Illness Representations of Hypertension among Nepali Patients at a Tertiary Care Hospital Clinic: An exploratory survey

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ABSTRACT

Article

Background: The prevalence of stage 2 hypertension approaches one-third in adult Nepalis and despite inexpensive effective treatment, long-term compliance is poor. World-wide, a major impediment is the incongruity between hypertension and patients' symptom-based illness representations. The Common-Sense Model of Self-regulation was used to investigate Nepali illness representations through open-ended interviews of patients with hypertension.

Methods: In a tertiary hospital setting, 50 self-identified hypertensive patients were interviewed about their representations of health, hypertension, and hypertensive treatment. Responses were analyzed with a modified Interpretative Phenomenological Analysis.

Results: An Ayurvedic-influenced health model appeared in illness identity and coping responses. Hypertension was identified as a serious disease having observable, wide-ranging symptoms with chronic and intermittent timelines. Concerns included side-effects and barriers to treatment.

Conclusions: Further confirmation and investigation of Nepali common-sense hypertension models in a sample size sufficient for factor analysis is warranted for effective adherence interventions.

Keywords: Common-sense model; hypertension adherence; illness representations; Nepal

INTRODUCTION

The prevalence of stage 2 hypertension approaches one-third of adult Nepalis.¹⁻⁴ Despite effective and inexpensive treatment, long-term compliance is poor and population reductions in morbidity and mortality associated with hypertension are not observed.⁵⁻⁹

World-wide, a major impediment to adherence is the incongruity between hypertension and patients' symptom-based representations of illness, a crucial issue about which, according to a recent Cochrane Report, there has been only limited insight.¹⁰ The "Common-Sense Model of Self-Regulation" (CSM) is a widely-used paradigm describing the dynamic process by which people, informed by socio-cultural context and personal experience, identify health threats, formulate

illness and treatment representations, and adopt and evaluate coping responses.^{11,12} This exploratory study identifies Nepali common-sense themes to elaborate in a larger study that will ground culturally-targeted clinical and public health messages for effective interventions increasing hypertension medication adherence.¹²

METHODS

With approval of the Ethical Review Board of the Nepal Health Research Council (#208/2019), one-time interviews were conducted with a convenience sample of 25 adult men and 25 adult women attending outpatient medical clinics in National Academy of Medical Sciences (NAMS), Bir Hospital during July 2019 till September 2019. A same-sex interviewer asked patients if they had hypertension and those who self-identified were asked to be interviewed on their beliefs about their disease and its treatment; a modest financial incentive

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(NPR 500) was offered. After providing written informed consent, patients were interviewed in Nepali in a private, quiet room for approximately 25 minutes with responses recorded on tape. The interviewers employed open-ended, nondirective interview technique in asking patients a series of 14 questions focused on the CSM illness-representation dimensions (Figure 1), along with treatment representations, appraisal strategies, and ongoing health behaviors (Appendix I).



Figure 1. The common-sense model of self-regulation.

Patients were recruited and interviewed by an interviewer of the same gender who did not present as a clinician in order to encourage open discussion of personal topics, for example menstrual fluid retention or impotence, and avoid the impression that patients were being quizzed on recall of their doctor's communications. Interviews were conducted in Nepali in a private, quiet room, and lasted about 25 minutes, with responses recorded on tape. Care was taken to avoid delaying or interfering with physician visits and other clinical care, which limited the extent of responses sought. Interviewers then transcribed and translated the interviews into English. Interviews were entered into a cloud-based password-protected computer database in English with the file identified by number only.

In analyzing the English-translated interview data, we used a modified Interpretative Phenomenological Analysis (IPA) approach in which we identified categories and themes from the actual interviews, organized them along the dimensions of the CSM model, and then explored implications of the themes.¹³ An investigator (A.S.) experienced in thematic analysis of qualitative data coded the responses in an iterative process after identification of themes in patient health and disease models. The open-ended, non-evaluative interview process precluded

qualitative analyses, nor were they necessary. Codes for each question were created from patients' expressions of their views, allowing unbiased patient models to emerge, then a second pass coded the interviews, using responses from other prompts if they directly referenced a topic. Finally, patient themes applying to wellness, disease, and specifically hypertension, were identified and the specific interviews employing them recorded, along with the tally. The object was to identify assumptions and elements of the models that guide behavior. In reviewing the data, some questions were not answered by some patients. However, if the patient said, "I do not know," it was recorded as a response. Patients sometimes answered or elaborated on an issue in response to a different question, and that information was used to code the relevant question.

Finally, the analysis often recorded the frequency of a specific response, e.g., a symptom or health behavior, as well as how many patients provided that response.

RESULTS

Sources of Health Information Hospitals and doctors were cited by 17 and 19 patients respectively, and other members of the health care system were mentioned by 16 people. Health information sources also included public media: 18 patients received information from traditional media of radio, TV, and newspaper including 2 from government public awareness programs; 8 more from social media; 4 from the internet; and 3 from medical literature. Finally, patients were informed by their social networks, citing family (9), and friends and neighbors (9), as well as their personal experience (4).

First sources of health care These were a hospital (35), medical shops (9), health posts and district health care centers (9), and doctors (5).

Patients reported General Health Promotion Habits without usually specifying if they were currently following them. They cited keeping water, food, clothes, and living spaces clean (25) and exercise (17) as well as the more specific exercise of yoga (2). Avoiding junk food or eating nutritious food (16) and pure, chemical/ pollution-free food (2) were brought up, as well as avoiding: oily/sour/spicy food (9), salt (2), sugar (3), food grown underground (1), alcohol and smoking (1), unprescribed medicines (1). Along with food and exercise, sleep was mentioned: Early to bed/early to rise (1) and adequate rest (1). Individual responses also referred to lifestyle/attitudinal habits: low stress (2), meditation (1), happiness (1), work/rest balance (1) and possibly the above-mentioned yoga (2). Finally, eating

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at correct times (1) and drinking warm water (1) were mentioned.

Initial identification of Patient's hypertension: There were 33 patients who presented with symptoms that they identified as caused by hypertension, and another 6 patients didn't clearly identify their attribution. Together, these patients most commonly reported headache/heavy head (21) and dizziness/imbalance (17). Fifteen other widely varied symptoms were reported, among them pain other than headache (7), nausea and vomiting (3), loss of consciousness (2), and also anger (1), loss of appetite (1) and difficulty opening eyes (1).

Is Hypertension Always There? Of the 36 people who stated that hypertension will always be there, 16 also stated that they would always have to take medication. However, during the course of the interview, 4 patients described an episodic model: specific episodes lead to high blood pressure, while another 10 reported that once blood pressure was brought under control with medication, they might stop treatment or continue with herbal medicines.

Illnesses Similar to Hypertension Noted were diabetes (30), heart disease (14), thyroid problems (13), and cholesterol issues (10) as well as 16 other serious illnesses.

Causes of Hypertension: The most frequent causes suggested were diet-related: diet unspecified (11); too much salt (10); spicy/oily foods (8); imbalance in diet/irregular eating (8); and high fat/high calorie diet (6). Stress (24) was frequently named. Genetic causes were also blamed (7) as well as other behaviors: limited exercise (7); alcohol (4); and inadequate sleep (4).

Signs of Hypertension: While 8 patients reported no signs of hypertension, the remaining 42 monitored a wide variety of 27 different symptoms. The most frequently experienced symptoms were dizziness/fainting (25) and headache (22); the other 25 symptoms were less frequent and included, for example, fever (3) and angry behavior (4).

Problems Associated with Hypertension: The commonest problems associated with high blood pressure were heart conditions/high heart rate (17); stroke/paralysis/ slurred speech/weak hands and feet (17); diabetes (14); kidney disease (10); and falling/dizziness (10).

Treatments Other than Medication: The most frequent treatment was exercise including morning walks and

yoga (28), with an additional 4 people specifying walking barefoot on the grass in the morning. Next was reducing salt intake (19). Other diet-related treatments included "unspecified diet" (14); avoiding high fat and/or oily, spicy food (11); avoiding meat and fish (5); drinking enough water (5); and avoiding tobacco, alcohol and drugs (3). There were 30 mentions of specific vegetables, herbs or flowers, most of them bitter. Meals on a schedule (1), green leafy vegetables (3), home-made food (1) and a balanced diet (1) were also brought up. Behavioral interventions were avoiding stress (6), meditation (1), and adequate sleep (1).

Obstacles to Treatment: The time demands and complications of attending clinic and getting test results (11) were brought up, as well as costs of the visit and the medicine (11). Difficulty finding transportation or someone to assist in the trip were also mentioned (4).

Medication Concerns: Side Effects and Dependence The majority of patients had no concerns (29), but some were concerned (18). One patient commented, "Everyone these days is suffering from high blood pressure so I am not scared. I feel it is somewhat like fever since everyone is suffering from it." Two patients did try and stop medication, and reported bad consequences.

Medication Concerns: Long-term Effects 23 patient had no concerns about long-term treatment, while 27 did. Of these 27, 5 mentioned specific side effects, and another 7 cited the financial burden. Two patients reported being told by family members not to start medication, in one case because she would become dependent on it.

What Would You Hope Doctors Will Tell You? Patients varied in the interpretation of this question. Some wanted medication adjustments based on blood pressure (8). Others wanted more treatment direction: how to take meds (4), or diet, exercise, or stress relief recommendations (14).

Themes across questions: While specific demographic information was not sought, the responses regarding sources of health information and care and language about health promotion indicate a high level of education and perhaps higher than average level of financial resources in the studied population. The following discussion of interview themes must be interpreted in this context.

In discussing hypertension, 42 patients were monitoring specific symptoms in appraising their disease, while of the 44 patients who were experiencing symptoms at the time of diagnosis, 33 attributed those symptoms

to hypertension. Secondly, responses implied different timeline models in response to different questions. A chronic model which required medication for life was referenced by 31 patients, while 4 referenced a intermittent model in which blood pressure would rise in specific situations, such as eating spicy food, and be normal otherwise. An acute model, with time-limited treatment and a cure, was referenced by 8 patients. Five patients described hypertension as an imbalance with medication acting like, "...a high-voltage fuse" to maintain balance.

A third theme is concern with side effects and dependence on medications. This seems striking in this population which appears to be under care for hypertension longterm.

A fourth theme is a broad concept of balance as critical in health, revealed in responses concerning health promotion habits and causes of hypertension. Because of frequent mention of the importance of balance in diet and life as well as dietary recommendations specific to Ayurvedic practice, the interviews were coded for the presence of Ayurvedic-influenced elements. There is an overlap with medical models that confounds this analysis; for example, both systems recommend exercise and avoiding salt. Even without counting responses common to both systems, there was a substantial Ayurvedic influence. Interviews from 41 patients contained 93 responses related to Ayurvedic concepts and recommendations, which views health as a balance of the four physical energies, or *dosha*, of the body, with the predominance of the "hot" pitta dosha associated with hypertension. Ayurvedic treatment frequently involve eating specific foods, with bitter foods balancing too much pitta. Cooling practices, such as walking in the cool morning dew barefoot also balance too much pitta. Physical balance of the doshas is reflected in a balanced temperament; anger is associated with too much pitta.

DISCUSSION

Acknowledging that the patients were mostly urban dwellers with access to allopathic medical services, we focused on patient ideas that might be critical in hypertension management regardless of particular characteristics of the subjects.¹¹ We are concerned that western, high-income-country models for addressing hypertension may not be appropriate for other settings, similar to international and subculture investigations in public health.^{14,15} The details of instrument phrasing, translation, interviewer style, and broad and narrow analytic strategies here may have contributed to an incomplete or mis-emphasized understanding of the core subject.

Acknowledging these limitations, how do these respondents, who are taking treatment for hypertension, understand their disease and its treatment? Hypertension was identified as having a wide variety of observable symptoms by 42 of 50 patients interviewed. The hypertension identity involved headaches and dizziness, and included emotional and vague elements as well as specific physical problems. Diet, exercise, and stress played a role in both causes and treatments. One patient summarized the situation perceived: "People have no problems after treatment, but I see they have problems before treatment." Hypertension was also identified as a serious disease, rather than a "silent" condition. The most prevalent health timeline was not so much chronic illness as ongoing wellness, with a causal model seemingly informed by the Ayurvedic concept of humors whose balance determines one's disposition and health that has historically been part of Nepali health practice along with allopathic medicine.14 Similarly, a Kathmandu study employing the Extended Brief Illness Perception Questionnaire (BIPQ) found that patients were influenced by the experiences and information inherent in Nepalese culture.¹⁵ These elements of illness representations are significant influences on compliance behavior in Nepal and therefore the necessary groundwork for effective health communications.¹⁶ It should be noted that both allopathic models and Ayurveda prescribe changes in diet, exercise and stress management, so the models are not contradictory in their coping responses. The differences lie in the illness and appraisal representations. When hypertension is perceived as an indication of a more general imbalance in the forces influencing mind and body in health as well as illness, a wide range of symptoms, from paralysis to emotional responses, may be used to assess its presence and appraise treatment efficacy. The more diffuse illness representation, including emotional responses, complicates this appraisal. For example, barriers to treatment included transportation and economic difficulties, both major stresses, and stress was identified as a cause of hypertension. Thus, the need to acquire medication may be experienced as contributing to hypertension in the long-term. In contrast, Western investigations of patient models of hypertension described a more targeted process: a specific vector causing the illness monitored by a specific symptom, which could be appraised for treatment efficacy.¹¹

Beyond elucidating the role of socio-cultural context in our theoretical framework, investigating the elements of patients' common-sense models that contribute to medication nonadherence is therefore crucial to designing effective educational messages.

CONCLUSIONS

These interviews suggest further investigation to confirm and elaborate the themes of varied and diffuse symptomatology, nonallopathic health models, longand short-term medication concerns, and treatment barriers, as well as their role in medication adherence. The symptomatic identity of hypertension and how urban Nepali patients ground their understanding of health and illness will be key in creating more effective educational messages about hypertension for a population in which the major issue is treatment adherence.

REFERENCES

- Hasan M, Sutradhar I, Akter T, Das Gupta R, Joshi H, Haider MR, et al. Prevalence and determinants of hypertension among adult population in Nepal: Data from Nepal Demographic and Health Survey 2016. PloS One. 2018 May 31;13(5):e0198028.[Article]
- Dhital SM, Karki A. Dealing with the burden of hypertension in Nepal: current status, challenges and health system issues. Regional Health Forum [Internet]. 2013 [cited 2020 December 29]. Available from: <u>https://apps.who.int/iris/bitstream/handle/10665/205784/</u> <u>B4954.pdf?sequence=1&isAllowed=y</u>
- World Health Organization WHO, Society for Local Integrated Development Nepal, Central Bureau of Statistics, Nepal Government of Nepal. Nepal STEPS noncommunicable disease risk factors survey 2005 [Internet]. 2005 [cited 2020 December 29]. Available from <u>http://ghdx.healthdata.org/record/nepal-steps-</u><u>noncommunicable-disease-risk-factors-survey-2005</u>
- Sharma SK, Ghimire A, Radhakrishnan J, Thapa L, Shrestha NR, Paudel N, et al. Prevalence of hypertension, obesity, diabetes, and metabolic syndrome in Nepal. Int J <u>Hypertens. 2011:821971.[Article]</u>
- Institute for Health Metrics and Evaluation (IHME). Nepal profile. Seattle, Washington: University of Washington [Internet]. 2019 [cited 2020 December 29]. Available from: http://www.healthdata.org/nepal
- Thapa A, Bidur KC, Shakya B, Yadav D, Lama K, Shrestha R. Changing epidemiology of stroke in Nepalese population. <u>NIN. 2018;15(1):10-8. [Article]</u>
- Bhandari B, Bhattarai M, Bhandari M, Ghimire A, Pokharel PK, Morisky DE. Adherence to antihypertensive medications: population based follow up in Eastern

Nepal. J Nepal Health Res Counc. 2015;13(29):38-42. [Download PDF]

- Shrestha B, Ferdoush Z, Rabbi F, Hossain A. Adherence to medications among Nepali hypertensive population: a hospital-based cross-sectional study. Biomedical Journal. 2018;2:5.[Download PDF]
- World Health Organization (WHO). Adherence to longterm therapies: evidence for action. Geneva, Switzerland [Internet]. 2003 [cited 2020 December 29]. Available from: <u>https://www.who.int/chp/knowledge/publications/</u> <u>adherence_report/en/</u>
- Nieuwlaat R, Wilczynski N, Navarro T, Hobson N, Jeffery R, Keepanasseril A, et al. Interventions for enhancing medication adherence. Cochrane Database Syst Rev. 2014 <u>Nov 20;2014(11):CD000011.[Article]</u>
- Meyer D, Leventhal H, Gutmann M. Common-sense models of illness: The example of hypertension. Health Psychology. 1985;4(2):115-35.[Article]
- Leventhal H, Phillips LA, Burns E. The Common-Sense Model of Self-Regulation (CSM): a dynamic framework for understanding illness self-management. J Behav Med. 2016;39:935-46.[Article]
- Tuffour I. A critical overview of interpretative phenomenological analysis: A contemporary qualitative research approach. J Healthc Commun. 2017;2(52).
- Wasti HR,RandallJ, Simkhada P, van Teijlingen E. In what way do Nepalese cultural factors affect adherence to antiretroviral treatment in Nepal? Health Sci J. 2011;5(1):37-47. [FullText]
- Maharjan, S, Chinnawog T, Kritpracha C. Illness perception among patients with hypertension in Nepal. JNHC[internet]. 2017 [cited 2020 December 29];4(2). Available from: <u>http://dl6.globalstf.org/index.php/ inhc/article/view/1897</u>
- Shakya R, Shrestha S, Gautam R, Rai L, Maharjan S, Satyal GK, et al. Perceived illness and treatment adherence to hypertension among patients attending a tertiary hospital in Kathmandu, Nepal. Patient Prefer Adherence. 2020 Nov 20;14:2287-300.[PMC]