Narratives and Newcomers: Rethinking Culturally Appropriate Health Care

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Abstract: Cultural appropriateness has become an important conceptual tool for health care professionals serving diverse patient populations. Physicians and other health care providers working in urban communities are increasingly challenged to provide care that is responsive to the health needs and beliefs of immigrants, refugees and other newcomers to mainstream health services. This paper argues that notions of cultural 'sensitivity' or 'competency' help health practitioners acknowledge professional and biomedical biases, but also risk dehistoricizing and hence disempowering newcomers by failing to recognize culture as a dynamic process. Without attention to the ways in which newcomers actively produce culture and make sense of illness experience, health care workers ignore the contexts in which people become ill and hence cannot act as healers. By presenting the case of one newcomer to the Canadian health care system, I argue that narratives provide a valuable tool for health practitioners to understand how newcomers actively engage and come to terms with illness, without defining them as determined by a set of cultural beliefs or practices.

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Narratives make not only good stories but also good medicine.
- Howard Stein, 1998

Introduction

"Anthropology? That's interesting. Maybe we could talk sometime? Maybe you'd like to hear some of my stories?" John is beginning to take an interest in people again. After being estranged from his wife and two sons, and living and drinking for several years on the streets of Toronto, John is rebuilding his life. He continues to suffer from hepatitis C, diabetes and arthritis, but he is beginning to develop an understanding of his troubles. He is making links with his community, taking care of his mental and physical health, and actively recreating his identity through artwork and making crafts. "In order to know yourself, it is important to know where you come from," John told me. "By the way, Sam, I'd like to tell you about when I..."

I met John while working as a research intern at a community-based health care centre (CHC) in Northwest Toronto[1]. In cooperation with my internship supervisor and a family physician, I co-designed a clinical observation project to explore the applicability of ideas and concepts in medical anthropology to the provision of health care to new immigrants and refugees. I was interested to learn how medical anthropology students could work collaboratively with community health care professionals to understand how CHC's provide health care for 'newcomers', many of whom are accessing the Canadian health care system for the first time. This experience compelled me to reevaluate some of the dominant concepts and practices in the field of cross-cultural health care, particularly the notion of 'newcomer' and the practice of culturally appropriate care. How do people who have been marginal(ized) in various ways (socially, culturally, economically) experience the social and health system for the first time? How can mainstream health practitioners provide care for newcomers in a way that values cultural diversity, understands the specific sociocultural contexts that shape people's lives, and builds trust and relationships over the long term?

This paper suggests new directions in the conceptualization and practice of health care to newcomers. By 'newcomers' I refer to those individuals (immigrants, refugees, homeless) who are new to formal health services in Canada, as well as people who are renewing contacts with health and social agencies after years of marginalization from the mainstream structures of Canadian society. Based on my internship experience, as well as a review of the literature on immigrant and refugee health, narrative-based medicine, and the patient centred medical model, this paper encourages health researchers and practitioners to rethink approaches variously glossed as culturally appropriate, sensitive, or competent. It opens up a discussion on the ways in which narrative-based medicine can be more explicitly incorporated into providing care for newcomers. Narrative-based medicine can complement and strengthen approaches built on the notion of culturally appropriate care by listening to people's stories and participating in the *processes* of lived illness experience. This paper provides an example of how applied anthropologists can work collaboratively with health professionals on issues of cross-cultural communication and health care. In doing so, it points to ways of opening a dialogue and finding common terminology between practitioners and researchers to address issues of mutual theoretical and practical concern.

Cross-Cultural Health Care in Canada

Since the passing of the Multicultural Act in 1988, there has been increasing interest among health professionals and health researchers in Canada to design and implement health care services and programs that are accessible and sensitive to people from a wide range of social, cultural, and religious backgrounds. Since the late 1980's, a wealth of academic literature, training manuals, and committee reports has emerged on access to health care by immigrants and refugees and the cultural competence of mainstream health practitioners (Juliá 1996; Masi *et al.* 1993b; Waxler-Morrison *et al.* 1990; Majumdar 1995). By employing the concept of "multicultural health"—defined as "health care that is culturally, racially and linguistically sensitive and responsive" (Masi *et al.* 1993a) — health planners and practitioners aim to ameliorate the low levels of client satisfaction and poor adherence to treatment regimes among newcomers. Within this framework, it is argued, the individual must be understood as shaped by a cultural context, which includes shared norms, values, beliefs, and practices among a particular group of people (e.g. Nigerian refugees, homeless, White middle class) (Dyck 1992; Waxler-Morrison *et al.* 1990). It is also argued that physicians need to have a better knowledge of the cultural and socioeconomic issues affecting the lives of individuals seeking care (Juliá 1996). Without attitudinal changes towards people from diverse backgrounds, interactions between newcomers and physicians may be fraught with conflict, resulting in low patient satisfaction, physician frustration, and poor health outcomes (Masi *et al.* 1993a).

Literature and training in cross-cultural health care has provided important insights into the different health and illness experiences of newcomers to the Canadian health care system. Several authors point out that cultural groups are not homogeneous but heterogeneous, consisting of people with different social, religious and political affiliations (Harwood 1981; Masi *et al.* 1993a). Guatemalans in Canada, for example, have different religious beliefs (Catholic, Protestant, Maya spiritualism), different ethnoracial backgrounds (Ladino and Maya) and different class connections (lower, middle, and upper) (Meredith 1992). As such, some of the literature argues that health practitioners working in CHCs and other health centres serving diverse populations need to appreciate the differences *within* particular ethnic or cultural groups and attempt to deliver care accordingly (Harwood 1981; Dyck 1992). It is pointed out that care givers *themselves* (typically White Euro-Canadians) have particular cultural beliefs that influence the kinds of care provided (Masi *et al.* 1993a; Waxler-Morrison *et al.* 1990). That is, mainstream health practitioners do not provide an objective, detached account of a particular illness, but rather enact a subjective, interpretive view of the patients' health needs (Greenhalgh and Hurwitz 1999).

Despite these important insights, much of the research and practice of culturally sensitive health care simplifies the concept of culture. Culture is typically viewed as shaped by an overarching set of beliefs and practices that determines the thoughts and actions of a group of people. In the context of health care to newcomers, this oversimplification risks neglecting patient illness narratives and dismissing what might not *fit* into a physician's understanding of what *ought to* constitute illness or healing in a certain group. These problems stem in large part from the ways in which recent medical texts define culture:

> *The totality of socially transmitted behavioral patterns, arts, beliefs, values, customs, lifeways, and all other products of human work and thought characteristics of a population of people that guide their worldview and decision making (Purnell and Paulanka 1998:2).*

This definition risks depoliticizing and dehistoricizing patients by failing to treat them, first and foremost, as shaped by—yet also shaping—the particular contexts in which processes of becoming ill and healing are lived and embodied (Green 1998; Kleinman 1988). Definitions of culture that emphasize fixity and sharedness neglect the contingent and dynamic processes by which culture is shaped and reshaped over time and space. Developing sensitivity towards the health and cultural beliefs of different groups may help health care providers diagnose effectively, but it does not enable care givers to improve the listening skills and relationship building that make up the *healing* process.

Biomedical professionals are often criticized for having a poor understanding of the cross-cultural meanings of health and illness (Harwood 1981). By failing to recognize the important ways that culture influences illness and health behaviours, they are criticized for being "culturally encapsulated" (Sue and Sue 1990:159). In response to this problem, programs have been designed to help health care professionals appreciate the diverse ways illnesses are expressed (Majumdar 1995). In these programs, health professionals are trained to develop sensitivity and understanding of cross-cultural expressions and meanings of illness (Purnell and Paulanka 1998). One problem with this approach, though, is that cultures are encapsulated in different ways. By emphasizing shared norms and values among cultures, as well as describing cultures as bounded by these beliefs and practices, health professionals risk encapsulating newcomers by defining them solely by their 'cultural difference.' One consequence of this is that the categories by which people are defined, labeled, and disempowered are left unchallenged. With this conceptualization of culture, family physicians and other care providers jeopardize ignoring or foreclosing the stories and narratives that actively *produce* culture and accompany the illness experience. The ability to value cultural, ethnic, religious, gender, class, and racial difference is indeed important for any health care professional who serves a diverse population of newcomers. Yet this understanding needs to be complemented by creating space for narrative and dialogue that can help the healing process.

The 'culturally sensitive' approach does not effectively enable health care providers to act as healers towards newcomers. It attempts to improve the cultural and health knowledge base of mainstream care givers but does not address the need to build patient-physician relationships. By neglecting to listen (deeply) to patient narratives, health care providers may fail to understand underlying illness causation, especially among newcomers who typically do not feel comfortable talking about particular problems with mainstream service providers (Freire 1995; Losaria-Barwick 1992; Muecke 1992). Much of the academic, policy, and training literature implies that once health professionals become aware of and sensitive to cross-cultural meanings of health and illness, then they will be equipped (have the proper conceptual tools) to provide care to people from a variety of cultural backgrounds. As a consequence, care providers may "dismiss the anomalous" (Greenhalgh and Hurwitz 1999:49) in diagnosing illness and neglect to understand the histories, contexts, and dynamic processes that shape illness experiences.

Narrative in the Context of Culturally Appropriate Health Care

My work as a research intern was particularly informative with regard to thinking about the ways a community-based health care centre—York Community Services (YCS)—attempts to serve newcomers. Having previously read a substantial amount of medical anthropology and cultural psychiatry literature on cross-cultural health care, I carried into the project certain assumptions and expectations about how physicians would work with diverse patients. What I anticipated, perhaps naively, was patient-physician misunderstanding, conflict over suggested treatment regimes, and low compliance. What I anticipated, perhaps unconsciously, were colourful, easy-to-identify cultural beliefs about illness causation and healing. What I anticipated, perhaps mistakenly, were easy-to-follow, free flowing patient stories about failed attempts to access 'the system' and cultural conflict with service providers.

Instead, what I heard were narratives: dense, contradictory, ambiguous, and piled up; there was always something more to be said (Stewart 1996). People worked through narratives to describe how they were feeling. There was talk about work, family, immigration, weather. These people, and their experiences, were not *bound* by a set of shared norms, values, or beliefs. Rather, these patients were actively *producing* culture by trying to come to terms with why they were ill. This is not to imply that groups of people at different times and places do not share histories, struggles, and collective social concerns. Rather, it suggests that trying to understand cross-cultural ways of expressing illness and health should not *foreclose* or *interrupt* health practitioners and researchers from seeing patients as steering the processes of becoming ill and healing through various modes of *telling*. Listening to these narratives helps community-based health care givers understand illness meanings, and provide more effective care as *healers* which in turn can improve patient-physician relationships and promote continuous care.

Narrative-based medicine has received considerable attention in recent health research, most notably a recent series of articles in the British Medical Journal. In this collection, editor Trisha Greenhalgh (1999:325) suggests that patients and physicians engage in narratives—broadly defined as interpretive acts of providing information—to make sense of the process of healing. "Rather than giving a snapshot of a patient's feelings and concerns at one time during an illness," Greenhalgh and Hurwitz argue (1999:50), "[a] narrative will follow these feelings and concerns through a sequence that begins before diagnosis and continues through the clinical encounter…" As a complement to evidence-based medicine, which aims to provide accurate, scientifically grounded diagnoses and treatments, narrative-based medicine can help draw-out meaning, context, and perspective from clinical encounters and relationships. Narratives not only involve individuals, therefore, but also the social settings in which people *live* and *retell* experiences of illness and healing (Launer 1999). In short, narratives embody the very anxieties, uncertainties, and hopes that accompany illness.

Research on narrative-based medicine also addresses the need for physicians and other health care givers to listen deeply—and constructively—to the stories they hear (Stein 1998; Elwyn and Gwyn 1999). According to Greenhalgh and Hurwitz (1999:50), "the core clinical skills of listening, questioning, delineating, marshalling, explaining, and interpreting may provide a way of mediating between the very different worlds of patients and health professionals." In doing so, deep listening to the stories and explanations that accompany a particular patient's illness can help to build care giver-patient relationships.

The Patient Centred Care Model, developed by the Family Medicine Research Unit at the University of Western Ontario, aims to find common ground and build trust between physicians and patients. "The essence of the patient centred method," says McWhinney (1996:435), "is that the doctor attends to the feelings, emotions, and moods, as well as categorizing the patient's illness." Giving primacy to long-term relationships, then, directs physician attention to the particulars of illness (McWhinney 1996). Relationships can be built by eliciting patient narratives on their past and current struggles with illness. The use of narrative or storytelling can contribute to diagnosis by creating a dialogic space for people to talk about certain issues and concerns that otherwise would not be discussed in the clinical setting. When working with newcomers, for instance, who are typically reluctant to discuss certain issues with health professionals (Freire 1995), the encouragement of narrative exchange can foster trust and confidence between physician and patient. While efforts to be culturally appropriate, sensitive, or competent may provide a useful knowledge base for practitioners in some health care settings, these approaches do not enable the care giver to actively engage and understand the *contexts* and *processes* by which people experience illness and healing.

A Newcomer's Narrative

My thoughts on the use of narrative-based medicine began to take shape after I met John. I have fond memories of our conversation on a sunny, brisk March afternoon in Northwest Toronto. We sat in an office usually reserved for medical students and started to talk anthropology. John was one of the few patients that I had met who did not assume I was interested in ancient Maya ruins, and instead engaged me in a discussion about his mixed ethnic background. "I'm from New Brunswick," John stated with a hint of pride. "My dad was a black from the States, and my mom a Native. I moved to Toronto when I was a young man, and I've had a pretty rough time here. Actually, I've had a pretty rough *life.*"

John explained to me that he has never felt like he belonged anywhere, or with anyone. He had cut himself off from other people in his community and had developed an increasing hatred for young people. Part black and part Micmac, John has had a tough time "fitting in," whether as a boy in the schoolyard or as an adult on the streets of Toronto. His feelings of lacking belongingness were linked to his problems with violence and drinking, both of which have caused him considerable mental and physical damage over the years. This in turn seemed to exacerbate his feelings of loneliness and isolation.

In October 1996, John first came to YCS as a walk-in patient seeking immediate care for multiple fractures after being beaten by a local street gang. He was feeling faint and was walking with a cane due to ankle injuries. He was sleeping on the floor at a friend's place and had no contact with his relatives. Eating irregularly and refusing to sleep at a shelter out of pride, John was battling multiple social and health problems.

Over the last few years John's life has begun to stabilize. Despite ongoing problems with alcohol abuse, heavy smoking, depression, and unemployment, he is beginning to develop an understanding—and be able to talk about—his past and current relationships with family, friends, and partners. He has reunited with his teenage sons and volunteers in an art therapy group for survivors of mental illness. He attributes his remarkable recovery to the help of housing, medication for his depression, social services, and an ongoing patient-physician relationship.

The use of narrative has been—and continues to be—an important part of John's health care. As both a therapeutic and diagnostic device, narratives have been used by John and his care givers to understand his health and social condition, and improve his sense of belonging in the local community. By narrating about his health concerns, John has tried to make sense of how his past is linked to his current health condition. In doing so, he has used storytelling to reconstruct his life and reinvent his identity. The use of narrative has helped John to develop a relationship with health care professionals that is built on trust and ongoing health care.

John is a medically complicated and ethnically mixed individual whose illness experiences force health researchers and practitioners to rethink the notion of culturally appropriate health care. While an appreciation of John's cultural, religious and social background may help to improve his compliance with suggested treatments, culturally competent approaches *alone* may risk ignoring John's complex retelling of illness experience through narrative. In this way, caregivers can begin to conceptualize patients as *producing* culture, and not simply following or subscribing to a set of shared beliefs and values. John's life is shaped by—yet he is also actively shaping—his Native identity through retelling his past and creating artwork which helps to crystallize his sense of self. To understand John as simply 'culturally different' or 'culturally bound' would have an affect of foreclosing the dynamic stories that form the process of illness and healing. A static approach also risks explaining away the complexities and anomalies that inevitably emerge during the process of establishing patient-physician relationships.

Conclusion

My conversations with John and community-based health care workers during this clinical observation project has opened up for discussion a set of issues that are of concern for many applied medical anthropologists and family medicine researchers. How can theories and concepts developed within these diverse fields be mutually informing *and* be relevant for practice? This project attempted to address the problematics of collaboration between anthropologists and health care workers by critically engaging the notion of 'culturally sensitive' care to newcomers. It found that cultural sensitivity is not enough. While notions of cultural 'appropriateness' or 'competency' help health practitioners acknowledge professional and biomedical biases, these approaches also risk dehistoricizing and hence disempowering newcomers by failing to recognize culture as a dynamic process. Without attention to the ways in which newcomers actively produce culture and make sense of illness experience, health care workers ignore the contexts in which people become ill and hence cannot act as healers.

Research collaboration offered an opportunity to negotiate some of the terminology and theory employed by medical anthropologists and health care workers. The study of the role of narratives in health care for marginalized populations provides a fruitful ground for professional collaboration, and, more importantly, improved patient care. For both health researchers and practitioners, a solid understanding of how culture shapes health beliefs and behaviours should be complemented by an awareness of the role of storytelling in expressing and giving meaning to illness experiences. Through the narratives and stories of patients like John, academics and caregivers are challenged to rethink dominant concepts in the provision of health care to newcomers to Canada.

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Endnotes

[1] This research is based on a four month research internship at York Community Services (YCS), Toronto, Canada, January—May, 1999. The project involved research collaboration with Kevin Pottie, Family Physician; discussions with several of Dr. Pottie's patients on their illness experienced; participation in staff meetings, administrative work, and hallway chats; and workshops with the YCS health team on the use of narratives in health care.

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