

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



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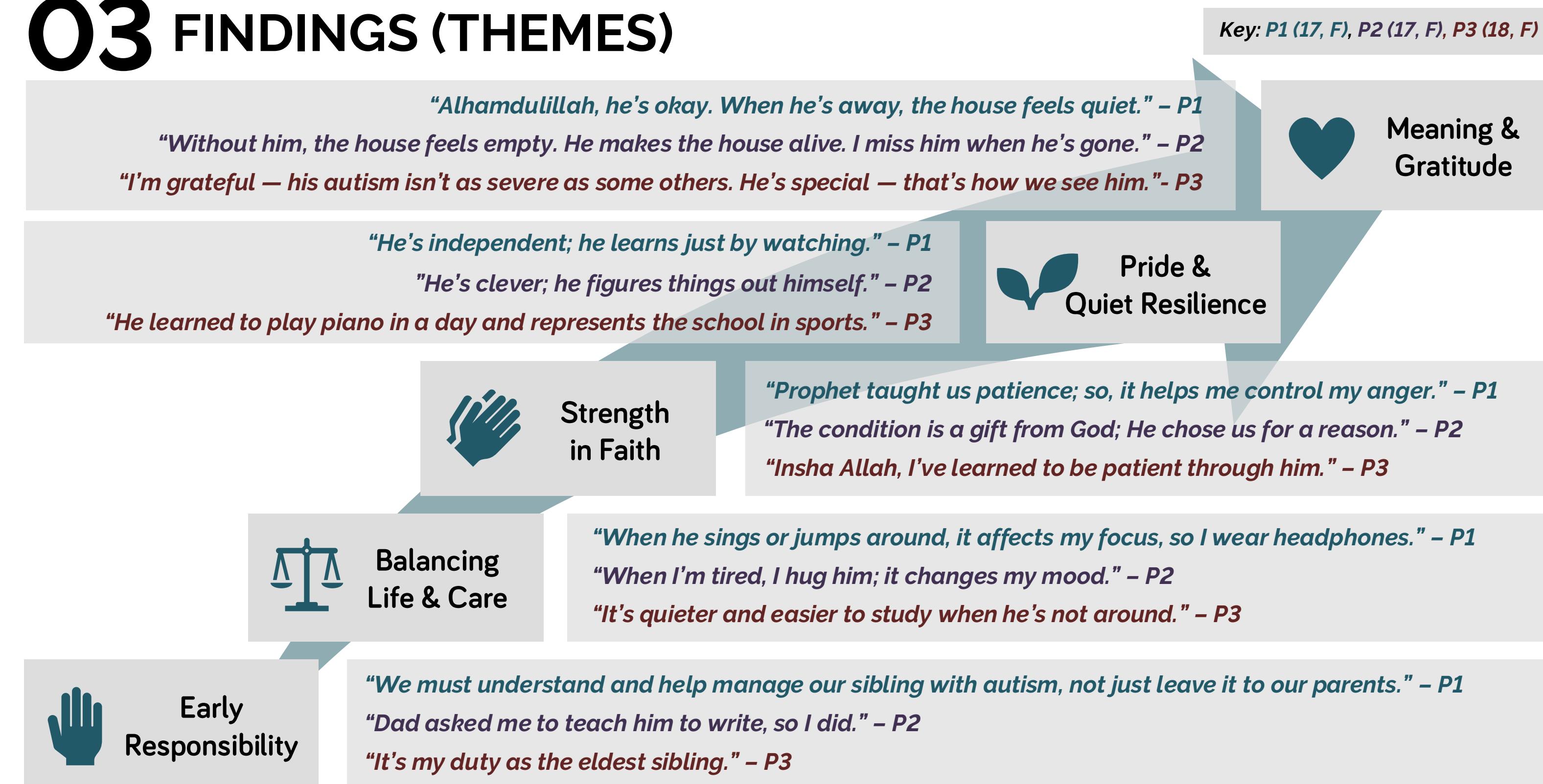
01 INTRODUCTION

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