The burden experienced by elders and family care givers in caring for the elderly in Batticaloa District

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Abstract

Healthy ageing is a desirable expectation of all communities in the world as well as in Sri Lanka. Elders receive both formal and informal care and is often a mix of both in a complementary relationship to each other. Caregivers would be aware of the physical and mental conditions and problems of the elderly people in order to cope up to meet their needs in the home setting. It is dynamic and evolves according to the care receiver's and caregiver's needs, abilities and schedules. Thus, this study was aimed to explore the perception among elders and care givers on the care given to elderly in their homes

The descriptive qualitative study was conducted by using an in-depth interview method which included audio recording. Data collection was performed among purposely selected twenty elderly patients and their care givers in five family practice settings in Batticaloa District. Verbatim transcripts were analyzed on the basis of content analysis method and themes were extracted

The perceptions among elders and caregivers on "care given" had revealed both positive and negative feelings. The study had showed majority of the elders had perceived negatively about the care they received. The major themes were emerged from the interview transcript of perception on care given to elders were "A burden life with diseases and experiences linked with dependency", "Proper disease management and life style modifications with better communication", "Timely services relatively good communication, but frustrated care", "Positive behavioral changes with kind caring attitude" and "Open hearted care with compassion". The major themes of perception on care giving by informal care givers were "Happy and blessing", "High prioritization for Activities of Daily Living (ADLs) and low for entertainment and recreational activities" and "Financial crisis and unemployability". Most of the care givers were females and felt that they lacked any special training.

The care giving process was undertaken by those informal care givers with very minimal practical and theoretical training. Thus, training on care giving is an urgent need for early identification of risk factors, prevention of complications and disabilities.

Keywords: Caregivers, Elders, Batticaloa, Qualitative study

Introduction

The growing elderly living with a number of diseases with functional dependence entails a complex life situation and causing a challenge. Prolonged illness, disability or simply the challenges of ageing can significantly alter the lifestyle of elderly individuals in whom their daily responsibilities become difficult. At the same time, elders need generalized care that combines respect, physical aid and company as well as efficient coordination of medical, personal and social service resources to enhance their quality life[1].

Elders are involved with both formal and informal caring[2]. But both have different characteristics and qualities of the assistance provided and they play varying roles in the lives of older people[3]. Whereas, the emotional capacity, awareness of the environment, social capacities, ability to communicate, ability to make logical connections are needed for effective care giving[4].

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Caregiver may provide emotional or financial support, as well as hands-on help with different tasks and helps an older person with the activities of daily living, health care, financial matters, guidance, companionship and social interaction[5]. In addition, the caregiver role can also include assistance with higher level activities of daily living ("Instrumental")[6] or to perform fundamental routine tasks (basic activities of daily living)[7]. The burden of care is one of the main consequences for family caregivers with chronic or progressive illness. This burden may lead the caregiver to postpone his/her own needs. The patient's close family members may experience poor psychological well-being (depression, anxiety), decreased satisfaction in relationships and poorer physical health[8].

Increased prevalence of long-term disability in the elderly population and change in the capacity of the informal support system are two interrelated processes reflecting trends demographic transition[9]. It evolves according to the care receiver's and caregiver's needs, abilities and schedules[10].

Informal caregivers are usually unpaid family members or friends, providing care on a fulltime or part time basis, due to emotional or economic reasons and are unaware sometimes of the physical, mental and socio-economic consequences that it might bestow upon them[11]. Prolonged care giving has negative effects on the emotional health and perhaps physical health of caregivers, even when it is voluntarily undertaken and a source of personal satisfaction. However, no study has been carried out to explore the perception of elders and care givers in Batticaloa district. Thus, this study was aimed to explore the perception of elders and the informal care givers on the care given to elderly in their homes.

Methodology

The qualitative approach was used as the effective study design to explore the perception[12] among elders and care givers on the care given to elderly in their homes. The study population was the elderly patients attending selected family practice centers for their health problems along with their informal care givers. Purposive sampling technique and the in-depth interviews were used for the data collection on the basis of theoretical saturation point where new data gathered by conducting further interviews no longer bring additional insight to the research questions[12].

The selection was mainly focused on those with more complex pattern and dependent cases rather than an elder with a simple problem. Participants were selected from five Family practice settings considering to represent urban, rural, Tamil and Muslim areas. Those were Kaluwanchikudy clinic, Ariyampathy clinic, Kathankudy clinic, Vithus clinic and Medi clinic Chenkalady Clinic. Saturation was achieved with twenty elderly patients and their care givers (twenty).

Semi structured in-depth interview guide was used as instruments for gathering information from individuals about their behavior, opinions, feelings, and experiences. Each interview was arranged in a suitable time and place essentially in a decent place at their living homes. Following introduction, the goal of the study was explained briefly and clearly. The informed written consent was obtained and confidentiality was maintained at every stage of data collection. Subjects were asked open ended questions and interviews were audio tape recorded with the participants consent. The successful interviews were lasted for more than sixty minutes. The interview was concluded with warm thanking.

Interviews were transcribed in full and analysis was based on the taped transcripts. The analysis of data was done manually by the PI based on a method described by Graneheim and Lundman (2004)[13]. Interviews were transcribed verbatim by the PI and then translated into English. The reliability of translation was checked by comparing translation done by a colleagues on a selected section of text with that of the researcher. The themes were identified from several thorough reading of the transcripts.

Ethical clearance was obtained from the Ethic Review Committee, Faculty of Health-Care Sciences, Eastern University, Sri Lanka. Permissions were obtained from relevant authorities before commencement of the study.

Results

The results are presented under two headings as perception among elders (Care receiving) and perception among caregivers (care giving).

Perception among elders (Care receiving)

Five major themes regarding care receiving have emerged from the interview transcripts. These themes with their quotations are described below.

Theme 1 – "A burden life with diseases and experiences linked with dependency"

The information regarding their "perception on aging" among elderly were emerged and described in their own words as below.

"I am no healthier enough to do any work I did earlier. It is of no use to me to exist further. I don't want to be a burden to anyone. So I must finish my life and go" (as burden)

"At the old age only, many will fall ill. Therefore we must be careful and see that we are not afflicted with any diseases" (as burden & as a stage with full of diseases).

"After the parents had given marriage to their children, the children look into only their own needs and put their parents in the home for the aged. Only a few children who are affectionate toward their parents look after them kindly" (as a responsibility act of children)

Theme 2 – "Proper disease management and life style modifications with better communication"

The information regarding their "types of needs" among elderly were emerged and described in their own words as below.

"Doctor should give us a diet chart as to what types of foods should be taken by elderly person."

"Advise to yoga exercise and to have nutritious foods and abstain from liquor, smoking."

"Must conduct awareness programmes in the villages about the elders' health."

"Public meetings should be held in public places on how we should be in our old age." (Life style modifications)

"Doctors should take special care and more attention on eye sight and generally they look after satisfactorily and behave kindly."

"We get mental satisfaction when they speak to us kindly and treat us."

"Doctors must be aware of the details of elders. They would have undergone a training to associate with elders. Above all they should check up the patients without reluctance. They must understand our problems."

"Since there are no trained staffs it is pointless of having many counters in big hospitals."

Theme 3 – "Timely services relatively good communication, but frustrated care"

The information regarding their "experience gained" among elderly were emerged and described in their own words as below.

"When I was admitted to the hospital for treatment for my illness I witnessed a doctor was scolding an elderly woman."

"I have observed that some nurses never gave respect for the elders and behaved with non caring attitude."

"Almost all the doctors associate with elders kindly and patiently, but not so at Government hospitals."

"I think that elderly persons should be treated kindly avoiding hard words."

"To the best of my knowledge all the doctors not only treat the elderly persons but also the others equally and well."

"As my daughter goes for work she has less time to chat with me. So she must do it in her leisure time." (Negative experiences)

Theme 4 – "Positive behavioural changes with kind caring attitude"

The information regarding their "expectations" among elderly were emerged and described in their own words as below.

"Doctors should not regard me as a patient, but a friend"

"Doctors should converse with us in an affable way with smiling face. As said "laughter" is the best medicine even a simple and single smile can cure any disease"

"We should not be ridiculed or demeaned but kindly inquire our shortfalls and illness and give treatment."

"I expect and like them to deal with patience in an affable manner"

"Should learn to speak politely and kindly with others and whoever it may be associated with love and mercy."

"If well ventilated clean and tidy place is set apart for us, that will be a great boom for us."

Theme 5 – "Open hearted care with compassion"

The information regarding their "Suggestions to improve" among elderly were emerged and described in their own words as below.

"Should be cared well, speak softly and kindly."

"They should understand my needs and defects and take care of me with open heartedly."

"If I am bed ridden I may be looked after properly, They must look after me till my death."

"I will be satisfied if I am provided with food and clothing until my death."

"My needs mainly financial needs are met by my children."

Perception among caregivers (care giving)

Perception on care giving by informal care givers were described under three themes which have emerged from the interview transcripts. These themes with their quotations are described below.

Theme 1 – "Happy and blessing"

The information regarding their "perception on care giving" among informal care givers were emerged and described in their own words as below.

"We must realize the difficulties that our parents had undergone to bring up us and understand their needs and look after them at the last phase of their life."

"It must be realized as to how hardship the parents would have undergone to bring up a child and be paid due attention on elders. Keep them always happy at the latter part of their life."

"Fulfill their desire and care them till their life", "Until the end of their life we want to provide care."

"As it is a virtuous deed it will be a blessing for us."

Theme 2 – "High prioritization for ADL and low for entertainment and recreational activities"

The information regarding their "experience of care giving" among informal care givers were emerged and described in their own words as below.

"Making necessary arrangements for elders to be in hygienic condition, providing nutritious food suitable for the age."

"Accompanying them to the places where they get peace of mind; desirable foods be provided with in time.

"Changing the places which are suitable for entertainment and recreation make facilities to meet their friends create chances to contribute to social welfare activities."

"Employing a care assistant to look after their interest."

Theme 3 – "Financial crisis and unemployability"

The information regarding their "limitations or barriers in care giving" among informal care givers were emerged and described in their own words as below.

"Financial strains are being a barrier for me to employ a care taker. If I go for work I have no time to maintain"

"Lack of time to look after mother, as financial strain to give for medical treatment at private hospital."

"There may be no hindrance in looking after them in the home where both husband and wife are not working in a family."

"As I go for work I rarely allocate time to be associated with them. Otherwise I have no other barriers.

Discussion

The perception among elders'on caring was as a part of children's responsibility. Nowadays it becomes to a state of impossible, because of increasing trend of female labor force participation and migration for employment to distant places within the country, and in some cases to foreign destinations. It also causes lacking of emotional or financial support, as well as hands-on help with different tasks[14]. But, elders perceptions could be accepted as the quality of life becomes important when it is well integrated, accepted, surrounded by love and respect and not rejected[15]. At the same time, the occurrence of biological decline, presence of multiple chronic diseases, cognitive impairment along with multiple prescriptions, changing quality of care, financial status of the family or the funding status in a welfare state might support the perception of elders on disease burden and children's responsibility[16].

Perception among elders on feeling freedom at older ages would be reasonable to some extent because Sri Lankan elderly have traditionally depended on the family as the main care giver and support base[17] and provision of care that maximizes independence, self-esteem and health related quality of life[18]. In addition, as parents had sacrificed a lot for their children, their accepted anticipations of their children would look after them well at their latter part of life. But, the reciprocal relationship of care and support between the elderly and young is a hallmark.

Family members are a vital, but often invisible, component in the system of long-term care for elders with chronic illnesses[19]. The factors influence the care giving process were, caregiver gender, income, and education[20] and gender differences are also especially important[10] and evidence confirms that most caregivers are women who assume this role based on cultural and structural reasons. The typical caregiver is a female family member who has married[21] and the daughters are the common source of care givers. At the same time, the informal care giving has been dominated by women with increasing international recognition[22].

Limitations of the study: The results could not be generalized to entire district as the sample size was small and concern over role of formal care givers was minimal in this study.

Conclusion

The majority of the elders had received care from informal care givers and their perceptions revealed both positive and negative experiences. Most of the informal caregivers were females and were unemployed, residing with their caring elders with very minimal practical and theoretical training. Care giving was especially on preventive and promotive aspects on possible disability limitations. Training on care giving among informal caregivers is an urgent need for early identification of risk factors, prevention of complications and disabilities. In addition, the recreational activities among elders are increasingly on the decline.

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