Chapter 32
Developing Community Ontologies in User Driven Healthcare

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ABSTRACT

In developing equitable health systems, the World Health Organisation (2005) advocates strengthening the repository of social science research to inform policy decisions affecting health care. The players include the patient, family and community members and health care professionals. This requires a genuine engagement with community perspective on health issues. This chapter examines how health care professionals can engage in understanding user perspectives in order to develop effective health care policies and programs. This case study explores how involving an indigenous community enabled them to develop an effective health promotion and malaria prevention initiative in a remote rural community in PNG It draws on participant narratives to explore user perspectives and understandings of the health impact of a focused health promotion and malaria prevention initiative. It illustrates that poverty dominates their health experiences. The chapter illustrates how the development of a collaborative empowerment approach to research can have a significant impact on the strategies members of indigenous communities can develop in order to optimise their health experiences. It argues that in order to develop effective approaches to health care policy and design health needs to be appreciated in the context of lived experiences of those affected.

INTRODUCTION

This chapter examines how health care professionals can work with a range of stakeholders in designing and delivering health care focused on service user needs. There are many theories about how individuals and communities can be encouraged to change their behaviours in order to improve their health status. However, many do not address the context and situated belief systems of the individual and the community that they live in. If the reference frames of the individual and or community are not addressed this may impact dramatically on the efficacy and effectiveness of health improvement and treatment initiatives. This chapter explores how health care professionals can engage in dialogue with stakeholders that respects the legitimacy of all perceptions and belief systems of health and illness. It examines how health care professionals can engage in understanding user perspectives in order to develop effective health care policies and programs. It argues that this type of approach will enable us to develop effective partnerships in designing and implementing user focused approaches to healthcare.

The chapter draws on the literature in developing partnership approaches to health service design and delivery. In order to explore the issues in context it reviews a case study that explores the experience of a small research project, conducted with members of the Kewapi language group in Papua New Guinea. It draws on participant narratives to explore user perspectives and understandings of the health impact of a focused health promotion and malaria prevention initiative.

BACKGROUND

Case Study Context in Papua New Guinea

There are over 800 language groups in Papua New Guinea each have separate cultures and traditions.

The research discussed in this chapter emerged from discussions with members of the Kewapi language group who live in an urban settlement in Port Moresby the capital city. It was extended to develop an insecticide treated bed net (ITN) initiative in the Batri villages in the Southern Highlands of Papua New Guinea.

Simms (2002) attests that people populating urban settlements in PNG survive in difficult circumstances. They live in poor housing and have limited access to basic amenities. Water is supplied via a standpipe which may serve up to 50 people and this may be cut off for days with no replacement available to them. They have no mains electricity and so live by natural light and candle light and by cooking on wood fires or on a primus stove. They have no access to refrigerators and have to shop for fresh food on a daily basis. Fifteen people made up of three immediate family units may live in a tiny dwelling of about 35 square meters. They share their water source and latrine with up to 40 other people living within a very small area.

Professor Simms (2002) affirms that settlement communities in PNG are poor places where basic amenities are scarce. He also asserts that they have a reputation for being violent areas where health workers are reluctant to enter. He comments on the abject poverty and extreme difficulties people face in coping with illness in such conditions. In a similar vein, the Voluntary Services Overseas (VSO) policy documents (VSO, 1999) state that it does not place volunteers in Port Moresby, since it is perceived to have problems with law and order. These conditions contribute to a range of debilitating conditions such as diarrhoea and malnutrition. In addition, the tropical climate means that diseases such as malaria, dengue fever, and tropical ulcers thrive.

Thus, members of the Kewapi language group face a myriad of health issues due to the context in which they live their lives. Poverty dominates their health experiences. The environment that they live in are poor; the standard of shelter basic

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