



Family Routines of Adolescents with an Autism Spectrum Disorder: A Literature Review



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Abstract

Background: The literature and government policy highlight the clinical significance of Autism Spectrum Disorder; the difficulties experienced by families and the importance of participation in family routines.

Purpose: It is important to conduct further research into this topic because it is common for families with children with ASD (FASD) to experience reduced health and wellbeing as a result of the difficulties associated with maintaining productive and meaningful family routines.

Method: A review of the literature was conducted which involved searching in relevant health and social care databases including AMED, CINAHL, Psycho Info and Pub Med snowball searching. After the quality check and data extraction of the included eight articles there were three main themes identified; mealtime as a challenging routine, social isolation and routines centred around the child with autism spectrum disorder (ASD).

Results: The findings from the themes identified gaps in the literature which included a lack of research conducted with FASD with adolescent's particularly in-depth qualitative research, in addition to the Mother's perceptions of the characteristics of ASD and their impact on family routines. The studies revealed that the characteristics of ASD can have a significant effect on family routines for FASD, highlighting the importance for further research.

Introduction

Family routines can be defined as structured patterns of performing activities that are repeated regularly in everyday life [1]. These are often completed out of habit with little afterthought; therefore do not hold special meaning for the person [1]. In contrast, family rituals describe activities that hold special meaning and value to all family members and are often repeated through generations [1]. Environment and culture have a huge impact on the development of family routines and rituals and so is an important factor to consider [2]. Family routines lay the foundation in which meaningful rituals can develop; therefore both are equally important to facilitate the smooth functioning of family life [1]. Maintaining family routines and rituals has been shown that to have many positive benefits for whole family health and wellbeing. Bossard & Boll [3] suggested that they increase stability within the family, which is important in helping families cope in times of stress. It is recognised that one of the first indicators of stress experienced by the family is when routines and rituals are disrupted [4].

A study conducted by Markson & Fiese [5] investigated rituals in families with children with asthma and whether these protected the children from experiencing anxiety symptoms. The study found that participation in meaningful family rituals was linked to lower

levels of anxiety experienced by the children. Furthermore, Fiese et al. [4] concluded that family routines and rituals are important to support the maintenance of family relationships, bring the family closer together and provide opportunities to share emotions/meaning and thereby improving psychological health and wellbeing. It is recognised that families with children with disabilities find it difficult to establish and maintain everyday routines and meaningful rituals, therefore missing out on the benefits that these experiences can provide [6]. Consequently the family's psychological health and wellbeing is often affected. Research that investigates factors affecting routines and rituals are therefore vital to help develop appropriate interventions tailored to support these families. It is recommended that investigations into this topic area should be performed through family narratives as they provide valuable, real life insights into the pattern of everyday life and the activities that shape their family identity [7].

Occupational Therapists need to consider the importance of family routines and rituals when implementing interventions. This is because the interventions suggested must be able to fit within the everyday functioning of the family and meet their values in order to be adopted into the family's way of life, to be effective [8]. In summary, the research evidence highlights the clinical significance of the impact of the characteristics of ASD on family

routines including the negative effects on the health and wellbeing of these families. This has determined the need for further research investigating the impact of the characteristics of ASD on family routines from the narratives of families with adolescents with ASD. A total of eight articles were selected for critical appraisal and were relevant to answer the following question; what are the experiences of family routines for families with individuals with ASD (FASD)?

Method

The electronic databases were searched between August-December 2014. The following databases were used; AMED, CINAHL, Psycho Info and Pub Med. The reasoning behind the choice of the databases was to gather literature on the research topic from many professional perspectives.

Inclusion and exclusion criteria

Articles included in the review were required to be written in English to ease translation, articles written in any other language were excluded. Articles were accepted from any year and with any formulation of family due to limited research on the topic. The child, adolescent or adult in the study needed to be diagnosed with Autistic Spectrum Disorder (ASD) to improve credibility of the results. Any studies where the individual did not have a diagnosis of ASD were excluded. Qualitative and quantitative designs accepted to explore all relevant literature.

The article was also required to examine the routines of the family as a collective unit because family routines involve family members doing activities together. Research also needed to be investigating family occupations/family routines and investigating the impact of the characteristics of ASD on family routines. Articles solely looking at the routines of the individual with ASD or parents on their own were excluded from the review as this would have provided information on individual routines rather than family routines. Background reading of the literature on ASD was performed to identify appropriate key terms to use in the search strategy [9].

The same search strategy was applied to all databases to ensure consistency. The limiter 'Abstract only' was used in Psych Info and the limiter 'Title and Abstract only' was used in Pub Med in order to reduce the high number of irrelevant articles while maintaining the relevant and valuable articles to the research question. Snowball searching and searching in Google was used alongside database searching to ensure coverage of all relevant literature [10]. The eight articles were reviewed by the qualitative and quantitative versions of the McMasters critical appraisal tool [11]. Critical appraisal was used to systematically evaluate the rigour of the research articles to ensure selection of good quality evidence in the review [12].

Results

Themes were identified within the literature to explore the current knowledge base regarding family routines with individuals with ASD in addition to areas that needed further exploration. This process identified gaps in the knowledge base which the

proposed study aims to fill. The findings from the six qualitative papers reviewed were presented in themes. These themes found within the narratives were then mapped to find shared ideas within all papers. There were also similarities in the findings of the two cross-sectional studies which showed significance in holidays and a trend toward significance in mealtimes. The process of comparing the findings from both the qualitative and quantitative papers revealed three main themes including; Mealtime as a challenging routine, Social Isolation and Routines centred around the child with ASD. The research suggests that the characteristics of ASD have a significant effect on family routines for FASD.

Gaps have been identified in the literature including; the need for research conducted with FASD with adolescents, as adolescents are different from children with whom most studies have been conducted [13], the need for in-depth qualitative research of FASD with adolescents due to limited research using this methodology and the need to gather the Mother's perceptions of the characteristics of ASD and their impact on family routines.

Discussion

The critical appraisal of the literature identified three main themes; mealtime as a challenging routine, social isolation and routines centred around the child with autism spectrum disorder (ASD).

Mealtimes as a challenging routine

Mealtimes are recognised as important moments of the day for families to be together, engaging in routines that give meaning [14]. However, for FASD this positive experience can be difficult to achieve often due to feeding difficulties [15] and mealtime behaviours [16] which can significantly impact family daily life.

Mealtime challenges were identified in 6/8 of the articles. Some papers discuss mealtime within everyday routines. However, Suarez et al. [17] and Marquenie et al. [18] have specifically looked at the occupation of mealtime. They have used phenomenological methods of enquiry which has had the benefit of providing in-depth, real life insights, broadening understanding [19]. This qualitative approach appears to be more appropriate to study mealtimes as the quantitative studies of Rodger & Umibalan [20] found no significance and Bagatell et al. [21] only a trend towards significance. These studies were not sensitive enough to capture the differences between the two groups. A major limitation of both studies was the small sample sizes which lacked power to detect any significant differences [22].

Bagby et al. [23] found that that FTD gave more positive reflections to their experiences at mealtime than FASD. This is supported by the findings of Marquenie et al. [18] and Suarez et al. [17] who found that mother's described family mealtimes as stressful. It has been noted that there may be an ethical issue in the Bagby et al. [23] study as the parents were paid for their participation. Although informed consent was obtained, it could be argued that the parent's decision was influenced by this incentive, and therefore not freely provided [24].

Bagatell et al. [23] attempted to improve the validity of the results by adding the qualitative element of three open ended questions. This data revealed that FASD ate together as a family less often and experienced more difficulties at mealtime than FTD with adolescents. However due to the small number and type of questions, they did not elicit the emotions captured in the qualitative study of Marquenie et al. [18]. The semi-structured interview method in Marquenie et al. [18] was better able to capture relevant information while allowing some freedom in responses [25].

The reasons behind mealtime distress included the child's need for sameness, food selectivity and difficulty sitting still at mealtimes. Suarez et al. [17] and Marquenie et al. [18] both found that children with ASD insist on sameness in the types of foods. However, the findings from Marquenie et al. [18] went further to describe this sameness extending to include cutlery, crockery, chair and position. Suarez et al. [17] investigated the perspectives of four Mothers. Although this is a small sample size which can impact the transferability of the results, the interviews were continued until data saturation was achieved. Data saturation is a quality standard in qualitative research as it is the point at which no new themes are emerging and ensures that relevant information is analysed [26]. This is supported by the findings in Marquenie et al. [18] who recruited a larger sample size of fourteen Mothers.

Suarez et al [17], Marquenie et al. [18] and Schaff et al. [27] found consistent findings that the limited variety of foods accepted by the child caused problems including cooking multiple meals, families eating separately and other family members rushing their meals to minimise the unpleasant experience. Schaaf et al. [27] conducted face-to-face interviews enabling researchers to establish rapport and result in more disclosure from participants. This method was in contrast to Suarez et al. [17] who conducted all interviews via telephone which had the potential to impact the results due to difficulty of establishing rapport affecting the level of information shared [28]. Despite this, both studies showed consistent findings.

Schaaf et al. [27] and Suarez [17] both found the child's inability to keep still during dinner a major factor disrupting mealtime routines. Schaaf et al. [27] linked this to sensory processing difficulties and used a standardised tool to assess this in the children improving the credibility of the results.

Social isolation

Social Isolation involves feelings of being alone due to minimal contact with meaningful others [29]. The majority of FTD engage in regular social activities such as going out to dinner or to the cinema as well as more occasional activities such as going on holiday [30]. However, evidence suggests that FASD rarely participate in these social activities due to the difficulties managing the characteristics of ASD [31].

A review of the articles consistently showed reduced social activity and social isolation. Both Werner [32] and Suarez et al. [17] found that families rarely went out for a meal whereas Schaaf et al. [27] found that families were unable to go to movies and sporting

events. A limitation of the Schaff et al. [27] study is that this finding has been described but has not provided insights as required in interpretive phenomenology [19], to explain how sensory processing difficulties may have affected the families reduced participation. The qualitative open-ended questions in Bagatell et al. [21] revealed that FASD were more insular and therefore more socially isolated than the FTD teenagers, describing how they spent more time with their immediate families and little time with extended families and friends. These findings collectively show that FASD limit the number of activities they participate in in the community as a family.

The qualitative studies of Werner [32], Schaaf et al. [27] and Hodgetts et al. [33] found that FASD rarely participated in holidays. Furthermore the quantitative findings from Roger & Umibalan [20] found that FTD scored higher than FASD for vacations, suggesting that FASD go on holiday less frequently due to the demands of managing the characteristics of ASD. This consistency of findings improves the trustworthiness of the results. It may be unsafe to extrapolate these findings to the wider population of FASD based on so few studies with limited participants, additionally Werner [32] and Umibalan [20] used convenience sampling introducing the possibility of selection bias [34]. However the collective result is indicative of little progress made in the support of such families in the ten-year gap between these studies.

As discussed, the papers found that it was challenging to participate in social activities as a family, however further findings from Schaff et al. [27] and Hodgetts et al. [33] suggested that there were also difficulties with going out as a family without the child with ASD or as a couple due to difficulties finding suitable childcare. Families were not able to take holidays without the child due to lack of respite. The narratives from Werner [32] also contained this finding. Bagby et al. [23] described families splitting up so one parent could stay with the child with ASD whilst the others enjoyed an activity, effectively providing their own childcare. These studies together suggest this is a common problem highlighting a lack of support both formal and informal. A limitation however, is that all of the studies were undertaken overseas; Australia, USA and Canada. The transferability of these findings to Great Britain with its National Health Service, social services, education and charitable foundations may be difficult [35].

The NICE guidelines [36] states the need for practical support for parents in their caring role, including short breaks and emergency plans. In addition, there are standards to support the access and participation in leisure activities. These guidelines have the potential to reduce social isolation and increase social participation of FASD in UK. However, the guidance does not explicitly express that this support should be family centred and therefore could be interpreted just for the child.

A major limitation of all the studies reviewed was the lack of assessment regarding the severity of the child's ASD as it is likely that the more severe the characteristics, the greater the impact on the families' ability to participate in social activities. There may be

a different level of support required for the different characteristics and abilities in children with ASD. The only study that has mentioned the severity of ASD is Werner [32] describing her participants to have “severe autism”, however a standardised tool was not used to assess this. Bagby et al. [23] has ensured that the children in their study were diagnosed with ASD using two standardised tools to improve the credibility of the results. However, again there was no assessment of the level of severity. There is also a lack of depth into the parents perceptions of the severity of the child’s characteristics. Their understanding and tolerance of their child’s difficulties and behaviour is likely to impact their choice to participate in social activities as a family.

Aggression could be argued as the most severe characteristic of ASD [37] and was investigated by Hodgetts et al. [33]. The findings suggest that aggression had a particularly detrimental effect on family participation in social activities. In contrast, none of the other studies have looked for aggression as a characteristic and therefore it is unknown whether this was present or a factor impacting the level of families’ social participation.

Routines centred around the child with ASD

FTD engage in a variety of routines which can include work, leisure and childcare commitments. In the right balance these can promote the health and wellbeing of the family [2]. However, a common experience for FASD is that their daily lives revolve around meeting the needs and demands of the child which can result in dysfunctional routines. Often the families’ main role is to care for the child with ASD and they rarely participate in social and leisure activities as a family [38].

A theme running throughout the qualitative articles is that family routines centred around the child/adolescent with ASD. Werner [32] concludes that the whole family and the whole day revolve around the needs of the child with ASD, controlling their lives. Marguenie et al. [18] and Suarez et al. [17] agreed with this finding. A positive of the Werner [32] study is the use of a reflexive approach by explicitly stating the influence of the researcher’s pre-conceptions of the responses and the use of appropriate methods to monitor and immunise their influence such as recording thoughts in a journal throughout the research process [39]. Suarez et al. [17] also used a journal to record the researcher’s thoughts, however a limitation was that these were not explicitly described and therefore difficult to ascertain whether they had an impact on responses.

Bagby et al. [23] found that the number of family occupations were limited whilst the amount of planning and time spent to deal with the child’s behaviour took over the day. Similarly to Bagby et al. [23] and Schaaf et al. [27] also looked at sensory related behaviours and found a reduction in number of activities undertaken and how the parents employed specific strategies to manage routines to accommodate the needs of the child with ASD. Hodgetts et al. [33] described how FASD with aggression had to be constantly vigilant and taking care of them was all consuming. The grounded theory approach used by Schaff et al. [27] and Hodgetts et al. [33] has been beneficial as it has allowed new theory to be generated about the

little known topic of the impact of sensory processing difficulties and aggression on family routines [40].

Within all the qualitative studies there is no evidence of pilot testing of the interview questions. This would have improved their credibility as it ensures that questions will answer the research title. Marquenie et al. [18] has used the same interview questions as Werner [32], this has the advantage that the questions have been validated by the previous research. The same theme was present in the quantitative study of Rodgers & Umibalan [20] using two separate questionnaires: Family Routines Inventory (FRI) and Family Ritual Questionnaire (FRQ). They found that the extent to which family routines were undertaken were higher for FTD than FASD and concluded that routines may be more orientated to meet the needs of the child with ASD. This suggestion is not grounded within their findings, it is conjecture. However due to the link with the [18] study undertaken at the same time with the same participants they have made this inference. Similar to Roger [20] and Bagatell et al. [21] used the FRI. Although the tool is validated, the questions may not be applicable to current family routines as it is 30 years old [1].

Bagatell et al. [21] was the only study not to identify the child centred theme in FASD. This limits the knowledge base in this area as no other study investigated adolescents. The majority of the studies have investigated children and therefore highlights a significant gap in the literature. Although all the studies investigated families they have varied in which participants they used for data collection. Roger [20], Marquenie et al. [18] and Suarez et al. [17] investigated Mothers. In the studies of Hodgetts et al. [33] and Bagatell et al. [21] mainly mothers, sometimes fathers. Schaff et al. [27] and Bagby et al. [23] investigated unspecified parents. A limitation of all studies was that the rationale for their choice of participant was not explained or controlled. The only study to investigate the family as a collective unit was Werner [32]. A positive from this study was that the descriptions of each family member recruited were detailed which improves the transferability of the results. However, the responses from each member of the family were not separated, making it difficult to establish differences/contradictions/similarities in their opinions.

Conclusion

Collectively the studies revealed that the characteristics of ASD can have a significant effect on family routines for FASD, highlighting the importance for further research. In addition, gaps in the literature were found which included a lack of research conducted with FASD with adolescent’s particularly in-depth qualitative research, as well as insight to the Mother’s perceptions of the characteristics of ASD and their impact on family routines. The findings increase the awareness of the importance of this subject to Occupational practice and encourage further higher quality research to be conducted that will benefit the lives of FASD. The review has shown that understanding the impact of the characteristics of ASD on family routines would provide better insight into the client’s needs. This knowledge is of great significance as it can be used to inform family centred interventions.

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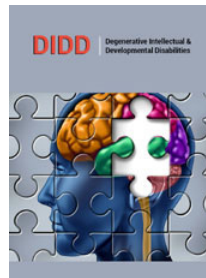
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