

# A VIEWPOINT OF *HOME-BASED CARE SERVICE* ON STROKE PATIENTS IN THE JAVANESE MOSLEM ETHNIC, INDONESIA: A QUALITATIVE STUDY

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(Key Words) Stroke, Javanese Ethnics, Family Care, Quality of Care

## 1. Background

The issue of quality health services is still the focus of various parties. To ensure effective, efficient, safety, and affordable health services, a *patient-centered care* approach should be undertaken (Institute of Medicine, 2001).

Usually health services run in the hospital, but can also be operated by home-based visits/ home-based care. According to Bokhour the quality of home-based care services is more difficult to assess than hospital service, because it is much influenced by the role of family as caregiver. The patient's perception of the quality of health care they received has been studied as a separate part of the health service performance assessment in the form of quality indicators (Bokhour et al., 2009).

Although patient and family involvement is important in constructing quality indicator, there is little evidence or literature that indicates the role of patients and families in the preparation of home-based care service indicators of stroke patients. Thus this study pursues to explore the expectations of stroke patients for the care they receive at home-based, the family, and the health workers as home-based care providers.

## 2. Method

This study used cross sectional qualitative explorative model. We collected the data by semi-structured interviews and focus group discussion. The data analyzed by grounded theory approach (Glaser & Strauss, 2006) and presented with COREQ systematics for qualitative research (Tong, Sainsbury, & Craig, 2007). This research has obtained a letter of ethics from the Ethics Committee of the Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada.

The main participants in this study were 10 stroke patients and 9 family caregivers. We also performed focus group discussions on home-based care services officers at primary health care. There were two questions asked to informants, namely;

1. What kind of patient condition is expected after receiving home-based care service?
2. What kind of family condition is expected after a home-based care service?

We transcript all interview data with verbatim transcription style. Determination of coding to theme was done with software open code version 13.

## 3. Results

Analysis with open code obtained 145 coding, which then grouped into 9 main variables related to quality of home-based care service on stroke survivor which were fulfilled daily living activity, free of complication, positive psychological condition, negative psychological condition, social activity, role in family, health counseling, family independence in patient care, and family coping.

The nine variables were then reduced to four themes i.e. physical well-being, self-actualization, psychological conditions and balance between family burden and coping.

## 4. Discussion

Indonesia still holds a patrilineal culture, even though married or adult son/daughter still gather with parents as a big family. This culture also carries the consequence that if the parent is sick then the caregiver is the child or the child's couple. The duty of child to taking care the parents is also influenced by the religion belief that most of the Indonesian population embraces Islam with the term "birrul waalidain" which mean devoted to parents as stated in Al-Quran surah Al-Isra 23-24, An-Nisa 36, Al - Ahqof 15-16 (Religious Department the Republic of Indonesia, 2000). This is what underlies the results of this study that the home-based care of stroke patients was entirely done by the child, wife or husband (family caregivers).

Most patients wish to recover, and able work again. Indonesian residents interpret illness and want to go to health facility when only they cannot work anymore. The existence of a stroke that causes weakness and limb paralysis resulted in almost all stroke respondents cannot work anymore. The patients and family members tend to consider that the physical well-being must be the most important factor.

Family health status becomes another key factor. Healthy, non-stressful families will have an impact on treated patients, such as when the family is healthy and happy, the patient will have better care, and vice versa, if the family is stressed and grumpy during the treatment, it will make the patient feel inferior and depressed (Lee, 2008).