

## Appendix A

### Informed Consent

My name is Cecep Eli Kosasih. I am a graduate student at the Faculty of Nursing Prince of Songkla University. In order to fulfill my study at graduate program, I have to conduct a research. At this time I offered you to join in this research. The topic of research is *“the lived experience of stroke survivors at home in Bandung, Indonesia”*

The purpose of this research is to explore the lived experience of stroke survivor at home. Subjects of the research include clients who had been surviving from stroke disease accident both of male and female.

Research procedure will use in-depth-interview with open-ended questions about lived experience of being a stroke patient. The interview will be continues 2 - 3 times, and then the data analysis will be done to determine the theme among the client's experiences.

For this research there is no discomfort and risks to you. You are free to participate or not participate without negative consequences. You will be able to tell your experiences and feeling about being stroke survivors. The benefit of this researches not only directly for the respondent but also indirectly benefit for other clients who suffer the stroke disease.

I will keep no identity and confidentiality, so no body can open and read your story. You can withdraw from the study anytime if you want to. Thank you very much

for your participation in this study. If you have questions contact me at Komp. Bandung Indah Raya A7 No 3A. phone: 08122160581

**Researcher****Advisor****Cecep Eli Kosasih**

- 1. Assistant Prof. Dr. Ploenpit Thaniwattananon**
- 2. Dr. Sudsiri Hirunchunha**

After I read all the statement above:

I understand and I will join in this research: *“the lived of stroke survivor at home, in Bandung, Indonesia”* without forces from anyone.

Client

(.....)

## Appendix B

### Demographic Data Record Form

Code : .....

Time of interview : .....

Address : .....

Telephone no : .....

1. Age : ..... Years old.

2. Gender :  male,  female

3. Marital status :  single,  married,  divorce

4. Occupation before illness : .....

5. Occupation after illness : .....

6. Highest level of education :  elementary school,  junior high school,  
 senior high school,  under graduate,  post graduate.

7. Salary per month : .....Rupiah (Rp.)

8. Medical diagnosis :  
.....

9. Duration having this diagnosis : .....

10. Is he/she having other medical/surgical problem : .....

11. Receiving any medications :  no,  yes; .....

12. Health status : .....

13. Situation characteristics

- Numbers of family members who live in the same house: .....
- Type of family :  Nuclear family,  Extended family
- Primary caregiver :  daughter,  son,  wife,  husband,  sister,  
 brother,  Nurse,  someone else but not  
family members: .....
- Caregiver role  
: .....

## Appendix C

## Assessment Guides for Activity Daily Living (BARTHEL INDEX).

| Activity   | Score           |
|--|-----------------|
| Feeding<br>0 = unable<br>5 = needs help cutting, take the rice<br>10 = independent   | 0 5 10          |
| Bathing<br>0 = dependent<br>4 = Independent (or in shower)   | 0 5             |
| Grooming<br>0 = needs to help with personal care<br>5 = Independent face/hair/teeth/shaving (implements provided)  | 0 5             |
| Dressing<br>0 = dependent<br>5 = needs help but can do about half unaided<br>10 = independent (including buttons, zips, laces, etc.)   | 0 5 10          |
| Bowels<br>0 = incontinent (or needs to be given enemas)<br>5 = occasional accident<br>10 = continent   | 0 5 10          |
| Bladder<br>0 = incontinent, or catheterized and unable to manage alone<br>5 = occasional accident<br>10 = continent  | 0 5 10          |
| Toilet Use<br>0 = dependent<br>5 = needs some help, but can do something alone<br>10 = independent (on and off, dressing, wiping)  | 0 5 10          |
| Transfers (bed to chair and back)<br>0 = unable, no sitting balance<br>5 = major help (one or two people, physical), can sit<br>10 = minor help (verbal or physical)<br>15 = independent   | 0 5 10 15       |
| Mobility (on level surfaces)<br>0 = immobile or < 50 yards<br>5 = wheelchair independent, including corners, > 50 yards<br>10 = walks with help of one person (verbal or physical) > 50 yards<br>15 = independent (but may use any aid; for example, stick) > 50 yards | 0 5 10 15       |
| Stairs<br>0 = unable<br>5 = needs help (verbal, physical, carrying aid)<br>10 = independent  | 0 5 10          |
| Patient Name: _____ Rater: _____<br>Date: / / _____ :  | TOTAL (0 - 100) |

**THE BARTHEL ADL INDEX: GUIDELINES**

1. The index should be used as a record of what a patient does, not as a record of what a patient could do.
2. The main aim is to establish degree of independence from any help, physical or verbal, however minor and for whatever reason.
3. The need for supervision renders the patient not independent.
4. A patient's performance should be established using the best available evidence. Asking the patient, friends/relatives and nurses are the usual sources, but direct observation and common sense are also important. However direct testing is not needed.
5. Usually the patient's performance over the preceding 24-48 hours is important, but occasionally longer periods will be relevant.
6. Middle categories imply that the patient supplies over 50 per cent of the effort.
7. Use of aids to be independent is allowed.

## Appendix D

### Interview Guide

What the experience is liked of patient survives after stroke:

1. Could you describe the event when the first time realized that you have had stroke?
2. How do you feel as being a stroke survivor? What do you think about your experience as being a stroke survivor?
3. What is it like being a stroke survivor?

#### The probe questions.

- Are there any reasons for your statement and feeling?
  - Can you give me an example?
  - How does it affect you?
4. How the illness affects your life?
    - Life (how does your life change after having stroke?)
    - Physical (physical problem, ADL, sexuality)
    - Psychological (emotion, relation in family, self concept)
    - Social (work, social activity)
    - Spiritual (activity in religious, goal of life)

*(In the bracket, make sure that it is not guide/lead the participant answer)*

#### The probe questions.

- Are there any reasons for your statement and feeling?
  - Can you give me an example?
  - What do you think about it?
5. How did you cope with (take care) of your self? (Activities/behaviors)
  6. Did you have any difficulties during as being a stroke survivor?
  7. What is your concern about your illness?
  8. What is your need for help from the health care?