

## Challenges Faced When Conducting Research with Young Australians with Refugee Experiences

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*Despite the fact that children and adolescents from refugee backgrounds have been identified to be at increased risk of a range of mental health and social adjustment problems, there is a paucity of research on their mental health status. This is because not only are there inherent difficulties working cross-culturally, such as obtaining population access and encountering language and cultural barriers, but also there are issues that arise when working with vulnerable children such as parents denying or restricting access in order to protect their child. In this paper we share some of the challenges we have encountered in the planning and data collection phases of a study of young Australians with refugee experiences (results expected 2008) and the attempts we have made to address these. In particular, implications for those considering conducting cross-cultural research will be discussed.*

### Background

A large Australian study of mental health and emotional problems among children and adolescents in the general population indicated that these problems affect 14-20% of all young people (Sawyer et al., 2000). However, this study did not specifically examine children from culturally and linguistically diverse backgrounds or young people with refugee experiences. A higher burden of mental health problems is likely to be present among refugee children and adolescents because they may have encountered traumas which include violence, physical and mental deprivation as well as displacement and experience of a new post-migration environment at a crucial stage in their emotional and social development (Fazel & Stein, 2002). Even if the child was born in a stable Western country they may still be exposed to sources of secondary trauma. Sigal's seminal work on second and third generation survivors of the holocaust attests to the fact that severe trauma can and does impact on subsequent generations (Sigal, DiNicola & Buonvino, 1988; Sigal, 1995, 1998). There is also wide scholarly agreement that primary and secondary traumatic experiences result in

increased prevalence of mental health problems in the child and adolescent refugee population (Fazel, Wheeler & Danesh, 2005 ; Hodes, 2000; McKelvey et al., 2002 ; Silove, Sinnerbrink, Field, Manicavasagar & Steel, 1997; Steel, Silove, Phan & Bauman, 2002 ; Tousignant et al., 1999). However, these studies have tended to focus on one particular age or ethnic group or specific psychiatric disorder.

This study aimed to identify the prevalence of emotional and behavioural problems as well as protective factors and help-seeking behaviours among South Australian children and adolescents with refugee experiences. For the purposes of this study children and adolescents were considered to have had refugee experiences if either they or their parents were born overseas and arrived in Australia as a refugee. We used the UN Refugee Convention definition of a refugee (Office of the High Commission for Human Rights, 2007). This study has used a mixed methods approach. The prevalence of Post Traumatic Stress Disorder (PTSD) and Depressive Disorders will be investigated via questionnaire. These have been identified as the most commonly reported disorders affecting refugee children (Ehnholt & Yule, 2006 ; McKelvey et al., 2002 ; Slodnjak,

Kos & Yule, 2002; Sourander, 1998 ; Thomas & Lau, 2002). We will also investigate protective factors by using quality of life, strengths and difficulties and resilience scales. The tools we have used in the questionnaire are listed in Table 1 and some of the rationale for their choice is outlined later in this paper. The study has also used qualitative techniques (focus groups) to further explore the extent to which these young people were seeking and receiving both formal and informal help.

In order to thoroughly examine these issues we chose to use 3 informants; parents, adolescent children and school teachers. We aimed to recruit 600 children and adolescents from a population of refugees currently residing in South Australia. The children's cultural background was either Asian (Afghani), Eastern European (Former Yugoslavia, Bosnia-Herzegovina), Middle Eastern (Iranian, Iraqi) or African (Sudanese and Liberian). These were chosen because they were among the top 20 refugee arrival groups to Australia over the past 10 years (Department of Immigration and Citizenship, 2007). One hundred participants from each of the 6 groups provides sufficient statistical power to determine prevalence rates for PTSD and Depression as well as enable comparisons between groups.

When planning our research we were aware of many of the methodological challenges associated with cross-cultural research. Some of these difficulties relate to population access, identifying and obtaining a representative sample, cultural and language barriers, limited availability of culturally validated instruments, and wariness of parents to trust researchers (Thomas & Lau, 2002). In spite of our careful planning we encountered obstacles during the data collection stage which caused delays. Now that data collection is close to completion we consider that the difficulties we encountered during data collection are likely to be common to those conducting research in this important area. The purpose of this paper is to share our experiences in the hope that those planning research in this area will be able to avoid some of the pitfalls we encountered. Key points from this paper were summarised in Table 2.

### *Population access*

Accessing refugees can be difficult because there is rarely a comprehensive list of people from this target population. However, this project had the advantage of access to the target population through an industry partner (IP). Whilst there are several service provision agencies who work with refugees in South Australia, we chose one which provides a settlement service for migrants and refugees in South Australia as an industry partner. Their contact with refugees during their settlement made this agency suited to be able to link us with many of the potential participants for our study.

Whilst our IP played a major role in allowing us access to potential participants we recognised that refugees who did not have contact with the IP would be unavailable to us. Therefore, in order to ensure a representative sample (as far as that is possible), we also used multidimensional approaches. These included advertising the project widely through both mainstream and ethnic media (radio and print) and promoting the project through schools, community and health services and at social gatherings of the target populations.

Many of the ethnic groups involved in our study are close knit and identify leaders to whom they will often defer. Therefore, it was important for us to notify these leaders about this study in order to gain their interest and support. This was achieved by the IP facilitating a meeting between the leaders and the research team and then sending them a follow up letter which included project details.

### *Cultural and language barriers*

When conducting research with this population it is important to acknowledge and respect cultural differences between the researchers and the participant population (Ehnholt & Yule, 2006). These cultural barriers can take the form of differences in normative expectations linked to gender, age or standing in the community. In this study we used bilingual workers as data collectors because they had the language requirements as well as cultural knowledge and contact with potential participants. Bilingual workers employed by the IP had already developed a rapport and trust with the communities because they were helping with the process of resettlement. However other bilingual workers, not employed by the IP, were also used especially those with contacts in communities no longer in touch with the IP. These workers provided us with much more than the ability to communicate

in two or more different languages; they also brought a level of experience, skill and expertise which was vitally necessary for this research.

#### *Bilingual worker training*

When discussing the role of bilingual workers in cross-cultural research, Raval (2005) indicates that one of the problems with using these workers is that they are not adequately briefed on the role they have to undertake. Therefore, we conducted a research training session for each of the bilingual workers associated with the project prior to them commencing data collection. This session included information about the project, the expected role and responsibilities of the workers including information about how to assist families to complete the questionnaire, answering questions and queries, and troubleshooting for difficult situations. Each worker was given a worker's manual to take and use as a guide for this somewhat unfamiliar research role.

The manual included information about the project, ethical issues, methods of recruitment, and instruments used. The purpose of this training was to familiarise the workers with the research in order to carrying out the data collection in a rigorous and ethical manner. At the completion of their formal training session they were also required to sign a statutory declaration to ensure they preserved the confidentiality of the research participants.

Whilst we considered that training the bilingual workers would reduce data collection errors, it did not eliminate them altogether. This was because those who worked in a service provision agency often treated the research as an extension of their usual work, that is, they did not differentiate between their usual consultancy work and the research. In order to be sure that each worker understood what was required we asked them to 'pilot' the questionnaire on 5 participants. These questionnaires were then checked with the worker and a researcher before the worker began data collection in earnest. Where the questionnaires were complete and without error, they were used. Otherwise the questionnaires were discarded. This enabled us to kept in close contact with the workers throughout the data collection period in order to keep them on task and on track (Table 2).

#### *Wariness of participants to participate*

Refugees were typically wary of researchers (Ehnholt & Yule, 2006) and thus establishing a trusting relationship is a prerequisite for those planning research in this area (Miller, 2004). In the case of this research the bilingual workers had already established a trusting relationship with many of the participants through their association with the IP. In fact sometimes participants only agreed to take part in the research because of their prior relationship with the worker. For example, one participant wrote on their consent form, "If it wasn't for my friend's (the worker) sake I would never participate in such a survey".

We used several bilingual workers for each language/ethnic group in order to take advantage of the networks each worker had within their own community and to ensure we cast our net as widely as we could within each community to maximise our chances of gaining as representative a sample, as possible.

Potential participants were given information about the project and were advised that their privacy and status with the IP would not be affected by their involvement in the study. In spite of these assurances we still encountered some level of mistrust amongst some participants. They were especially concerned about the demographic information identifying them or that the information gained from this research would somehow be used against them. One of the chief concerns, especially from those who have been in detention, was that they would lose their permanent protection visa if the study identified them as psychologically unwell. Other participants were concerned about a series of questions asking about their satisfaction with their new life in Australia. They felt that if they expressed a very natural desire to return to their homeland, immigration officials would be notified and have grounds to deport them. Both the research team and the bilingual workers worked hard to allay these concerns. One strategy we used was fortnightly meetings with the bilingual workers. Whilst these meetings were ostensibly to exchange completed questionnaires for new, and problem solve, another important element was to foster trust between the workers and researchers. We felt this was particularly important because we were not directly approaching participants during data collection (Table 2).

*Access to children*

Another challenge in cross-cultural research concerns access to children. If the parents and/or their children have been traumatised, it is understandable that parents will be especially protective of their children. A questionnaire which includes sections asking about traumatic experiences which the family and the adolescent may be trying to forget can therefore be something which the parents were naturally reluctant to complete. Many times the bilingual workers needed to spend time talking to potential participants about the aims, objectives and importance of the research prior to gaining participant consent. This was very time consuming and resource laden and should be factored into estimation of time for those planning research in this area (Table 2).

Whilst some cultural customs and beliefs were anticipated in the planning stages of this research we encountered some unexpected issues. For example, we were naturally required to obtain informed consent from each informant prior to their completion of the questionnaire. However, in some cultural groups once the parents had given consent they did not consider it necessary for their adolescent child to also give consent. Furthermore, many parent participants declined to give written consent as a way of ensuring that their responses were not passed on to authorities. When we realised the extent of this problem, we approached the Human Research Ethics Committee (HREC) for permission not to pursue the usual requirement for written consent.

Another issue we faced was parents being (understandably) protective of their children when it came time to seeking permission to interview the children's current school teachers. Some parents were concerned that once the school teachers knew their child had had refugee experiences that they would be somehow treated differently. Others simply wanted to give their child a "fresh start" in their new country. There was also a concern amongst some parents that teachers might gain the impression that the child had a mental illness if they learned that the family had participated in a study regarding mental health. About 25% of participants refused to grant permission for this aspect of the research.

On a more practical level, families with two children were given the opportunity for both

of their children to participate in the study. In order to maintain rigor and allow the parents to carefully consider their responses with respect to each child, we encouraged the parents to fill in the questionnaires on different days, ideally one week apart. If the families had three or more children then we considered that a maximum of two should be used in order not to over represent one particular family within the data set. The two children were selected for participation in the study using a "birthday technique" (Sawyer et al., 2000), whereby the two children with a birthday closest to the date of the interview were selected as the participants. However, we have encountered some cultural issues around use of this technique. Many of the cultural groups involved in this study do not celebrate birthdays and use approximate ages for their children. Still others have changed their child's birth date in the past either to make them appear older in order to go to school, or younger to allow them access to cheaper travel or accommodation whilst fleeing from their country. Furthermore, some of these cultural groups are not familiar with and do not use the Gregorian calendar. All of these issues made reliance on birthday and age somewhat problematic for us. Some families needed to randomly select two children's names from a hat rather than use the "birthday technique."

*Sampling*

In order to avoid putting refugees from such diverse cultural backgrounds together in a 'melting pot' during analyses, we avoided using proportional sampling and our approach was to set a 'quota' of 100 participants from each of the 6 different ethnic groups. We have established that 100 participants from each group will enable us to examine prevalence rates for the more common mental health and emotional problems. Those refugees who were interested in participating in the study were enrolled via convenience sampling until our quota of 100 participants from each of the 6 participating groups was filled. This involved close monitoring of the data collection and giving direction to the IP to concentrate their data collection in areas which were lagging as each quota was reached.

*Study Promotion*

We employed a number of strategies to promote and advertise our project. This involved print and electronic media as well as word-of-mouth. We produced a 'call for volunteers' flyer and developed a brochure which included information

Table 1  
*Instruments used for participant type*

<b>Instrument</b>	<b>Parent of Child 4-12 yrs</b>	<b>Adolescent 13-17 yrs</b>	<b>Parent of Adolescent 13- 17 yrs</b>	<b>School Teacher</b>
<b>UCLA PTSD reaction index for DSM-IV</b>	√ Parent Version	√ Adolescent Version	√ Parent Version	
<b>CDI</b>	√ Parent Version	√ Adolescent Version	√ Parent Version	√ Teacher Version
<b>SDQ</b>	√ Parent Version	√ Adolescent Version	√ Parent Version	√ Teacher Version
<b>PEDsQL</b>	√ Parent Version 8-12 only	√ Adolescent Version	√ Parent 'proxy' Version	
<b>CD-RISC</b>		√		
<b>Help Seeking</b>	√	√	√	
<b>Demographics</b>	√	√	√	
<b>ESL scale score (academic achievement)</b>				√

about the project. This flyer was distributed widely by the bilingual workers as well as members of the research team through conferences, community functions and school promotional activities. The brochure was used to promote the project through key people in the target communities and health professionals working in the ethno-specific agencies.

We also relied on word-of-mouth promotion by participants contacting others in their communities and promotion of our project through schools and community contacts.

#### **Method**

Johnson (2004) defines mixed methods as "the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study" (p.17).

We are using a mixed methods approach because we consider that *both* quantitative and qualitative research methods are important and useful especially when conducting this exploratory research.

There has been criticism of the use of the survey method in research with refugees (Guerin & Guerin, 2007). Although we were very concerned to try to establish a trusting relationship with the participants, we are aware that this does not necessarily mean that the information they have provided will reflect their authentic feelings, attitudes and beliefs (Miller, 2004). Reasons for this may include not wanting their community group to be perceived unfavourably, and wanting to please the researchers by giving them the data they believe they want. These were all well known limitations to this kind of research. We considered this may be especially true in our

survey because we were asking the adult to report on their perceptions of the mental health and well-being of their child. Hence we have avoided sole reliance on one research method. It may be interesting to note that the young people who participated in the focus groups do not seem to be under the same constraints as their parents and were actually keen to participate and were speaking quite freely about sensitive issues. We are therefore confident that by using a mixed methods approach that we will be able to provide a foundation from which to build an understanding of the mental health status and help seeking behaviours of child and adolescent refugees.

#### *Instruments*

The problem of translating and applying validated instruments in a cross-cultural setting is both controversial and problematic. In their seminal work on translation of health status instruments, Sartorius and Kuyken (1994) outline some reasons why this is so:

...differences exist between cultures on their concept of health and illness, levels of literacy, reading level, concordance between written and spoken versions of language, taboo subjects, and social desirability effects. Furthermore, certain features of language, such as idiom, are very difficult to translate, and abound in some health status instruments. Indeed, considerable variability exists in most of these factors even within the same culture (pp. 3-4)

We therefore approached this problem by careful consideration of the instruments we would use and how best to translate them.

#### *Choice of instruments*

The search for appropriate instruments was a complex one. There are well known limitations to using measures which have been largely validated in developed Western countries (Ehnholt & Yule, 2006). In order to ensure that we used instruments with the best levels of validity and reliability we contacted many experts throughout the world as well as relied on the expertise already within our team. The following criteria were important in our choice of instrument:

- Simple, clear and succinct language
- Previous use in a cross-cultural setting
- Availability and price/licensing costs of instrument
- Relevant to the purpose of the study

Taking these criteria into consideration the following instruments were chosen:

- UCLA PTSD-reaction index for DSM-IV (Pynoos, Rodriguez, Steinberg, Stuber & Frederick, 1998)
- Children's Depression Inventory (CDI) (Kovacs, 2003)
- The Strengths and Difficulties Questionnaire (SDQ)(Goodman, Meltzer & Bailey, 2003)
- Pediatric Quality of Life Inventory (PedsQL) (Varni, 2005)
- Connor-Davidson Resilience Scale (CD-RISC) (Conner & Davidson, 2001, 2003)

In addition to these instruments we developed questions to collect basic demographic data as well as one section specifically asking about help-seeking behaviour. Table 1 gives a visual representation of the participant groups and instruments used for each informant.

Whilst combining all these instruments into one questionnaire should enable us to thoroughly examine the mental health status of young Australians with refugee experiences, it was perceived by some participants as a lengthy questionnaire. Our advice to those planning research with refugees is to consider ways of reducing to a bare minimum the number and size of instruments used and to factor into the budget incentives for participant time (Table 2).

#### *Translation*

There is ongoing controversy and debate as to whether a directly translated psychometric instrument captures the same meaning as the original (Mason, 2005; Sartorius & Kuyken 1994). We believed that taking a rigorous approach to translation was important. We therefore used translators who were from the target cultural groups and were also knowledgeable in the area of mental health issues. We utilised National Accreditation Authority for Translators and Interpreters (NAATI) accredited "advanced" and "advanced senior" translators. These were used because of their awareness of the pitfalls of verbatim translation. The cost of employing these experienced translators added a considerable amount to the budget. Whilst it was a necessary expense, it is also one which should

Table 2  
*Checklist of hints and tips for those planning cross-cultural research*

Method	Qualitative, Quantitative or Mixed?
<b>The instruments</b>	<p>Aim to use short and simple instruments</p> <p>Consider the cross-cultural applicability of the instrument</p> <p>Allow plenty of time for translation and back-translation – it always takes longer than expected – particularly with languages that were tonal.</p> <p>Ensure that you have at least three available and qualified translators (a translator, back-translator and a back-up translator)</p> <p>Pilot the instruments</p>
<b>Population Access</b>	<p>Consider the potential industry partners you have available and the level of access they have to the participants.</p> <p>Identify your population's community leaders</p>
<b>The participants</b>	<p>Consider how you will manage access to children.</p> <p>Consider how you will foster trust.</p> <p>Consider offering incentives to participants (this may have ethical implications).</p>
<b>Bilingual workers</b>	<p>Spend time developing respect, rapport and a strong relationship with the bilingual workers. This is a particularly important consideration when not directly involved in data collection</p> <p>Thoroughly train the bilingual workers and where necessary provide ongoing contact and training.</p> <p>Monitor the work of the bilingual workers closely – they may need ongoing supervision and support to keep them on track and focussed.</p>
<b>Time</b>	Aim to overestimate the time it will take to collect data

be carefully factored in to the project budget by those planning research in this area (Table 2).

Once the instruments were translated into the participants' languages we had them back-translated into English in order to validate the quality of the translation and ensure meaning was not lost (Brislin, 1970 ; Maneesriwongul & Dixon, 2004). In some cases it was noticed during back-translation that the initial translation was not satisfactory and this required us to use another translator to redo the translation. This was particularly a problem in the 'tonal' languages e.g. Dinka. Obviously this is a resource intense aspect of research in this area and thus plenty of resources, both human and financial, should be allowed when budgeting for translation and/or interpreting (Table

2).

Another important consideration is that regardless of the quality of translation, a translated document cannot include the idiom and intent of the original document. For example one of the instruments we used gave the direction, "IMPORTANT! If your child is younger than 7 years of age, please tick the box below, skip this section and move to section 3." Participants from all language groups were confused by this direction. This was because whilst almost any Westernised English speaker would understand the implicit message i.e. "if your child is over 7, fill in this section", those from a non-English speaking backgrounds did not. This problem resulted in minor, but costly, revisions being made to the

questionnaires.

The translators and back-translators were rightly more concerned with translating and correcting errors in idiom, meaning and intent. However, it is also important that the translated instrument is free of grammatical and typographical errors. One way to ensure this is to pay a less expensive bilingual worker to review the questionnaire specifically to detect these kinds of errors as their presence impacts on readability.

#### *Time taken*

The questionnaire was time consuming to administer and this impacted on the study in terms of the time it took to collect data. It was also important for us to be flexible regarding how and where the questionnaires were administered. Some participants were happy to welcome the bilingual workers into their home but then spent some time prior to the administration of the questionnaire discussing practical difficulties that they were facing or exchanging social niceties. To avoid this, the bilingual workers who were working with literate families chose to drop the questionnaire off with the family and then return later to collect it. Another time saving approach we used was to invite some of the participant families to come to the IP to self complete the questionnaire either in an individual or group setting. This strategy also allowed for the provision of childcare as well as the opportunity for the adults to attend to other practicalities whilst they were there. However, these strategies were not without their problems and strict attention to detail was required in order to maintain rigor as well as participant confidentiality.

Researchers planning cross-cultural research should therefore allow plenty of time and resources and adopt more than one strategy for data collection in order to cater for the vast diversity within these cultural groups (Table 2).

#### **Conclusion**

Drawing upon a strong background in cross-cultural mental health, child psychiatry and epidemiology, the research team involved in the project is uniquely positioned to investigate the mental health and well-being of refugee children and adolescents in South Australia. We have the resources and expertise of two South Australian Universities and an industry partner. We have encountered some difficulties which we have shared in order to alert those planning research in this complex and challenging area to some of the

pitfalls that may be encountered along the way.

It is expected that the study will foster significant outcomes and benefits for the refugee community and refugee health and community services. Data obtained through the project will provide mental health care providers with a new and comprehensive understanding of the mental health status, resilience and help-seeking behaviours of children and adolescents from refugee backgrounds. This will help to inform settlement planning and improve the delivery of mental health services for the refugee population in South Australia.

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