



ISSN: 2091-2749 (Print)
2091-2757 (Online)

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Submitted

12 Jun 2018

Accepted

25 Dec 2018

How to cite this article

Samita Acharya, Katrina
Butterworth. Patient
perspectives on health in
chronic illness. Kathmandu,
Nepal. Journal of Patan
Academy of Health Sciences.
2018Dec;5(2):35-40.

Patient perspectives on health in chronic illness

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Abstract

Introductions: Medical students need to understand patients' perspectives about illness and its impact on their lives and family, to evolve as truly socially accountable physicians.

Methods: Medical students were assigned in pairs to visit a chronically sick patient over 6 months. They completed a portfolio exploring patient attitudes towards their illness, medication, concerns and beliefs. Themes were coded, and portfolios were reviewed independently. New themes were added during the review. Data was later compiled and discussed by the team to refine key themes and portfolios were reviewed to check for frequency.

Results: Fifty-eight students interviewed twenty-nine patients with a variety of chronic conditions. Areas identified included the important role of family and community. A major concern of 18/29 (62%) patients was the impact on the family emotionally, socially and financially of their illness. Other concerns were loneliness (5/29), uncertainty about the illness and deteriorating function. Spiritual issues were important, together with prayer. Some patients (7/29) viewed their illness as a punishment or curse and wanted to die. Other patients believed their illness was due to diet, physical or emotional stress, contagion or exposure to environmental factors. Two believed the oxygen for their COPD was addictive, so restricted its use.

Conclusions: As part of providing patient-centered care in the context of Nepal it is important to explore the level of family and community support available to the patient as well as the current impact on the family.

Keywords: chronic illness, non-communicable disease, perspectives

Introductions

The World Health Organization (WHO) predicted increase in global mortality from non-communicable diseases (NCD) by 17.6% during 2006 to 2015.¹ In Nepal, as in the rest of South Asia, there is increasing urbanization of the population with a corresponding rise in NCDs.

There has been little research into patient's attitudes towards chronic illness in the developing world. Knowledge and understanding of patient's perspectives about their health, the impact on their lives and family, and their attitudes towards medication, will enable a better, more patient-centered approach to the management. This in turn will lead to better patient care and hopefully better outcomes, specific to the Nepal context.

This study aims to explore the attitudes of Nepali patients and their families towards chronic illness and to deepen the understanding of what influences patients as they make decisions about their health.

Methods

Medical students are involved in the collection of qualitative data as part of their longitudinal patient exposure. Fifty-eight medical students in their first year of medical school were assigned in pairs to a patient with a chronic condition (e.g. chronic obstructive pulmonary disease, hypertension, renal failure, diabetes mellitus, rheumatoid arthritis etc).

The students were given a portfolio to complete with guidelines on the type of questions to ask and the areas they needed to explore with the patients. They were

instructed to visit the patients both in the hospital and once they returned to their own home on a regular basis (once or twice per month) over a six-month period. Before visiting patients, the students were given an introductory lecture on social perspectives and the importance of communication on health and medicine.

Students were asked either to tape (record) patient responses and transcribe at a later point, or to make verbatim notes while the patient was talking. All history taking was done in Nepali language and later translated by the students into English.

Informed, written consent was taken from all patients participating in the project.

Researcher reviewed a random sample of portfolios to begin initial coding, using questions (Table 1), partially derived from 'systematic narrative review of qualitative studies relating to people's experience of living with chronic heart failure'.²

Portfolios were then divided between two tutors (authors) and four students, reviewed independently looking for key themes arising from the patient interviews. Themes arising were coded and then analyzed for core concepts, new themes were added during the review. Data was later compiled and discussed by the authors to refine key themes and portfolios were again reviewed to check for frequency. Results were discussed between two authors and then compiled with a definition for each concept. Thematic codes were discussed and rearranged. After finalizing of coding, researchers went back to manually count the number of times a particular theme appeared within the portfolios.

Table 1. Leading questions for thematic areas

1	What are patients' understandings of the cause of ill health?
2	What is the impact of chronic disease on the activities of daily living in these patients?
3	How do patients with chronic disease cope with their condition: physically, emotionally and spiritually?
4	What factors influence, how a patient manages their condition? (Include their attitude towards medication here)

Results

A key theme arising was the 'important role of family and community' from qualitative data reviewed from 58 portfolios of twenty-nine patients with a chronic condition. The majority of patients had very supportive families 18/29 (62%). This was very important to their overall sense of wellbeing and to how well they coped with their illness. One woman spoke of how her husband loved her so much he donated his kidney to her.

Three patients (10.3%) specifically mentioned a poor relationship with family. All of these patients had concerns about being a financial as well as a social burden, with family members having to stop work to care for them. One family had to sell land to pay for the patient's care. Another relative whose mother had Chronic Obstructive Pulmonary Disease (COPD) yet continued smoking, said, "I earn money with lots of hard work and when my mother burns them with smoke my heart burns too". Some students noted that even when the patient didn't directly complain about the family, "her body languages speak that they are caring her as their responsibility rather than by their own interest."

Social impact of illness

Patients who found that their local community was very supportive were 21/29 (72.4%) and this was important to them. Support could be either social, through visits and chatting, or spiritual, praying together, or practical- helping them to get to hospital or offering care.

Six patients (20.7%) mentioned that they felt judged by their neighbors. They felt a social stigma because of their illness with loss of prestige or were ashamed of their appearance (patient with edema and kidney failure). This was very distressing, "living with sickness is not as troublesome as feeling abandoned by society and my family."

Impact on family

Twenty-six out of twenty-nine patients talked about the impact their illness had on their family. Four patients had family who had left

work in order to care for them. Others continued to work but found it difficult. Grandchildren were also affected and children were missing school to help take patients to hospital for appointments.

Attitudes towards medication

For medication, 24/29 (82.8%) knew when and how to take their medicines, though 18/29 (62%) really didn't understand why they were taking it or the side effects. As a result, a few patients sometimes missed taking their medicines. Among the older patients 8/29 (27.5%) family was important in reminding them to take their medicine.

Medication was an important financial cost to patients. One family had to sell their shop to pay for treatment. Out of total, 6/29 (20.6%) occasionally stopped treatment altogether for a while because they didn't have enough money. Another reason for stopping medication was frustration and a sense of hopelessness at the lack of improvement in their condition.

Two patients with COPD believed that both oxygen and their inhalers were addictive and damaging to their long-term health so they tried to restrict their use as much as possible.

Beliefs about the cause of illness

As these patients had a variety of chronic illnesses, there were a range of beliefs around the cause of illness. Dietary habits in particular were believed to be a cause of not just diabetes, but also COPD, arthritis and kidney disease. The COPD was believed to be associated with smoking, use of firewood for cooking and environmental pollution. In addition, patients believed that emotional tension, overwork and poor relationships with relatives (particularly the mother-in-law) were associated with their illness.

There were 7/29 (24.1%) who viewed their illness as a punishment or curse because of previous sin and wanted to die. One patient with renal failure believed her illness was due to a "bad patch", this is an astrological term related to an unlucky alignment of the stars.

Understanding of illness

Twenty out of twenty-nine (68.9%) patients understood that their illness was lifelong and required long-term treatment. Four patients said that they didn't really know what their illness was because no-one had explained it properly and one patient was quite distressed because she was expecting a cure and hoped she would one day no longer need medication.

Attitudes towards illness

Seventeen out of twenty-nine (58.6%) had a fairly positive attitude towards their life and illness. While mentioning sadness and occasional anger, they were resigned to the limitations they now had. This was generally related to their religious beliefs "life is ruled by god", "this is the way of life that god has destined for me". The majority of patients regularly visited the temple, monastery, church, mosque and other places of their beliefs or prayed at home. They found peace through praying and were not afraid of death.

Six out of twenty-nine (20.6%) was very miserable about their condition, speaking about living a "jailed life" and feeling that "death is better than such a cursed life." Bed bound with COPD, one patient spoke of how "God just left me in store and forgot me." Four patients (13.8%) felt that death was their best option because of the trouble they were causing their family. One of these patients said she was considering suicide in order to free her family from their financial struggle.

Patients' Concerns

A major concern of 18/29 (62%) patients was the impact on the family emotionally, socially and financially. They worried about the future education and marriage of children and they worried particularly about the economic burden they were on the family due to the cost of treatment.

Other concerns were loneliness 5/29 (17.2%), uncertainty about the illness and deteriorating function. One woman was mainly concerned about her relationship with her husband now that she was not capable of becoming a mother.

Discussions

In our study, the majority of patients had good family or community support, and seem to comply well with treatment. A review of the literature showed that patients with emotional support and help from family members, friends or health care providers were more likely to be compliant with treatment.³

Non-compliance with medication in this study was mainly due to the cost of treatment, rather than health care beliefs, or lack of understanding about the illness. The impact of financial problems has been found in many studies in developing countries.³ Although many Nepali patients do have strong spiritual beliefs about the cause of illness, similarly to patients in Pakistan⁴ and New Zealand Tongan patients⁵, this does not appear to impact on their compliance with medication.

Forgetfulness is a widely reported factor that causes non-compliance with medication or clinic appointments.³ In the context of Nepal, family played a major role in ensuring that patients didn't forget to take their medication. The finding that COPD patients worried about dependency on treatment, leading to reduced compliance has also been seen amongst patients with asthma in the USA.^{6,7}

In international studies, the major concerns of patients with a chronic illness often revolve around fear of their illness and losing a sense of control as well as social isolation.² While these issues are also important in Nepal, a larger factor seems to be their concern about the impact their illness is having on the family both socially and financially. Patients felt guilt and anxiety over being a burden to others. This may reflect the key role that family play in Nepal in care for patients as well as the close family networks in the context of low income and the lack of government provision of free health care. The frustration and uncertainty caused by dependency as well as fear of inadequate support provision has also been noted in the literature.^{8,9}

Of concern is the changing social setting and family structure of the Nepali community from the joint family to a nuclear family system.¹⁰ With the increasing urbanization of society, more men and women are working outside the home and the neighborhood system is also not as comprehensive and supportive as it used to be.¹¹ This is likely to result in an increase in the number of chronically ill patients staying at home alone, leading to both loneliness and anxiety.

There has been little research done on what Nepali people perceive as the cause of ill health. Study suggests that HIV is seen as a punishment for something bad the person has done either in the past or in a previous life.¹² Illness may also be seen as caused by demons or witch attack, something confirmed in our study. This belief is prevalent not just amongst patients but also within Nepali society which may explain the finding that 6/29 (20.6%) patients felt judged by their local community and isolated from it as a result.

In our study, spiritual factors were important not just as a potential cause of illness but also in terms of the patient's response to their illness. The spiritual beliefs of a patient are rarely addressed in the context of a medical consultation in Nepal. Nepali patients also seem to attribute at least some of their illness to social and emotional stressors. Our study suggests that in the case of patients with a chronic illness it is important to explore these issues.

Limitations of our study is the qualitative data for this study was gathered by junior medical students who did not have a lot of expertise in the collection of "clean" data. Some of the information in the portfolios was therefore a distillation of the student's interpretation of the patient's experiences rather than direct quotations.

As all interviews were carried out in local languages (Nepali or Newari) and were then translated into English, there may have been some inaccuracies in translation. A few patients only spoke Newari and some students

only spoke Nepali, so that information was collected by translation from relatives.

As part of providing patient-centered care in the context of Nepal it is important to explore the level of family and community support available to the patient as well as the current impact on the family. Cost of treatment should be considered in every patient with an effort to provide the best care at the lowest possible cost. A sensitive discussion on the patient's spiritual beliefs around their illness should be included in the consultation.

Conclusions

This study supports that in Nepal there are generally very good social and family support systems. Poor economy and financial issues were major concerns for patients. Family and social support helped patients to cope with the disease but the financial burden imposed on the family by the disease caused emotional stress to the patient.

Acknowledgements

We express our gratitude to students Nihar Shrestha, Anjit Phuyal, Dheeraj Jaiswal and Prakriti Bhattarai for their help during review of the portfolio for data collection.

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