

Toward a Culture-informed Epidemiology: Combining Qualitative and Quantitative Research in Transcultural Contexts

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Abstract This article presents a model for research that aims to address challenges in transcultural psychiatric epidemiology. The model involves eclectic application of quantitative and qualitative techniques, namely: focus groups, in-depth interviews, snowball sampling and population surveys. The qualitative methods help provide information on the context of symptoms, illness experience and disease. These methods provide the background information needed to shape research questions, to modify instruments for local situations, and to interpret collected epidemiological data. Examples are provided.

Key words epidemiology • ethnography • qualitative • quantitative • transcultural

Development of the DSM and ICD diagnostic systems as well as psychometric measures of cognitive, affective and psychosocial variables has strengthened psychiatry. However, the discrepancy between universal scientific objectives and the experiences of human beings within local cultures continues to evoke discussion about current psychiatric research methodology and diagnostic paradigms (e.g. de Vries, 1997; Fabrega, 1994; Van Ommeren, Sharma, Makaju, Thapa, & de Jong, 2000).

Discussion of existing psychiatric classification systems has focused on

a number of issues. First, most authors agree that universal characteristics in the presentation of psychopathology are prominent to the extent that biophysiological factors play a role, but that various idioms of distress, as well as illness factors, are culturally specific and better explained within a sociocultural paradigm (e.g. Littlewood, 1991). In addition, international standardization of diagnoses conceals the cultural and historical specificity of present psychiatric classification and undermines its validity in non-Western cultures (Brody, 1994; Fabrega, 1994; Littlewood, 1992). This bias is especially problematic when illness is classified in one cultural setting according to the diagnostic categories of another without re-ascertaining (construct) validity (Kleinman, 1977). The latter problem, also known as category fallacy, is compounded by the skip rules in the algorithms of current structured diagnostic interviews: the root questions of the instrument only probe for core questions derived from Western predetermined categories and may lead to meaningless profiles of prevalence rates across cultures.

Psychiatric epidemiology has tended to focus exclusively on a few DSM or ICD diagnoses – neglecting cultural diversity in the assessment of psychopathology. This occurs despite recommendations that cultural epidemiological research would improve if it would address culturally important categories of mental distress with instruments constructed to measure local as well as Western (DSM or ICD) categories (Guarnaccia, Good, & Kleinman 1990; Littlewood, 1990; Murphy, 1982; Weiss, 2001). Translation of Western diagnostic instruments to non-Western cultures has proven to be challenging (e.g. Bravo, Canino, Rubio-Stipec, & Woodbury, 1991; Ketzner & Crescenzi, 2002). It is still unclear to what extent the emotional worlds of diverse people can be faithfully translated.

Transcultural psychiatric research can be strengthened. Cultural variables and their context must be studied to distinguish abnormal from normal behaviour. Because most research involves the use of Western research instruments not validated for specific cultural settings, qualitative data need to be collected to increase understanding of the context, allowing for easier validation of measurements and improved interpretability of results.

This article presents a model for data collection that attempts to address these issues. The model has been informed by the ‘new cross-cultural psychiatry,’ which has been concerned with the ways in which people within local cultures experience health problems (Kleinman, 1977). Important concepts are the *combined emic-etic* approach, the *disease-illness* approach and the *explanatory model* approach. In the combined emic-etic approach, the researcher first chooses an etic construct and then develops emic ways of measuring it. This implies that instruments are constructed locally in each cultural setting. Through such an approach, an

emically defined etic construct can be obtained and used for comparisons (Berry, Poortinga, Segall, & Dasen, 1992; Triandis & Draguns, 1980). Yet, as shown by Canino, Lewis-Fernandez, and Bravo (1997), there are limits to the extent of possible incorporation of local cultural diversity into an established instrument before the alteration leaves the instrument incapable of measuring the original construct. The disease–illness dichotomy (Kleinman, Eisenberg, & Good, 1978) involves distinguishing the sufferer’s views based on local culturally influenced accounts of sickness from health professional concepts of sickness. Sickness in terms of the patient’s view is called *illness*, and sickness in terms of health professional views is called *disease*. Kleinman’s (1980) explanatory model concept has been applied in three ways: (i) to specify semantic networks linking the experience of patients, healers, and other concerned parties; (ii) to refer to perceived causes of illness; and (iii) to look at the ‘cognitive distance’ between patients and practitioners (Weiss, 2001).

The model presented here is an update and elaboration of an earlier version (de Jong, 1994). During the last 10 years, the model has been eclectically applied during epidemiological research in a number of socio-cultural settings in Africa and Asia and in Europe among immigrants and refugees (de Jong, 2000, 2002a; de Jong et al., 2001; Van Ommeren, 2000; Van Ommeren et al., 2001). We provide examples in this article.

Stage I: Identifying Problems among the Subpopulation through Focus Groups

The first stage of the model involves the organization of focus groups (Krueger, 1988; Morgan, 1988) to identify problems as well as risk and protective factors at the population level. Focus groups involve organizing group discussion by six to ten persons on one or two research questions proposed by the group facilitator. Data collection relies on the interactions among people in the group. Focus groups produce qualitative information that is useful for a variety of objectives. For example, focus groups can lead to specific information about the problem to be studied, the concerns or needs of a community, subjects related to health risks, or subjects related to service delivery. Depending on the problem, focus groups may be organized on several levels, such as focus groups involving politicians and policy-makers, representatives of the district, or heads of the family. Focus groups help give insight into the sociocultural and political context. The procedure also facilitates eliciting information on customs and coping strategies that have developed.

To illustrate, focus groups were used to make an inventory of psychosocial problems among the 180,000 Sudanese refugees in North Uganda (de Jong, 2002a). In contrast to considerable research showing that women

tend to be at risk of problems and disorders in restructuring societies (Patel, Araya, Lima, Ludermit, & Todd, 1999), focus groups among Sudanese refugees suggested that Sudanese women function better than their husbands. It appears that most women have been able to keep their traditional identity as caregivers within their families, and many women have been able to add to the family income through brewing alcohol or through cutting and selling grass for thatched roofs. However, one of the big burdens of Sudanese refugees families is the idleness and related alcohol abuse among those adult men who have lost their traditional roles as income providers. In particular, peasant men have problems because they have not been able to farm in North Uganda; and refugee males who previously worked in offices or business also have problems, because they have lost much socio-economic status.

Participants in focus groups may be selected on the basis of gender, ethnic group, status, trust, community residence, and knowledge of the community (de Jong, 1987). Moreover, focus groups with health workers or clinicians on the theme of a case discussion may help elicit information on the impact of a problem or an illness on individuals and their families. The group may also look at the relation among life events, social support, coping, and the onset or exacerbation of a problem. Conversely, depending on the interest of the researcher, a focus group of respondents or patients may talk about themselves, about the health workers or about the services provided.

Focus group methodology has several limitations (Morgan, 1988), including relatively chaotic data collection. Focus groups are unlikely to be productive on topics that produce conflict between team members or on topics about which local participants feel uncomfortable revealing their opinion in a group setting. Pre-testing is helpful to determine whether a topic will work in a focus group. Replicability of focus groups findings is a concern. For that reason, it is important to run more than one focus group per subpopulation, otherwise it is possible that the researcher observes little more than the unique dynamics of selected participants (Morgan, 1988). Thus, if a researcher perceives the need to run separate focus groups for men and women, he or she will need to run at least two focus groups with male participants and two with female participants. However, two focus groups per topic per subpopulation often does not generate consistent data, and the researcher will need to continue to run focus groups until a clear picture arises regarding the subpopulation's views. Within certain cultural contexts, focus groups may be less productive. For example, in Nepal, a highly hierarchical society with a caste system, we observed that participants have a tendency to show agreement with those persons in the group who are considered to have the highest position in the social hierarchy.

Overall, focus groups can be helpful to explore critical topics, identifying concepts, and developing research questions. Focus groups thus help decide what variables are important to measure during the epidemiological study. Of note, focus groups after completion of the epidemiological study (i.e. after Stage IV) can be useful to help interpret findings.

Stage II: Studying Individuals through In-depth Interviews

The approach used in the second stage of this model is an elaborate, phenomenological illness-history or in-depth interview commonly referred to as an *illness narrative*, *thick description* or *person-centred ethnography* in the anthropological literature (Holman, 1997; Kleinman, 1988) and as *psychobiography* among personality psychologists (McAdams & Ochberg, 1988). In-depth interviews are used to create knowledge about the personal world of human behaviour, subjective experience and psychological processes. This method enables us to 'grasp, beyond the language of symptoms, the complex inner language of hurt, desperation, and moral pain of living an illness' (Kleinman, 1988). Also, in-depth interviews are very useful to gain the background knowledge needed to overcome the challenges of translating and adapting instruments. In addition, these interviews help elicit culturally marked disorders, their personal and interpersonal significance, patient and family explanatory models, individual and family coping styles, protective mediators, and symptom symbols.

In Nepal, we conducted ten narratives, which provided background information on the persecution of Nepali-speaking refugees from Bhutan (Sharma & Van Ommeren, 1998). Also, the narratives made it clear how Hindu torture survivors use *Karma* as an explanation for suffering and how such an explanation can contribute to positive coping. The narratives indicated that the interviewed refugees frequently expressed distress through the use of metaphors. However, most of the expressed complaints were somatic in nature. Interviewed torture survivors reported pain mostly at places where they had been beaten. Nevertheless, physical investigations typically showed normal findings, and many survivors did not view somatic symptoms as possibly related to mental processes.

In-depth interviews are extremely useful to ascertain what issues and phenomena are considered important to the local population to ensure the study of relevant research questions. For example, in Nepal, the findings from the narrative research (as well as clinical observation) pointed us toward further study of medically unexplained somatic complaints among torture survivors.

Snowball Sampling

To select participants for in-depth interviews and focus groups, a number of standard sampling methods are available, which are well described in text books (e.g. Bernard, 1995). We draw special attention here to snowball sampling (Biernacki & Waldorf, 1981; Goodman, 1961; Kaplan, Korf, & Sterk, 1987), a sampling method that is being used with increasing frequency to study hard-to-reach populations. Snowball sampling involves selecting individuals using referrals by insiders within the population to be studied. An individual who has been selected on a certain characteristic (e.g. being an illicit drug user) will be asked to list others with that same characteristic. From this list (at least) one person will be randomly selected and approached for an interview. In turn, the interviewee will be asked to list others with again the same characteristic, and again one person will be randomly selected from the new list, interviewed, and asked to list others with the same characteristic. The process will be repeated several times. In this manner, it is possible to not only better understand social networks but also to study research domains covering delicate matters. The technique is especially useful to find marginal research populations that are often difficult to study using conventional sampling techniques. Examples of such research populations include local healers (Jurg & de Jong, 1992), specific immigrant groups (Khavarpour & Rissel, 1997; Organista, Organista, Bola, Garcia de Alba, & Castillo, 2000), torture survivors (Sharma & Van Ommeren, 1998), rape survivors (Campbell et al., 1999), and also refugees living outside refugee camps, people with HIV, and people with uncommon disorders. Specific strategies for analysing data from snowball sampling have been developed and are available in the literature (Spreen, 1993). The disadvantage of snowball sampling is that the generalizability of the sample is limited, because not every individual in the population of interest necessarily has an equal chance of being selected through snowball sampling. For example, gregarious individuals with relatively large social networks are more likely to be selected than individuals who prefer to live more isolated lives. Thus, snowball sampling is best applied to study small populations of people who are likely to know each other.

Stage III: Preparing for the Epidemiological Study

To prepare for the epidemiological study, Stage III of this model suggests organizing meetings of researchers, colleagues and representatives of the research population. Preferably colleagues should have experience in the research area but not be immediately involved. During the meetings the effects of setting and respondents' experience are discussed and integrated into the research plan. The goal is to increase the study's relevance

by linking research methods and design to actual respondent experience. It implies a process of negotiation that is important in areas where psychopathological models have proven to be disputable, such as, for example, the areas of post-traumatic stress disorder (PTSD) and mass trauma. During the meeting, participants try to reach agreement about the problem definition. The aim is to achieve *member validity* (Mehan & Wood, 1975), that is, the potential that respondents are able to recognize themselves in the basic research results.

Preparation for the epidemiological study involves translating and adapting instruments with the aim of achieving content, semantic, concept, criterion and technical equivalence (Flaherty et al., 1988). *Content equivalence* denotes that each item of the instrument is relevant within the cultural context. For example, in many low-income contexts outside the West, it is senseless to attempt to assess conduct disorder by asking if the adolescent goes to school, because his or her family may be too poor to pay school fees. *Semantic equivalence* concerns whether, after translation, the meaning of the item has remained the same. For example, with regard to PTSD, the translation of the word *nightmare* in Cambodian language has a different meaning for traumatized Cambodians, because they indicate these kind of dreams with the emotionally unloaded notion *sramay* – meaning that they are visited by a deceased family member during the night. *Concept equivalence* means that the same theoretical construct is measured in the two cultures. Concept equivalence is thus the antonym of the aforementioned ‘category fallacy’ (Kleinman, 1977). *Criterion equivalence* is related to the question whether the outcome of measurement of the variable is in agreement with another criterion, such as an independent assessment by a psychiatrist familiar with the culture. For example, many well-adjusted respondents in African countries will provide a positive answer to the question of whether someone wants to harm them. A local psychiatrist will not consider this as evidence for a paranoid delusion, because fear of witchcraft or sorcery is the norm (de Jong, 1987). *Technical equivalence* is related to the question whether it is sensible to administer a research instrument or procedure in another culture or whether this would lead to systematic biases. This type of equivalence is related to the question whether the interviewer is associated with an emotionally loaded institution; whether questions have to be asked in the positive as well as in the negative form; whether there is enough privacy in the research setting; whether the optimal interpersonal distance in that culture has been taken into account; and whether the communication is not disturbed by the distance between interviewer and respondent in terms of sex, ethnicity, socio-economic status or rural background (de Jong, 1987). Social desirability response sets, such as acquiescence, threaten the technical equivalence of a measure.

Achieving a satisfactory translation is difficult, because it involves weighing a variety of concerns related to the occasional conflicting aims of reaching the five aforementioned kinds of equivalence. Even the best translators must have difficulties keeping these concerns in mind during the translation of numerous items. For that reason, we have developed a Translation Monitoring Form, which is a simple tool that ensures that the translators check the different concerns for each item (Van Ommeren et al., 1999). Use of the form requires monitoring of the following procedures: (i) translation by bilingual, indigenous translators; (ii) review of translation by a bilingual professional; (iii) testing of the translation through focus groups existing of relatively uneducated, monolingual, local lay people (which is essential to ensure that the translation is understandable); (iv) comparison of a blind back-translation with the original instrument; and (v) pilot testing. Use of the form ensures that for each item there is a record of all concerns that have been taken into consideration during the translation. Such a record can prove very valuable when trying to understand anomalous findings.

The adapted and carefully translated instrument may be complemented with questions probing for local categories of distress to move beyond the DSM or ICD categorization. However, one should be aware that most existing instruments' algorithms to generate diagnoses do not allow insertion of additional questions. One way to circumvent this problem is by adding culture-specific modules to the questionnaire or to assemble all the newly generated items in a separate questionnaire.

Once the instruments have been prepared, it is important to study the psychometric properties of the instruments (Allen & Yen, 1979) and, if necessary, continue to make the needed adaptations until one has evidence of a reliable and valid product. Overall, the effort and resources necessary to properly prepare for data collection are large and often underestimated.

Stage IV: Epidemiological Survey

In our model the actual epidemiological study of the population, sub-population or clinic-based samples takes place after the preparation and validation of instruments, which has been informed by the qualitative research. The standard practices of psychiatric epidemiology are beyond the scope of this article and have been described elsewhere (e.g. Kleinbaum, Kupper, & Morgenstern, 1982; Tsuang, Tohen, & Zahner, 1995). Yet, we do draw attention to one type of statistical analysis, cluster analysis, which is a multivariate technique that allows the researcher to clarify to what extent diagnoses of a specific culture agree with DSM or ICD diagnoses (e.g. Beiser, Cargo, & Woodbury, 1994). In general, most psychiatric epidemiological research will lead to the generation of data allowing for

the determination of prevalence, incidence, comorbidity and remission rates as well as their correlates, such as risk and protective factors. Other than limitations based on epistemological grounds (Husserl, 1970), the main limitation of the epidemiological method is that results are descriptions or inferences on the population or subpopulation level. Individual variations fall beyond the scope of epidemiology, even when it has been culture-informed through qualitative methods.

Conclusion

Combining different approaches as outlined in the model will improve epidemiology in transcultural settings. The various approaches outlined above are best implemented flexibly depending on the context and purpose of the research. In our experience the above methodology is also useful for programme development, including project identification and assessment missions involving assessment of community needs. Especially the qualitative methods are important to get insight into the sociocultural context to set up culture-informed public mental health programmes (de Jong, 2002b; Somasundaram, van de Put, Eisenbruch, & de Jong, 1999).

The model may be summarized as follows. Human behaviour should be studied within its sociocultural context moving among the population, subpopulation, and individual levels. Research studies should be enriched by culture-specific qualitative data describing concepts and variables that can then be used to collect and interpret quantitative data to answer worthy research questions. Michael Agar, an anthropologist working in drug abuse research, has used the term *quantitative research* to describe tightly integrated quantitative and qualitative research (Agar & Murdoch, 1994). We need 'quantitative' research to achieve culture-informed epidemiology.

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