The SCCS-R Model: Parenting Challenges in Families of Children with Autism

Hazlina Abdullah[1*], Myra Aidrin Mohd Ali[2], Nursyuhada' Ab Wahab[1], Dini Farhana Baharudin[3], Zarina Ashikin Zakaria[1], Rahimah Saimin[1], Norhana Abdullah[1]

[1]Faculty of Major Language Studies, Universiti Sains Islam Malaysia, Bandar Baru Nilai, 71800 Nilai, Negeri Sembilan, Malaysia.

[2]Kolej Genius Insan, Universiti Sains Islam Malaysia, Bandar Baru Nilai, 71800 Nilai, Negeri Sembilan, Malaysia.

[3]Faculty of Leadership and Management, Universiti Sains Islam Malaysia, Bandar Baru Nilai, 71800 Nilai, Negeri Sembilan, Malaysia.

hazlina@usim.edu.my
myraadirin@usim.edu.my
syuhada@usim.edu.my
dini@usim.edu.my
zarina@usim.edu.my
rahimahsaimin@usim.edu.my
hana66@usim.edu.my
*Corresponding Author
hazlina@usim.edu.my

Abstract

Autism is a severe childhood developmental disorder that comes with its own set of challenges and consequences for families. Once their child is diagnosed with autism, mothers and fathers will need to redefine their parenting journey as autism can have an overwhelming impact on family life especially with regard to the responsibilities shouldered by parents. In this study, the authors explore the experiences of parents who have children with autism. Using the qualitative approach which suits the aim, three mothers and three fathers of autistic children were interviewed in semi-structured interview sessions. The in-depth face-to-face interviews have garnered rich stories about their hurdles, coping strategies and expectations. Through the thematic analysis method, the authors discover notable findings regarding the problems and challenges faced by parents, which lead to the formation of the SCCS-R model. The model illustrates five main emerging themes from the data gathered: self, child, community, system and religion. It is established that the experiences and challenges could be partitioned according to different layers starting from the parents' Self, the Child, and going further to the Society and the System at large, enfolded by Religion. Our findings can enlighten parents especially those with newly detected autistic child, and relevant parties involved in developing and providing programmes for parents.

Keywords: ASD, autism, parents, challenges, model

Introduction

Globally, about 52 million autism spectrum disorder (ASD) cases are reported (Baxter et al., 2015) and 1 in 160 children worldwidehas ASD (WHO, 2021).In Malaysia, there are approximately 8,000 to 9,000 children born every year who may be autistic (Dina Murad, 2019).Owing to the rising rates of children being diagnosed with ASD, there is a pressing need to look into the condition of parents as they are the backbone of the family.

Like many other learning disabilities, ASD also comes with its own set of challenges and consequences for families, especially parents. When a child is officially diagnosed to have autism, parents will have to redefine and reposition their parenting voyage. This is because raising a child with ASD is definitelynot a straightforward task.Parenting a child with ASD often causes tension and pressure in families. While there is an increasing number of research and documentation concerning thediverse feature of ASD, a consistent construction of understanding towards family's pains and distresses seems to be needing further research especially in the Malaysian setting.

Thus, this study is seen as very timely and highly pertinent because many studies have shown high level of stress faced by parents of children with autism (Baker-Ericz, Brookman-Frazee & Stahmer, 2016; Golfenshtein, Srulovici & Deatrick, 2016;Rutgers & Ijzendoorn, 2007).

Past studies

Being gifted with children is a wonderful experience for most parents. Nevertheless, many studies reveal that parents of children with ASD are confronted with daunting challenges and an increased risk of psychological distress (Yaacob, Yaacob, Muhamad, Zulkifli, 2021).

Parenting a child is tough but parenting a child with ASD is even more challenging. As ASD is a chronic disorder, it requires parents to spend a substantial amount of time for the child. Previous studies have shown that parents found it challenging to deal with the behavioural deficits, restricted social interaction and communication, and strict ritualistic behaviours of children with ASD (DePape & Lindsay, 2015; Ilias, Liaw, Cornish, Park, Golden, 2017). It is possible that individuals with ASD also have a secondary diagnosis, such as Attention Deficit Hyperactive Disorder or intellectual disability that can make parenting even difficult (Weitlauf, Vehorn, Taylor, Warren, 2014). Findings from previous studies have also revealed that the presence of children with ASD in the family influences different aspects of parental and family life, such as marital relationships, sibling relationships, family socialisation patterns, and daily routine (Hayes & Watson, 2013).

Furthermore, a review of the literature shows that parents with ASD children experienced higher stress levels (Ilias, Liaw, Cornish, Park, Golden, 2017; Hall, Fruh, Zlomke, Swingle, 2017) and anxiety and depression (Bitsika & Sharpley, 2004) , felt isolated (Divan, Vajaratkar, Desai, Strik-Lievers & Patel, 2012; Nealy, O'Hare, Powers & Swick, 2012), and had a decreased quality of life (Vasilopoulou& Nisbet, 2016) compared with parents of a normal child (Meirsschaut, Roeyers & Warreyn, 2010) or one with other disabilities, such as Down Syndrome (Wang, Michaels & Day, 2011). All these issues were compounded by the child's maladaptive behaviours, regular outbursts, hyperactivity,

aggression, repetitive behaviours, and lack of social interaction (Hayes & Watson, 2013). Due to the public lack of awareness of ASD children distinctive characteristics and behaviour, parents of ASD children were more susceptible to stigmatisation, leading to poor wellbeing (Broady, Stoyles & Morse, 2017).

A study conducted in Malaysia by Shin, Mohd Normal, McConnell, Joo & Dhillon Joginder Singh (2018) reported that there are four major challenges faced by parents of children with ASD. The first is lack of knowledge about ASD. The parents revealed that they had no prior experience in handling a child with ASD since they have never heard of ASD before the diagnosis of their own child. The second theme is the impact of ASD on their lives. This shows the challenges that the parents faced when raising a child with ASD and how it affects their lives. The third challenge is barriers and challenges in seeking speech therapy. The parents also faced difficulties in finding suitable intervention services before and after their child's diagnosis. The last challenge is positive aspects of receiving speech therapy. This revealed the parents' experiences with Speech Language Therapists and the constructive results that have been received from speech therapy interventions.

Another study in Malaysia found that parents of children with ASD experience higher levels of stress than parents of normal children. In their study of 30 parents of ASD children and 36 parents of typical children, Lee, Ong, Lee, and Nazri (2017) discovered that the former group of parents had significantly higher parenting stress levels than the latter group. Bakri et al. (2019) used the Parenting Stress Index 4th Edition (PSI-4) to assess the dimensions of stress in 52 parents of children with ASD. They discovered that the respondents scored highest for the distractibility/hyperactivity subscale in the child domain and highest for the depression subscale in the parent domain, implying that both child and parent characteristics influence stress levels.

In the Malaysian context, it is understandable that parents of children with ASD shoulder additional responsibilities, time, and effort, particularly when it comes to financial costs and the children's behaviour (Shin et al., 2020). Parents of ASD children often experience marital strain and disrupted family life as a result of their children's challenging behaviour, as well as fewer opportunities to socialise with their communities (Allik et al, 2006; Myers et al, 2009).

It is essential for professionals and stakeholders to become more aware of the challenges faced by parents in the lives of children with autism and they need to find more effective ways of giving support to these special parents. Thus, the current study is timely, and the proposed framework is important to add to the literature of parent experiences and challenges, particularly one that emphasises the coping strategies that parents can use as guidance.

Methodology

This research uses the case study approach to examine the problems and challenges those parents of autistic children face in raising their autistic child. By delving into their personal experiences (Patton, 2002), the authors were able to identify emerging themes whichtranspire from one-to-one interview sessions with the parents. As shown in Table 1, sixMalay Muslim parents consisting of three mothers and three fathers (pseudonyms are used

to ensure confidentiality)were interviewed one-to-one based on an interview protocol prepared by the authors. The participants were selected through the purposive and snowball sampling methodsto make sure the participants chosen would represent information-rich cases—that is, individuals with certaintraits who could help the authors with this study (Creswell, 2009).

Table 1. Demographic data for parents of children with ASD

Parent pseudonym	Gender	Age	Education level	Child's age	Child's age at diagnosis
Nani	Female	40	Degree	10	5
Kayla	Female	43	Degree	6	4
Syasya	Female	46	Diploma	10	5
Aydan	Male	42	PhD	14	3
Khairi	Male	35	PhD	7	1 1/2
Amar	Male	46	Master	6	4

Before the interview sessions, the participants were briefed about the objective of the studyandabout any implicated ethical issues which might arise, all of which arekey stepswhencarrying out research (Creswell, 2012; Teddlie & Tashakkori, 2009).Every participant also signed a consent form stating the important information regarding the study, and also informing them that the data would only be used for research purposes and theirprivacy would not be disclosed.

Each interview session took around 1 hour 30 minutes, conducted in a casual manner following the participants' availability and convenience. All interview sessions were audiotaped with permission from the participants, transcribed verbatim and then analysed thematically through reading and re-reading the transcriptions, coding, and discovering the recurring themes.

Findings and Discussion

As mentioned earlier, the aim of the present study is to explore the difficulties and hardships encountered by parents of autistic children. All of the parents in this studyunderwentvery challenging phases in raising their autistic child. Through the narrations about their attachment and engagements with their children, various themes have emerged.

By analysing and dissecting the rich data obtained in this study, the authors are proposing a model on challenges faced by parents of ASD children. The model is called the SCCS-R model (see Figure 1 below). This model comprises five layers: (1) Self, (2) Child, (3) Community, (4) System and (5) Religion. From our analysis, along with the earlier findings on challenges faced by fathers (Hazlina Abdullah et al., 2021) and mothers (Hazlina Abdullah et al., 2022), we have identified five themes of parental challenges faced by the fathers and mothers of autistic children, represented in the proposed model. These key themes exemplify experiences regarding the challenges that parents of children with ASD went

through starting from the parents' self, the child, and going further to the society and the system at large, enfolded / embraced by religion. We establish that the experiences and challenges could be partitioned according to different layers. Each of the layers is discussed below (see Figure 1).
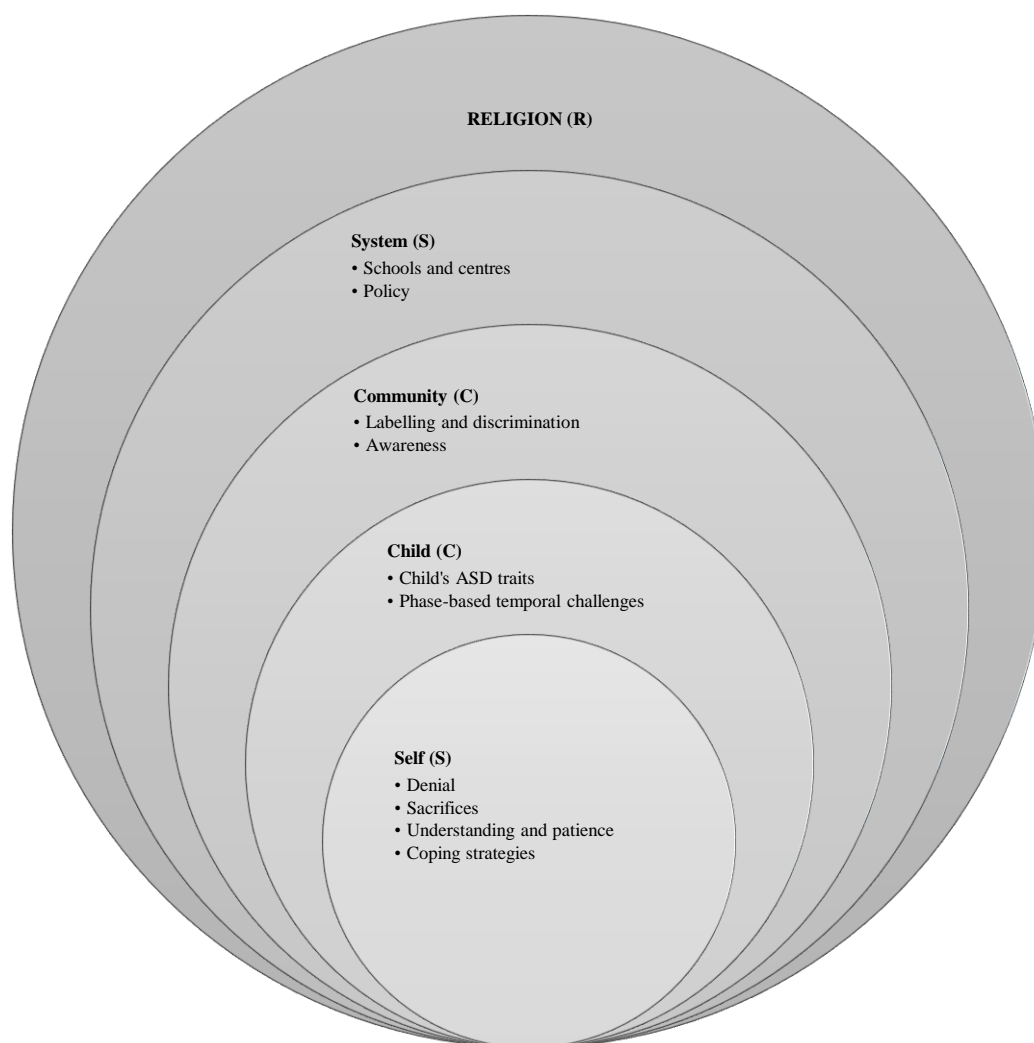
Figure 1: The SCCS-R model of parents' experiences with autism spectrum disorder.

Layer 1: Self (S)

The inner-most layer (Self) encapsulates the challenges of 'fighting' with their own self. Firstly, all parents voiced out that it was very hard for them to really admit that their child was diagnosed with ASD. Everyone went through a denial phase before they could move forward. Next, the parents made huge sacrifices—emotionally, physically, financially—throughout their lives. In addition, the parents required high level of

understanding and patience in handling their autistic child. Within the Self too, lies the coping strategies employed by the parents in order to manage various stressors that they are facing. Table 2 shows the excerpts for the different elements under the Self layer, as articulated by the parents in this study.

Table 2. Layer 1 of SCCS-R Model: Self (S)

Layer 1	Component	Quotation
Self (S)	Denial	*"Of course, initially we felt sad. Normal, but alhamdulillah we passed that phase quickly. Maybe because of family support – in-laws, my own family. All understood and willingly accepted ... if we continue crying, the child is still like that. Better for us to deal with it ..." (Khairi).*
		"Who wants this? Are there any moms who want a child like this? Nobody. No mom in this world would want her child to be called disabled, or defective or anything of that sort. We also don't want it. *(Syasya).*
	Sacrifices	*"When I scold him, he would be very sad ... Dads – their specialty is different (compared to moms). But dads have to be like moms too. 'Feel' a bit more – stronger emotions ..." (Aydan).*
		"We spent a lot on our son's treatment, and education – we sent him to the public school and also extra sessions at the physio centre ..." (Khairi).
		"Monthly expenditure is also high, but we do it for our son ..." (Amar).
		"It is hard to commute to HUKM, an hour from home ... so we took the private occupational therapist, which is closer to our house, even though it's a bit expensive" (Nani).
		"I took unpaid leave for 3 years and 7 months" (Nani).
	Understanding and patience	*"The most difficult thing ... I can still tolerate his delayed speech, but when it comes to dangerous things... that's too dangerous. For example, he's holding the phone, he doesn't know the right way, he threw the phone, and it broke! We cannot scold him" (Amar).*

	"… when he plays his bicycle for example, unlike other normal children who know at least to look first if there is any car etc, but for him, he will just go and ride out of the gate without being aware of the danger of being hit by the car…" (Aydan).
	"He cried. Even if we console him, he refused. We didn't even know the reasons. But now we know… he doesn't want his little brothers to make so much noise. We need to find the reason …" (Khairi).
	"The challenge is when he selectively chooses what he wants and doesn't want to do. When we ask him to do this and that, he refuses. We really need to be patient, really patient … many times, we have to do together with him. Butyes, that is a real challenge …" (Khairi).

Past studies show that parents are unlikely to have self-denial. Perhaps the thoughts of what is best for the children have overpowered the feelings of sorrow and self-pity on the 'misfortune'. This study, although there areincidencesof self-denial, one shows a more intense emotion than the other.This may be due to the fact that both subjects differ in genders and parental roles. Most mothers, naturally, will be more emotional than fathers and are more attached to the children. The father in the study, on the other hand, diverts the negativity of self-denial towards acceptance and being optimistic with his 'self'. Similar to the previous studies, this research shows significant evidence on the sacrifices of 'selves', namely, monetary when it comes to providing the best education for their children and time spent to focus on the caring of their children. One interesting sacrifice shown in this study is the interchanging or swapping of parental roles, which one has to embrace the role of their spouse when it is required in certain situations. It is also illustrated in the findings that 'self' is also challenged when dealing with their children who cannot differentiate between what is right and wrong, and this calls for their utmost patience and understanding. Past studies do not discuss much on this perspective of challenge faced by parents as the reason may be that the challenge focuses more on the child's behavioural deficits that outweighs the focus on the parents.

Layer 2: Child (C)

The second layer moves to the autistic child, in which two elements become major difficulties for the parents. The autistics traits of the children include one-way communication, alone, aloof and participate in silence, sensory issue such as super sensitive hearing, aggressive behaviour, unique views, routine based, attention to details, obsessions, and moody and tantrum (Hazlina Abdullah et al., 2022). Another problem that parents

encounter with regard to the child are the phase-based temporal challenges wherebythe parents related their experiences of different challenges throughout the journey of parenthood. Each of them has uniqueexperience at different phases.

Table 3. Layer 2 of SCCS-R Model: Child (C)

Layer 2	Component	Quotation
Child (C)	ASD Traits	*... It is challenging to understand the communication aspect. Two-way communication is definitely difficult (Nani).*
		The issue is when people are learning, he doesn't follow instructions. He goes and sits at the back. He isolates himself(Nani).
		Maybe she doesn't know how to tell. She doesn't like to share (Syasya).
		She cannot listen to loud voices. Children crying – she cannot, it causes headache (Syasya).
		She sits under the table and shut her ears. She just can't. *Her hearing is very sensitive (Syasya).*
		I thought he was OK with loud noises. When he entered school, he punched his friend. The issue was because his friend talked too much (Nani).
	Temporal phase-based challenges	*"It's the early phase when we wanted to do the early intervention. To know him. I think that was the hardest phase. Just started to know him. How to teach him to do toilet-train. Teaching him how to eat is difficult too. At that time, he did not use his hand, he used the spoon. So, the most difficult was the early, beginning stage. To know him" (Aydan).*
		"The challenge was when he already 3 years old, but we had to manage him like a baby. He was still in diapers ..." (Khairi).
		"I think every phase presents a different challenge. I mean, during childhood, I wanted him to have two-way communication. Once two-way communication was

	achieved, there was the school issue. Ok with the school issue, we looked at his classmates ... never ending" (Nani).
	"The most effort that I put in was when he was 4 or 5 years old... when he had just been diagnosed with ASD—and when he entered school. That was the most—because we wanted to help him with readiness for school". (Kayla).

Although ASDis described as a spectrum disorder as the traits differ from one to another ASD child, behavioural deficit of an ASD child in relation to communicationis an ultimate challenge for parents to cope with as the exhibition of such behaviour is a defining trait among ASD children. Almost all studies, including the present, mention the behavioural deficit that involves breakdowns in communication, as illustrated in the findings above. In this study, mothers especially, find that it is challenging to handle their children's withdrawal from communicating and socialising. Deduction on the reasons for such behaviours, such as difficulty in understanding what others say and over sensitive towards sounds, are made through observation, which shows that the mothers are still grappling in identifying what causes certain behaviours. This disorder also delineates different traits in the spectrum that define phases, which parents may find that the challenges are endless and unpredictable.

Layer 3: Community (C)

Moving further from the Self and the Child, the analysis brings us to the third layer that is the Community. The parents interviewed also face challenges from other people surrounding them. Even though autism is becoming more prevalent in Malaysia, many still do not truly understand the situation which makes them label, stereotype and sometimes discriminate autistic children. Awareness about autism is still very much lacking, which is another challenge for the parents.

Table 4. Layer 3 of SCCS-R Model: Community (C)

Layer 3	Component		Quotation
Community ®	Labelling discrimination	and	*"I don't want (to take care of her at school). My friends will say that I have a disabled little sister. They always make fun of me because of that" (Syasya).*
			"If Ali punched someone, Ali is wrong". *"Why all of a sudden he goes around punching people.... Because if he wants to explain, I don't*

	think he can. He cannot tell why. In the speech phase itself, we have to teach him how to answer 'Why' questions. The 'Why' must be taught" (Nani).
	"Labelling – once we put a child under special needs there will straightaway be a certain mindset. Sometimes parents refuse to declare. On Facebook people will say many things making them uncertain whether to open up or not. This is because of labelling" (Nani).
Awareness	*"There must be some kind of assistance in terms of helping the [ASD] children; because I think after Form 5, they will be 19, and they will live like other people. So, they will be our neighbours. If they do awkward things, it means that we have isolated them—we have not prepared them to live among the "normal" members of society" (Nani).*
	"But we didn't prepare the society to recognise who are the ones with special needs. One more thing, what to do with them? We will assume many things if we don't know or don't understand" (Kayla).

Past studies show that be it the Western culture or the Asian, all experience challenges in the community when it comes to ASD children. The stigmatisation is still inherently encircling the community wherever an ASD child is present. The findings illustrate that the perception of the community lies in the negative interactions among the children with the normal ones, for example being perceived as different or being blamed for reacting to something, as in the case of Ali above. Accordingly, even with the term ASD alone, children are labelled and discriminated,resulting doubts among parents of ASD children to share the challenges they are facing with the community. These also boil down to the fact that the public lacks awareness as shown in the findings. The failure in acceptingpeople with ASD 'living' together within the society is that the latter are not prepared to handle these special people due to the lack of education on how a community can understand and assist them with living normally.

Layer 4: System

The fourth layer extends to the bigger view which is the system. All parents in this study agree that they have difficulties finding suitable schools and centres for their ASD child. Locating the right school is very importantas better social outcomes could be realised if the autistic child is given the opportunity to mix and socialise with their normal peers (Ledford & Wehby, 2015; Watkins et al., 2017).This can assistthe child's self-esteem and self-concept (Boutot & Bryant, 2005;Kasari, Locke, Gulsrud & Rotherham-Fuller, 2011). But finding a suitable school or centre that is credible and offer expert services (e.g., speech and occupational therapy) is always a challenge for the parents.

Apart from that, the parents expressed their hopes and expectations toward the policy of special needs children, specifically with regard to autism. They believe that some policies need to be revisited and reassessed so that special needs education in Malaysia can be elevated to a higher standard. And this canensure that autistic children are honoured and celebrated.

Table 5. Layer 4 of SCCS-R Model: System (S)

Layer 4	Component	Quotation
System (S)	Suitable schools and centres	*"At 5 years old, I sent him to a kindy, and was rejected, because he didn't sit, refused to follow instructions … After that, I sent him to the second kindy…" (Nani).*
		"Services like these are not many" (Syasya).
	Policy	*"I personally think that they should relook at the policy. For example, if we want to treat a child about his or her learning, we have to treat properly on the learning aspects. So, there shouldn't be too many … we can mix. No problem. But if we mix, we need to consider whether the child is high or low functioning. If we mix simply mix all, it will be problematic. So, there should be a division between the high and low functioning groups – high in one group, low in another group" (Aydan).*
		"The curriculum is different; it will not be the same. We may have one standardised curriculum. But from the assessment angle, it will be different. Now, teachers in our special education system, we have RPI (Rancangan Pendidikan Individu) [Individualised Teaching

Plan]. But as far as I'm sending my son to school, there don't seem to be any. This RPI actually will be discussed with the teacher – how do you want your child to learn or gain? The teacher will make a plan as agreed together. Teachers and parents should both agree for the child's education" (Amar).

Past studies in the Malaysian context have significantly exhibited this particular challenge of which parents find that the system, which is the schools and policy in the country assisting the special need children,is still green. Parents claim that the scant availability of suitable schools has caused them to send their children to the mainstream environment, which creates more problem to the children.Teachers as experts are limited resulting to 'unfair' treatments by the mainstream teachers who are not capable of handling such children.Parents find that it is a challenge for them to penetrate the current education system when there is no collaboration between parents and teachers in deciding what is best for the children in terms of teaching and learning environment, learning objectives, as well as assessments.

Layer 5: Religion

It is discerned that in confronting the problems and challenges when handling their autistic children, parents resort to God and religion. Even though there are many obstacles to cope with, which sometimes left them exhausted and shattered, at the end of the day, they muster their courage and managed to pull themselves together by really accepting what is fated to them. This spiritual aspect is prevalent in all parents as all of them 'survive' their quest in parenting an ASD child by holding tightly to their religious belief and dependency on Allah SWT. By embracing Islamic virtues, they become much more accepting and optimistic to move forward and put up further fights for their child.

Table 6. Layer 5 of SCCS-R Model: Religion

Layer 5	Quotation
RELIGION (R)	*"For me, alhamdulillah. My strength is my wife ... we need to go back to religion, to really accept ..." (Aydan).*
	"So, it makes us accept, accept ... redha, redha, redha" (Amar).
	"It's ok. This is 'anak syurga' (the son of heaven). Accepting the fact makes us ok. Other people are fine with it, why don't we? So, it makes us quickly move on and think about what to do. No matter how hard we cry, the boy will still be like that. So, it's better for us to deal with whatever affecting his future. We have to think that way ..." (Khairi).

"Who wants this? Are there any moms who want a child like this? Nobody. No mom in this world would want her child to be called disabled, or defective or anything of that sort. We also don't want it. We want our children to be ok ... but thinking of it, when we go to classes, and join associations, we gradually feel proud. A bit of pride, in which God (Allah) did not award children like this to everybody" (Syasya).

"Firstly, we have to calm ourselves down. We need to be patient, to 'istighfar' [to get the strength from Allah to show us the right way. To remind ourselves that Allah sent her to us. Not solely for us, for us AND for people around us. People might view this as easy. But to make ourselves patient is a problem too" (Kayla).

"So, I think this is a way that Allah wants to draw me closer to Him. I feel this is the silver lining, because I think now, I am stronger than before" (Nani).

Unlike most studies,the parents in this study, despite the challenges, have reflected the positivity and optimism toward the caring of their ASD children and the core to this optimism is their strong hold on religion. The challenges are braced by '*redha*' which means accepting wholeheartedly to the decision of God and thinking of good thoughts about God. In other words, they positively shift the feelings of being unfortunate parents into God's blessings in disguise as illustrated above.

Conclusion

This study documents what participants have undergone in their parenting journey of children with ASD. The parents spoke at length about the different challenges they have faced with the majority indicated how demanding and taxing it was for them to care for their autistic children. The endless, constant challenges pose certain impacts on the parents, affecting their mental and physical well-being, aside from struggling to search for proper coping mechanisms. The findings of this study, which lead to the development of the SCCS-R model, is anticipated to be of much help for parents, mainly those who recently knew about their child's autistic condition. The model can systematically assist the parents—bothmothers and fathers—to learn, anticipate and understand the hardships of nurturing and caring for an autistic child. The distinct layer by layer challenges identified through this study can minimise parents' overwhelming feelingsand steer them to face each trial in a more organised and structuredmanner. Starting with the baby steps of discovering one own Self, proceeding to the Child, moving on to the Community and progressing to the greater System, complemented by a solid foundation of Religion, parents of ASD child are capable in dealing with stress, thus remain sensible and stable in caring for their special child.

Following this, the study would enlighten the factors contributing to the problems and challenges those parents of autistic child encounter atdifferent stages. Importantly, this study would also address issues like the significance of social support, peer groups and the larger social systems.Through the SCCS-R model proposed in this article, parents can know and prepare themselves so that they will be more resilient towards the challenges and problems that emerge whilst taking care of their ASD child. Better equipped parents will more likely present better living conditions for an autistic child. Additionally, this study would be valuable to health care professionals and other parties involved withASD children.

Acknowledgement

References

1. Allik, H., Larsson, J. O., & Smedje, H. (2006).Health-related quality of life in parents of school-age children with Asperger Syndrome or High-Functioning Autism.*Health and Quality of Life Outcomes*, 4, 1.https://doi.org/10.1186/1477-7525-4-1

2. Baker-Ericz MJ, Brookman-Frazee L, Stahmer (2016). A: Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities*, 30, pp. 194–204.

3. Bakri, A.H., Rosli, N.A., Mohd Kasirun Z., Md Nasir M.H.N., Othman F. & Tengku Kasim T.S.A. (2019). Dimensions of stress in parents of children with autistic spectrum disorder.*Makara Journal of Health Research*, 23(3), pp. 127–131.

4. Baxter, A.J., Brugha, T.S., Erskine, H.E, Scheurer, R.W., Vos, T. & Scott, J.G. (2015).'The epidemiology and global burden of autism spectrum disorders.'*Psychol Med*, 45(3), pp. 601-13. doi: 10.1017/S003329171400172X.

5. Bitsika, V.& Sharpley, C.F. (2004).'Stress, anxiety and depression among parents of children with autism spectrum disorder.'*Aust. J. Guid. Counc*. 14, pp. 151–161.

6. Boutot, E. A., & Bryant, D. P. (2005).Social integration of students with autism in inclusive settings.*Education and Training in Developmental Disabilities*, 40(1), pp. 14–23.

7. Broady, T.R., Stoyles, G.J., Morse, C. (2017).Understanding carers' lived experience of stigma: The voice of families with a child on the autism spectrum. *Health Soc. Care Community*, 25, pp. 224–233.

8. Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methodsapproaches (3rd ed.)*. Sage Publications, Inc.

9. Creswell, J. W. (2012). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research (4th ed.)*.Boston, MA Pearson.

10. DePape, A.M., Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder.*Qualitative Health Research*, 25, pp. 569–583.

11. Dina Murad (2019). More kids diagnosed with autism, FOCUS, Sunday, 15 Sep 2019. The Star.https://www.thestar.com.my/news/nation/2019/09/15/more-kids-diagnosed-with-autism accessed 28 April 2020.

12. Divan, G., Vajaratkar, V., Desai, M.U., Strik-Lievers, L., Patel, V. (2012).Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Research*, 5, pp. 190–200.

13. Golfenshtein, N., Srulovici, E. & Deatrick, J.A. (2016). Interventions for reducing parenting stress in families with paediatric conditions: An integrative review. *J Fam Nurs*, 22, pp. 460-492.

14. Hall, H.R., Fruh, S., Zlomke, K.& Swingle, H. (2017).A qualitative analysis of the experiences of minority parents of children with autism spectrum disorder.*Adv. Neurodev. Disord*, 1, pp. 79–88.

15. Hayes, S.A.& Watson, S.L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders,*43, 629–642.

16. Hazlina Abdullah, Nursyuhada' Ab Wahab, Dini Farhana Baharudin& Myra Aidrin Mohd Ali (2021). Unravelling the Challenges and Coping Mechanisms of Malaysian Fathers with Autistic Children. *Turkish Online Journal of Qualitative Inquiry (TOJQI)*, 12(8), pp. 4520-4533. DOI: 10.17569/tojqi.60515.

17. Hazlina Abdullah, Ratnawati Mohd Asraf, Myra Aidrin Mohd Ali, Nursyuhada' Ab. Wahab, & Dini Farhana Baharudin (2022). The Challenges in Raising Autistic Children: The Voices of Mothers. *International Journal of Evaluation and Research in Education (IJERE),* 11(1).

18. Ilias, K., Liaw, J.H.J., Cornish, K., Park, M.S.& Golden, K.J. (2017).Wellbeing of mothers of children with 'autism' in Malaysia: An interpretative phenomenological analysis study. *J. Intellectual Development Disabilities,* 42, pp. 74–89.

19. Kasari, C., Locke, J., Gulsrud, A., & Rotherham-Fuller, E. (2011). Social networks and friendships at school: Comparing children with and without ASD. *Journal of Autism and Developmental Disorders*, 41(5), pp. 533–544.

20. Ledford, J. R., & Wehby, J. H. (2015). Teaching children with autism in small groups with students who are at-risk for academic problems: Effects on academic and social behaviours. *Journal of Autism and Developmental Disorders*,45 (6), pp. 1624–1635.

21. Lee, J.X., Ong, S.I., Lee, V.Y. & Fairuz Nazri, A.R. (2017).Parenting stress among Malaysian parents of children with autism spectrum disorder (ASD).*Medicine & Health*, 12, pp. 42-55.

22. Meirsschaut, M.; Roeyers, H.; Warreyn, P. (2010).Parenting in families with a child with autism spectrum disorder and a typically developing child: Mothers' experiences and cognitions.*Res. Autism Spectr.Disord*. 4, pp. 661–669.

23. Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). My greatest joy and my greatest heart ache: Parents' own words on how having a child in the autism spectrum hasaffected their lives and their families' lives. *Research in Autism Spectrum Disorders*,3(3), pp. 670–684. https://doi.org/10.1016/j. rasd.2009.01.004

24. Nealy, C.E., O'Hare, L., Powers, J.D.& Swick, D.C. (2012). The impact of autism spectrum disorders on the family: A qualitative study of mothers' perspectives. *J. Fam. Soc. Work*, 15, pp. 187–201.

25. Patton, Michael Quinn (2002). *Qualitative research and evaluation methods*.3rd Edition. Thousand Oaks, CA: Sage Publications.

26. Rutgers A.H. &Ijzendoorn M.H. (2007). Autism, Attachment and Parenting: A Comparison of Children with Autism Spectrum Disorder, Mental Retardation, Language Disorder, and Non-clinical Children. *J Abnorm Child Psychol*, 35, pp. 859-70.

27. Teddlie, C. and Tashakkori, A. (2009).*Foundations of mixed methods research: Integrating quantitative and qualitative approaches in the social and behavioural sciences*. Sage, London.

28. Shin Ying Chu, Siti Nor Syamim Aqila binti Mohd Normal, Grace E. McConnell, Joo Siang Tan & Susheel Kaur Dhillon Joginder Singh (2018). Challenges faced by parents of children with autism spectrum disorder in Malaysia.*Speech, Language and Hearing*, 23 (4). pp. 221-231. DOI: 10.1080/2050571X.2018.1548678

29. Shin Ying Chu, Hyeran Park, Jaehoon Lee, Khadijah Kamil Shaharuddin & Chun Hong Gan (2020). Self-stigma and its associations with stress and quality of life among Malaysian parents of children with autism.*Child: Care, Health & Development*, 46(4). Pp. 485-494. DOI: 10.1111/cch.12771.

30. Vasilopoulou, E.&Nisbet, J. (2016).The quality of life of parents of children with autism spectrum disorder: A systematic review. *Res. Autism Spectr.Disord*., 23, pp. 36–49.

31. Wang, P., Michaels, C.A.& Day, M.S. (2011).Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities.*Journal of Autism and Developmental Disorders*, 41, pp. 783–795.

32. Watkins, L., O'Reilly, M., Ledbetter-Cho, K., Lang, R., Sigafoos, J.& Kuhn, M., et al. (2017).A meta-analysis of school-based social interaction interventions for adolescents with autism spectrum disorder.*Review Journal of Autism and Developmental Disorders*, 4(4), pp. 277–293.

33. Weitlauf, A.S., Vehorn, A.C., Taylor, J.L.& Warren, Z.E. (2014).Relationship satisfaction, parenting stress, and depression in mothers of children with autism.*Autism*, 18, pp. 194–198.

34. World Health Organisation (WHO) (2021).Autism spectrum disorders.https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

35. Yaacob, W.N.W., Yaacob, L.H., Muhamad, R.& Zulkifli, M.M. (2021).Behind the scenes of parents nurturing a child with autism: A qualitative study in Malaysia.*Int. J. Environ. Res. Public Health*, 18, pp. 8532. https://doi.org/10.3390/ ijerph18168532

36. Yogesh Hole et al 2019 J. Phys.: Conf. Ser. 1362 012121