The Difficulties and Obligations Faced by Family Members when Caring for Paralysis Patient

Dr. Khaing Myo *, Yin Nwe Wah**

INTRODUCTION

Paralysis

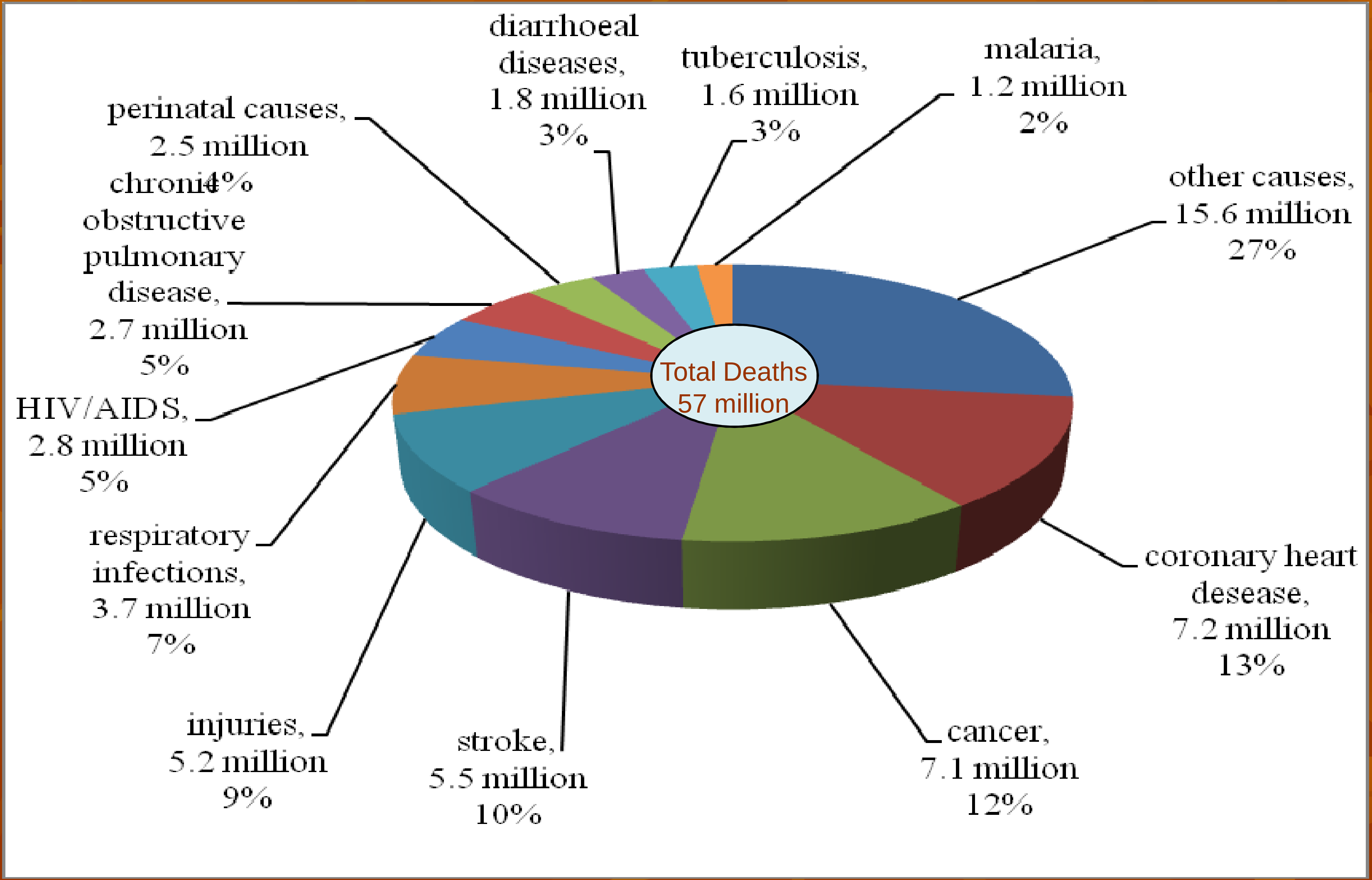
-the **third** most common cause of death worldwide,

-accounting for **10%** of all deaths and exceeded only by coronary heart disease and cancer.

According to WHO,

-It is also a leading cause of functional impairments, with **20%** of survivors requiring institutional care after 3months and **15% to 30%** being permanently disabled.

Figure 1.1 Stroke compared with other causes of death (2002) [WHO 2004]



In 2004, in South East Asia and the Western Pacific Region, 1.8 and 3.3 million people, respectively, suffered a first-ever stroke.

In the same year, 1 816 000 people in China and 727 900 in India died from a stroke.

In Myanmar,

- the fifth leading cause of mortality and **2.7%** of all other causes of mortality (2009) according to the Health in Myanmar 2011.

- ❑ According to the great changes in life styles and extreme climate in Myanmar, paralysis patients are continuously increasing in each year .

- ❑ It is a life-changing event that affects not only paralyzed patients themselves but their family members and caregivers as well.

- Paralysis is also a major cause of premature death and long-term disability, placing a burden on the individual, on families, on medical services and on society too.

- It is a sudden and devastating illness - however many people are unaware of its widespread impact.

The health care burden of paralysis

- ☐ It is substantial, due not only to healthcare costs, but also to high rates of morbidity and premature mortality.

- ☐ It exacts a substantial burden on the individual directly affected, their family and carers, and society as a whole.

- This is true not only in terms of economic pressure but also in terms of the time commitment of family members as well, as they have to adjust and manage care for the sick person, sometimes of a life-long duration.

- In those circumstances, it radiates the decrease in social happiness of care givers and the family.

- changes the socio-cultural context of the family for many problems like socio-economic, health services and national policy for particular disease.

- It becomes the largest problem if the family is poor and state support system for health is not enough for those people.

- This study will be conducted with the care givers and use qualitative approach to explore the burden of Paralysis and its socioeconomic burden among families.

Furthermore,

- to explore socio-economic burden of the care giver and families
- their perception to take care of patient
- seeking treatment pattern from acute to chronic

- would be beneficial not only for the house hold health care but also medical services and even health policy of the particular disease.

OBJECTIVES

1. To identify the socio-economic burdens and health burden of caregivers taking care of paralysis patient

2. To explore the perception of caregivers on taking care of paralysis patient

3. To explore the treatment seeking pattern of paralysis patient

Methodology

- **Research site**

  The site of study is Aung Myae Thar ZanTownship (Obo Quarter)(having one paralysis patient in family)

- **Research period**

  Three months

Method of the study

- Qualitative research method will be used as the principle tool to address and answer the main research questions.

- In depth interview with the key informants who takes care to the paralysis patient with interview guide

- face to face interview - designed to obtain the information about the socio-demographic characteristic of family and care giver

Samples and sampling of the study

- The simple is 6 people having paralysis patient member according to their groups (position of family (head / least), sex , Rich or Poor group)

- interviewed at least twice using a semi-structured interview process.
- Four of the six caregivers - interviewed in their homes,
- while the other two - interviewed at the hospitals in which their family members were being treated.

Data collection

- In depth interview will be used in order to cover all possible facets associated with the conceptual framework and research objectives (Res Q and R data = Word)

Data analysis and interpretation

- will be carried out from all sources on information after categorizing the data. By reviewing the answers of the family member, content analysis of their answers will be done.

Research Findings

Nature of the Care Givers

- According to the individual income, most of the care givers are dependent in the family and the less busy person in that family.(Only one care giver gave up his business totally to take care his wife.)

- They are very active in every work and mostly talkative. Most of the care givers are at primary to high school education status

- They felt very sorry not for the care giving but for the patient's diseases. They all are satisfied with their care.
- Almost all regarded as this is the great chance to pay back for their mother, husband or wife.

- It is clear that all family members share the health and living expenses incurred when taking care of the paralysis victims;
- however, despite the economic hardships they face, **none of the caregivers blame** the paralysis patients themselves.

Cultural and Religious Beliefs of CG

- Due to their cultural beliefs and the Buddhist context in Myanmar, caregivers instead feel sympathy for the patients; as people who need to be taken care of.
- All the caregivers said that taking care of their paralyzed relatives gives them the opportunity to give something back - to those who had once done a lot for them.

- also mentioned the merit to be gained through doing good deeds, a point which relates to a belief in the afterlife among Buddhists.
- Buddhist teaching and Myanmar culture help the patients and care givers to become relax and to be content at the present condition.

- Whenever the patient became aggressive, the care givers and family members told the patient to understand and remember dhamma talks by lord Buddha.
- They encourage the patients not to be upset and to try hard to be healthy like before.

Economic burden

- the greatest problem in family. Some patients and the family felt very sorry and down-hearted as they have no money to pay for treatment.

- All families tried hard to give treatment fee and staying cost.

- Some pt are supported by near relatives as daughters, son in law, etc.

Treatment Seeking Pattern

- All patients have to be cured by Western doctor immediately after attack and almost all did not satisfy with the treatment.
- And they took the home visit treatment by Folk Healers TMPs and also by Western doctor.
- More severe patient went to private clinic and the treatment became transfer into Traditional Medical Practitioners or TM H. Treatment seeking pattern is generally as follow:

Western doctor. / Western Private Clinic

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Neurotherapist or physiotherapist (regd or non-reg:)

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and then TM Practitioners or TM Hospital

(TMH = The last but the best)

Western and TM Services

The difficulties they faced at the Western Dr / Clinic are very high charges and service problem by them.

Almost all satisfy the TM Practitioners or TMH services. But they are still problem in Transport fee to go to TMP of TMH repeatedly.

- Some patients attended Western Hospital for a few days to know the severity of paralysis and cause of it. **(amazing point)**
- All patients use TMP and TMH to recover.
- On arriving home, the patients totally rely on the care givers for food and treatment regime

Physical Problems of Care Givers

- On taking care of patient, the care givers faced some problems at the earlier time as they didn’t expect that condition and due to some upset and sad feelings too.
- Most Care givers felt low back pain in some circumstances but it was just acute and relieved by some TM Balm. Insomnia, stress and tiredness are also felt.

Emotional problem

- Though all the caregivers expressed satisfaction with the medical services, they are clearly worried about the treatment and rehabilitation costs incurred.
- Moreover, due to the long period of time they have been taking care of their paralyzed relatives, high levels of emotional stress and tension were also mentioned.

Medical and transport Costs

- Although TM practice fees are not high, they have to pay for their food and staying costs and they are relatively costly.

- They earnestly want to get the cheap hospital transport service (ambulance) as they have difficulties in transferring patient to and from the hospital or clinic and the home.

Conclusion and Suggestion

Good stroke care centres

- (including rehabilitation centre, physiotherapy centre and good ambulance service) are necessary to open in each TM Hospitals or clinics to get the quick relieve of it. (Patients and care givers of working group can return to their work to increase household income and national resources.)

- It should include the team of rehabilitation staff (physiotherapy, occupational therapy, speech therapy, dietetics) who work with the nursing staff to ensure that rehabilitation starts from Day 1.
- It should also include involvement of careers in the rehabilitation process and close collaboration with community services to ensure a smooth transition of care from the hospital.

Quality Progressive Management of Stroke

- According to the treatment seeking pattern of paralysis patient, the quality progressive management of TM is relatively important in Traditional Medical Practitioners and traditional medical hospital or clinic.

Public Education and Intervention

- The public administrators need to provide the prevention and early intervention for the stoke disease.
- Private public partnership (PPP) is needed to incentivize the patients and provide to prevent effectively. It is also needed a strong, long term national commitments to promote health, wellness and to provide the healthy diets, lifestyles and health education programs.

Role of NGOs

Social welfare association (including rehabilitation centre, physiotherapy centre and ambulance service) is the most important requirement for the paralysis patient and family to get early recovery.

Public Awareness

Some of the goals for reducing the burden of stroke are as follows:

- Raise awareness of the symptoms of stroke among the general public

- Improve understanding that time is brain and early treatment of stroke improves outcomes
- Co-ordinate acute stroke care through streamlined, multidisciplinary pathways
- Widen availability and access to specialist stroke units
- Consolidate skills training for the patient and family

PPP and Emotional Support Group

Emotional support groups should be set-up for the caregivers,

either in the hospitals (while the paralysis victims are hospitalized)

or in the community.

These support groups would not only provide emotional support for the caregivers, but could also be used as a space to share experiences, health knowledge, home remedies and other techniques - to be used when taking care of the patients.

Acknowledgement

- DG of DTM
- Rector of UTM
- Mrs Thapin, Aja Surya and CMU AP
- Div, Dis and TS and Local Authorized Person
- All the persons who collaborate to become this national congress.

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Thank you