

**APPENDIX A**  
**LIST OF EXPERTS**

---

Three experts were consulted regarding the content validity of the Demographic Data Record Form, the Interview Guide and the Observation Guide. They were:

1. Associate Professor Dr. Boovandee Petcharat  
Faculty of Nursing, Prince of Songkla University
2. Assistant Professor Dr. Ploenpit Thaniwattananon  
Faculty of Nursing, Prince of Songkla University
3. Dr. Umaporn Boonyasopun  
Faculty of Nursing, Prince of Songkla University

**APPENDIX B**  
**QUALITATIVE STUDY INFORMED CONSENT FORM**  
**FOR PARTICIPANT**

---

**Investigator:** Miss Lim Phaik Hooi

**Explanation of Procedures**

You are being asked to participate in a research project designed to study the experiences of family caregivers caring for family members with chronic schizophrenia at home, in Kelantan. This study is being conducted by Lim Phaik Hooi, a master student at the Faculty of Nursing, Prince of Songkla University, Thailand. If you decide to participate in this study, you will be asked questions from Demographic Data Record Form and to participate in interviews with the researcher to explain and describe your experiences related to your caring.

The interview will be in Malay language (Bahasa Malaysia) and will take more than one occasion. Each interview will last about 60 to 90 minutes. The interview will be audiotaped by the researcher and later transcribed verbatim. There will be no identifying of names on the tapes or reports. You will be asked to review transcriptions of the interview and comment about the transcriptions of the study.

**Risks and Comforts**

There are no known risks to participation in this study. However, it is possible that during the interview you may feel a little anxious or sad when recalling your experiences of caring. Some may say that telling their experiences make them feel better. Your participation is voluntary, you have the right to participate or not to participate. There will be no penalty if you decide not to participate. There is neither cost nor will there be any payment to you for your participation.

**Benefits**

The information gathered will be used to write research report and may be presented at professional meetings. The information will help nurses and other health care professionals to understand the concept of 'caring' by family caregivers caring for family members with chronic schizophrenia and to promote better care for them as caregivers.

**Confidentiality**

All information and your responses in connection with this study will remain confidential. Only the researcher and the advisors are eligible accessing the data. Neither your name nor any identifying information will be used in the reports of the study. The tapes will be destroyed after completion of the study.

**QUALITATIVE STUDY INFORMED CONSENT FORM  
FOR PARTICIPANT  
(continued)**

---

**Withdrawal from Participation**

You have the right to withdraw from participation anytime without any problems prior to completion of data collection.

**Legal Rights and Signatures**

You will receive a copy of this consent form. Your signature on the form will indicate that you understand what is involved and that you consent to participate in this study.

\_\_\_\_\_  
(Name of Participant)

\_\_\_\_\_  
(Signature of Participant)  
Or thumb print

\_\_\_\_\_  
Date

Lim Phaik Hooi  
(Name of Researcher)

\_\_\_\_\_  
(Signature of Researcher)

\_\_\_\_\_  
Date

If you have any questions now or at anytime during the study, please feel free to ask or discuss with me. You can contact me at the following address:

Lim Phaik Hooi  
Master in Nursing Science  
Faculty of Nursing  
Prince of Songkla University  
Hat Yai, Thailand  
Tel: (074) 213 060 extension 5209

## APPENDIX B

### MALAY TRANSLATION FORM QUALITATIVE STUDY INFORMED CONSENT FORM FOR PARTICIPANT

### BORANG KEIZINAN KAJIAN KUALITATIF UNTUK PESERTA

---

Penyelidik: Lim Phaik Hooi

#### Penerangan Prosedur

Anda dipelawa untuk menyertai satu projek kajian untuk mengkaji pengalaman yang dialami oleh penjaga (caregiver) bagi ahli keluarga yang mengidap penyakit skizofrenia kronik, di rumah, di Kelantan. Kajian ini adalah dikaji oleh Lim Phaik Hooi, seorang pelajar sarjana di Fakulti Kejururawatan, Universiti Prince of Songkla, Thailand. Jika anda bersetuju untuk menyertai kajian ini, anda akan ditanya beberapa soalan dalam Borang Rekod Demografik serta menyertai dalam temuduga untuk menerangkan dan menghuraikan pengalaman penjagaan anda.

Temuduga akan dijalankan dalam bahasa Melayu (Bahasa Malaysia) dan akan ditemuduga lebih daripada satu kali. Setiap temuduga dijangka akan mengambil masa sekurang-kurangnya 60 hingga 90 minit. Temuduga akan dirakamkan dan kemudian dicatatkan (transcribed). Nama-nama yang dikenalpasti tidak akan dirakamkan dalam pita. Anda akan diminta untuk mengimbas dan memberi komen berkenaan salinan temuduga kajian yang dirakamkan.

#### Risiko dan Keselesaan

Tiada ada sebarang risiko yang mungkin dialami dalam kajian ini, tetapi bila ditemuduga, kemungkinan anda akan berasa sedikit ketidakselesaan atau kesedihan semasa menceritakan pengalaman berkaitan dengan penjagaan anda. Persetujuan untuk menyertai kajian ini adalah secara sukarela. Anda berhak untuk menyertai atau tidak menyertai kajian ini. Tiada ada penalti dikenakan jika anda tidak bersetuju, dan juga anda tidak akan dibayar sebarang bayaran jika bersetuju menyertai kajian ini.

#### Manfaat

Data yang diperolehi akan digunakan untuk laporan penyelidikan. Data ini akan membantu para jururawat dan profesional kesihatan lain memahami konsep penjagaan (caring) oleh penjaga (caregivers) terhadap ahli keluarga yang mengalami skizofrenia kronik serta mempromosi penjagaan yang lebih efektif.

#### Kerahsiaan

Nama-nama yang dikenalpasti tidak akan dicatatkan dalam laporan kajian ini. Pita-pita akan dimusnahkan selepas tamat kajian.

**MALAY TRANSLATION FORM  
QUALITATIVE STUDY INFORMED CONSENT FORM  
FOR PARTICIPANT**

**BORANG KEIZINAN KAJIAN KUALITATIF  
UNTUK PESERTA  
(sambungan)**

---

**Menarik Diri dari Penyertaan**

Anda boleh menarik diri dari menyertai kajian penyelidikan ini pada bila-bila masa.

**Pengesahan dan Tandatangan**

Anda akan menerima satu salinan borang keizinan untuk simpanan anda. Tandatangan anda dalam borang ini mengesahkan bahawa anda memahami segala prosedur kajian dan anda telahpun memberi keizinan untuk menyertai dalam kajian ini.

\_\_\_\_\_  
(Nama Peserta)

\_\_\_\_\_  
(Tandatangan Peserta )  
atau Cap Jari

\_\_\_\_\_  
Tarikh

Lim Phaik Hooi  
(Nama Penyelidik)

\_\_\_\_\_  
(Tandatangan Penyelidik)

\_\_\_\_\_  
Tarikh

Jika terdapat apa-apa persoalan sekarang atau bila-bila masa, anda boleh berbincang bersama-sama saya pada bila-bila masa. Saya dapat dihubungi melalui alamat berikut:

Lim Phaik Hooi  
Master in Nursing Science  
Faculty of Nursing  
Prince of Songkla University  
Hat Yai, Thailand  
Tel: (074) 213 060 extension 5209

**APPENDIX C**  
**DEMOGRAPHIC DATA RECORD FORM**

---

Code: \_\_\_\_\_

Date of 1<sup>st</sup> interview: \_\_\_\_\_

Time of interview: from \_\_\_\_\_ to \_\_\_\_\_

Residence: \_\_\_\_\_

Telephone number: \_\_\_\_\_

**Part I: Caregiver Characteristics**

1. Age: \_\_\_\_\_ years
2. Gender: \_\_\_\_\_ male, \_\_\_\_\_ female
3. Religion: \_\_\_\_\_
4. Marital status: \_\_\_\_\_ single, \_\_\_\_\_ married: \_\_\_\_\_ divorced: \_\_\_\_\_ widowed: \_\_\_\_\_
5. Can you read or write in Malay language? \_\_\_\_\_
6. What is your highest level of education obtained? \_\_\_\_\_
7. What is your occupation before? \_\_\_\_\_
8. What is your occupation now? \_\_\_\_\_
9. How long have you been caring for this 'sick' family member? \_\_\_\_\_
10. Do you know what chronic mental illness your 'sick' member is suffering? \_\_\_\_\_
11. What other roles/responsibilities do you have in the family besides caring for this 'sick' family member? \_\_\_\_\_

**DEMOGRAPHIC DATA RECORD FORM (continued)**

---

12. What is your relationship with this 'sick' family member? \_\_\_\_\_

13. What is your income per month? RM \_\_\_\_\_

14. Is it adequate to meet your needs? \_\_\_\_\_ yes, \_\_\_\_\_ no

- If no, why? \_\_\_\_\_

15. Who paid for the hospital expenses for this 'sick' family member? \_\_\_\_\_

16. Condition now:

- Physical: \_\_\_\_\_
- Emotional : \_\_\_\_\_
- Social: \_\_\_\_\_
- Personality: \_\_\_\_\_

**Part II: Care-Recipient Characteristics**

1. Age: \_\_\_\_\_ years

2. Gender: \_\_\_\_\_ male, \_\_\_\_\_ female

3. Marital status: \_\_\_\_\_ single, \_\_\_\_\_ married: \_\_\_\_\_ divorced: \_\_\_\_\_ widowed: \_\_\_\_\_

4. Occupation before illness? \_\_\_\_\_

5. Occupation after illness? \_\_\_\_\_

6. Highest level of education obtained? \_\_\_\_\_

7. Does he/she know what chronic mental illness he/she is suffering from? \_\_\_\_\_

**DEMOGRAPHIC DATA RECORD FORM (continued)**

---

8. Medical diagnosis: \_\_\_\_\_

9. Duration having this diagnosis? \_\_\_\_\_

10. Number of admissions to hospital? \_\_\_\_\_

11. Is he/she having other medical/surgical problems? \_\_\_\_\_

12. Condition now:

- Physical self-care hygiene: \_\_\_\_\_

- Cognition: \_\_\_\_\_

- Emotional: \_\_\_\_\_

- Social: \_\_\_\_\_

13. Receiving any medications? \_\_\_\_ yes, \_\_\_\_ no

- If yes, specify: \_\_\_\_\_

14. Requiring supervision /without supervision \_\_\_\_\_

**Part III: Situational Characteristics**

1. How many other family members live in the same household? \_\_\_\_\_

- Specify : \_\_\_\_\_

2. Types of family:

- \_\_\_\_ nuclear family ( \_\_\_\_ parents, \_\_\_\_ single parent, \_\_\_\_ sons/daughters, or

- \_\_\_\_ extended family ( \_\_\_\_ grandparents, \_\_\_\_ parents, \_\_\_\_ sons/daughters,  
\_\_\_\_ other relatives)



**DEMOGRAPHIC DATA RECORD FORM (continued)**

---

3. Who else (besides the 'sick' family member) in the household needs your help?

---

4. Who else in the household assist you in the caring of the 'sick' family member?

---

5. Is there any other support given to this 'sick' family member?  yes,  no

- If yes, specify what kind of support given (physical, psychosocial or emotional):

---

---

**APPENDIX D**

**INTERVIEW GUIDE**

---

- |   | Notes/Comments |
|---|----------------|
| 1. Please tell me what happened when you take care of him/her all this while? |                |
| <b>Probe:</b>   |                |
| (a) In the morning  |                |
| • What do you do?   |                |
| • What are the reasons for saying that?                                       |                |
| • What is the result or does it work?   |                |
| • How do you feel?  |                |
| • What does it mean to you?   |                |
| <br>(b) In the afternoon?   |                |
| (Use probe as in a.)  |                |
| <br>(c) In the evening?   |                |
| (Use probe as in a.)  |                |
| <br>(d) At night?   |                |
| (Use probe as in a.)  |                |
| <br>(e) When you are go out?  |                |
| (Use probe as in a.)  |                |
| <br>(f) When there is disruptive behavior?                                    |                |
| • How do you feel?  |                |
| • What do you do to cope?   |                |
| - medication?   |                |
| - signs and symptoms?   |                |
| - anything else?  |                |
| • Any reason for doing that?  |                |
| • What does it mean to you?   |                |
| • Any reason for saying that?   |                |
| • What is the result or does it work?   |                |
| • How it affects other members?   |                |
| • What's the impact?  |                |
| • How often this occurs?  |                |

## INTERVIEW GUIDE (continued)

---

- |  |                       |
|--|-----------------------|
| <p>2. When caring for your member with chronic Schizophrenia, what does 'caring' mean to you?</p> <p>3. How do you feel when caring for him/her?<br/><b>Probe:</b><br/>(a) What are the reasons for saying that?</p> <p>4. What are your needs when caring for him/her?<br/><b>Probe:</b><br/>(a) Are there any reason for saying that? (physical/emotional/psychological/social/spiritual)<br/>(b) Give examples?<br/>(c) How do you feel?<br/>(d) What other needs do you need to have?<br/>(e) What else do you consider?<br/>(f) How does it help you?<br/>(g) Any reason for saying that?</p> <p>5. What are the impacts of this caring?<br/><b>Probe:</b><br/>(a) How do you feel?<br/>(b) Any reason for saying that?(physical/emotional/psychological/social/spiritual)<br/>(c) Can you give me an example?<br/>(d) How has it affects you? (positive/negative)<br/>(e) In what way?</p> | <p>Notes/Comments</p> |
|--|-----------------------|

I have asked you a lot of questions. Maybe there is one thing that I should have asked. Is there anything else that you think is very important to know while taking care of him/her?

End with .... You have shared a lot of your experience with me. I want to assure you that all information will be kept confidential. Before we end, may you tell me what do you think of this interview? Thank you so much for taking this time of yours to share with me.

**APPENDIX E**  
**OBSERVATION GUIDE**

---

**1. Overview of Environment Surrounding the House**

1.1. Main features present (mosque/community health centers/shops or stores  
housing units/roads /public transportation

---

1.2. Major activities going on

---

**2. Overview of Environment Within the House**

2.1. Main features of the physical setting

---

2.2. Major activities going on in the house

---

2.3. Number of households present (specify who)

---

2.4. Presence of things that specify belief/religious system

---

2.5. Safety hazards

---

2.6. Cleanliness

---

**3. Caregiver Characteristics/Situations**

3.1. General appearance

---

3.2. Activities and interactions going on

---

3.3. Verbal communication behaviors

---

**OBSERVATION GUIDE (continued)**

---

3.4. Nonverbal communication behaviors

---

3.5. Types of affect manifest during interactions

---

3.6. Activities when begin and when schedule to end

---

3.7. Events that are disruptive to the activities or situations

---

**4. Care-Recipient Characteristics/Situations**

4.1. General appearance

---

4.2. Activities and interactions going on

---

4.3. Verbal communication behaviors

---

4.4. Nonverbal communication behaviors

---

4.5. Types of affect manifested during interactions

---

4.6. Activities begin and when schedule to end

---

4.7. Events that are disruptive to the activities or situations

---

## VITAE

**Name** Ms Lim Phaik Hooi

**Date of Birth** 27th February 1958

### Education Attainment

<b>Degree</b>	<b>Name of Institution</b>	<b>Year of Graduation</b>
Bachelor of Nursing	University of Sydney, Australia	1996
Advanced Nursing Education	University Malaya, Malaysia	1991
Critical Care Nursing	University Science Malaysia	1988
Basic Nursing	College of Nursing, Ipoh, Perak, Malaysia	1983

### Professional Activities:

Paper Presentation: Lived Experiences of Family Caregivers Caring for Members with Chronic Schizophrenia at Home in Kelantan, Malaysia. International Conference on Traditions, Evidence and Innovations in Nursing. March 21<sup>st</sup> - 23<sup>rd</sup>, 2002 at Royal Phuket City Hotel, Phuket, Thailand.