The International Journal of Special Education
2005, Vol 20, No.2.

THE RETROSPECTIVE EXPERIENCES OF A MOTHER OF A CHILD WITH AUTISM

Mariann Krausz,
York University
and
Judit Meszaros
Semmelweisz University

This unique study used qualitative research methodology to investigate the first 18 years of parenting experiences of a mother of a child with autism. The purpose of this single case study was to record and understand the effect of autism on a mother's life retrospectively, to identify and analyse issues and themes that have shaped her life, to understand the stages and characteristics of a parent adaptation to a child with autism, and to form implications that could be learned from the participant's experiences.

It is written as a narrative which is a form of meaning making that organizes human experiences into temporally meaningful episodes. By using the narrative approach, the authors were able to authentically document the steps of accepting a child's handicapping condition, which is an extremely difficult and often a heart-breaking process. Data was collected through in-depth, semi-structured interviews. Eleven consistent themes emerged from the interview data. One new theme; falling apart *which was coined by the authors, and two coping strategies;* advocating *and* setting limits, *surfaced which were not represented previously in the literature. These new discoveries, the participant's successful instrumental and palliative coping strategies and the implications of having a child with autism on her life are discussed.*

The impact of a severe disability is never restricted to the individual with the disability. Members of the immediate and extended family are affected in varying degrees. Numerous studies have documented the high level of stress experienced by parents of children with severe disability (Byrne& Cunningham, 1985; Crnic et al., 1983; Donovan, 1988; Dumas et al., 1991; Flynt, & Wood, 1989; Gallimore, et al., 1999; Kazak, & Marvin, 1984; Konstantareas & Homatidis, 1991; Milgram & Atzil, 1988; Minnes, 1988; Noh, et al., 1989; Singer, & Farkas, 1989; Rodrigue, et al., 1990, Wikler, 1981).

Based on their literature review on life stresses, Wolf, et al., (1989) suggested that there are many potentially threatening events and life circumstances that arise due to the child's disability. These events are characterized by their intensity, magnitude, duration, and unpredictability which tend to constitute the most stressful situations.

Autism is a puzzling disability. Based on his observations of his patients, Kanner (1943) believed that most children with autism *have come into the world with innate inability to form the usual biologically provided affective contact with people* (p.250). Beside their communication and behaviour characteristics, people with autism also have trouble distinguishing other people's intentions, knowledge, will and desires from their own. The possibility that children with autism lack *theory of mind* (Premack, & Woodruff, 1978) which refers to our understanding of the feelings, beliefs and desires of others has been suggested on the basis of their peculiar inability to relate to and communicate with others in a predictable way (Baron-Cohen, 1991; Frith, 1993; Hobson, 1991). This construct may prove to be a useful framework to gain better understanding of autism and of the stress encountered by the parents of children with this handicapping condition.

The intensity and magnitude of communication and behavioural problems of children with autism, together with the atypical and persistent care-giving demands they impose and the unpredictability of their prognoses, place their parents at high risk for stress (Bebko, et al., 1987; Bristol & Schopler, 1984; DeMyer, 1979; Dunn, et al., 2001; Hastings & Johnson, 2001; Koegel, et al., 1991; Noh, et al., 1989, Robbins, et al., 1991; Skinner, et al., 1999; Tarakashwar & Pargament, 2001).

Numerous studies have examined the experience of living with a child with autism (Dudziak, 1986; Dunn et al., 2001; Fong et al., 1993; Hastings, & Johnson, 2001; Talor-McDonnell, J., 2000). Issues identified by these studies included the child's resistance to change, the child's destructive behaviour and temper tantrums, sibling's coping difficulties, mothers' isolation, social and communicational, family related concerns, education and related services, relationships with professionals, independence of the child and his/her future concerns.

Coping

According to McCubbin, (1979) coping is seen as behaviours, cognitions or perceptions directed at the resolution or alleviation of potentially stressful life events. During these times, resources are managed by the family system in order to decrease vulnerability to stress. Harris, et al., (1991) summarized the two major models of dealing with stress: instrumental and palliative strategies. Instrumental strategies (i.e., parent education, information programs) focus on empowering parents to implement change in the person or the environment. Palliative strategies, such as self-help groups, enable parents to tolerate stress through internal mechanisms.

Having an infant with disability is often experienced by parents as the death of the expected normal, healthy child It has been suggested that parents of a child with a disability have to go through the grieving process (denial, bargaining, anger, depression, and acceptance) in order accept their child's handicapping condition. (Saligman & Darling, 1989: 86.)

These stages are virtually identical with the five stages of the grieving process associated with death and dying (Kubler-Ross, 1969). Grieving is an initial way of coping with a child's severe disability, but parents use a variety of other coping strategies to adapt their lives to their child's condition.

Coping strategies identified by parents of children with autism are spousal support, acceptance of the child, formal services and programs, family oriented training programs and reliance on a social network (Bristol, 1984; Dunn, et al., 2001; Fong, et al.; 1993; Harris, et al., 1991; Hastings & Johnson, 2001; Robbins et al., 1991; Rodrigue, et al, 1990, Skinner, et al., 1990).

The purpose of this single case study is to record and understand the effect of autism on a mother's life retrospectively, to identify and analyse issues and themes that have shaped her life, to understand the stages and characteristics of parents adaptation to a child with autism, and to form implications that could be learned from the participant's experiences. Looking at her life retrospectively may allow the participant to relive her experiences and put them in perspective. This is the first study that investigates the long term affect of autism on a parent's life instead of just taking a snapshot at a certain age. The authors believe, that this approach can lead to important information that are the results of time, maturity and reflection on the parent's part.

Procedure

This paper presents a qualitative case study, which is characterized by the researcher spending substantial time on site, in personal contact, reflecting and revising meanings of events (Stake, 1994). This study is written as a narrative which is a form of meaning making that organizes human experiences into temporally meaningful episodes (Brune, 1990; Conelly & Clandinin, 1990, Clandinin & Conelly, 1999; Polkinghorne, 1988). This method was chosen because narrative inquiry allowed us to successfully capture our subject's personal and human dimensions. Looking at her life retrospectively instead of looking at certain segments allowed us to reveal how this mother's stories changed over time as her child matured and she lived through different experiences. In this study our interest rested on a number of key issues gleaned from the literature and from one of our personal experiences as a teacher of students with autism, such as attachment, adaptation, coping, grieving and stress. Information collected from two initial and one follow-up in-depth semi-structured interviews provided a rich data base of the above mentioned key issues. The semi structured interview questions focused on diagnosis, understanding autism, support networks, schooling, changes in family life, and expectations. This type of interview was chosen to allow the participant to narrate her experiences and elaborate on them.

All interviews took between 2 hours and 2 hours and 30 minutes to complete and were audio-taped. Verbatim transcripts were made of each interview. Data collected from the interviews were used to construct the narrative of the case study. In advance, the participant was asked to gather memory prompts such as baby books, and photographs for the interviews in order to enhance her memory and to provide valuable visual information to the interviewer about the participant's life.

The Analysis of The Transcripts

After initial overviews, the transcripts were read several times in their entirety to perform a discourse analysis. Discourse refers to *talk*, the way people account for their experiences. The text was analysed to isolate any similarities, differences and variations where the participant talked about her parenting experiences, the way her relationship with her son evolved over time and the way her life has been effected by her son's handicap. Extracts from the interviews were placed under broad headings such as *Diagnosis, Coping* or *Maturing as a parent* and eleven dominant discourses (See Table I) were identified and are presented in the case study.

After the identification of the dominant discourses (Marshall, 1994,), the last interview was conducted when the final step of triangulation to assure the authenticity in the findings (Clandinin & Conelly, 1999; Mathison, 1988,) was done. Based on the participant's feedback the narrative was revised.

While analysing the participant's discourse the writers describe their own understanding of the text, trying to remain faithful to the experiences of the interviewee's descriptions of her life. Some segments of the text are included in the case study to allow the reader to assess the researchers' interpretative conclusions. In terms of presentation, the use of ellipses (...) indicates that there is material omitted from the extract.

CASE STUDY

Linda who works full time is a single mother living on her own in a small town. She has two sons; Richard and Philip. Richard, the older son, moved out a couple of years ago and Philip lives in a group home. Philip was diagnosed with autism at age four. He is 19 years old, has few practical skills and uses a limited number of signs to communicate.

Linda is a great interviewee. She is very articulate and animated. Her personality is friendly and warm. Linda had her first son, Richard, when she was 28 years old. Philip was born six years later. His birth weight was very low (3 pounds 11 ounces) and he was released from hospital when he was four weeks old. Philip was so tiny, Linda felt he needed all the love she could give him. Philip was six month old when Linda separated from her husband (later on they divorced). From then on, she raised her two sons by herself with a lot of support from her parents.

The discourse of *Diagnosis*

Up until 18 months Philip seemed to relate to people around him and reached his physical milestones on time. The only abnormal behaviours were the lack of babbling sounds, bouncing on his toes, and flapping of his hands from early on. After his first birthday Philip began to change. He became distant and his face had a blank expression. After a while Linda could no longer deny that something was wrong with Philip. This is when she and her mom began their quest for his diagnosis. Initially most specialists told them that Philip was fine and he would grow up being normal. Philip was diagnosed with autism around the time of his fourth birthday. After the diagnosis was made, Linda and her sons were able to access all kinds of special services (a special preschool program, after school care, a support worker once a week

Table 1.

Themes and sub-themes that emerged from the case study.

Themes	*Sub-themes*
1. Diagnosis	• uncertainty before the diagnosis • circumstances around the diagnosis • fighting for a label • why does he have autism?
2. Encountering autism	• non-responsiveness • behavioural problems • attachment • impaired theory of mind • grieving • feeling united
3. Fruitless sacrifices	• fruitless sacrifices • missing out on things
4. Day-to-day living/Stress and Coping	• getting through the day • self-help activities • financial problems • informal support • formal support • living arrangements • advocating • self-preservation
5. Getting adequate treatment	• group home • medical care • schools
6. Mother as teacher	• teaching basic skills • discouragement • introducing leisure activities • taking pride in his accomplishments • being open to new approaches
7. Hopes and fears	• changing hopes • constant fear for his physical safety • worries after puberty
8. Social reactions	• acceptance by family and strangers • feeling stigmatized • people can be helpful too
9. The other child	• meeting his needs • sibling's extra responsibilities • brothers with a strong relationship
10. Falling apart	• emotional crash • treatment
11. Maturation as a parent	• accepting the child • long term effects • victories • lessons learned from this experience

and a sibling workshop for Richard). Linda felt that she had to fight to get the label *autism* for her son.

Fighting for a label. Yes, it seems very strange to want to call your child, to have that handicap to put that name, but it's the only way you can help the child. (…) You know, he needed that. We *needed someone to say; yes, he has this problem and he needs to go to a special preschool, he needs therapy, he needs this or that. And so we were hoping to get a definite diagnosis for that reason. And just because, you know, once you have an answer, then you can begin to deal with it. When you have just a lot of uncertainty, how are you supposed to deal with that? Not knowing anything.*

The discourse of *Encountering Autism*

Around 18 month, Philip started displaying all of the main symptoms of autism, but for Linda the hardest one to deal with was his lack of responsiveness.

But you know, we just thought; he's gone. You know, he's just gone. This is what he is gonna be, he is just gone. He is not, he is not, he didn't have a personality, that you could get to know him. You just took care of him, you'd never get to know him.

Philip was placed into a group home at age eight on a temporary basis and five months later he moved to the group home permanently. Even major changes like this did not seem to effect Philip's non-responsiveness. He did not show any signs of disapproval of his new living arrangement. Besides his non-responsiveness, Philip displayed a variety of behavioural problems. He spent countless hours throwing his blocks in the air or throwing everything at the wall. Between 18 month and 10 years of age, Linda did not obtain any sign of recognition from her son. This was devastating for her because she was so desperate to receive some kind of human response from him.

But I think for me the worst part was that he got to the stage where he didn't care if I came or if I went and when I would go to work in the morning and my mom would be holding him and saying 'Wave good-bye to your mommy' and he wouldn't wave, he wouldn't look, he'd just be looking around. And when I would come home and say, "Hi Philip, mommy's home! Mommy's home, mommy's home" he would look up and he would look away, he wouldn't care.

Linda had to be very patient. Philip was ten years old when he first began to show signs that were clearly his signals of recognition and his attachment. For a while, as Linda went through the grieving process, hope and denial set in. She went to bed every night hoping that she would wake up to see a 'normal' Philip the next morning.

For one thing, he was always such a beautiful little child. And he would fall asleep at night. And I would go in to kiss him on the forehead and make sure that he was OK. And he just looked perfect. Like you couldn't believe that anything was wrong with him. It was like, I was so sure I could just kiss his forehead and he'd wake up in the morning and he'd be fine.

Along the process of grieving, acceptance and trying to plan for the future, Linda has progressed and regressed many times. Throughout her struggle with Philip's autism, sometimes she has felt united with her son. On some level, they merged and they felt peace within themselves.

And I'd take him to the sand box, you know, and he was just playing with the sand by me. And I'd just sit there and read my book quietly. And I thought, you know, two people who just don't want to be bothered right now, you know, we wanted to be left alone. And so we kind of enjoyed being alone together. At least I did. I thought, it's kind of effortless. I don't have to be boisterous and play tag and catch and everything. I can just, you know, be with him. It was comfortable for him for me. We were just at ease, together. And at times like that I'm not grieving that he's not talking to me. I'm thinking; 'This is fine just the way it is.

The discourse of *Fruitless Sacrifices*

Linda had to disregard her own needs many times in order to adjust her life to Philip’s ever changing needs. Although she recognizes the positive impact her sacrifices had on Philip, Linda felt, that they came at a great personal cost. She also indicated her frustration that despite all of her suffering and her efforts as a mother, autism still exists and the struggle of parents of children with autism remains the same.

The discourse of *Everyday Living, Stress and Coping*

Philip’s resistance to personal care made every little care taking activity an enormous one. Linda, feeling frustrated, thought that as Philip's mother she should know how to reach him and since she could not, she was failing. Using a variety of self-help activities such as going for a walk, jogging and listening to music helped her to get through the day. These self-help activities were like a First-aid Kit for her, being free of cost and available at any time unlike any other type of scheduled help.

Philip's annual summer camp, especially designed for children with autism, cost more than her salary for the summer. Money was tight during the rest of the year too. Sometimes Linda had to ask her parents to help out. Linda often wondered whether she would have survived the first ten years of Philip's life without her parents support. As a family, the three of them have always made their decisions together regarding Philip's care. Linda also, received a lot of informal support from her colleagues at work and her best friend.

Linda's main source of formal support came from a worker provided by Parents Helping Parents. The worker visited Linda's home once a week for many years and taught her how to work with her son. Linda respected and accepted the worker's opinion since she had learned how to care for a child with autism from first hand experience.

Linda has learned to believe that people with handicaps have just as many rights as anybody else. Since her son is unable to speak for himself, it is her job as his mother, to express his needs and fight for his rights. She has become an advocate for her son.

Linda was an active member of a few parental organizations affiliated with autism. Despite her intention to assist them, she felt helpless and unable to contribute in a meaningful way to different parental organizations that required her assistance. She did not have the resources to cope with the added responsibility. As a way of self-preservation, Linda has had to set limits to the amount of time that she would participate in these organizations. Perhaps placing Philip in a group home was an act of self-preservation as well for Linda.

The discourse of *Getting Adequate Treatment*

Looking back, the single most stressful event in Linda's life with Philip was placing him in the group home. She was unable to care for him without the appropriate before and after-school program. Therefore she had to place him in the group home prematurely. This decision was not a gesture of giving up instead it was creating arrangements that could work for everybody. Now Linda is happy with her son's living arrangements. However, she is still angry about being forced into a situation without being mentally prepared.

Linda had mostly positive experiences with Philip's schools. She is especially happy with Philip's current school where teachers are willing to change the program to suit the student instead of trying to plug him/her into an established program.

The discourse of *Mother as Teacher*

Teaching Philip basic self-help and social skills was an enormous task and everything was a slow and strenuous process. Looking back, Linda believes that the only way to teach Philip and other children with autism is to repeat things over and over and over until finally it becomes a part of their behaviour. Once it is learned it is there to stay. Now, at age 19, Philip is beginning to level off in his progression. Philip learned how to eat with utensils, use the toilet independently and he looks into people's eyes. He now understands some verbal language which makes it a lot easier for Linda to connect with him. His mother is the first one to cheer for his accomplishments. Now Linda has shifted her focus from teaching her son practical skills to teaching him how to enjoy a variety of leisure activities.

The discourse of *Hopes and Fears*

Linda's hopes regarding Philip's future have changed a number of times. As her understanding of his condition crystallized, her hopes became more and more realistic. Her major fear was Philip's inability to recognize danger. As a result, Linda has learned to employ a number of cautionary measures when she is with her son. Puberty has brought new worries as Philip's psychosexual development reached a new stage. Linda is in the process of adapting to this new situation.

The discourse of *Social Reactions*

People's reactions to Philip's disability were also a source of stress for Linda. She has resigned to the fact that her son may display some troubling behaviour in public conversely, she has experienced some positive reactions from strangers. Linda sometimes feels stigmatized. She does not have an *average* life since she does not have an *average* son. The way her life runs is very different from others in her age group.

(...) And I just, you know, even when I meet new people ... I'm not a secretive person, but it's to begin to tell them what's been going on in my life it's like a soap opera. I'm even embarrassed to tell a person, you know (chuckle). I just kind of play down a lot, casually mention on the side that my son is home on weekends because he lives in a group home. And I don't make a big deal, because people go: "Oh my god!" You know, and it's like very comical, this is just like horrendous. And I don't want that kind of a reaction, you know.

The discourse of *The Other Child*

Although Philip needed constant attention, Linda tried her best to attend to Richard's needs as well. Her concern that she might not meet Richard’s needs was an additional stressor for Linda. Philip’s disability had a great impact on Richard’s life. He shared the anticipation and excitement of the arrival of his newborn brother. He also shared the grief and the pain that accompanied his brother's autism. Richard was eager to establish a relationship with his brother. While doing so, he applied the same basic behavioural principles that were used by his mother which in turn provided him with a vehicle for relating to his brother and also relieved his mother of some small portion of child care.

The discourse of *Falling Apart*

For the longest time Linda felt that things in her life had fallen into their place and she was able to deal with her divorce and Philip's autism without any major setback. She never stopped to think about how she was doing. It came to her as a total surprise that those years under tremendous anxiety and stress could come back to haunt her.

You asked me a couple of times; How did I cope with that? How did I get through that? And I didn't even know what to say to you. Because nobody really ever asked me that before. Nobody seemed to care (chuckle) how I was coping as long as Philip was doing okay, you know. I never really thought about that, about how I coped with it. But it's interesting, that just .... Everything seemed fine back then, you know, when the kids were little and Philip was going through all those bad things. But now, that Richard’s living with his dad, and he's like 24 and a half, and Philip's in the group home and I don't have a lot of stress in my life, and some quiet time for myself. And now my nerves are just a wreck. You know, I ended up going to a psychiatrist. And I just said: "You have to do something because I have to work and I'm a mess! I cannot work you know." He feels it's delayed stress syndrome. And I, I said: "But you know, I didn't have any stress. Everything was fine. I had my parents supporting me and the kids are fine. Everything worked out fine. And he said: "You didn't feel it then, you're feeling it now. Because now everything is done and you have time to feel it." It's seems a little strange to me (chuckle), but that's what he said.

Perhaps with her boys living away Linda needs to learn how to live her own life without ongoing parental responsibilities. It seems as if she had to relearn the skills necessary to live on her own.

The discourse of *Maturation as a Parent*

Linda has matured as a parent by accepting her son, by successfully managing her life in spite of her hardships and by learning and applying the lessons that her experiences with her son with autism have taught her. This is how she summarized retrospectively her life with her son with autism.

I guess a lot of it was that I really wanted him so much that it didn't matter what was wrong, that I would just wanted a baby and wanted to take care of my baby. (Every time when Linda said the word baby, her eyes lit up.) And whatever he was OK, because I really wanted that baby, you know (chuckle). And I have disappointments, but I don't know. I also have a lot of things that I'm proud of too. A lot of accomplishments. And I've been very lucky, as far as help and getting assistance and that kind of thing. Things have fallen together very, very well. And I haven't been left high and dry.

Philip's condition has created some long-term effects on Linda's life as well. When she is trying to glance into her future she can see a lot of uncertainty. She used to believe that she would remarry and when retirement came she would walk with her husband hand in hand along the beach somewhere in Florida. Now, she is certain that this dream will never be realized. Linda used to think that most people's lives were perfect in comparison to hers. She is not so quick to think that anymore. Despite this, at times she has even felt victory.

When they were younger, I didn't feel, you know, that I was getting anywhere or accomplishing anything. It was just kind of making it from day to day and getting through. As I said, you know, I seemed to be okay. And then I heard a couple of instances like for example that one man, that I know, his wife left and he had a 4 year old daughter, she left the daughter. And he gave the child to his parents to raise. And I said: "Why? What's the problem?" And he said: "I can't possibly raise a child and work full time." You know, things like this made me realize; Well, why cannot he? I can work full time and raise two kids and one of them has a real problem and I'm still here to talk about it. I did okay. I mean I have ... I didn't have to go on welfare or get assistance. I ended up, you know, going to night school and getting my certificate.

Patience, the lesson that Linda values most was the hardest to learn. The process of internalising this lesson ran parallel with the process of accepting Philip's autism.

I think when you raise a child like Philip, he teaches me more than I will ever teach him. I'm not a very patient person but I learned how to be patient with Philip. I always wanted everything to happen instantly. But I've learned that some goals are long term and I've settled down and I've become less impatient, less frustrated. That's a good thing to learn. I'm surprised I ever did it. That is not the way I was. I'm just more comfortable and content and satisfied with my life and with the way things go, the speed at which things happen. That's good experience for me. Took a long time (chuckle) to learn.

Summary

This study examined one mother's narrative in which she expressed and created self-understanding of her life in relationship to her child with autism. Our aim in this analysis was twofold: a) to identify the major themes that have shaped our participant's life, understand her coping strategies, document the process of acceptance, and b) to see if by looking at her life retrospectively would allow us to document new, emerging themes that have not been able to be captured by previous studies that have investigated parenting experiences only for a short period of time.

The responsibilities of parenting a child with autism last a life time. Linda does not seem to protest against that. By accepting her son's autism, she has accepted the demands that his condition places on her life. Linda's acceptance is manifested by her ability to collaborate with professionals, to make realistic short and long-term plans for Philip and pursue personal interests unrelated to her son. Her son's non-responsiveness was the most painful part of raising him. The fact that Philip did not recognize her and others as a person validates that people with autism lack *theory of mind* (Premack, & Woodruff, 1978) and it was one of the major stressors encountered by our subject.

Although Linda did come to terms with her son's diagnosis and mobilized herself to provide the appropriate resources for him, signs of chronic sorrow which was first described by Olshansky (1962) were evident. He described this mourning experience of the parent of a child with a developmental disability as one in which there is never full recovery. Rather, there are periodic episodes of acute sorrow often triggered by major developmental milestones that reawaken painful feelings of loss. It has been suggested that parents of a child with a disability have to go through the grieving process (denial, bargaining, anger, depression, and acceptance) in order to be capable to plan realistically for their family's future (Witcher, 1989). Although Linda did go through those adaptational stages very quickly, this framework did not seem to be her major way of coping with her situation. Rather, it was the first of many steps that she had to take on her road to successful coping. Linda used instrumental (teaching her son, having a worker from Parents Helping Parents) and palliative (jogging, listening to music, and relaying on her parents' support) strategies to promote her acceptance of her son and develop adaptive parenting responses appropriate to his needs. Her parents proved to be the source of her most valuable informal support. Although she was able to access a variety of informal supports, there was one important coping strategy, relying on spousal support, that Linda could not access. Besides validating the findings of the existing literature on coping which has identified spousal support, acceptance of the child, formal services and programs, family oriented training programs and reliance on a social network as successful coping strategies employed by parents of children with autism, we identified two new coping strategies based on our case study

The first new coping strategy is related to one of Linda's strategies of self-preservation *Setting Limits*. She found herself unable to meet the expectations from parental organizations of being an agent of change, in addition to coping as a parent. Very often these organizations can only sustain themselves by relying on their members' work. This puts these parents into an awkward position when they need to choose between their own or their association's well being.

The second new coping strategy is *Advocating*. Learning to be a vocal and strong advocate for her son is a major part of Linda's coping. Although, she was unable to effectively participate in supporting the right of children with autism as a member of a group (parental organizations), she was successful in formulating and expressing her son's individual needs. Her approach to advocating has been non confrontational, however, she needs people to make arrangements to accommodate her son with his special needs and that in turn makes her life easier.

Issues related to raising a child with autism have been described in existing literature as the child's resistance to change, the child's destructive behaviour and temper tantrums, sibling's coping difficulties, relationships with professionals, education and related services, mothers' isolation, social and communicational, family related concerns, independence of the child and his/her future concerns. Our discourse analysis has validated those issues and brought up a new one. This new issue is related to Linda's *empty nest* depression. When Richard leaves, and Philip resides successfully in a group home, she loses her mission and her ability to sustain falls apart. This emotional crash or *falling apart* underlines the need for a new type of support which would assist parents in coping with their new living arrangements when their child with a severe disability leaves home. Moreover, it is a major emotional challenge to accept and raise a child with autism. Parents would greatly benefit from on-going counseling to enable them to deal with their everyday challenges of supporting their child with autism.

This study adds to the available literature by describing two new coping strategies and a new issue/theme that effects parent's life who raise children with autism, and validates our intent to examine retrospectively the progression of coping and the association between coping and successful adaptation strategies among parents of children with autism.

Interpretation of the findings reported herein, however, must be made in light of certain methodological considerations. This was a single case study. Our subject's experiences and coping strategies are in part due to her personality. There is no such thing as a typical child with autism. Consequently, each parent's experiences with a child with autism are unique.

One area of future research could focus on the retrospective experiences of a larger representation of parents of children with autism to validate and discover successful adaptive strategies. The authors believe that by listening to these parents' stories, by documenting and analysing them we could learn valuable information that can be transferred from parent to parent.

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