Evaluation of Home Caregiving Program by Jordanian Stroke Patients' Caregivers: Qualitative Study

Andaleeb Abu Kamel^{1*} Hussein Mohammed²

- 1. Faculty of Nursing, Al-Zaytoonah University, PO Box: 130 Amman (11733) Jordan
- 2. Faculty of Nursing, Al-Zaytoonah University, PO Box: 130 Amman (11733) Jordan
- * E-mail of the corresponding author: andaleeb@zuj.edu.jo;andaleebabk@ymail.com

Abstract

The purpose of this qualitative study was to explore caregivers' perception and evaluation of a home caregiving program entitled by "*There is a Patient in Our Home*". Seven Jordanian women were recruited purposefully from a governmental hospital in Amman. Data was collected through face-to-face interviews. Researcher used semi-structured questions to elicit credible responses. Content analysis was used to analyse data. Before discharge from hospital, women were "inadequately prepared" for their caregiver role. In home, women expressed "incompetency" in performing caregiving activities. The available sources of caregiving information and skills were culturally inappropriate for the women. Language, simplicity and attractiveness of the movies were areas of "satisfaction". Verbal commentary guidelines associated with each caregiving step was a strong point of the program. Women expressed "dissatisfaction" for lack of certain subjects. Before hospital discharge, providing families with culturally convenience caregiving educational program will increase caregivers' knowledge and competencies, subsequently stroke patients' general health will improve and frequency of rehospitalisation rate could be declined.

Keywords: Arab, Caregiver, Family, Home-Caregiving, Jordan, Stroke

1. Introduction

According to World Health Organization (WHO), in Jordan as well as in other developing countries there is growing numbers of people who suffer from stroke due to many risk factors, and due to changes in life style (WHOa, 2013). Long term physical disability and dependency in performing Activities of Daily Living (ADL) are common manifestation of the stroke disease (WHOb, 2013). It has been found that a considerable number of stroke patients will survive from five to ten years after initial incident of stroke. Furthermore, one-fifth of stroke victims require long term care (WHO, 2006). Stroke survivors need intensive long term home-care and assistance in their ADL from family members, close friends or paid attendant (WHO, 2006).

In a unique Jordanian survey; family members play a major role in providing care for physically dependent patients especially if they were elders. In the same survey, the majority of patients have inadequate health insurance, or cannot access health care services (Mahasneh, 2000). At the same time, delegate providing home care for patients by other than family members is considered as a social stigma in Arab-Muslim culture (Al-Heeti, 2007). In Jordan, the health policies have included all elder people in civil health insurance services since 2007. However, the emphasis of health care is directed to the secondary level of care than the tertiary level (National Council for Family Affairs, [NCFA], 2008). In most Arab countries, the Long-term care institutions have not been given similar consideration as acute care services and hospitals (Kronfol, 2012). Taking into consideration the previous facts, lack of governmental home health care services for chronically ill and disabled patients is inadequate. Consequently, the burden of home caregiving of disabled patients including stroke patients is exclusively a responsibility of families.

2. Background

The strong family relationship and the influence of religion and culture force Arab family members especially women to respect and provide an obligatory care particularly for disabled elder people (Hussein, 2010). There is an agreement in caregiving literature about the un-met needs of stroke patients' families in addition to an inadequate support of them in their caregiving journey. Fulfilment of families' needs for information and psychosocial and emotional support were prevalent in literature, however, physical and practical caregiving training were less frequently documented. (Maclsaac, Harrison & Godfrey, 2010). Collins and Swartz (2011) reported that the physical, psychological and financial burden of caregiving on families is significant. Additionally, Collins and Swartz reported different aspects of family support such as Psycho-education, skills training, and counseling services that consequently have positive outcomes on both patients and their families. Experimental research provide evidence about the benefits of some designated programs directed to caregivers to improve their theoretical knowledge, caregiving skills and attitude (Smith & Bell, 2005; Bayik & Uysal, 2010; Noelker & Browdie, 2012). Before hospital discharge, need assessment for family and patient is a key principle for better outcomes. Furthermore, using different types of educational materials, multimedia and computer stimulated learning and videos are recommended in caregiving literature to provide better home care for patients

(Cameron, 2013). In well developed countries there is evidence about preparing families for the caregiver role such as the experience of Family Caregiver Alliance (FCA). The FCA is an organization with a mission of 'improving the quality of life for caregivers and those they care for through information, services, and advocacy"(FCAa, 2014). To enable the FCA to achieve its mission, caregiver-focused video on FCA channel on YouTube website was established. The FCA channel presents many visual family caregiving topics such as home safety, personal care, and other self care aspects (FCA b, 2014). The previous example is helpful for families to guide them to have information, practical guidelines, and support from a professional health care team. Unfortunately, there are inadequate caregiving resources directed to Arab families, either in written or in multimedia forms.

The purpose of this qualitative-phenomenology study was to explore a group of Jordanian women's perception and evaluation of a caregivers program entitled by "There is a Patient in Our Home". Preparing caregivers and providing them with credible and updated home caregiving information through video source may have an impact on caregiving recipient in addition to caregivers in term of physical health and quality of life. Obtaining evaluation and feedback on "There is a Patient in Our Home Program" helps the researchers in assessing the benefits and the pitfalls of the program from group of people who really experienced the burden of long term home caregiving duties. Consequently and based on participants' feedback, researchers will work on a modified second edition of the caregiving program.

3. "There is a Patient in Our Home" Program

"There is a Patient in Our Home" is an educational program directed to Jordanian families as caregivers for chronically ill-dependent patients or elder dependent care recipients. This program is part of a project intended to meet one of the Jordanian community needs that target home caregivers. After thoroughly reading updated and credible relevant literature, seventeen basic home caregiving skills material and scripts were written by researchers and then were reviewed by expert nurses. A professional art-media production company produced the video film series. A famous Jordanian actor and two nurses were engaged in performing the video films as a patient role and as family caregivers' role. Basic Activities of Daily Living (BADL) in addition to Instruments Activities of Daily Living (IADL) were the main subject matter of the educational series. Bathing, hair shampooing, changing bed clothes, shaving, nail care, proper positioning, maintaining patient's safety, taking medication and walking are examples of the educational video films. The total time of the entire skills was 120 minutes. Each film lasting for less than 10 minutes and films were recorded on compact disk (CD).

4. Method

4.1 Design

The philosophical framework adopted in the study was the phenomenology. Worth noting here is the effectiveness of the program under investigation "There is a Patient in Our Home" was quantitatively investigated in a recent quasi-experimental study (Mohammed & Abu Kamel, 2014). Using phenomenology approach in this study, could uncover participants' experience and perception regarding program evaluation, benefits, and weaknesses. These areas could not be measured in a tight controlled empirical design.

4.2 Sampling and Participants

Seven women who were engaged in providing home caregiving activities for stroke relatives during the study were selected. Researchers used the purposive sampling procedure to recruit the most informative caregivers. During follow-up visit for the rehabilitation center, in the largest governmental hospital in Amman, persons who accompanied stroke patients were asked if they were unpaid and primary caregivers for the patients, if their answers were "yes" they were asked to participate in the study. Researchers intentionally recruited women for this study because it was found that home caregiving is a women career in Jordan (Mahasneh, 2000; Abu Kamel, Bond, Froelicher, 2012) as well as globally (UN, 2011). Being women primarily and being wife, mother, sister, daughter and daughter–in-law are the criteria of being primary caregivers for different types of caregiving recipients (FCA c, 2014).

4.3 Data Collection

In-depth, semi-structured and individualized face-to-face interviews were conducted. Data about participants' age, type of relationship with caregiving recipients, and level of dependency of caregiving recipients were collected. Researchers relied on relevant literature in constructing caregiving issues and the list of questions that to be discussed with participants (appendix 1). Six meetings lasting for 15-30 minutes for each woman were held in her home as naturalistic context to have most credible and honest data (Polit & Beck, 2004); the first two meetings were designed to collect data about participants' caregiving background, difficulties, and their perception about their own caregiving competencies. Before the third meeting, each caregiver was given a full caregiving program on CD and they were asked to watch it as much as they wanted for two weeks.

Appendix 1. Example of issues discussed and questions asked to participants during interviews				
	Before discharge from hospital, what type of preparation did you receive to enable you to enact as a competent caregiver?			
First meeting questions	 Why did you not hire a home nurse to assist you in the burden of caregiving? What do you think the major problem you faced during giving care to your relative? 			
	• If caregiving is difficult, which part of caregiving do you think was the hardest for you to handle?			
Second meeting question	• What do you wish to learn to become a competent caregiver?			

Women were given the caregiving program on CD

Third, Fourth, and Sixth meeting questions	Tell me about your feeling when you watched the films.			
	• Regarding the caregiving skills you have watched, what topics did you find most helpful for you?			
	• Regarding caregiving skills you watched, what were the weak points yo have noticed?			
	• Do you think that your daily caregiving skills were changed after viewing the caregiving films? If yes, which skill and why?			
	• Was there any caregiving area you wish to be added to the caregiving video skills?			

Additionally, caregivers were asked to document any note, comment or question to be discussed during the next meeting. The subsequent meetings points were targeting the caregivers' comprehension and level of satisfaction with the watched caregiving films. Data saturation was the point where researchers decided to finish data collection.

4.4 Data analysis:

To attain the participants' insights on the inquiry, the audiotaped interviews and the field notes were analyzed after critical and frequent reading the transcripts. Coding of the data and categorization were employed scrutinizingly Researchers investigated regularities, patterns and themes in order to capture the essence of participants' experience. Synchronizing with data analysis, researchers asked participants about the emerged findings to yield well-validated results.

4.5 Trustworthiness of the Study

To ensure credibility of the data, member-checking technique was utilized by asking participants to provide critical feedback on researchers' interpretation of their responses. Additionally, one peer debriefing session with two experts in caregiving research area was conducted to make certain about validation of the yielded data. To assess transferability of the emerged themes, researchers checked findings with three caregivers other than the study participants, who have similar inclusion criteria of the participants.

5. Ethical Consideration

The proposal of this study was reviewed and proved by Scientific Research and Ethics Committee in Al-Zaytoonah University in addition to Scientific Research Committee in the selected hospital. Participants were asked to sign a consent form after thoroughly full disclosure of the purpose, procedure and timeline of the study. To maintain confidentiality women were given a pseudonym and a confidentiality pledge was signed with them.

6. Results

6.1 Characteristics of Participants

The age of women ranged between 30-79 years, with a mean age of 51.8 years. Half of the women were married. The time since women started providing care for relatives ranged between 2-10 years with mean duration of six years. Three women were daughters, two women were wives, and one was a daughter-in-law and the other was a sister. Five women had less than six years of education. All women were unemployed. Six of the women were living with stroke patients in the same house. Only one woman reported that she received relief from caregiving activities because she was married and had to leave patient at midday time. Stroke patients who received care by

women had a diagnosis of stroke with different residual effect on functional abilities in term of dependency level in addition to effect on speech (Table 1).

acpenaeney.				
Name	Age	Relationship to patient	Caregiving Duration by year	Level of Dependency and communication of the patient
Maha	44	Daughter	7	Partially physical dependent and able to talk
Maysoon	50	Daughter	9	Completely physical dependent and unable to talk
Wafa	30	Daughter	5	Partially physical dependent and unable to talk
Suhair	48	Daughter -in Law	2	Completely physical dependent and unable to talk
Zahia	79	Wife	10	Partially dependent able to talk
Huda	61	Wife	5	Partially dependent able to talk
Hanan	51	Sister	4	Completely dependent difficult to talk

Table 1. Participants' age, type of relationship with patients, duration of caregiving and level of patient's
dependency.

6.2 Before Discharge: Preparation for Caregiver Role.

There is agreement between the participants about the insufficient preparation for caregiver role before patient's discharge from hospital. Rarely, the health team professionals provided detailed home caregiving information even though the participants asked for it. Frequently caregivers expressed dissatisfaction with the caregiving educational material they received. The caregiving educational materials such as printed-papers and books, or verbal instructions, in addition to internet sources for caregiving information were not efficient for all participants to be competent caregivers. Each method has its drawback in term of appropriateness of the information for their level of comprehension, their language, or because of mistrusting the visited websites for credible and updated caregiving information.

Wafa'a: "When my dad was in hospital, nurses and physicians did their best to get him back on his feet again and to get him back home with best health status. We do appreciate that. But, nobody, neither nurses nor physicians imagined how we, as family, would continue providing care for him. They didn't even ask me if I had the basic principles or skills of home caregiving".

Maha: "well, you know what; nurses and physicians expected me and my family to be competent as caregivers by "default". I remember a nurse -in rush- gave me with some tips about how to prevent bedsores. She repeatedly talked about turning my dad from side to side every couple of hours. This was very helpful, but she did not teach me how to do it on practice! Got lost! How bad!".

6.3 Returning Home: Source of Caregiver Information

Hanan: "Before her discharge(sister), the only thing that was given to me was a piece of printed paper which included 15-20 brief points of caregiving tips, and if you asked me to list five of those points right now, I would not remember any". Summing up of 24 hours daily caregiving tasks in few points made me lose my head in some hard caregiving times".

Wafa'a: "Reading how to care for him from books is like a self talk! Nobody can correct you if you think, or, in some upsetting instance act incorrectly. How can I tell that I really understand caregiving actions if they are written just in words!" Reading words may give me some information, but how can it give me skills to practice caring"!

Zahia: "In occasionally exceptional times, when I accompanied my husband for his health visits, some nurses gave lectures about home caregiving, but you know they stand in front of group with maybe 10 or 20 caregivers and patients at the same time. I cannot figure out what I really want to know. Each one has his own needs and unique questions. Because of that I leave the lecture. You know, it's not worthy wasting time in such lectures to have little or no information at all."

The insufficient caregiving information provided to caregivers and the feeling of unpreparedness lead caregivers to be self-dependent in searching for caregiving information from different sources. Seeking accurate and credible caregiving information require a family caregiving library and family caregiving references which are not widely available or are inappropriate because of language barriers. Taking into consideration the participants' age and the low level of education, some printed or recent internet access are considered inappropriate for them.

Maysoon:" It was very difficult for me to see my mom need some help and I could do nothing for her. The first week was awful because I didn't know how to intervene even how to comb her hair! I felt afraid to harm her with any unintentional movement or act. I remember that on one day I called a private nursing center for more than 25 times, can you imagine that!! It was madness to call a nursing center to ask sometimes a trivial question like how I can change her pants!! I heard a nurse laughing, I felt ashamed".

Huda: "Actually, I wish I have had high level of education, so I could read English or even search for any information on the internet. I feel fed up sometimes".

Suhair: "My experience as a caregiver for my mother-in-law taught me how to be self reliant. I remember I sat for of my computer for three unbroken hours to learn how to give her bath from YouTube site. It was helpful sometimes, but the problem was all bathing videos on You Tube were targeting students or professional caregivers where all caregiving medical equipment and specialized utensils were used. But in my case, giving bath using the ordinary home utensils was a big challenge. I even adopted and created many caregiving items by myself".

In well-developed and industrialized countries, the long-term health care for chronically ill patients and the follow up home health services are the responsibility of health care system. In Jordan, the home caregiving services are provided by paid nursing centers in addition to very limited non-profit and nongovernmental institutions.

Huda: "There are many nursing homes which provide paid caregiving activities. For me it is difficult to hire private nurse for my husband actually, because I expected to pay a lot for each visit per working hours and that was not suitable for me.

Maha: "Seeking private nurse to provide care for dad is not an acceptable decision for me or for my family. I will be like disgraced or dishonored by my family and neighbors. In my surroundings (environment), only bad sons fail to provide care for their parents and push them to non-relatives and foreign to care for them". 6.4 Incompetent Caregiver

Participants perceived being a competent caregiver differently, according to their own experience and the dependency level of their relative. Meeting relative's daily needs and maintaining relative's hygiene indicated that caregiver is competent and efficient for participants. For other participants, protecting relatives from surrounding hazards showed acceptable level of caregiving competency they possessed. One of the major problems expressed by caregivers is the difficult communication with patients, which lead them to feel uncertain about what they do.

Maha: "I am not an expert caregiver, as you know, but my caregiving task goes appropriately when I give him bath or when I don't smell a stench".

Suhair: "*I* am proud, you know why? Because while my mother-in-law in her bed, I never allowed any accident or injury to happen to her especially when I bathed her or moved her out of bed, Thank God. My poor neighbor had once fallen down while he was napping. He got pelvic fracture "sadly" though he also had private nurse".

Huda: I know I make out well in providing caregiving activities for my lovely husband when I can manage his medication time line. It is very difficult to give him seven types of medication in different times; morning, midday, and night with different doses, it is mess, right!

Hanan: "I am ready to provide every day and night body care for my sister, but it is hard and heartrending for me to see her seeking and asking for something which I cannot grasp. My sister's speech is often incomprehensible very often and that has pushed me to feel uncertain about anything I do for her. I consider myself fortunate if I communicate with her even for few seconds a day".

6.5 Satisfaction vs. Dissatisfaction

In general, feeling of satisfaction regarding the caregiving education program out-weighted the dissatisfaction responses. The major area of satisfaction was presenting caregiving information in the participants' own mother language. Another area of satisfaction was the simplicity and clarity of the information provided, where every step of skill explicated by vocal commentary guidelines with rational behind each step. Feeling of attraction to continue watching the caregiving series attributed, for participants, to engaging a famous actor in the patient role in the series of the caregiving program.

Suhair: "Learning by your own from You Tube or other similar sources is good, I cannot ignore that, but the problem is the scarce caregiving Arabic source. For me, I cannot understand English. Imitating some instruction just because you see it was horrible for me...... In this program, surely I can understand and avoid any wrong action caused by language barrier".

Hanan: "I bought a book with a lot of pictures that depicted the caregiving task very clearly, but observing caregiving duties step-by-step by motion and listening to commentary guidelines for each step were very helpful to retain the gained information, especially when you watch a famous Jordanian actor play the patient role. That made me interact with each movie".

Wafaa: "You know, drawings are better than words, and motion pictures are better than drawings. And the best is to watch caregiving as a real life movie".

Zahia: "I think I liked every piece of the movies, but the most important matter was the simplicity of the information provided".

Maha: "I'd rather prefer the movies over other sources of caregiving material because they gave me "the rationale" behind each step of caregiving task; I mean I hate blindly copying or mimicking some acts without knowing why I am doing that".

The content of the presented information was a major consideration for some participants. Five of participants were feeling satisfied the content of the program, however, they asked for some additional information in the

future similar work such as; home pain management, caregivers' own health, and preparing caregivers for loss in case of their beloved ones' death.

Maysoon: "I am satisfied with what I have watched, the presented skills were the most important for me to learn, the home safety measures and medication instruction were the chief skills that attracted me. Because I think everything that threats my mother's safety has become serious and a priority for me to learn".

Wafaa: "I like every moment of the films but I think there are some subjects I wish to be added in the subsequent editions, sure if there are any. For example, home pain management with traditional methods is important. I don't prefer to give my dad painkiller every now and then. I would like to provide him with the most tender measures to relieve his pain and suffering".

Maha: "I wish to give more attention to how I care for myself as a caregiver not only how to provide caring to my dad. I am frequently suffering from backache, joint pain, difficult sleeping and many other complaints. I think all of my suffering resulted from heavy caregiving duties. I believe that good caregiver's health leads to good patient's health, right!".

Maha: "I expect every morning to wake up from sleep and find my dad dead. I starting asking myself what shall I do? How can I live alone? Then mere idea makes my blood run cold. I feel tense and down the whole day. I advise the authors to give some hints about stress relieving technique and how to get over the feeling of loss in case of death of a beloved diseased relative".

7. Discussion and Recommendation

With the projected increasing number of chronic and disabling diseases including stroke, many Jordanian families, especially women, will become caregivers within next decades (Brown, Mokdad, Walke, As'ad, Al-Nsour, Zindah, et al. 2009). In Jordan, the need of a family member to care for chronically disabling relative is essential particularly with the absence of adequate governmental home health care services for citizens. The long-term institutions in Arab countries are usually operated by voluntary, non-profit, charitable agencies or by the private sector, which has made their services unaffordable or inaccessible for a large number of families (Boggatz & Dassen, 2005; Kronfol, 2012). However, family members themselves perceive transferring such a responsibility to strangers as social stigma and a violation of religious instructions (NCFA, 2008).

Because Arab culture values the filial piety and respect of next of kin even if they are disabled, the maintenance of home caregiving for them is an ideal choice for Jordanian families. To ensure standardized family long-term home-care, a culturally sensitive intervention that should be designated and guided by theoretical framework was suggested (Subgranon & Lund, 2008). As mentioned earlier, historically caregiving is a women career (FCAc, 2014). Woman in Jordan has primitive role as caregiver for her family and for sick members even if she has full-time employment (National Centre for Human Resource Development, 2004).

The types of relationship with patients were being daughters, spouses, and daughters-in-law. This figure of relationship reflects the traditional extended family function in providing a disabled relative with required care. Additionally the presence of daughters-in-law as caregivers indicates the pattern of socialization of women to be fundamental part of their husbands' families.

The NCFA (2008) documented factual challenges facing families in being helpful caregivers, the first challenge is the financial problem, and then the bulk of caregiving time and the most serious challenge is the lack of knowledge and skill to provide safe home care. Learning caregiving skills by "trial and error" is serious information presented in caregiving literature (Sawatzky & Fowler-Kerry, 2003).

Similar to previous study (Yaffe & Jcobs, 2008), health care team does not adequately respond to the needs of patients' families regarding nature of disease, home care, or other instructions. In other instance, caregivers prefer to receive caregiving knowledge and skills from credible and experienced health care team, however, health care team perceives stroke caregivers as inadequately involved in education and caregiving training (Ang, et al., 2013). Scientific research provides evidence about optimistic results of different types of caregiving education programs (Smith & Bell 2005; Maclsaac, et al., 2010; Bayik, & Uysal, 2010; Noelker & Browdie, 2012; Cameron, 2013). Health care team in Ang, et al.s' study (2013), recommend to design individualized tailored training program based on caregiver's need assessment and level of competencies.

Narrative responses of the women showed that adoption of a caregiver role was not expected. When patient discharged from hospital, women's preparation for the heavy caregiving duties and responsibilities was inadequate, or was inappropriate for them in terms of content, material, used media channel, or language. The authors of "There is a Patient in Our Home" program assume that this program is culturally appropriate for Arab Jordanian caregivers and could satisfy their needs.

Nursing research reported different caregiver's unmet needs such as spiritual, psychological, emotional, physical, practical and informational (MacIsaac, et al. , 2010). Moroni, Sguazzin, Filipponi, Bruletti, Callegari, Galante, et al. (2008), in their psychometric study, recommended the use of Caregiver Need Assessment Questionnaire as a practical tool to identify family needs and support their competencies. A wide range of caregiver assessment tools were presented in scientific report of Family Caregiver Alliance (FCA, 2012). The purpose of this report

was to provide a collection of caregiver instruments that addresses the multidimensional aspects of the caregiving experience. It is recommended to invent, adopt and revise caregiver measures to be suitable for Arab caregivers. Meeting the patients' ADL is a core demand of caregivers. Assisting in bathe, feeding, change diaper and toileting are examples of skills caregivers need to have competency in practice (Ang, et al, 2013). This finding supports the women responses regarding their satisfaction with the content of the program.

In general, the program "There is a Patient in Our Home" satisfied women's needs regarding language of the movies, verbal comments that synchronized with each step of the skills, and the well-known actor who attracted women's attention. Other successful areas of the program are the content covered, and the simplicity of information.

Family Caregiver Alliance provides families with an opportunity to feel prepared for new caregiver role (FCA d, 2014). On their website, they present detailed caregiving articles and tips such as available community resources, caregiver self-help and the potential impact of caregiving on patients and on family members.

Medication is essential area of caregiving information (Ang, et al. 2013), in the present study, seeking information about medication such as painkiller or non-pharmacologic remedies by women is an important request. However, since medication has risky effect, it is recommended to share information regarding specific medication or therapies with the responsible physician and pharmacist.

Women's responses indicate lack of content about managing caregiver loss in case of their beloved relative's death. A supplementary content about the missed information needed by women will be taken into consideration. Communication technology has helped to make transferring of caregiving information and skills convenient, easier and universally accessed. Caregiver community in addition to community health professionals can create an Arab caregiving resource center considering their language, culture, customs, in addition to caregivers' own preferences and needs. One of unique example of caregiving resource centers is the Visual Education Center for Caregivers (videocaregiving, 2014). Arab caregiver community can have the benefits of communication technology such as You-tube, facebook, and other social media to be connected, informed, and motivated, and to share their experiences with other caregivers globally.

8. Strength and Limitation

This study is a unique investigation targeting Jordanian caregivers and using a culturally sensitive caregiver educational program in Arabic language. This study provides some important information to guide the national health policy makers to support stroke patients' caregivers and reinforce their knowledge and caregiving skills through real life movies. Scarce of caregiving literature in Arab and Middle East area is considered a limitation in the study because of the inadequate caregiving database. Relying on caregiving programs and experiences in other foreign countries could not be beneficial in structuring Arab culture specific caregiving program. Other limitation in this study was the participant request of improving communication with stroke patients. Researchers recommend investigating this subject within a multidisciplinary research team including speech therapist and rehabilitation professionals.

9. Relevance to clinical practice

Based on the finding of the study, caregiving educational program in real life performance movies can prepare family for competent, safe, and cost effective manner. Upon patient discharge from hospitals, nurses can provide the caregiving series on CD to stroke and disabled patients' families as a part of family education. During home visit, community health nurses can promote family's caregiving skills and competencies through "There is a Patient in Our Home" Program.

9. Future research direction

Future research could be directed toward replication of this study on other types of care recipients and other caregivers in different settings. Investigating "There is a Patient in Our Home" Program and similar caregiving programs through outcome research approach to measure their effectiveness on different scope of variables is highly recommended. Finally, a multidisciplinary research team to cover more caregiving aspects such as emotional, psychological, spiritual, and physical health problems is recommended.

10. Conclusion

"There is a Patient in Our Home" is a caregiving educational and training program. It is a promising work that satisfies Jordanian stroke patients' caregivers. Providing information and explain each step of caring procedure in Arabic language, in easily accessible channel in addition to real life performance is the participants' feedback of the program. The situation in Jordan requires involving of the family in health education and discharge plan of stroke patients through attractive real life performance movies.

Acknowledgment

The study was part of a funded project of Al-Zaytoonah University of Jordan. Researchers would like to extend sincere thanks to the women who participated in the study. Thanks are also expressed to Jordanian Nursing Council, Dr. Hania Dawanni and Mr. Moh'ed Abu Hummaid, Wafa'a Shtaiwi. My great thanks go to Najah Shawish for her cooperation in reviewing the scientific content of the program. Thanks must go also to the Freedom Media Production Company (Taha family) for their creative work. Thanks to Mr. Nabeel Al-Kawni, for his great performance of the patient role.

References

1. Abu Kamel, A. Bond, A. E., Froelicher, E. (2012). Depression and caregiver burden experienced by caregivers of Jordanian patients with stroke. *International Journal of Nursing Practice*, 18: 147–154.

2. Al-Heeti, R. (2007). Why nursing homes will not work: caring for the needs of aging Muslim American population. *The Elder Law Journal*, 15(1), 205-209.

3. Ang, S., Tin, A., Pavitar, G., Ng, W., Lee, K., Lim, L. et al. (2013). A Qualitative Study into Stroke Caregivers' educational needs –perspectives of caregivers and healthcare professionals. *Proceedings of Singapore Healthcare*, 22(3), 166-174.

4. Bayik, T., Uysal, A. (2010). Evaluation of an elderly care-training program for women. *International Nursing Review*, 57, 240-246.

5. Boggatz, T. & Dassen, T. (2005). Ageing, care dependency, and care for older people in Egypt: a review of the literature. *International Journal of Older People Nursing* in association with Journal of Clinical Nursing 14(8), 56–63.

6. Brown, D.W., Mokdad, A. H., Walke, H., As'ad, M., Al-Nsour, M., Zindah, M., et al. (2009). Projected burden of chronic, non-communicable diseases in Jordan. *Preventing Chronic Diseases*, 6(2), 1-3.

7. Cameron, V. (2013). Best Practices for stroke patient and family education in the acute care setting: a literature review. *Med-Surge Nursing*. 22(1), 51-55.

8. Collins, L. & Swartz, K. (2011). Caregiver care. *American Family Physician*, 83(11), 1309-1317.

9. FCA (2012). Selected Caregiver Assessment Measures: A Resource Inventory for Practitioners. Retrieved Sept 12, 2014 from https://caregiver.org/sites/caregiver.org/files/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf

10. FCAa. (2014). Mission and values. Retrieved Sep 9[°] 2014 from <u>https://caregiver.org/mission-values</u>

11. FCAb. (2014). CAREGIVERdotORG, Videos. Retrieved Sep 10^o 2014 from http://www.youtube.com/user/CAREGIVERdotORG/videos

12. FCAc. (2014). Women and caregiving: facts and figures. Retrieved Sep 11, 2014 from https://www.caregiver.org/women-and-caregiving-facts-and-figures

13. FCAd (2014). Preparing caregiver, new to caregiving, daily home caregiving. Retrieved Sep 13[,] 2014 from <u>https://www.caregiver.org/</u>

14. Hussein, S. (2010). The role of women in long-term care provision: perspectives on aging in the Arab and Islamic world. A paper presented in the 10th Islamic countries on statistical sciences conference (ICCSS-10). Retrieved Sept 12[,] 2014 from <u>http://www.academia.edu/</u>

15. Kronfol, N. M. (2012). Delivery of health services in Arab countries: a review. *Eastern Mediterranean Health Journal*. <u>18, (12)</u>, 1229-1238.

16. Maclsaac, L., Harrison, M., & Godfrey, C. (2010). Supportive needs of caregivers of individuals following stroke: a synopsis of research. *Canadian Journal of Neuroscience Nursing*, 32(1), 39-46.

17. Mahasneh, S. (2000). Survey of the health of the elderly in Jordan. Medical Journal of Islamic Academy of Sciences 13(1), 39-48.

18. Mohammed, H. & Abu Kamel, A. (2014). The effect of home caregiving program for family members providing care for chronically ill relative client. *Journal of Education and Practice*, ISSN (Paper) 2222-1735 ISSN (Online) 2222-288X.

19. Moroni L., Sguazzin C., Filipponi L., Bruletti G., Callegari S., Galante., et al. (2008). Caregiver need assessment: a questionnaire for caregiver demand. *G Ital Med Lav Ergon*, 30(3), 84-90.

20. National Centre for Human Resource Development. (2004). Factors affecting women's participation in the private sector in Jordan. Retrieved Sep 13[,] 2014 from <u>http://www.nchrd.gov.jo/</u>

21. National Council for Family Affairs. (2008). The national Jordanian strategy for senior citizens. Retrieved Sep 8, 2014 from www.ncfa.org.jo/Portals/0/eldery%20strategy%20en.pdf

22. Noelker, L. & Browdie, R. (2012). Caring for the Caregivers: developing models that work. *Generations*. 36(1), 103-106.

23. Polit, D & Beck, C. (2004). *Nursing Research: Principles and Methods*. 7th ed. Lippincott Williams & Wilkins, Philadelphia.

24. Sawatzky, J. & Fowler-Kerry, S. (2003). Impact of caregiving: Listening to the voice of informal caregivers. *Journal of Psychiatric and Mental Health Nursing*, 10: 277-286.

25. Smith, S. & Bell, P. (2005). Examining the effectiveness of Savvy Caregiver Program among Rural Colorado residents. *Rural and Remote Health.* 5, 466. Retrieved Sep 11[,]2014 from <u>http://rrh.deakin.edu.au</u>

26. Subgranon, P. & Lund, D. (2008). Maintaining caregiving at home: a culturally sensitive grounded theory of providing care in Thailand. *Journal of transcultural nursing*, 11(3), 166-173.

27. UN. (2011). Current status of the social situation, wellbeing, participation in development and rights of older persons worldwide. Retrieved Sept 11[,] 2014 from <u>http://www.un.org/</u>

28. Videocaregiving. (2014). Stroke dealing with it I, stroke dealing with it II. Retrieved Sep 13[,] 2014 from <u>http://www.videocaregiving.org/caregiving.php</u>

29. WHO. (2006). Neurological disorders: public health challenges. Retrieved Aug 13, 2014 from http://www.who.int/mental_health/neurology/neurological_disorders_report_web.pdf

30. WHOa. (2013). A global brief on hypertension, silent killer, global public health crisis. Retrieved Aug 13, 2014 from <u>http://apps.who.int/iris/bitstream/10665/79059/1/WHO_DCO_WHD_2013.2_eng.pdf</u>

31. WHOb. (2013). Cardiovascular diseases, facts. Retrieved Aug 14, 2014 from <u>http://www.who.int/mediacentre/factsheets/fs317/en/index.html</u>

32. Yaffe, M. & Jcobs, B. (2008). Education about family caregiving. *Canadian Family Physician*, 54, 1359-1360.

The IISTE is a pioneer in the Open-Access hosting service and academic event management. The aim of the firm is Accelerating Global Knowledge Sharing.

More information about the firm can be found on the homepage: <u>http://www.iiste.org</u>

CALL FOR JOURNAL PAPERS

There are more than 30 peer-reviewed academic journals hosted under the hosting platform.

Prospective authors of journals can find the submission instruction on the following page: <u>http://www.iiste.org/journals/</u> All the journals articles are available online to the readers all over the world without financial, legal, or technical barriers other than those inseparable from gaining access to the internet itself. Paper version of the journals is also available upon request of readers and authors.

MORE RESOURCES

Book publication information: <u>http://www.iiste.org/book/</u>

IISTE Knowledge Sharing Partners

EBSCO, Index Copernicus, Ulrich's Periodicals Directory, JournalTOCS, PKP Open Archives Harvester, Bielefeld Academic Search Engine, Elektronische Zeitschriftenbibliothek EZB, Open J-Gate, OCLC WorldCat, Universe Digtial Library, NewJour, Google Scholar

