

Case Report

Essential rehabilitation services in a rural setting using patient and family centred care model: a case report

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ABSTRACT

Chronic diseases have a significant social and economic effect on individuals and societies. These diseases require lifelong care and management. Individuals with chronic diseases need to focus on complications, treatment and prevention. Self-efficacy for performing self-care behaviours is important to bring a change in lifestyle in these individuals which will eventually help in successful personal disease management. This case discusses a typical patient and family centered care (PFCC) model where the lifestyle changes of a 14-year-old male hemophilia patient were successfully managed. This hemophilia patient required constant medical services, however there were constraints like low accessibility and affordability to healthcare centers. In this model, patients and family members are made partners and collaborators in delivering a sustainable focus on the patient. This model has helped in reducing the frequency of hospital visits and caretakers valuable time. Patient and family-centered care enables patients to self-manage treatment and facilitate doctors to attend other critical cases efficiently. The implementation of PFCC in managing a hemophilia patient turned out to be immensely useful and thus could improve the patient's quality of life.

Keywords: Public health, Health education, Patient centred care, Haemophilia, Patient and family centred care

INTRODUCTION

India is a home for the 1.2 billion population, where 70% of the population resides in the rural areas.¹ Accessibility and availability of health care are important for ensuring a community's general health status. The ratio of doctors to patients in India is a serious concern as one government doctor is available for every 11,528 people, one bed for every 1833 people, and one nurse for every 483 people.² Inadequate infrastructure, human resources, equipment, drugs and meagre allocation of the health budget in the public sector has resulted in nearly two-thirds of all households (65%) in the country seeking health care for many ailments from the private medical sector.³

Data shows that less than 50% of the populations are covered by a health scheme or insurance. The rise in chronic non-communicable diseases in the country has increased cost both to the patient and hospitals.

Among all the states in India, Kerala ranks first with the highest proportion of both females and males with education (90% and 95% respectively) and with a male to female ratio as 1:1.084.^{4,5} In Kerala, literacy is recognized as a fundamental right especially among women. The intrinsic value of education may be instrumental in improving health. The married women mostly play an important role in household decision making such as health care and other household purchases which emphasis on women's empowerment in

the state. The usual source for information among the women is reading the newspaper, watching television or listening to the radio. This case report discusses a patient centered care model in a rural setting.

CASE REPORT

A 14-year-old haemophilic male patient accompanied by his mother was brought to the department of public health dentistry, Government Dental College, Kottayam, Kerala.

The patient presented with pain and sensitivity in relation to lower right back tooth for the past few days. The pain was continuous in nature and aggravated during the night. The past dental history showed that patient had undergone a temporary restoration of the right lower back tooth 2 years ago. Upper anteriors were proclined and orthodontic treatment was given. Due to discomfort, the orthodontic treatment was discontinued. Intermittent gingival bleeding was also a common complaint.

Patient resides in Kumarakom a rural community of Kottayam district. Both parents have formal education. Father who works for daily wages is the bread-winner of the house. The financial status of the family has been indexed as BPL (below poverty line) by the Government of Kerala. A health insurance scheme, the Rashtriya Swasthya Bima Yojana (RSBY) launched by the Union Government of India for BPL families (absolute poor) has brought relief to the family against high medical expenses as well as access to quality medical care.

The patient was detected with severe haemophilia A around 4 years of age and his younger male sibling has the same condition. Haemophilia A is an X-linked hereditary bleeding disorder due to the deficiency of coagulation factor VIII. Haemophilic arthropathy is a condition which affects the daily activities of living due to swelling and bleeding of the joints. The patient's activities such as carrying books to school, doing daily homework, playing with friends are restricted. The patient does selective food choices and restricts from taking hard, crispy food and hot drinks. A soft and cold diet is preferred to reduce the tendency of bleeding gums. High need for medical services, low accessibility to reach the health centres had been the challenges the patient faced. Pain with swelling and bleeding at the joints are the common symptoms. At times during the night, the patient's health problems have been spontaneous. The mother has been empowered by the patient's physician towards medical emergencies to give intravenous factor VIII administration whenever the patient suffered bleeding and severe pain in the joints. Regular physiotherapy session has brought relief to the patient. Eventually, the mother became her son's regular physiotherapy instructor. To improve the joints mobility swimming session was included. Sudden bleeding gums could be controlled by the local application of powdered tranexamic acid tablets (anti-fibrinogen). The spectrum of rehabilitative services provided by the mother has

reduced the frequency of hospital visits for the patient who is suffering from multiple morbidities.

This case represents a typical patient centered care model. Patient and family-centered care (PFCC) is health care that is compassionate and respectful of patients and their families. In this model of health care, patients and family members are made partners and collaborators in delivering a sustainable focus on the patient. This collaboration does not imply the decisions are made by the family or the patient himself. Safe and effective health care depends on the ability of the physician to demonstrate fundamental patient-centered skills that are important in health and disease. With adequate input from the physician a redesigning of the current state of care delivery can be done which will not only improve the experience of care but also improves the outcome and reduces the cost. This will further ensure that patients have the education and support they need to make decisions and participate in their own care.^{6,7}

DISCUSSION

A study conducted by van Olmen et al to assess the scope of patient centered care for the diabetic patients in Cambodia has shown positive results. The main objective of the study was to evaluate the 'MoPoTsyo programme' which aims at empowering people to self-manage their condition by creating networks of community-based peer educators.⁸ According to Gould, a patient centered tobacco management can be offered to all patients irrespective of their attitude towards quitting and could thus increase the quit rates. The relationship between the patient and health professional aiding in the quitting process was found to be encouraging.⁹ Community-based Te Whiringa Ora programme assessed by Carswell demonstrated person-centered and integrated care to chronically ill (COPD) patients in Eastern Bay of Plenty, New Zealand. Integrated care management can bring a more active participation of patients and their families. This concept is very similar to the patient-centered care.¹⁰ The patient's assessment by an exploratory research conducted by Marshall et al concluded that they were unaware of the patient-centered model of care and must be incorporated into the existing health system.¹¹

CONCLUSION

For patients to maintain health and treat diseases with self-care in a safe and effective manner, physicians should be able to demonstrate fundamental patient-centered skills. Providing patients with the knowledge and training to treat at home can reduce anxiety, and provide comfort to the patient and family during the treatment period. Kerala, having a high literacy rate and high cultural value in education (particularly for women), can make patient-centered care easy to implement. How successful patient-centered care is for states where literacy rates are poorer is yet to be studied.

Many chronic diseases have significant social and economic effect on individuals and societies resulting in high medical expenditure. The treatment is life long and focuses on complications, treatment and prevention. Costs to patients and service providers can also be reduced with effective implementation of patient centered care.

This model of care enables patients to self-manage treatment and facilitates doctors to attend critical cases efficiently. For a successful disease management the individual must have a central role in their care which can bring a change in life style and help them to control their risk factors. Quality healthcare outcome in patient centered care depends upon patient's compliance to physician recommendations.

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