

# Lived Experiences of Typically Developing Adolescents with Siblings Diagnosed with Autism Spectrum Disorder in Malaysia



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## 01 INTRODUCTION

- Autism Spectrum Disorder (ASD) affects about **1 in 100 children worldwide**, with rising diagnoses in Malaysia.<sup>1, 2</sup>
- Siblings of children with ASD often take on **extra caregiving roles**, particularly in **collectivist cultures** like Malaysia.<sup>3</sup>
- These roles can foster **resilience** but may also lead to **stress, isolation, and emotional challenges**.<sup>4</sup>
- Most existing studies are **based in Western contexts**, leaving a gap in understanding the Malaysian experience.<sup>5</sup>
- The study aims to explore the lived experiences of Malaysian adolescents with siblings diagnosed with ASD.

## 02 METHODOLOGY

- Design:**
  - Qualitative study using Interpretative Phenomenological Analysis (IPA).
- Participants:**
  - Six adolescents (aged 16–19) were planned; three were interviewed through autism therapy centres.
  - All participants (n=3) were female adolescents aged 17–18, each with a younger brother diagnosed with autism (ages 6–9).
- Interviews:**
  - One-to-one, semi-structured, ~60 minutes, in English or Malay.
- Data Handling and Analysis:**
  - Audio-recorded, transcribed verbatim, anonymised, translated, and analysed using IPA via NVivo.

## 03 FINDINGS (THEMES)



## 04 DISCUSSION

- Comparison to literature;**
  - Participants took on caregiving roles and adjusted routines to support their brothers with autism, echoing international findings of **early maturity** and **emotional strain** among siblings.<sup>3, 4</sup>
  - Unlike many Western studies, caregiving was viewed not as a burden but as a **moral and spiritual duty**, reflecting **collectivist family values**.
- Novel findings;**
  - Siblings framed autism through **religious and cultural meaning**, describing their brothers with autism as “special,” “not severe,” or a “gift from God.”
  - Described **vigilance for safety**, such as closely watching and protecting their brother with autism.
  - Demonstrated **resilience** through **patience, emotional regulation, and advocacy**.
  - Social media** offered an **informal space for learning**, where participants drew inspiration from other families.
  - Faith helped transform stress into **acceptance and gratitude**, reflecting **culturally grounded coping**.
- Limitations;**
  - Based on **three participants**, aligning with IPA’s idiographic **depth rather than generalisation**.
  - Limited diversity but yielded **rich contextual insights** into Malaysian sibling experiences.
- Implications;**
  - Highlights the need for **sibling-inclusive and faith-sensitive programmes**.
  - Integrating **cultural, spiritual and digital learning elements** into family and school support may enhance **resilience**.
  - Informs the development of **family-centred interventions** in Malaysian autism services.

## 05 CONCLUSION

- Siblings of children with ASD balance **caregiving with schoolwork** under family and social pressures.
- Despite challenges, they show **resilience** through emotion regulation and positive reframing.
- Findings highlight the need for **sibling-inclusive, faith-sensitive support** within Malaysian autism services.
- Future work will explore **sibling gender** or **cultural differences** and **wider regional perspectives**.

## 06 REFERENCES

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