

CHAPTER 10

DATA ANALYSIS

The following analytical process adapted from Colaizzi (1983), and utilised in a study by Haase (1987) was used;

1. Listening to and transcribing the taped interviews in order to acquire a sense of each protocol's meaning.

The researcher acquired a feeling for and a familiarity with the descriptions (protocols) provided by the participants by listening to the audiotapes a few times and then transcribing them. All participants could readily recall a specific and significant encounter with a non-disabled peer group which had evoked a sense of high self-esteem or low self-esteem. Because of the speech difficulties of some participants, this was a time consuming exercise. All the participants were requested to relate the specific encounter with a group of non-disabled peers in a fair amount of detail, describing how they felt and what they thought at that time, as well as how the situation

was resolved. Encounters with non-disabled peers appeared to have been very rare and therefor made quite an impression on most of the participants. Most of the participants appeared to have had few opportunities to share such experiences with others and seemed very keen to relate these to the researcher.

2.The extraction of significant sentences and phrases which directly pertains to feelings of self-esteem.

Within the eight protocols a total of ninety-five significant statements and phrases were identified which pertained to aspects of self-esteem.

3.Formulating the significant statements into a more general re-statement.

The re-formulation of significant statements into more general forms known as re-statements. The purpose of this is to transform the concrete descriptions and language of the participants into the language of science.

4. Significant statements and their re-statements are studied to derive and record a sense of their meaning, the formulated meaning.

Significant statements and re-statements are then studied to derive and record a sense of their meanings. Each of these formulated meanings is developed keeping its context in mind. Concepts, labels and processes were thus identified and clarified.

5. The formulated themes are derived from the formulated meanings and organized into theme clusters and theme categories.

Themes which were organized from the formulated meanings were then organized into theme categories and clusters to allow for the emergence of themes common to all participant protocols. According to Colaizzi (1983), it is important to note that where certain discrepancies appeared in themes, these would not necessarily be eliminated since logical discrepancies could nevertheless be existentially real and valued. Nor were data ignored which on the surface did not seem to fit. The researcher should here rely upon his tolerance for ambiguity

and should be cautious about prematurely generating any theories in order to eliminate the discordance.

6.Integration of themes into an exhaustive description of the experience of self-esteem.

An exhaustive description of the self-esteem in physically disabled adolescents in a non-disabled environment was derived. This is a narrative integration of all the themes, theme clusters and categories of themes. The exhaustive description was developed to gain insights into the structure of the lived experience of self-esteem in physically disabled adolescents in a non-disabled environment.

7.Formulation of the statement of the essential structure of self-esteem.

From the exhaustive description, the essential structure was derived. The essential structure of self-esteem is viewed as an integration of the common components of self-esteem identified in the exhaustive descriptions.

8. Validation of the essential structure of self-esteem by the participants.

All the participants were available for a short discussion on the essential structure of self-esteem as derived from their descriptions in this study. The full description of the essential structure was read to the participants, with the occasional clarification when concepts and terminology were considered complicated. Participants asked questions when anything was unclear. To ensure that there were no areas of uncertainty, the researcher also paused frequently to enquire whether specific elements of the essential structure were experienced by the participants. There was agreement that the essential structure reflected their experience.

To demonstrate the above-mentioned analytical process, two of the case studies (protocols) will be analysed and discussed. The analysis of the other six case studies will be found in the Appendix.

Case study 1

Most of my friends are disabled. I feel very uncomfortable with non-disabled people. There is this girl who stays opposite us who is my age, and who only comes to visit me about once a month. Anyway, I don't really mind because she is a tomboy, she likes playing rugby and soccer and moves around with the boys. This might be why she does not come to visit me a lot.

Sometimes I feel I don't really belong with other people. I'm not..that...I'm not the type of person to be with them...the type of person they are...they may feel I shouldn't be with them. That's how I feel. That I'm something different. Like people, if they see an alien, they'll think that they are totally different to you, to humanity...but that's how I feel, like I'm something different...I'm not a person, yeah, like that. (sigh). Feeling like something different, you don't feel like a person at that time.

Sometimes it's also like that at home. When my cousins go to the shop, they'll never allow me to go, or there are so many things they never allow me to do just because I'm disabled.

They just say no and it stays no. You have no choice. But if it is like my brother who is younger than me, then they say : "Yes you can do it anytime". But with me...uhm...it is always no, no, no. Even when I argue with them, they get all angry, that's why I just leave them the way they are. Because if I must like just tell them that I feel hurt and that they are like that with me just because I'm disabled...they feel that they can just tell me what to do, and I must just do it just because I'm disabled. Then it gets...I don't know...I don't know what they think...but they probably think that I am bad or something.

I can get quite angry. Just say sometimes like...gosh...ok, like sometimes my mother...uhm...now I'm slow, I'm very slow, and I can't help it, it is part of my disability. Now I don't know how to explain it to her. Now she always says: "Can't you move faster, can't you do that faster, must you always be so slow"...and everything...and then I told her that her that it is part of my disability, and she says that you are hiding behind your disability all the time hey, Is that now going to be your excuse everytime I tell you to do something. I tell her: "Not for everything, there are certain things

that...uhm...it is part of my disability, and I can't just change overnight...and being very slow, I can't change it at all".

They can't take it...like they never got used to it, even though I've been like this since the age of two when I fell ill. Even though they have known me for so long, and they've been living with me since I became disabled, they still can't accept it...they can't take it...like sometimes it looks like my mother is going to explode or something when I am so slow, I try to be fast, but it is so difficult. Like once something was on the stove...I was busy with my homework, and something was burning. My mother called me to take it off, but I couldn't get there fast enough. She almost exploded.

Disability just gets in the way of everything...that's how she most probably feel...ok...being slow not with everything, just sometimes.

Case study 1.(a)

2.The extraction of significant sentences and phrases which directly pertain to feelings of self-esteem.

- 1.1 " Most of my friends are disabled. I feel very uncomfortable with non-disabled people."
- 1.2 " Sometimes I feel I don't really belong with other people."
- 1.3 " I'm not...that...I'm not the type of person to be with them...the type of person they are."
- 1.4 " They may feel I shouldn't be with them. That's how I feel. That I'm something different. Like people, if they see an alien, they'll think that they are totally different to you, to humanity...."
- 1.5 " That's how I feel like I'm something different...I'm not a person, yeah, like that.(sigh)Feeling like something different. You don't feel like a person at that time.
- 1.6 " When my cousins go to the shop, they'll never allow me to go, or there are so many things they never allow me to do just because I'm disabled."

- 1.7 " They just say no and it stays no. You have no choice."
- 1.8 " Even when I argue with them, they get all angry, that's why I just leave them the way they are."
- 1.9 " Because if I must like just tell them that I feel hurt and they are like that to me just because I am disabled...they feel that they can just tell me what to do, and I must just do it just because I'm disabled. Then it gets...I don't know...I don't know what they think...but they probably think that I am bad or something."
- 1.10 " Just say sometimes like...gosh...ok, like sometimes my mother...uhm...now I'm slow, I'm very slow, and I can't help it, it is part of my disability. Now I don't know how to explain it to her."
- 1.11 " I told her that it is part of my disability, and she says that you are hiding behind your disability all the time hey! Is that now going to be your excuse every time I tell you to do something?"
- 1.12 " They can't take it...like they never got used to it, even though I've been like this since the age of two when I fell ill."

1.13 " Even though they have known me for a long time, and they've been living with me since I became disabled, they still can't accept it...they can't take it...like sometimes it looks like my mother is going to explode or something when I am so slow."

1.14 " Disability just gets in the way of everything...that's how she must probably feel."

Case study 1.(b)

3. Formulating of the significant statements into a more general re-statement.

- 1.1 Being with non-disabled people makes me uncomfortable.
- 1.2 I don't feel I belong with other people.
- 1.3 I am not like other people, and therefore they do not want to be with me.
- 1.4 Other people might not want to be with me, and that just makes me feel that I am very different from them.
- 1.5 The feelings of being different makes me feel less of a person.
- 1.6 Others prevent me from doing things because of my disability.
- 1.7 When others decide something affecting me, I feel I have no choice.
- 1.8 When I try to stand up for myself others get angry, so I leave it alone.
- 1.9 Others feel they have the right to treat me in a certain way just because I am disabled, and when I express my unhappiness about it they make me feel bad.

1.10 I find it difficult to explain the implications of my disability to my mother.

1.11 My mother feels that I hide behind my disability and use it as an excuse.

1.12 No matter how long they have known about my disability my family still can't accept it.

1.13 Even though they have lived with my disability for a long time they still become angry at my slowness

1.14 My mother feels that my disability gets in the way of me functioning normally.

Case study 1.(c)

4. Significant statements and their re-statements are studied to derive and record a sense of their meaning, the formulated meaning.

- 1.1 Non-disabled people can evoke feelings of anxiety, insecurity and ill-confidence in her.
- 1.2 She sometimes has feelings of being unworthy and incapable of being with other people.
- 1.3 She often feels that she does not possess all the qualities and abilities which other people have, and therefore she sometimes has feelings that others do not wish to interact with her.
- 1.4 When others find it difficult to interact with her it reinforces the feelings of being different.
- 1.5 The feelings of being different from other people make her question her worth and competence as a person.
- 1.6 Her disability restricts her from doing things, and prevents others from seeing what she is capable of doing.
- 1.7 Others have almost complete control over her life and give her no choice in matters concerning her.

- 1.8 Non-disabled persons do not respond well to her confronting them, and therefore they just withdraw and leave her alone.
- 1.9 Disability places her at a disadvantage when it comes to relating to non-disabled people, where she finds it difficult to express her true feelings, for fear that others may form an incorrect opinion of her.
- 1.10 Communication with her mother regarding the implications of disability in daily life is very difficult.
- 1.11 Her mother believes that she uses her disability as a means to exercise control over her.
- 1.12 The family finds it very difficult to accept and adjust to her disability.
- 1.13 Not only has the family not adjusted well to the her disability, but they also respond to it with anger and rejection.
- 1.14 She views her disability as an obstacle to effective normal functioning in all areas.

Case study 1.(d)

Description of themes emerging from the participant's narration.

Being with non-disabled persons is an unfamiliar situation for the participant. The presence of non-disabled persons evoke discomfort, anxiety, insecurity and ill-confidence, as it highlights differences. Physical disability limits the ability to visit others, but it also limits visits from others. The participant is also aware of the differences in others, e.g. the tomboy friend, and believes that this difference can explain certain behaviour, e.g. lack of contact with the participant.

There is a sense of lack of belonging, of a difficulty others have to be associated with her. This difficulty others have to be associated with her reinforces the feelings of being different. There is a feeling of being different, almost to the point of feeling, like a non-human, a non-person. This raises feelings of unworthiness.

The disability not only restricts her from doing things, but it also prevents others from seeing what she is capable of doing. She loses a sense of control over her life, leaving her with little choice over issues which affect her directly.

There is also a sense of discrimination, where people less competent than herself are viewed as more capable. Her competence is constantly questioned and in turn she begins to constantly question her own competence.

Being disabled can also be very disempowering, giving rise to feelings of impotence, of having no voice to argue her case. Others also do not respond well to assertiveness from her, giving rise to a sense of resignation and feelings of being "bad" in the eyes of others.

Others become impatient about the practical consequences of the disability, e.g. the slowness, and this can result in feelings of anger. Poor communication leads to incorrect perceptions about the implications of the disability, poor adjustment to the reality of the disability and poor acceptance by others. Because of the rejection and

unreasonable demands of others, she is beginning to develop a feeling of responsibility for the implications of the disability.

Disability is viewed as the major stumbling block, cutting her off from meaningful interaction and relationship with others and limiting her possibilities and confirming her umwelt and mitwelt.

Case study 2

First I want to say that I have not had many experiences with non-disabled children my age. Now I'm sure you are familiar with the MusicActive programme. I joined them this year and I met a few people there, and I'd like to speak of that. Now all the people I met there...I did not have a chance to have nice long conversations with them...Whoever I met, I only met for a short time, although I did meet some of the people regularly everytime I met...mostly I met little groups of people everytime. Anyway, I think I liked it that way because I wanted to meet as many people as I can.

First of all, I would like to say that I met this girl...her name was Shireen. She is in Matric now and she also came to the MusicActive. So, like for the first three weeks, she was always with me, always around...like helping me with the wheelchair and so forth. Then I met another girl, that was also in the third week, and then I introduced her to Shireen, and so then Shireen did not speak to me anymore...not such a lot. Then she was with this other girl, Lynette, all the time. So...I didn't like feel bad, because I know like...that normal

people like to flock together...uhm...like birds of a feather. So, I know that, it always happens and it's not the first time for me, that something like that had happened.

But I just want someone to...like always be the same with me...to react in a certain way towards me. Like Shireen was very friendly, never sounded critical or anything. So I would just like someone to stay with the same feeling, not change after a while. Whereas normally you would get a normal person reacting to disabled person as...based on first sight..saying: "Oh look at her she can't do this, she can't do that...". Shireen thought I was okay, I was nice to be friends with... I don't like it when people change like that towards you. It makes me feel bad. Because, I mean...(interruption). Now where was I? Feelings...well...I just feel bad if that happens...like Lynnette and Shireen becoming friends...even though I know why that is happening, because...uhm...they like...uhm...to be friends with one another, or they would like to move off. I can understand, and I don't feel that bad anymore. I've become used to it. Before, when I was younger, I thought now why is this happening, although that time I also



could not understand it, but it sort of felt worse than now.
So..I don't really mind what happened.

There was this one boy at Music Active...his name was...
uhm... Isaac. We spoke a lot to me during the six weeks. He
actually ... he never went straight to another friend or
anything...although he was also mingling with others, he
always spoke to me in a certain way...with the same feeling.
He said I was a decent person...and...I mean he always sort of
thought the same of me. When I told him I did music at school,
so he asked me what kind of songs I liked.

We had a nice conversation. And that one I liked. Shireen
never reacted badly towards me. After she met Lynette, Lynette
and she would always talk to me, they would never leave me
out, but they were always more buddy-buddy. They were closer.
Like whatever Lynette wanted, they would do it. They would't
like ask me or anything, if I would like to go upstairs or if
I wanted to go outside at break. I really didn't think it was
fair of them...uhm ...I mean I'm also human, I would also
like to be asked you know. But I have been through it all...it
happened many times before.



So I usually don't meet people my age who are not disabled, it was only at Music Active. I normally meet people older than me. At home, also because I can't go out to play outside, and people don't want to come inside. So, I speak to my brother who is two years younger than me...and my two year old sister...we have lots of fun with her.

I have come to terms with my disability long ago. I mean I was at an ordinary school before I came here. I already then understood my problems. I don't expect much...too much of myself. Although at the other school I was a bit more normal. I mean I have peripheral neuropathy, that is a weakness in my nervous system. Even though my bones are still strong, because of the nerves they don't carry the message from the brain to the muscle, therefore I can't walk. I wished I could do more. But I know, okay maybe one day I could do things again, but I am not expecting anything. When I was younger I had a recurring thought that children were talking about my disability. I think normal people are scared of the difference between us and them. That we can't do so much as them, frightens them somewhat I think.



Case study 2.(a)

1. Extraction of significant sentences and phrases which directly pertain to feelings of self-esteem.

- 2.1 " Then I met another girl,...and then I introduced her to Shireen, and so then Shireen did not speak to me anymore...not such a lot. Then she was with this other girl Lynette all the time. So...I didn't feel bad, because I know like...that normal people like to flock together...uhm...like birds of feather.
- 2.2 " But I just want someone to...like always to be the same with me...to react in a certain way towards me."
- 2.3 " Like Shireen was very friendly, never sounded critical or anything."
- 2.4 " So, I would just like someone to stay with the same feeling, not change after a while."
- 2.5 " I don't like it when people change like that towards you. It makes me feel bad."
- 2.6 " Although he was mingling with others, he always spoke to me in a certain way...with the same feeling. He said I



was decent person...and...I mean he always sort of thought the same of me."

- 2.7 " They wouldn't like ask me or anything, if I would like to upstairs or if I wanted to go outside at break."
- 2.8 " I really didn't think it was fair of them...uhm...I mean I'm also human, I would also like to be asked you know."
- 2.9 " I have come to terms with my disability long ago. I mean I was at an ordinary school before I came here. I already then understood my problems. I don't expect much...too much of myself."
- 2.10 " I wish I could do more. But I know, okay maybe oneday I could do things again, but I am not expecting anything."
- 2.11 " When I was younger I had a recurring thought that children were talking about me...about my disability."
- 2.12 " I think that normal people are scared of the difference between us and them."
- 2.13 " That we can't do so much as them, frightens them somewhat I think."



Case study 2.(b)

2. Formulating of the significant statements into more general re-statements.

- 2.1 When my non-disabled friends click together, I understand that non-disabled people prefer each other's company.
- 2.2 I want people to react the same towards me all the time.
- 2.3 I like people who are friendly and non-critical
- 2.4 I want people to convey the same feelings all the time.
- 2.5 When people change towards me I feel bad.
- 2.6 I don't mind it when non-disabled people mix with others as long as they still have the same feelings and thoughts about me.
- 2.7 They never asked me when decisions had to be taken
- 2.8 I would like to be asked things, I think it is fair and my right as a human being.
- 2.9 I understand my disability and have come to terms with it, therefore I do not expect too much of myself.
- 2.10 Despite my disability I wish I could do more, and while I still hope, I do not expect anything.



2.11 I used to have a constant feeling that non-disabled children were discussing me and my disability.

2.12 I think that the concerns non-disabled people have are often based on their fear of the differences they see between us and them.

2.13 Non-disabled people are afraid when they see how disabled we are.



Case study 2.(c)

3. Significant statements and re-statements are then studied to derive and record a sense of their meanings.

- 2.1 She accepts that non-disabled people relate to each other in ways which can easily exclude her.
- 2.2 She needs to feel assured that the non-disabled person can form a constant and consistent pattern of interaction with her.
- 2.3 She wants non-disabled people to relate to her in a friendly and non-judgemental way.
- 2.4 She feels that the basis for the relationship should be genuineness, trustworthiness and reliability.
- 2.5 When she detects a change in non-disabled people's attitude towards her, she feels very vulnerable and negatively disposed towards herself.
- 2.6 She does not demand an exclusive relationship with non-disabled people, as long as she is assured that others' attitude towards her remains positive and unchanged even

when they are with their non-disabled friends.

2.7 Non-disabled persons should consult her about anything which would indicate a recognition of her needs being considered.

2.8 Being asked for her opinion is a recognition by others of her worth and competence as a person.

2.9 She recognises the limitations imposed by her disability and accepts the need to curtail expectations about her own abilities.

2.10 She remains hopeful still for improvement in her condition, but realistically she is not expecting anything.

2.11 She used to have a strong feeling that others would discuss her because of her disability.

2.12 She feels that the differences in abilities and appearance between disabled and non-disabled people can evoke a sense of fear in non-disabled people.

2.13 She feels that the inability of disabled people to perform the range of functions which non-disabled people can perform routinely can evoke fear in non-disabled people.



Case study 2.(d)

4. Description of themes emerging from the participant's narration.

Although the participant has had only infrequent and irregular contact with non-disabled people, she expressed a desire to meet as many people as possible. She expressed concern that when non-disabled people interact, they relate to each other in ways which exclude her. This used to hurt her, but she has since developed an understanding of why this is happening. She does not demand an exclusive relationship with non-disabled people, but does not want them to change their feelings and attitude towards her because of her disability.

She is also concerned about the erratic nature of people's response towards her and expressed a wish that people should relate to her in a consistent manner. She was also concerned about the tendency of non-disabled people to form an opinion based entirely on appearance and their perception about what a disabled person can do based on physical appearance.

It is important for her to be consulted before any decisions are taken which would affect her. She views this as a recognition of her needs being considered by others and this is ultimately a recognition of her worth as a person.

She comments on the restriction placed on her to go and visit and interact with people her own age and also mentions the restriction her disability places on others visiting her. Her relationships are therefore mainly restricted to close family members older or younger than her.

While she often still fantasizes about an improvement in her condition, she has developed a realistic understanding about the nature of her disability. She recognises the limitations imposed by her physical disability and accepts the need to curtail her expectations about what she is able to do.

She recognises the difficulty non-disabled people have in dealing with the differences in appearance and ability. She describes this feeling as fear on the part of non-disabled. They are fearful, because seeing how disabled someone else is makes them feel vulnerable and powerless.

5. The formulated themes are then organized into theme clusters and theme categories.

Themes which were organized from the formulated meanings are then organized into categories and clusters to allow for the emergence of themes common to all participant protocols.

According to Colaizzi (1983), it is important to note that where certain discrepancies appeared in themes these would not necessarily be eliminated since logical discrepancies could still nevertheless be existentially real and valued. Nor were data ignored which did not seem to fit.

The following 5 theme categories, consisting of 20 theme clusters were delineated:

1. Characteristics of the social encounter

1.1 Theme clusters

1.1.1 The sense of the unfamiliar

Others speak of matters you have no knowledge of, they relate to each other differently, they have experiences which you cannot relate to, the pace of activities are unfamiliar, views



non-disabled setting as "normal", and hence different, feels removed from the everyday experience of non-disabled peers,

1.1.2 Irregular nature of the social contact

Need to meet more non-disabled people, only make contact when invited to functions, only meet non-disabled under exceptional circumstances, relate mostly with disabled peers,

1.1.3 Physical difficulty in establishing contact

Disability limits visits to others, and to get visits from others to you, contact limited to family, younger children and adult supervisors, views disability as the primary cause for exclusion from social activity,

2. Experience of the social encounter

2.1 Theme clusters

2.1.1 Awareness of physical differences

Presence of non-disabled raises awareness of physical differences, others' impatience at slowness, others' reluctance to accommodate physical limitations, exclusion from

physical activities, feels isolated and conscious of limitations.

2.1.2 Awareness of different social standing

Difficulty others have to communicate and associate with disabled, feelings of being a non-person, a non-human, an alien, mentally and/or emotionally disturbed, non-disabled speak about the disabled in the third person,

2.1.3 Emotional response to social encounter

Feels responsible for obstacles to social interaction, presence of non-disabled evokes feelings of discomfort, anxiety, insecurity, ill-confidence and lack of trust in others and in self, feelings of not belonging, feelings of disempowerment, no decision-making ability, competence is queried by others and by self, sense of resignation, feels bad in the eyes of others, feels inadequate and incompetent, unpleasant experience, sense of anger, evokes feelings of isolation and resentment,

2.1.4 Experience of exclusion

Irregular contact with non-disabled, non-disabled relate in ways which exclude disabled, disability limits possibilities of meaningful interaction and relationships with non-disabled, non-disabled have common experiences which exclude disabled, non-disabled perceive disabled as different, incompetent, dependent on others, difficult to communicate with, emotionally unstable, difficult to manage and to accommodate in activities, disabled have feelings of loneliness, non-disabled people ignore presence of disabled person, disabled feels invisible, physical limitations are not taken into account when planning activities, easy to forget about disabled person's presence.

3. Experience of the body in the social encounter

3.1 Theme clusters

3.1.1 Body as central theme in existence

Awareness of physical limitations in a non-disabled setting, need for assistance to move around, difficulty in walking up

stairs, the activities of the non-disabled peers highlights limitations of the body.

3.1.2 Body as non-compliant

Unable to participate in games, complete a short hike, freely visit others, freedom of movement observed in others emphasises restrictive nature of physical condition.

3.1.3 Body as undependable

Need to present himself as competent and independent, falls in front of others, feeling humiliated, vulnerable, frail and inadequate, need for assistance from others.

4. Coping with the social encounter

4.1 Theme clusters

4.1.1 Dealing with prejudices and expectations

Views inappropriate behaviour of non-disabled as lack of insight, deals with inappropriate behaviour in a humorous way, conceals hurt at prejudiced behaviour, non-disabled does not expect disabled to achieve or perform competently.

4.1.2 Concealing disability

Limits conversation for fear of revealing inadequacies, limits number of non-disabled persons to communicate with, avoids situations which focuses attention on physical disability, refuses to attend functions where non-disabled are present, does not reveal the special school attending, hides scars on legs by wearing long pants, concealing disability avoids uncomfortable situation for non-disabled friends, views relationship between disabled and non-disabled as unequal, hence the need to conceal disability to be treated as equal, disability prevents others from seeing and appreciating the real person.

4.1.3 Utilising potential

Others are unaware of disabled person's potential, uses every opportunity to display skill, when feeling confident and competent to perform, disabled person does not hesitate to perform, when feeling confident about performance, then others' responses are less important, competes to assess own sense of self-worth and competence, competes to measure non-disabled people's openness to accepting disability and

abilities, opportunities to demonstrate competencies, enhances sense of self-worth.

5. Developing relationships with others

5.1 Theme clusters

5.1.1 Initiating contact

Fearful of initiating contact, poor experience of contact with opposite sex, concerned about poor impression disabled might present to non-disabled, concerned about communication skills, concerned about evoking a negative response from non-disabled

5.1.2 Understanding difficulty of non-disabled people

Forms opinions based on physical appearances, assumes that disabled is unable to comprehend conversation, communicate effectively, make own decisions, assumes others are more capable to speak on disabled person's behalf, non-disabled bypass disabled when needs are addressed, inappropriate offers of assistance by non-disabled, fear by non-disabled people of behaving inappropriately, making inappropriate comments or asking inappropriate questions, avoid contact with disabled,



non-disabled people have ambivalent feelings about achievements of disabled, can treat disabled in a condescending and over-protective way, tries to conceal awareness of disability.

5.1.3 Understanding nature of friendship

Understands that non-disabled peers have much in common, does not demand exclusive friendship with non-disabled, wants consistency, no erratic change in attitude or feelings, friends change when in the presence of non-disabled peers.

5.1.4 Acknowledging disabled person's needs

Important to be acknowledged as having worth as person and to be competent, wants consultation on matters affecting the disabled, wants to be able to make decisions, disabled need to speak for themselves.

5.1.5 Gaining acceptance

Need to prove sense of worth to non-disabled, requires opportunities to gain acceptance, need to work harder than others to gain acceptance, not afraid to confront and correct

misperceptions, not be filled with self-pity or to refrain from tackling a difficult situation, need to convince non-disabled that achievement and success is not incompatible with disability, find acceptance only within familiar settings eg. special schools.

5.1.6 Embracing disability

Awareness by others of disability, compels disabled to embrace disability, will take time to recognise it as an essential part of self, accept the dependent and vulnerable nature of disability, manage difficulties in a positive and constructive way, conscious of the abilities, competencies and strengths of disabled, embrace disability as a permanent and unchangeable part of self, embracing disability eliminates restrictive nature of the disability.

5.1.7 Communication

Uncertain about communication with non-disabled, tends to avoid communication with non-disabled for fear of eliciting negative responses and further rejection, poor communication can lead to incorrect perceptions, feels that non-disabled



talk behind their backs, need to engage non-disabled in a positive manner, regular and open communication can lead to acceptance as equal, positive input from significant others allow disabled to look beyond limitations and become empowered.

5.1.8 Family relations

Difficulty of family to accept disability, lack of understanding of the implications of disability, difficult to accommodate implications of disability in daily activities, poor communications and relationships within family, sense of alienation within the family, desire to improve family relations, but not always successful.

6. Integration of themes into an exhaustive description of the experience of self-esteem.

An exhaustive description of self-esteem in physically disabled adolescents in a non-disabled environment was derived. This is a narrative integration of all the themes, theme clusters, and categories of themes. The exhaustive description was developed to gain insights into the structure of the lived experience of self-esteem in physically disabled adolescents in a non-disabled environment.

The experience of the body is central to the experience of self-esteem in physically disabled adolescents in a non-disabled environment. By virtue of the exclusive nature of the two environments, disabled and non-disabled, there is an unfamiliarity and strangeness that pervades the encounter between physically disabled adolescents and their peers. Neither have the experience and skill to interact and communicate effectively.

The encounter presents the disabled adolescents with an extraordinary situation where their body is experienced as corps-objet, i.e. it is thematized. The body is experienced as



socially conspicuous, non-compliant and undependable. Physical difference and limitations confront them at every turn.

The world for the disabled adolescent is a strange place where geographical and temporal boundaries are extremely shrunken and impoverished experientially .

Disability, however, is viewed not so much as a limitation in physical activity, but as a disruption of the I-World relation which accompanies disability. While to the non-disabled person, the disability is viewed as alien, to the disabled adolescent it is the relationship to the world which is the alienation which is of greater concern.

The experience of being perceived by others as ill, socially incompetent, mentally handicapped or emotionally immature, angers and hurts the disabled adolescent. The difficulty of non-disabled peers to communicate effectively with the disabled is viewed as a logical result of this misperception.

Disabled adolescents also experience exclusion from the life-world of the non-disabled. They perceive others as sharing common experiences and relating to each other in ways

which exclude them. Very little attempt is made to accommodate their needs. They often feel ignored and invisible in the presence of their non-disabled peers. There is a sense of loneliness, both within social settings as well as within their families. They recognise the limitations of friendships with non-disabled peers, and demand only recognition, affirmation, acknowledgement of needs and a sense of acceptance and respect.

Disabled adolescents are frequently also impeded in their attempts to initiate contact, by their own anxiety and concerns about estranging their non-disabled peers because of their perceived communication difficulties or socially inappropriate behaviour. They often feel themselves unworthy of and incompetent in forming and sustaining a relationship with their non-disabled peers. To compensate, they attempt to conceal their disability, minimise their contact with others, limit conversation and avoid encounters with non-disabled peers.

Disabled adolescents also develop a deep understanding of the challenge that disability presents to the non-disabled



peers. The prejudice, fear, inappropriate behaviour, erroneous expectations, ambivalent feelings and condescending manners of the non-disabled peers, arouse anger and pain in them. At the same time, however, it also awakens a sense of fulfilling a task. They realise that their task is to conquer insurmountable barriers, overcome humiliating failure and labour endlessly to gain acceptance and to convince others and themselves that disability is not incompatible with performance and competence.

They begin to recognise that while disability might be alien to others, it is not alien to who they are as persons. The initial disdain and denial in response to others' fears and prejudices is slowly replaced by a reclaiming and a reconnection with the scattered pieces of their identity. By embracing their disability, they again feel whole and intact. They recognise their potential, and feel confident to demonstrate their competencies to others. It is through involvement that potential is allowed to flourish and self-esteem is fostered. They do face frustrations and disappointments in their inability to accomplish certain tasks in the same manner as their non-disabled peers. How they deal

with these frustrations depends to a large measure on the reactions and responsiveness of their world.

7. Formulation of the statement of the essential structure.

From the exhaustive description, the essential structure was derived. The essential structure of self-esteem is viewed as an integration of the common components of self-esteem identified in the exhaustive description.

The phenomenological understanding of self-esteem of physically disabled adolescents in a non-disabled environment could be described as follows;

The lived experience of self-esteem in physically disabled adolescents in a non-disabled environment, is an interpersonally assigned characteristic that occurs with the interaction of the individual with non-disabled peers.

The initial phase of the lived experience entails a conflict with the strangeness and unfamiliarity of the non-disabled world, the perception of exclusion from this world, a sense of loneliness, feelings of being invisible, a non-person.

An understanding develops of the conflict and difficulty in non-disabled people to relate appropriately to disabled people. There is a recognition that the fears, prejudices and condescending or hostile feelings exhibited by non-disabled people towards disability, often reflect their own unconscious anxieties and feelings of vulnerability about wholeness, perfection, loss and weakness, anxieties which are readily aroused by contact with the disabled.

As the nature of the situation is revealed, it is viewed as demanding and perplexing, but not futile. A variety of negative and positive responses are experienced. There is an initial feeling of detachment and disavowal of the disability. Concealment and avoidance of contact are some of the initial responses. Minimising communication for fear of incurring rejection or experiencing humiliation are also common.

This is followed by a recognition of their intactness, of recognising the disability as an integral part of who they are, a part they cannot live without. The problem is not the disability itself, but the disruption in their relationship with the non-disabled environment brought about by the

disability that is the problem. By embracing their disability they can now engage and challenge their environment. They seek opportunities to demonstrate their competence, demand a recognition of their needs, insist on being consulted, becoming involved in decision making and acceptance by others as equals. There is a feeling of growth taking place. The adolescents are encouraged to continue to maintain and improve their relationships with others.

They endeavour to develop skills to navigate the non-disabled world, to put others at ease when they fear their own words in conversation with the disabled, to firmly decline assistance while simultaneously showing genuine appreciation of the helping motive, to secure a helping hand when needed, or even to reach out and force their presence on others who have not acknowledged them. A feeling of acceptance occurs when the disabled adolescent acknowledges that their disability is not incompatible with feelings of self-worth and demonstrations of competence.

8. Validation of the essential structure by study participants.

Since all the participants were easy to reach, and available, they were contacted and asked to confirm that the essential structure of self-esteem was the same as they had experienced it. They were interviewed and asked whether the descriptive results accurately reflected their experience. Care was taken to explain complex concepts and terminology, and all participants were encouraged to ask clarifying questions. They all agreed that the description of the essential structure of self-esteem accurately reflected their experience.

CHAPTER 11

DISCUSSION ON FINDINGS

While the non-disabled community has over the years developed a considerable intellectual tolerance and empathy of disabled conditions, beneath the surface, most people still unfortunately have feelings of pity, abhorrence and even involuntary revulsion. On the surface these feelings are often masked by outward signs of kindness, over-concern or embarrassment. Generally, however, the majority of the non-disabled community simply avoid any contact with disabled people, and therefore do not even have to deal with their true feelings with regard to disability.

Studies on children's understanding of their physical disabilities has found that by the age of 8 years children have developed an understanding of the functional limitations and implications of their disability (Dunn, et al. 1988).

This knowledge did not, however, significantly affect their ability to socialise with others, or increase their understanding of why certain children might not want to play

with them. As disabled children grow up, they begin to develop an understanding as to why non-disabled people might be avoiding them. The realisation that they are being avoided because of their disability, is usually a most painful discovery. As a result the child either wants to correct the disability or fantasizes about it "disappearing" completely, but realizes that it is out of his control and cannot be changed. The permanence of the disability is truly realized during adolescence. In the end, the young person could begin to feel impotent, defective and inferior; self-image is altered and self-esteem plunges.

Frequently, low self-esteem is reinforced over the years, as negative attitudes toward the disabled have been shown to increase with age in children (Kashani, 1986). It is also interesting to note that as the disabled child becomes older, he becomes more aware of society's ideal image, and like his normal peers is also reluctant to be associated with other disabled children (Du Plessis, 1991). This awareness of societal norms unfortunately also leads to a degree of self-rejection (Seidel, et al. 1975).

Cerebral palsied adolescents are unique among the disabled population, since they have never lived in a non-disabled body. Rather, the disability is an inherent part of their sense of body and self. Like other salient parts, the disability contributes to a sense of identity, and is in need of acceptance, appreciation and affirmation from the environment.

This study, as well as other research on the attitudes of non-disabled people towards disability, reveals a preponderance of negative perceptions. These include that disabled people are sick, helpless, childlike, incompetent, asexual and inherently socially and intellectually inferior. In short they are often perceived as non-persons.

In part, these perceptions reflect a lack of contact with and realistic information about the lives of disabled people. Non-disabled often use their own incomparable experiences with illness and temporary disability to arrive at assumptions about the helplessness and dependency of disabled people. Unfortunately, non-disabled people fail to appreciate the process of adaptation and creative problem-solving which can occur over time as a result of living with a disability.

It must also be recognised that the root of non-disabled people's fearful and sometimes hostile feelings towards disability, reflects their own unconscious anxieties regarding wholeness, perfection, loss and weakness, anxieties which are readily stimulated by contact with disabled people.

The disabled adolescent is particularly sensitive to the responses and reactions of their non-disabled peers. There is an almost immediate sense of exclusion and alienation from meaningful interaction with the non-disabled environment. From a phenomenological perspective this can be understood in the context of their perception of their body, which constitutes a central theme in the lives of physically disabled young people.

The explanation offered by Moss (1989), may be useful in this regard :

" Unlike all other objects, my body is something I live and only secondarily know. I act through it, perceive the world through it, and without explicitly reflecting on the body....It is one's own body that phenomenological psychology calls the lived body."

(p. 68).

The lived body is normally bypassed. Something out of the ordinary has to happen for the body to become subject to reflection and analysis.

For disabled adolescents it is often the very encounter with the non-disabled environment, with all its negative perceptions, inappropriate responses and unwarranted fears which constitutes such an extra-ordinary situation. People confront the world through their whole body. They are their body, i.e. it is bypassed (corps-sujet), more than they have a body, i.e. it is thematized (corps-objet). This study reveals that 'having a body' very often dominates when it comes to disabled adolescents.

The body is construed by the disabled adolescent as non-compliant, unreliable and socially conspicuous. Such a body is thematized in a negative way. According to Mulderij (1996);

" We humans seem to be programmed in such a way as to pay attention to everything which is the slightest bit different; and so we look at disabled children. A persistent phenomenon. Many children feel uneasy about being caught in another's gaze. All of a sudden, and

unmasked for, a mirror is held up to the body, which was hitherto not conscious of itself." (p.315).

Thus being looked at is a central experience in the lives of disabled adolescents in a non-disabled environment. The gaze from others is a constant reminder of them being physically different.

Along with this sense of being physically different, the disabled adolescent finds himself or herself excluded not simply by the environment as such, but by definition because of the limitations of his or her body. They are left on their own, and loneliness can dominate the existence of adolescents with disabilities. Many are very adult-oriented or over-reliant on family members. According to Erwin (1993):

" Loneliness is associated with negative patterns of self-perception and low self-esteem, a self-blaming attributional style, lower expectations for social outcomes, social skills deficits such as inappropriate self-disclosure, excessive self-attention, an inability to establish comfortable intimacy, and a tendency to make negative judgements of self and others." (p.216).

This sense of being different is accompanied by feelings of being a non-person. The manner in which others interact and relate to the disabled adolescent reinforces such feelings.

The mutual difficulty experienced by both disabled and non-disabled young people to initiate effective communication and develop meaningful relations was very apparent. On the part of the non-disabled there were fears of behaving inappropriately, lack of insight into the nature of the disability and preconceived notions about various social, intellectual and emotional implications based entirely on physical appearance. On the part of the disabled adolescent, there appeared to have been unsubstantiated concern about their inability to communicate effectively, fear about receiving rejection because of poor social skills, concern about their ability to perform in a socially appropriate manner because of their physical difficulties and a fear of being abandoned by newly found friends.

Disabled adolescents expressed a great need to be provided with opportunities to participate in a non-disabled environment, to compete in areas where they feel competent and

confident, to be provided with choices and to exercise their ability to make decisions for themselves. Young disabled people who are denied choice and the possibility of making independent decisions are intuitively less likely to develop a sense of responsibility, self-worth and competence, and consequently less likely to participate in adult society and relationships (Clarke & Hirst, 1989).

The study confirms the view that disability, from a phenomenological point of view, is more than a condition affecting the body, it is an important and essential component of who the disabled adolescent is because of the I-World nature of its disruptions. Disability is therefore best understood as a condition of the world as well as the body.

It is important also to recognise that the ordeal of anguish and distress often experienced and reported by the disabled adolescents, may result from amongst others, internal psychic conflicts involving sense of self, self-esteem, inability to fulfil expectations or negative perceptions of self or others regarding disability. From a phenomenological perspective, anguish, distress and feelings of lowered self regard, results



from infringement of, or impending threat to the integrity of the individual, not simply the body and its functions (Williams, 1984).

CHAPTER 12

CONCLUSIONS AND RECOMMENDATIONS

12.1 Introduction

There is nothing simple and straightforward about peer relationships for children with cerebral palsy. According to Field, (1984);

" Poorly developed social skills, peer rejection and few friendships are major defining characteristics of handicapped children. Furthermore, they are persistent characteristics, not subject to spontaneous recovery or easy treatment". (p.75)

Not only are friendships important for social, cognitive and emotional development of children, but links have also been established with functioning later in life during adolescence and adulthood (Cooper & McEvoy, 1996).

Children with cerebral palsy have been found to be hindered early in life in their social interaction. Distorted countenance, slurred speech and abnormal gait and posture, can easily disrupt the so-called 'infant elicited social

behaviour' of adults. The child easily acquires the reputation of being difficult to make contact with. "Handicap often leads to problems of attachment, and poor attachment is predictive of poor patterns of peer relations." (Erwin, 1993, p. 200).

When young people approach adolescence, they become fully aware of the long-term implications of that disability, and this initial realisation can be exceedingly stressful. This may coincide with the stresses of adjusting to the demands of school, changes in the relationships with parents and siblings or the exposure to new situations and encounters with non-disabled peers or others who appear to be more competent.

To presume that this initial realisation will be enough to ensure that the disability is assimilated without effort into a mature but active acceptance is to be oblivious to nature of awareness. Awareness is a process not an event. Young peoples initial realisation of the implications of their disability will be built on, and coloured by, life experiences and by attitudes and events both external and internal to themselves.

The factors which affect self-esteem are as numerous and as unique as individuals' learning to organise their experiences and fulfil their needs. Each person brings a multitude of factors of physical competence, of social interactions and personal needs and family background to their life experiences, which render ludicrous the application of an objective and empirical formula to predict and understand levels of self-esteem in disabled adolescents.

To understand the dynamic and plastic nature of disability, is to understand the realm between the power of the world in which an individual is embedded and the freedom of that individual to stand up in defiance and opposition to that world. To conclude that an individual creates himself and herself entirely, is to leave that individual worldless. On the other hand, to conclude that the world is all powerful, is to reduce the disabled individual to an organism which requires physical and functional restoration (Williams, 1984).

The non-disabled world often views disability as something alien and invasive which requires restoration and correction. To the disabled adolescent, however, it is the alien nature of

the relationship with the non-disabled environment, which is the alienation which is of greater concern. The study has shown that social acceptance is not only about how others perceive the non-disabled adolescents. There is a greater reward accompanying social acceptance. The more disabled adolescents are socially accepted within a group, the more opportunities exist for them to develop and to utilise their social skills . Over time these experiences contribute towards the development and enhancement of self-esteem (Abrahams, et al. 1979).

12.2 Promoting self-esteem in disabled children

The question of how best to prepare young disabled people for their interaction with and inclusion in the mainstream society is a question which confronts parents, doctors, educators and psychologists alike. Each one of these role players has a very specific and demanding task.

There is firstly a responsibility on the medical profession to treat the whole child and not simply the disability. Since physical treatment is likely to be the most manifest aspect of the treatment program in the early years, parents see

professional interest and attention to physical development taking priority over other facets of development, namely, intellectual and social development. Since the medical approach and treatment is most often directed towards the child's areas of greatest disability, parents in turn find themselves concentrating most heavily on the child's deficits, and failing to appreciate or positively respond to areas of competence and uncomplicated development. Should the focus be almost entirely on the physical disability, it would come as no surprise that parents exhibit some loss of affection and positive acceptance when there is no significant improvement in their child's physical condition.

The disabled child's understanding of physical differences is influenced by his or her perception of how parents and the environment perceive the difference. It would seem that one of the most important determinants of the body image of any child is not so much the actual characteristics of the body, but rather parental and cultural attitudes towards these characteristics.

For all children, disabled or not, the acceptance and approval in response to all aspects of the child's body and self is essential for the development of healthy self-esteem. This includes the parent's ability to show pride and pleasure in the disabled part of the body, as one valid aspect of the child, and to communicate appreciation and respect for the child's unique and often different-looking ways of doing things. The result can be an environment at home which allows children to develop their potential and feelings of competence as well as positive feelings about body and self.

It must also be conceded, however, that parents do not wittingly add to their children's difficulties. They all too often experience great difficulty dealing not only with their own feelings of pain, guilt, confusion and prejudice, but also the cruelty, intolerance, ignorance and hostility of the environment. Even those parents who adequately resolve their own conflicts, and fully appreciate their child, cannot always protect the child from society's negative perceptions.

Parents need help in finding ways to explain prejudice to their disabled children, to distinguish facts about their

disability from societal distortions about these facts. When parents do not make direct and factual statements about disability, space is created for fantasy and confusion.

Parental silence can be experienced as a confirmation of social stereotypes, whereas parental communication can serve as a counterbalance. While parents cannot single-handedly change conventional views about disabled people, they can help counter these misperceptions through direct statements which communicate positive and realistic expectations about their disabled children.

Children also need to develop an awareness that social interaction is frequently more burdensome for disabled people because of social stigma and prejudice. They will often experience unjust rejection based solely on their physical appearance. Parents can continually provide opportunities for disabled young people to talk about their pain and confusion. Parents can assist adolescents to distinguish real prejudice from typical frustrations everyone feels when negotiating social and sexual relationships. Parents need to let their children know that socializing can be an arduous and often a

precarious exercise, but it is not impossible, and when navigated properly can be very exciting and rewarding. Finally, parents should not succumb to the prejudices of society and restrict their children's interaction with the non-disabled environment, nor should they allow feelings of guilt to make them become over-protective. The basic rule about improving peer relations and gaining social acceptance, is to start as early as possible. Language and communication skills and social relationships with the non-disabled environment, should be fostered as early as possible. If one waits until adolescence, one would find non-disabled peers showing greater impatience with the limitations and less acceptance of the disabled individual.

After the parents, the disabled adolescent's educators are the most influential adult figures in their lives. The function of the education programme for children with disabilities is to develop and foster optimum independence and functioning. It should, however, not only focus on ensuring that the adolescent has the necessary cognitive tools, vocational and daily living skills for independent survival, but should give equal attention to developing social and personal skills.

Educators can play a vital role in developing the adolescent's understanding and ability to adapt, the skill to initiate and form new relationships, to negotiate and resolve conflict, to develop an enquiring and inquisitive disposition, to assume personal responsibility in all activities and to involve them in as many decision-making processes as possible. Educators should realise that they are required to educate children for living and not simply to earn a living. Needless to say, it would be extremely beneficial if this programme started as early as possible, and ideally within a mainstream school setting (Anderson & Clarke, 1982).

12.3 The need for psychotherapy

Finally, there is the possibility, and frequently the need, for individual psychotherapy or group therapy to assist the adolescent to develop a more positive self-concept. Many of the disabled adolescents expressed themselves in their descriptions as being overly self-critical, anticipating failure, feeling different and strange in a non-disabled environment, and consider others as being rejecting, discriminating or disapproving even when they are not. The

existential feeling that you have no definite identity, that you are a non-person, is perhaps the most profound existential crisis a person can experience. The most exaggerated expression of this feeling could mean that the individual has no faith in his existence as a person. These feelings are particularly evident during adolescence, when the individual is attempting to crystallize his identity, and feels seriously alienated, lonely or confused. Psychotherapy can play a unique role in this healing process.

Psychotherapy should focus amongst others on restoring the integrity of the person (Cassel, 1992). In the case of congenital disabilities like cerebral palsy, the loss experienced by the adolescent is not a loss of body part or function, but rather the loss of their original sense of intactness and completeness as human beings with disability as an integral part of who they are. Psychotherapy with disabled people is often about restoring self-esteem rather than developing it. Future research could focus on the phenomenological explication of the experience of psychotherapy, both within an individual or group context, with physically disabled adolescents.



12.4 Summary

The phenomenological method of investigation has made it possible to explore aspects of self-esteem in physically disabled adolescents, which would not easily be accessible through an empirical study. By allowing the participants to describe their interactions with others in a non-disabled environment as fully as possible, they have conveyed not only their experiences, but also the meanings contained in these experiences. These meanings transcend the subjective experience and make available to others worthwhile knowledge about disability and self-esteem.

The phenomenological method provides us with a deeper and clearer understanding of what the experience of disability is like for disabled adolescents in a non-disabled environment. The research results amplify our understanding of these experiences and could lead to two important consequences. Firstly, we can begin to appreciate and be more aware of and sensitive to those involved in these experiences, a particularly significant consequence for those in the helping and education professions. Secondly, social action and

public policy can be amended and directed in a way that is more responsive to the needs of the disabled community.

More importantly, however, this study has shown that not all physically disabled adolescents have severe difficulties with self-esteem. Many young people have confronted and adequately resolved the intactness/defectiveness dilemma they face daily in a non-disabled environment. They ensure that they are accepted and respected as complete people, and have survived society's negative perceptions of them. They have on the whole developed and perfected a valuable skill. They can navigate the non-disabled world without renouncing their disabilities as a vital aspect of their self. They recognise, and at times are deeply hurt and angered by the prejudice they observe and experience around them, but they refuse to accept it as an accurate portrayal of who they are. When necessary, they may seek to conceal the limitations which their disability imposes on them, at times they may even seek to conceal their disability, but they never seek to conceal themselves.