THE UNIVERSITY OF MELBOURNE

Extending RE-ORDER (Re-organising care for depression and related disorders in the Australian Primary Care Setting) – Tasmanian and cross cultural component.

Final Report to Australian Primary Health Care Research Institute (APHCRI)

Professor Jane Gunn MBBS, FRACGP, DRANZCOG, PhD
Primary Care Research Unit, Department of General Practice, University of Melbourne

Dr Renata Kokanovic BA(Hons), PhD
Primary Care Research Unit, Department of General Practice, University of Melbourne

Dr Danielle Newton BA, PGradDipPsych, PhD
Primary Care Research Unit, Department of General Practice, University of Melbourne

Dr John Furler MBBS, FRACGP, Grad Dip Pub Hlth, PhD
Primary Care Research Unit, Department of General Practice, University of Melbourne

Professor Chris Dowrick BA MSc MD CQSW FRCGP FFPHM
Department of Primary Care, University of Liverpool. United Kingdom

Professor Helen Herrman MBBS, MD, FRANZCP, FFPHM, FAFPHM
ORYGEN Research Centre, University of Melbourne
WHO Collaborating Centre for Research and Training in Mental Health, Melbourne

Dr Emily Hansen BA(Hons), PhD
Discipline of General Practice, University of Tasmania

Professor Carl May BScEcon, PhD, AcSS
Institute of Health and Society, Newcastle University. United Kingdom

CONTENTS

EXECUTIVE SUMMARY

This study adds a cross cultural component to the existing reorder study funded by APHCRI within stream 3.

Background

Culture is a critical influence on the way health professionals and consumers conceptualise depression and on the subsequent patterns of help-seeking and provision. This has been recognised by both Commonwealth and State Governments in the inclusion of cross cultural considerations and use of interpreter services in the planning and delivery of mental health services and in the development of specialised Trans-cultural mental health units. Despite this, very little research exists on the topic of depression among migrant communities in Australia. In particular, literature suggests that concepts of depression are not universal across cultures and that simple attempts to translate concepts from one culture into another ignore the way in which language is an active instrument of cultural construction. Diagnostic tools and screening instruments for depression cannot simply be translated without a deeper understanding of how notions of depression, sadness and dysthymia, emerging from Western biomedical cultures, are understood or have meaning within other cultures.

These complexities are particularly important in primary care, where practitioners, with a range of training and skills in psychiatry and working with a health system with barriers to accessing specialist mental health care, are dealing with unfiltered presentations and often heuristic notions of depression that are at odds with formal diagnostic criteria developed within secondary care settings.

The current study aims to develop insight into these issues and provide evidence to underpin best practice models of mental health care for patients from all cultures.

Study settings and methods

The study was set in a Victorian and Tasmanian site and focused on three ethnic minority communities (Vietnamese and East Timorese in Melbourne and Sudanese in Tasmania) with a range of migrant and refugee experiences and a group of Anglo-Australians. Community members were recruited from General Practice and a range of community organisations and contacts, and at times utilised the help of key community spokespeople. 77 semi-structured interviews were conducted, including 26 with health, welfare and interpreting professionals providing primary health care services to these communities. Interviews with community members focused on a narrative of experiences of migration, depression, stress, troubles and worries (as well as explanatory models of these), use of health services and life impact. Health professionals were encouraged to recount stories of providing care to these communities for depression and related symptoms and to explore their own concepts of depression. Interviews were conducted with the assistance of trained bilingual research assistants, were tape recorded and underwent a rigorous transcription process.

Findings

The study employed rigorous methods in exploring a difficult topic in a challenging context. It has been completed in a timely manner and has generated a rich data set that will be subject to ongoing analysis.

Tentative findings have been fed back to the Melbourne site (November 2007) to health professionals involved in and with an interest in the study. Two international conference presentations have been made and two journal papers have been prepared and submitted. One paper is a small case study of three participants, while the remaining research outputs have focused on the challenges of cross-cultural research in this setting and conceptual domain.

The research provided invaluable insights into the need for reflexivity in working across cultures and contested domains. While the study employed rigorously trained cross-cultural research assistants and cultural informants, we nevertheless had to deal with

personal and political relationships within communities that had important implications of recruitment and the sorts of data we had access to. One important finding of the study, reported in the submitted paper, is about the dimensions of researcher reflexivity needed in this sort of work. This reflexivity will influence the subsequent and ongoing data analysis.

The case study paper discusses how, in these three accounts, while feeling marginalized from their own ethnic community through their symptoms, these three patients experienced being diagnosed as 'depressed' by a practitioner with whom they already had a strong relationship, as, in one sense, an affirmation, functioning to connect these patients with mainstream culture in their adopted country.

It is not possible to present further definitive results of the study as yet. Copies of submitted papers and a further 2-3 anticipated papers will be forwarded to APHCRI on acceptance for publication.

Conclusion

The study has added significant value to the reorder stream 3 study. The Community Health Centre from Melbourne is included among practices for the implementation phase of Stream 3. Data collected from this particular setting is included in Stream 3 practice forums.

The insights gained from the study, focused on enriched understanding of concepts of depression, the influence of context and environment on illness narratives and experiences of health care as well as insights into reflexivity in research will inform ongoing data analysis within both this study and the stream 3 study and will fill an important gap in the international literature.

INTRODUCTION

This study was funded by APHCRI Stream 5 to include a cross-cultural component in the re-order study funded within APHCRI Stream 3. The re-order project is aimed at re-examining the way in which people experiencing symptoms of depression are cared for in the community. The research aims to apply complexity theory and the model of complex adaptive systems to our existing research data gathered from patients and practitioners, in order to identify the minimum specifications for effective primary mental care and put these minimum specifications into practice while monitoring the impact on patients and practice outcomes. As is often the case in general practice research, the main re-order study did not include a cross-cultural component. We have included a cross-cultural perspective to the stakeholder input and practice based implementation phases of re-order to elicit stakeholder views on the influence of cultural factors in determining the personal experience, interpretation and clinical presentation of depression. This will inform culturally appropriate primary care service models. We have included a Tasmanian perspective to the stakeholder input, cross-cultural component and practice-based implementation phases of re-order to increase the generalisibility of the re-order Stream 3 findings.

Very little research exists specifically on the topic of depression among migrant communities in Australia. Exploring cultural differences is important as this has a significant impact on the perspective both clinicians and patients bring to their relationship, affects the process of communication of the mental health problem between people from ethnic minority communities and practitioners, and significantly affects diagnosis and treatment. Ethnic minority communities are usually left out of mainstream primary care research for a number of reasons; including funding constraints related to interpreting and translating costs, despite evidence that, for these communities, general practitioners (and the primary care health system in general) are a predominant source of assistance in addressing their mental health needs (Martin, Kilgallen, Dee, Dawson, & Campbell, 1998; Mihalopoulos, Pirkis, Naccarella, & Dunt, 1999). To address some of the above issues, this study was designed with the aim of exploring the experience of

'depression' and service use among ethnic minority communities in Victoria and Tasmania.

Three ethnic minority communities were selected as informants regarding their cultural experience of depression and service usage - Vietnamese and East Timorese communities in Melbourne and the Sudanese community in Tasmania were selected as the focus of this project as they are all refugee communities representing a mixture of longer-term, more established, and newly arrived refugee communities. A sample of Anglo-Celtic Australians were included to explore more in depth issues identified through telephone interviews as the part of the main re-order study. The ethics approval for this study was granted by the University of Melbourne and University of Tasmania.

This report comprises a summary of the literature review undertaken, describes the aim, setting and methods for the project, and outlines plans for publication and dissemination of the findings.

THE CONTEXT OF THE STUDY

Australian mental health policy

Australia's mental health policy environment is among the most comprehensive in the world and the coherence in its implementation in the past decade between Commonwealth and State and Territory levels has been impressive. Despite the embracement of cultural diversity in Australia since the early 1970s through policies of multiculturalism, reforms to mental health policies and programs that embrace cultural and ethnic diversity have only become noticeable during the past decade. These include the development of national standards for mental health services to accommodate cultural diversity within the National Mental Health Strategy and Plan, the establishment of specialist 'transcultural' units within state mental health services, the establishment of a national transcultural mental health network and information service, and the implementation of various models of care such as bilingual clinical services, additional government funding for interpreters, and the implementation of ethnic mental health consultants who work across services.

In addition to these specialized developments there has been a general recognition that all levels of illness prevention and mental health promotion must consider ethnic and cultural diversity in the community. The Australian National Mental Health Strategy has endorsed the United Nations' Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care and recognises that people with a mental illness may require not only specialist public and private mental health services, but also community based mental health care (Mihalopoulos et al., 1999). The National Inquiry into the Human Rights of People with a Mental Illness reiterated the importance of cultural issues in mental health policies, program planning and service delivery, and encouraged the employment of multilingual staff and staff with training in cross-cultural issues. The Inquiry also suggested that general practitioners, psychiatrists, nurses and mental health workers should receive appropriate training in cross-cultural issues.

At the state level, all policies make reference to ethnic minority groups. However, Victoria, New South Wales, Western Australia and Queensland have specialized Transcultural Mental Health policies and fund specialist Transcultural Mental Health Centres that are committed to mental health service improvements for ethnic minority communities. To a greater extent than the Commonwealth policies, State policies consider the mechanisms by which improvements in service provision are to be enacted. The Victorian policy (2002) for example lists several relevant programs such as bilingual case management, transcultural secondary consultation, ethnic mental health consultants, the Victorian Transcultural Psychiatry Unit, and the Victorian Foundation for the Survivors of Torture.

These important national and state policy developments have not been matched by research to develop the necessary evidence base to support further improvements in mental health care services to ensure that they are accessible and appropriate to the needs of Australia's culturally diverse community. In particular, it is important to gain a deeper understanding of concepts and 'theories' of 'depression' across cultures in order to improve mental health policy and the practice of care for all ethnic minority groups, as these are central factors determining how people access care and assistance for mental

health problems. Thus it is important that differences in lay peoples' theories and expressions of mental illness and mental health are considered when we seek to interpret what people do to improve their health (Mallinson & Popay, 2007).

Cultural diversity and mental health policy in Australia

Australia is a nation of immigrants, home to many ethno-cultural, religious and language groups. Around 40% of Australia's population are from culturally and linguistically diverse backgrounds (Australian Bureau of Statistics, 2002), with over 120 language groups being represented. This diversity poses a challenge for equitable, high quality primary care. Very little research exists on the topic of depression among migrant communities in Australia (Dusevic, Baume, & Malak, 2001), particularly in primary care, although it is known that both bilingual and monolingual general practitioners play crucial roles in the delivery of mental health services to members of ethnic minority communities, particularly in the detection and diagnosis of mental health problems, referral, treatment and management, family support, and mental health promotion (Mihalopoulos et al., 1999).

Depression is a global health problem, accounting for up to 10% of years lost to disability in developing countries and that this proportion is likely to increase in years to come (Murray & Lopez, 1996). As such, a pressing need exists to examine cross-cultural differences in the causes, course, and treatment of depression (Kirmayer & Jarvis, 2006).

Culture and depression

Much of what is known about the role of culture in psychopathology comes from qualitative ethnographic research (Kleinman, 1987). A key international debate in mental health and cultural diversity centres on the extent to which mental disorders should be considered universal entities as opposed to distinct 'cultural realities'. Previous researchers have rejected the tradition of Euro-American psychiatry and psychology in relation to the experience of depressive illness stating that there is significant evidence to argue against a Universalist view (Good & Kleinman, 1985). This view argues that across cultures there are profound differences in:

> the social organization, personal experience, and consequences of such emotions as
> sadness, grief, and anger, of behaviours such as withdrawal or aggression, and of
> psychological characteristics such as passivity and helplessness or the resort to altered
> states of consciousness (Good & Kleinman, 1985) (p. 492).

Variability in the experience and manifestation of depression across cultures can present a significant problem for the efforts of mental health promotion and mental illness services, in preventing, diagnosing and treating depression, and supports the need for robust research into the conceptual underpinnings of notions of depression and associated mental states across cultural groups.

Culture is one of the most critical influences determining how individuals perceive and interpret their environment. Questions about what kinds of interpretations of one's environment are considered 'normal' and what are considered to be disordered go to the heart of the critique of the possible universality of depression (Good & Kleinman, 1985). Social and culturally based understandings of depression immediately raise questions such as: is the concept of depression relevant across cultures; is its Western meaning valid across cultures; are certain cultural groups at greater risk for depression, and why might this be; does culture affect interpretations of unhappiness, resulting in different responses, and what are the implications of these different interpretations; are there cultural variations in the expression, manifestation and experience of depression/unhappiness; and if depression takes a different course and has different outcomes, how might the needs of sufferers best be met?

An edited volume by Kleinman and Good, published in 1985, signalled a breakthrough in the ways not only depression, but mental illness generally, were understood:

> Dysphoria – sadness, hopelessness, unhappiness, lack of pleasure with the things of the
> world and with social relationships – has dramatically different meaning and form of
> expression in different societies…members of such societies vary not only in how they
> express dysphoric emotion; they seem to experience forms of emotion that are not part of
> the repertoire of others.. so dramatic are the differences in the cultural worlds in which
> people live that translation of emotional terms required much more than finding semantic
> equivalents. Describing how it feels to be grieved or melancholy in another society leads

> straightway into analysis of different ways of being a person in radically different worlds (Kleinman & Good, 1985) (p.3).

Kleinman and Good thus argue that depression and related concepts are extremely complex, and that the issue of whether and how emotions such as unhappiness, sadness, despair, anguish, misery, melancholy and so on are relevant across cultures becomes highly important. At a fundamental level, they ask whether the concept of prolonged unhappiness, from which the Western phenomenon of depression derives, exists across cultures:

> On the one hand, universalists claim that the emotions are innate, biologically based states that are modified only slightly by culture. On the other hand, relativists claim that, while emotions may have a physiological basis, this biological component is insignificant when compared to the impact of cultural factors (Kleinman & Good, 1985) (p.1).

Simply using English language categories such as happiness and sadness delimits the possible interpretive categories available. It has been argued that while it might be possible to identify words in each language which relate to negative emotions, emotions which may be comparable to sad-like feelings or depression, the conceptual grid provided by any one particular language will not necessarily be congruent across cultures (Wierzbicka, 1999). To privilege the grid provided by the English language obscures the possibility of other ways of experiencing and expressing negative emotion. As Lutz has pointed out:

> In their discussions of the nature of depression, many Western psychologists place primary emphasis on the depressed person's self-reproach and loss of interest in 'pleasurable activities'. What is particularly deviant about the depressive is his failure to engage in the 'pursuit of happiness' or in the love of self that is considered to be the normal and basic goal of persons. This seemingly natural goal is in fact a culturally moulded goal, one that contrasts with other possible definitions of normalcy in which, for example, primary emphasis might be put on taking care of children and other relatives, or on experiencing morally correct but perhaps unpleasant emotions such as shame or righteous indignation (Lutz, 1985) (p. 70).

The role of language seems critical. Studies have found that there is no word for depression in many non-western cultures (Marsella, 1978). It has been found that distinct clusters of depression-type words exist in the languages of Japan, Indonesia, Sri Lanka,

and the US but that for Korea, Malaysia, Puerto Rico and Australian indigenous languages depression-type words were subsumed by sadness clusters (Brandt & Boucher, 1986). It was argued that depression is the affective state of diminished feelings, particularly marked by the loss of positive, affirming emotions, and this loss or diminution remains acute, irrespective of language and culture. However, no equivalent word was available across most language groups. This has implications for clinical practice.

It has been argued that translating depression diagnostic instruments which have been developed in one culture, into other languages and applying them in other cultures, presumes symptoms are decontextualised reflections of physiological states, rather than being local idioms of distress (Good & Kleinman, 1985). Taking symptoms which have become part of a constellation of characteristics of a 'condition', and translating them to other languages does little to determine whether the condition is actually a cross culturally valid phenomenon. It also ignores the other ways in which distress may be experienced and articulated in different cultures. Quite often psychiatric disorders from other cultures are excluded from consideration. Kirmayer and Jarvis (2006) conclude that:

> the partitioning of distress into categories of mood, anxiety, somatoform, and dissociative disorders in contemporary nosology does not reflect the natural co-variation of symptoms and syndromes. As a result, local clinical presentations of disorders that are in some way related to depression may differ substantially from the descriptions in DSM-IV-TR (American Psychiatric Association, 2000) (Kirmayer & Jarvis, 2006) (p 710).

To summarize the problems identified so far in terms of depression research:

- There is no clear definition of depression
- There are no cross culturally valid and reliable clinical diagnostic tools
- The emotion states relevant to depression are not necessarily universal

Professional and cultural interests of the West (e.g., of the medical profession and drug companies), influence the debates around these issues.

Cultural differences generally will have a significant impact on the perspective patients and practitioners bring to the relationship. Given the conceptual and linguistic complexities outlined above, a mismatch between understandings of emotion states between mental health patients and practitioners will be particularly important and have a significant effect on diagnosis and treatment. It is therefore important to explore local interpretive forms and explanatory models as well as how these are used by people in constructing a life narrative (e.g., in interpreting individual life events, understanding notions of spirits, social conditions, fertility issues, and physical processes) (Kleinman, 1980). Thirdly, it is important to note what forms disorders of interpretation take. It has been argued that depressed people tend to focus exclusively on the negative and that in some settings negative thinking may actually be a cultural norm and therefore not a disorder of interpretation. Finally, the relationship between the common Western biomedical psychiatric discourse of depression and the related but distinct discourses in other cultures is worthy of study.

All of these issues coalesce in the setting of seeking health care for emotional distress. Clearly presentations of "depression" are a function of both patients' ethnocultural background and of the structure of the health care system they find themselves in, and the diagnostic categories and concepts they encounter in mass media and in dialogue with family, friends and clinicians (Kirmayer & Jarvis, 2006).

Depression in primary care

It has been commented that effective treatment of depression in primary care settings presents unique challenges, due to the complex, unfiltered generalist nature of work in primary care (Bentley & Katon, 2006). Other challenges include training issues (primary care medical practitioners training in diagnosis and management of depression is highly variable) and system issues (e.g., Patient's brief visits discourage comprehensive assessment, counselling, treatment planning and follow up; primary care providers perceptions about difficulties in contacting psychiatrists for consultations or referrals) can create a cultural and physical separation of primary and specialty care practice' which limits decision support.

These challenges add to the conceptual uncertainties outlined earlier. At a practical level, depressive symptoms are often intertwined with social stressors, medical symptoms, and chronic medical illness, resulting in competing priorities for attention by general practitioners (Klinkman, 1997; Rost, Nutting, & Smith, 2000). Patient's psychosocial factors such as their individual understanding of their illness, their treatment preferences and sense of stigma associated with a diagnosis of depression, are all additionally complex in a cross cultural context (Roeloffs, Sherbourne, & Ununtzer, 2003). Clinicians who learn to work collaboratively with their patients, as well as with cultural brokers and colleagues from other cultural communities, will be better able to identify patient issues and uncover cultural resources that can complement and, at times, supplant conventional psychiatric treatment (Kirmayer, 2003).

Cultural diversity, depression, and research in general practice
There is limited research in Australia on cultural diversity in general practice. Our study is one of the few exploratory studies examining in-depth issues of depression management in general practice, focusing on ethnic minority patients. Furthermore this study provides important information on doctor-patient communication in depression care; highlights the challenges of working with interpreters when dealing with complex mental health issues, and explores doctors' perceptions of the depression experience for people from ethnic minority groups.

Equity issues
Embedding cultural diversity concerns within specialist and mainstream mental health policy and deepening our understanding of ideas of depression and related concepts in different cultural contexts are important aspects of striving for improved and more equitable health outcomes for patients with emotional distress and depression-related conditions across our community.

Equity of care involves a consideration of both access to care and quality of care. As we have discussed, provision of language services and financially accessible care is not, in

the case of a complex, socially and culturally contingent condition such as depression, sufficient to ensure equity of access to high quality primary care for emotional distress. Our study is based around ethnic communities in Australia and Tasmania with a common background in refugee experiences and war in their countries of origin, with a high burden of emotional distress. Our focus on the understanding that practitioners have of providing depression care across different cultures as well as on the experiences of patients with emotional distress as they seek help from clinicians in primary care, will have important implications for policy makers and practitioners in addressing issues of equity of care and outcomes.

This sort of research, employing observational methods where the unique ecology and contextual setting of primary care is allowed into the study rather than being excluded as a contaminating influence, is critical for building important and relevant evidence to underpin cross cultural mental health care in the community.

THE CURRENT STUDY

As previously discussed, very little research exists specifically on the topic of depression among migrant communities in Australia. Exploring cultural differences is important as this has a significant impact on the perspective both clinicians and patients bring to their relationship, affects the process of communication of the mental health problem between people from ethnic minority communities and practitioners, and significantly affects diagnosis and treatment. Ethnic minority communities are usually left out of mainstream primary care research for a number of reasons; including funding constraints related to interpreting and translating costs, despite the evidence that, for these communities, general practitioners (and the primary care health system in general) are a predominant source of assistance in addressing their mental health needs (Martin et al., 1998; Mihalopoulos et al., 1999). To address some of the above issues, this study was designed with the aim of exploring the experience of depression and service use among ethnic minority communities in Victoria and Tasmania, and Anglo-Celtic Australians in Tasmania.

Three ethnic minority communities were selected as informants regarding their cultural experience of 'depression' and service us - Vietnamese and East Timorese communities in Melbourne and the Sudanese community in Tasmania were selected as the focus of this project as they are all refugee communities representing a mixture of longer-term, more established, and newly arrived refugee communities. A sample of Anglo-Celtic Australians were included to explore more in depth issues identified through telephone interviews as the part of the main re-order study. The ethics approval for this study was granted by the University of Melbourne and University of Tasmania.

The setting (s)

The main Melbourne site for the recruitment of study participants from East Timorese and Vietnamese backgrounds was the North Richmond Community Health Centre (NRCHC). The Sudanese and Anglo-Celtic Australians were recruited from Tasmania. The NRCHC centre has a long history of service provision in the Richmond area and mainly caters to underprivileged and socially disadvantaged communities, many of whom reside in the housing commission estates nearby. The Centre mandates a philosophy of providing culturally appropriate primary health care and social services to disadvantaged individuals and groups, particularly refugees and newly arrived communities.
The Centre's Mission statement is:

- To work in partnership with culturally and socially diverse communities to promote and improve: equity, health, and well being

The centre's Vision is:

- To be an innovative organization, responsive to and supportive of community needs and aspirations: open to change and challenges

(Source: http://www.nrchc.com.au/nrchc/.)

The Centre offers a range of health and welfare services to people who reside in the City of Yarra including general practice, dentistry, nursing, welfare, refugee advocacy and settlement issues, individual and family counselling, drug & alcohol counselling and support, mental health programs including psychiatric consultation and community based programs like art and culture. The Centre employs multidisciplinary and multilingual

staff and there is also a strong volunteer focus. Among their client base is a high proportion of people from East Timorese and Vietnamese backgrounds. According to the NRCHC Annual Report 2005-06, among clients utilising the centre in the last financial year amongst a total of nearly 4000 clients, there were just over 1,400 clients born in Australia; approximately 780 clients born in East Timor, and just over 600 clients born in Vietnam.

Study methods

Participants

Twelve East Timorese, 12 Vietnamese, 12 Sudanese, and 15 Anglo-Celtic Australian participants were recruited to the study. These participants were identified by their doctor as having experienced depression and/or were being treated for depression and were invited to participate in an interview about their depression experience and depression care. See Appendix 1 for demographic details.

Recruitment Methods

Differing recruitment strategies were utilised for each group of participants and are outlined below.

East Timorese and Vietnamese participants (Melbourne site)

As mentioned above, East Timorese and Vietnamese participants were primarily recruited from the North Richmond Community Health Centre (NRCH). One of the principle investigators (JF) on the project is employed as a GP at the NRCH and facilitated collaboration with the centre. The study was presented to the GPs and Executive Manager of Primary Health at the centre. After initial approval and support for the study, the researchers liaised with key community workers representing the Vietnamese and East Timorese communities in order to inform them about the research study, provide written information, and discuss with them the possibility of a future interview.

Initial analysis of the NRCHC centre's client data base by JF revealed that since the 1st of January 2006 people seen in the practice by any doctor with a diagnosis recorded of depression was 144, of which on name scan 34 were possibly Timorese or Vietnamese

and 277 people had been prescribed an anti-depressant class of medication of which on name scan 55 were possibly Timorese or Vietnamese.

These statistics informed discussions with the wider study group about the criterion for recruiting study participants. A consensus was reached and the recruitment criterion was established as people who were born in East Timorese/Vietnam and who:

- Had a diagnosis of depression in the last 12 months or
- Had been prescribed anti-depressants in the last 12 months and
- Had been in Australia longer than 12 months

Based on this selection criterion, JF analysed the general practice database and prepared a list of potential study participants. The patients treating doctor was identified and each GP was given a list of their patients who were deemed eligible for the study. Initial contact with the patients was made either face to face during a consultation with their GP or over the phone with the assistance of the centre's interpreters or community workers. The study was explained to the patients and permission was asked for their contact details to be passed on to the researchers. If the patient agreed to this, they were contacted by researchers who explained the study in more detail and invited them for an interview. If they agreed to participate, a time and place for interview was then organised. Prior to the interview, participants were provided with a plain language statement and were given a consent form to sign.

Sudanese participants (Tasmanian site)
On the advice of key stakeholders associated with the Sudanese community, a different recruitment strategy was utilised for the recruitment of Sudanese participants to that utilised with Vietnamese and East Timorese Melbourne site participants.

The initial approach was to enlist the assistance of two GPs at a practice known by researchers to have relatively large numbers of African refugee patients. These GPs were requested to inform any Sudanese patients with depression about the study. This method did not result in the recruitment of any Sudanese participants to the project. The

subsequent approach was largely informal and relied heavily on word of mouth about the study. Among our research team were two bicultural research assistants who, as part of their employment on the project, spent time at Sudanese community gatherings, a refugee trauma centre, and a large public hospital. Sudanese individuals who had been treated for depression either currently or in the past by counsellors and Sudanese individuals who felt that they had experienced depression without receiving any formal treatment or diagnosis were recruited to the study via this informal process.

Anglo-Celtic Australian Participants (Tasmanian site)

Participants were recruited from a single suburban practice in Hobart. Database searches were performed using diagnosis of depression and medications commonly used to treat depression (e.g., SSRIs, TCAs) as search terms. This was done by one of the GPs working at the practice. A total of 137 patients to be contacted were extracted from the database.

An administrative officer from the MRI acted as a third party to co-ordinate the mail-out. The first 80 participants in the database were selected for the first mail-out. Of these, 8 patients were excluded, being under 18 years of age or residing in an aged care facility. A total of 72 participants were then sent an invitation to participate with a letter and information sheet explaining the nature of the study, risks involved and that their GP would not know whether or not they had participated in the study. The quota of 15 was reached fairly quickly and there was a total of 22 registrations/expressions of interest.

Participants were contacted once they had registered their expression of interest by phone or by mail. As the response was so rapid, it was possible to get a balance of sexes and attempt to get a reasonable distribution of ages.

Health Care Professionals

Seventeen Melbourne health care professionals (GPs, social and welfare workers, interpreters) and 9 Tasmanian health professionals with experience in treating depression or working with individuals experiencing depression were interviewed. The majority of the GPs and all of the welfare workers and interpreters for the East Timorese and Vietnamese communities at the NRCH were interviewed as part of the project. The psychiatrist and other allied health professionals who worked at the centre on a sessional basis were also interviewed.

Interview Structure for Community Participants

A semi-structured interview with a free flowing narrative approach was utilised for the gathering of information from participants. This involved a questioning system based on what the participant was saying as opposed to questioning in a prescribed and formulaic way. A list of key areas to be covered during the interview was compiled and these included:

- Arrival to Australia and associated experiences
- Illness experience/narrative
- Explanatory model
- Service use & response to treatment (e.g., what kind of assistance they have received/they would like to receive and from whom to assist the community/family/the individual in dealing with problems causing distress/ depression)
- Impact on life

Interview structure for Health Professionals

The topics covered for this group included:

- GP's & health professional's own views of depression (concept and ideal management, including etiology of depression, the diagnostic process and treatment of depression)
- their own experiences/issues working in this particular setting (community health centre) with these particular communities and members of the community who are

attending a centre for issues related to mental health, particularly depression/depressive symptoms)

- providing concrete examples (a story) of clinical encounters (negotiating diagnosis and treatment) with people experiencing symptoms of depression (focusing on the actual patients they care for)

Interviews with community members and health practitioners lasted from 1 to 2 and half hours; all interviews were audio- recorded and transcribed. Most interviews with community members were conducted with an aid of bi-lingual research assistants, who translated during the interview and transcribed audio materials.

In addition to the interview, the researcher and bilingual RAs took detailed field notes following each interview. A particular focus was on non-verbal cues displayed during the interview, the interaction and dynamic between researcher and participant, and general impressions and reflections during the interview.

FINDINGS

This study addressed an important but complex and contested issue across four language and culture groups and two settings. A total of 76 interviews were conducted in four languages and rigorously transcribed using a method that allows us to understand and analyse not only conceptual and explanatory models of depression and depression care, but how interpreters play a role in the shifting use of language as these concepts are negotiated and constructed across cultural interfaces. The study has thus been completed in a timely manner, in challenging circumstances and has generated an important database which can now be subject to detailed and ongoing analysis.

Recruitment and training of bilingual staff

In Melbourne, a research fellow and bi-lingual research assistants (RAs) were employed to assist with data collection. Bi-lingual RAs were crucial to the success of the recruitment and interviewing phase of the study. The important aspects of the selection criterion were that they were proficient in written and oral English and Vietnamese/Hakka; they had experience in interpreting/translating, they had some tertiary

education, and were familiar with the health sector. The role of the bilingual RA was not only that of translation but also required them to act as a cultural informant, giving culturally sensitive advice and providing information that facilitated the process of engaging with members of the particular community which they represented. Part of their role was to assist participants in feeling at ease so that they would feel safe and comfortable discussing private and sensitive matters with the researcher.

The bilingual RAs undertook intensive training on the role of interpreting and translating, ethics and role differentiation. For example the issue of conflict of interest was explored in relation to the individual in the role of research assistant and the individual as a member and representative of a particular community. The issue of confidentiality also formed a large component of the training, and the bilingual RAs were required to sign a confidentiality agreement as part of the employment to safe guard the information collected during the interview.

In Tasmania, two research assistants were employed and supervised by EH, Tasmanian site co-investigator on the project. Sudanese bi-lingual workers were engaged to assist with interpreting during interviews with Sudanese participants.

Challenges in conducting cross-cultural research

There are particular challenges associated with conducting research on depression among ethnic minority groups and many of these challenges had to be negotiated by the researchers during the present research project. Currently we are finalising a methods paper discussing this in detail, and here we present briefly some major issues impacting on this work. The bilingual research assistants employed to work on the project were crucial to the success of the recruitment and interviewing phase of this study for a number of reasons. The employment of bi-lingual research assistants with developed links with communities in the study was motivated by an understanding of trust as central to the success of the relationship between participants and researchers (Hardin & McFarland, 2000; Shavers, Lynch, & Burmeister, 2002) and a notion that developing trust requires communication and the building of relationships over a long period of time (Corbie-Smith, Thomas, & St. George, 2002). We were aware that developing trust is made more

difficult when participant and researcher do not share the same culture (Eide & Allen, 2005), history and experiences, and when researching a topic as sensitive as depression. Therefore the bilingual research assistants provided researchers with a way of negotiating these obstacles.

However, there were limitations to the links the bilingual research assistants formed for us within their respective ethnic communities. While these people significantly influenced and added to the credibility and validity of the project through their support, it has been suggested that community leaders may also work to their own agendas, influencing access to some or all community participants (Sixsmith, Boneham, & Goldring, 2003). Through our research, we learned that animosities existed among various ethnic groups in their country of origin. It appeared that these animosities transferred from their 'homeland' and transferred to Australia, when people arrived as refugees. The divisions were based on ethnic origins, religion, class, main language spoken, connection to indigenous culture, colonial experiences and different refugee and migration experiences. Inter-group and intra-groups political differences added a further impediment to the recruitment of participants. Divisions meant that the 'community' was quite fragmented and each section was distinct, based on experiences embodied in history of the 'community'.

Some other problems we encountered in the course of the study were related to the fact that we, as non-members of the researched communities, needed to rely on formal and informal 'community leaders'/ 'community workers', in their professional and non-professional capacity, to assist us with access to the study participants. Throughout this process it became apparent that welfare workers conceptualized 'depression' in different ways resulting in a mixture of referred participants. We also found that the 'power' of community workers participating in this research, who at the same time occupied the position of community leaders, was strongly linked to their own negotiation of difficult boundaries of ethnicity, personal cultural crossing points, the acquirement of new knowledge, and their professional position.

Cross-cultural research is about negotiating boundaries and finding ways as outsiders to community, to become 'insiders' to some degree. As researchers, we had to carefully consider the shifting, political nature of the role of 'community leaders', and the potential for this to impact in a 'very real' way on gaining entry to the world of community members as research participants.

DISSEMINATION AND FUTURE ACTIVITIES

We have chosen not to report early analysis and findings here as the data generated by the study is rich and complex, and will provide material for analysis over the next twelve months and beyond. To report tentative findings which at this stage must remain incomplete and superficial would not do justice to the depth of material generated by the study nor to the complexity of concepts and theories held within it. Nevertheless already two papers and two international conference presentations have resulted from the study, details of which are outlined below.

In November 2007, a summary of the findings were presented to the staff of NRCHC for their feedback. This Community Health Centre is included among practices for implementation phase of Stream 3. Data collected from this particular setting is included in Stream 3 practice forums.

To date, two papers have been drafted based on this study. The first paper (see below) details the project methodology and will be submitted in February 2008 to the journal *Qualitative Health Research.*

Politics of 'doing' research on cultural difference in mental health.

Abstract
Successful community engagement is often a crucial component of effective qualitative research. We reflect on our experience of engaging with ethnic minority communities, in a study of help-seeking for depression. We explain how community engagement is a complex process, which can provide important insights into the way illness is

constructed. Contested notions of ethnicity, culture, community and depression were the domains in which personal and public politics were played out.. We worked with bilingual research assistants who provided an entrée to the community. Despite this, disparate community sub-groups and key players vied for input to and control of the research agenda. We conclude that negotiating the politics of these processes requires great reflexivity and is itself a powerful seam of data, adding richness to findings about the experience of mental distress in a community seeking to locate itself within mainstream society.

The second paper (see below) presents an analysis of three Vietnamese interviews and was submitted to *Medical Anthropology Quarterly* in January 2008.

A care-full diagnosis: three Vietnamese-Australian women and their experience of becoming 'mentally ill'.

Abstract

A great deal of literature has been written about the disempowering intent and effect of Western biomedical discourses and practices. Biomedical approaches, it has often been argued, attempt to take illness out of the intimate social contexts within which it becomes meaningful for people; and in so doing, it has been argued, biomedical approaches become dominating and disempowering for those outside of the White, middle class social positions from which such understandings and approaches emerge. In contradiction of such understandings, we are presenting in this paper material drawn from interviews that we conducted as part of a study exploring cross-cultural understandings and experiences of 'depression' in Australia. In particular, we are focusing on the accounts of three Vietnamese speaking Vietnamese-Australian women. Although the biomedical diagnosis of "mentally ill" that their Australian doctors had given to them was in many ways foreign to them, these women did not experience this diagnosis as meaningless or disempowering. Finding themselves marginalized by their "Vietnamese" families and communities these women understood the diagnosis to be a positive affirmation of their acceptance into a more caring Australian society.

In addition, two conference presentations based on the findings were delivered at the Australian Sociology Association conference in Auckland, New Zealand, December 2008.

We are continuing data analysis and will draft a further 2-3 major papers based on the results of the study. These will be submitted to social sciences and medical journals by the end of June 2008. Our research team will benefit from a two month visit from Professor Carl May, our co-investigator on Stream 5 project, who will be working closely with Dr Renata Kokanovic on finalising Stream 5 papers and submitting them for publication.

Copies of all papers arising from the study will be forwarded to APHCRI on publication.

REFERENCES

Australian Bureau of Statistics. (2002). 2001 Census Community Profile Series Australia. from
http://www8.abs.gov.au/ABSNavigation/prenav/ViewData?&action=404&documentproductno=0&documenttype=Details&tabname=Details&areacode=0&issue=2001&producttype=Community%20Profiles&&producttype=Community%20Profiles&javascript=true&textversion=false&navmapdisplayed=true&breadcrumb=PLD&#Expanded%20Community%20Profile

Bentley, S., & Katon, W. J. (2006). Depression in primary care. In D. J. Stein, D. J. Kupfer & A. F. Schatzberg (Eds.), *The American Psychiatric Publishing textbook of mood disorders*. Washington DC: American Psychiatric Publishing.

Brandt, M. E., & Boucher, J. D. (1986). Concepts of depression in emotion lexicons of eight cultures. *International Journal of Intercultural Relations, 10*(3), 321-346.

Corbie-Smith, G., Thomas, S., & St. George, D. (2002). Distrust, race and research. *Archives of Internal Medicine, 162*(21), 2458-2463.

Dusevic, N., Baume, P., & Malak, A. (2001). *The development of a framework for suicide prevention among culturally and linguistically diverse communities in New South Wales*. North Parramatta, NSW: Transcultural Mental Health Centre.

Eide, P., & Allen, C. B. (2005). Recruiting Transcultural Qualitative Research Participants: A conceptual Model. *International Journal of Qualitative methods, 4*(2), 1-10.

Good, B., & Kleinman, A. (1985). Epilogue: Culture and depression. In A. Kleinman & B. Good (Eds.), *Culture and Depression: Studies in the Anthropology and Cross-Cultural Psychiatry of Affect and Disorder*. Berkeley, Los Angeles & London: University of California Press.

Hardin, J., & McFarland, M. (2000). Avoiding gender and minority barriers to NIH funding. *Journal of Nursing Scholarship, 32*(1), 83-86.

Kirmayer, L. J. (2003). Failures of imagination: The refugee's narrative in psychiatry. *Anthropology and Medicine, 10*(2), 167-185.

Kirmayer, L. J., & Jarvis, G. E. (2006). Depression across cultures. In D. J. Stein, D. J. Kupfer & A. F. Schatzberg (Eds.), *Textbook of Mood Disorders* (pp. 611-629). Washington DC: American Psychiatric Publishing.

Kleinman, A. (1980). *Patients and Healers in the Context of Culture: An Exploration of the Borderland between Anthropology, Medicine and Psychiatry*. Berkeley: University of California Press.

Kleinman, A. (1987). Anthropology and psychiatry. The role of culture in cross-cultural research on illness. *The British Journal of Psychiatry, 151*(4), 447-454.

Kleinman, A., & Good, B. (1985). Introduction: Culture and depression. In A. Kleinman & B. Good (Eds.), *Culture and Depression: Studies in the Anthropology and Cross-Cultural Psychiatry of Affect and Disorder*. Berkeley, Los Angeles & London: University of California Press.

Klinkman, M. S. (1997). Competing demands in psychosocial care: a model for the identification and treatment of depressive disorders in primary care. *General Hospital Psychiatry, 19*, 98-111.

Lutz, C. (1985). Depression and the translation of emotional worlds. In A. Kleinman & B. Good (Eds.), *Culture and Depression: Studies in the Anthropology and Cross-Cultural Psychiatry of Affect and Disorder*. Berkeley, Los Angeles & London: University of California Press.

Mallinson, S., & Popay, J. (2007). Describing depression: ethnicity and the use of somatic imagery in accounts of mental distress. *Sociology of Health & Illness, 29*(6), 857-871.

Marsella, A. J. (1978). Thoughts on cross-cultural studies on the epidemiology of depression. *Culture, Medicine & Psychiatry, 2*(4), 343-357.

Martin, S., Kilgallen, B., Dee, D., Dawson, S., & Campbell, J. (1998). Women in a prenatal care/substance abuse treatment program: Links between domestic violence and mental health. *Maternal & Child Health Journal, 2*(2), 85-94.

Mihalopoulos, C., Pirkis, J., Naccarella, L., & Dunt, D. (1999). *The role of general practiitoners and other primary care agencies in Transcultural Mental Health care*. Melbourne: Australian Transcultural Mental Health Network.

Murray, C., & Lopez, A. (Eds.). (1996). *The Global Burden of Disease: A Comprehensive Assessment of Mortality and Disability from Diseases, Injuries and Risk Factors in 1990 and Project to 2020*. Geneva: World Health Organisation.

Roeloffs, C., Sherbourne, C., & Ununtzer, J. (2003). Stigma and depression among primary care patients. *General Hospital Psychiatry, 25*, 311-315.

Rost, K., Nutting, P., & Smith, J. A. (2000). The role of competing demands in the treatment provided primary care patients with major depression. *Archive of Family Medicine, 9*, 150-154.

Shavers, V., Lynch, C., & Burmeister, L. (2002). Racial differences in factors that influence the willingness to participate in medical research studies. *Annals of Epidemiology, 12*, 248-256.

Sixsmith, J., Boneham, M., & Goldring, J. (2003). Accessing the community: Gaining insider perspectives from the outside. *Qualitative Health Research, 13*(4), 578-589.

Wierzbicka, A. (1999). *Emotions accross languages and cultures: Diversity and universals*. Cambridge: Cambridge University Press.

APPENDIX 1: DEMOGRAPHIC INFORMATION OF PARTICIPANTS

Table 1 Socio-demographic characteristics of Vietnamese study participants - Melbourne site

Characteristics	Females N=9	Males N=3	Total N=12
Average age	48 (Range 34-63)	48 (Range 44-54)	48 (Range 34-63)
Year of arrival			
1970s	0	1	1
1980s	3	2	5
1990s	4	0	4
2000s	2	0	2
Martial status			
Married	2	1	3
Separated not divorced	3	0	3
Divorced	3	0	3
Single never married	1	2	3
Ethnicity			
Vietnamese	8	2	10
Chinese	1	1	2
Religious beliefs			
Buddhism	7	2	9
Catholic	1	0	1
Christian	1	1	2
Living arrangements			
Alone	5	0	5
With children	1	0	1
With spouse	0	1	1
With spouse and children	1	0	1
With parent(s)	2	1	3
Unrelated flat mate	0	1	1
Highest education completed			
Primary completed	1	0	1
Some secondary	4	2	6
Secondary completed	2	1	3
Tertiary	2	0	2
Employment status			
Full-time employment	1	0	1
Part-time casual	2	0	2
Unable to work due to disability /sickness	3	2	5
Full-time studies	0	1	1
Home duties	1	0	1

Characteristics	Females N=9	Males N=3	Total N=12
Unemployed looking for work	1	0	1
Unemployed no visa status	1	0	1

**Table 2 Socio-demographic characteristics of East Timorese study participants –
Melbourne site**

Characteristics	Females N=8	Males N=4	Total N=12
Average age	51.9 (Range 33-79)	40.3 (Range 20-71)	48 (Range 20-79)
*Year of arrival**			
1970s	2	0	2
1980s	1	3	4
1990s	4	1	5
2000s	1	0	1
Martial status			
Married	2	2	4
Separated not divorced	2	0	2
Single never married	1	2	3
Widowed	3	0	3
Ethnicity			
Timorese	2	2	4
Chinese	5	2	7
Indonesian	1	0	1
Religious beliefs			
Buddhism	1	0	1
Catholic	4	3	7
Christian	2	1	3
Chinese folk religion	1	0	1
Living arrangements			
With children	4	0	4
With spouse	1	0	1
With spouse and children	2	1	3
With parent(s)	0	1	1
Other family member	1	0	1
Unrelated flat mate	0	2	2
Highest education completed			
No formal education	1	0	1
Some primary	2	1	3
Primary completed	1	0	1
Some secondary	3	0	3
Secondary completed	1	1	2
Tertiary	0	2	2
Employment status			
Retired	2	1	3
Unable to work due to disability /sickness	2	1	3
Full-time studies	0	2	2
Home duties	4	0	4

Table 3 Socio-demographic characteristics of Anglo-Australians study participants – Tasmanian site

Characteristics	Females N=9	Males N=7	Total N=16
Average age	58.3 (Range 40-84)	45.8 (Range 21-86)	53 (Range 21-86)
Martial status			
Married	5	3	8
Widowed	1	2	3
Divorced	2	1	3
Single never married	1	1	2
Religious beliefs			
Church of England	4	2	6
Catholic	1	2	3
Other Christian	1	1	2
Unknown	0	1	1
None	3	1	4
Living arrangements			
Alone	1	1	2
With children	2	0	2
With spouse /defacto	3	1	4
With spouse/defacto and children	2	3	5
With parent(s)	0	1	1
Unknown	1	1	2
Highest education completed			
Primary completed	1	0	1
Some secondary	1	2	3
Secondary completed	2	4	6
Secondary completed & TAFE	2	0	2
Tertiary	2	0	2
Unknown	1	1	2
Employment status			
Full-time employment	1	4	5
Part-time casual	3	0	3
Unable to work due to disability /sickness	0	1	1
Full-time studies	0	1	1
Retired	4	1	5
Unknown	1	0	1

Table 4 Socio-demographic characteristics of Sudanese study participants – Tasmanian site

Characteristics	Females N=7	Males N=5	Total N=12*
Average age	56.5 (Range 51-62)	32 (Range 29-35)	41.8 (Range 29-62)
Year of arrival			
1990s	0	1	1
2000s	2	2	4
Martial status			
Married	0	1	1
Widowed	1	0	1
Separated not divorced	1	0	1
Single never married	0	2	2
Ethnicity			
Kuku	1	1	2
Dinka	0	1	1
Bair	0	1	1
Acholi	1	0	1
Religious beliefs			
Catholic	1	0	1
Christian	1	3	4
Living arrangements			
Alone	0	1	1
With children	2	0	2
With spouse	0	1	1
Unrelated flat mate	0	1	1
Highest education completed			
No education	1	0	1
Tertiary	1	3	4
Employment status			
Full-time employment	0	1	1
Part-time casual	0	1	1
Unable to work due to disability /sickness	1	0	1
Full-time studies	0	1	1
Home duties	0	0	0
Unemployed looking for work	1	0	1
Unemployed no visa status	0	0	0

*Demographic information for 7 participants is missing.

Table 5 Socio-demographic characteristics of health professionals – Melbourne site

Characteristics	Females N=11	Males N=6	Total N=17
Average age	52.1 (Range 41-64)	42.8 (Range 36-55)	48.1 (Range 36-64)
Year of arrival			
1970s	2	0	2
1980s	3	3	6
1990s	1	0	1
Unknown/N/A	5	3	8
Occupation			
General Practitioner	4	3	7
Psychiatrist	0	1	1
Interpreter	3	0	3
Social/community worker	3	0	3
Volunteer community organisation	1	2	3
Country of birth			
Australia	2	3	5
Vietnam	5	1	6
East Timor	4	2	6

Table 6 Socio-demographic characteristics of health professionals – Tasmanian site

Characteristics	Females N= 3	Males N=6	Total N=9
Average age	40.7 (Range 35-50)	50.7 (Range 42-69)	47.3 (Range 35-69)
Year of arrival (if applicable)			
1980s	0	1	1
2000s	1	1	2
Unknown/NA	2	4	6
Occupation			
General Practitioner	1	4	5
Psychologist	0	1	1
Nurse	1	0	1
Social/community worker	1	1	2
Country of birth			
Australia	2	4	6
Sudan	1	1	2
UK	0	1	1