

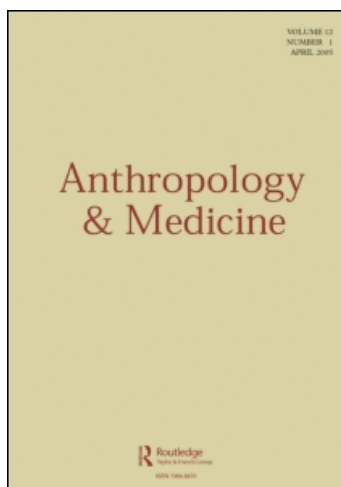
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Taking the MINI to Mustang, Nepal: methodological and epistemological translations of an illness narrative interview tool

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Illness narratives and explanatory models have been a research focus for the discipline of medical anthropology for decades. In recent years, standardized qualitative research tools have been developed to elicit illness narratives as a means of conducting socio-cultural analysis and as a springboard for health-related interventions – particularly with reference to communities experiencing rapid socioeconomic transition or those in which trauma has been experienced. Nevertheless, gaps persist in terms of the latent methodological and epistemological challenges of translating and transplanting such research tools to new contexts. This paper chronicles the adaptation of the McGill Illness Narrative Interview (MINI) for use in the culturally Tibetan region of Mustang, Nepal. This analysis is based on 44 in-depth interviews using an adapted version of the MINI to elicit narratives about experiences of illness. The MINI proved to be a compelling research tool, particularly in terms of engaging research assistants in the field. Yet its deployment in a context where distinctions between individual and social suffering can be blurred, where the dichotomization of ‘religion’ and ‘medicine’ makes little sense, and where understandings of causality are rooted in the concept of *karma*, revealed the extent to which the MINI – and, by extension other such qualitative research tools – emerges from particular models of narrative construction and assumptions about the relationships between self and other, cause and effect. Concluding recommendations are made regarding the adaptation of this tool to other settings.

Keywords: explanatory models; illness meaning; medical anthropology; narratives; Nepal; Tibet

Introduction

For more than three decades, eliciting personal narratives about experiences of illness has provided methodological structure and analytical insight to researchers

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in the fields of medical anthropology, sociology, and trans-cultural psychology, among others. Scholars and clinicians have developed a number of standardized qualitative research tools to draw out illness narratives. Such theoretically driven, semi-structured interview schedules have been used to: gather data for socio-cultural analysis, improve communication between patients and providers in clinical settings, help develop health-related interventions, and evaluate health programmes and therapeutic regimens. These methodologies aim to improve understanding of health behaviour and experiences of suffering in socio-cultural context. Qualitative interview schedules have become particularly well integrated into research and intervention aimed at communities experiencing rapid socioeconomic transition or among populations that have experienced trauma or suffer from particular diseases, chronic illness, and medically unexplained symptoms. That said, some of these tools have been more successful than others in eliciting complex rather than positivist narratives, accounting for cultural bias, and dealing with diverse patient responses. In addition, most of this research has been conducted in North America or Europe; less work has explored the methodological and epistemological issues that surface when such research tools are translated into new contexts.

The first author has been conducting fieldwork in the culturally Tibetan region of Mustang, Nepal, for more than 15 years. Much of this work has focused on practitioners of Tibetan medicine, or *amchi*: their training and practice, the professional and socio-economic transitions they are undergoing, and their interactions with both health-development and conservation organizations. In an effort to understand better where Tibetan medicine fits within a suite of health care options and strategies used by villagers from Mustang, and as part of crafting a larger research project on the impacts of labour migration and social change on health seeking behaviour among people from Mustang, a turn towards people's stories of suffering seemed necessary. The first author intends to share the results of this work with local and regional government offices and non-governmental organizations (NGOs) involved in health delivery.

In what follows, the authors discuss the adaptation of the McGill Illness Narrative Interview (MINI) for use in Mustang. First, the MINI is contextualized in relation to other interview schedules. Critiques of models that predate the MINI and the conceptual rationales which led to the MINI's creation are explored. In the next section, Mustang, Nepal, is located with reference to key social, historical, and political forces that have shaped residents' lives and influenced their understanding of suffering and wellbeing as well as their access to health care. Next, the author explains how and why the MINI was adapted for use in Mustang, highlighting points of conflict, confusion, and accommodation that occurred. Some preliminary themes that emerged from the content of the interviews, yet which are relevant to the methodological arguments made herein, are then discussed. In conclusion, the authors argue that, while the MINI proved to be a compelling research tool – particularly in engaging research assistants and students in the field – its deployment in this context revealed the extent to which the MINI still emerges from particular culturally inflected models of narrative construction and epistemological assumptions about the relationships between self and other, cause and effect. Finally, the authors offer some pragmatic recommendations regarding the adaptation of the MINI to other settings.

Contextualizing the MINI

Formalized questionnaires to elicit consistent and comparable illness narrative data have been broadly applied across geographical and disciplinary territories – from anthropology and culturally informed epidemiology to trans-cultural psychiatry (Trostle and Somerfeld 1996). Such interviews are administered in the hopes of learning more about the relationship between people's health beliefs and their health-related behaviours. Many illness narrative instruments are based on the concept of the explanatory model (EM). First articulated by Arthur Kleinman (1981), EMs are personal interpretations of the aetiology, treatment, and outcome of an illness, by which a person gives meaning to his/her condition. While EMs remain central to social studies of the phenomenology of illness, the extent to which formal interview schedules are capable of eliciting comprehensive patient illness representations can be limited by a number of cultural, linguistic and methodological barriers. (Indeed, the problem of whether or not an individual EM results in a broader or collective understanding is faced by all ethnographic work centred on illness narratives.) This has led to continuous (re)development of such research tools.¹ Two of the most widely used interview schedules to precede the MINI are the Explanatory Model Interview Catalogue (EMIC) and the Short Explanatory Model Interview (SEMI).

The EMIC aims to identify 'normative cultural explanatory models as well as the diversity and implications of individual variation' (Weiss et al. 1992, 820). Within the EMIC, patterns of distress, perceived causes, preferences for seeking treatment, and general illness beliefs constitute a framework for operationalizing an EM. Datasets generated through EMIC interviews can include quantitative variables and prose, which are cross-referenced for analysis of the illness experience and its practical implications (Weiss 1997, 235). The development of the EMIC drew heavily upon anthropological theories, including the distinctions between emic and etic perspectives and between illness and disease (Weiss 1997). The EMIC is designed to 'serve as a foundation that could support a cultural epidemiology compelling enough to influence mainstream psychiatry, medicine, or public health' (Weiss 1997, 241) and to provide a 'method for studying cultural features of medical and psychiatric illness' that can 'generate a database of explanatory models' (Weiss et al. 1992, 828).

The EMIC has been adapted for use in a range of settings (cf. Raguram et al. 2001; Weiss et al. 2001; Lee et al. 2000, 2001; Jadhav et al. 2001; Kohrt et al. 2004; Guarnaccia et al. 1996; Weiss et al. 2008).² While use of the EMIC has been widespread, and while many researchers have praised its merits, it has not avoided critique. In their work with Chinese immigrant populations in Canada, Lee et al. (2001, 105) note, 'Sometimes the flow of their narrative broke from the structure of the interview, and insofar as the EMIC has an agenda, some balance and guidance is required to ensure that items are covered systematically'. In their research on depression among white Britons in London, Jadhav et al. (2001) discuss the problem of survey length and interviewer/interviewee fatigue as well as the potential influence of interviewer characteristics on participants' responses. They also note that the EMIC can lead to an uncritical proliferation of coding categories, which can become 'counterproductive' at the level of analysis (Jadhav et al. 2001, 67). Guarnaccia et al. (1996, 349) raise a similar point.

The Short Explanatory Model Interview (SEMI) was developed by Lloyd et al. (1998) to meet the needs of large-scale epidemiological fieldwork. It was first piloted

with whites, African-Caribbean, and Asians with 'common mental disorders' in South London, and with a similar population in Harare, Zimbabwe (Lloyd et al. 1998). Since then, the SEMI has been used to elicit EMs in diverse populations (cf. Athula et al. 2008; Joel et al. 2003; Shankar et al. 2006; Silove et al. 2008). Like the EMIC, the SEMI has generated both praise and critique. Athula et al. (2008) found the SEMI useful in structuring clinical responses to patients with medically unexplained symptoms. Yet Joel et al. (2003, 68) acknowledge difficulties in 'converting qualitative responses to quantitative measures and performing detailed analysis' and note that the instrument 'may not meet rigorous ethnographic standards'. McCabe and Priebe's SEMI study of schizophrenia highlighted the limitations of using an operationalized method to assess EMs, for, as they note, 'Individual accounts of cause of illness were not fixed but fluid and often people did not cite a single, but multiple causes' (McCabe and Priebe 2004, 29). These critiques reveal central difficulties in reducing complex, varied narratives to discrete categories or models of experience that are correlated, in turn, to particular quantitative health outcomes. Critiques of the EMIC and SEMI have often centred on coding and data analysis, and are thus shared, at some level, with *any* qualitative interview; yet the critiques also point to methodological and epistemological limitations of these tools that are emergent from the highly structured nature of EM inquiry elicited through these tools.

An emerging body of literature suggests EMs may not represent a comprehensive enough approach to eliciting illness narratives. Some time ago, Young (1981, 1982) critiqued the emphasis on causal relationships underlying the EM paradigm, stating that it assumes a 'rational man' producing logical and coherent accounts, rather than a realistic patient who may conceive of his illness in a variety of ways. Williams and Healy (2001, 465) assert that the EM is 'too fixed to fully convey the fluid status of beliefs.' Concerns about an over-reliance on the EM paradigm have dovetailed with critiques concerning positivist assumptions about what constitutes 'culture' and 'belief' on the one hand, and 'causes' and 'effects' of illness on the other. Waldram (2006, 77) argues the EMIC is 'guided by the assumption of a more or less uniform cultural base among the participants, and the many and varied perceived causes are presented as if they represent, in totality, the explanatory or folk model of a singular group of people, a cultural group'. Does a collection of individual EMs add up to a broader, collective cultural understanding? To what extent are individual EMs shaped by culture or context, not only in a traditional 'ethnographic setting' sense, but also through the process of being elicited through a formal interview? These tools have been criticized for their closed-ended analysis and their inability to 'produce narratives of sufficient spontaneity and depth to allow more intensive methods of narrative and discourse analysis' (Groleau et al. 2006, 675).

As early as 1982, Allan Young identified 'chain complex' and 'prototype' narratives as concepts that could be elicited to complement and diversify EM paradigms. In *chain complexes* 'past experiences are linked metonymically to present symptoms through a sequence of events surrounding the symptoms without any explicit causal connection,' while *prototypes* include 'reasoning based upon salient episodes or events in one's own or others' experiences, which allow individuals to elaborate the meaning of their illness through analogy' (Groleau et al. 2006, 676). Critiques about cause-effect assumptions embedded in EM-based tools, as well as a need to account for more types of narratives, laid the groundwork for the

development of an interview schedule that incorporates the narrative elements of prototypes, chain complexes, *and* explanatory models: the McGill Illness Narrative Interview (MINI).

The MINI begins by eliciting an open-ended illness narrative, followed by sections that garner prototype and EM narratives through specific prompts, a section on treatment, and a final section on the impacts of illness on the interviewee's life. The MINI is also designed to elicit different types of narrative structures, even though these are often intermixed in the course of ordinary conversation (Stern and Kirmayer 2004). The MINI has been used in a number of studies: among immigrant and minority populations in Western contexts (Kirmayer et al. 1996; Groleau and Kirmayer 2004; Groleau et al. 2006; Groleau et al. 2007; Whitley et al. 2006) and with patients in North American milieu dealing with chronic illness (Walker 2008). These studies affirm that the MINI gives 'access to complementary modes of meaning and reasoning (causal, analogical and metonymical) in cultural, political, economical and historical contexts' (Groleau et al. 2007, 736). However, there is a paucity of literature on the MINI's use in other contexts. One of the few MINI-inspired studies conducted outside North America or Europe was a project on depression related to severe morbidity in Uganda (Muhwezi et al. 2008). However, this study focused on caregivers who described the illnesses of their patients, rather than patients themselves. In summarizing his research in Uganda, Muhwezi acknowledges,

The adaptation process was not without risks. Using research instruments developed for use in industrial Western societies in central Ugandan settings raised intellectual discomfort. [Such methodological tools] still need to be validated in different cultural contexts in Africa before their wholesale use as trusted data collection research tools in the future (Muhwezi 2007, 45).

Issues such as these inspired the first author to consider adapting the MINI for use in Mustang, Nepal. It was posited that taking the MINI to Mustang could further anthropological inquiry not only about experiences of health and illness in this locale, but also about the extent to which such research tools – even those as thoughtfully designed as the MINI – can translate across diverse linguistic, cultural and medical terrain.

Locating Mustang

Mustang is a high-altitude region in the rain shadow of the Himalayas, which borders China to the north. Most settlements are located between 2000–3800 metres. Jomsom, the district headquarters, is linked to Pokhara, the nearest city, by flights from a small airport and by trails; no all-season motor road links the district to any urban centre. Mustang encompasses most of the Annapurna Conservation Area Project (ACAP), Nepal's largest protected area. The district is home to approximately 14,000 individuals (2001 census), whose households and property are partitioned into 16 Village Development Committees (VDCs). Most Mustangis identify as followers of Tibetan Buddhism and/or Bön, the indigenous religion of the Tibetan plateau (Lopez 2007; Ramble 2008). Shamanic and tantric practices, regimes of 'civil religion' that govern social behaviour and natural resource use, and the worship of local deities further define the cultural landscape of Mustang (Samuel 1993; Ramble 2008). Like other regions of high-mountain Nepal, people

from Mustang have historically depended on agriculture, animal husbandry, and regional commodity trade to wrest survival and even prosperity from this harsh landscape (Snellgrove 1988; Vinding 1998; van Spengen 2000).

While Mustang was incorporated into the nation-state of Nepal in the 18th century (Ramble 2008, 24), the area maintains cultural, economic and political alliances with Tibet – not least of which is the lineage of kings, descendants of western Tibetan nobility, who, since the 14th century, have wielded cultural and locally circumscribed political influence over northern Mustang (Dhungel 2002). In addition, Mustang was occupied by Tibetan Resistance forces from 1960–1974 (Peissel 1967; Craig 2008b). A permanent Tibetan settlement has existed in southern Mustang since the 1970s, and currently a road is being built north from Lo Monthang to the Tibetan border (Craig 2002). Due in part to this sensitive political history, foreign access to northern parts of the district was prohibited until 1991, and is now permitted on a restricted basis. In contrast, villages in southern Mustang have been a locus of tourism since the late 1970s, and are more accessible to roads and regional markets. These designations have real-world effects for the people of Mustang with respect to economic opportunities and the provision of government services, including health care.

As in the rest of Nepal, biomedical health care only became available in Mustang during the mid-20th century (Justice 1986). Even today, biomedicine remains limited in scope and quality. A 15-bed hospital in Jomsom provides the most comprehensive biomedical facilities in the district. Government Health Posts and Sub-Health Posts are found at the village level, and are staffed by health workers with limited training. ACAP maintains some VDC-level health facilities, as do several foreign NGOs. Biomedical technologies and medical supplies remain minimal; there are no critical care facilities in the district. People from Mustang with means opt to seek biomedical care in Pokhara or Kathmandu at private hospitals or clinics, often coinciding with trips to urban centres for trade or pilgrimage. As in other culturally Tibetan communities, many turn to *amchi* as well as ritual healers such as diviners (*mopa*) and tantric specialists (*ngakpa*) in the event of illness (cf. Gerke, forthcoming; Schrempf, forthcoming; Prost 2008; Kunwar et al. 2006; Samuel 1999). In Mustang today, there is virtually no formal interaction between *amchi* and government health care services, despite professionalizing efforts on the part of Nepal's *amchi* (Craig and Bista 2005; Craig 2008a).

Within this social landscape, patients frequently make pragmatic choices about when and how to access biomedicine, Tibetan medicine, and ritual healing based on economic constraints and their own understanding of the nature of their illness (cf. Schrempf, forthcoming; Samuel 2006a). Tensions can surface, however, between government health workers, on the one hand, and local healers and patients, on the other. Many government health workers stationed in Mustang are Hindus from lowland, Nepali-speaking areas. Typically, these individuals do not speak local Tibetan dialects and adopt patronizing attitudes toward their fellow citizens of Buddhist/Tibetan cultural extraction – a reality that reflects Nepal's position, until 2006, as the world's only Hindu polity, and one whose populace has been socially divided since the mid-19th century according to a caste-based legal code (Höfer 1979). In addition, some health workers do not report to duty at rural posts, or surface only to collect their salaries before returning to more comfortable environs. This breeds resentment. Many interviewees expressed mistrust of Nepali

health workers' clinical skills. They were wary of using government supplied pharmaceuticals. Some expressed scepticism that biomedicine could successfully address illnesses that emerge from specific Tibetan cultural understandings, which are, in turn, informed by a moral cosmology connected to Buddhism and Bön.

Labour migration and political unrest in Nepal over the past decade have further contributed to changes in how, where and at what cost people from Mustang address their health care needs. During the decade-long civil war between Maoist forces and Nepal's army and police (1996–2006), Mustang remained the only district in the country that did not see active combat. However, this conflict – along with the chance to earn social and economic capital by working abroad – propelled many people (especially those under 40) to leave Mustang for destinations such as Kathmandu, India, Japan, Korea, and the United States in search of wage labour (Craig 2002). In recent years, cash remittances have allowed family members in Nepal to access more (biomedical) health care services than they otherwise could have afforded. Yet out-migration has also contributed to health problems. For example, some interviewees correlated local labour shortages to increased joint pain, arthritis, and problems of 'excessive worrying'. Shortages of ritual specialists who perform ceremonies to supplicate local spirits were also thought to affect the health of individuals and the greater community – a point to which the authors will return below.

Taking the MINI to Mustang

In considering various illness narrative templates, the first author was drawn to the MINI for two main reasons. First, a named disorder is not viewed as a prerequisite to use the MINI. It was not the goal of this research to focus on one particular disorder, but rather to explore multiple ways illnesses are named and understood, and to chart the range of health problems that surfaced through responses. The MINI seemed to theoretically account for just how varied people's reasoning and narratives surrounding illness can be. Second, the use of a standardized template facilitated data collection by more than one person. Indeed, part of the first author's motivation for adapting the MINI was that this project would benefit from the employment of both a student research assistant (the second author) and a Nepali colleague (the third author) who is trilingual (Nepali, Tibetan, English) and from a neighbouring culturally Tibetan region.

The MINI went through four stages of adaptation before it was deployed in Mustang. Using the MINI template from Groleau et al. (2006), the basic five-section format was retained. The interview process began with a brief description of research goals:

1. To learn more about illnesses and health problems that you and others in your village suffer from and how they are treated;
2. To better understand the challenges you and others in your village face in staying healthy and recovering from illness;
3. To listen to your ideas about how to improve the health of people in your family and village; and
4. To learn more about the relationship between Tibetan medicine and Western medicine in Mustang, since both are practiced here.

This was followed by a human subjects protocol that facilitated oral consent and asked if the interview could be audio recorded. From those who consented to be interviewed, basic demographic information (age, gender, village, and education

experiences) would then be elicited. Next, adjustments were made to the phrasing of questions.

Since interviewees would not necessarily be recounting narratives about one specific disorder, it was necessary to begin by asking if the interviewee was currently suffering from any health problem(s) or had recently experienced a health event and, if so, to name this. In essence, this shifted to the beginning of an interview a question that would have otherwise initiated the later EM section of the MINI. Culturally appropriate terms were also added throughout the document, e.g. referencing *amchi*, *mopa*, and *lama* among the types of healers an individual might have sought out in the course of addressing a health problem. Since the MINI was not being used to gather information about one specific health issue, to search for ethnophysiological equivalents to biomedically named disorders, or to understand medically unexplained symptoms, questions that seemed calibrated for such purposes were eliminated.³

The next stage entailed translating this document into Tibetan, back translating it for accuracy, piloting the template, and then adjusting the scope and organization of the template accordingly before full-scale data collection could begin. The initial English-language document that emerged from this process of adapting the MINI template is included as an appendix. The Tibetan translation of the initial English-language document is also included as an appendix. This collaborative process revealed a number of structural and socio-linguistic elements of the original MINI that, while perfectly reasonable in English, were not meaningful, or became redundant, in Tibetan. The most analytically interesting of these – given the intellectual history that gave rise to the MINI – was the relationship between the initial illness narrative section and the later EM section. In Tibetan, these two parts overlapped in tone and focus, provoking comments such as ‘you already asked me that’ or ‘weren’t you listening when I told you about that before?’ The illness narrative itself prompted discussions of causality and symptoms that, in the original MINI, are divided between two sections and reflect theoretical assumptions about how a causal narrative might proceed.

Other questions in the EM section caused interviewees to feel reluctant or unable to answer. This was specifically the case with questions such as ‘What usually happens to people who have this health problem?’ or ‘How do other people react to someone who has this health problem?’ Interlocutors perceived such questions as (a) outside the purview of their own expertise; (b) indicative of private family matters or something that should only be discussed between a patient, his/her family, and an *amchi* or religious figure, and/or (c) too variable as to provide useful information. Many interviewees did not want to speak about the health problems of other people, although most were very open about narrating their own experiences. In this cultural context, words have power: they are agentive. Just as the act of speaking *mantra*, or even eating papers on which prayers have been written can help heal someone (Garret, forthcoming), so too can the act of *mi kha*, which means both ‘gossip’ and ‘evil eye’, cause physical harm to the subject of that negative attention (Kapstein 2007). Furthermore, as has been noted in the context of clinical research being conducted in Tibetan communities (Adams et al. 2007), reporting the possibility of adverse events in the course of enrolling subjects in a research study can be conceived of as causal, should that person develop such a health problem or experience an adverse event in the future.

In contrast, interviewees were willing to hypothesize in general terms about the relationship between Tibetan medicine and biomedicine, and to offer specific examples from their own experience about how these two modes of healing have figured into their understandings of illness aetiology, as well as their choices with respect to treatment. The original prototype section of the MINI, which relies heavily on comparison between the interviewee's personal experience and that of other people, again revealed discomfort in speaking for anyone else's experience. Yet when such questions were phrased with reference to problems that the entire community faces, and collective responses to these issues or suggestions for how to ameliorate such problems, they became acceptable and elicited detailed responses. Many interviewees also requested more concrete examples of illness types or treatment approaches as prompts within the interview schedule itself. Based on initial responses, the MINI was transformed such that the new Section 1 combined open-ended prompts to elicit illness narratives with specific questions to emerge from the EM framework, thereby collapsing the original Sections 1 and 3. The next two sections focused on medical attention and responses to treatment, followed by questions trained on life impacts, which were not changed much from the original. The revised prototype questions were reserved for Section 4 (Section 2 in the original) and adapted prompts so that they were more geared around community/village approaches to addressing health issues rather than comparing individual experiences.

In addition to these sections, a short section that focused on pregnancy and childbirth (and that was only administered to women) and one that addressed medical pluralism were crafted. These sections were envisioned as a way to ask a few additional questions related to medical and social change in Mustang. The pregnancy and childbirth questions were meant to elicit information about the extent to which childbearing is becoming (bio)medicalized in a region that has been marked by high infant and maternal mortality, and to get a sense of how patterns of resort related to maternal and child health might be changing in a contemporary context. The medical pluralism section helped to elicit more comprehensive illness narratives, and, as such, took on direct importance for the MINI. In their initial narratives, people did not necessarily include discussions of the relationship between different forms of healing; rather, they tended to focus on biophysical (though not only biomedical) experiences or therapies in response to MINI prompts – perhaps indicating a mimetic experience, in which Mustangis responded to what they thought non-local researchers meant by terms like 'illness' and 'medicine'. Yet in response to questions about non-biomedical techniques and practices, including rituals and the use of Tibetan medicines, some interviewees added personal, specific stories – new strands to narratives that had initially downplayed or simply omitted mention of these avenues to care or conceptualizations of illness causality.

The final version of the adapted MINI was administered in September 2008 to 44 randomly recruited individuals, equally split for gender, and ranging in age from 30–90 years, with the majority between 50 and 70 years of age. This demographic fact attests to changes in Mustang as a result of out migration, both for education and for wage labour. These numbers are particularly revealing since September represents the beginning of the harvest season, when labour demands are greatest. All MINI interviews were conducted with individuals whose first language was a local dialect of Tibetan, although interviews often included both Nepali and Tibetan language.

Interviews were conducted in both restricted and unrestricted regions of Mustang, and in villages that are located both on and off major trekking routes and roads.

Narrating causality, social suffering and community transformation

Several key themes emerge from these interviews, which reflect the ways in which one's choice of methodology shapes the data one gathers. First, there is the issue of what counts as, or constitutes, a 'health problem'. As Figure 1 shows, the range of reported illnesses cross a spectrum: biomedically named disorders such as TB and hepatitis; illnesses that emerge from Tibetan medical aetiology such as blood-wind (*trak-lung*) disorders or problems with the channels (*tsa*); and illnesses that represent syncretic folk aetiologies that draw on both biomedical and culturally Tibetan disease categories and social experiences. 'Gyastric' is a case in point. In both Nepali and local Tibetan dialects, the term connotes gastro-intestinal upset and is sometimes associated with ulcers, indigestion and gall stones; these, in turn, are often connected to a diet that, by interviewees' own accounts, is too high in fat, spice, or alcohol. However, Gyastric can also link to somatized anxiety and can be associated with 'wind' (*lung*) and 'phlegm' (*pékan*)-related disorders. Sometimes, the chief symptom or primary biophysical complaint served as the 'name' of the health problem, even though the narrative itself revealed a network of interwoven causes, conditions, symptoms and diagnoses. Furthermore, seven individuals indicated that they did not suffer from a specific 'health problem,' but they went on to provide narratives of suffering, many of which were linked to points of psycho-social and/or socio-economic hardship in their lives. For instance, one man in his late 40s began his narrative by talking about the death of his parents when he was an adolescent;

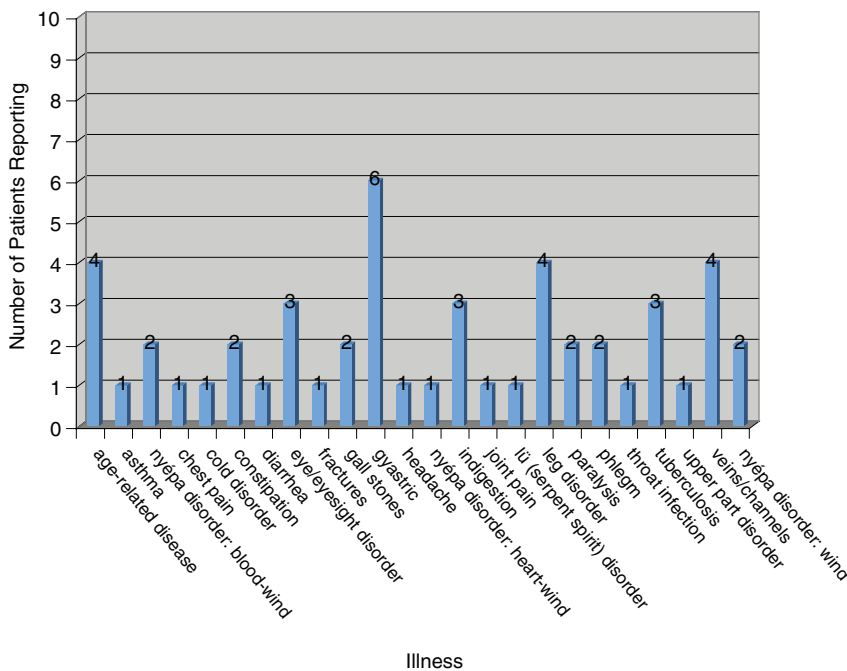


Figure 1. Illnesses reported in patient interviews.

this eventuated in stories of his abuse of alcohol and liver problems, which he understood as related.

Second, strategies for dealing with health problems depended on a broad conceptualization of the nature of the illness in question, which often cascaded into correlations between type of illness and most effective treatment. Many interviewees stressed that it was important not just to ask if someone had recovered from a health problem, but *why* someone had or had not responded to treatment. This raises an interesting epistemological point. While responses were not uniform, it can be generally said that the moral logic inherent in Tibetan understandings of *karma* and *tendré* structured certain responses – perhaps prototypes – to emerge from the MINI. *Karma* (*lä* in Tibetan) means ‘work’ or ‘action.’ It is governed through the individual accrual of merit (*sonam*) or sin (*digpa*) and spiritual defilement (*drip*) over the course of sentient lifetimes. Individual actions from past lives come to bear on one’s experience in this life, and how one acts in this life contributes to the possibilities for suffering or cessation of that suffering in future lives. In concrete terms, this means that a person’s bad behaviour – such as a propensity to drink, to neglect household deities, or to speak badly about others – can both cause and impact health problems and treatment. The concept of *tendré*, which means both karmic coincidence and interdependent *karma* experienced between individuals or groups, combined with issues surrounding the power of *mi kha*, or gossip, as described above, further complicates the notion that one would want to directly compare individual experiences of illness.

As Figure 2 shows, many people sought out a combination of biomedical, Tibetan medical, and ritual treatments. The ability to access multiple healing modalities and make choices about what modality to use for a given disorder was

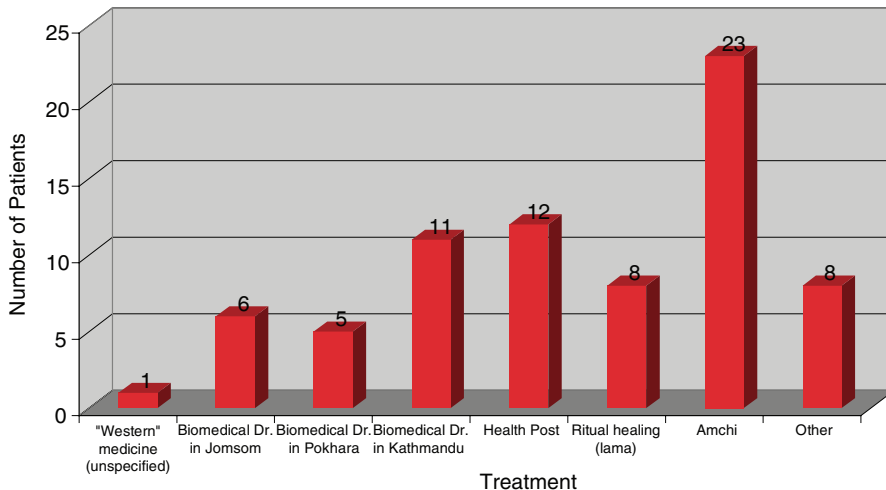


Figure 2. Treatments used by patients interviewed.

Note: The ‘other’ treatment category included: eating well, staying in a dark room, visiting a hot spring, visiting a health camp, using sea buckthorn (*L. Hippophae rhamnoides*) paste, exercising and becoming happier. While visiting a health camp would include accessing biomedical care provided by foreign tourists, all of the others indicate types of self treatment and behaviour change.

highly valued. As one female interviewee put it, 'People have more and more diseases these days, so all types of medicines must work together to help solve the problems.' Some respondents also offered comments such as, 'Tibetan medicine is good because it has no side effects, but Western medicine is good because it acts quickly and is powerful'. This was true even though, at times, these generalized responses actually contradicted their own individual narrative with respect to their use of healing modalities – revealing the ways that EMs and prototypes can often contradict each other. Treatment efficacy was often described in pragmatic terms based on individual or family assessment of patient outcome over time. The use of divination (*mo*) was widespread, and was often used to explain – and, in some ways, to authorize – the illness narrative, as well as to guide choices people made about the course of treatment they should pursue (cf. Schrempf, forthcoming; Gerke, forthcoming). Some felt that biomedicine helped them but that they ultimately could not sustain the financial commitment it entailed. Others found relief for their conditions through ritual healing: from exorcism (*döndre pung*) to the use of protective amulets (*sungwa*) or ingestion of consecrated substances (*jinden*).

These data are further couched within specific cultural, ontological, and medical concepts: namely, the relationship between the five cosmo-physical elements (*chungwa nga*) of earth (*sa*), air (*lung*), fire (*mé*) water (*chu*), and space (*namkha*) which comprise our bodies (*lu*), our consciousness (*sem* or *namshey*), and the universe; and between the elements and the three 'deficiencies' or 'faults' (*nyépa*) – often translated as 'humours' – of wind (*lung*), bile (*tripa*), and phlegm (*pékan*). Such concepts are fundamentals of Tibetan medical theory, which, in turn, emerge from Buddhist understandings about morality and the nature of human suffering; they also shape vernacular understandings of health, illness and bodily processes. Moreover, many Mustangis understand some illnesses (e.g. certain skin disorders, paralysis, mental afflictions, types of tumours or growths, etc.) to be caused by nefarious spirits (*lü*, *sapdak*, *dön*, *nyen*, etc.) who exist within particular environments and must be properly propitiated to avoid illness or suffering. While illnesses are interpreted as having specific causes and karmic conditions within individuals, this does not obviate collective responsibility for stewarding specific environments, in both materialist and spiritual terms (cf. Vargas, forthcoming). Such acts of stewardship can help to address the course of an illness episode or even a chronic condition within an individual, as well as collective ill-health.

Third, the political economy of health care was a crucial component for a number of people describing both specific illnesses and general health problems, and also figured prominently into how interviewees constructed their narratives. In the original MINI, questions that might evoke political-economic commentary seem geared toward the sections on services and response to treatment, and impact on life. However, Mustang interviewees often began their narratives with discussions of social suffering and structural violence: poverty, class/caste divisions within Mustang and associated social stigma, outmigration or other shifts within the family structure, physical or emotional abuse within a family, Mustang's relative isolation and associated government neglect (including poorly trained health workers, lack of medicines, and cultural differences with government health care providers), among other factors. This often led to specific stories about an illness or illness episode, punctuated with discussions of treatment strategies, particularly lack of choice with respect to treatment. A woman who complained of paralysis in one leg and arm

attributed her divorce and later socio-economic hardship to this condition, stating that, 'The community respects people who can work hard. Since I cannot work very much, my husband found another wife.' She noted that her condition began after she became infected while travelling, and that she had tried biomedical means to address the problem over time, but that these treatments had been costly and only marginally effective.

Finally, in many interviews, the machinations of modernity were viewed either as the root of certain health problems, or as the cause of ineffective treatment. In these moments, the MINI illness narratives channelled social critiques about the ways that Mustang, Nepal, and the world at large was changing. Some interviewees connected the decline of (Buddhist) morality and the increase in greed, the neglect of local deities, the increasing consumption of non-local foods, and the outmigration of young people as well as the neglect of community elders to particular health problems. Others noted connections between the increasingly monetized economy – as one interviewee put it, 'Money speaks the universal language' – and a decline in respect for, or attention paid to, lamas or other religious figures, to specific disorders or conditions. Yet many interviewees noted in general terms that the health and longevity of people in their families and villages had improved over the past few decades. Finally, a number of interviewees articulated old age, and the winding down of a life span, as both a named disorder ('aged disease' or 'old age disease') and the causes and conditions giving rise to that disorder. Many also noted that old people preferred Tibetan medicine while young people preferred biomedicine. The empirical validity of these statements remains to be seen, given interviewee demographics. However, one can tentatively conclude that the data contain both prototypes and chain-complexes that articulate relationships between community transformation, socio-economic change, age, and the health of individuals.

While it is difficult to speak directly about the specific causes and conditions of anyone else's suffering, it remained not only plausible but imperative to interviewees that one consider the cosmo-physical, socio-cultural, and political-economic environments in which the illness has occurred. This fact pushes a re-examination of any neat dividing line we might be tempted to draw between the realms of 'religion' and 'medicine' and instead to focus on what Geoffrey Samuel has called the 'mind-body-society-environment complex' (Samuel 2006b, 123), and what Elisabeth Hsu (1999) speaks of as the 'body ecologic', in addition to Lock and Scheper-Hughes's (1987) eponymous 'individual-social-body politic' paradigm.

Conclusion

The data generated in Mustang not only speaks to the MINI's adaptability and utility in the field, but also productively reflects epistemological assumptions within the MINI structure. In Mustang, the MINI was successful in allowing for multiple pathways to meaning, avoiding the critiques waged against research tools that rely more exclusively on the EM. Ideas of 'prototypes' and 'chain complexes' proved useful tools to think with, and will undoubtedly be important in embarking upon detailed content analysis of the interviews themselves. While the interview tool did not, perforce, privilege individual experience, it did tend to place more emphasis on individual (if not totally discrete) illness experiences that were then

compared, viewed metonymically, or understood as part of a larger medico-social context. The MINI allowed for socio-centric concepts of self and personhood to be articulated, and allowed for interviewees to make political points through the vehicle of an illness narrative. Yet the ways Mustangi respondents complicated assumptions about cause and effect as well as the relationship between individual and collective experience challenge one to carefully consider what is accomplished by labelling one narrative a 'prototype', another a 'chain complex', and others still a 'traditional' EM in terms of how it narrates the circumstances of, and conditions giving rise to, illness.

Navigating within the confines of – or even translating and transforming – a formal template brings to the fore issues of power, representation, and the social construction of scientific knowledge, as much as it is also capable of eliciting rich data. As the architects of the MINI (Groleau et al. 2006) point out, issues related to gender, age, nationality, language and rapport all shape data collection. In the case of deploying the modified MINI in Mustang, there were two data collection units, each of which came with challenges and opportunities. The second and third authors comprised one data collection team, while the first author conducted other MINI interviews independently. For the student and Nepali researcher, the time it took not only to conduct the interview but also to provide rough English back-translation proved a significant obstacle. The student's age and relative inexperience, paired with a well-regarded and culturally astute translator, presented additional benefits and drawbacks: some interviewees felt compelled to share their experiences with this team, while others were reticent to reveal intimate details about their experiences.

While credibility was not a problem for the first author, positionality was. This person's established cultural competency and linguistic ability in Mustang made recruiting potential interviewees relatively easy. However, Mustang is a small place and many people associated the author with the *amchi* with whom this individual has worked for many years; at times it was difficult to conduct interviews without the presence of one of these *amchi*, at least for some part of the interview. Random recruitment was also difficult, although not impossible, since these *amchi* colleagues often wanted to introduce the author to patients whose illness experiences were particularly complex, chronic or otherwise intense. In the case of all researchers and data collectors involved in this study, interviews designed to collect the narrative of an individual usually became family affairs. While such multivocality or lack of privacy might be construed in a Western research context as a breach of confidentiality or as 'noise' in the data, these circumstances actually put interviewees at ease.⁴ The collective voices of family members alongside interviewees not only revealed salient information, but were also very real reminders of how contextual and, in a sense, unstable, any one illness narrative ever is.

In summary, a number of methodological lessons and practical recommendations emerged through the process of adapting the MINI for use in Mustang. Formalizing the structure of interview schedules can allow for consistency in data collection around a particular issue and can serve as an apt teaching tool with researchers of varying experience and ability. However, as many social scientists have noted, working within the confines of such a tool can also hinder communication, disrupt narrative flow, and reinforce social differences between interviewers and interviewees in ways that informal interviewing and participant-observation tends to minimize,

assuming researchers have cultivated social rapport. Indeed, while a full content analysis of the MINI interviews remains to be written, the initial review of transcripts shows that interviews that elicited the most nuanced narratives were the ones in which interviewers did the least amount of talking, and in which specific questions were put into dialogue with the interviewees' responses to initial prompts in each section of the template, rather than those interviews that proceeded in a more methodical, checklist-like fashion. Pragmatically speaking, adaptation of the MINI by health-development practitioners and/or academics to other social contexts will likely benefit from a pilot phase and subsequent revisions to the tool. This process might include initial interviews with respondents from different age cohorts and/or those who have access to different types of health services. The adapted MINI was also elastic enough to allow for inclusion of sub-questions relating to specific moments in the life cycle (such as pregnancy and childbirth), in addition to the ways its structure accommodates inquiry into specific illnesses or symptoms.

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Notes

1. For example, the World Health Organization's Probe Flow Chart of the Composite International Diagnostic Interview has been criticized for its lack of adaptability, and the broad assumptions it makes which do not hold true in many cultures (Van Ommeren et al. 2000). The Illness Perception Questionnaire (IPQ) (Weinman et al. 1996) has also been linked to cultural bias (Bhui and Bhugra 2002, 7). The more recent publication of the Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al. 2002), has addressed some of these concerns, but this instrument, like its predecessor, still assumes a biomedical model and has not directly addressed issues of cultural bias.
2. A special issue of *Anthropology & Medicine* (Vol. 8, No. 1, 2001) was devoted to EMIC-based research. Several studies have also applied the EMIC alongside standard, quantitative epidemiological tools such as the Structured Clinical Interview for the DSM-III-R (SCID), the Revised Clinical Interview Scale (CISR), and the Hamilton Depression Rating Scale (Weiss et al. 1995; Henningsen et al. 2005; Patel et al. 1995; Raguram et al. 1996; Weiss et al. 1992).
3. An example of such a question in the original MINI reads 'Have you considered that you might have [INTRODUCE POPULAR SYMPTOM OR ILLNESS LABEL]?'
4. The authors thank one anonymous reviewer for the note that, from a methodological perspective, such data could be productively analyzed through a conversation analysis, to examine how each person's account is influenced by others and how a consensus story emerges.

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Appendix

McGill Illness Narrative Interview (MINI)
 Revised for research in Mustang, Nepal - Sept. 2008

Date: _____
 Location: _____
 Interviewer: _____

Part 1 – Explanation of Research and Informed Consent

Namaste! Thank you for taking some time to speak with me. I am a researcher who is interested in learning about the health care and illness experiences of people in Mustang. I would like to ask you some questions about a specific time that you have been sick or suffered from a health problem. This could be a health problem that you are currently experiencing, or one that you have suffered from in the past. There are no ‘correct’ answers to these questions. I want to know your thoughts and opinions.

1. To learn more about illnesses and health problems that you and others in your village suffer from and how they are treated; 2. To better understand the challenges you and others in your village face in staying healthy and recovering from illness; 3. To listen to your ideas about how to improve the health of people in your family and village; and 4. To learn more about the relationship between Tibetan medicine and Western medicine in Mustang, since both are practiced here.

Do you agree to be interviewed?

YES _____ NO _____

Do you agree to have the interview recorded?

YES _____ NO _____

You can stop the interview at any point. You can also decide not to answer any questions that you do not want to answer.

Part 2 – General Information

No.	Age	Gender	Village	Ward	VDC	Education

Section 1: Illness Narrative – *The Story of Your Suffering*

1. What is the name for your health problem, or the illness that you have suffered from?
2. When did you experience it for the first time?
3. How did you know that you were experiencing this problem/illness?
4. What happened to you this first time?
5. Did something else happen?
6. If you received help from someone – like a family member or other villager, a doctor, health worker, amchi, or lama – the first time you experienced this problem, tell me about your visit and what happened afterwards?
7. At this time, did you receive any medicine or other treatments? If so, what were they?

Section 2: Prototype Narrative - *Examples of Related Experiences*

1. In the past, have you ever had a health problem or illness that is similar to the one you just described? [If “yes” then ask 2.; if “no” ask 3.]
2. In what way is this other health problem/illness similar to or different from the one you just described?
3. Has any person in your family or your village ever experienced a similar health problem to yours? [If “yes” then ask 4.; if “no” ask 5.]
4. How is your health problem/illness similar to or different from the problem faced by your family member or fellow villager?
5. Have you ever learned about someone else who has the same health problem as you on television, radio, magazines, newspapers or the Internet? [Only use age and literacy-appropriate examples of media. If “yes” then ask 6.; if “no” go to next section.]
6. If so, in what ways was that person’s problem similar to or different from yours?
7. Is this a common health problem/illness in your village?
8. What are some of the most common or most difficult health problems/illnesses in your village?

Section 3: Explanatory Model - *Causes and Conditions of Problem*

1. Are there any other words or sayings that describes your health problem/illness?
2. What causes this problem?
3. Are there any other causes of this health problem/illness?
4. Why did your health problem/illness start when it did?
5. What happened inside your body and your heart-mind when this problem occurred?
6. Did any other important event happen at that time?
7. If so, is there a relationship between this event and your health problem/illness?
8. Is your health problem/illness connected to any other event in your life? If so, what events and why are they important?

Section 4: Medical Attention and Response to Treatment – Addressing Your Suffering

1. If you went to a doctor, amchi, lama, or health care worker for help, what did this person tell you the problem was called?
2. Did you go to more than one person? If so, who else did you seek help from?
3. What did this other person or people say you were suffering from?
4. Did this person/people give you any medicines, external therapies, or diet and behavior recommendations to follow? [list all of the treatments, therapies, and recommendations and who prescribed each.]
5. Have you been able to follow the path of treatments? Why or why not?
6. What made the treatments have beneficial effects?
7. What made the treatments difficult to follow or lack beneficial effects?
8. What other medicines, external therapies, or help have you used?
9. What other medicines, external therapies, or help would you like to receive?
10. Were there any treatments that you expected to receive that you did not?
11. Have you done any specific religious practices or rituals to help recover from this health problem/illness?

Section 5: Impact on Life - How has this health problem affected your life?

1. Do you feel well now?
2. Are you worried about suffering from this health problem/illness again?
3. How has suffering from this problem changed the way you live?
4. Has suffering from this problem changed or the way you feel about yourself or the ways others view you?
5. What has been the most difficult part of recovering from this health problem/illness?
6. What has been most helpful in recovering from this health problem/illness?
7. What do you think should be done to help others in your family or village who suffer from this problem, or similar problems?

- གཏོང་དགོས་མེད་ན་ཏེ་བ་གསུམ་པར་མེད་པ་དགོས།
- ༡ ལྷ་ཉིད་ནས་གསུང་རྒྱུ་དེ་གཏམ་གྱི་འཕྲོད་འབྲེན་གྱི་དཀའ་ངལ་དང་སྤྱད་གཞི་དེ་དག་གི་ཆ་མཚུངས་པ་གང་ཡོད་དང་། ཡང་ན་མི་འདྲ་བའི་ཆ་གང་ཡོད་དམ།
- ༢ ལྷ་ཉིད་ཀྱི་འཕྲོད་བསྟེན་གྱི་དཀའ་ངལ་སྐོར་གྱི་སྤོང་ཚོར་དེ་བཞིན་རང་གི་ནང་མི་ལམ་ཡུལ་མི་གཞན་ལ་ཡང་དེ་དག་གཅིག་མཚུངས་འདྲ་ཡོད་དམ། ཡོད་ན་ཏེ་བ་བཞི་བ་གཏོང་དགོས་མེད་ན་ཏེ་བ་ལྷ་པར་གཟིགས།
- ༣ ལྷ་ཉིད་ཀྱི་སྤོང་བཞིན་པའི་ཚོར་སྤོང་དང་བད་གཞི་དེ་ལྷ་ཉིད་ཀྱི་ནང་མི་ལམ་ཡུལ་མི་གཞན་དང་གཅིག་མཚུངས་ཇི་ལྟར་ཡིན་པ་དང་མིན་ཚུལ་ཇི་ལྟར་ཡིན་ནམ།
- ༤ ལྷ་ཉིད་ནས་ད་བར་གསུགས་མཐོང་རྒྱུ་ལྟོན་འཇུག་པར་རྩི་ཡོ། ཚགས་ཤོག་དང་དྲ་རྒྱ་བཅས་ནས་རང་གི་འཕྲོད་བསྟེན་གྱི་དཀའ་ངལ་དེ་དང་སྤོང་བཞིན་མཚུངས་པར་སྤོང་བའི་གང་ཟག་དེ་དག་ནས་སྤོང་བཞིན་གང་ཡང་བཞེས་སྤོང་ཡོད་དམ། ཡོད་ན་ཏེ་བ་དྲུག་པ་གཏོང་དགོས་མེད་ན་ཚོན་པ་རྗེས་མའི་ནང་གཟིགས་ཤོགས།
- ༥ གལ་ཏེ་ཡོད་ན། གང་ཟག་དེ་དང་ལྷ་ཉིད་དབར་གྱི་ཆ་མཚུངས་ཚུལ་ཇི་ལྟར་ཡིན་དང་། མི་མཚུངས་པ་ཆ་གང་དང་གང་ཡིན།
- ༦ ལྷ་ཉིད་ཀྱི་སྤོང་བཞིན་ལམ་འཕྲོད་བསྟེན་གྱི་དཀའ་ངལ་དེ་ཡུལ་གྱི་ནང་དུ་རྒྱུན་ལྷན་གྱི་ནང་གཞི་དཀྱུས་མ་ལྟ་བུ་ཡིན་ནམ།
- ༧ ལྷ་ཉིད་ཀྱི་ཡུལ་སྤོང་ནང་རྒྱུན་ལྷན་གྱི་ནང་གཞི་ལམ་འཕྲོད་བསྟེན་གྱི་དཀའ་ངལ་དཀྱུས་མ་དང་ཚེས་རྩིས་པའི་ནང་གཞི་གང་དང་གང་ཡིན་ནམ།

ཚན་པ་གསུམ་པ། འབྲེལ་བཅོམ་གྱི་དཔེ་མཚོན། བད་གཞིའི་རྒྱ་རྒྱུན་དང་གནས་སྤངས་ཀྱི་དཀའ་ངལ།

- ༡) དེ་ལས་གཞན་པའི་ལྷ་ཉིད་ཀྱི་སྤོང་བཞིན་ལམ་འཕྲོད་བསྟེན་གྱི་སྐོར་ལ་གསུང་རྒྱུ་འདྲ་ཡོད་དམ།
- ༢) འཕྲོད་བསྟེན་གྱི་དཀའ་ངལ་དེ་དག་གི་རྒྱ་རྒྱུན་གང་ཡིན་ནམ།
- ༣) དེ་ལས་གཞན་པའི་རྒྱ་རྒྱུན་གང་ཡང་ཡོད་དམ།
- ༤) ལྷ་ཉིད་ཀྱི་སྤོང་བཞིན་ལམ་འཕྲོད་བསྟེན་གྱི་དཀའ་ངལ་དེ་ཇི་ལྟར་དང་ཐོག་མར་ག་དུས་འགོ་འཇུགས་པ་ཡིན།
- ༥) འཕྲོད་བསྟེན་གྱི་དཀའ་ངལ་དེ་དག་གྲུང་སྐབས་ལྷ་ཉིད་ཀྱི་གསུགས་ཤོ་དང་སེམས་ཀྱི་ནང་ཚོར་སྤོང་བ་འདྲ་ཡོད་གི་འདུག་གམ།
- ༦) སྐབས་དེར་དམིགས་བསལ་གྱི་བྱེད་སྐོར་ལག་གནང་ཡོད་དམ།
- ༧) གལ་ཏེ་ཡོད་ན། ལྷ་ཉིད་ཀྱི་སྤོང་བཞིན་ལམ་འཕྲོད་བསྟེན་གྱི་དཀའ་ངལ་དང་བྱེད་སྐོར་དེའི་བར་འབྲེལ་བ་གང་འདུག་གམ།

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- ༣ འཕྲོད་བརྟེན་གྱི་དཀའ་ངལ་དེའི་སྐྱེ་ཉིད་ཀྱི་མི་ཚེའི་ཐོག་སྐྱུན་ལུགས་ཀྱི་དཀའ་ངལ་ག་རེ་ཕྱད་གྱི་འདུག
- ༤ སྐྱེ་ཉིད་ཀྱི་འཕྲོད་བརྟེན་གྱི་དཀའ་ངལ་ལམ་སྐྱུང་གཞི་ལ་འགྱུར་ལྡོག་གི་རེ་བ་ཡོད་དམ། ཡང་ན་དེའི་སྐོར་
བསམ་ཚུལ་ལམ་གང་ཟག་གཞན་གྱི་མཐོང་ཚུལ་ཇི་ལྟར་ཡིན་ནམ།
- ༥ འཕྲོད་བརྟེན་གྱི་དཀའ་ངལ་ལམ་སྐྱུང་གཞི་དེ་ལས་གྲོལ་ཐབས་ཀྱི་ཚད་དཀའ་ངལ་ཆེ་ཤོས་གང་འདུག་གམ།
- ༦ འཕྲོད་བརྟེན་གྱི་དཀའ་ངལ་ལམ་སྐྱུང་གཞི་དེ་ལས་གྲོལ་ཐབས་ཀྱི་ཚད་མཐུན་འགྱུར་ཕན་ཐོག་ཆེ་ཤོས་གང་
ཡིན་ནམ།
- ༧ སྐྱེ་ཉིད་ནས་ནང་མི་ལམ་གང་ཟག་གཞན། ཡང་ན་ཡུལ་མི་རྣམས་ལ་ནད་གཞི་ལམ་འཕྲོད་བརྟེན་གྱི་དཀའ་
ངལ་འདི་ལྟ་བུ་ཕྱོགས་མཚུངས་པ་མཉམ་བ་རྣམས་ལ་ཕན་ཐོག་ཞབས་ཞུ་སྐྱབ་དགོས་སམ།