

International Journal of Nursing and Health Care Research

Bronson SL. Int J Nurs Health Care Res 9: 1116.

DOI: 10.29011/2688-9501.101116

Research Article

Caring for a Child with Angelman Syndrome in Hong Kong: A Qualitative Study

NG TY Bernadette^{1*}, TIU MH Mimi¹, CHAN HY², CHEUNG WH³, CHU KP Emily⁴, CHUNG KK⁵, HO SS⁶, HON CY⁷, KAM LK⁷, KWOK PY Rachel², MOK YT⁴, TONG KW⁸, WONG TY⁹

¹School of Nursing and Health Studies, The Open University of Hong Kong, Hong Kong

²Prince of Wales Hospital, Hong Kong

³Baptist Hospital, Hong Kong

⁴Princess Margaret Hospital, Hong Kong

⁵Kwong Wah Hospital, Hong Kong

⁶Tai Po Hospital, Hong Kong

⁷Ruttonjee & Tang Shiu Kin Hospital, Hong Kong

⁸Queen Elizabeth Hospital, Hong Kong

⁹Caritas Medical Centre, Hong Kong

***Corresponding author:** NG Ting Yan Bernadette, Senior Lecturer, School of Nursing and Health Studies, The Open University of Hong Kong, Ho Man Tin, Kowloon, Hong Kong. Tel: +852-31202625; Email: tyng@ouhk.edu.hk

Citation: Bernadette NGTY, Mimi TMH, CHAN HY, CHEUNG WH, Emily CKP, et al. (2019) Caring for a Child with Angelman Syndrome in Hong Kong: A Qualitative Study. Int J Nurs Health Care Res 10: 1117. DOI: 10.29011/2688-9501.101117

Received Date: 11 September, 2019; **Accepted Date:** 10 October, 2019; **Published Date:** 14 October, 2019

Introduction

Angelman Syndrome (AS) is a rare genetic disease caused by chromosomal abnormalities [1,2]. This disease is incurable, life-threatening and chronically debilitating. It originates in early childhood and affects a small proportion of the general population [3]. In Hong Kong, 55 cases have been diagnosed from 1995 to 2015, and three to five cases are newly diagnosed every year [2]. When a child is diagnosed with a rare genetic disease, caregivers experience severe distress [4]. The parents of these children face a lifetime of challenges and personal sacrifice, including inadequate accessibility to health services and support and the lack of experienced healthcare professionals [3].

Parents of children with disabilities inevitably face different challenges daily, including physical care, medical needs, educational needs, treatments and caring responsibilities, resulting in increased stress levels of the entire family, particularly the caregivers [5]. The challenging behaviours and behavioural features, such as short attention span, increased sociability, hyperactivity, aggressive behaviours and sleep disorders of the child, also contribute to

the psychological distress, such as stress, anxiety and depression [6]. Mothers of children with disabilities reported lower levels of happiness, self-esteem and self-efficacy than mothers of normal children [5]. In addition, repeated exposure to caring-related stressors exposes caregivers to major and minor physical health problems [7]. A greater number of headaches, sleep disturbances, gastrointestinal problems and respiratory infections were found in parents caring for children with intellectual disabilities than those whose children have no intellectual disabilities [8].

Family roles and function are being modified to realise an effective strategy for caring of children without self-care abilities and maintaining the family balance despite the continuous rounds of childcare [4]. Missed opportunities to spend quality time with partners have negatively impacted family relationships [9]. Furthermore, parents are forced to be advocates of their children and 'fight' for the appropriate care in medical and social services [10]. Parents of children with rare diseases reported being unsatisfied with health professionals because of their inadequate knowledge and awareness of the disease, inability to provide a definite diagnosis and inadequate support towards family planning

[3]. The diagnostic process is prolonged because of the limited accessibility to genetic services and other supporting services; consequently, parents fail to fully prepare themselves for future situations that may happen to their child [2,3]. Particularly with inadequate support, parents have endless worries about their children's future life [4] as they have become highly dependent to their caregivers.

Cultural and other aspects of support services are important to children with AS and their caregivers. Support services can be classified into social, educational and residential care support. Some families of children with rare genetic diseases must seek for support groups abroad because of the lack of available or accessible local support groups [11]. Many parents are in favour of sending their children to the same school as their peers without disabilities and have promoted the importance of training educators on AS and having an open communication and cooperation between schools and parents [12]. On the other hand, poor standards of residential care services, such as high staff turnover rate and physical abuse, have been reported in other countries, resulting in untruthful relationships between parents and the staff of residential care services [10].

Owing to Chinese culture, families with members with intellectual disabilities may be socially stigmatised and judged, because the Chinese are concerned about the reactions or social expectations of other people. Some traditional Chinese families even hold a moral view that having a child with disabilities is a punishment for the wrongdoings committed by the family in the past [13]. However, the cultural influences of caring for a child with AS on families have not been widely investigated. Most studies on such topic have been conducted in Western countries and seldom mentioned the cultural impacts on caring. The influences of the mixture of Eastern and Western cultures on the parents of children with AS in Hong Kong remain poorly understood. Furthermore, there are very little studies about AS in Asia countries, many AS studies are conducted by western medical researchers but very few descriptive studies focused on parental experiences of caring a

child with AS. Even some of the Western studies have included the parental experiences of caring a child with AS, which are included several groups of other rare diseases, so it was unable to provide a comprehensive description on parental experience on AS.

The aim of this study is to understand the experience of parents of caring for a child with AS in Hong Kong. The result can evaluate and advocate the needs of parents with AS child regarding the health care services, social supportive care services for parent and their families, parental experience of day-to-day issues of rearing a child with AS, impacts of caring for a child with AS, parental coping patterns, positive experience of having a child with AS and wishes of the parents, thereby to bridge the gap between the expectations and the needs of the parents in future.

Methods

Study Design

A qualitative descriptive study was conducted to provide a comprehensive view of the parental experience of caring for a child with AS in Hong Kong. The parents were subjected to semi-structured face-to-face interviews in their preferred places as participants are more likely to share information when they are in their favoured places where they can feel comfortable and relaxed [14]. This research design allows the researchers to understand the experience of the participants [15].

Participants and Setting

Convenience sampling was used. With the help of the Hong Kong Angelman Syndrome Foundation (HKASF), the parents who met the inclusion criteria were invited to participate in the study: parents who are the primary caregivers of children with AS, children with AS living in Hong Kong and parents who are able to communicate in Cantonese, Putonghua or English. From 1995 to 2015, 55 cases of AS have been diagnosed in Hong Kong [2]. The accessible population was the parents who joined HKASF. Amongst the 26 families that joined, only eight parents participated in the study, their profile is given in (Table 1).

Participant	Parents/marital status	Education level	Number of children	Age of the children with AS	Relationship with parents	Job	Religious
1	Father/ Married	University	1	5	Son	Flexible working hours	No
2	Mother/Divorced	Secondary school	1	33	3	No	No
3	Mother/Married	Secondary school	1	22	Daughter	Full-time	No
4	Father/Married	University	1	6	Son	No	No
5	Mother/Married	University	1	6	Son	No	Yes
6	Mother/Divorced	University	2	13	Daughter	No	Yes

7	Mother/Divorced	Secondary school	1	28	Daughter	Part-time	Yes
8	Father/Married	University	2	7	Daughter	Full-time	No

Table 1: Characteristics of parents and age of their children.

Data Collection

The semi-structured interviews were conducted from November 2016 to January 2017. The interviews provided researchers with a direct approach to listen to the voices and experiences of the participants. All interviews were conducted in a meeting room by two researchers, of whom one was the interviewer and the other was the observer. The observer was responsible for recording the non-verbal data. All interviews were audio-recorded to ensure that no data were missed [14]. All interviews lasted for approximately 45 to 60 min to obtain in-depth information [16]. All interviews were directed by an interview guide (Appendix I), which included a list of topic and open-ended questions and was formed according to the study objectives.

Data Analysis

Data analysis was performed concurrently with data collection. All audio-recorded interviews were converted into verbatim. The meaningful phrases in the transcripts were highlighted for data reduction and then coded. Themes were formed by putting similar codes together, and the relationships amongst different themes were investigated during thematic analysis [15]. According to [17] framework, testing the rigour of the study should consist of several elements, including credibility, transferability, dependability and conformability.

All researchers participated in coding and analytic decision-making to reduce the risk of biased decisions. The prolonged engagement throughout the research process allowed the researchers to be familiar with the data. The researchers used reflective notes to prevent personal or previous experiences and values from affecting the interpretation of the data. Sufficient details and descriptions were provided in the report such that readers can evaluate the applicability of the findings to other contexts and gain a thorough understanding of the research design and its implementation [18].

Ethical Considerations

Ethical approval was obtained from the Open University of Hong Kong. An information sheet on the study was given and explained to the participants. A written consent was obtained before the interview session. Participants were allowed to withdraw from the study at any time. Pseudonyms were used to protect the privacy of the participants. All data were stored in encrypted files and only accessed by the researchers and their supervisors.

Results

Six themes were identified, experience of the diagnostic process, day-to-day issues of rearing a child with AS, impacts of caring for a child with AS, parental coping patterns, positive experience of having a child with AS and wishes of the parents. The responses and feelings of the parents with young age and adult age child with AS were quite different, the parents with adult age AS child had already accepted the diseases, they didn't feel it is a bolt from the blue, whereas the parents with young age AS child were grieved and shocked.

Experience of The Diagnostic Process

The doctors have made considerable referrals to different specialties for diagnostic investigations and symptom management due to unfamiliar with the disease.

Prolonged and Complex Diagnostic Process

Starting from 6 months, we found that she had some developmental delay. Then, doctors referred her to different specialties such as physiotherapy, occupational therapy, neurosurgery... paediatric neurosurgery, dietetic and orthopaedics (Father 8).

The diagnosis could only be obtained in the clinical genetic service department, and patients had to wait for at least one year for follow-ups.

It was found that the clinical genetic service department requires a year to arrange the follow up appointment and review the report with patients (mirthless laugh). Yes. This is ... a "Standard. (Father 1).

Parents' Reactions When A Diagnosis Has Been Made

Some parents were shocked with the diagnosis of an incurable disease.

Parents were worried about their children's future because of uncertainties.

What will be her future? Do we need to take care of her for lifelong? How can we take care of her afterwards? Whether taking medication or not? (Father 8, whose daughter was diagnosed at the age of 20 months).

Some parents felt relieved and accepted what had happened to their children.

Anyway, she has difficulty in learning, so I was feeling relieved because there is a reason for her. (Mother 7, whose daughter was diagnosed at the age of 5).

Day-To-Day Issues of Rearing a Child with as

Children with AS cannot perform self-care independently. As such, parents are responsible for all daily activities.

Non-Stop Caring Rounds Caused Physical Illness

Common challenging behaviours of children with AS include seizures, sleep problems, motor and balance problems and intellectual disability. Parents have to spend a lot of time to take care of their children and caused physical illness. Some parents agreed that their physical illnesses are induced by stress because of non-stop caring round.

Since I have taken care of her for several years, I have experienced some diseases such as peptic ulcer, facial nerve paralysis, joint pain, muscle pain. (Father 8).

Unpleasant Experience from Support Services and Society

Parents had undergone unpleasant experiences in various aspects, including seeking help from social workers; relying on allied health, school or residential care services; and interacting daily with the public.

Social workers were unable to understand the difficulties and fulfil the needs of the parents.

The social workers know nothing about it. They actually cannot feel or understand how serious the disease is. If you hold your 6-year-old child who cannot walk, they may finally think it is serious (Father 8).

Parents perceived that their children were not being accepted by the public, making them become unwilling to bring their children out.

Others may think why your child walks with a strange gait. They may look back at us even walking away (Mother 6).

Unsatisfactory Experience with Allied Health, School and Residential Care Services

The Hospital Authority provided limited resources or services for children. Parents needed to find Private Physiotherapy (PT) and Occupational Therapy (OT) services.

Hospitals can only provide sparse physiotherapy services, maybe once a month. We need to find some private services to help our children (Father 1).

Insufficient manpower of special schools

There is one teacher only (Mother 5).

Governmental hostels for adults with AS had long queueing times. In some cases, the hostel offered might be far away from home.

At the beginning, the government assigned one hostel which is far away from my home (Mother 2).

Now, the waiting time for a vacancy in hostels is around 15 years (Mother 3).

Private residential care homes had insufficient manpower and delivered poor service. Parents found bruises on their children.

Sometimes she came back home with bruises on her body. The company hired new immigrants. Maybe the caring method in the mainland are different from Hong Kong, I believed that there is some bullying occurred. The biggest problem is insufficient manpower (Mother 2).

Impacts of Caring for a Child with as

Caring for a child with AS imposes negative impacts on the parents, including changes in the daily schedule, career and social network.

Daily Schedule Modification

At that time, I had to take care of my parents-in-law and three sick people at the same time. I was very stressful at home (Mother 3).

Work Adjustment

I changed the work related to insurance and hence it allows a more flexible time to care for him (Father 1).

Changes in Social Network

The friends that I kept in adolescence are detached (Mother 3).

Parental Coping Patterns

Decreased Social Participation

Parents were being doubted of their abilities to take care of their children, pushing them to decrease their social participation with friends and families.

We were quite unsociable. We just like staying in an island. Even in Lunar New Year, we would not participate in any family gathering. (Father 8)

Need for Religious and Social Support

Parents perceived that people with religious beliefs tended to love others.

People in church would care about you and pray for you (Mother 5).

Parents obtained information and social support from peer groups, which provided up-to-date information on children with AS.

I joined and got plenty of useful information related to AS from the AS Foundation in United Kingdom, for example, the behavioural pattern, the medication, the signs and symptoms that patients of AS may have (Mother 7).

Development of Positive Thinking

Parents started to think positively after they had cared for their children for a period of time. They appreciated the abilities that their children already had.

Positive Experience of Having A Child With AS

Information is stated that AS children cannot walk independently. Fortunately, my daughter can walk at least. Therefore, I think I cannot be so greedy (Mother 7).

Strengthened Family Relationship

Most parents invited their family members in extended families to care for their children. Several parents noted that not only the partners but also the extended family members became closer to one another.

They (relatives) searched AS information and gave us a printed copy. They look forward to playing with her and inviting us to their family gathering (Mother 6).

Increased Perception of Self-Efficacy

Parents perceived that they could provide adequate and suitable care to their children.

I could remain imperturbable, which was beyond my expectation. We are capable of fulfilling different needs of my children with the courage of change (Father 8).

Wishes of the Parents

As regards the unpleasant experiences with healthcare professionals and unexpected incidents in residential care services, parents hoped to increase the resources of residential care services and establish trustful relationships with healthcare professionals.

Allocate More Resources on Residential Care Services

Children may live in residential care homes for the rest of their life once their parents become old or unable to take care of them. Parents hoped that the number of subsidised residential care homes would increase to reduce the long waiting time of vacancies and allocate more resources.

I hope that the government can put more resources in residential care homes. When children with AS grow up, there is a place for them to live (Father 1).

Develop A Trustful Relationship with Healthcare Providers

One parent hoped that nurses should become more knowledgeable about rare diseases and be supportive to families.

I wish the nurses can learn more about the disease (AS), so the nurses can provide more relevant information or refer us to support group (Father 8).

Discussion

The parents of children with AS expressed a negative experience in the diagnostic process, which is similar to the experience of parents of children with rare diseases in previous studies. The parents found the process of receiving a diagnosis for their children to be difficult and protracted [3]. In addition, healthcare professionals lack an awareness of genetic syndromes [19], and most of them cannot provide specific medical advices because of the lack of experience and knowledge of diseases [10]. Self-directed learning by healthcare professionals can solve the problem of inadequate knowledge on rare genetic diseases. Moreover, only one genetic screening clinic provides diagnostic services for rare genetic diseases in Hong Kong [2], and this clinic can only be accessed with the referral by doctors. Such limited accessibility of the service prolongs the diagnostic process.

A previous study stated that the emotions expressed by parents when receiving a rare disease diagnosis were shock, stress, anger and relief [20]. Shock and stress resulted from feelings of uncertainty and insecurity for the future health and wellbeing of their children [20]. In the present study, parents felt relieved because they believed that a definite diagnosis could illuminate what had happened to their children. Moreover, one parent whose child was diagnosed at an older age felt acceptance because she had already become used to caring for her child with special needs. Therefore, the emotional responses of parents whose children were diagnosed at an older age were not that strong compared with those parents whose children were diagnosed at a younger age. However, parents whose children were diagnosed at an older age faced a long period of emotional distress, such as feelings of stress, frustration and anxiety, as they initially had no information on their children's condition without a definite diagnosis [21].

Therefore, early diagnosis is important so that parents can cope better, access support and services and plan for the future [22]. Apart from the knowledge provided by healthcare professionals, the perceived level of support given by healthcare professionals is also important. Parents hoped that an open communication and trustful relationships would be developed between families and healthcare professionals. Parents believe that their children are well cared for when the health professionals show understanding, acceptance of parents' personal views and respect [23]. In fact, active listening is necessary for health professionals to identify parental concerns, help in future planning and implement appropriate interventions

for the family [24].

Impacts were observed on parents who cared for a child with AS. The behavioural features of children with AS increased the perceived stress [25]. Perceived stress and challenging behaviours are the main predictors of physical health problems [8]. In spite of physical health, caring for children with AS will influence the daily schedule, career prospects and social network of the parents. Caring for children with rare diseases has been linked to increased demands for time to care [26]. This phenomenon may be due to the constant caring rounds, which cause difficulties to time management of parents for work, social activities, caring children with AS.

The impacts were observed not only in the parents but also in the families. Caring for children with AS not only strengthens the relationship of partners but also brings the nuclear family and the extended families closer, because they work together as a team. This finding is slightly different from that of a previous study, which indicated that only the relationship of partners became closer [5]. Support services include the Provision of Physiotherapy (PT) and Occupational Therapy (OT), school services and residential care services. Frequent and regular PT can enhance gross motor function and balance [27], and OT can improve fine motor and oral motor control [28]. However, parents perceived that the services provided by the Hospital Authority and schools for children with severe intellectual disability were limited, causing them to seek for private services, which were much more expensive.

As for residential care services, parents were concerned about the problems of insufficient governmental hostel vacancies, insufficient staff supervision in private residential care homes and insufficient resources and manpower. The high staff turnover rate may be the reason for the insufficient manpower, which affects the quality of care provided and results in physical abuse of the residents [10]. Parents hoped that the resources of residential care services will be increased. This finding is in contrast to a previous study, which stated that parents of children with intellectual disabilities in Australia preferred their children to live in large groups amongst their peers rather than in small, dispersed community housing and with non-disabled peers [29].

Parents received both positive and negative reactions from the public. This finding differed from that of a previous study, which found that parents experienced only negative reactions when going out with their children [10]. The enhanced education and increased promotion by the government may increase the acceptability of disability in modern society. In addition, the promotion of AS through social media has increased after the establishment of the HKASF, helping the public to gain more understanding of AS. A higher level of social support from friends and family will cause a lower level of parenting stress [30]. Significant negative relationships existed between self-efficacy and parental stress

[31]. Parents who perceive that their children are difficult to manage may negatively evaluate or underestimate their parenting ability [32]. A significant negative relationship exists between self-efficacy and child behavioural problems [31]. In the past, parents had lower self-efficacy because they perceived that their children were difficult to manage. Over time, parents learned more about their children, and the challenging behaviours were diminished.

For coping strategies, decreased social participation was used before and at the early stage of getting a definite diagnosis of their children. This finding differed from that of a previous study, which indicated that decreased social participation was not used by parents of children with rare diseases [33]. Moreover, owing to the influence of Chinese culture, people were more likely to maintain harmony and avoid conflicts [34]. Therefore, parents tended to decrease social participation with friends and families during this period. The use of religious coping by parents was found in this study, and this finding is consistent with that of a previous study, which indicated that religious coping is frequently used by parents with rare diseases [33]. Religious coping is a way to receive emotional support, and it is the most effective coping strategy during the onset of stressful events [35].

Parents with AS children tended to seek social support after a definite diagnosis is given. A possible explanation is that religious coping cannot actually improve stressful situations [33], and engagement coping strategies, such as seeking for social support, seeking for up-to-date information and developing positive thinking [36], are useful for relieving stress [37]. However, some barriers hinder parents from using engagement coping patterns. For example, seeking for social support and developing positive thinking depend on the size of the social network and personal characteristic of parents, respectively [36], whereas seeking for up-to-date information depends on the educational level of parents, that is, whether they can understand the information, which is mostly available in English.

Study Limitations

The participants were recruited from the HKASF during its activities. Only some parents from the foundation could be recruited through the invitation in the activities. Therefore, the hidden families that did not participate in the activities may not be accessed. The parental experience of the parents from the hidden families may be different from those who are actively involved in the foundation. To address these limitations, all members of the foundation must be invited through email to gain access to all active and passive members of the foundation.

Conclusion

This study expanded the knowledge on the parental experience of caring for a child with AS in Hong Kong. Prolonged diagnostic process; non-stop care rounds; insufficient information

and inadequate resources of health services, hostels and special schools were the factors affecting the physical and psychological health of the parents. There is a need to evaluate and advocate the needs of parents of children with AS with regard to the supportive care services so as to bridge the gap between the expectations and needs of parents. By understanding the daily difficulties of parents, healthcare personnel, service providers and the government can collaborate mutually to facilitate and optimise the development of children with AS and increase the public awareness for AS.

Acknowledgments

This study was supported by the Hong Kong Angelman Syndrome Foundation (HKASF).

References

1. Love V, Richters L, Didden R, Korzilius H, Machalicek W (2012) Sibling relationships in individuals with Angelman syndrome: A comparative study. *Developmental Neurorehabilitation* 15: 84-90.
2. Luk HM, Lo IFM (2016) Angelman syndrome in Hong Kong Chinese: A 20 years' experience. *European Journal of Medical Genetics* 59: 315-319.
3. Pelentsov LJ, Fielder AL, Laws TA, Esterman AJ (2016) The supportive care needs of parents with a child with a rare disease: Results of an online survey. *BMC Family Practice* 17: 88.
4. Weng HJ, Niu DM, Turale S, Tsao LI, Shih FJ, et al. (2012) Family caregiver distress with children having rare genetic disorders: A qualitative study involving Russell-Silver syndrome in Taiwan. *Journal of Clinical Nursing* 21: 160-169.
5. Bruce JE (2010) Family quality of life in families of children with Phelan-McDermid Syndrome: A rare genetic disability (Unpublished master's thesis). McGill University, Montreal.
6. Griffith GM, Hastings RP, Oliver C, Howlin P, Moss J, et al. (2011) Psychological well-being in parents of children with Angelman, Cornelia de Lange and cri du chat syndromes. *Journal of Intellectual Disability Research* 55: 397-410.
7. Miodrag N, Hodapp RM (2011) Chronic stress and its implications on health among families of children with intellectual and developmental disabilities (I/DD). *International Review of Research in Developmental Disabilities* 41: 127-161.
8. Gallagher S, Whiteley J (2013) The association between stress and physical health in parents caring for children with intellectual disabilities is moderated by children's challenging behaviours. *Journal of Health Psychology* 18: 1220-1231.
9. Pelentsov LJ, Laws TA, Esterman AJ (2015) The supportive care needs of parents caring for a child with a rare disease: A scoping review. *Disability and Health Journal* 8: 475-491.
10. Griffith GM, Hastings RP, Nash S, Petalas M, Oliver C, et al. (2011) "You have to sit and explain it all, and explain yourself." mothers' experiences of support services for their offspring with a rare genetic intellectual disability syndrome. *Journal of Genetic Counseling* 20: 165-177.
11. Anderson M, Elliott EJ, Zurynski YA (2013) Australian families living with rare disease: Experiences of diagnosis, health services use and needs for psychosocial support. *Orphanet Journal of Rare Diseases* 8: 22.
12. Leyser Y, Kirk R (2011) Parents' perspectives on inclusion and schooling of students with Angelman syndrome: Suggestions for educators. *International Journal of Special Education* 26: 79-91.
13. Wang P, Michaels CA (2009) Chinese families of children with severe disabilities: Family needs and available support. *Research and Practice for Persons with Severe Disabilities* 34: 21-32.
14. Streubert HJ, Carpenter DR (2011) Qualitative research in nursing (5th Edition) Philadelphia, PA: Lippincott.
15. Mayan MJ (2009) Essentials of qualitative inquiry. Walnut Creek, CA: Left Coast Press.
16. Ellis P (2010) Understanding research for nursing students. Exeter: Learning Matters.
17. Lincoln YS, Guba EG (1985) Naturalistic Inquiry. Beverly Hills, CA: Sage.
18. Shenton AK (2004) Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information* 22: 63-75.
19. Watson SL (2008) Families and differential diagnosis of developmental disability. *Journal on Developmental Disabilities* 14: 51-61.
20. Pelentsov LJ, Fielder AL, Esterman AJ (2016) The supportive care needs of parents with a child with a rare disease: A qualitative descriptive study. *Journal of Pediatric Nursing* 31: e207-e218.
21. Lim F, Downs J, Li J, Bao XH, Leonard H (2012) Barriers to diagnosis of a rare neurological disorder in China—lived experiences of Rett syndrome families. *American Journal of Medical Genetics. Part A* 158A: 1-9.
22. Pelentsov LJ, O'Shaughnessy PK, Laws TA, Esterman AJ (2014) What are the supportive care needs of parents caring for a child diagnosed with ectodermal dysplasia: A rare genetic disorder? *International Journal of Child Health and Human Development* 7: 23-29.
23. Russell S, McCloskey CR (2016) Parent perceptions of care received by children with an autism spectrum disorder. *Journal of Pediatric Nursing* 31: 21-31.
24. Smith J, Swallow V, Coyne I (2015) Involving parents in managing their child's long-term condition—A concept synthesis of family-centered care and partnership-in-care. *Journal of Pediatric Nursing* 30: 143-159.
25. Clayton-Smith J, Laan L (2003) Angelman syndrome: A review of the clinical and genetic aspects. *Journal of Medical Genetics* 40: 87-95.
26. Dellve L, Samuelsson L, Tallborn A, Fasth A, Hallberg LR (2006) Stress and well-being among parents of children with rare diseases: A prospective intervention study. *Journal of Advanced Nursing* 53: 392-402.
27. Kara OK, Mutlu A, Gunel MK, Haliloglu G (2010) Do the physiotherapy results make us happy in a case with 'happy puppet' (Angelman) syndrome? *Case Reports* 2010: bcr0620103081-bcr0620103081.
28. Williams CA, Driscoll DJ, Dagli AI (2010) Clinical and genetic aspects of Angelman syndrome. *Genetics in Medicine* 12: 385-395.

29. Shaw K, Cartwright C, Craig J (2011) The housing and support needs of people with an intellectual disability into older age. *Journal of Intellectual Disability Research* 55: 895-903.
30. Jones L, Rowe J, Becker T (2009) Appraisal, coping and social support as predictors of psychological distress and parenting efficacy in parents of premature infants. *Children's Health Care* 38: 245-262.
31. Small R, Markman BS, Hillman S, Hoffman A, Weisfeld G (2010) A comparison of parental self-efficacy, parenting satisfaction, and other factors between single mothers with and without children with developmental disabilities. *ProQuest Dissertations Publishing*, Wayne State University, Michigan.
32. Giallo R, Treyvaud K, Cooklin A, Wade C (2013) Mothers' and fathers' involvement in home activities with their children: Psychosocial factors and the role of parental self-efficacy. *Early Child Development and Care* 183: 343-359.
33. Picci RL, Oliva F, Trivelli F, Carezana C, Zuffranieri M, et al. (2015) Emotional burden and coping strategies of parents of children with rare diseases. *Journal of Child and Family Studies* 24: 514-522.
34. Leung K, Brew FP, Zhang ZX, Zhang Y (2011) Harmony and conflict: A cross-cultural investigation in China and Australia. *Journal of Cross-Cultural Psychology* 42: 795-816.
35. Rees T, Freeman P (2007) The effects of perceived and received support on self-confidence. *Journal of Sports Sciences* 25: 1057-1065.
36. Aimee A (2015) Men's perceptions of the impact of coping strategies activated or taught during workshops on their psychological well-being (Unpublished master's thesis). University of Stavanger, Norway.
37. He S, You LM, Zheng J, Bi YL (2016) Uncertainty and personal growth through positive coping strategies among Chinese parents of children with acute leukemia. *Cancer Nursing* 39: 205-212.