

THE CHALLENGES AND COPING MECHANISM OF ADOLESCENTS WITH SIBLINGS WITH DEVELOPMENTAL DISABILITIES

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Abstract: Adolescents who have a sibling with developmental disabilities were more likely to have more challenges and unpleasant emotions compared to adolescents who have a sibling without developmental disabilities. Besides, the sibling relationships with developmental disabilities siblings were most likely to be affected negatively due to the deficits in cognitive, language, and social skills. Due to the challenges and unpleasant emotions among adolescents with disability siblings, this study was aimed to identify the coping strategies and sibling relationships of the adolescents with developmental disabilities siblings in Malaysia. Besides, this study also aimed to evaluate the perceptions of the adolescents who have a sibling with developmental disabilities in the family functioning. This study was conducted using qualitative research with phenomenological design on 10 participants. The participants were recruited through purposive sampling methods and data were obtained by conducting semi-structure interviews. Based on the result, the most common coping strategies used by the adolescents who have a brother or sister with developmental disabilities were emotional-focused coping strategies. Half of the adolescents reported positive sibling relationships with their brother or sister with developmental disabilities, another half of the adolescents were not. Besides, most of the adolescents perceived poorer communication, problem-solving, decision making, and less satisfaction of leisure time in the family. Therefore, parental training or counselling should be provided to the family who have a child with developmental disabilities to help the family, included the adolescents to have better coping strategies and sibling relationships to overcome the difficulties.

Keywords: Sibling of Developmental Disabilities, Coping Strategies, Sibling Relationships, Family Functioning

INTRODUCTION AND BACKGROUND

It is a joyful and exciting moment for the family when there is a new-born, however, if the new-born is suffering any developmental disabilities, it would turn the family from joyful to worried and eventually it will be a stressful event for the family members. The presence of a child with developmental disabilities in a family is more likely to bring along unforeseen affects to the family (Davis & Kiang, 2018; Hsiao, 2018). Adolescents who have a sibling with developmental disabilities also are found to face different challenges, but they were less likely to receive helps and support from the society (Roper, Allred, Mandleco, Freeborn, & Dyches, 2014). It is important to provide help and support to the adolescents who have a sibling with developmental disabilities as siblings have unique relationships that highly influences the development of the adolescents (Takataya, Mizuno, Kanzaki, Sakai, & Yamazaki, 2019; Tomeny, Ellis, Rankin & Barry, 2017). As individuals who have a sibling with developmental disabilities were more likely to suffer from behaviours and psychological problem (Haukeland, Fjermestad, Mossige, & Vatne, 2015) as well as lower well-being compared to individuals who have a sibling without developmental disabilities (Fullerton, Totsika, Hain, & Hastings, 2016).

The challenges of the adolescents who have a sibling with developmental disabilities may different from parents who have a child with developmental disabilities (Tsai, Cebula, Liang, & Fletcher-Watson, 2018; McHale, Updegraff, & Feinberg, 2016). As the adolescents were more likely to face challenges due to the disruptive or awkward behaviours of the siblings with developmental disabilities which have made the adolescents feel embarrassment at the public (Lovell & Wetherell, 2016). Besides, adolescents who have a sibling with developmental disabilities are more likely to have the difficulties in expressing their emotions (Tsai, Cebula, Liang, & Fletcher-Watson, 2018) which reported to have contradict feelings that they have difficult to deal with. For example, they may feel irritated but also worried to their sibling with developmental disabilities at the same time. Adolescents who have a sibling with developmental disabilities also more likely to exhibit behaviour problem and poorer relationship with their peers (Fullerton, Totsika, Hain, & Hastings, 2016). As the adolescents may have the limited chance to learn reciprocal relationship and social behaviours between mates who have the similar age due to the disabilities of their brother or sister with developmental disabilities (Hughes, Mcharg, & White, 2018).

Sibling is one of the important people in our life as the sibling relationships with the siblings are unique and have significant influences on one's life development (Takataya, Mizuno, Kanzaki, Sakai, & Yamazaki, 2019). Hence, positive sibling relationships were more likely to be a protective factor for externalising and internalising problem (Dirks, Persram, Recchia, & Howe, 2015). Adolescents who have a sibling with developmental disabilities more likely to exhibit externalising and internalising problem (Lovell & Wetherell, 2016) due to lesser positive sibling relationships with their sibling (Tomeny, Ellis, Rankin, & Barry, 2017). The lesser positive sibling relationships more likely caused by the deficits in social communication, language, and cognitive in the sibling with developmental disabilities, where the adolescents find hard to bond and communicate with the sibling with developmental disabilities (Rossetti & Hall, 2015). However, the results were not consistent as many factors may differ the sibling relationships of the adolescents and their sibling with developmental disabilities, such as severity and types of the disabilities, behaviours problem of brother or sister with developmental disabilities (Moen, Hedelin, & Hall-Lord, 2016), parental factors (Tsai, Cebula, Liang, & Fletcher-Watson, 2018), and cultural differences (Choi & van Riper, 2014).

As there are many challenges to grow up with a sibling with developmental disabilities, it is important for adolescents to identify effective coping strategies to cope with the stress. Individual who used effective coping strategies was more likely to change a stressful situation into a more pleasant situation which may also bring beneficial effect in future (Crowe & Lyness, 2014) hence, adolescents who have better and effective coping strategies were more likely to have better sibling relationships with their sibling with developmental disabilities. Due to previous researches of Carlson and Miller (2017) as well as Fiske, Pepa, and Harris (2014), coping strategies such as attending skills training programmes help to develop better communication skills for the parents and adolescents in communicate with the sibling with developmental disabilities which more likely to improve the quality of the relationships.

Previous studies about child with developmental disabilities have put much effort into understand the child him or herself and also the parental factors on children with developmental disabilities such as the quality of

the health care services for children with developmental disabilities (Chien et al., 2018; Chien et al., 2017; Teles, Resegue, & Puccini, 2016), effect of parental health or parental stress on raising children with developmental disabilities (Arim, Miller, Kohen, Guevremont, Lach, & Brehaut, 2019; Faw, 2018; Felizardo, Ribeiro, & Amante, 2016; Karakas & Yaman, 2014). Hence, due to the excessive attention to the children with developmental disabilities and the parents, there are limited studies on individual who have a sibling with developmental disabilities, so it is important for researchers to conduct researches on the effect of children with developmental disabilities on their sibling's life and development which also included the sibling relationships.

It is challenging and impactful to grow up with a sibling with developmental disabilities. Both negative and positive impacts have been reported by previous studies (Takataya, Mizuno, Kanzaki, Sakai, & Yamazaki, 2019; Vatne & Zahl, 2017). Research showed individuals who grow up with a sibling with developmental disabilities are more likely to suffer from lower mental health well-being (Haukeland, Fjermestad, Mossige, & Vatne, 2015). However, there are studies showed individual who grow up with a sibling with developmental disabilities showed more emphatic, responsibilities, and appreciation compared to their peers (Takataya, Mizuno, Kanzaki, Sakai, & Yamazaki, 2019; Tsai, Cebula, Liang, & Fletcher-Watson, 2018). Due to the inconsistent results, it is an obligation for the researcher to conduct in-depth research to have better understanding the experiences of individual who have a sibling with developmental disabilities including their challenges and the coping strategies.

Based on the overview, previous studies tended to underestimate the effect of a sibling with developmental disabilities on adolescents. Hence current study is aimed to identify the coping strategies of the adolescents who have a sibling with developmental disabilities, in order to have a deep understanding of the coping strategies of the adolescents and the effectiveness of the coping strategies. Besides, current study also aimed to explore the experience of sibling relationship of the adolescents who have a sibling with developmental disabilities, in order to understand whether the disabilities of the sibling with developmental disabilities have affected the quality of the sibling relationships.

METHODOLOGY

Qualitative research with a phenomenological design has conducted to have a better understanding in the participants' relationship and coping strategies with developmental disabilities siblings in a natural setting.

Total 10 adolescents from the age of 13 to 17 who living with their parents and a brother or sister with developmental disabilities were recruited by using purposive sampling method. Children who were under 12 years old were not recruited due to the level of understanding as they may not be able fully express themselves accurately. All participants were recruited at the state of Selangor as Selangor has the highest population in Malaysia (Department of Statistic Malaysia [DOSM], 2019).

The 10 adolescents were participated in 45 to 60 minutes of semi-structured interview. A semi-structured interview was used as there is a list of interview questions have been prepared, but probe questions have been asked to have more clarifications and explanations from the participants. Before the interview session, parents of the participants and participants have been given the information letter and inform consent. Researcher have debriefed the information letter and inform consent for both parents and the participants, then obtained the agreement from both parties to make sure the parents and participants understand the nature of the study and the rights as a participant in the study.

The interview questions were developed using the research questions and validated with subject matter experts before the pilot test. Besides, some questions were adapted and amended from Revised Way of Coping Checklist (WCCL-R) (Vitaliano, Russo, Carr, Maiuro, & Becker, 1985) to identify the coping strategies of the participants, Sibling Relationships Questionnaire (SBQ) (Furman & Buhrmester, 1985) investigate the sibling relationships of the participants, and Beavers Interactional Scales (Beavers & Hampson, 2000) to evaluate the perception of participants in the family functioning. The interview questions were divided into four sections such as the demographic information of the participants, the coping strategies, sibling relationship, and the perception of adolescents with developmental disabilities siblings on the family functioning. The interview data was transcribed after every interviews. The transcribed data was validated by the subject matter experts to define and interpret the unclear phenomena through nonnumerical methods of measurement that focus on meaning and

insight. The interviewer also has conducted observations with the participants in the natural setting as the triangulation process for the unclear responses from the participants.

The collected data were analysed using thematic analysis, which included the six steps of analysis (Braun & Clarke, 2006). The steps are including data familiarisation, data coding, theme developing, theme reviewing, theme defining and naming, writing up the report. In the first step, data familiarisation, all the data that have been collected were being transcribed and noted down the important ideas. Then, from all the data, interesting or consistent responds from all participants were group into a systematic way, which is the second step, data coding. Next, potential themes will be group together based on the similarities and differences from the coding. After the potential themes have been developed, the themes were reviewed by the expertise to ensure the coherent of the theme. Then, the themes were being defined and named. Lastly, all the data were being finalized for analysis.

RESULT

Sample

A total of 10 adolescence (4 males, 6 females) participants from Selangor were participated in the study. The age of the participants was from 13 to 17 years old, while the age of the participants' siblings with developmental disabilities were from the youngest at 10 years old to 25 years old. Two participants were Malays, seven (7) were Chinese, and one (1) was an Indian. Out of 10 participants, six (6) participants have a brother or sister with Autism Spectrum Disorder, three (3) participants have a brother or sister with Down syndrome and one (1) participant has a brother or sister with Intellectual Developmental Disabilities. Besides, two (2) participants were from a divorced family which they are staying with their mother.

The relationships of adolescents with siblings with developmental disabilities

Based on the results, participants view their relationships with the sibling with developmental disabilities into the feeling of (i) closeness or warmth, (ii) conflict, and responsibility.

Closeness or warmth. Like other siblings, most of the participants have reported they have the positive feelings towards their sibling with

developmental disabilities regardless of the disabilities of their sibling. Most of them reported that their relationships between their sibling with developmental disabilities were no differ from other, although sometimes their sibling with developmental disabilities may irritated.

“Hmm... I think we are close. He will come to ask for my help instead of my another younger sister, I think maybe because I am always helping him with his stuff. And only I have his DIY card on my birthday, even my parents don't have it, I feel quite happy for that, because it means I am very special to him and he feels how much I care him.” (P7, 17)

Besides, out of three participants have reported they have very close relationship with their sibling with developmental disabilities. The participants also appreciate the presence of their sibling even though they may differ from other.

“I like him very much. Although sometimes I can be really angry with him, but still I think I am lucky to have him as my little brother. We do all things together, we go swimming class together, we go jog together, we do homework together at home, and we play together. I think I will be very lonely without him.” (P4, 13)

However, there are some participants do not feel the same, which they reported less closeness relationship with their sibling with developmental disabilities.

“I don't really have the close feeling with her, and sometimes I avoid having any interaction with her, especially at outside.” (P3, 13)

Conflict. Participants reported that they have conflict with their sibling with developmental disabilities as well.

“We always have fun together but at the same times we always argue. He cannot take turns and share the things, if I don't let him to do the things that he wants first, then he will start to scream and cry.” (P4, 13)

“He starts to angry with me when he loses while we are playing video games. it can’t be always I am letting he wins; I want to win in the games too.” (P9, 14)

Hence, like most of the siblings, regardless of the disabilities, participants who have sibling with developmental disabilities have conflict with their siblings as well.

Responsibility. Participants have described that they have the strong feeling of responsibilities towards their sibling with developmental disabilities regardless they have strong or weak attachment towards each other.

“I don’t know whether I have the love for her or not, but I know that I have the responsibility to take care of her if my mother pass away.” (P6, 16)

“He is annoying, but I am his sister, so whenever he needs, I will take care him.” (P10, 15)

Compared to the feeling of closeness and conflict, the feeling of responsibility seems to be the important factors that holding the sibling relationships of the participants and their sibling with developmental disabilities. Participants have also reported that they worried about the future of their sibling with developmental disabilities, hence as a family member, they feel that they have the responsibility to take care of their sibling with developmental disabilities.

Coping strategies of adolescents who have a sibling with developmental disabilities

Based on the results, three commonly used coping strategies have been utilized by the participants, which is (i) emotional-focused coping strategies, (ii) social support, and (iii) avoidant.

Emotional-focused coping strategies. It also defined as passive coping strategies which participants used to distract themselves from the stressful events or negative feelings. Such as keeping journal, participating in sport activities, or listening to music.

“I go out and play basketball with my friends. That is the time I can relax myself.” (P2, 17)

“I write diary every night before I sleep. I write everything in the diary.” (P7, 17)

All participants have reported they used emotional-focused coping strategies to cope with the stress and unpleasant feelings or emotions. Most of the activities that involved were keeping journals, engaging in sport activities, watching television, and listening to music.

Social support. It is meaning the participants seek for social support from other family members or friends, which they will talk about the challenges or stress that they are facing in life with the sibling with developmental disabilities.

“I didn’t talk about the challenges to my parents, but sometimes I will talk to elder.” (P1, 14)

“I will talk to my parents and complain my brother about the naughty things he did. They (parents) will just listen to my complain, after that I feel okay.” (P4, 13)

“The challenges that I faced are hard to explain to my friends because they do not know about anything of my brother. So, I only talk to my parents or another sister, sometimes grandparents, if they come to visit us.” (P7, 17)

Most of the participants have seek for social support from their parents, other sibling without developmental disabilities, or friends. Most of them prefer to talk to another sibling who without developmental disabilities as the sibling has experienced the same feelings with themselves, therefore, for them the sibling can empathy and understand their feelings and challenges.

Avoidant. It may describe an individual ignore or deny their unpleasant feelings when come to a stressful or unpleasant situation. There were three participants have been used avoidant to cope with their stress and unpleasant feelings which they ignore the uncomfortable situation and

have not tried to talk about their problem with others or engage in some activities to relief their negative emotions.

“Sometimes we were playing, then suddenly he will angry and cry, I also don’t know why. When that happens then I will just stop playing with him and ignore him.” (P9, 14)

“He likes to ask so many questions. After I answered him the questions, he will continue ask why, and non-stop. I feel angry to him at that time but at the same time I feel guilty, because I know he is different, so I just ignore him, pretending I did not hear him.” (P10, 15)

DISCUSSION

Adolescents stated that future path is one of the factors that contribute to their happiness in their life (Khoo & Zhooriyati, 2020). However, they are more likely to feel less positive warmth and close relationship to their sibling with developmental disabilities. For instance, Tomeny, Ellis, Rankin, and Barry (2017), reported that individuals who have a sibling with Autism Spectrum Disorder have lesser positive sibling relationship dues to several factors such as the severity of the disabilities, parental factors, and birth order. It has proven that the severity of the disabilities of the sibling with developmental disabilities may influence to the sibling relationships (Taylor, Burke, Smith, & Hartley, 2016). As the impairment of the social communication, language, cognitive abilities, and disruptive behaviours of the sibling with developmental disabilities may affected the interaction (Laghi et al., 2018). Hence, those who have a sibling with severe level developmental disabilities may have less positive sibling relationship as they have limited reciprocal relationship with the sibling, or vice versa.

Like all the siblings, even though having a sibling with developmental disabilities, adolescents still have argued and conflict with their sibling with developmental disabilities as well. Individuals who have a sibling with developmental disabilities were reported most likely to have conflict due to the externalising behaviour problems, while individuals who have a sibling without developmental disabilities were more likely to have conflict due to internalising problems (Begum & Blacher, 2011).

Besides, adolescents who have a sibling with developmental disabilities are more likely to have high and strong senses of responsibility to take care of their sibling with developmental disabilities regardless of the closeness relationships between them. Aligned to the study of Leane (2019), adolescents who have strong and close relationships with their sibling with developmental disabilities develop the sense of responsibilities intrinsically, while those have fewer close relationships with their sibling with developmental disabilities develop the sense of the responsibilities to take care of their siblings due to the feeling of guilty and moral evaluation. As the adolescents feel that they are responsible to take care of their sibling with developmental disabilities, as they are blood related and the sibling has no one except for them.

As the relationship with siblings with developmental disabilities causes stress and unhappiness to the adolescents, they used various methods as their coping mechanism to overcome their negative feelings. The adolescents with developmental disabilities siblings were more likely to utilize emotional-focused coping strategies as a mean to cope with their challenges and unpleasant feelings. Based on the previous study by Gorjy, Fielding, and Flalkmer (2017) and Haukeland, Fjermestad, Mossige, and Vatne (2015), individuals who have a sibling with developmental disabilities or rare disorder tend to use emotional-focused coping strategies such as physical exercise, journal writing, listening to music or used self-positive instructions to cope with the unpleasant feelings. Hence, emotional-focused coping strategies were commonly used which may be due to the easier ways to release and express the negative emotions and high accessibility for the adolescents. By using emotional-focused coping strategies, adolescents are able to redirect their unpleasant feelings and emotions into other forms, such as writing down the feelings, listening to music for calming down the emotions, or releasing the energy through exercise.

Besides, adolescents also seek for social support as a coping strategy to overcome their stress and anxiety. Haukeland, Fjermestad, Mossige, and Vatne (2015) reported that adolescents tend to show their emotions to their siblings. Basically, the presence of a typical developmental sibling is more likely to become a supporter compared to parents when an individual has a sibling with developmental disabilities (Luijckx, van der Putten, & Vlaskamp, 2017). Adolescents prefer to talk about their concerns or

problems to another sibling who is without developmental disabilities, as the sibling is most likely experiences the similar challenges and feelings. Therefore, by telling the problem to the sibling without developmental disabilities, adolescents received more empathy and understanding, which help the adolescents feel supported and relief.

On the other hand, adolescents also used avoidant as a coping strategy to ignore their unpleasant feelings. Avoidant have been used by the adolescents as adolescents tend to prevent their sibling with developmental disabilities from meltdowns and avoid increase burden of or worry their parents (Tsai, Cebula, Liang, & Fletcher-Watson, 2018). Adolescents who used avoidant coping strategies are more likely to have wishful thinking (Young & Limbers, 2017) therefore, they are more likely to have a thought of “what if they don’t have a sibling with developmental disabilities” rather than take action to resolve the challenges they are facing. Besides, adolescents who used avoidant coping strategies tend to not discuss or tell the challenges or problems that they are facing to others, they most likely to keep inside with them.

Besides of the coping strategies and sibling relationships, the study also revealed the perspective of adolescents towards the family functioning in the family. Adolescents have seen the family was showing low effective family functioning. Based on the researches of Walton (2018) and Moen, Hedelin, and Hall-Lord (2016), the family who have a child with developmental disabilities have shown poorer family functioning. This might due to the less satisfaction of leisure time that reported by the adolescents. The dissatisfaction or unenjoyable time together with the family members may have lessen the intimated relationship between the family members (Walton, 2018). Therefore, the family functioning has been influenced negatively as individuals do not enjoy to spend time together with the family.

Lack of communication within the family which may also be a factor of resulting poor family functioning. According to the Circumplex Model (Olson, 2011), cohesion, flexibility, and communication are the important dimensions to determine family functioning. Of the three dimensions, communication is the most important as it facilitate the family’s cohesion and flexibility. Hence, with the lack of communication within the family, the family more likely to exhibit poorer family functioning. The family

lack of communication may due to the emotional stability of the parents. Parents who raised a child with developmental disabilities more likely to be emotions instability which has led to exhausted and fatigue and resulted parents less likely to put effort to interact with the family, therefore, communication within the family was limited (Caicedo, 2014).

Beavers System Model of Family Functioning have stated, a family with healthy family functioning was flexible with changing the family styles according to different conditions. Family who has adolescents, needed to change the centripetal family styles to centrifugal family styles, because centrifugal family styles were more likely to promote independency of family members (Beavers & Hampson, 2000) which the adolescents seek for during the period of adolescence. Parents who less likely to be flexible in switching the family style or empower the independency of the adolescents, more likely to demote the family functioning. Hence, parents who have adolescence children are encouraged to empower the independency of adolescents in order to enhance the family functioning.

CONCLUSION

This study has implicated that the important of providing support to the family members of the individual with developmental disabilities especially the adolescents who have sibling with developmental disabilities. Therefore, in order to improve the quality of the family functioning, training or workshop about raising or growing with a child with developmental disabilities should be provided to the family who have a child with developmental disabilities. These could be behaviour management training, social skills training, or parenting training. By participating in the trainings, parents and siblings more likely to have better understanding the disabilities of their sibling with developmental disabilities. As those trainings may increase the knowledge and skills in managing disruptive behaviours of and communication with the sibling with developmental disabilities. Besides, by attending training or workshop, parents are more likely to seek more information about non-government organizations that support the families who have a child with developmental disabilities, and thus the family able to obtain more resources for help. Therefore, it is important for the family members which included both parents and siblings to attend training or workshop to increase their knowledge.

In the nutshell, this study has provided the perspective of the adolescents who have a sibling with developmental disabilities in Malaysia. This study also provides the important idea to the society that the adolescents who have a brother or sister with developmental disabilities were needed to be supported as well as the parents of the children with developmental disabilities.

REFERENCES

- Arim, R. G., Miller, A. R., Kohen, D. E., Guevremont, A, Lach, L. M., & Brehaut, J. C. (2019). Changes in the health of mothers of children with neurodevelopmental disabilities: An administrative data study. *Research in Developmental Disabilities, 86*, 76-86. doi: 10.1016/j.ridd.2018.12.007
- Beavers, R., & Hampson, R. B. (2000). The Beavers System Model of family functioning. *Journal of Family Therapy, 22*, 128-143. doi: 10.1111/1467-6427.00143
- Beavers, R., & Hampson, R. B. (2003). Measuring family competence: The Beavers Systems Model. In F. Walsh (Ed.), *Normal family processes* (3rd ed., pp. 549-580). New York, NY: Guilford Press.
- Begum, G., & Blacher, J. (2011). The sibling relationships of adolescents with and without intellectual disabilities. *Research in Developmental Disabilities, 32*, 1580–1588. doi: 10.1016/j.ridd.2011.01.056
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:10.1191/1478088706qp063oa
- Caicedo, C. (2014). Families with special needs children: Family health, functioning, and care burden. *Journal of the American Psychiatric Nurses Association, 20*(6), 398–407. doi: 10.1177/1078390314561326
- Carlson, J. M., & Miller, P. A. (2017). Family burden, child disability, and the adjustment of mothers caring for children with epilepsy: Role of social support and coping. *Epilepsy & Behavior, 68*, 168-173. doi: 10.1016/j.yebeh.2017.01.013
- Chien, A., Kuhlthau, K., Toomey, S., Quinn, J., Okumura, M., Kuo, D., Houtrow, A., Van Cleave, J., Landrum, M., Jang, J., Janmey, I., Furdyna, M. and Schuster, M., (2017). Quality of Primary Care for Children With Disabilities Enrolled in Medicaid. *Academic*

- Pediatrics*, 17(4), pp.443-449.
<https://doi.org/10.1016/j.acap.2016.10.015>
- Chien, A., Toomey, S., Kuo, D., Van Cleave, J., Houtrow, A., Okumura, M., Westfall, M., Petty, C., Quinn, J., Kuhlthau, K. and Schuster, M., (2019). Care Quality and Spending Among Commercially Insured Children With Disabilities. *Academic Pediatrics*, 19(3), pp.291-299. <https://doi.org/10.1016/j.acap.2018.06.004>
- Choi, H., & van Riper, M. (2014). Maternal perceptions of sibling adaption in Korean families of children with Down Syndrome. *Journal of Intellectual Disability Research*, 58, 962-977. <https://doi.org/10.1111/jir.12126>
- Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches*, (5th ed.). Thousand Oaks: SAGE Publications Inc.
- Crowe, A., & Lyness, K. P. (2014). Family functioning, coping, and distress in families with serious mental illness. *The Family Journal: Counseling and Therapy for Couples and Families*, 22(2), 186-197. <https://doi.org/10.1177/1066480713513552>
- Davis, R., & Kiang, L., (2020). Parental stress and religious coping by mothers of children with autism. *Psychology of Religion and Spirituality*, 12(2), pp.137-148. <https://doi.org/10.1037/rel0000183>
- Department of Statistics Malaysia. (2019). Demographic statistics third quarter 2019, Malaysia. Retrieved from https://www.dosm.gov.my/v1/index.php?r=column/cthemByCat&cat=430&bul_id=YkdwYkZYOVQ5WFJ4dXhEeINpbGRmZz09&menu_id=L0pheU43NWJwRWVVSZklWdzQ4TlhUUT09
- Dirks, M. A., Persram, R., Recchia, H. E., & Howe, N. (2015). Sibling relationships as sources of risk and resilience in the development and maintenance of internalizing and externalizing problems during childhood and adolescence. *Clinical Psychology Review*, 42, 145-155. <https://doi.org/10.1016/j.cpr.2015.07.003>
- Faw, M. H. (2018). Supporting the supporter: Social support and psychological stress among caregivers of children with severe disabilities. *Journal of Social and Personal Relationship*, 35(2), 202-223. <https://doi.org/10.1177/0265407516680500>
- Felizardo, S., Ribeiro, E., & Amante, M. J. (2016). Parental adjustment to disability, stress indicators and the influence of social support.

- Procedia – Social and Behavioral Sciences*, 217, 830-837.
<https://doi.org/10.1016/j.sbspro.2016.02.157>
- Fiske, K. E., Pepa, L., & Harris, S. L. (2014). Supporting parents, siblings, and grandparents of individuals with autism spectrum disorders. In Volkmar, F. R., Paul, R., Rogers, S. J., & Pelphrey, K. A. (Eds.), *Handbook of Autism and Pervasive Developmental Disorder* (4th ed., pp. 933 – 945).
- Fullerton, J. M., Totsika, V., Hain, R., & Hastings, R. P. (2016). Siblings of children with life-timing conditions: *Psychological adjustment and sibling relationship*. *Child: Care, Health and Development*, 43(3), 393-400. <https://doi.org/10.1111/cch.12421>
- Furman, W., & Buhrmester, D. (1985). Children’s Perceptions of the Qualities of Sibling Relationships. *Child Development*, 56(2), 448 – 461. <https://doi.org/10.2307/1129733>
- Gorjy, R. S., Fielding, A., & Falkmer, M. (2017). “It’s better than it used to be”: Perspectives of adolescent siblings of children with an autism spectrum condition. *Child & Family Social Work*, 22(4), 1488-1496. <https://doi.org/10.1111/cfs.12371>
- Haukeland, Y. B., Fjermestad, K. W., Mossige, S., & Vatne, T. M. (2015). Emotional experiences among siblings of children with rare disorders. *Journal of Pediatric Psychology*, 40(7), 712 – 720. <https://doi.org/10.1093/jpepsy/jsv022>
- Hsiao, Y. J. (2018). Parental stress in families of children with disabilities. *Intervention in School and Clinic*, 53(4), 201-205. <https://doi.org/10.1177/1053451217712956>
- Hughes C., McHarg, G., & White, N. (2018). Sibling influences on prosocial behaviour. *Current Opinion in Psychology*, 20, 96-101. <https://doi.org/10.1016/j.copsyc.2017.08.015>
- Karakas, G., & Yaman, C. (2014). The role of family in motivating the children with disabilities to do sport. *Procedia – Social and Behavioral Sciences*, 152, 426-429. <https://doi.org/10.1016/j.sbspro.2014.09.22>
- Khoo, Y. S., & Zhooriyati, S. M. (2020). *An Exploration on Adolescents’ Meaning in Life, Life Satisfaction and Happiness: A Qualitative Study*. MNNF Publisher.
- Laghi, F., Lonigro, A., Pallini, S., Bechini, A., Gradilone, A., Marziano, G., & Baiocco, R. (2018). Sibling relationships and family functioning in siblings of early adolescents, adolescents and young

- adults with autism spectrum disorder. *Journal of Child & Family Studies*, 27, 793-801. <https://doi.org/10.1007/s10826-017-0921-3>
- Leane, M. (2019). Siblings caring for siblings with intellectual disabilities: Naming and negotiating emotional tensions. *Social Science & Medicine*, 230, 264–270. <https://doi.org/10.1016/j.socscimed.2019.04.022>
- Lovell, B., & Wetherell, M. A. (2016). The psychophysiological impact of childhood autism spectrum disorder on siblings. *Research in Developmental Disabilities*, 49, 226-234. <https://doi.org/10.1016/j.ridd.2015.11.023>
- Luijckx, J., van der Putten, A., & Vlaskamp, C. (2017). A value burden? The impact of children with profound intellectual and multiple disabilities on family life. *Journal of Intellectual & Developmental Disability*, 44(2), 184-189. <https://doi.org/10.3109/13668250.2017.1326588>
- McHale, S. M., Updegraff, K. A., & Feinberg, M. E. (2016). Siblings of youth with Autism Spectrum Disorders: Theoretical perspectives on sibling relationships and individual adjustment. *Journal of Autism and Developmental Disorders*, 46(2), 589-602. <https://doi.org/10.1007/s10803-015-2611-6>
- Moen, O. L., Hedelin, B., & Hall-Lord, M. L. (2016). Family functioning, psychological distress, and well-being in parents with a child having ADHD. *SAGE Open*, 1-16. <https://doi.org/10.1177/2158244015626767>
- Olson, D. H. (2011). Faces IV and the Circumplex model: validation study. *Journal of Marital and Family Therapy*, 37(1), 64–80. <https://doi.org/10.1111/j.1752-0606.2009.00175.x>
- Roper, S. O., Allred, D. W., Mandleco, B., Freeborn, D., & Dyches, T. (2014). Caregiver burden and sibling relationships in families raising children with disabilities and typically developing children. *Families, Systems, & Health*, 32(2), 241-246. <https://doi.org/10.1037/fsh0000047>
- Rossetti, Z., & Hall, S. (2015). Adult sibling relationships with brothers and sisters with severe disabilities. *Research and Practice for Person with Severe Disabilities*, 40(2), 120-137. <https://doi.org/10.1177/1540796915592829>
- Takataya, K., Mizuno, E., Kanzaki, Y., Sakai, I., & Yamazaki, Y. (2019). Feelings of siblings having a brother/sister with Down Syndrome.

- Archives of Psychiatric Nursing*, 33, 337-346.
<https://doi.org/10.1016/j.apnu.2019.01.001>
- Taylor, J. L., Burke, M. M., Smith, L. E., & Hartley, S. L. (2016). Families of adolescents and adults with intellectual and developmental disabilities. *International Review of Research in Developmental Disabilities*, 50, 3-37.
<https://doi.org/10.1016/bs.irrdd.2016.04.001>.
- Teles, F. M., Resegue, R., & Puccini, R. F. (2016). Care needs of children with disabilities – Use of the Pediatric Evaluation of Disability Inventory. *Revista Paulista de Pediatria (English Edition)*, 34(4), 447-443. <https://doi.org/10.1016/j.rppede.2016.02.015>
- Tomeny, T. S., Ellis, B. M., Rankin, J. A., & Barry, T. D. (2017). Sibling relationships quality and psychosocial outcomes among adult siblings of individuals with autism spectrum disorder and individuals with intellectual disability without autism. *Research in Developmental Disabilities*, 62, 104-114.
<https://doi.org/10.1016/j.ridd.2017.01.008>
- Tsai, H. W. J., Cebula, K., Liang, S. H., & Fletcher-Watson, S. (2018). Siblings' experiences of growing up with children with autism in Taiwan and the United Kingdom. *Research in Developmental Disabilities*, 83, 206-216.
<https://doi.org/10.1016/j.ridd.2018.09.001>
- Vatne, T. M., & Zahl, E. (2017). Emotional communication in support groups for siblings of children with disabilities. *Patient Education and Counseling*, 100(11), 2106-2108.
<https://doi.org/10.1016/j.pec.2017.05.021>
- Vitaliano, P. P., Russo, J., Carr, J. E., Maiuro, R. D., & Becker, J. (1985). The ways of coping checklist: revision and psychometric properties. *Multivariate Behavioral Research*, 20, 3-26.
https://doi.org/10.1207/s15327906mbr2001_1
- Walton, K. M. (2018). Leisure time and family functioning in families living with autism spectrum disorder. *Autism*, 23(6), 1-14.
<https://doi.org/10.1177/13623613188124>
- Young, D., & Limbers, C. A. (2017). Avoidant coping moderates the relationship between stress and depressive emotional eating in adolescents. *Eating and Weight Disorders – Studies on Anorexia, Bulimia and Obesity*, 22(4), 683-691.
<https://doi.org/10.1007/s40519-017-0396-7>