

PARTICIPANT INFORMATION SHEET

1. Study Information

Protocol Title:

Lived Experiences and Mental Health Needs of Fathers of Children on the Autism Spectrum in Singapore: A Phenomenological Study

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2. Purpose of the Research Study

You are invited to participate in a research study. It is essential that you first take time to read through and understand the information provided in this sheet. Nevertheless, before you take part in this research study, the study will be explained to you and you will be given the chance to ask questions. After you are adequately satisfied that you understand this study and that you wish to take part in the study, your consent will be implied by your continued participation (e.g., completing the survey and proceeding with the interviews). You will be given a copy of this information sheet to take home.

You are invited because you have fulfilled our inclusion criteria of being a Singaporean or Singaporean Permanent Residence (PR) father who;

- Identifies as the father (biological, adoptive, or stepfather)
- Resided in Singapore for at least 1 year prior to the interview
- Is between 21-65 years old
- Has a child diagnosed with autism spectrum disorder who is less than 18 years old
- Can read, speak and comprehend English.

You should not be participating in this study if you have any physical or mental conditions which will interfere with your ability to participate in the interview, or if your child has not received a formal ASD diagnosis. Please inform the Principal Investigator if you fall into any one of these exclusion criteria.

This study is carried out to find out the lived experiences, perceptions of mental health and their mental health needs of fathers of children on the autism spectrum in Singapore; and to inform the development of a mental health intervention for fathers of children on the autism spectrum in Singapore.

This study will recruit up to 20 subjects from the National University Hospital over a period of 2 years and 6 months.

3. What procedures will be followed in this study

If you take part in this study, you will be invited to participate in a questionnaire and two interviews. Should you want to participate in this study, demographic data will be collected from you via a self-administered questionnaire, which will not take more than 10 minutes. You will need to inform us of your background data, such as age, ethnicity and nationality. Any data (eg. age, gender, height, weight) collected relating to your child will be self-reported by you. All the collected data from the interview recordings will be kept confidential, not be divulged to any party other than the researchers and will only be used for this study purposes after which it will be discarded and not used in any other future research activities.

The semi-structured interviews will be arranged at a time and place that is most convenient for you. The two-time online virtual interview will take approximately 45-60 minutes and will be conducted via Zoom/ Microsoft Teams/ Whatsapp or phone call based on your software preference. It is intended as an opportunity to share your experiences with caring for your child and the feeding strategies used at home. No face-to-face interviews will be conducted.

The interview will be audio recorded and later transcribed into text form. Those parents and/or caregivers who do not consent to the audio recording of their interviews will not participate in the interview. Recordings of interviews will be deleted upon the conclusion of the research. You will be given a pseudonym in the interview to protect your identity. As part of the presentation of results, your own words may be used in text form. Quotes will be made anonymous so that you cannot be identified from what you said.

During data analysis, you may be re-contacted for verification of your quotes from the interviews. However, this is optional and you may indicate that you do not wish to be re-contacted after the interview is over.

“Incidental findings” are findings that have potential health or reproductive importance to research participants like you/your child and are discovered in the course of conducting the study, but are unrelated to the purposes, objectives or variables of the study. There will not be any incidental findings arising in this research.

4. Your Responsibilities in This Study

If you agree to participate in this study, you should follow the advice given to you by the study team. You should be prepared to participate by completing the questionnaire and two interviews as instructed in the procedures above.

5. What Is Not Standard Care or Is Experimental in This Study

This study is being conducted because the mental health needs of fathers of children diagnosed with Autism Spectrum Disorder, have yet to be explored. We hope that your participation will help us identify the mental health needs of fathers of children diagnosed with Autism Spectrum Disorder in Singapore.

The completion of the interview and the questionnaire is not part of your or your child’s standard care and is conducted for research purposes only.

6. Possible Risks and Side Effects

This study involves two semi-structured virtual interviews. There is no foreseeable or predicted physical or psychological risk, harm and/or discomfort for you in participating in this study. A breach in confidentiality is not expected as good data collection and storage practices will be implemented. Physical hardcopies of your data will be stored in a locked cabinet in the research office in Alice Lee Centre for Nursing Studies. Digital copies of your data will be kept in password-protected documents on the laptops of the study team members. No individuals outside the study team will be able to gain unauthorized access to your data. However, a non-negligible risk still exists.

While sharing your experiences of childcare and the management of your child’s chronic condition, there is a slight chance that you may experience emotional distress. You will be allowed to skip the question if you do not feel like answering a particular question during the interviews.

If you experience any distress during your participation in this study, please use the following resources:

[NUH Directory of Support Groups](https://form.gov.sg/63a005bdb8509f0012092f9a)
<https://form.gov.sg/63a005bdb8509f0012092f9a>

Samaritans of Singapore (SOS)

24-hour hotline: 1767

24-hour CareText (via WhatsApp): 9151 1767

E-mail: pat@sos.org.sgCaregivers' Pod @ Enabling VillageWebsite: <https://enablingvillage.sg/tenants-all/caregivers-pod/>

SG Enable Infoline: 1800 8585 885

Email: caregivers@sgenable.sg**7. Possible Benefits of Participating in the Study**

There is no assurance that you will benefit from participation in this study. However, your participation in this study will contribute to the knowledge of the experience of parents and/or caregivers of children with feeding difficulties in Singapore. The study's outcome will provide baseline data for future intervention studies relating to supporting parents and/or caregivers of children with feeding difficulties associated with chronic medical conditions, and improvement in the current practices and support you receive from healthcare providers.

8. Alternatives to Participation

If you choose not to participate in this study, you and your child will continue to receive standard care for any condition.

10. Costs & Payments if Participating in the Study

There will be a \$15 reimbursement after each interview (\$30 at the end of 2 interviews), involved with your participation in the study. The transfer will be made via PayNow and you will be required to send a screenshot of the transaction upon receiving each payment.

11. Voluntary Participation

Your participation in this study is voluntary. You may stop participating in this study at any time. Your decision not to take part in this study or to discontinue your participation will not affect your or your child's medical care or any benefits to which you are entitled. If you decide to stop taking part in this study, you should tell the Principal Investigator. However, the data that have been collected until the time of your withdrawal will be kept and analyzed. The reason is to enable a complete and comprehensive evaluation of the study.

Your doctor and/or the Investigator of this study, may stop your participation in the study at any time if they decide that it is in your best interests. They may also do this if you do not follow instructions required to complete the study adequately. If you have other medical problems or side effects, the doctor and/or nurse will decide if you may continue in the research study.

In the event of any new information becomes available that may be relevant to your willingness to continue in this study, you (or your legally acceptable representative, if relevant) will be informed promptly by the Principal Investigator or his/her representative.

12. Compensation for Injury

The study team does not anticipate any physical related injuries arising from your research participation since the research purely involves a self-administered questionnaire and a semi-structured interview. However, if you follow the directions of the doctors in charge of this study

and you are physically injured due to research procedure(s) given under the plan for this study, the National University of Singapore will pay the medical expenses for the treatment of that injury.

Payment for management of the normally expected consequences of your treatment will not be provided by the National University of Singapore.

The National University of Singapore, without legal commitment, will compensate you for the injuries arising from your participation in the study without you having to prove the National University of Singapore is at fault. There are however conditions and limitations to the extent of compensation provided. You may wish to discuss this with your Principal Investigator.

By providing verbal/implied consent to participate in this study, you will not waive your legal rights or release the parties involved in this study from liability for negligence.

13. Confidentiality of Study and Medical Records

Your participation in this study will involve the collection of “Personal Data”. “Personal Data” means data about you that makes you identifiable (i) from such data or (ii) from that data and other information which an organization has or is likely to have access. This includes medical conditions, medications, investigations, and treatment history. However, in this study, your/your child’s medical records will not be accessed by the study team.

Information and “Personal Data” collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available. Your records, to the extent of the applicable laws and regulations, will not be made publicly available. All the data will be stored in a locked cupboard and authorized-access-only computer in the Alice Lee Centre of Nursing Studies office. Only the principal investigator and co-investigators will be able to access the data.

However, the National University Health System (NUHS), National Healthcare Group (NHG) Domain-Specific Review Board, and the Ministry of Health will be granted direct access to your spouse/partners’ original medical records to check study procedures and data, without making any of your information public. With consent, you (or your legally acceptable representative, if relevant) are authorizing such access to your study.

Data collected and entered into the Case Report Forms are the property of the National University Hospital (NUH) and the National University of School’s Yong Loo Lin School of Medicine (NUS-YLLSoM). In the event of any publication regarding this study, your identity will remain confidential.

Research arising in the future, based on this Personal data, will be subject to review by the relevant institutional review board.

By participating in this research study, you are confirming that you have read, understood, and consent to NUH’s Personal Data Protection Notification available at <https://www.nuh.com.sg/personal-data-protection-act>, and NUS-YLLSoM’s Personal Data Protection Notification at <https://nus.edu.sg/ormc/personal-data-protection/>.

14. Who To Contact if You Have Questions

If you have questions about this research study, you may contact the Principal Investigator, Dr. Shefaly Shorey, Alice Lee Centre for Nursing Studies, Yong Loo Lin School of Medicine, National University of Singapore, by phone at 66011294 or by email at nurssh@nus.edu.sg

In case of any injuries during the course of this study, you may contact the Principal Investigator, Dr. Shefaly Shorey, Alice Lee Centre for Nursing Studies, Yong Loo Lin School of Medicine, National University of Singapore, by phone at 66011294 or by email at nurssh@nus.edu.sg

The study has been reviewed by the NHG Domain Specific Review Board (the central ethics committee) for ethics approval.

If you want an independent opinion to discuss problems and questions, obtain information and offer inputs on your rights as a research subject, you may contact the NHG Domain Specific Review Board Secretariat at 6471-3266. You can also find more information about participating in clinical research, the NHG Domain Specific Review Board, and its review processes at <https://ethics.gri.nhg.com.sg/>.

If you have any complaints or feedback about this research study, you may contact the Principal Investigator or the NHG Domain Specific Review Board Secretariat.

15. Consent to be Contacted for Future Research (Optional)

You are being asked for permission to be contacted in the future for participation in research studies that you may be suitable for. If you agree to be contacted, your information and contact details will be entered and stored in a secured database in Alice Lee Centre for Nursing Studies. Your information and contact details will not be released to any parties outside Alice Lee Centre for Nursing Studies without your permission. When investigators from Alice Lee Centre for Nursing Studies identify you to be suitable for a particular research study, the investigators or authorised personnel from Alice Lee Centre for Nursing Studies will contact you to inform you about the research study. Your decision to be contacted for future research studies is completely voluntary and separate from your decision to participate in this study. Your decision will not affect your medical care or any benefits to which you are entitled. You may change your mind at any time by contacting the Principal Investigator, Dr Shefaly Shorey at nurssh@nus.edu.sg.