

Burden and coping strategies of parents of children with attention deficit/ hyperactivity disorder in Hong Kong: A qualitative study

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Abstract

Aim: Attention deficit/hyperactivity disorder is a prevalent mental disorder among children worldwide. The parents of children with ADHD experience great burden. However, burden and coping styles of these parents are seldom explored. The present study aimed to illustrate the burden and coping strategies of parents of children with Attention deficit/hyperactivity disorder.

Design: A descriptive qualitative study design was employed.

Methods: Samples were recruited from a general primary school in Hong Kong using convenience sampling. An information sheet was provided to participants, and written informed consent was obtained. Content analysis was conducted after the interviews were recorded and transcribed verbatim. COREQ reporting guidelines were used.

Results: Individual, face-to-face interviews were conducted, using a semi-structured interview guide with 12 parents of children with attention deficit/hyperactivity disorder. Four themes (academic burden, children's social dependence, uncertainty regarding parenting strategies before diagnosis and emotional hardship) and three themes (acting according to situation, employing problemfocused coping methods and acceptance) emerged for burden and coping strategies, respectively. Coping strategies processes were also found. Medical diagnosis was reported to be a critical point for parents to shift their coping strategies. Timely interventions, such as early assessment and diagnosis, are recommended during or after medical diagnosis.

1 | INTRODUCTION

Attention deficit/ hyperactivity disorder (ADHD) is commonly prevalent among children worldwide. More than 40,000 children are estimated to suffer from ADHD, with the average prevalence rate reaching approximately 6.4% (Liu et al., 2018; Sayal et al., 2017). ADHD is a mental disorder marked by inattention, hyperactivity and impulsivity; it interferes with cognitive and social development of children. These

symptoms commonly manifest in children below 12 years of aged (National Institution of Mental Health, 2020). Children with ADHD have higher activity levels, combined with the inability to control their temper as compared with age-matched peers (American Psychiatric Association, 2013). Children with ADHD face obstacles in social relationships and in academics, which parents perceive as a burden (Aili et al., 2015; Lan et al., 2015). In Hong Kong, parents are the main caregivers of children with ADHD (Lan et al., 2015).

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2 | BACKGROUND

Burden is defined as the presence of problems, difficulties or adverse events that affect the life of a patient's significant other (Ebrahimi et al., 2018; Ganguly, 2010; van der Voort et al., 2007). Literature has reported that burden refers to parents' symptoms and behaviour or the physical or psychological consequences of the illness on caregivers. Parents worldwide face the burden of caring for children with mental illness. In a study in Singapore, 31.3% caregivers of felt distress, and 33.3% revealed that the stigma of caring for children with mental illness was upsetting. The results demonstrated a high burden on caregivers due to self-stigma and lack of resources and public and financial support (Tan et al., 2012). Another study (Liu et al., 2007) stated that Chinese caregivers perceive significant caregiver burden while caring for children with mental illness and use limited coping patterns to maintain a functional family life. In addition, parents' caregiving burden and their coping strategies are negatively correlated.

Coping is a dynamic process. Given that the factors influencing coping consistently change, individual adapts the coping ability or style as the situation and burden shift (van der Voort et al., 2009; Weisser et al., 2015). Previous studies have highlighted coping strategies employed by parents. Mothers use emotion-focused strategies more often, whereas fathers typically adopt problem-focused strategies (Manor-Binyamini, 2011). One study stated that self-reliance, seeking help from supernatural power, seeking social support and avoidance are well-known coping strategies among Chinese parents (Lam & Mackenzie, 2002). Additionally, burden is associated with coping style. This has been illustrated in a study (Iseselo et al., 2016) describing how the coping style employed is determined by parents' appraisal of stress induced by burden. Caregivers using problem-focused techniques would experience a decreased caregiver burden and better outcomes (Manor-Binyamini, 2011; Picci et al., 2015; Liu et al., 2007).

In general, the education system in Hong Kong emphasizes competition. There are entrance examinations for 3-year-olds enrolling for kindergartens and for 6-year-olds enrolling for first grade. Parents also place their unborn or newborn babies on the waiting list of elite kindergartens or kindergartens that are connected to elite primary schools. Administrators push their teachers and students to deliver high scores to obtain high levels of achievement in examinations in primary school. This elitist system discourages teachers from accommodating individual learning needs as they are occupied with meeting demands of the prescribed curriculum and drilling their students to perform well in examinations (Poon-McBrayer, 2004).

The Hong Kong Education Bureau launched an integrated project in 1997. Students with learning difficulties were encouraged to be integrated into the general school with the help of various types of remedial support. However, resource teachers and students with special education needs (SEN) had to adhere to the standard curriculum. Under this system, teachers who teach students with learning difficulties experience high stress. Students with learning difficulties always perform substantially below grade level in several subjects.

Teachers experience difficulty in maintaining class examination achievement with SEN students integrated into class. In addition, teachers in schools with integration are not required to have training in teaching SEN children. Teachers in Hong Kong express their stress, frustration and burnout from managing SEN children in the classroom (Forlin, 2010; Poon-McBrayer, 2004). Furthermore, in Hong Kong, parents and children also experience high stress due to planning and competing for elite schools starting from the kindergarten level. Parents of children with ADHD experience extraordinarily harsh conditions because their children experience difficulty in learning due to the symptoms of their condition (Lan et al., 2015; Law, 2019).

Support for children with ADHD is insufficient in primary schools in Hong Kong (Law, 2019; Wu & Zhang, 2011). Children with ADHD, respective of their intelligence level, are assigned to regular schools with school policy support under an integrated education policy. Although the Education Bureau of Hong Kong has assigned varied support strategies for SEN students, numerous drawbacks remain in the system. First, in the existing policy, the Education Bureau assigns an educational psychologist to primary schools. They assess suspected students, provide psychotherapies to confirmed SEN students and offer counselling to SEN students and their families. However, with the shortage of manpower and limited resources, one educational psychologist is responsible for 12 primary and secondary schools (Wu & Zhang, 2011). Thus, the services provided are insufficient and reactive, rather than proactive. Students with ADHD are referred to mental health services in the public sector for treatment follow-up, causing support services for these students become scattered. Children with ADHD and their families experience severe burden on account of having to commute around the city to seek special training and attend assigned mental health services. Second, the Education Bureau of Hong Kong suggests that primary schools with SEN students must assign SEN teachers to support such learners. The SEN teacher is expected to conduct before- or after-school tutorial classes or provide need-based supports to these students. Schools assign a senior teacher with considerable experience in teaching SEN students. However, training on teaching SEN students is not mandatory for assigned teachers. SEN teachers have insufficient knowledge to handle students with ADHD, dyslexia and other mental disorders. Further, they are responsible for standard teaching work and maintaining the top-class achievement. Most of them experience exhaustion or burn out. Finally, students with ADHD and their parents experience academic burden due to lack of access to sufficient or suitable support in schools.

With increasing prevalence rate of ADHD (Cheung, et al., 2015; Wang et al., 2017; Liu et al., 2018), parents of children with ADHD play an irreplaceable role in the mental health of their children. However, there is a significant knowledge gap on burden and coping styles of these parents. Information regarding the coping model among parents of children with ADHD could help in shaping supportive services and estimating the most appropriate time for interventions. However, to date, no study has explored the coping processes

of parents of children with ADHD in Hong Kong. The results of overseas studies on burden and coping mechanisms of parents with children with ADHD cannot be applied to the unique context observed in Hong Kong. This study aimed to explore the burden and coping process of parents of children with ADHD in Hong Kong.

3 | METHODS

3.1 | Design and sampling

This descriptive qualitative study used an interactionist approach (Yamagata-Lynch et al., 2016). As this study did not aim a high level of interpretation of reality, it attempts to explore the burden and coping strategies of parents of children with ADHD in Hong Kong. Thus, a descriptive qualitative design was best suited to establish the meaning of burden and coping processes among these parents (Sandelowski, 2010; Vaismoradi et al., 2013). Convenience sampling was adopted (Pilot and Beck, 2018). Five local primary schools in distinct districts in Hong Kong were approached to recruit participants but only one responded. Due to time constraints, participants were recruited from a local primary school with a supporting class for students with ADHD. Recruiting information was distributed to all parents of the supporting class. Parents who were interested in the study responded to the research assistant.

3.2 | Setting

Face-to-face interviews were conducted in a classroom provided by the primary school. The research assistant interviewed participants individually. Privacy and quiet environments were endured during the interviews. The interviews were conducted after school or on weekends, depending on participant availability.

3.3 | Data collection

Semi-structured interviews were conducted by research assistants, after receiving interview skill training from the authors. Interviewers conducted interviews based on an interview guide (see Appendix S1). Each interview lasted 60–90 min; they were audio-recorded, and field notes were taken. All the participants were interviewed once.

3.4 | Data analysis

A framework method for the analysis of qualitative data was adapted (Gale et al., 2013). Interviews were audio-recorded and transcribed verbatim for content analysis. The written transcripts were read and re-read. In addition, researchers listened and re-listened to all audio recordings. Keywords were then coded. The data were subsequently

examined line by line, meaningful units were closely examined, and issues of similar concern were placed under sub-themes with shared properties were clustered into higher-order themes. Themes requiring further investigation were identified and discussed with another researcher. These discussions assured that the themes were relevant to the decision trail to enhance the trustworthiness of the data. Discrepancies were resolved, and consensus was reached through verbal discussion and revisiting raw data (Slevin & Sines, 2000). A detailed description of the interviews was provided to the participants to verify the grounded data, and the descriptions of the findings were checked by two participants to ensure the trustworthiness of the study. The COREQ guidelines were used for reporting (see Appendix S2).

3.5 | Trustworthiness

To ensure credibility, member checking was performed. During the interview, research assistants restated and summarized information with the participants during the interviews. Additionally, participants were asked to clarify the accuracy at the end of the interview. The findings of the study were sent to the participants for their feedback on the accuracy of meaning, and an audit trail was developed to ensure dependability. Furthermore, peer reviews were employed. Two researchers provided suggestions after reviewing the data collected from each interview. The code–recode procedure was employed to ensure the trustworthiness of the data. The verbatim transcriptions were checked with the original audio-tape recordings, and thick descriptions were used to enhance the trustworthiness of the data (Pilot and Beck, 2018).

3.6 | Ethical considerations

An information sheet was provided to each participant. Written informed consent was obtained from all the participants before the interview. Participants were informed about the aims of the study and about their rights as participants. They could rightfully refuse participation and withdraw from the study any time. All data and information collected were regarded as confidential and were not disclosed to unauthorized individuals. The identity of participants was represented by codes to ensure confidentiality. All collected data were destroyed on completion of the study.

4 | RESULTS

Twelve interviews were conducted until data saturation (Sandelowski, 2010). Table 1 presents the demographic data of the participants. The burden and coping strategies of parents of children with ADHD were explored. The results are elaborated in the following paragraphs.

Four themes were determined with regard to burden, namely, academic burden, children's social dependence, uncertainty regarding

TABLE 1 Characteristics of participants

	No. of participants
Demographic background of informants	
Age	31–43 years old
Gender	
Male	3
Female	9
Number of children in family	
One child	2
Two children	10
Education level of informants	
Primary level	1
Secondary level	10
Tertiary level	1
Employment status	
Full-time job	6
Part-time job	1
Unemployed	5
Marital status	
Married	12
Daily caring hours to the child with ADHD	
≤3 hr	2
4–8 hr	5
More than 8 hr	5
Time of diagnosis of the patient	
In kindergarten school	3
In primary school	9

parenting strategies and emotional hardship. An interrelationship was found between these burdens. Furthermore, three themes were determined with regard to coping, namely, acting based on situation, employing problem-focused coping methods and acceptance (see Appendix S3). A coping process was established based on the results after the three themes on coping were identified.

4.1 | Burden

4.1.1 | Academic Burden

This theme focuses on high academic stress in primary schools in Hong Kong. Both children with ADHD and their parents experience extreme pressure from schools. Teachers call the parents and request their follow-up when their child is unable to keep pace in academics. None of the parents were able to meet schools' demands. In addition, all the children in this study had comorbidities of dyslexia in writing and reading. Participants expressed that their children were barely able to keep pace with the teaching content under the inclusion education policy in primary schools. Moreover, comorbid

conditions such as dyslexia further ruined their children's academic performance.

Stress...I think it will be extremely stressful in primary 5, as he is lagging behind...he will probably be promoted to a below-par secondary school.

(Participant 3)

Demands from school teachers really pose immense pressure to me. They call me almost every day to report his (the child with ADHD) slow progress and failures in quizzes in school. I start palpating whenever my phone rings.

(Participant 10)

4.1.2 | Children's social dependence

Parents pay more attention to their child with ADHD than to their other children. They worry that their children are bullied by classmates or stigmatized by the public. Furthermore, children with ADHD were unable to resolve interpersonal conflicts by themselves. Thus, parents were required to intervene in social interactions. Such interventions restricted children's development of problem-solving and social skills, causing children to become dependent on caregivers when faced with difficulties in daily living. Parents simultaneously become engrossed in their irreplaceable caring role and become unwilling to give their children independence. Finally, this perceived responsibility becomes a burden for parents.

He (the child) is dependence. Perhaps he knows that his ability is not as high as that of other children. He will show helplessness when nobody helps him in daily activities and seeks my help. I cannot resist his appeal.

(Participant 2)

He (the child) always threw temper tantrums when upset in interpersonal relationships...the psychiatrist reckoned that it was a kind of dependence on persons he trusted.

(Participant 1)

4.1.3 | Uncertainty in parenting strategies before diagnosis

Almost all parents expressed that they experienced resentment and frustration before their children were diagnosed. Figure 1 illustrates the constitution of the burden. They believed that their children were extremely active and out of control and felt incapable of disciplining them as they were unaware of their children's underlying condition. Almost all parents felt enlightened on learning about the ADHD diagnosis and understood that the

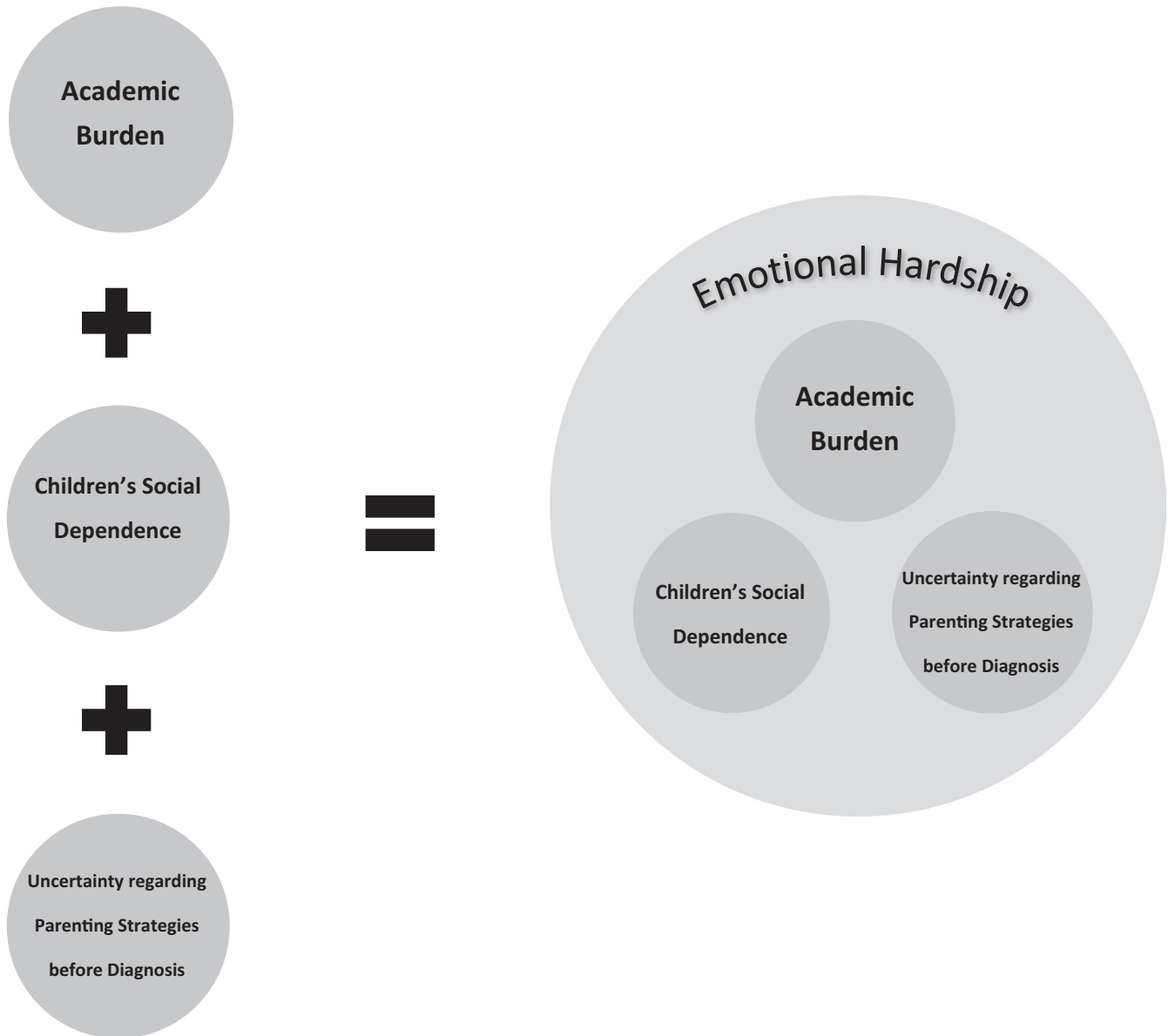


FIGURE 1 Constitution of burden of parents with children having ADHD

conventional parenting strategies were inapplicable to their children's needs.

We (mother and the child) cried together almost daily before diagnosis, as I didn't know how to teach him (the child) well.....when he (the child) was primarily diagnosed with ADHD, the truth came out.

(Participant 1)

After the assessment, I felt a sense of relief because I knew why he (the child with ADHD) was so naughty and out of control, and why all (parenting and teaching) methods (to the child with ADHD) were in vain.

(Participant 10)

I felt relief once diagnosis was confirmed. I now knew what was happening. What we had done (i.e. authoritarian parenting style) to him before were totally wrong!

(Participant 2)

At least I knew what to do after the diagnosis.

(Participant 8)

4.1.4 | Emotional hardship

The accumulated emotional response induced by the academic burden, dependence of the child and ineffective parenting strategies

pre-diagnosis was intolerable for parents. They experienced hardship and resentment in daily interactions with their children, which led to daily conflicts. Parents also felt helpless in nurturing their children. However, their emotional hardship was relieved after confirmation of ADHD diagnosis.

I am so annoyed when teaching him homework. He was always distracted. He would lose concentration despite prompting him repetitively.

(Participant 4)

Teachers always complain about him (the child). This has caused a lot of resentment. I do not know what more I can do.

(Participant 9)

4.2 | Coping

With the above burden, parents of children living with ADHD developed coping strategies, including “Acting according to situation,” “Employing problem-focused coping methods” and “Acceptance.”

4.2.1 | Acting according to situation

Conventionally, given the fierce competition in the education system in Hong Kong, parents begin planning for their children's education, right from pre-school level to ensure that their children can be admitted to elite high schools. However, parents of children with ADHD recognize that they can no longer chalk out a plan for their children's career. They can only act in response to the changing situation. Several parents felt apprehensive about their children's future. For instance, they were worried that their children might be shifted to an inferior high school for their unsatisfactory academic performance. However, other parents opt to live in the moment and not worry about their child's future. This was because they eventually recognized that their children's prospects will not be the same as those of other children; hence, they cannot exert as much control.

I would not aim high now...I hope he (the child) will happy in whatever he does.

(Participant 7)

He (the child) just does in his best (in the future).

(Participant 8)

I learnt to let go and never compare (my child) with the other children...and stay calm regarding his (the child) prospects.

(Participant 9)

4.2.2 | Employing problem-focused coping methods

Meeting school teachers' demands was a major source of stress for parents. First, to solve this burden, all parents in the study hired a private tutor to help their child with schoolwork. All parents expressed that private tutors alleviated their academic burden. Second, aiming for high academic scores was unrealistic for their children, under the ordinary school curriculum. Therefore, parents shifted to a practical solution; that is, they paid more attention to fostering other potentials or nurturing their children's disposition rather than focusing on academic results.

I'm fortunate enough to have a nice private tutor who helps him keep up with school work.

(Participant 4)

My private tutor prevents me from having conflicts with him (the child) regarding academic work.

(Participant 1)

It's not realistic to boost his academic result...it is more practical to develop his potentials.

(Participant 6)

Now, I (the parent) believe that developing his (the child) personality is far more worthy and realistic than struggling with his examination scores.

(Participant 10)

4.2.3 | Acceptance

Confirmed diagnosis is a key mediator in re-appraising a situation and reducing stress of the burden. Acceptance of diagnosis and medication regimes could alleviate the emotional struggle. Almost all parents felt a sense of relief after the confirmed ADHD diagnosis of their children. They quickly accepted the diagnosis and sought a treatment plan. The sense of relief was due to the identification of the root cause for their children's behavioural problems and the hope that the right medicines will be acquired for treatment.

The school teacher always complains that my son does not concentrate during classes. My son is easily distracted. A pencil falling on the floor attracts his attention, and then he will play with the pencil for the whole lesson. I cannot tolerate complaints from teachers, so I accept the medication.

(Participant 10)

After acceptance of diagnosis, we (the parents) confirmed the direction and know how to manage my son.

(Participant 7)

4.3 | Process of coping

In this study, coping was dynamic throughout the caregiving journey. Parents in this study experienced academic burden and interpersonal relationship burden. These burdens constitute emotional hardship. However, all parents expressed that emotional hardship was aggravated before the ADHD diagnosis of their children was confirmed. This was because they were unaware of their children's condition and were unable to manage their children's symptoms. All parents felt a sense of relief after learning that these symptoms were caused by ADHD. After diagnosis, they developed a positive outlook and problem-focused (e.g. hiring a private tutor) and emotion-focused coping strategies (e.g. acceptance of the diagnosis and treatment-seeking). While the academic burden and interpersonal relationship burden still persists after diagnosis, their emotional hardship reduced due to the use of appropriate coping strategies.

5 | DISCUSSION

When comparing the findings of this study, it was found that parents in western countries experience stress due to teacher demands (Hibbitts, 2010; Gwernan-Jones et al., 2015). This finding is consistent with the findings of the present study. Teachers initiated communication with parents regarding their children's problems in school. It was also common for teachers to exert pressure through school exclusion or discipline children unfairly. In addition, studies (Fossati et al., 2020; Walerius et al., 2016) have found that children with ADHD were socially dependent. This is consistent with the findings of the present study. Parents of children with ADHD failed to promote their children's socialization. Parents perceive dependence as a burden because they wish for their children to be raised as socially independent beings. In addition, parents of children with ADHD experienced distress and a sense of powerlessness. (Fossati et al., 2020). Parents of children with ADHD report a higher prevalence of mental health problems, such as depression and anxiety, than parents of children without ADHD (Cheung and Theule, 2016; Durukan et al., 2018). This was similar to the emotional hardship experienced by participants in the present study.

According to the literature (Robertson et al., 2007; Song et al., 2014; Bauer et al., 2012; Lloyd and Hastings, 2009), parents of children with ADHD adopted adaptive coping and problem management. These strategies were similar to "acting according to situation" and "employing problem-focused coping methods" in the present study. Nevertheless, Oelofsen and Richardson (2006) stated that parents of children with ADHD employed internal locus of control, high sense of coherence, perceived support and optimistic as coping strategies. These coping strategies were not found in participants of this present study.

Studies seldom explored the coping process of parents of children with ADHD. In this study, it was found that the diagnosis of ADHD was a critical factor in helping parents to adapt their coping strategies. A study (Mueller et al., 2012) stated that parents are reluctant to seek medical assessment for their children's problems as

diagnosis and medication of illness, especially mental illness, causes their children to feel stigmatized. Taking medication made children with ADHD feel different from peers. Similarly, parents in Hong Kong worry about the stigma their children face postdiagnosis. Therefore, most of them deny the symptoms and delay the diagnosis until their children can no longer keep up with schoolwork, and teachers start sending complaints. School teachers are the first to identify, become alerted to symptoms and recommend medical or psychiatric consultation to the parents of suspected children. Ironically, results of this study showed the positive impact of diagnosis on parents. Almost all of them felt emotional relief on the confirmation of ADHD diagnosis as it gave them direction to resolve their children's problems. The findings of this study showed that medical diagnosis can help parents adapt an appropriate parenting method and effective coping strategies.

All the participants reported that their children had dyslexia as a comorbidity, which resulted in their children's weak academic performance. This condition was the main stressor for the parents. Despite several parents expressing that they were unconcerned with their child's poor academic performance, they were still pressurized by school teachers. This condition reveals the lack of specific support or treatment for children with dyslexia, which is one of the root causes of the academic burden experienced by children with ADHD and their parents (Poon-McBrayer, 2004). Therefore, children with dyslexia, their parents and school teachers endure the negative consequences of current education policy and curriculum.

5.1 | Relevance to clinical practice

This study revealed the significance of early assessment, diagnosis and intervention in the reduction of stress and burden on parents of children with ADHD. Itai and Yoram (2011) suggested that early prediction by using predictive factors is possible. Furthermore, early diagnosis will pave the way for significant future benefits for children with ADHD. Second, a new nursing role could emerge to respond to the burden of parents with SEN students. Additionally, this study illustrates the struggle of parents of children with ADHD. Support from educational psychologists and SEN teachers is notably insufficient in terms of number and training, respectively. Parents of children with ADHD also show poor management regarding development of their children's social skills. School nurse, specifically a registered psychiatric nurses, could assist in this case as they have comprehensive knowledge of emotional therapies, psycho-education, counselling, behavioural modification, social skills training and enhancement, symptom management, treatment opportunity and treatment compliance. Further, they could offer tailor-made care plan to students with ADHD and their parents, provide outreach services and address the needs of students with ADHD in school. Therefore, essential services could be integrated, and students with ADHD and their families could obtain significant support from a multi-disciplinary team (educational psychologist, SEN teacher and registered psychiatric nurse) in school, preventing them

from commuting around the city to seek mental health services and academic support. This new emerging role of nurses and the service delivery model could overcome the drawbacks of the current education system and relieve the burden of parents with SEN children.

5.2 | Limitations

The present study was the first to explore the burden and coping strategies of parents of children with ADHD in Hong Kong. While the aim of this study was completely achieved, the main limitation of this study was that participants were recruited from the same site, which might influence transferability of the results. The generalizability of this study is limited by the small sample size of one school (Oun & Bach, 2014). Second, the samples were collected from a general primary school. The SEN students in this institution have comparatively mild emotional and behavioural symptoms, whereas other SEN students with severe disabilities are referred to special schools (Poon-McBrayer, 2004). In the future, multiple sites with diverse sociodemographic backgrounds are recommended for a better understanding of the experiences of parents with children with ADHD.

6 | CONCLUSION

Parents of children with ADHD experience tremendous challenges and different types of burden in caring for their children. In this study, academic burden was a key challenge, posing immense stress to parents. Moreover, the parents' coping process was illustrated, and medical diagnosis was a critical point in causing parents to shift their coping strategies. This study sheds light on the mechanisms through which nurses can support children with ADHD and their parents in a timely and appropriate manner.

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CONFLICT OF INTEREST

We declare that there is no conflict of interest.

DATA AVAILABILITY STATEMENT

The data of this study are available in research Wong Wing Chi.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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