



Interview topic guide: Household carers (English version)

Interviewer introduction:

- Introduce self and TULAY project
- Briefly explain the purpose of the interview and what topics will be covered
- Check how much time the participant has available
- Check they have read and understood the study information do they have any questions?
- State the interview is voluntary and they can withdraw at any time or request removal of data before it is analysed
- Highlight data protection data (contact details, interview recording, photos/videos) will be stored securely; personal details will not be shared outside the research team; any names/local places/hospitals you mention will be removed from interview transcripts and reports
- Check consent form has been completed if not, do this now
- Re-confirm consent for video- or audio-recording the interview (log interview start and end time) and start recording

Notes for interviewers and notetakers: Focus on the questions (middle column) and use the prompts as necessary. Give the participant time to think of their own answer before giving examples. For the household carer interview, **the carer and interviewer must not be in the presence of the person with stroke** as this may affect the answers of the carer.

Topic	Questions	Prompts	
EXPERIENCES			
About you	Could you tell me a bit about yourself and the person you care for or support?	E.g. Occupation / education; relationship with cared for person; duration of caregiving; current health status of person with stroke	
	What was your occupation before you became the carer of?	Probe on their life before they became a stroke carer	
Photo/video	Note: Participants are invited		
elicitation (refer	to prepare photos and videos		
back to	that reflect what is important		
throughout the	and significant to them right		
interview)			







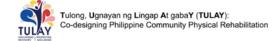


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	now or their experiences of caring	
	Option A: If Participant has photo(s) or video(s) to share Can you describe/explain the photo or video you have provided?	Option A: What does it mean? Why did you choose this image/video? Why is this important to you? (ask further probing questions as appropriate)
	Option B: If Participant has no photos or videos prepared, interviewer may ask participant to draw or show something that represents their experience of caring for the person with stroke. Take a photo of this with the participant's consent.	Option B: How do you feel about this drawing/item? (ask further probing questions as appropriate)
Experiences of caring for the person with stroke	In what ways do you support (person with stroke)?	Physical; practical; psychological/emotional; financial; spiritual
	What is one thing you have loved about supporting (person with stroke)?	E.g. spending more time together; seeing them start to get well
	What has been the most challenging aspect of supporting (person with stroke)?	Anything now or in the past. E.g. change of relationship; resistance from person with stroke; lack of external support
	How has supporting (person with stroke) affected your life or wellbeing?	E.g. work; social life; physical health; finances; emotional wellbeing
	How has supporting affected the household in general?	E.g. household members that stopped schooling; forced to take on extra work; ways to augment income









BARRIERS AND ENABLERS				
Overall support	Have you received any formal or informal support or as a carer?	Probe on type of support		
	Have you received any financial support or compensation? If yes: government or nongovernment? How much compensation? Do you feel that this is sufficient?	E.g. Philhealth; private corp.; civil society organisation groups; charities, etc.		
	Have you received any social/psychological support as a carer? If yes: who provided this? How could it be improved?	E.g. Social support groups; wider community groups; other family member support; mental health services; counselling, etc.		
	Do you feel that you want to talk to someone other than those in your household for emotional support?	E.g. Psychologist; professional; faith healer; spiritual adviser, etc.		
	Have you received any training in looking after someone with a stroke? If yes: who provided this? How could this support be improved?			
	Do you think that where you live (i.e. region, urban or rural area) had any effect on the support you received as a carer? How? Please explain.	Probe more on this		
Knowledge, skills and confidence as a carer	Where did you (or do you) get information about stroke and caring for someone with	E.g. health professionals; support groups; online; other sources of information		













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	stroke? Was there anything that you wanted to know that would have helped you? (knowledge)			
	What skills do you think are important in your role as a carer? Are there skills you think are important to develop? (skills)	E.g. communication; listening and understanding; supporting while encouraging independence		
	What (if anything) would help you feel more confident in your role supporting	E.g. more information; support from health workers; sharing		
	(person with stroke)? (confidence)	experiences with other carers		
Other barriers and enablers	Is there anything we have not discussed that gets in the way of supporting (person with stroke) to do more of what they want to do?			
	What would help you to support (person with stroke) in doing more of the things they love?			
RECOMMENDATIONS				
General improvements to services supporting people with stroke and carers	Based on your experience, what improvements can be made to the stroke rehabilitation and care systems in your area?	E.g. access to healthcare facilities; more support groups; training of health workers; public awareness; improved funding; greater involvement of family carers.		
Recommendations for TULAY programme	We are looking to design a new self-management programme for people with stroke and their families or carers in your community.			













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	What would you like it to include?	E.g. types of activities (exercise, music, relaxation); shared experiences of other
	What resources or tools would help you?	carers; meeting other carers; progress tracker or diary; stories; videos; pictures.
	Would you prefer:	, p. c.
	Written or online resources? Website or app?	Probe on preferred content and format. Any other
	Guided by a care professional or work through with the	suggestions?
	person with stroke?	
	Group or one-to-one therapy?	
Top tips and advice for other carers	What are your top tips for other people like yourself who are supporting a person with	
	stroke?	
	What advice would you give to people (like health workers)	
	who are supporting carers?	
Additional	Do you have any final	
comments	thoughts or additional comments?	
	Do you have any questions for the interviewer?	

Interviewer summary:

- Summarise key points discussed during the interview.
- Ask if there is anything they would like to discuss further and state that you are available to
 discuss the study, especially if there are any issues that arose or discussion points that may
 have caused distress.
- Check they are still happy for the recorded interview/photos/videos to be used for the purposes stated on the consent form.
- Thank the participant for their time and insights. Give token.
- Ask if they would like to receive a summary of study findings.





