.....(Pause). Let's pause for a moment there at the car story."

Mom: "Uh – huh"

Morne: "If you, say for instance, you had to go for your driver's licence, um, would you be able to close the doors and put your hand on the steering wheel and that kina stuff?"

(Angie confirms)

Morne: “You can. Okay. And, um, would you be able to manoeuvre the gears as iis on the floor?”

Angie: “Uh – huh”

Mom: “She believes she will do that. She’s got that positive attitude that she’s gonna do that thing – she’s gonna drive a car. She believe it.”

Morne: “Okay. So.....you know the overwhelming theme that comes out of this, is the fact that you have an unbelievably strong will”

Mom: “Yes she does. Since baby already she had that will. She’s gonna walk – ‘I’m not gonna walk with splints, I’m going to walk’ And she brought herself to walk. She was three months and she sat up, because she believe she can sit. Nine months, um, started eating on her own – I mustn’t feed her anymore – she wants to eat now. That’s why, um, its..... its from growing up already that she was like doing her own thing.....”

Morne: “Uh – huh”

Mom: “Sitting on the floor sliding on her bum – ‘I’m going to walk’, and she did it. So, I never had any problems with her in that. I just need to be, as a baby, explore things for yourself. You feel the ground, you feel this, you feel that and you must decide what to do with it. But as she grew up she always – ‘Im going to do that, I can do that’. She never said, ‘I can’t do that’. ‘I can wash’ ‘How are you going to wash you? Show me how you gonna wash you?’ And she showed me. How did you get soap on your washcloth now? Put it in between my hands and just rub. How are you gonna wash your neck? Now you must show me. For me it was..... I was just sitting. Oh, it was amazing. She threw the washrag, put it in your mouth and it fell on the chest. How are you gonna wash your neck? Because you can’t lift your arms up and she use her chin to wash her neck.....”

Morne: “Uh – huh”

Mom: “.....and I was just sitting. Now, how are you gonna do your back now? And she threw her washrag up and.....the amazing part of it hey, its like the washrag fell open to be on the back.....”

Morne: “.....wow”

Mom: “.....It fell open.....”

Morne: “.....wow..”

Mom: “She threw it with her mouth, and.....and, and it was there to and she leaned back and she washed her.....”

Morne: “Wow!”

Mom: “Who taught you that? ‘Myself, cause I can do it’ And I just said to myself, ‘you said you can do that thing. So, it comes to your mind, that is how I think that thing comes to your mind and that thing knows you gonna throw me..... Its, its a piece of rag. You’re gonna throw it now, but I know, I know it must be open and it just fall in that position and she’s done.....”

Morne: “Wow....”

Mom: “And I just come and I check on her. But she moans, she can do it....”

Morne: “Absolutely, absolutely. And you know the amazing thing that I’m just thinking now is the fact that she compensates so well for the things that she cannot do.....”

Mom: “.....yes”

Morne: “.....and she’ll find a way, and she’s so creative, you know. She has this creative way of doing things for herself”

Mom: “Ja, ja. And finding that that is suited for me.....”

Morne: “.....Uh – huh”

Mom: “So, I’m gonna do it. Like the beginning of the.....(inaudible).....I gave it to her, and she said, ‘mommy, must I put it around your neck?’(inaudible) Now, I can do it’. How you gonna do it? And you know, it took her about ten to fifteen minutes. And she struggled and I was coming in an, ‘I can do it, I can do it. And afterwards.....(inaudible).....and she struggled and I asked her. And she said she wanne dress herself. And I said, ‘how you gonna do that?’ ‘I can do that’. The one leg is in the one pants and the other leg is on the other side. ‘Now, how you gonna pull it up?’ She gonna go lie flat on the bed leg up and, wiggle, wiggle, wiggle and she got up and she, wiggle, wiggle , wiggle, and she fastened it herself.....”

Morne: “.....wow”

Mom: “Struggling, struggling, it took her an hour to put on her jeans or whatever, but she did it by her own. She wants to do it. ‘How did you put your top on?’ ‘Oh, it was so.....I was just sitting.....”

Angie: “It was a secret....”

Morne: “It was your secret. Let’s hear your view”

Angie: “.....(inaudible) and when my mommy came in, my top was finished on”

Mom: “I asked her, ‘how did you put it on? How did you put your arms in? How did you.....?’ ‘I just wiggled and.....’ She explored on her own, doing things on her own – for dressing her and undressing her and all that. So, I just leave

her – ‘you go on. You will find a way to do a thing’. But she did. And for me, it was so amazing just to see all the time I’m dressing you and now I learned that you can dress yourself”

Morne: “Okay. Would I be correct in saying that you planned it, you planned the way you gonna dress yourself all along without your mom knowing about it?”

Angie: “Yes”

Morne: “And so eventually the day she saw you do it you surprised her in actual fact.”

Angie: “Yes....”

Morne: “And that’s why she was so stunned...”

Mom: “.....yes”

Morne: “You kept it all to yourself. That is so cool, that is so cool. And that is why, for me that is one of the positives.....”

Mom: “Uh – huh”

Morne: “.....(inaudible) the way you compensate for the things that you cannot do physically. Okay, so that is how the – that is with regards to dressing yourself. Are there other positives, or other ‘secrets’ that you have?”

Angie: “No...”

Mom: “I see she can dress her now. It must be like a sweater or whatever.....(mumbling)”

Morne: “Okay. So, what other things can you do for yourself?”

Angie: “Brush my teeth.....”

Morne: “Brush your teeth...”

Angie: “I wash my own face.....its only that”

Morne: “Okay. So mom, the fact she’s willing to help herself.....”

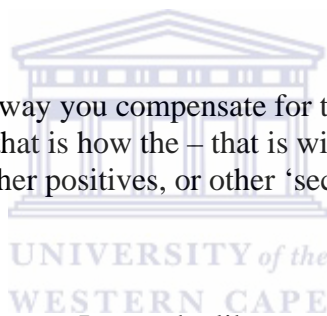
Mom: “Uh – huh”

Morne: “.....that is, she has a strong will.....”

Mom: “.....yes....”

Morne: “.....that’s what’s positive about her A.M.C.”

her comfortable.....”



Morne: “Absolutely, absolutely....”

Mom: “.....(inaudible). She will sit the whole day with a book on her bed and write. She will.....I thought she wouldn't be able to write, but um, she struggle, but she can write. She can..... ‘Don't use your toes, don't use your mouth’. I think that was the first thing she did – that was in her mouth and she was using her toes, using her toes, and I said, ‘no, use your hands! You must feel that is a pen that you hold in your hand’ and then she started to..... ‘I can write, hey!’ ‘Yes, you can write’ And for, for most of the time, the family they, they quite stunned by.....they can't believe that she's writing. ‘She wrote that’. ‘No, she can't write’. By them it's like she can't write. ‘How's she gonna hold a pen?’ ‘I can write. Can you see now?’ give her pen and paper and she'll write to you. And they were amazed and they said, ‘oh my god! I never thought she can write. I always thought she can't write. How does she then go to school? How does she write her work?’ She can write. They were amazed to see she can write. They always thought she can't write, she can't use her hands, so she showed them, yes she can....”

Morne: “Do you think that their shock derives from the fact that they had this.....this perception that she's unable to write, but they did not take into account her will to write”

Mom: “Yes, yes. They are quite shocked, ja. They were. When they saw her books.....(inaudible)..... I always go through her books checking up...”

Morne: “Uh – huh”

Mom: “.....and he asked, ‘did she write this?’ And I.....(inaudible)..... He couldn't believe this. I'm telling a lie. How can I tell a lie? You give her a pen, take a pen and give her a piece of paper and then she can show you how she write.....”

Morne: “.....absolutely”

Mom: “.....and she did it. He just, for my brother – in – law, it was – he just, ‘she has such a beautiful handwriting for a person that is disabled’. He couldn't believe it. And now, when was it, now in September holiday, he came there and the family came also, ‘how is Angie doing in school?’ He is concerned, ‘how is Angie doing in school? What was her results for her.....exams?’ And I took out rapport and showed it to him. And he said, ‘no, you did quite well, hey!’ It's not that you can't do better, she can do a little.....(rambling)..... They always say to her, ‘I'm not gonna pressure you or anything, but um, you did well. They always like that. They always congratulate her. That what you did is good. They never put her down in a sense, saying this or saying bad things or so. They always like motivate her in doing – and they always tell her, ‘what you want to do in life – you must go for it....(inaudible)..... You,

you – the fact that you are disabled ...(inaudible)...and don't let other people put you down – what you think is right – you go for it. They always motivating her in that stuff'

Morne: "So in other words in saying those motivating stuff....."

Mom: ".....ja"

Morne: ".....they are, um, reinforcing that....."

Mom: ".....ja"

Morne: ".....positive sense of self and that strong will....."

Mom: "Ja.... They saw the strong will that she has and they told her, 'you can go for this, because you're quite intelligent' she can always hold a conversation with the family, with her uncle and that....."

Morne: ".....Uh – huh"

Mom: ".....and then they talk and that and they can ask her questions, and then um, she'll answer them, and they'll say she's quite intelligent. She has a mind that tells her that she wants to do that. She always has a laugh. She wants to drive her own car and I said, 'no, if that then she tells me, 'I'm going to drive' and then...(inaudible).... I'm going to teach you how to drive. And she said, 'yes'. They're quite, they are, they motivate her a lot...."

Morne: "So, they are willing to help her....."

Mom: "Yes"

Morne: ".....with whatever she wants to do...."

Mom: "Yes. And my brother – in – law, they are like, where-ever she wants to go or whatever, they will tell me, 'don't worry, I will come pick her up, and I will see that she get's there in time and that. So they do....."

Morne: "Okay. So....." (Interrupted by mom)

Mom: "They are quite content in what she needs or whenever she needs to go or whatever, school work....."

Morne: ".....uh – huh"

Mom: ".....they're always checking up, always phoning, how did she do in the exams and they'd like to see the reports....."

Morne: ".....uh – huh"

(Silence)

Morne: “Okay. Um, you know it’s quite good to hear that there are, that she has this positive support system around her.....”

Mom: “.....uh –huh”

Morne: “.....on which she can build on a good sense of self.....”

Mom: “.....yes...”

Morne: “Okay. When you are, say for instance you are amongst non-disabled people – do you educate them with regards to your condition? And were there ever times when you talked about your condition that is A.M.C.?”

Angie: “No....”

Morne: “No. So, you didn’t have to educate people and say, ‘this is my condition, this is what it’s called, and.....”

Angie: “No...”

Morne: “No. Mom were there ever time when you told people about A.M.C. and what it means?”

Mom: “Yes. Sometimes they would ask me what is Angie’s condition and I would tell them it’s Arthrogryposis. And by knowledge of what the doctors told me, um, that she was born with this – Arthrogryposis, it’s a kind of arthritis that the child, the joint problems and the muscular problems. And some would ask, ‘now how was it the way she was born?’ And I said, ‘well when they open (me) I was like a kind of a, um, in the shape of a pear – half of a pear. My womb was like that and I never had any fluid in myself, and she was like this. Just bear – without any fluids. And she was just lying there – just bare without any fluids there in my womb and that. And for the first time seeing her like that, I was um, I always like to know how did you feel, how did you react for your first born, for being disabled. And I said it was like, it was traumatic. I was heartbroken, but I had to accept it. In the long run, I had to accept it.....”

Morne: “.....uh – huh”

Mom: “And, uh, I...(inaudible).....in hospital. And she’d always be in hospital for five days and all that. And I had to adapt to all those things. And I had to accept that God made her like that and God gave her to me like that. So, um, there’s nothing else I could do about that.....”

Morne: “.....okay”

Mom: “So as time grows, I had to accept that I have to do things for her and when she like got to like the age three to four, she asked me, ‘why am I like this? My hands are gonna stay like that?’ And um, I just... I was shocked, cause its the first time she that she was looking at herself and asking these questions. And

I just said, ‘well, God made you like that. There is nothing you can do about it. So, you just need to accept the fact that you are gonna be disabled. We’re gonna be together in this. We’re gonna see what we can do about it, and today you are big – you are fifteen.....(inaudible).....now you can explore yourself – what’s its all about. And she had to um like.....(inaudible)..... you were in grade? What grade were you in?.....”

Angie: “When?”

Mom: “....where you had to write about yourself?”

Angie: “Seven...(inaudible).....”

Mom: (inaudible)

Morne: “So you wouldn’t share what you wrote?”

Angie: “About disability.....(pause).....we made a copy. We had to find out about the disability by the physios. We found it and we must write it down in the book.”

Morne: “So, you, you talked about your, you um, wrote a little autobiography about who you are and.....”

Mom: “....uh-hum”

Morne: “.....and your condition.....” (Angie interrupts)

Angie: “Each one has a disability and everyone had to write about their own disability”

Morne: “Okay. Okay, so its um, were you asked to write about your disability only?”

(Both mom and Angie confirms)

Morne: “Okay. (Pause). So how did that feel?”

Angie: “Okay....”

Morne: “It felt okay?”

Mom: “Now, she came to me and she asked me about her disability. I said, ‘no, you have Arthrogyrosis’, and um, she had to go do her own research. So I said, ‘no you have to go find out yourself, talk to the physios and all that. They gave her all the info, and she had to write it down and.....(inaudible).....And um.....(inaudible).....she had to add a photo of herself for being like that.....”

Morne: “....uh-huh”

Mom: “.....So I gave her a photo, when she was like still on the floor – sliding on her bum. And I said, ‘that was the only one that you can now give to her. That is a perfect one that you can give there now. Tell then that you were all on the floor moving around.....”

Morne: “....uh-huh”

Mom: “.....on your bum, took hold here and that. And a copy of that.....”

Morne: “.....uh-huh”

Mom: “.....She still have, um, have to keep it there just to, um, just to tell the other children that she was like that....”

Morne: “....Ja.....”

Mom: “...you see... And um, she got points for it....”

Morne: “.....okay....”

Mom: “Ja, she got points for it....(inaudible question being asked my mom).....”

Angie: “Fifty....”

Morne: “Fifty! Wow....”

Mom: “Yes, she got points....”

Morne: “Wow! That’s so cool....”

Mom: “Ja, she got points....(inaudible)...knowing that she is actually the only Arthrogyrosis in the class. (Pause).....you see. So um, the others are more your spina bifida.....”

Morne: “....uhmmm”

(Angie interrupts very softly)

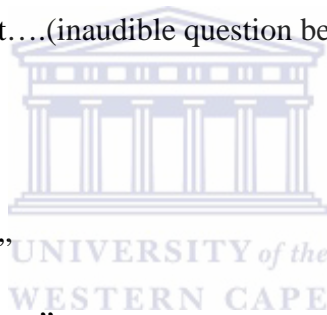
Mom: “Spina bifida. And what was the others? There’s such a lot of dinges, but um, she’s actually the only Arthrogyrosis” (Inaudible mumbling)

Morne: “Okay..”

Mom: “She go that like, like....(inaudible)...fifty up, which I was quite amazed...”

Morne: “Okay. So, in other words-you were quite unique in your class because you were the only one with Arthrogyrosis?”

Angie: “Uh-huh”



Morne: “Okay. Just a last question, mom. How do people usually react when you tell them about Arthrogryposis?”

Mom: “They are quite, um,..... ‘where does it come from?’, ‘how does it happen?’ (Long pause)....”

(Mumbling by Morne)

Mom: “They always wanna know, how does it happen. I said, ‘I have never done my research actually on that’ That’s why I was like, like I said before, like they said, it’s a muscle and a bone problem....”

Morne: “....uhmm”

Mom: “So um, there are quite a ...a – they just wanna know more about it. About this....(inaudible)....and I always just tell them that, and.... There are places where you can go to, because... like I’ve known, like what doctors told me, ‘it’s a very rare thing’, its, its all comes here after part, and um.... So um, like the family, they are just amazed and just to see her now, they are quite (inaudible). Because when she was born she was quite small and all that, um... The legs were turned and everything was...and just to see her now they are, they can’t believe that it is Angie. That it is she who was born on that time and look at her now.....”

Morne: “.....uh-huh”

Mom: “.....and look at her mouth. And she is like ‘cheeky’ and....she can talk and she can do things a little for herself, and that”

Morne: “Ja. So they are quite, um,..... So I think its because Arthrogryposis is such a rare condition. People have vever hear about it.....”

Mom: “.....ja...”

Morne: “.....and you know, its, its sounds interesting, because its not like the other conditions such as cerebral palsy for instance where you can see where it’s... Not only can you see, but it’s um, it, it happens more often than children born with Arthrogryposis.... (Mom confirms).....for instance”

Mom: “...uh-huh...”

Morne: “....and um.....”

Mom: “But cerebral palsy is like a...a daily um, how can I say, um....it’s like a yearly thing. Every year such a child is born....”

Morne: “Uh-hum, uh-hum....”

Mom: “But with Arthrogryposis, its like a very.....”

Morne: "It's rare....."

Mom: "It's very rare, ja..."

Morne: "Okay. So um, I think you have answered the questions that I had on....."

Mom: "Uh-hum"

Morne: ".....social coping with Arthrogyrosis and it seems as if she is doing quite okay with A..M.C. and that she is, um, that she can hold her own in social, in social situations and stuff. Um, ja....so allow me to say thank you so very much for this opportunity....."

Mom: "Uh-hum....."

Morne: ".....to get a looking into her life and how she perceives life to be with Arthrogyrosis....."

Mom: "Uh-hum..."

Morne: ".....and what it means to her to have Arthrogyrosis and how she cope with it. And uh, it would like to, to wish you well with your future and um each and every endeavour that you wanna, that you wanna take on, from here onwards. Again, thank you so very much"

Mom: "Ja, thank you very much, Morne....."

