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What do caregivers of stroke survivors consider as activities of daily living: a qualitative interview and a descriptive survey?

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Abstract

Background. Stroke can result in the loss of activities of daily living (ADL). When caregivers focus on improving ADL, better outcome can result. However, what is considered as activities of daily living may differ between one culture and another, and between one country and the other.

Aim. The aim of the present study is to explore what caregivers of stroke survivors consider as ADL.

Findings. The caregivers consider in addition to the activities in the existing ADL scales, activities such as looking after kids, seeking for knowledge and Muslim prayer and ablution as parts of ADL.

Conclusion. It is important that rehabilitation programs after stroke consider what the patients and their caregivers consider as ADL.

Key words: stroke, caregivers, activities of daily living, rehabilitation, functional recovery

Introduction

Stroke is a non-traumatic, focal vascular-induced injury of the central nervous system which typically results in permanent damage in the form of cerebral infarction, intra-cerebral hemorrhage and/or subarachnoid hemorrhage (Cheung, 2014). People who survived a stroke may have different outcomes as a result

of impairment in motor, cognitive and perceptual/sensory functions. These impairments often lead to activity limitation and participation restriction (Jette et al., 2005) which in turn further reinforce the impairment, and create a vicious cycle. This vicious cycle usually may also result in loss of or dependence on caregivers in activities of daily living (Miller et al., 2013).

Activities of daily living (ADL) are activities like bathing, dressing, eating and toileting people carry out which are necessary for their daily independent life. It has been estimated that, between 25% and 74% of the 50 million stroke survivors worldwide may need assistance or are fully dependent in activities of daily living on caregivers (Miller et al., 2013). Thus as a consequence, improvements in impairments (Bhogal et al., 2003) and participation restriction (Jette et al., 2005) could be influenced through the help of caregivers. In fact, when caregivers focus on promoting independence in activities of daily living, patients may become more independent in ADL (Bhogal et al., 2003).

Nevertheless, what constitutes activities of daily living (ADL) may differ from one culture to another and from one country to another. For instance, a recent study by Abdullahi and colleagues (Abdullahi et al., 2015) showed that the Muslim prayer and ablution are deeply entrenched ADL among the people of Kano, a North-western State of Nigeria. Since ADL may differ among different people and cultures, and that caregivers can help in promoting independence, the knowledge of what stroke patients' caregivers consider as ADL is paramount in designing rehabilitation programs after stroke. Additionally, patients and caregivers have their perceptions of the functional status and the meaningfulness of the activities they patients can perform or not (Davis et al., 2006; Dickerson et al., 2012). Therefore, the aim of this study is to explore what caregivers of stroke survivors consider as activities of daily living.

Method

The study was a Qualitative Interview and a descriptive survey exploring and describing stroke patients, caregivers' views of what they consider as activities of daily living (ADL). The population of this study was all stroke patients caregivers who accompany them to Murtala Muhammad Specialist Hospital (MMSH) Kano. A total sample of 47 participants who accompany stroke patients undergoing rehabilitation in the above named hospital were used in the study. Participants were included in the study only if they gave a written consent after they were debriefed about the study.

The Institutional Review Board of Kano State Hospitals Management Board gave ethical approval for this study. Data of the study was collected using a Qualitative Interview Guide and Descriptive Survey Questions Proforma and Demographic Characteristics Proforma (see appendix I for the details). Each of the study

participants was individually interviewed and surveyed. Their responses were recorded using a tape recorder. The qualitative data collected was then coded and transcribed and themes generated were analyzed using content analysis (see appendix II for the variables coding). The data generated from the descriptive survey was analyzed using descriptive statistics of percentages.

Results

Forty seven participants with age range 21-57 gave consents to participate in the study. Out of this, 55% were females and 45% were males. The demographic characteristics of all the participants are shown in table 1.

For the qualitative data, the themes generated include social interaction, mobility, toileting, grooming, seeking for knowledge, dressing, eating, cooking, looking after kids, sweeping, bathing, praying, washing and ablution (see table 2 for more details). For the descriptive survey, more participants answered yes to 7 out of 11 questions, and more participants answered no to 4 questions out of 11 (see table 3 for more details).

Table 1. Demographic characteristics of participants

Age range	25-57
Gender	Male 21(45%) Female 26(55%)
Marital status	Single 9(19%) Married 33(70%) Divorced 2(4%) Widow/ Widower 3(6%)
Education	Tertiary 9(19%) Secondary 12(26%) Primary 11(23%) Informal 5(11%) None 10(21%)
Relationship	Husband 3(6%) Wife 1(2%) Brother 5(11%) Sister 4(9%) Mother 6(13%) Father 9(19%) Grandmother 5(11%) Grandfather 5(11%) Cousin 3(6%) Friend 7(15%)

KEY: n=number of participants, SD=Standard Deviation, %=percent

Table 2. Matrix analysis of the interview

Participants	Q1	Q2	Themes
1	Eating, visitation, conversation, problem solving, cooking, ablution, transfer, toileting, looking after kids, prayer	Toileting, ablution and prayer	Social interaction, mobility, toileting, grooming, seeking for knowledge, dressing, eating, cooking, looking after kids, sweeping, bathing, praying, washing and ablution.
2	Cooking, eating, toileting, bathing, dressing, grooming, conversation	Toileting and feeding	
3	Standing, bathing, brushing, toileting, working, hair combing, nail grooming, seeking for knowledge, prayer, conversation	Toileting	

4	Bathing, taking medication, prayer, ablution, brushing, nail grooming, combing hair, conversation	Mobility
5	Standing, feeding, ablution, prayer, walking, toileting, conversation	Walking
6	Transfer, eating, dressing, conversation, prayer, communication	Communication
7	Transfer, brushing, cooking, eating, dressing, toileting, conversation, prayer, ablution	Transfer, toileting
8	Eating, praying, toileting, ablution, prayer, conversation	Toileting and bathing
9	Cooking, brushing, toileting, bathing, washing, eating, dressing, conversation	Toileting, prayer and bathing
10	Conversation, eating, cooking, nail grooming, bathing, prayer, ablution	Eating
11	Eating, conversation, standing, walking, ablution, prayer, dressing, toileting	Toileting, eating and dressing
12	Transfer, eating, dressing, bathing, toileting, problem solving, ablution, prayer, conversation, social interaction	Bathing
13	Sweeping, washing plates, cooking, washing, bathing, eating, toileting, transfer, stair climbing, social interaction, ablution, prayer, nail grooming	Washing plates, bathing and transfer
14	Transfer from bed to chair, ablution, prayer, eating, dressing, conversation, toileting	Eating and prayer
15	Washing plates, cooking, eating, washing clothes, conversation, ablution, prayer, nail grooming, transfer	Cooking and toileting
16	Walking, bathing, dressing, transfer from chair to bed, toileting, ablution, prayer, eating, conversation, nail grooming, brushing	Pray while standing, personal hygiene
17	Eating, bathing, mobility, toileting, brushing	Mobility
18	Bathing, eating, dressing, washing, ablution, prayer, toileting, conversation	Eating and toileting
19	Transfer, eating, bathing, dressing, grooming, toilet hygiene	Eating and toileting
20	Eating, ablution, praying, toilet hygiene, conversation, bathing, dressing, brushing, walking	Ablution and praying

21	Bathing, dressing, walking, toileting, conversation	Bathing and eating
22	Bathing, eating, toileting, mobility, brushing	Mobility
23	Eating, standing, conversation, bathing, dressing, brushing, prayer, ablution, eating	Standing and eating
24	Brushing, toileting, dressing, hair grooming, walking, nail grooming, bathing	Walking and bathing
25	Walking, ablution, prayer, standing, eating, bathing, dressing	Ablution and prayer
26	Eating, bathing, conversation, toileting, hair grooming, transfer	Eating and bathing
27	Dressing, walking, toileting, ablution, prayer, eating, conversation	Walking, eating, toileting
28	Toileting, ablution, prayer, dressing, eating, conversation, walking, brushing	Ablution, prayer, walking and eating
29	Transfer, conversation, bathing, nail grooming, prayer, ablution, toileting,	Bathing, toileting and prayer
30	Washing plates, cooking, eating, bathing, kids rearing, ablution, prayer, walking	Looking after kids, toileting, eating and walking
31	Dressing, bathing, eating, social interaction, toileting, standing, walking, sitting, ablution, prayer	Praying
32	Bathing, walking, eating, dressing, conversation, toileting	Walking
33	Bathing, dressing, eating, brushing, mobility, prayer, ablution, toileting	Eating
34	Cooking, dressing, eating, conversation, ablution, prayer, toileting	Toileting and dressing
35	Eating, cooking, kids rearing, bathing, dressing, washing dishes, washing, toileting	Cooking and bathing
36	Dressing, eating, ablution, prayer, toileting, cooking, hair grooming, social interaction, conversation	Cooking, toileting and prayer
37	Bathing, eating, brushing, nail grooming, conversation, toileting	Bathing and toileting
38	Dressing, bathing, toileting, cooking, conversation, washing plates	Toileting

39	Bathing, dressing, walking, toileting ablution, transfer from bed to chair, prayer, brushing	Ablution, prayer and walking
40	Washing, toileting, bathing, dressing, eating, stair climbing, conversation, sweeping, walking, cooking	Bathing, cooking and walking
41	Dressing, bathing, eating, brushing, toileting, walking, conversation, prayer, ablution	Eating and toileting
42	Bathing, cooking, standing, walking, dressing, kids rearing, nail grooming, brushing, toileting, eating	Cooking and eating
43	Toileting, eating, conversation, dressing, conversation, grooming, prayer, ablution	Eating, conversation and toileting
44	Oral hygiene, bathing, eating, dressing, toileting, conversation	Eating
45	Eating, dressing, brushing, prayer, ablution, conversation, toileting	Prayer
46	Cooking, eating, bathing, dressing, grooming, conversation	Toileting and eating
47	Bathing, brushing ,toileting, walking, working, eating	Working

Table 3. Responses to the descriptive survey questions

QUESTION	YES	NO
1) Do you consider ablution as an ADL?	28(59.6%)	19(40.4%)
2) Do you consider prayer as an ADL?	29(61.7%)	18(38.3%)
3) Do you consider conversation as an ADL?	30(63.8%)	17(36.2%)
4) Do you consider grooming as ADL e.g combing, nail cutting?	26(55.3%)	21(44.7%)
5) Do you consider mobility as ADL?	18(38.3%)	29(61.7%)
6) Do you consider toileting as ADL?	41(87.2%)	6(12.8%)
7) Do you consider feeding/drinking as ADL?	45(95.7%)	2(4.3%)
8) Do you consider washing as ADL?	6(12.8%)	41(87.2%)
9) Do you consider dressing as ADL?	31(65.9%)	16(34.0%)
10)Do you consider social interaction as ADL?	3(6.4%)	44(93.6%)
11) Do you consider transfer from bed to chair or wheelchair as ADL?	12(25.5%)	35(74.5%)

Discussion

Stroke can alter roles in carrying out activities of daily living. In some cases, patients are dependent on their caregivers for ADL (Jongbloed et al., 1993; Scholte et al., 1998) who are noted to be important for the patients' improvement especially when they focus on the patients' improvement in ADL (Boghal et al., 2003; Jette et al., 2005). However, it was reported that, what constitutes ADL may differ among people (Abdullahi et al., 2015). We therefore conducted a qualitative interview and a descriptive survey to explore and describe what stroke patients' caregivers consider as ADL.

From the result of this study, activities such as social interaction, mobility, toileting, grooming, seeking for knowledge, dressing, eating, cooking, looking after kids, sweeping, bathing, praying, washing and ablution are considered as activities of daily living by the caregivers of stroke patients. This finding underscores the importance of interactive communication between the therapists and the patients, and their caregivers in designing rehabilitation programs for patients with stroke. Previous finding (Stewart et al., 2000) showed how patient centered care can result in better recovery and overall self-reported health.

The interesting findings in this study as expressed by some of the participants include cooking, sweeping, and looking after kids which are considered as part of their ADLs. Another participants also expressed seeking for knowledge as part of ADLs. These activities are not documented in the existing scales used in assessing ADLs. However, these findings show that, people tend to prioritize their ADL needs. For example, a group of 80 year - olds ordered their ability in ADL in which they ranked cutting nails and feeding as the most difficult and last, respectively (Kingston et al., 2012). Considering the accuracy and reliability of caregivers' report of their patients' ADL status (Miller et al., 2013), it is very important we hear from the caregivers what they consider as ADL in their patients. This will help all the stakeholders including the therapists, the patients and their caregivers collaborate in designing a robust rehabilitation program for the patient.

Conclusion

It is important that rehabilitation programs after stroke consider what the patients and their caregivers consider as ADL.

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Appendix I: Qualitative Interview Guide and Descriptive Survey Questions

Part A: Qualitative Interview Guide

1. What do you consider as activities of daily living (ADLs)?
2. What are the most important you wish the patient will be able to do?

Part B: Descriptive Survey Questions

1. Do you consider ablution as ADL?
2. Do you consider prayer as ADL?
3. Do you consider conversation as an ADL?
4. Do you consider grooming as ADL e.g combing, nail cutting?
5. Do you consider mobility as ADL?
6. Do you consider toileting as ADL?
7. Do you consider feeding/drinking as ADL?
8. Do you consider washing as ADL?
9. Do you consider dressing as ADL?
10. Do you consider social interaction as ADL ?
11. Do you consider transfer from bed to chair or wheelchair as ADL?

Appendix II

Variables Coding

V1- variable name = Social interaction, variable description= communication, conversation.

V2- variable name = Eating, variable description= eating or feeding.

V3- variable name = Mobility, variable description = mobility, transfer, walking

Variable 4-variable name = Toileting = toilet hygiene, toileting and personal hygiene.

Variable 5- variable name = Dressing, variable description = dressing.

Variable 6- variable name = Grooming, variable description = brushing, combing hair, nail cutting, nail grooming.

Variable 7 - variable name = Studying , variable description = seeking for knowledge.

Variable 8 - variable name = Cooking, variable description = cooking.

Variable 9 - variable name = Looking after kids, variable description = looking after kids.

Variable 10- variable name = Sweeping, variable description = sweeping, mopping.

Variable 11 - variable name = Bathing, variable description = bathing, showering.

Variable 12- variable name = Prayer, variable description = muslim prayer.

Variable 13 - variable name = Washing, variable description = washing plates, washing dishes and washing clothes.

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