The Subjective Experiences of Attention-Deficit/Hyperactivity Disorder of Chinese Families in Hong Kong: Co-Construction of Meanings in Multiple Family Groups

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The subjective experiences of Chinese children in Hong Kong with attention-deficit/hyperactivity disorder (ADHD) are underexplored. This article reports the results of a qualitative study that aims to understand the subjective experiences of children with ADHD in Hong Kong, taken from among a clinical sample of Chinese families with children struggling with ADHD who have participated in cross-disciplinary research of multiple family groups (MFG). The participating children revealed the subjective experiences of their struggle with the disorder in response to their parents' concern at a "press conference," one of the MFG activities, which underscored the importance of developing a new social work model to meet the multiple psychosocial service needs of these families. The article concludes with the discussion of the implications for the new model.

KEY WORDS: *attention-deficit/hyperactivity disorder; child mental health; multiple family groups; stimulants*

Around 8.9 percent of all school-age boys in Hong Kong suffer from attention-deficit/hyperactivity disorder (ADHD) (Leung et al., 1996), which is characterized by developmentally inappropriate levels of inattention, impulsivity, and overactivity (American Psychiatric Association [APA], 2013). The estimated male-to-female ratio is 6–8 to 1 (Hong Kong Society of Child Neurology and Developmental Paediatrics, 2008). Children with ADHD suffer from executive dysfunctions (Brown, 2013) that subsequently lead to their emotional, behavioral, peer, and school maladjustment (Barkley, 2002; Mikami & Normand, 2015). Managing ADHD is a demanding task for parents that lowers parental self-esteem (Gingerich, Turnock, Litfin, & Rosén, 1998) and self-confidence (Alizadeh, Applequist, & Coolidge, 2007). The tension in parenting also affects the parents' marital relationships, and these families often have a high rate of separation and divorce (Johnston & Mash, 2001). All these negative effects of ADHD on children and their families indicate the multiple psychosocial service needs of these families.

As in many countries, pharmacological treatment is offered as a first-line treatment in Hong Kong (Hong Kong Society of Child Neurology and Developmental Paediatrics, 2008), when psychosocial intervention is insufficient (So, Leung, & Hung, 2008). In spite of compelling evidence to support its superiority in alleviating the symptoms of ADHD (MTA Cooperative Group, 1999), pharmacological treatment is criticized for failing to meet the psychosocial service needs of the families of children with ADHD (Greene & Ablon, 2001); meeting these needs is an integral part of holistic care.

In response to the psychosocial service needs of these families, the multiple family group (MFG) research project was developed by our cross-disciplinary clinical team coming from the university's departments of social work and psychiatry (Ma & Lai, 2014). The MFG is an activity-based treatment modality that promotes mutual understanding and mutual aid within the families and among the group members to develop their resources and coping skills in the face of a common challenge (Asen & Scholz, 2010; Eisler, 2005). The MFG is also a successful means for engaging parents in mental health services (Gopalan et al., 2010).

One of the core MFG activities is a "press conference" that is modified from Asen and Scholz's (2010) MFG model. This activity creates a playful context in which parents and children can negotiate

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the meanings of ADHD and discover solutions to their problems. Based on Epston's (1999, 2014) concept of therapy as co-researching the problem, we analyzed the qualitative data that emerged from each press conference of the four MFGs. The findings describe the concern parents have about their children with ADHD and the subjective experiences of these children in relation to pharmacological treatment, family, school, and peer relationships. In the field of ADHD, the majority of local research is predominantly based on the biomedical model; the subjective experiences of children and their families struggling with ADHD are grossly neglected. We intend to fill this knowledge gap.

LITERATURE REVIEW

Rafalovich (2004, 2005) explored the experiences of parents who had gone through the process of having their children's academic and social difficulties medicalized as ADHD, and how their domestic lives were therefore dominated by expert advice. Other studies (Austin & Carpenter, 2008; Carpenter & Austin, 2007; Kildea, Wright, & Davies, 2011; Singh, 2004) described mothers' experiences of being blamed for poor mothering in response to their children's problematic behavior in light of the mainstream discourse about good mothering. Fathers were described as feeling vulnerable due to their identification with their sons' ADHD behavior and perceived medication to be unnecessary; hence, they withdrew from the decision to use medication, leaving the mothers as the major caregivers (Singh, 2003).

Children with ADHD appeared to be struggling with and overwhelmed by the sense of "badness" resulting from the disorder, even though their behavioral difficulties were improved by medication (Kildea et al., 2011; Singh, 2007b). Singh (2011, 2013a) further explored these children's moral understanding and sense of responsibility for their problematic behaviors and their use of ADHD medication to enhance their moral agency.

Local studies have focused on the prevalence (Leung et al., 1996), diagnosis (Ho et al., 1996), comorbidity (Shea, Lee, Lai, Luk, & Leung, 2014), and treatment outcome (Chan, Hung, Lee, & Wong, 2010; So et al., 2008); the subjective experiences of these families have rarely been investigated, except for a study by Ma and Lai (2014) that explored the experiences parents of children with ADHD had in their engagement with service providers, and with the difficulties their children encountered at school.

These studies provide insights into the parents' suffering and the children's struggles regarding their sense of self. However, the parental concerns about the subjective experiences of their children's struggles with the disorder remain unidentified in Chinese societies such as Hong Kong. Moreover, these studies are based on the individual perspectives of parents and children; the construction of meanings of living with ADHD at the family level remains unknown. The knowledge gained from our study will help to reveal the psychosocial needs of families of children with ADHD so that services for the management of ADHD will be enhanced accordingly.

METHOD

Our qualitative research draws on the data collected from the parent–child dialogues that emerged during the press conference, one of the core activities of the MFG conducted by us for families of children with ADHD. The press conference aims to place children with ADHD in the role of experts so they can talk about their experiences of ADHD in response to their parents' care and concern. The parents take up the role of reporters who interview the participating "child-experts" (Asen & Scholz, 2010). The parents prepare "interviewing questions" on their own through a discussion in the parents' group, and the children discuss their experiences of ADHD in relation to different aspects of their lives in a children's group. Through discussions during the preparation phase of the press conference, the participating families share their experiences of living with ADHD. The press conference usually lasts around an hour. The parent-reporters take turns to ask the child-experts questions, and the child-experts answer on their own initiative. Most of the time, the child-experts help to supplement their experiences relating to one question, and the parent-reporters further explore those experiences. The conversation is then gradually expanded to include the whole group.

Epston (1999, 2014) suggested that therapy is "co-researching" the "problem" that affects the person. In the process of therapy, the client and the therapist join together as "co-researchers" to investigate and explore the problem. Therapy is also a linguistic process, in which the use of language facilitates the construction of meanings for the words used to describe the lived experiences of both clients and therapists (Kristensen & Koster, 2014) and the discovery of solutions to the problem. Apart from its therapeutic use, therapy is a process of the "co-production of knowledge" (Epston,

1999), and done in such a way that the "insider knowledge," which has been subjugated by the mainstream discourse, reemerges in the therapeutic context (Epston, 2014).

The research value of the use of the press conference comes from the insider knowledge generated from the linguistic process between the parents and the children of the press conference, especially as the interviewing questions are generated and initiated by the parents and every reply from the children is in response to their parents' concern. Therefore, the parents and the children can make sense of their experiences of living with ADHD at the intersubjective level. The knowledge embedded in the press conference is specific to their predicament.

Placing children in the expert role playfully reverses the "interaction order" that is regulated by the social status of the parties in the conversation, and rooted in the "politically charged communicative dynamics" among the parties in the conversation, to define the nature of the issue of the conversation (Rafalovich, 2005, p. 27). By giving their "expert responses" to the parental concerns as presented by the parent-reporters, the children can define the issues from their "expert" perspective and this facilitates their expression of those issues (Singh, 2007a).

The experiences of the families described in this article are taken from four MFGs. The research was approved by a university ethics committee, especially regarding our method of collecting data from children. The families were referred by a local child psychiatric unit and had children with a normal IQ and with a confirmed diagnosis of ADHD. Informed consent was obtained from the participating parents and children after explaining the research aims and procedure and that their participation was voluntary at the pre–group interview conducted by the authors. Pseudonyms are used in this article to ensure anonymity.

There were 20 participating families, with one grandmother, 14 fathers, 19 mothers, 21 children with ADHD (16 boys, five girls), and 10 siblings. Eighteen of the families were intact, two were divorced, and one was bereaved. Four families were receiving welfare assistance; the remaining families did not report significant financial stress. The age range of the children with ADHD was six to 10 years; 16 of them were receiving pharmacological treatment.

With informed consent from the families, the press conferences from the four MFGs were video-recorded and transcribed, with the accuracy of the transcriptions checked. The process of data analysis was divided into generative, interpretive, and theorizing phases. In the generative phase, data were read in detail to generate lists of meanings and coded notes. In the interpretive phase, connections and patterns in the themes were identified. In the theorizing phase, the meanings and implications of the categories were further identified (Connolly, 2003). Debriefing meetings were conducted by the first and second authors during the analysis process to identify the meanings, themes, and theoretical explanation of the data and to minimize the authors' potential interpretive bias because of their prolonged engagement in the child mental health field and being mothers in their personal lives.

RESULTS OF THE STUDY

The development of the themes of this study at different stages of analysis is illustrated in Table 1. These themes indicate how parents and children co-constructed the meaning of their ADHD experiences and highlight the parents' concern and their children's experiences of medication, stigmatization, and moral awareness of their behaviors.

Parents' Feelings of Ambivalence about Medication

At the press conference, participating parents raised questions about their children's adjustment to school, including their homework completion and their experiences of being bullied by their classmates and teachers. The parents were also curious to learn about the impact of ADHD on the children's moods and family relationships from the children's perspective.

While exploring the children's experiences with using ADHD medication, including its effectiveness and side effects, the parents expressed their worry about their children being dependent on medication to keep them in control of their behavior instead of them using their own moral judgment to behave properly. The parents frequently asked about alternatives to medication to help their children, but they were ambivalent about using these alternatives because of the response their children would get from teachers if they knew the children were not on medication.

> Some kids do not know about the side effects of taking medication; they only know that they will behave better after taking medication and receive praise from their parents. How should

Table 1: Summary of Findings

Theorizing Phase	Conceptual Categories	Themes
Parents' feeling of ambivalence about medication	Parental concern	School adjustment
		Child's mood
		Family relationship
		Impacts of medication
Children's will to behave well	Children's perceived changes in self after taking medication	Performance enhancement
		No instant effects
		Loss of temper
ADHD medication as a problem-solving strategy	Children's perceived changes in the environment	Changes in family relationship
		Changes in attitudes of teachers and classmates
Medicated self is part of me	Children's perceived side effects of ADHD medication	Would not stop taking ADHD medication
		Negative physical effects
Children's moral awareness of their behaviors	Alternative to ADHD medication	To be comforted
		To be forgiven
		To feel secure

Note: ADHD = attention-deficit/hyperactivity disorder.

> parents make them understand that they cannot depend on medication in the long run? How do we make the children understand medication is not a long-term plan? . . . But if they don't behave at school, they are punished by the teacher. Will they become more unrestrained, less afraid of [their teachers]? Then, will their teachers become neglectful of those children with that kind of problem, and just let them do whatever they want? The teachers would not care about their homework, being late to school . . . , and other bad habits? (David's mother, MFG1)

ADHD Medication as a Problem-Solving Strategy

The participant children shared the negative impact of both ADHD and ADHD medication on their relationships with parents. For example, in MFG4, the participating children described the mechanism of their negative reaction to their parents under the influences of ADHD medication.

> **Sue's father:** Do children with ADHD love their parents?
> **Hilary:** They do, but sometimes they find their parents are too nagging and they become moody and they have a feeling that they don't like their parents.
> **Kelvin:** I think it is about their thinking and the side effects of the ADHD medication. Because they lose their temper after taking medication, when their parents pick on them over minor things, they will get mad easily. (MFG4)

The participating children revealed the change in attitude of their teachers and classmates after knowing they were taking ADHD medication. Most of the children in our MFGs needed a second dose of medication at lunchtime. However, there was no private space at school for the participating children to take their medication, so they had to take the medication in the cafeteria or in the classroom, with other classmates watching them. Moreover, some of them reported that if they got into trouble in the classroom their teachers would not punish them if they knew the children had taken their medication, which was the first thing their teachers would check. They reported having experiences of being laughed at and bullied by their classmates, and being called names such as "insane person," "having rabies," or "an inmate from mental hospital," and some classmates spread the rumor that one "should not talk to an inmate from a mental hospital." They also reported having a feeling that they were looked down on by others at school.

However, some of them did not want to stop taking the medication because they considered it helpful, despite the side effects. Taking medication has become part of their problem-solving strategy to improve family relationships, to avoid conflicts with parents when they fail to meet the behavioral expectations of their parents, and to avoid punishment from teachers, besides enhancing their performance.

> **Joe:** My mother, she wants people to have things done immediately, if not she would be very anxious.

Ken's mother: How much time should he be given?
Joe: Should give him some more time.
Ken's mother: So you are saying children with ADHD will not do things immediately. . . . So how can I make them do things immediately?
Joe: [*helplessly*] You ask some other kid's opinion then. (MFG3)

In real life, Joe insisted on taking medication even though there was no improvement in his performance according to his self-report and his parents' and teachers' observations. He also suffered from severe side effects, like loss of appetite and facial tics. However, taking medication helped him to defend himself against complaints from teachers and avoid his parents being mutually blamed over parenting issues on those occasions when he failed to comply with school regulations.

Children's Will to Behave

The effect of the ADHD medication did not come instantly. Some participating children still needed to put in a lot of effort to meet the social expectation of being good children.

Ben's mother: Is it very hard for a child with ADHD to control himself and be patient [at school]? Or is it that he wants to control himself but he can't? . . . Is it too hard for him? Does he want to behave better?
Ben: Just can't do it.
Ben's mother: Is it that being good is a very tiring thing? Or is it just too hard?
Ben: It is very hard . . . very tiring . . . very tiring. It is very tiring for [children with] ADHD to be good. That is why they don't want to behave.
Ben's mother: Would it be easier if they take medication?
Ben: It is not so hard to be good after taking the medication.
Ben's mother: So you can do it easily?
Ben: It is not that easy. (MFG2)

With the help of ADHD medication, most of the participating children reported that they could be more attentive and showed improvement in their behavior, emotions, and academic performance, despite suffering from side effects such as loss of appetite, insomnia, and limitations in their capabilities in sport. However, not all of them found medication to be helpful, because it did not help them eliminate their problems. They revealed that their will to focus was crucial for the medication to take effect.

Ken's mother: Professor Joe, do you think the medication is effective?
Joe: It is not necessarily having an effect.
Andy: [*screamed out*] It has no use!
Joe: Because in that four hours, the problems are not eliminated. . . . It just makes all the problems concentrated at one point [the time when the medication effect is over], you will revert [to fight with people] as soon as the effect is over.
Joe's father: So, do you still like taking the ADHD medication?
Ken: It is a difficult question. . . . I don't feel willing to, because the body is like being tied up. . . . If the child with ADHD takes medication, but his attention focuses on other things, he would be absentminded, there is a possibility that he might bully other children in another way round. . . . When the effect of the medication is over, he is like a prisoner escaped from prison.
Joe's father: Is it difficult for them to get along with others?
Joe: I don't want to talk to people after taking stimulant medication. I am dull in class, even people ask me questions, I don't hear. (MFG3)

"The Medicated Self Is Part of Me"

Some of the children also found that the medication has become part of them, so that they did not consider the alternative of not taking medication.

Joe's father: Do children with ADHD like taking ADHD medication?
Ken: It is hard to say, if not taking the medication, [I] am not used to it . . . because some people have got used to taking the medication.
Ken's father: How is that feeling?
Ken: It is like a part [of you] is missing. (MFG3)

Children's Moral Awareness

The parents asked the participating children about their perceived alternatives to ADHD medication. The parents often suggested using rewards as a behavioral control method— like praising and giving little gifts—and using punishment to modify their children's behavior and emotions. Some of the children

voiced their need for a better understanding of ADHD on the part of others, and expressed that comfort, forgiveness, and security from parents and teachers were important in the improvement of their behavior. This implies children's moral awareness of their behaviors.

> **Isaac:** At school, teachers have to tell other classmates, "You should not think he is really bad . . . he just has ADHD," and comfort him. . . . [You should] comfort him, and his ADHD symptoms would be eased. (MFG2)

* * *

> **Emily:** Children with ADHD should try to talk to their parents, so that the parents can be more familiar with their children.
> **Hilary:** If the parents can get along with their children normally, it would be better if they can feel secure, and feel that they love them, then, it would help a little . . . they will not throw a big temper [tantrum] next time. You need to find time to get along with them . . . I mean, if they make minor mistakes, don't punish them only; make them feel [that] their parents love them, as it would help to improve their emotions. (MFG4)

DISCUSSION

The co-constructed narratives suggest that both the parents and the children were active agents with a sense of mastery in managing ADHD. With the help of ADHD medication, the children improved their ability to meet the social expectations for their performance in different aspects of life, despite suffering from the side effects of the medication and stigmatization at schools, where protection of their privacy was inadequate. At the same time, the children used the ADHD medication as a coping strategy to defend themselves against complaints from teachers and to avoid conflicts with family members. Similar to most of the parents of children with ADHD in Hong Kong, they chose to use medication because of the pressure and lack of support from school (Ma & Lai, 2014) and the unavailability of psychosocial intervention (Chan et al., 2010). The use of medication has become a coping strategy in managing the seemingly unsupportive environmental context (for example, school and peers), apart from its original purpose as a symptom alleviator.

The concerns of the parents expressed in the press conference revealed that management of ADHD is more than symptom alleviation; they worried about the adjustment of their children to different aspects of life. Most important, they were concerned about the moral development of their children and the long-term dependence on medication. This reflects that as the parents did not perceive their children's behavioral problems to be a totally medical problem, they were anxious to explore the alternatives to medication suggested by the children due to the academic pressure.

The children at the press conference demonstrated their cognitive ability to differentiate between both the effects and the side effects of the medication, including physical, psychological, and relational effects. Whether or not the medication has any positive effect depends on the children's will to focus and assume moral responsibility. They revealed their experiences with stigmatization at school because of the administration of medication. These experiences suggested some crucial factors affecting the children's drug compliance, the improvement of medication effects, and the areas in which they need assistance.

Besides medication, the children long for comfort and forgiveness from their significant others, including parents, siblings, and teachers. They want adults to help explain to others that they are not bad; they just have ADHD. This implies that the children had a moral awareness of their behavior and were experiencing a sense of badness. Moreover, the feeling of "being tired of being a good child" was expressed at the press conference. In our contemporary world where children are overscheduled and highly institutionalized (Gómez Espino, 2013), being a good child has become an impossible task. The children revealed that they felt their medicated self was part of them, and they felt like a part of them was missing if they did not take their medication. The medicated self has the possibility of posing a threat to the authenticity of the core self and the development of moral agency in the children (Singh, 2013b). The subjective experiences of the children indicated that they need help to overcome the sense of badness and deal with the stress of meeting the demands from the social discourse of being a good child. It also suggests that there is a need to explore further whether the development of their core self and moral agency is affected by the medicated self.

The heavy reliance on ADHD medication also discourages these families from exploring possibilities in parenting and relating to each other. It also

fails to deal with the diversity of parental concerns and the stress and blame the parents experienced, as suggested by, for example, Austin and Carpenter (2008) and Singh (2003, 2004).

Children are not often involved in decision making regarding medical treatment in the United Kingdom and the United States because of the limitations in children's cognitive abilities (Singh, 2007a) and the protective stance of the parents and helping professionals toward the best interests of the children (Coyne & Harder, 2011). This situation is similar in Hong Kong. The continuation of medical treatment is based on a review of the effectiveness of symptom control from the perspectives of parents and teachers and the presence of physical side effects. Muting the voices of the children in the decision-making process takes away a valuable chance for families to negotiate their own solutions, which is crucial for the development of the children's moral responsibility and self-agency. At the same time, it subjugates the children's expression of their deeper psychosocial needs in dealing with the stigmatization and the demands of the social expectation of being a good child in our contemporary society. Existing treatment for children with ADHD in Hong Kong is a partial solution to a complex mental health problem and is unresponsive to the multiple psychosocial needs of the families of children with ADHD.

This calls for a new treatment model to enrich existing biomedical-based treatment. Singh, Filipe, Bard, Bergey, and Baker (2013) suggested an "ecologically sensitive" treatment for children with ADHD, one in which the ecological systems—including the individual, relational, social, and broader political and cultural contexts that shape the child's development—should be carefully investigated. As illustrated by the present research, the subjective experiences of both parents of children with ADHD and the children themselves imply a wide range of unmet psychosocial needs. Using medication as a coping strategy has a potential risk of overdose. These subjective experiences should be emphasized and carefully examined within the children's ecological systems to identify the different aspects of the difficulties involved and their need for help and perceived solutions, to develop the children's resilience, and to evaluate their use of different strategies for coping together with the potential risks of those strategies. Intervention is made to respond to clients' needs by pooling relevant resources, instead of reducing a complex problem to the simple solution of prescribing medication.

Social workers should bring the children's voices back into the decision-making process and the administration of medication, and expand the clinical space to make room for the parents and their children to negotiate their own solutions to their difficult situations and experiment with the solutions and possibilities in their parent–child relationship. Treatment also should involve connecting these families so they can exchange their experiences of living with ADHD. Through their exchange, these families build up mutual understanding and mutual aid that help to improve their difficult situations.

The waves of economic changes and educational reforms in the past years in Hong Kong have increased the academic demands placed on children and parents' accountability for academic underachievement (Choi, 2005). This anxiety in the parents due to this accumulated accountability has taken away their ability to mindfully nurture their children. The mental health of both parents and children is overwhelmed by the mainstream discourses of good children and good parents shaped by rapid socioeconomic–political changes. Social workers need to reflect on these discourses and their potential to marginalize these families, instead of applying them as a yardstick in their clinical practice.

CONCLUSION

The press conference, as one of the core activities of an MFG, provides an experiential platform for parent–child conversation in which they can co-construct the meaning of their ADHD experiences. The findings of this study reveal the parents' feelings of ambivalence toward using ADHD medication to help their children, their children's use of medication as problem-solving strategy, and their experiences of the negative effects of ADHD and medication. Some children also reported that the medicated self has become part of them and their needs to be comforted, forgiven, and understood can be an alternative to medication to help them improve their behavioral problems. These findings have expanded the understanding of the subjective experiences of ADHD in the Chinese context and provided insights for the review of existing treatments for ADHD, including the social discourses of good children and good parents in our society. It has also enriched the understanding of the psychosocial needs of the families of children with ADHD, which is important for the services and management of ADHD in the social work field.

An ecologically sensitive model is needed to enrich existing biomedically based treatment.

However, the small sample of the present study can hardly be used to generalize our findings to other Chinese children with ADHD. The co-construction of meanings is affected by the nature of the relationships between the researchers and the participants and among the participants themselves. There is a possibility that the findings in the present study were affected by the relationship dynamic between the parents and children in the sample, for example, that the children said what was acceptable to the parents. This limits the generalizability of the present study.

Further research on the subjective experiences of children with ADHD that addresses the researcher and participant relationship, which affects the co-construction of the meanings of ADHD, is needed. Moreover, further research is needed on the efficacy of the application of ecologically sensitive models in helping the families of children with ADHD. **HSW**

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