

Suffering and Love between Genders: A Narrative Analysis of Autistic Children's Parents

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Abstract

This article studies the gendered suffering and meaning associated with illness and parenthood among parents of autistic children in Taiwan. Autism is a lifelong developmental disorder which has no visible abnormalities, and which occurs more often in boys than girls. Autism has been affecting increasingly more children worldwide; therefore, it is important to understand the illness experience of autistic patients and their families. Using narrative analysis, this article examines the following: (a) the gendered social suffering experience of the parents of autistic children, and (b) meaning of the illness on the role of motherhood. The research data were mainly collected from in-depth interviews with parents and from parents' postings on online forums.

First, this article argues that the parents' suffering experience is social because it has been constructed primarily through the medical and educational contexts, as well as because of the negative social discourses about autism in Taiwan. These discourses include two contradictory viewpoints about the boundary between normality and abnormality: "Autism is NOT a disease, but merely a result of poor parenting," and "Autism IS a serious disease which is incurable." Furthermore, the social suffering of autistic parents can be seen as gendered as mothers usually have more caregiving responsibility and suffer more stigma than fathers.

Second, this article develops a concept of "illness-parenthood narratives" to identify how the mothers interpret the meaning of the illness and as a response to the social discourses against autism. The mothers create a "narrative of acceptance" and a "narrative of progress" to justify their devotion to the children and to defend their love for the child's life.

Finally, this article highlights how the parenthood of autistic children is a special case, the study of which can provide new dimensions for caregiving and gender studies. Implications for future research are also addressed.

Keywords: autism, parenthood, narrative analysis, social suffering, gender studies

1. Introduction

The issue of autism has caused wide public concern across the world. The incidence of autism has increased rapidly in Taiwan in recent years; however, little is known about families' experiences of autism. Autism has a huge impact on family life and the caring responsibilities of parents. Moreover, the impact of autism on parents is gendered both in terms of experience and the meaning of parenthood.

This article studies the gendered suffering and meaning associated with illness and parenthood among parents of autistic children in Taiwan. Using narrative analysis, this article discusses how parents interpret the meaning of autism and their parenthood with regard to their caring responsibilities. Moreover, the uniqueness of autism in Taiwan is emphasized.

2. Autism and Autistic Patients in Taiwan

Autism is a neurodevelopmental disorder characterized by impaired social functioning and communication skills, and by abnormality in unusual behaviors and interests. The disorder often lasts into adulthood and its symptoms can affect every aspect of a patient's life. Autism is also known as autism spectrum disorder (ASD); as it is a spectrum disorder, this means it includes different types of symptoms and degrees of severity, so every autistic child may behave totally differently. The patients have no visible abnormality and some are talented in certain areas; however, some may also have some degree of intellectual disability. Autism still remains a mysterious disorder in the field of medical research. Its cause, diagnostic criteria, and treatment are under heated discussion (Mash & Wolfe, 2009; Chiu et al., 2011).

The most curious thing about autism is that it is becoming increasingly prevalent all over the world. A growing body of data suggests that the reported cases of autism have increased rapidly in the US¹ and in Taiwan. The data from the Department of Statistics, Ministry of the Interior show that the number of autism cases in Taiwan was 13,580 in 2013, a significant increase from 2001 when there were 2,550 cases.² Moreover, autistic children comprised approximately one-tenth of disadvantaged students in general schools.³ While it is difficult to understand why the number of cases has increased, the data remind us that it is important to understand the experience of autistic patients and their families.

3. Literature Review

There is a vast number of social science studies on autism. However, the literature often overlooks the families' experiences of autism including how the social context impacts on their

experience. I will review three parts of relevant literatures in this chapter and highlight their contributions and limitations.

3-1. The Medical Context of Autism

Why does a variation in social communication or restricted interests become a medical problem called “autism”? Several social science studies discuss how the “medicalized” view of autism began; i.e., they have examined how the concept of “autism” emerged and how its meaning has changed over time (Nadesan 2005; Feinstein 2010).

On the other hand, due to the limited knowledge about autism, the parenting experience of autistic children’s parents has also been constructed by an “uncertainty in medicine” (Fielding 1999; Chang 2009). As previously mentioned, the etiology, diagnosis, and treatment of autism are still open to debate, and the medical procedure of autism is full of uncertainty. Medical professionals often find it difficult to offer clear answers to parents about whether their children have autism or not, what therapy is best for their children, and to what extent we can say that children have “recovered” from autism (Soong 2009).

This article does not intend to discuss the issue of “medicalization” and “uncertainty in medicine” in detail; nonetheless, it seems these concepts are important in order to understand the blurred boundaries of autism in the narratives of autistic children’s parents.

3-2. Caring for Autistic Children

Family is the basic care unit in peoples’ daily life. When a family member is ill, the family often acts as a single unit to make medical choices (Chang 2009). As is often the case with the families of autistic children, parents assume the primary caregiver role. Because the obvious symptoms of autism tend to emerge in toddlerhood, other family members, and in particular parents, have to take care of the children and make all the medical decisions. How do parents deal with their children’s autism? How does autism affect families? In this section, I will review three specific themes within the literature in order to seek answers to these questions.

3-2-1. “User-Professional Relationship” and “Stress and Coping” in Autistic Families

Fan-Tzu Tseng’s (2008, 2010) studies regarding children with “developmental delays” in Taiwan are some of the most relevant and inspiring research for this article. Tseng argued that the parents of children with developmental delays act as “logisticians” who do not accept medical services passively; rather, they place much effort into the carework and learn new skills in the

process. Tseng's articles provide many insights into caring for children with "developmental delays"; however, they mainly focus on the topic of "user-professional relationship," and overlook the suffering of the parents and the meaning of illness. Moreover, as Tseng covered all kinds of developmentally delays in children, the uniqueness of autism was not mentioned in these articles.

There is also a great deal of literature which discusses parents' stress and coping strategies. Researchers investigate how autistic children's parents deal with the stress of the carework, and the coping strategies they employ (Li & Lo 2010; Hsieh & Lo 2010; Chen et al. 2009). As Tseng highlights, these articles focus on a passive parenting style, which neglect the positive actions performed by parents.

This article uses narrative analysis to broaden the scope of the issue, including families' experiences of autism. To avoid the limitations of "user-professional relationship" studies and the passive approach adopted by "stress and coping" studies, I aim to understand parents' suffering and their love towards their children.

3-2-2. Social Suffering: Caring for Autistic Children

How does autism affect families? Many social science researchers, such as David E. Gray, have focused on the illness and parenting experience in autistic families. Gray (1994, 2002) analyzed the stress and stigma of autistic children's parents in Australia. He found out that the most stressful problems for the parents included a lack of normal language, disruptive and violent behavior, inappropriate eating and toileting, and inappropriate sexual expression. Although autistic children's parents may share similar stigma as the parents of children with other disabilities, the low visibility of an autistic person's disability makes them experience a different type of stigma. The parents suffer from what Goffman called "courtesy stigma"; moreover, parents, and especially mothers, have to bear the stigma of "irresponsible parents." Though many parents would like to "pass" as a "normal" family, they are unable to prevent their children from a wide range of social activities and therefore fail to "pass."

Woodgate, Ateah, and Secco's (2008) research on autistic children's parents in Canada showed similar results. Autistic children and their parents seem to "live in a world of their own." Parents feel isolated from the social world as a result of a lack of social awareness about autism, the full schedule for recovering courses, lack of support from other family members and extended family, and low accessibility to medical and educational systems. Fletcher et al. (2012) also highlighted female primary caregivers experience considerable "costs," including financial and work costs, costs to the health of family, social costs, and costs to overall family life.

The parents are not only anxious about the development of their children, but they are also tortured by various pressure derived by autism. I use the concept of “social suffering” developed by Arthur Kleinman to analyze the parents’ suffering experience, and I argue that this concept can offer new insights into the issue. Kleinman (1997: 320-321) considered suffering is “social,” which means that suffering is a “transpersonal engagement,” “societal construction,” and “professional discourse.” The concept of “social suffering” draws attention to how the social context constructs the experience of suffering. Using this concept, I will analyze the suffering experience in the narrative of parents within the framework of the social context, and discuss the effects of gender.

3-2-3. The Gendered Nature of the Caregiving Role

Most social science studies on autistic children’s parents only focus on the mothers. These studies briefly mention that the mothers are usually the main caregivers of autistic children, and quickly jump into their research questions. Furthermore, it is difficult to recruit the fathers as subjects because they are often busy with their work and are reluctant to discuss issues pertaining to their autistic children. It is reasonable for these studies to focus solely on the mothers’ experience, and they indeed contribute to broadening our understanding regarding the situation of autistic families. However, these studies tend to bypass the issue of gender, or take the gendered nature of the caregiving role for granted.

Some researchers critically analyze the gender differences in the caring responsibilities among parents with autistic children. Traustadottir’s (1991) study discussed gender issues in relation to parents of children with disabilities. She argued that “the primary role of the father is to be a supporter,” namely to provide financial support and be supportive of the mother’s dedication (pp. 220-221). Moreover, she suggested that families of children with disabilities are more likely to follow the traditional pattern of family life with “a breadwinning husband and a full-time wife and mother” (p.225). Gray’s (2003) article about the parents of children with high functioning autism also indicated the gender differences in the caregiving role, and noted that the most striking difference is the differing personal impact of their child’s illness. The fathers reported that their children’s condition did not significantly affect them. In contrast, the mothers claimed that their children’s autism severely affected their emotional wellbeing and their careers.

This article investigates the gendered nature of caring responsibilities for autistic children in Taiwan. Due to limited research data and lack of space, this article focuses more on the mothers of autistic children; however, it aims to place motherhood into the context of gender relations. In addition to suffering, the role of the caregiver has a positive side; i.e., the happiness that comes with

loving their children. Using a narrative analysis, I will discuss both parents' suffering and their love towards their children.

3-3. Narrative

Narrative can refer to the process of making a story, or the result of the process (Polkinghorne 1988). Illness narratives are an important topic in narrative studies. Hyden (1997) pointed out that narrative is one of the most powerful forms for expressing suffering associated with illness, and patients' narratives give voice to suffering outside the domain of the biomedical voice. Narratives offer an opportunity to fit the illness disruption into a new framework of life history, and reconstruct a state of coherence and interrelatedness.

However, the researchers often pay less attention to the narratives of the caregivers. While the illness affects the patients, it also has a considerable impact on their caregivers, such as the parents of autistic children. The narratives told by parents are about their suffering as well as the meaning of parenthood. I call these narratives "illness-parenthood narratives," and I argue that this concept can help us understand the care experience of autistic children's parents.

Gray (2001) also looked at the experiences of parents' with autistic children through narrative analysis. Gray's studies showed three types of illness narratives told by parents; he argued that all these narratives are presented as attempts to reconcile with the moral dimension of the illness experience and link to the cultural "master narrative" of science, politics, and faith. They are described as the narratives of "accommodation," "resistance," and "transcendence."

While Gray's article shed light on how parents with autistic children deal with autism, it does not delve into the meaning of parenthood or the gender difference in the narratives. Landsman's (2008: 108-142) narrative analysis of mothers with "imperfect" babies, including those with intellectual disabilities, cerebral palsy, autism etc., offered some thoughts on the issue of parenthood and gender. Landsman showed that mother's motherhood and personhood of the babies were denied by American culture, so the mother's narrative was "performative." The narrative asserted full motherhood and personhood by claiming the desired ending of the children's future attainment. Landsman also suggested that "mothers' lived experience of their child's disability is itself structured by the story they tell (p.141)," which indicated the dynamic interaction between experience and narrative.

In addition, Gill and Liamputtong's (2011) research on mothers of children with Asperger's syndrome deals with the concept of "the paradox of motherhood." Motherhood provides women with a sense of reward and fulfillment, but it is also physically and emotionally demanding and

limits their personal identity and careers. Furthermore, given the social expectation that mothers should feel happy and satisfied with their role, it is difficult for mother to express negative feelings about mothering. These paradoxical feelings would be more evident for women with a disabled child due to the heavy demand for care. Mothers of autistic children are anxious that they do not do enough for their children or fail to live up to the “ideal” image of motherhood. They often mask their stress, anger, frustration, and fatigue in public and with friends, pretending they can handle all the problems.

Nevertheless, Landsman’s as well as Gill and Liamputtong’s studies also treat motherhood as an isolated concept, and fail to analyze it within a framework of gender relations. The goal of this article is to explore the gendered narratives of autistic children’s parents, and investigate the issue of autism and parenthood in the context of Taiwan. Narrative analysis is one of the best approaches to study the level of experience, meaning, and their interaction in the context of social structure and temporal dimensions. Through narrative analysis, this article aims to discuss the gendered suffering and meaning of parenthood and illness with parents of autistic children.

4. Research Questions and Research Methods

This article studies the gendered suffering and meaning of illness and parenthood in autistic children’s parents in Taiwan. Using narrative analysis, this article focuses on two research questions. First, it examines the gendered social suffering experience of the parents of autistic children. I treat my research data as the parents’ “illness-parenthood narratives,” and investigate the social suffering contained in the narratives. Second, it studies the meaning of the illness on the role of parenthood. Due to data and space limitations in this paper, I focus on the mothers’ narratives, examining how the mothers interpret the meaning of illness as well as parenthood through the typology of narratives.

The research data were mainly collected from in-depth interviews with parents and from parents’ postings on online forums. I conducted the interviews with the parents of autistic children from four families; they were recruited as key interviewees by snowball sampling.⁴ One of the parents’ online forums is a discussion board on “Babyhome.com,”⁵ the other is a private ASD parents’ supporting group on Facebook. In both online forums, there are considerably more postings by mothers than by fathers.

5. Gendered Social Suffering

Taking care of mentally or physically challenged children takes an immense amount of time and effort, and the parents of autistic children tend to suffer more because of the unique autism

context. Autism is a disorder full of “uncertainty in medicine,” and autistic children’s parents face several ambiguous situations in the process of seeking diagnosis and treatment. On the other hand, it is not easy to find appropriate schools or recovering courses for autistic children. As a lack of medical and educational resources is an additional burden for the parents, I argue that the suffering experience is “social.”

Further, these factors also widen the gender difference in the division of caring responsibilities. In my data, the division of work in autistic families in Taiwan is similar to previous research. Mothers usually assume more caring responsibilities than fathers, and fathers are either supportive or indifferent towards their children. Caring for a child with autism is so challenging that it may totally change the life plan of the main caregiver; the responsibility of care often falls on the mothers’ shoulders.

Most autistic children’s families are two-parent nuclear families or three-generation families.⁶ Many mothers have their own jobs and the paternal grandparents take care of the children before the mothers discover that their children have autism. However, it is nearly impossible for mothers to balance a career and caring responsibilities. The mothers need to take their children to several recovery courses, deal with issues pertaining to their children’s behavior at school or in public, and teach daily living skills to their children.

The care is so demanding that many mothers give up their jobs and become fulltime housewives. For example, Ting’s mother quit her job when she discovered that Ting had autism. She thought that Ting’s grandparents could not give him the special education he needed, so she assumed the role as her child’s primary caregiver. She arranged all kinds of recovering courses for Ting, and both she and Ting were exhausted by the full course schedule. As Ting’s father was the breadwinner, he was seldom with Ting.

Some mothers continue working while also acting as the primary caregiver. Thus, they have to simultaneously manage their work in the workplace and carework at home. Some mothers work for financial reasons, but others look for employment due to the emotional burden of the experience. Sam’s mother is a part-time teacher at a night school; the class schedule is flexible so that she can handle both work and care. Sam’s mother commented:

I had to take care of him at every moment, which almost drove me crazy! I couldn’t bear to be with him all the time, so I found a job. [...] I choose to look for a job not for the money, but because it give me an emotional outlet.

The other reason that Sam's mother was able to take on a job was because of the support she received from Sam's father. Sam's father is a fulltime government officer. He shares almost half of the carework, and he agrees that his wife should pursue her career. However, I find that Sam's mother still assumes slightly more caring responsibilities than her husband;⁷ she noted she is lucky that Sam's father is "willing to help." The use of the word "willing" suggests that she assumes that Sam's father has a choice as to whether or not he helps with the caring responsibilities; however, she does not have the right to choose. Moreover, the use of the word "help" reveals that the role of Sam's father in carework is an assistant rather than the primary caregiver.

The gender differences are more evident in most autistic families. Many mothers feel content if their husband can be the "supporters" in carework; the work of the supporter often only includes "paying for the pricy recovering courses" and "driving the child and mother to the courses." In some special cases where the fathers are the main caregivers, it is often because the mothers are unable to take on this responsibility.⁸

Gender differences also exist in the context of the extended family. While extended family members on the mothers' side offer to help in the carework,⁹ autistic families seldom receive help or support from the father's extended family. The latter is because the families are indifferent to their difficulties or they discourage them from seeking treatment. As gender differences in extended families may be unique to Taiwan, further research is required on this issue.

The gender differences regarding suffering relates to both physical and emotional challenges. There are two kinds of social discourses against autism, and the mothers are more likely to be blamed by these discourses. They include two contradictory viewpoints about the boundaries between normality and abnormality: "autism is NOT a disease, but merely a result of poor parenting," and "autism IS a serious disease that is incurable." Both of these viewpoints hold negative attitudes regarding autism and autistic families.

Historically, some medical researchers thought that autism was caused by parent's coldness towards their children, and especially their mothers. This theory was called "refrigerator mother theory," and has now been widely discarded (Feinstein 2010). However, the tendency to blame mothers for their children's misbehavior still exists. Many interviewees and on online postings noted that people accuse them of spoiling their children; they also stated that people do not believe their child "has autism." As the medicalization of autism has only recently begun in Taiwan, community awareness and understanding about autism is low. The elderly are more likely have prejudices against autism due to lack of medical knowledge. For example, one mother posted the following on Babyhome:

My in-laws still think my child is “okay.” Although my son has a moderate disability card, they just regard the diagnosis as an excuse that I don't take good care of my son.¹⁰

This discourse of “autism is NOT a disease” tends to consider the children to be “normal” and criticizes the parent’s parenting style. On the other hand, the contradictory discourse of “autism IS a serious disease” also coexists. “Autism” itself is often considered as a terrible and incurable disorder, and autistic children may be deemed useless and not worthy to live due to the illness. Autism is a spectrum disorder; however, if the child receives the label of autism, he or she is often considered as “a child with special needs permanently.” Sam is a child with autism and attention deficit hyperactivity disorder (ADHD). When I asked Sam’s parents how they explain Sam’s illness to others, Sam’s mother said that she would just mention ADHD to acquaintances. She does not mention that Sam has autism until they know each other well. She said the reason she makes this decision is that ADHD sounds “ordinary;” however, an autistic child tends to be regarded as “special.”

Autism is considered to be a serious disorder, and autistic families are often regarded as unfortunate families. Furthermore, illness is a sign of “karma” according to the traditional religion in Taiwan; this means that misfortune is caused by bad deeds performed by an individual or their relatives in a past life. For example, one Daoist priest told Andy’s mother that Andy’s autism resulted from Andy’s grandfather killing too many dogs. In autistic families, the child’s illness may be seen as evidence of their parent’s karma.

These two social discourses against autism are contradictory; however, they coexist and significantly impact autistic families. The parents of autistic children have to respond to these discourses and search for the meaning of the illness in order to support themselves. Thus, the parents develop the “illness-parenthood narrative.” The mothers of autistic children often take on the majority of caring responsibilities, and they suffer from more negative social discourses than the fathers. As the narrative and experience interact with each other (Landsman, 2008), the mothers tend to develop the narratives to a greater extent than the fathers. In the next paragraph, I show that mothers create two kinds of “illness-parenthood narratives.”

6. The Mothers’ “Illness-Parenthood Narrative”

The way mothers interpret the meaning of autism and parenthood is related to the public opinion of autism. Mothers create a “narrative of acceptance” and a “narrative of progress” as response to two negative social discourses against autism respectively.

A “narrative of acceptance” is to accept that the children have autism, and to think the children need special medical and educational resources. Because there is no evidence of disability in an autistic child's physical appearance, their mothers have always considered them as “normal.” When mothers discover that their children are “abnormal” and “have autism,” the news is shocking. Due to the pressure of the “golden period” of therapy, mothers of autistic children have no time to waste. Many mothers adopt a “narrative of acceptance”; consequently, they accept the children’s illness as well as their identity as a mother of an autistic child. They also emphasize the importance of not caring about what other people think. For example, when mothers discuss how they explain their child’s autism to others, they said:

You don't have to think too much. As long as you accept the way your child is, you aren't afraid of others' opinions.¹¹

When we really accept our children, what relatives and friends think no longer matters.¹²

Moreover, when mothers adopt a “narrative of acceptance,” this does not mean they passively accept medical explanations. Rather, they actively create this narrative to struggle against the social discourse of “autism is NOT a disease.”

It is important to note that the mothers encounter this kind of discourse not only in the public sphere, but also within their families. The grandparents often do not believe that the children have autism and need to seek treatment, especially the paternal grandparents. In some families, the children’s father also doubts the diagnosis. In these families, the mothers are the primary caregivers; they try to persuade their husbands to accept the children’s illness and explain their need for special resources, however, this often does not work. These mothers feel frustrated and have no choice but to stick to a “narrative of acceptance.”

However, autistic children are not in the “sick role” in the short-term. The disability of the children may be long-term, and the challenge in illness and parenting for the mothers exist on a daily basis. How do the mothers interpret their motherhood, and motivate themselves to continue? They create the second “illness-parenthood” narrative, a “narrative of progress.”

A “narrative of progress” follows a “narrative of acceptance”; the former is against the discourse of “autism IS a serious disease.” As the children grow up, the gap between the

development of autistic children and their peers is more evident, and others may doubt the ability of the autistic children. The mothers use a “narrative of progress” to argue that the development of their children does fall behind, but they can catch up with their peers. While a “narrative of progress” admits the children’s disability, it emphasizes that the disability is not permanent. As quoted by various mothers:

My child is 2.5 years old, and he was recently diagnosed with autism. But I think he keeps progressing. When he bumps into his head, he can say “never mind” or just say “ohh,” which makes me see endless hope [for my son].¹³

My husband and I see a little hope for my child. He is receiving treatment now. I believe he will progress more and more, and catch up the level of other children.¹⁴

The mothers with a “narrative of progress” believe their children are likely to grow out of the symptoms of autism with their help. Hope of progress enables parents to devote themselves to their children without feeling any regret. One mother explained:

The reason why I left my job without pay was to “avoid any regret.” As long as I have tried my best to help [my child], I will feel relieved no matter the outcome, and I won’t feel that I owe her. However, if I don’t help her as much as I can, I will definitely regret it in the future.¹⁵

As some children with autism are considered to have better outcomes than other children with disabilities, mothers of autistic children are more likely to develop a “narrative of progress.” However, endless hope also comes with frustration. Ming’s mother commented that the development of autistic children is like a bottomless pit, because you never know their limit. Sometimes it makes her feel very frustrated; she believes that it may be easier to care for a child with intellectual disabilities.

On the other hand, a “narrative of progress” emphasizes the strength of the children. Some mothers are proud of their children’s talents, like their ability to swim or play a musical instrument, and some value the kind-hearted nature of their children despite their lack of social skills. For some high-functioning autistic patients, the boundaries of normality and abnormality are blurred, and the mothers may challenge these boundaries. For example, one mother with an autistic son wrote the following on her blog: “I like my child’s stubbornness. If his stubbornness is not harmful to his health and doesn’t break any laws, I don’t think he should be the same as others.”¹⁶

Moreover, some mothers view autism as a special gift. Ming's mother said the experience of taking care of Ming makes her a better mother. Andy's mother, a Christian, also considered Andy as one of God's treasures. Through this narrative, autism is reinterpreted in a positive way.

The reasons why mothers create these narratives is to defend themselves against the negative social discourses of autism, and to look for meaning in order to continue to face life's daily challenges. Most of the mothers' narratives mention the "narrative of acceptance" and "narrative of progress." These two kinds of narratives are not exclusive, but they are often mixed together. The mothers choose one or both of them depending on what kinds of social discourses they encounter.

Moreover, this is not to say that fathers lack an "illness-parenthood narrative"; rather, they may create other narratives. For example, Andy's father knows Andy's symptoms of autism well, but he said he did not really "believe" Andy had autism till now. If Andy's father was the main caregiver, without a "narrative of acceptance," he may not be motivated to deal with Andy's autism.

The "illness-parenthood narrative" is about parental suffering and love. By adopting a "narrative of acceptance" and "narrative of progress," the mothers of children with autism intend to persuade others that they are responsible mothers. Through the narrative, they explain they were not responsible for the illness, and they are doing their best to seek treatment for the children. Many mothers worry they are "unfit mothers," and the mothers of children the disabilities are more anxious about this. Due to the blurred boundaries of autism, autistic children may be not considered as ill and they may have the opportunity to develop. This places greater pressure and more resources on their mothers, which leads to the construction of an "illness-parenthood narrative." These two narratives help the mothers to prove that they are indeed good mothers.

7. Conclusion

Using narrative analysis, this article examined the effects of gender on experiences, and the meaning of illness and parenthood among autistic children's parents in Taiwan. This article demonstrates that the parents' suffering experience is constructed by the social context, and their experience is gendered. Mothers are the main caregivers and suffer from more social discourses against autism. In order to support themselves and justify their motherhood, the mothers develop "narratives of acceptance" and "narratives of progress."

This article deeply investigated the meaning of illness and parenthood among parents of autistic children, and discussed the interaction between experience and the meaning of caregiving. It captured the negative, positive and ambivalent side of caregiving, and highlights the social context of Taiwan, such as family structure, family relationship, and the social discourses against autism.

Moreover, the uniqueness of autism can provide new dimensions for caregiving and gender studies. The finding of this article illustrates that mothers of autistic children not only experience gender inequality with regards to caring responsibilities; they also tell stories, which leads them to feel empowered and fulfilled.

This article has several limitations that need to be addressed. The narratives of fathers are required in order to analyze the data further. Due to space limitations, this article does not address the issue of social class and the severity of autism. Autism is a special case in social science studies and a neurodevelopment disorder effecting people around the world. Thus, there is a need to further explore the experiences of autistic families.

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Notes

- ¹ For example, see <http://www.cdc.gov/ncbddd/autism/data.html>.
- ² The data are from Ministry of the Interior. Retrieved from <http://www.moi.gov.tw/stat/index.aspx>.
- ³ The data are from Special Education Transmit Net. Retrieved from <http://www.set.edu.tw>.
- ⁴ Four autistic families were included in this research: Andy's mother and father were interviewed separately, Sam's parents were interviewed at the same time, and I interviewed Ting's and Ming's mother. Andy, Sam, Ting, and Ming are all boys aged 9-18. All the families belong to the middle class.
- ⁵ <http://www.babyhome.com.tw/>
- ⁶ A "three-generation family" refers to autistic children and their parents who live with the children's paternal grandparents.
- ⁷ For example, when we discussed the difficulties of caregiving, Sam's father said that his wife spends more time with Sam, and she has more negative experiences about being with Sam in public.
- ⁸ For example, a posting written by a father, who is the main caregiver, noted that his wife has serious emotional problems, which prevents her from being able to care of their children. It was posted on 01/2013 on Babyhome.com.
- ⁹ All of the four families I interviewed mentioned this point.
- ¹⁰ It was posted on 08/2013 on Babyhome.com.
- ¹¹ This is quoted from an interview with Andy's mother.
- ¹² This is a passage from a Facebook group posting on 08/2014.
- ¹³ This is a passage from a Facebook group posting on 09/2014.
- ¹⁴ This is a passage from a Babyhome posting on 12/2013.
- ¹⁵ This is a passage from a Babyhome posting on 7/2012.
- ¹⁶ <http://helpasperger.blogspot.tw/2014/06/qal.html>