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Qualitative Case Study on Challenges Recoupled Parents Encounter Raising Step Children with ASD

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Abstract

The purpose of this study is to address the lack of research into the challenges and issues recoupled parents face when raising their step/biological children with autism spectrum disorder (ASD) together in a stepfamily environment. Data shows clinicians, community support services, and policy makers are recognising that stepfamilies are the fastest growing family form to date and hypothesising stepfamilies will become the norm as the most prominent family form in most western countries. Ongoing research recognises the importance of understanding parents' experiences and perspectives of having a child with ASD, and resourcing and managing their child's everyday needs, behaviour and necessary treatments. Research exploring the parents' journey of supporting a child with ASD will benefit families and other relevant formal and informal supports involved with that child. Stepfamilies are distinctly different to the nuclear family in design, origin and function. The researcher, through a small-scale qualitative case study, interviewed two recoupled parents to gain insights from their own personal and stepfamily experiences. This study has substantiated the existing research and highlighted other specific challenges and issues recoupled parents of children with ASD face. The researcher uses the term step/biological children throughout this article in recognition that the child/children is/are connected to one parent as a blood child and the stepparent through the biological parents' choice in re-partnering. The outcome of this research indicates the need for recoupled parents to have a forum to express their subjective experiences in raising children with ASD. The interviewees articulated the need for further understanding from professional and informal supports when working with children and parents in a stepfamily form.

Keywords

Stepfamily, Autism Spectrum Disorder (ASD), Recoupled Parents

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Qualitative Case Study on Challenges Recoupled Parents Encounter Raising Step Children with ASD

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The purpose of this study is to address the lack of research into the challenges and issues recoupled parents face when raising their step/biological children with autism spectrum disorder (ASD) together in a stepfamily environment. Data shows clinicians, community support services, and policy makers are recognising that stepfamilies are the fastest growing family form to date and hypothesising stepfamilies will become the norm as the most prominent family form in most western countries. Ongoing research recognises the importance of understanding parents' experiences and perspectives of having a child with ASD, and resourcing and managing their child's everyday needs, behaviour and necessary treatments. Research exploring the parents' journey of supporting a child with ASD will benefit families and other relevant formal and informal supports involved with that child. Stepfamilies are distinctly different to the nuclear family in design, origin and function. The researcher, through a small-scale qualitative case study, interviewed two recoupled parents to gain insights from their own personal and stepfamily experiences. This study has substantiated the existing research and highlighted other specific challenges and issues recoupled parents of children with ASD face. The researcher uses the term step/biological children throughout this article in recognition that the child/children is/are connected to one parent as a blood child and the stepparent through the biological parents' choice in re-partnering. The outcome of this research indicates the need for recoupled parents to have a forum to express their subjective experiences in raising children with ASD. The interviewees articulated the need for further understanding from professional and informal supports when working with children and parents in a stepfamily form. Keywords: Stepfamily, Autism Spectrum Disorder (ASD), Recoupled Parents

The various forms of families such as nuclear, single parents, adoptive, foster parents, same sex couples and stepfamilies, all have their own specific origin, design and family dynamics (Malcuit, 2013). These diverse families need support and direction from professionals, such as psychologists, counsellors and family therapists, at a more formal level, but also those who provide support and understanding at the informal level, for example, extended family and friends. Second marriages can struggle under the pressure of unrealistic expectations (Scarf, 2016). Having children who have ASD adds another level of complexity to the stepfamily form (Hayes & Watson, 2012). When a parent with a biological child re-partners or remarries, the understanding between the couple of what roles the stepparent plays can be contentious and this may magnify when a child with ASD is involved (Sim, Cordier, Vaz, & Falkmer, 2016). Further research in this field is paramount to gain a greater understanding of stepfamilies who have children with ASD. A stepparent's knowledge of ASD in comparison to that of the biological parent who has been dealing with the issues and behaviors of the child since birth will vary depending on the age of the child when the

stepparent becomes a part of the family (Centre of Autism Research, 2014). Even if the stepparent has knowledge of ASD, they cannot come into the family as an instant “therapist,” instead gradually establishing themselves as a stepparent, a new partner and new significant adult in the home (Graham, 2010). Children with ASD are more likely to react to change in a negative way (Centre of Autism Research, 2014; Jenson, Shafer & Holmes, 2015). Biological parents can support the stepparents’ in their role through building trust in their partner/spouse enough to relinquish the fierce protection and control they have over their family which they have become accustomed to as a single parent. This can result in the stepparent participating without judgement and input as a caring significant adult in that child’s life (Jensen, Shafer, & Holmes, 2015). This outcome positively decreases stress in stepchildren and children with ASD (Kersh, Hedvat, Hauser-Cram, & Warfield, 2006; Papernow, 2013).

There is growing research that shows stepfamilies can be successful and content family forms (Anderson & Greene, 2013); however, this depends on relevant encouragement, education and supports (Australian Institute of Family Studies, 2007), both informal and formal, to meet their unique challenges (Graham, 2010). Success also depends on a sense of cohesion (SOC) between the couples in stepcouple relationships which promotes honest communication (Cartwright, 2010), settled, secure stepchildren (Jensen, Shafer, & Holmes, 2015), realistic pre-conceived expectations, positive working parenting relationships with former partners who are the other biological parents and quality couple time together without step/biological children (Coleman, Ganong, & Fine, 2000). Stepfamilies deal with constant unpredictable change, and children with ASD struggle in situations where there is little predictability. SOC between these couples is essential in them dealing with the changes and their extensive involvement in the child’s treatment and management for ASD.

The growth of diversity in family forms needs to be addressed (Cowan, Field, Hansen, Skolnick, & Swanson, 2014). Within most western societies, family definitions have been altered and redefined many times to fit into situational changes, gain inclusive acceptance, and a sense of belonging within society (Coontz, 2004; de Vaus, 2004). The stepfamily form amongst other family designs has significantly increased in western society (Georgas, 2003). Historically and traditionally, families within western societies are defined as married parents with biological children (Cribb, 2009). Community, government, and professional supports have been designed to suit that model (Hayes, Weston, Qu, & Gray, 2010). The Australian Family Law Act 1975 has few written guidelines, policies and legislation on stepfamilies. The legislation, policies and family law in Australia excludes other family forms that do not fit in the nuclear family form (McDonald, 2011). The Australian Family Law Act 1975 defines parental responsibility as meaning “all the duties, powers, responsibilities and authority which, by law, biological parents have in relation to their children” (p. 149). Stepparents who share the duties of caring for stepchildren have very few rights or legal responsibilities unless it is an official decision by the family court (Stepfamilies Australia, 2017). This can be a complex issue for any family, but it may be exacerbated for families with a child with ASD, due to the reaction to change that a child with ASD may experience (Centre of Autism Research, 2014; Jenson, Shafer & Holmes, 2015).

The term stepfamilies will be defined by the authors as two adults who through marriage or cohabitating have come together as a family unit whom one or both have children from previous relationships that have ended for varied reasons. Stepfamilies Australia (2017) differentiated stepfamilies from nuclear families by adding ex-partners/wives/husbands and their new partners/wives/husbands to the definition of stepfamilies. The differences between the nuclear and stepfamily form still lacks in clarity and agreed upon definitions (Hartley & McDonald, 1994). Other identified key differences between the step and nuclear family are the biological parents have a longer relationship with their biological children than with their new partner/stepparent (Howdon, 2007).

The research outcomes from previous studies suggest it is far more difficult raising a child with ASD than children with another disability, or no disability at all (Brobst, Clopton, & Hendrick, 2009). Current research showed high levels of stress in both parents with children with ASD (Harper, Dysches, Harper, Roper, & South, 2013). Previous evidence-based reasons for this are: (a) limits on family connection and social opportunities with all family members; (b) family disharmony; (c) poor marriage quality; (d) poor emotional health; (e) financial struggles; (f) expression of affection in the couple's relationship; (g) lack of family communication; and (h) family adaptability (Hartley et al., 2010). These issues vary in intensity due to the varied diagnoses and symptoms of children with ASD, the age and development of children, the age of parents, the characteristics of the parents themselves and the state of their relationship (Gray, 2008).

The challenges couples face are psychological, emotional, and social stresses (Zablotsky, Bradshaw, & Stuart, 2013), social isolation and the lack of empathy from the community (Higgins, Baily & Pearce, 2005). The child's impaired social and communication skills, inability to adjust to change, and a lack of social networks for the whole family creates much strain on the couple and the rest of the family (Harper et al., 2013). ASD in children can impair their ability to emotionally react and connect to their parents. The styles of interaction towards their parents may change each time there is contact between them due to the varying factors in the child's environment and own thought processes (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011).

Children with ASD battle interaction, communication, restricted repetitive interests and behaviours, obsessions, meltdowns, and sensory sensitivities (Schaaf, et, al, 2011). Another cause of parental stress is the child with ASD's antisocial and disruptive behaviour, which can include self-injury, tantrums, and obsessive/compulsive behaviours that make it difficult for a family to live a normal family life (Harper et al., 2013). This may be very distressing, confusing and confronting for new stepparents and stepsiblings to adjust to and be understanding towards these behaviours whilst adjusting to the changes that come with establishing and finding a sense of belonging in their stepfamily, which can also be stress producing for all family members (Deal & Holmes, 2016; Harper et al., 2013).

Stepfamilies and ASD

Children have many issues to which they need to adjust when becoming a stepfamily; there are multiple transitions for the children moving from a nuclear family, to a single parent family, then to stepfamilies (Papernow, 2013; Zeleznikow & Zeleznikow, 2015). This creates many challenging issues, such as moving communities, homes and adjusting to new significant adults connected to their separated parents and living under the same roof (Scarf, M, 2013), with new expectations and rules in the re-established family homes (Australian Institute of Family Studies, 2007; Dunn, 2002; The relationship between the biological parent and child who lives separately from the child significantly changes (Wallerstein, Lewis, & Packer-Rosenthal, 2013). Other challenges for the family involve a healthy development in relationships between the stepparent and stepchild, the siblings, and a new extended family from the new partner (Cartwright, 2010). Former partners can have animosity towards each other, which can create conflicted loyalties for the step/biological children and can create hostility towards the stepparent (Papernow, 2018).

A search of the literature for studies on stepfamilies raising children with ASD reveals few articles. There are blogs and articles written by service providers who work with stepfamilies that are not built on empirical qualitative research but through personal experience and psychologists working with stepfamilies in this situation. One article from "Smart Stepfamilies' organisation that works towards empowering stepfamilies towards success and

training service providers to understand and work with stepfamilies in a relevant way gave some advice for couples in this situation (Deal & Holmes, 2016). The advice for step couples' is to discuss the children's development and how it is different from that of their neuro-typical children. The new partner needs to understand the past struggles that have been overcome previous to their involvement. It is important to share all the progress of the biological parent and child and the stages involved in this process. The new partner needs to also be made aware of the finances involved in raising a child with ASD, how to discipline the child, and a general approach in managing the child on a daily basis (Centre of Autism Research, 2014) Other essential discussions centre on managing the stepchild's meltdowns and the importance of the biological parent and stepparent establishing an agreement regarding the general approach to working with and disciplining the child with ASD. If the re-coupled parents have a lack of consistency, this can cause confusion and anxiety for the child (Centre of Autism Research, 2014). The biological parent needs to take time to be an educator to the stepparent (Deal & Holmes, 2016; McHenry, 2014), giving them resources to develop their understanding of ASD and the impact ASD has on their family. As mentioned previously the professional sector are beginning to produce articles on their website in response to stepfamilies requesting support in raising their children with ASD. In light of this dearth of research around the complexities that stepfamilies face raising a child with ASD, this study aims to investigate the challenges recoupled parents face. The purpose of this research is to bring attention to the need for empirical research on the challenges that recoupled parents encounter raising step/biological children with ASD. The aim is to explore with recoupled parents through semi-structured interviews their experiences within their stepfamily context of raising a child with ASD.

The first author, Sonia's, interest in this topic was conceived from her personal experience as a biological mother and stepmother of 12 years who has the joy and the challenges of having both a biological child and a stepchild with ASD. As a remarried parent, she came across challenges in meeting the needs of her step and biological children on the spectrum. One example that caused ambiguity in her role as a stepmother was the difference and definitions of her legal rights and responsibilities as a stepparent compared to a biological parent which are very different. Sonia's personal sense of parental obligation and desire to support both children with ASD were the same. The Family Law Act (Stepfamilies Australia, 2017), service providers, educators and other community supports did not see it that way. As a primary carer stepparent, Sonia was unable to offer the much-needed support for her stepson that the freedoms of being a biological parent gave her in supporting her biological son with ASD. There were many other challenges Sonia experienced, that she discovered through her professional field that other stepfamilies were also struggling with and were searching with little avail to find knowledge and answers. Sonia has been working with families for over thirty years, working in primary schools counselling families. Some of these were stepfamilies struggling with the challenges related to their stepfamily context that arose supporting their child with ASD. Sonia's goal is to create empirical evidenced based discussion with recoupled parents to provide new knowledge, a greater understanding and begin the development of a resource network base on this topic to stepfamilies, family service providers and educators. The second author, Penny, is a lecturer in special and inclusive education. Prior to this, she was a high school English teacher and coordinated the programs in schools for students with diverse needs. Through this, she has taught many students on the autism spectrum and she often worked with parents, married and separated, to support the child.

Against this backdrop the goal of this paper was to answer the following research question:

What are the challenges recoupled parents face raising a child on the autism spectrum?

Methodology

The qualitative methodology utilised allows for an insider's point of view, meaning it opens the opportunity to collect data via the participants' opinions and experiences within the researched phenomenon and their contextual environment where their experience is played out and interpreted (Baxter & Jack, 2008). It is against this backdrop that the goal of this paper evolved to answer the research question; what are the challenges recoupled parents encounter raising stepchildren with ASD? The case study approach works alongside the systematic approach allowing the researcher to focus on the understanding that these stepfamilies are a unique, interactive, and reactive unit within other wider community systems that have their own set of values, beliefs, and rules (Cridland, Jones, Caputi, & Magee, 2014). The aim is to gain their understanding of their perceptions, interpretations of their family design, relational connections, relevant support networks, and the impact on all the individuals within their stepfamily. A case study design puts the emphasis on why individuals do what they do and how their behaviour changes as they respond to the context of their environment (Cridland et al., 2014). The use of two case studies also offered a degree of external credibility as input could be compared and explanations built (Yin, 2014; Rowley, 2002). The case study utilized semi-structured interviews, focusing on two stepfamilies, drawn from a similar geographical area. The study considered specific impacting dynamics with regard to the structuring of interviews, participant recruitment, obtaining consent, and considering the setting of interviews (Cridland et al., 2014).

The semi-structured interviews provided in-depth data collection from the interviewees, while allowing them to include details they considered pertinent to the research question (Cridland et al., 2014; Dew, Balanndin, & Llewellyn, 2008; King et al., 2006). Semi-structured interviews allowed for some flexibility, and a detailed conversation, while still bearing the research question in mind (Carrington & Graham, 2001). Furthermore, the researcher was keenly aware of the sensitivity of the nature of the data collected, as the participants were experiencing challenges within their relationships with partners and stepchildren and it was essential that the researcher be sensitive, as the importance of the human experience could not be overlooked (Baxter & Jack, 2008). Case studies have the additional benefit of allowing the researcher to explore both general and specific phenomena within context (Yin, 2014). Data collection and analysis were planned loosely around a set of possible questions. Examples of these are:

Has, and if so how has, your child with ASD strengthened your relationship?
What issues did you face as a re-partnered couple negotiating how to support the child with ASD in a stepfamily form?
Outside of the family what supports would be valuable to your relationship and your children with ASD?"

Approval was granted for the research through the ethical review board. All interviews were recorded and transcribed; the data were then read multiple times to establish themes, links and connections. This was most apparent through a perusal of word frequency and similar ideas (Creswell, 2009). For example, some of the words and concepts that were a regular part of the interviews of both couples, were stress, exhaustion, conflict, need for support, and community professional understanding. Similar and contrasting viewpoints were identified through careful scrutiny of the data. In the interviews the participants discussed what they believe is essential for others to understand about their family forms and the issues they encountered Each couple was interviewed together, to gain a clear perception on their cohesion and connectedness in

their relationship and the impact that has in offering a healthy, supportive environment for their stepfamily and child with ASD.

Analysis

We analysed the interview responses separately by examining and interpreting the taped interview. Sonia did member checks for the process of quality control. We provided the participants with a copy of the transcript of the interview via an organised second visit by Sonia, and after them reading it through their approval was given (Angen, 2000). No changes were required. Our findings gave an understanding of each couple's own challenges, sense of rewards, and their overall experiences of their specific family life. The accounts of each interview focused in particular on their emotional and cognitive responses to the situations in which they found themselves, their way of dealing with the challenges they faced as a couple and the extent to which outside systems within their community have been supportive or helpful to them.

The interviewees came from a metropolitan suburb in Victoria. The families' names are pseudonymous to protect their identities: Couple A: John and Ruth have a nine-month old biological daughter. They have been together for four years. John has no children from a previous relationship and works full time in IT. Ruth has two biological daughters from a previous relationship and is a full-time mother at home to Maddi aged nine and Amber aged seven, both of whom were officially diagnosed with ASD at the age of four. Couple A do not have former partners with whom they co-parent. Ruth's former partner died and there was not a previous partner mentioned by John. John's parents are not supportive of their union due to the children having ASD and their son dealing with this as his first experience of parenting. Ruth's parents attempt to support both John and Ruth but due to their minimal understanding of ASD, they are misunderstanding the children's behaviour. As a couple, they feel very isolated and under-supported as a stepfamily who have children with ASD.

Couple B: Julia and Charles have been married for 10 years and have a biological daughter, Lisa, who is five years old. Julia is a full-time mother at home. Charles also is a full-time husband and father at home. They have chosen this lifestyle to offer each other support raising the children with ASD as they lack understanding supports outside their relationship. This does cause financial stress at times, particularly when covering the costs for supports for the children with ASD. Julia has two children from two previous relationships, Jeff, who is eleven and Peter who is seven. Both Jeff and Peter were diagnosed with ASD. Charles has a son, Kye, from a previous relationship, who is now eleven. Both Kye and Lisa are developing at age appropriate levels. Couple B has former partners who are involved at different levels in co-parenting roles. Julia's mother has Jeff living with her full-time. Julia has weekend and holiday access with him. The grandmother makes most of the decisions for Jeff though Julia participates in the decision making and management process related to Jeff's ASD.

Results

What can be ascertained from this data is that stepfamilies' experiences and interpretations of raising a child with ASD vary depending on how all of the family members have adjusted and responded to the change within the stepfamily (Deal & Holmes, 2016). In addition, we ascertained how extended family and other community/professional outsiders have influenced and supported the family. We were able to put the findings from the data analysis into four important issues. We did this through thematic coding which entails going beyond descriptive understandings to viewing all the text in a more analytical way by

identifying relevant themes through their words and how they present their response (Gibbs, 2007, 2010).

Transitioning into a Stepfamily

The initial transition into a stepfamily was difficult for Couple B. Julia stated, “We had three separations within a month of becoming a stepfamily due to conflict over how we parent the stepchildren with ASD and our children without ASD.” Charles stated, “I was frustrated by one set of rules for my stepchildren with ASD and another set for my biological son, it seemed like favouritism and was unfair.” The extended family did not support Julia’s relationship with Charles, which created further anxiety and animosity between the couple and their extended families, which reflected on to the children. Charles said, “I wanted to support Julia in raising the children, but in her family’s eyes I was treated like the bad guy, it was emotionally draining.” With this complex issue in play between the couple, it negatively influenced their ability to communicate in healthy ways to support the children with ASD.

The nature of a stepfamily is that there may be court processes that the nuclear family does not typically experience. Julia and Charles are one of these families that are continuously negotiating consistent access routines with the former partners and agreements on the treatments of each child with ASD and consistent support of everyday issues with behaviour related to ASD. They reported, “Our children with ASD are distressed by the arguing and disrespectful behaviour from our parents and previous partners.” Kye, being neurotypical and a stepbrother to his siblings with ASD, has had to learn a lot about why they behave in certain ways, which at times has been difficult and frustrating for him. Julia says, “Kye has had lots of trouble at school socially and learning as he is focused on protecting his stepbrother with ASD, he has been in fights with other kids over this, he gets embarrassed and distressed.” Julia and Charles wished more support was given to Kye around being a stepsibling to a boy with ASD.

Couple A has found the experience of their children adjusting into stepfamily life different to that of Couple B. Ruth’s former partner died, and in her view, this does alter the stepfamily dynamics. Ruth says, “There are only two of us under the same roof making decisions about our girls; I don’t need to worry about a third or fourth party which is a relief for me.” It is significant that John and Ruth can make all the decisions together without having to consult any other adults. They are not restricted by court orders, or parenting plans. John said, “I developed a healthy connection with the girls by joining in with family activities Ruth did with them before I came along.” Over an extended period, his participation created a relationship and a bond of friendship between them. Within a year, the girls were responding to him more positively. “I was able to participate in disciplinary responsibilities with my stepdaughters in which they responded like any child would to a biological parent.” When it comes to legal rights of a stepparent, John says, “I am aware and frustrated by the restrictions and limitations the title stepparent puts on me.” He explains how embittered he feels by how he is treated differently to the biological parent by the wider community. The couple state working together on the complex issues the girls’ face “are exhausting and taxing on our relationship.” Ruth says, “We are so focused on the two children in a more therapeutical way addressing ASD related problems, so we feel time poor and emotionally drained to work on other areas of our relationship.” They both explain how this is a concern for them, as they believe having a healthy couple relationship is paramount to them being more effective and energised in meeting the needs of their children with ASD.

Strengths and Challenges

Both couples needed more time to consider and articulate what strengths developed in their relationship from raising children with ASD in comparison to the discussion regarding the challenges. When asked the question Julia was quick to respond by saying, “There were no strengths and we were ready to separate within a few months of moving in together.” As both Julia and Charles reflected on the question further, they could see some strengths had come out of their perseverance of the challenges they were facing as a stepfamily raising children with ASD. Charles said, “We chose to both be full time home carers to allow more time to nurture our relationship and deal with the issues we were struggling with around the children with ASD.” Julia said, “We relied and liked depending on each other for support, when we did have a break from our children we desired to be together socially instead of others.” They went on to explain that as a couple they understood one another better in their family context than anyone else and both found comfort in that. Both couples stated that they felt protective of their children with ASD and desired to work together to protect the children. Ruth said, “I stopped at nothing getting in the way of getting help for my girls with ASD, I never accepted no for an answer and John whilst he did not attend all the meetings he was in the background researching what supports were available and encouraging me in my assertiveness.” Both couples shared that they depended on each other heavily for support in their parental roles and at a social and friendship level. Both mothers, Julia and Ruth, showed great perseverance, determination, and energy in advocating for the needs of their children with ASD. This was evident in connecting with support groups and accessing the professional and community services that were available to them. Ruth said, “I never gave up trying to get support; I let them know how desperate my need was.” Julia said, “I gained support from Facebook groups of mothers who had children with ASD. They shared their stories and we discussed resources and supports we found beneficial for our children with ASD and for ourselves when we were struggling to cope.”

Couple B felt that having children with ASD in their family weakened their couple relationship due to having different levels of understanding of ASD and different views on child rearing from previous relationships. Charles says, “We argue about different ways our children with ASD should be treated.” Charles, in reference to his stepsons, explained that, “It becomes complicated when my biological son is treated differently because he does not have ASD and it can seem that there are different rules for the step ASD children than my biological son.” Julia was open in saying, “I was more protective of my biological children with ASD as I only completely trusted my own ability to meet their needs and lacked faith in Charles understanding to do so.”

Couple A and B had to come to terms with the issues that came from becoming a stepfamily and dealing with pressures for which they were unprepared when dealing with children with ASD at the same time. A distressing challenge Couple A dealt with when establishing their stepfamily was the lack of acceptance from their extended families including John’s mother whom showed concern regarding him being an “instant” parent to children who have ASD. John said, “My mother told me outright not to commit to being a partner and stepparent as they have too much problematic baggage.” This created disconnection between him and his mother. Couple B struggled with the children favouring the biological parent, Charles said, “My stepchildren would only come to me when Julie was not at home, I felt less of a parent towards my stepchildren when Julie was present to them.” They also struggled with dealing with ex-partners who were not committed to working together in supporting the children’s needs with ASD and in general. Julia said, “My children’s biological fathers did not provide routine or consistency when it came to access visits or day to day living, we would always fight about this as our children with ASD desperately needed more consistency in their lives.” These challenges have created complex issues for them as a couple and as parents. These

may be issues that many re-partnered couples face, but they can be more intense due to the complexities involved when step parenting and parenting a child with ASD (Harper et al., 2013).

Both couples were dealing with anxiety, exhaustion, and a lack of connectedness and intimacy with one another. Ruth stated, "I got to the point where I contacted a psychologist and said if I don't get some help with my girls with ASD I am ready to kill myself." Ruth is now seeing a psychologist that gives her strategies to manage as a parent raising children with ASD. John mentioned, "I am also on anti-anxiety medication but find it hard to speak to strangers, Ruth directs me to helpful articles to read." Julia and Ruth both said, "I am too tired to have sex." Ruth said, "I would like John to offer a massage at the end of the day and not expect anything from me as I have little to give." However, all four interviewees said that they felt a sense of connectedness as parents coming from their common goal to care for their children with ASD. Couple B have neurotypical children and they deeply care for their children who according to the psychologists are meeting all developmental expectations at appropriate ages and stages. The challenge for them is balancing and meeting the needs of their two children with ASD, which takes up much of their time and energy, and still have time and energy for the other children. Both couples found it a challenge juggling the needs of all members in the family and taking care of the relationship and themselves individually.

Support Networks

Both couples had mixed emotions regarding support networks; they recognised the need to have time and space to nurture their relationship. Trusting family sources and professional respite to care for the children was very difficult for both couples. They are not confident of others ability to appropriately deal with their children's needs related to ASD. Charles and Julia have not had regular respite; Julia says, "It is difficult to find consistent days when access visits with the children's non-resident parents are not on regular consistent days." Couple A does have access to professional respite one night a week. Since they have re-coupled their social networks, and family relationships have altered to the point where neither of them as a couple have others they equally feel they can connect with during this time; this is difficult, as they desire this very much. Ruth says, "On our night out finances are an issue as much of our money goes on the needs for the girls." Both couples find that joining social groups can cause social anxiety in the children. Charles states, "It's safer for us to go out as a family as we will handle the ASD behaviour properly, and we cannot guarantee other carers will do that." The parents avoid these situations, which can cause further social isolation for the whole stepfamily, which is distressing for them when they need to make new social connections due to the loss of old ones from their previous nuclear family.

Professional Services and Community Support

Both couples agreed on the need for changes in professional and community services that would create more relevant and substantial support for parents and families in their situations. They felt concerned by the lack of knowledge professionals and community service workers have on ASD. Charles explains, "I want my children with ASD to join sports clubs but know that the service providers would have no idea how to care for my stepsons in this environment." They believe many individuals within the community have little understanding of people with ASD and stepfamily forms. Julia said, "Charles and I want to see more discussions had at a bureaucratic level on the financial pressures for stepfamilies and for the extra costs of supporting children with ASD." Couple A believes that the lack of funding given to the professional and community services results in many families having to wait too long or

end up with no help at all. Ruth said, “I was told by service providers there could be over a year of waiting before my girls can get treatment like speech pathology.” Couple B suggested that Medicare should fund specialists that the children need for their ongoing social, emotional and cognitive development. Both Ruth and Julia are full-time mothers and caregivers, as the children with ASD need intensive daily support. Julia says, “The funding availability is too restrictive so many children miss out because they don’t fit into the criteria. The other set of biological parents do not help financially and are not cooperative with following through with the professional recommendations of support for the children with ASD.” Both couples would like to see more education, patience and compassion within the community overall. Ruth and Julia shared stories from their own experiences where people would say inappropriate and offensive remarks to them in front of the children. Ruth gave an example where a woman said to her, “Your child needs a good smack,” when the child had a meltdown in a shopping centre. Both couples want more access to relevant supports that allow them to care for their stepfamily relationships and in turn support their children more effectively. Both couples want to see all teachers in schools better resourced and informed on how to best support and educate children with ASD. Ruth believes, “The teachers are more focused on believing I am an overprotective mum with poorly behaved children than understanding my child’s responses to their environment and learning they are ASD related.” Educators need to learn about the added complexities involved for stepfamilies with a child with ASD. Julia states, “My children with ASD function differently at school depending on if they have had unexpected access visits with their biological fathers’ who does not take their ASD needs into account on the visit.” Julie goes on to explain how her sons are more likely to have meltdowns and not cope with the pressures of school when dealing with unexpected changes within their stepfamily form.

Discussion

This study contributes to the public debates and literature of families functioning with ASD by researching the need to be more specific in regard to stepfamilies (Centre of Autism Research, 2014). Adjusting, understanding and adapting to raising a child through remarriage is very different to having children in a nuclear family (Australian Institute of Family Studies, AIFS, 2007; Thomas, Hanson, McLean, & Thomson, 1994). When step/biological children become a part of a stepfamily, the previous relationships they had inside their nuclear family changes dramatically, at the same time they are dealing with establishing new family relationships (Thompson, 2013).

For children with ASD these significant changes happening at the same time can create overwhelming distress, anxiety, and behavioural issues within the home as that is where the children depend on consistency, routine and relief from difficult social interactions (Boyd, McDonough, & Bodfish, 2013; Higgins, Baily, & Pearce, 2005). This study is also in response to respecting diversity and rejecting a one-size-fits-all approach when addressing issues that affect entire families (The Step Family Foundation, 2016). Little empirical research could be found that assessed the unique issues that come with a stepfamily raising children with ASD (Vigo, 2012). This dialogue explores the experiences of these two couples supporting and advocating for their children with ASD. Parenting a child with ASD can create cohesion within the parents’ relationship (Pisula & Kossakowska, 2010). Strengths developed within stepfamilies were mentioned in some studies (Coleman, Ganong, & Fine, 2000), but most focused on a deficit model (Australian Institute of Family Studies, 2007; Baker-Ericzen, Brookman-Frazer, & Stahmer, 2005). The interviewees struggled to see the establishment of strengths at first as they were consumed by their own individual, relational and family challenges relating to raising a child with ASD. Couple B organized time together as a couple to grow and protect their intimacy and to discuss the day-to-day parenting of their children.

Both couples rely on each other for support and understanding of their unique family circumstances. Couple A found establishing a trusting supportive relationship depended on Ruth seeing John developing a positive relationship with her children.

The complexity of establishing and maintaining healthy step couple and stepfamily relationships can be both emotionally and mentally exhausting. Some of the issues that can arise are feelings of competition, limited autonomy, intrusion of privacy, anger and sadness (Jensen, Shafer, & Holmes, 2015). Both couples endeavoured to meet each other's emotional and mental health needs, which at times were a struggle for all of them. This led to a poor sense of cohesion in the relationships (SOC). Both couples struggled individually with the emotional, physical, and psychological stress that came from the intensity of raising their children with ASD. This is not unique to recoupled parents, yet within a stepfamily form with children who have ASD, establishing a healthy SOC between the couple can be complex (Pisula & Kossakowska, 2010). Some of the issues that got in the way for both couples and created conflict and distance between them were the extended families' judgmental opinions on re-partnering with a parent of a child with ASD, and intolerance towards behavioural challenges and the new extended family's lack of knowledge on ASD (Centre of Autism Research, 2014; Deal & Holmes, 2016). Couple B stated that they were overwhelmed, angry and felt powerless with the disunity and animosity between the separated biological parents and a few of the former and extended family members. The antagonism between these family members made it impossible to create everyday consistency, routine for the children, and agreement on treatment options. The contention this caused between the couple at times resulted in discord within their relationship, leaving them feeling very perplexed in meeting the needs of their children with ASD.

Couple B spent the earlier years in their relationship in disagreement on how to raise a child with ASD and general parenting styles. Charles as a stepparent felt like a "ghost in his home"; he felt ignored by his stepchildren and confused by what his role was as a stepfather, whilst at the same time trying to function fulltime as a biological father in the same home. At times this created division and distance between them. Julia and Ruth, as the biological parents, have experienced the frustration and exhaustion of carrying the bulk of the childcare, as that is the recommendation from professional services working with stepfamilies, yet, contrastingly, services supporting children with ASD recommend that couples work closely together due to the need of each parent needing positive support and guidance from one another. Both lots of professional advice for these couples are direct contradictions that create confusion and distress for both couples.

Both couples had very different experiences and views on parental roles and responsibilities within the stepfamily and the impact it has on their children with ASD. Ruth was relieved to have a partner to offer her support after the loneliness she felt as a single mother. The introduction of a stepparent was a welcome distraction to her children who were sad, as they did not have a relationship with their biological father. As recommended by stepfamily services Ruth took on the bulk of the disciplining and establishing the boundaries of her biological children (Cartwright, 2010; Graham, 2010). At times because the parenting role between them was not equal in decision-making and in the support of managing the behaviour of the child with ASD, Ruth felt the isolation revisiting at times and John was overwhelmed with the expectations Ruth had of him, particularly with his lack of knowledge of ASD. Couple B, both being stepparents, had to define and negotiate the step relationships with each other's children. They found this complicated as the maternal grandmother had a lot of influence on her grandchild, Jeff, and this affected the ability for Couple B to work together to establishing consistency in each home for Jeff. The literature clarifies the need for children with ASD to have consistent routines with daily predictable patterns that minimises confusion, distress and anxiety (Autism Spectrum Australia, 2016).

Charles and Julia and the other biological parents in the children's lives were not in agreement and do not work together in creating a consistent productive environment for the management of the children with ASD. Current data shows that the family transition into a stepfamily for a child can have negative outcomes on their academic performance, emotional adjustment and behavioural difficulties if the recoupled parents cannot work together parenting in their new roles as both biological and stepparents (Pryor, 2014). Conflict between Couple B occurred due to the disagreements they had over parenting the children. Julia took it on herself to decide on the style of parenting when they could not resolve the child related issue together. This was a frustration for Charles, who felt he was not respected in his parenting role, mainly by the children, but also sometimes by Julia. Julia's response to this was, "I am in the habit of protecting my children with ASD from others that lack the knowledge to make the right decisions for them and that includes how I respond to Charles' parenting suggestions when I disagree."

These couples have not been together for as long as each biological parent has been with their children from a previous relationship. In a nuclear family, the couple's relationship is more advanced than the child-parent relationship when they decide on having children (Zelevnikow & Zelevnikow, 2015). Couple B separated three times in the beginning of establishing the stepfamily, as they could not cope with the stresses and aggravations that came with parenting together (Hock, Timm, & Ramisch, 2011) and dealing with the extraordinary pressure in caring for their children with ASD.

Support networks that come from family, community and clinicians are essential for families who have children with ASD (Kennedy & Kennedy, 1993). Stepfamilies of children with ASD desire for these networks to understand and support them in their establishment and ongoing development of their family as they have a different form and function to that of the nuclear family that needs a greater understanding, which will result in appropriate support by the wider community and professionals. The interviewees were frustrated and distressed by the difficulty in finding relevant resources and supports from the professional and community networks, raising the concern that fighting for access to support services is causing high levels of aggravation and stress for couples with children with ASD (Schieve et al., 2007).

Current data (Ganong & Coleman, 2017) shows grandparents are more likely to be accepting and offer constructive support than other family members such as aunts and uncles due to the grandparents perceiving themselves as a biological extension of their grandchildren. Step grandparents can find it more challenging to connect and establish bonds of affection with their step grandchildren (Ganong & Coleman, 2017). The stepchildren may not readily connect with them, particularly if they already have secure close relationships with their biological grandparents. Step grandparents do not have the historical connection with their stepchildren that the biological grandparents have. It takes time, communication, and commitment to identify their role in the new family design (Gold, 2017). The step grandparent's first experience of ASD may begin from their children re-partnering. This puts them in a complex catch up position in comparison to the biological grandparents who may have been involved from the child's diagnosis and participated in the child's treatment and management plan. The new stepfamily form needs to define and provide boundaries around extended family members' participation in supporting the children with ASD. Both couples interviewed, whilst they still have contact with their parents, found that the relationships between the children's step and biological grandparents were difficult at times as there were many differences in opinions over the couple's remarriage and the stepparents taking on children with a disability (Kennedy & Kennedy, 1993). Julie's relationship with her new mother-in-law became a supportive relationship, as the mother-in-law was determined to learn about ASD and understand how ASD affects her step grandchildren. The feedback from professional services that focus on supporting families who have children with ASD stresses the importance of having a helpful

and understanding extended family, along with positive social networks that give parents a break from their role. Parents can feel isolated due to the aggressive behaviors their children display in public because of ASD (Hodgetts, Nicholas, & Zwaigenbaum, 2013). Other research claims that social supports such as family, friends and other neighborhood supports improve the wellbeing of the parents both physically and mentally, which in turn positively influences the development of their children (Zablotsky, Bradshaw, & Stuart, 2013).

Placing stepfamilies in the mix, the situation becomes more complex. Not only do both the couples interviewed not venture out far without their children, due to a lack of suitable babysitters that know how to support children with ASD, their different experiences with their new extended families have also not always been supportive of their stepfamily union. This created conflict and cut off a significant support network. Both the extended families know little about ASD and struggle to cope with the difficult behaviours that are characteristic of ASD. Coming together as a stepfamily creates many changes that can separate the family from previous support networks. Former extended family and friends that no longer offer support due to the new stepfamily (which Couple B has experienced), changing schools, neighbourhoods, and employment can all cut off important support systems that existed prior to the formation of the stepfamily (Cartwright, 2010).

Couple A have one night a week of respite care. Whilst this couple have mixed feelings about the respite they receive, the data has shown that respite care reduces stress for parents raising children with ASD (Harper et al., 2013). Other qualitative research using interviews had parents discussing how they were turned away from home-based services because the child with ASD was not responding to the strategies, and had disruptive behaviours (Hodgetts et al., 2013). Couple B, due to realising they would not qualify for respite, decided that Charles would not seek employment. They have decided to keep it that way as Julia feels she will not manage as effectively without her partner's full-time support.

John and Ruth shared a common goal that they are both committed to provide the relevant care and support that will offer the best opportunities for their girls; Ruth was more driven and aggressive in achieving this goal, which at times caused disharmony within their relationship. They both recognise the importance of trying to be compassionate, patient, and understanding regarding the needs of the girls. They both comprehend the importance of applying this to their relationship, though they have found it difficult due to differing views on their relational needs, their own parent's attitudes towards their relationship, their opinions on ASD and their contrasted view on the benefit of support networks for their recoupled relationship.

Other studies have shown that couples who have had therapeutic support for stepfamilies found that the therapy was not helpful, as the therapist lacked knowledge and expertise regarding stepfamilies (Giles-Sims & Crosbie-Burnett, 1989; Gonzales, 2009). Gonzales discusses how very few resources and an absence of cultural rules and guidelines leave stepfamilies with little idea of what to expect and how to deal with the challenges they face. The couples interviewed felt that most services lacked time, money and understanding in supporting their children and the parents.

Strengths and Weaknesses

The results of this study suggest that more strategies for stepparents and supports would increase couple cohesion and connectedness when dealing with the stresses of the new family form and the additional stress of parenting children with ASD. Based on these results, it is recommended that the focus be on strengths, instead of viewing this family situation from a deficit perspective. There are also implications for those professionals working with stepfamilies of children with ASD. The professional and community services need more

funding and more education on how to best support stepfamilies raising children with ASD. In addition, teachers need to be better resourced and informed on how to best support and educate children with ASD and the added complexities involved for stepfamilies with children with ASD. Further research is recommended in the form of a longitudinal study that focuses on family services, comparing controlled groups that have the choice between a program specialising in support for stepfamily couples raising children with ASD and general family services supporting re-coupled parents with children with ASD. This research should look at the effectiveness of more relevant and direct information, as well as support given to stepfamily forms over a period of time.

Conclusion

This study explored the issues re-coupled parents grapple with when raising a child with ASD in a stepfamily form. Two couples who have re-partnered and are living in a stepfamily form were interviewed. Both couples were open and passionate about the stresses that came about for all family members adjusting, understanding and supporting a child with ASD. The couples were able to identify some strengths that have formed from working and supporting one another in caring for the child with ASD. The discussions revolved around how their interpretation of their experiences have influenced how they respond to their situation and environment. Each couple discussed in detail the positive and negative issues that have influenced them as a couple and individuals in how they work to support their step/biological child with ASD. The outcome of this is that support agencies for the families and schools need more information and resources on the specific needs of stepfamilies with children with ASD.

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Author Note

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