

## A STUDY OF THE EXPERIENCES OF PARENTS WITH HOME-SCHOOLED PRE-ADOLESCENT CHILDREN WITH SEVERE MULTIPLE HEALTH PROBLEMS

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*This study examines the difficulties encountered by parents caring for pre-adolescent children who have severe multiple health problems. Working within the frameworks of narrative psychotherapy (Spence, 1982; Viederman & Perry, 1980; Vitz, 1992; Benjamin, 1998), the researcher examined parents' discourses and identified the strategies they employed to deal with their situations (Maynard, 2003). The results show that the participants' ability to tell their stories to others who empathize with them provided an essential therapeutic function (Obeng, 2008). The most important discourse strategy identified was the use of words that have strong implications for dealing with emotional valence.*

The importance of understanding the narratives of parents of children with severe multiple health problems cannot be over emphasized. This is because narratives constitute an important way of learning about the self (Bruner 1990; 1994). Also, narratives offer special form of talk in interaction for understanding and explaining human action (Polkinghorne 1988). According to Bruner (1990) and McAdams (2001), the stories people construct about themselves and their social worlds are key aspects of their identities. Luckmann (2008) bolsters the above claim by noting that the constitution of meaning in experience and action forms the basis of social and communicative interaction and also provides the basis for an analysis of the communicative formation and transmission of personal identity, knowledge, and historical social words. Pearrow and Sanchez (2008) also discuss the role of personal epistemology in providing a framework for researchers to understand how individuals view their world. It comes as no surprise, therefore, when psychotherapists, especially *narrative psychotherapists*, use narratives or *storied nature of human conduct* Sarbin (1986), as an important operational construct in dealing with their clients.

The importance of a narrative-based model in interpreting and understanding clients' pasts is discussed in the literature on psychotherapy by notable scholars such as Viederman and Perry (1980) and Viederman (1983). The above authors used short life histories for interpreting relatively healthy clients facing acute crises. Spence (1982) also introduced the notion of narrative truth, as distinct from historical truth, for understanding clients' pasts. Vitz (1992) bolsters the claim about the importance of narrative in psychotherapy by calling for the introduction of a narrative model to help enrich psychotherapy and counseling. For their part, Frank (1961), Spence (1982), and Adler and McAdams (2007) discuss, in some detail, therapeutic gains of storied narratives during psychotherapy sessions. With respect to *therapeutic discourse*, Leahy (2004) defines this as talk-in-interaction that represents the social practice between clinicians and clients. It is a kind of discourse that helps victims to cope with or adapt to their difficult situations (Goffman, 1967) in order to remove what is emotionally burdensome off their *chests* and consequently to restore them to a condition better than the existing one.

According to narrative psychotherapists (Sarbin, 1986), there is the tendency for humans to make sense of otherwise unrelated events by imposing a narrative structure on them in order to help give meaning to a specific situation and also to assist in predicting or anticipating how such a situation will likely evolve.

Narrative psychotherapy helps to deal with a large range of issues, such as self-hate, guilt, and family problems. Observing clients experiences through their narratives helps one to understand their individual lives. It also gives an insight into their specific problems and how they deal with them.

From the above literature, we observe the important role of narratives in helping to provide insight into the social and emotional lives of people. This study, therefore, examines the extent to which narratives of parents caring for children who have severe multiple health problems serve as a communicative means to convey their personal emotional states and how that helps to stimulate responses from people around them. In particular, the study examines discourse strategies used by parents to express the problems they encounter in caring for the children, how they deal with these problems, and the extent to which they felt powerful or powerless.

## **Method**

### *Study Design*

The data for this study consist of transcripts of the recorded narratives of parents with children who have severe multiple health problems. Data were collected in 2007. The data are composed of participants' narratives of their *bad news* and *frustrations* (Maynard, 2003). Participants were also asked about their experiences in raising children with health problems. Participants were recruited within a 50-mile radius from Indianapolis, the capital of Indiana, in the United States.

Participants were selected for this study through the snowball and purposeful sampling techniques (Patton, 1990). Ten parents with children who have health problems were contacted for the pilot study and all agreed to take part in the study. Two parents (3 excerpts) qualified for this case study work because their children had various severe multiple health problems and were home-schooled because of the severity and multiplicity of the children's illness.

Another reason for selecting the two parents for this case study was that their children were in pre-adolescence, and as noted by Feldman (2007), children in pre-adolescence (children in middle childhood) spend most of their time in school and outside parental control of their conduct. However, the children whose parents participated in the present case study were home schooled and spent almost all their time with their parents. This situation provided a unique opportunity to examine the caring environment of such families.

Also, parents of children of the above age group were selected for this research because, by their very nature, pre-adolescence and adolescence constitute periods during which children develop psychologically and emotionally (Chavand, Grandjean & Vignes, 2007). Regarding children with severe multiple illness who are in these age groups, if such periods are not appropriately managed, their illnesses can disrupt their families' cohesion and adversely impact their lives.

### *Procedure*

Data collection began after authorization from an institutional review board was received and after participants had been contacted and agreed to take part in the study. The participants were interviewed separately and were encouraged to narrate their experiences about caring for their home-schooled pre-adolescent children, more specifically how they dealt with their problems. The interview questions were preset, however, as the interview progressed, more questions were developed based on the contributions of the interviewees.

Participants' narratives were audio-recorded by the author and her graduate research assistant and later transcribed orthographically by them. The participants were interviewed again at a later date through the process of *renewal of connection*. In the transcription, pseudonyms were used instead of participants' real names to conceal their identity and to create anonymity.

### *Coding and Data Analysis*

Two people independently assessed the content of the participants' stories with the intent to identify common communication strategies used by the participants in expressing their problems and in indexing their emotional states. In a way, the coding was both descriptive (it identified the way and manner in which the stories were told) and interpretive (what the communicative strategies signified). The coding took two months to complete and both coders agreed on the descriptive and interpretive categories.

Data analyses involved closely examining the content of participants' narratives and making claims based on the narratives. By so doing, we explore the notion of meaning and how stories are used as vehicles by which participants communicate meaning. Specifically, we examine the kinds of words used by the participants to index specific situational feelings. We synthesize and analyze how

participants deconstruct meaning of the reality of their lives (self-identity) and relationships (Strupp & Binder, 1984). Claims made will be supported with excerpts drawn from the narratives to ensure evidentially and to give credence to such claims.

#### *Theoretical Underpinnings of the Study*

The study is done within the framework of *narrative psychotherapy* (Benjamin, 1998; Kalmykova and Mergenthaler, 1998; Labov and Fanshel, 1977). According to Sarbin (1986), narrative psychotherapy refers to a viewpoint or a stance within psychology which is interested in the *storied nature of human conduct*. Working within the framework of narrative psychotherapy requires the researcher to listen to and to give attention to each participant's *dominant story*. Through participant's narratives, we explore the notion of meaning and how stories are used as vehicles through which meaning is communicated.

In this study, we examine the kinds of words used by the participants to index specific situational feelings. Thus, besides examining the semantic import of specific words used by the participants, we also explore the emotional valence associated with and/or indexed by such words. Working within the framework of narrative in psychotherapy will enable us to examine the ways that the research participants experienced the problem areas of their lives, their expectations, and suggestions for other people dealing with similar situations as theirs.

### **Results**

#### *Case Study 1*

Context: A woman in her thirties talks about caring for 12 year-old child who was diagnosed with multiple physical problems (e.g., hearing loss and vision impairment), cognitive problems (e.g., autism and language disorder) and behavioral/emotional problems (e.g., hyperactive behavior, obsessive-compulsive disorder, personality disorder and anxiety disorder). She noted that the child's health problems were identified at birth, but not officially diagnosed until age four and half.

The woman noted:

#### Excerpt 1

*Parent: The emotional trauma of caring for a child who is mean is stressful, exhausting, and overwhelming. His episodes of meanness, anger, and frustration sometimes made me feel crazy. But I know all these problems are due to his sickness. I put in so much love and energy, and to have him to be so mean sometimes makes me unhappy. Anyway, I know his unpredictable behavior has something to do with my divorces. There's no way my family can get out of this loop. The stress on my children and me is chronic.*

The above excerpt provides considerable insight into the participant's personal emotional state. Specifically, a systematic attention to the excerpt shows that the participant was emotionally *overburdened*. Several discourse markers indexed the above emotional state. For example, the participant used emotionally charged adjectives such as *crazy*, *emotional*, and *mean*, all of which denote cognitive burden. Other adjectives used, such as *exhausting*, *stressful*, and *overwhelming*, all have the semantic feature [+desperation]. Another adjective used to index the participant's emotional state was that denoting perpetuity of a negative event or state of affair. The word, *chronic*, used in the sentence *The stress on my children and me is chronic*, shows the perpetuity of the participant's emotional state and/or burden. Furthermore, the participant's use of antithetic construction, *I pour so much love and energy into him, and to have him to be mean back sometimes make me unhappy* indexed the emotional state of experiencing lack of reciprocity, not being appreciated, and the state of feeling betrayed.

Another discursive strategy that provided a window of opportunity for us to observe the participant's personal emotional state was her use of nouns such as *trauma* and *stress*. The above nouns have the semantic features [+ high emotional valence] and [+ high (physical) sensation].

In expressing the emotional state of entrapment, the participant resorted to the use of an existential sentence: *There's no way we can get out of this loop*. Like other existential sentences, use of the above existential sentence is evidentiary and a confirmation of being in a state that cannot be changed or altered by the participant. It signifies absolute and complete shutting off of all possible scenarios and an acceptance of the *status quo*.

On the question of how and/or whether a participant's narrative could itself be viewed as therapeutic, an observation of the excerpt below shows that, telling others about her problems, getting emotional

support from people around her, and reading books that dealt with the problem she was dealing with helped to mitigate her anxiety and stress and made her feel loved.

Excerpt 2.

Context: Participant responds to a question about the extent to which talking to others, especially a professional, helped to ease the emotional burden on her (the participant) and what suggestions she had regarding assisting caregivers in a situation similar to hers.

*Parent: I got lots of help from my therapist. She would let me call and talk to her, and this helped tremendously. She understood what I was dealing with in a way that no one else could. She told me that things felt crazy because I was dealing with a crazy situation, and this helped me a lot. I got a lot of support from her. I also coped by reading lots of books about his problems—it helped to understand his problems better and read about ways to help him and to help my children and myself. I also coped by getting lots of love and great results from my other two children. They responded in normal, expected ways to my parenting efforts. As a suggestion to help other caregivers, I will say: Respite care!!!!!!!!!!!! Adequate, help from others so I can have a life sometimes and universal healthcare for such children [sic].*

From the above excerpt, we observe the participant indexing the type of help she received from a professional therapist with expressions and words such as *lots of help* and *helped tremendously*. The quantifier *lots of* and the adverb *tremendously* signify and/or index a situation in which the recipient got more than an anticipated assistance and a sense of assurance and a subsequent mitigation of a stressful situation. Use of the first person singular pronoun, *I*, as well as the active voice, signify contentment, being in charge, and hence, being in a situation of power, taking charge of a situation, and trying to make things better.

An important issue raised in the above discourse is the participant's suggestion about ways of helping other caregivers dealing with a situation similar to hers. Her suggestion points to the fact that caregivers caring for children with severe multiple health problems face an unusual life, may not *have a life* at all, and that assistance in the form of baby-sitting and universal care could ease the burden on such caregivers. The participant's use of 12 exclamation marks signifies the importance she attached to *respite care*. In discourse-pragmatics, the use of more than the required number of punctuation, such as exclamation marks, signifies the importance the discourse participant attaches to the point being made (Moonwomon, 1995).

#### Case Study 2

Context: A thirty-three year old woman whose daughter (age ten10) was suffering from several health problems talks about her experiences. She noted that her daughter's health problems included such physical disorders such as low muscle tone, a seizure disorder, hearing problems, rapid transit of digestive function with incontinence, malformed left ear, bladder/kidney problems, heart problems, vision problems, paralyzed right side of face, bladder incontinence, growth hormone deficiency, high blood pressure, frequent respiratory and ear infections, malformed jaw, loose joints, hyper-nasality in speech, and a swallowing disorder requiring gastrointestinal tube feedings daily.

She noted:

Excerpt 3.

*Parent: Her care has been challenging for us and we have suffered a lot and this has impacted my life. My daughter experiences stigmatization from her physical looks. The stress of caring for her numerous health problems may have led to our divorce. The care of our daughter is covered partially by insurance, but we owe a lot of money, and this is burdensome and stressful to me. Sharing my pain and burden lessens my stress and brings me some relief. But, I normally don't have anyone to tell my problems. People get fed up very easily. Children with special needs severely interrupt parents' normal roles and activities including sleep. Parents are often overwhelmed by the amount of medical visits. It is very emotionally challenging to handle all these problems. We have considerable stress.*

A careful and systematic attention to the above excerpt and others found in the data shows that participants use specific word categories such as *verbs*, *adverbs of manner*, *quantifiers*, *gerundive adjectives*, and other *discourse categories* to index their emotional states (such as stress) and their unique difficult circumstances (such as divorce and/or financial difficulties). Also, participants' ability

to narrate their problems is viewed by them as therapeutic since it *lessens their pain* and *brings them relief*.

In talking about the extent and scope of the problems she encountered in raising her daughter, the participant used the quantifiers *numerous*, *considerably*, *most*, *significant*, and *wider*. Apart from the word *wider*, which has the syntactic feature [+comparative], all of the above adjectives have the syntactic feature [+superlative]. Also, all of them have the semantic feature [+excessive]. Thus, through the narrative, we see that the participant's condition, be it emotional, financial, or social, constituted a rather difficult experience; one that she would have wished never happened or whose occurrence and impact on her personal, social, and emotional life could have been mitigated.

Furthermore, the participant's use of verbs, like *suffer* and *impacted*, that denote physical sensation suggest that she may not have been at ease, that she may have been emotionally troubled, or that her relationship with people around her may have been in jeopardy as a result of the child's condition. Like the other participant, this participant alludes to the fact that her divorce and loss of friends were the result of her child's condition.

Also, the verbs *lost* and *separated* index both a social and an emotional space or gap created by the impact of the child's condition. In showing the extent of the child's developmental deviations' and the impact on her own life, the participant used emotionally-laden expressions, such as *emotionally challenging*, *we have considerable stress*, and *stress of caring for her numerous health problems may have led to our divorce*. Such expressions explicitly unveil the narrator's social-emotional state.

With respect to whether the participant felt powerful or powerless, we observe from the excerpt that she felt powerless. She spoke about being *overwhelmed*, about having *interrupted sleep*, about *challenges with professional care*, and about *not having people ready to listen* to her. All the above suggest that, as much as she may have wanted to be in control of the situation, the medical system setup and the social-emotional context within which she had to operate made her powerless, exacerbated her plight, and made her overly dependent on a not-so-helpful system.

### **Discussion**

An observation of the data shows that, through their narratives, participants conveyed such emotional states as, frustration, the feeling of sadness, desperation, being stressed out, and being overwhelmed. With respect to ways in which they experienced the problem areas mentioned above, we learned from the participants' narratives that they experienced and/or underwent the above emotional states as a result of inadequate professional assistance and having to stay home almost all the time caring for the children. Other reasons included lack of understanding of the children's condition by relatives and hence insufficient support from them, and sometimes, through the *meanness* meted out to them by the children with behavior problems.

Regarding the extent to which participants felt powerful or powerless, an observation of the participants' narratives and the results showed that, although they were motivated by the desire to care for their children to be as successful as possible, the participants felt powerless. They felt overwhelmed by the enormity of the daily tasks of caring for the children and barely got by, whereas sometimes they felt entrapped, guilty (although the children's condition was not their making), helpless, and overcome with anger and the thought of not being in control.

Furthermore from the data, we learn that, although giving bad news about diseases or one's difficult circumstance may be hard and face threatening for a narrator given the stigma attached to some diseases and difficult circumstances, being able to narrate such news to a sympathetic individual offers relief to the narrator. In the words of Maynard (2003) the capacity of people encountering difficulties in life (be it illness or social-emotional), being able to narrate their plight in an atmosphere that bolsters social solidarity helps to generate effective remedial action thereby making such narratives therapeutic. This study contradicts Weenig, Groenenboom, and Wilke's (2004) assertion that bad news is transmitted more often if the recipient was a friend rather than a stranger. In this study, not only were the participants willing to narrate their experiences to us strangers, given the fact that they saw their narratives as therapeutic, they were willing to tell their stories again during subsequent visits (Obeng, 2008). There is no doubt that the sympathy and empathy that we may have shown toward the participants may have contributed to the ease and frequency with which they narrated their plights. The researchers learned from the results that the most difficult things faced by the participants were the

impact of their children's disability on their married lives (the fact that they had been married at least twice at the time of the study and yet were divorced).

Also, the participants' narratives suggested that their social lives were greatly impacted by their children's disability given the fact that they spent long hours with the children. They complained about getting inappropriate care for the children, dealing with stress, dealing with some family members who were in a denial, and dealing with relatives and neighbors who sometimes did not understand what they were going through.

With respect to discourse strategies, participants' use of words with strong implications for dealing with emotional valence shows the extent to which language, cognition, and emotion inform each other.

### Conclusion

This study has implications for views on children's health, for the field of social work, and for the field of children's emotional health. In particular, it highlights the plight of physically and mentally challenged children, especially the problems they encounter in their daily lives and the impact of the problems on their immediate family members and on issues relating to their acceptance or rejection by society. The study also highlights the help such children need in order to survive in a world in which they require the goodwill and sacrifice of their caregivers. Furthermore, the study highlights issues relating to adaptation to the children's home-schooling environment and the amount of effort needed to function in such contexts.

With respect to the parents, the study has shown the sacrifices they make, their frustrations, their determination in ensuring that their children succeed despite their difficult circumstance, and their joy and satisfaction with the occurrence of success in bringing up such children even if such success is minimal. An important lesson learned from this study is the fact that there is the need for a holistic approach in dealing with the problems faced by parents who have children with multiple severe health problems. Specifically, such approach should look at the child by taking into consideration the nature of their health problem, the child's persona, his needs, as well as his overall context or environment. The parents' socio-economic, cultural, and socio-emotional state, as well as the social services available to her and her child or children should also be taken note of and be adequately addressed. With respect to emotional health, the study highlights the importance of psychotherapy and the need to provide a platform for parents caring and schooling physically and mentally challenged children to air their frustration and to seek help. Creating such a platform or avenue and providing professional help will help reduce instances of stress and will help them achieve optimal health.

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