

An exploration of the experience of parents with children with autism spectrum disorder after diagnosis and intervention

Ben Milbourn^{1*}, Marita Falkmer^{1,2}, Melissa H. Black¹, Sonya Girdler¹,
Torbjorn Falkmer^{1,3,4}, Chiara Horlin¹

¹School of Occupational Therapy & Social Work, CHIRI, Curtin University, Perth, Western Australia, Australia

²School of Education and Communication, CHILD Programme, Institute of Disability Research, Jönköping University, Jönköping, Sweden

³School of Health and Welfare, Jönköping University, Jönköping, Sweden

⁴Department of Medical and Health Sciences, Linköping University, Linköping, Sweden

*Corresponding author: ben.milbourn@curtin.edu.au

Abstract

Delays and difficulties in both diagnosis and access to services can compound existing stressors experienced by families with children with autism spectrum disorder. Early and accurate diagnosis and appropriate intervention may not only improve child-specific outcomes but may also mitigate some of the stressors impacting family relationships and quality of life. We aimed to understand the experience of over 500 families that had sought autism spectrum disorder diagnosis and intervention, their perceptions of the efficacy of these services, and the impact that this process had on their family life. Parents overwhelmingly described frustration with access to a timely diagnosis, specialized intervention services, and funding that impacted their family life and relationships. However, parents simultaneously reported positive perceptions of change as a consequence of diagnosis and effective intervention.

Keywords: autism; diagnosis; services; family; qualitative

Introduction

Having a child with autism spectrum disorder (ASD) is known to place additional pressure on parenting relationships (1), unaffected siblings (2,3), and family quality of life (4-7). The characteristics of ASD such as a need for routine or ritualistic behaviours, difficulty in communicating, and sensory preferences can present significant challenges to parents (7). Caring for a child with ASD has been associated with increased fatigue, higher levels of stress, and increased feelings of isolation (8), with the pervasive impact of ASD on the family unit being previously described as the family 'becoming autism' (9).

The early provision of services to children with ASD and their families is necessary not only for improved long-term outcomes for the child (10) but also their families. An early diagnosis is essential to access these services; however, for many reasons, the precise diagnosis of ASD in young children before 3

years of age is difficult (11) and often delayed. Although it is generally agreed that earlier diagnosis and access to intervention leads to better outcomes (10), difficulties in receiving a diagnosis and accessing appropriate intervention services may also act as stressors that compound negative outcomes.

Due to the pervasive and heterogenous nature of ASD (12), parents are often required to navigate a range of early intervention (EI) and behavioral interventions aimed at reducing ASD-linked impairment in social, communicative, and cognitive domains. Although several early and behavioral interventions have shown efficacy in improving child-related outcomes (13-15), little is known of the parents' experiences of early and behavioral intervention. Although intervention is typically targeted at child-related outcomes, it is likely that intervention will also influence parental and family life (7). The putative reciprocal benefits of

intervention services to the family unit are of increasing interest to both researchers and service providers.

Research measuring the capacity of intervention to effect change in the family domain is sparse, and focuses on short-term outcomes or benefits specific to particular intervention programs. Some limited research has examined parental satisfaction with EI services (16,17) and their perceived effects on family life (18,19). Similarly, investigations of behavioral interventions have primarily examined the perspectives of parents involved in the intervention process, such as in home-based early intensive intervention (20) or parent-mediated programs (21). These investigations are largely focused on the immediate impacts of intervention, with a particular focus on parental stress (20,21). Limited research has investigated the impact of intervention on the family more broadly. Although some research has indicated positive effects of intervention on family outcomes, the effects of EI and behavioral intervention as they are perceived by parents may not always be positive or equivocal (20,22). Critically, parenting stress and pessimism regarding intervention and behavior therapies may even counteract the benefits in improving child outcomes (23).

Understanding the experience and perceptions of parents and families that have sought a diagnosis or services for their child with ASD will provide insight into potential barriers to seeking or adhering to treatment regimes, their impact on family quality of life, or mindset when seeking services for at-risk siblings. Given the transactional and reciprocal effects (7) between family life, behavioral problems, and ASD symptomatology, there is a significant need to understand the experience and perceptions of parents of children with ASD during these critical periods. We aim to qualitatively explore the experience of diagnosis, treatment, and perceived impact of EI and behavioral therapies, for families with children with ASD, as reported by the parents of these children.

Methods

Data were obtained as part of a larger project examining the costs associated with raising a child with ASD (24). The primary measure was a multidimensional questionnaire comprising of 73 items collecting information on sociodemographics; diagnosis, treatment, and intervention history; education and child-care usage; and family life. For a copy of the full questionnaire, refer to Horlin et al. (24).

Two open-ended questions relevant to these analyses were as follows:

- “Has your child’s ASD-related intervention/behavioral therapy improved your family life?”
- “Do you feel that earlier access to intervention may have led to more improvements in your child’s quality of life?”

For each question, parents were further asked to rate their agreement on a five-point scale ranging from yes definitely (5) to not applicable (1).

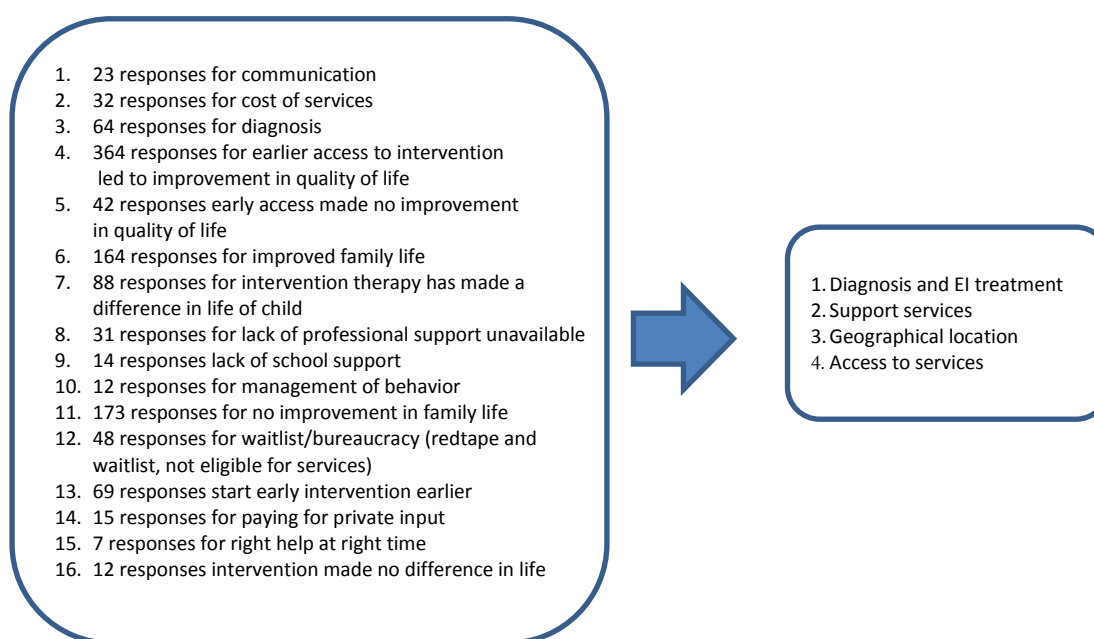
Participants and procedures

Ethical approval was obtained from the Curtin University Human Research Ethics Committee (HR 138/2012) and the internal ethical review board of the Disability Services Commission (DSC) in Western Australia. The questionnaire was distributed by post to families with children registered as having an ASD on the DSC client register. Only families with diagnosed children currently under the age of 18 years were included. At the time of the mail-out, 3965 children were registered with the DSC from 3723 families. Families with more than one child under 18 received one questionnaire for each child with ASD. Of the questionnaires mailed out, 3494 were sent to families with one child with ASD, 217 questionnaires were sent to families with two diagnosed children, 11 questionnaires were sent to families with three diagnosed children, and 1 questionnaire was sent to a family with four children diagnosed with ASD. Of the 3723 questionnaires (covering 3965 children) sent out by the DSC, 192 were returned as “address unknown”. In total, 521 questionnaires were returned, resulting in a 15% response rate. The characteristics of the included 521 children with ASD are presented in Table 1, including information on the respondent, and the sex, age, and diagnosis of the child. Questionnaire responses were entered into a data file using IBM SPSS version 20 and analyzed using SAS version 9.2 statistical software. A drop-out analysis was carried out 6 months after the original data collection period. A random sample of 405 families registered with the DSC was contacted for a telephone follow-up. Non-respondents were then asked to answer an abbreviated form of the questionnaire over the phone. For the purposes of comparisons between those who did and did not respond to the long-form questionnaire that was sent out by mail, independent-samples *t*-tests were used to compare the ages of children, chi-squared tests were used to compare categorical demographic variables, and Mann–Whitney U tests were carried out to compare calculated cost variables (24). It is noteworthy that only questions covering the out-of-pocket treatment costs and the loss of income from employment reduction could be calculated for both respondents and non-respondents.

TABLE 1. Characteristics of respondents of the questionnaire

	N	%
Total	521	
Respondent		
Biological mother	421	81
Biological father	87	17
Grandparent	5	0.96
Foster parent	4	0.77
Step parent	1	0.2
Other	1	0.2
Child		
Age [mean (SD)] (years)	9.92 (4.17)	
Male	431	83
Female	90	17
Diagnosis		
Autism	272	52.60
High functioning autism	128	24.70
PDD-NOS	76	14.70
Asperger syndrome	36	7
Other	7	1.40
CDD	2	0.40

Note. CDD, childhood disintegrative disorder; PDD-NOS, pervasive developmental disorder - not otherwise specified

**FIGURE 1.** Emerging subthemes and subsequent overarching themes

Data analysis

Qualitative responses for Questions 63 and 64 were transcribed into a word-processing document and exported into NVivo data management software (25). A content analysis approach was adopted (26) and the data were inductively coded (27) to create nodes relating to a response made. Each response was carefully interpreted and coded into an initial list

of 16 emerging sub-themes by adding up the most recurring responses. The themes were then checked and confirmed by the research team and then connected to achieve a set of four overarching themes (Figure 1) including diagnosis and EI treatment, support services, geographical location, and access to services. The themes were then further cross-checked with the research team (28) and

written up using quotes to illustrate the themes. To triangulate the findings derived from the qualitative analysis (29), quantitative responses to the Likert scale components of Questions 63 and 64 were analyzed using descriptive statistics including determining the percentage frequency of responses.

Results

Diagnosis and early intervention treatment

The “diagnosis and EI treatment” theme was applied to responses detailing the impact and outcomes of diagnosis and treatment. Statements that referred to the impact of EI treatment yielded 364 responses indicating a perceived improvement in quality of life for the child. Respondents described outcomes for their child including the ability to verbally communicate with other children and family members, self-control of behavior, and social skills:

“Without intervention my son would not be verbal - he would have only used 6 words”

Similarly, 164 responses touched on the direct link between EI and improvements in family life. Respondents described how intervention supported family members to form strategies that allowed the child to develop and facilitated their involvement in the child’s everyday life. Impact on family life was directly related to families’ ability to get a diagnosis. Respondents indicated that this was the crucial first step in accessing services, and both the process and wait could negatively impact family life:

“We were floundering, our marriage was suffering and I thought I had a mental problem. Once she was diagnosed and we tried and used every option available, our life changed dramatically over a two week period. We had light at the end of the tunnel”

Inability to get a diagnosis impacted upon both child and family in terms of how the child’s behavior was viewed by others. Respondents believed that services were often reluctant to make a diagnosis:

“Many doctors were unwilling to diagnose for the first few years which lead to the delayed diagnosis. Through no fault of our own, but through faults of the medical system, our son missed out on early intervention programs”

Support services

The theme of “support” referred to families’ experiences with healthcare and school services, and how their child benefited from these services. Forty-five responses were made to a lack of support from health services, with a key sub-theme being a sense of isolation and disempowerment:

“We were walking zombies, we didn’t know why he did what he did, didn’t know what to ask, who to believe, where to go. We kept falling through the hole in the system, till they found us again”

Respondents described a general feeling of frustration: not being listened to by services and staff not having the knowledge or experience to diagnose or refer to appropriate services:

“I feel I was met with closed doors at my GP - no referral to a pediatrician. I kept being told [he will grow out of it, He’s a bit behind but it’s OK]. [The GP] would not listen to a mother’s instinct - he was my second child - I knew something was wrong. The GP even yelled at me - [What do you want me to do about it?]”

Similarly, within education settings, respondents indicated frustration with the support and understanding offered by school services, particularly the lack of understanding and specialist of teaching staff:

“I have an entire folder of information showing my request for help and guidance from her primary school teachers. No one took me seriously”

Geographical location

The theme “geographical location” was applied to statements associated with difficulty accessing service on the basis of location. Eighteen responses cited geographical location as a barrier that inhibited their access to services to support their child, particularly respondents living outside of Perth in rural and regional locations:

“We live in rural Western Australia, Yes 1000’s of kilometers from Perth. Services are all but non-existent here but [I] lived in Perth prior to diagnosis where he was receiving lots of therapy for his other diagnosis. We have to travel to Perth for treatment where we can”

In rural locations, the availability of treatment was also influenced by the periodic visits of specialists throughout the year. In particular, support with adequate training to meet the individual needs of the child was limited due to geographical location:

“Our child is extremely disabled. We live in a rural setting and intervention support services are limited and in our experience and woefully inadequate in providing the type of support we need”

When respondents were able to access services, they reported a positive impact on both the family and the child’s quality of life; however, this was

countered by their continued frustration at having to travel to Perth to access services:

“The last ten years of therapy for my son have helped him extremely and have had a huge positive impact on our way of life. However the access to services was limited by age, location and lack of funding”

Access to services

“Access to services” referred to responses on funding, wait times, and cost. The impact of waiting for a diagnosis to access services had a ‘knock-on’ effect in terms of accessing EI. Thirty-four responses were made in relation to waiting to access EI after diagnosis. Respondents described waiting between 6 and 12 months for services:

“The diagnosis process took months, then it was nearly a year before actually receiving any services due to waiting lists. So much for early intervention”

“It is confusing enough to receive a diagnosis, then it seems it is up to ASD families to go through a myriad of confusing paperwork, etc. to find therapists, funding, etc.”

Referral to appropriate services as well as the cost of EI was identified as a barrier to supporting their child. Thirteen responses were made regarding paying for private input for their child:

“Virtually zero government assistance necessitated private funding for intervention in the early years, which was an absolute necessity that he benefited from”

Respondents also expressed frustration with the cut-off age for intervention. This was related to the perceived unwillingness of medical staff to diagnose early and resulting in a child receiving delayed EI treatment or ageing out before access.

Frequencies

Rating scale responses for Question 63 “Has your child’s ASD-related intervention/behavioral therapy improved your family life” are shown in Table 2. Analysis of response frequency indicated that respondents felt strongly that EI improved family life, with 71.3% of respondents indicating that EI assisted ‘somewhat’ or ‘definitely’.

Similarly, responses for Question 64 “Do you feel that earlier access to intervention may have led to more improvements in your child’s quality of life?” showed that 78.4% of respondents agreed that earlier access to intervention would have led to improved child’s quality of life ‘somewhat’ or ‘definitely’ (Table 2).

TABLE 2. Frequency responses for Likert scale components of questions

	Frequency	% [†]
Intervention has improved family life		
Not at all	43	10
Neutral	81	18.8
Yes somewhat	159	36.8
Yes definitely	149	34.5
Total [‡]	432	100
Would earlier access to intervention have led to more improvement in child’s QoL		
Not at all	39	8.5
Neutral	60	13
Yes somewhat	94	20.4
Yes definitely	267	58
Total [‡]	460	100

[†]Based on valid responses only.

[‡]Total excluding missing responses

Discussion

In understanding the experience and perceptions of parents who had sought diagnosis and services for their child with ASD, we have found resoundingly positive views on the impact and benefits of intervention services, irrespective of delayed diagnosis or intervention. Despite the positive perception of the outcomes of intervention to the diagnosed child and reciprocal benefits to the family more generally, parents overwhelmingly expressed their frustration regarding the process of receiving a diagnosis, as well as seeking funding support and intervention services. Indeed, parents reporting a reluctance from medical professionals to formally diagnose their child is alarming, particularly given the impact that late diagnosis has on accessing funding and services.

Although parents understand the importance of EI in children with ASD, this knowledge has been shown to contribute towards increased stress in families (30). Parents of children with ASD have reported significant pressure associated with ensuring that their child is receiving appropriate services during the EI time period, with delays in accessing a diagnosis and services exacerbating parental concern (30). This sense of urgency experienced by parents is likely to contribute towards the frustrations associated with support and services available to their child. These findings highlight the need to provide support to parents pre-diagnosis. With the increasing prevalence of ASD (31) and the association between early access to services and child outcomes (10), upskilling medical and staff professionals involved in identifying at-risk children may also be necessary.

Access to supports and services has been identified as an important moderator between stressors and outcomes (32). Ensuring access to appropriate supports is therefore essential for better long-term

family outcomes. Given the pervasive impacts of ASD on family life and the transactional nature of parental perceptions and child outcomes, providing increased support to families during the pre-diagnosis, diagnosis and post-diagnosis stage may be beneficial. Increased involvement of families in decision-making and intervention processes may allow clinicians to better understand the family context to ensure that appropriate support is being provided to these families.

Many of the barriers and stressors identified by parents are known to be exacerbated for families living rurally; however, here, parents have highlighted that in addition to complicated access to services, both the perceived skill and specificity of services available to them impacted their experience and the perceived efficacy of treatment of their child with ASD.

Limitations

Although this research has provided critical insight into the perspectives of parents of children with ASD during the process of receiving a diagnosis and EI, the results must be interpreted with caution. The experiences of respondents in the current study may be influenced by the particular time points and contexts in which the data were collected. It is possible that the funding and service provision structures available to respondents at the time of data collection may have influenced the results and that other contexts may yield differing perspectives. Although this study has a considerable sample size, it is likely that the perspectives presented by respondents in the current study do not adequately capture the experiences of all care-givers of children with ASD and it is possible that those respondents who did participate in this study introduced a particular bias to the results (33). Although attempts have been made to reduce bias in interpreting these results, the potential for researcher bias must also be acknowledged (33). Although the questionnaire enabled participants' greater anonymity and allowed a significantly greater population to be reached, this may have contributed towards a distorted interpretation of the data. Finally, the majority of respondents in the current study were biological mothers (24). It has been shown that mothers and fathers differ in their experiences of caring for a child with health conditions such as ASD, and may use differing coping strategies. Mothers, in particular, may show significant levels of stress and reduced quality of life (34). Although it was not possible to examine sex differences in the current study, it is possible that mothers and fathers differ in their perception of EI and behavioral intervention on family outcomes.

Conclusion

By acknowledging these parent-reported challenges, we highlight that many of the frustrating stressors associated with having a child with ASD appear to be external, situational, and bureaucratic. Yet, the presence of these stressors and delays in access can coexist with a positive perception of change and improvement as a consequence of eventual diagnosis and access to intervention. Although not a conventional qualitative study, the collective experiences of this large sample of parents highlight the importance of fully understanding the family context for all professionals interacting with families pre-diagnosis and post-diagnosis. The quotes extracted from responders are illustrative of experiences that may be anecdotally known to some professionals, but provide beneficial insight for all medical and health professionals, service providers, government agencies, and funding providers, as well as parent and family advocates. The views expressed by these parents may also inform future quantitative research investigating parent attitudes towards diagnosis and treatment, and the impact that these processes may have on the family.

Acknowledgements

Reinie Cordier, Aoife McNally, Kirsty Oehlers, Mandy Richards, Geoff Cole, Susan Peden, staff at Disabilities Services Commission; Caitlin Axford, Fiona Choi, Helen Weldergergish, Rachel Owens, Rex Parsons, Richard Parsons, Stephen Lawrie, Gal Rose, Tim Parkin, AIM employment AAWA.

Funding

This study was funded by the Department of Social Services (DSS) in Western Australia, formerly the Department of Families, Housing, Community Services and Indigenous Affairs, with in-kind support of the Autism CRC, established and supported under the Australian Government's Cooperative Research Centres Programme.

Ethics

This research project was given Human Ethical Approval at Curtin University in Perth, Western Australia (reference number HR 138/2012) and conforms to the provisions of the Declaration of Helsinki as revised in 2000 and 2008 concerning Human and Animal Rights. Informed consent was obtained from all participants prior to data collection. To ensure participant anonymity, there is no identifying data within the content of this manuscript to identify participants.

Conflicts of interest

All authors declare no conflicts of interest.

References

1. Hock R, Timm T, Ramisch J. Parenting children with autism spectrum disorders: A crucible for couple relationships. *Child Fam Soc Work* 2012;17:406-15.
2. Moyson T, Roeyers H. The quality of life of siblings of children with autism spectrum disorders. *Exceptional Children* 2011;78:41-55.
3. Wigston C, Falkmer N, Vaz S, Parsons R, Falkmer T. Participation in extracurricular activities for children with and without siblings with autism spectrum disorders. *Dev Neurorehab* 2017;20:25-39.
4. Vasilopoulou E, Nisbet J. The quality of life of parents of children with autism spectrum disorder: A systematic review. *Res Autism Spectr Disord* 2016;23:36-49.
5. Pozo P, Sarriá E, Brioso A. Family quality of life and psychological well-being in parents of children with autism spectrum disorders: A double ABCX model. *J Intellect Disabil Res* 2014;58:442-58.
6. Lee L-C, Harrington R, Louie B, Newschaffer C. Children with autism: Quality of life and parental concerns *J Autism Dev Disord* 2008;38:1147-60.
7. Karst J, Vaughan Van Hecke A. Parent and family impact of autism spectrum disorder: A review of proposed model for intervention evaluation. *Clin Child Fam Psychol Rev* 2012;15:247-77.
8. Woodgate R, Ateah C, Secco L. Living in a world of our own: The experience of parents who have a child with autism. *Qual Health Res* 2008;18:1075-83.
9. DeGrace B. The everyday occupations of families with children with autism. *Am J Occup Ther* 2004;58:543-50.
10. Filipek P, Acardo P, Ashwal S. Practice parameter: Screening and diagnosis of autism: Report of the Quality Standard Subcommittee of the American Academy of Neurology and the Child Neurology Society. *Neurology* 2000;55:468-79.
11. Wing J, Gould J, Gillberg C. Autism spectrum disorders in the DSM V: Better or worse than the DSM IV. *Res Dev Disabil* 2011;32:768-73.
12. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (DSM-5®)*. Washington: American Psychiatric Publishing; 2013.
13. Reichow B. Overview of meta-analyses on Early Intensive Behavioural Intervention for young children with autism spectrum disorders. *J Autism Dev Disord* 2012;42:512-20.
14. McConachie H, Diggle T. Parent implemented early intervention for young children with autism spectrum disorder: A systematic review. *J Eval Clin Practice* 2007;13:120-9.
15. Peters-Scheffer N, Didden R, Korzilius H, Sturmey P. A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with autism spectrum disorders. *Res Autism Spectr Disord* 2011;5:60-9.
16. Kohler F. Examining the services received by young children with autism and their families: A survey of parent responses. *Focus Autism Other Dev Disabil* 1999;14(3):150-8.
17. Smith T, Buch G, Gamby T. Parent directed, intensive early intervention for children with pervasive developmental disorder. *Res Dev Disabil* 2000;21:297-309.
18. Dillengurger K, Keenan M, Gallagher S, McElhinney M. Parent education and home based behaviour analytic intervention: An examination of parents' perceptions of outcome. *J Intellect Dev Disabil* 2004;29:119-30.
19. Hume K, Bellini S, Pratt C. The usage and perceived outcomes of early intervention and early childhood programs for young children with autism spectrum disorder. *Topics Early Child Spec Edu* 2005;25(4):195-207.
20. Hastings R, Johnson E. Stress in UK families conducting intensive home-based behavioural intervention for their young children with autism. *J Autism Dev Disord* 2001;31:327-36.
21. Bearss K, Burrell T, Stewart L, Schahill L. Parent training in autism spectrum disorder: What's in a name? *Clin Child Fam Psychol Rev* 2015;18:170-82.
22. Williams K, Wishart J. The Son-Rise Program: Intervention for autism: An investigation into family experiences *J Intellect Disabil Res* 2003;47:291-9.
23. Osborne L, McHugh L, Saunders J, Reed P. Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *J Autism Dev Disord* 2007;38:1092-103.
24. Horlin C, Falkmer M, Parsons R, Albrecht MA, Falkmer T. The cost of autism spectrum disorder. *PLoS One* 2014;9:e106552.
25. Welsh E. Dealing with data: Using NVivo in the qualitative data analysis process. *FQS* 2002;3:2. Art. 26.
26. Joffe H, Yardley L. Content and thematic analysis. In: Marks D (Ed.). *Research methods for clinical and health psychology*. London: SAGE; 2004. p. 56-64.
27. Fereday J, Muir-Cochrane E. Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *Int J Qual Methods* 2006;5:80-92.
28. Ryan-Nicholls K, Will C. Rigour in qualitative research: Mechanisms for control. *Nurse Res* 2009;16:70-85.
29. Onwuegbuzie A, Leech N. Linking research questions to mixed methods data analysis procedures 1. *Qualitative Rep* 2006;11:474-98.
30. Edwards A, Brebnar C, McCormack P, MacDougall C. The early intervention message: Perspectives of parents of children with autism spectrum disorder. *Child Care Health Dev* 2017;43:202-10.
31. Waterhouse L. Autism overflows: Increasing prevalence and proliferating theories. *Neuropsychol Rev* 2008;18:273-86.
32. Dunn M, Burbine T, Bowers C, Tantleff-Dunn S. Moderators of stress in parents of children with autism. *Community Ment Health J* 2001;37:39-52.
33. Krefting L. Rigor in qualitative research: The assessment of trustworthiness. *Am J Occup Ther* 1991;45:214-22.
34. Bromley J, Hare D, Davidson K, Emerson E. Mothers supporting children with autistic disorders. *Autism* 2004;8:409-23.