
3-25-2013

Recruiting Ethnically Diverse Participants into Qualitative Health Research: Lessons Learned

Hagar Renert

University of Calgary, hrenert@hotmail.com

Shelly Russell-Mayhew

University of Calgary, mkrussell@ucalgary.ca

Nancy Arthur

University of Calgary, nancy.arthur@unisa.edu.au

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Recommended APA Citation

Renert, H., Russell-Mayhew, S., & Arthur, N. (2013). Recruiting Ethnically Diverse Participants into Qualitative Health Research: Lessons Learned. *The Qualitative Report*, 18(12), 1-13. <https://doi.org/10.46743/2160-3715/2013.1542>

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Abstract

The inclusion of ethnically diverse populations in health research is crucial for addressing ethnic disparities in health status and care. Despite this need, non - dominant ethnic groups continue to be under - represented in health studies. The reasons may be at least partly due to the difficulties inherent in recruiting such groups for research. In this article, we attempt to assist researchers , who are seeking to conduct inclusive qualitative health research , by sharing some of the lessons we learned in the process of recruiting ethnically diverse immigrant women for a qualitative study on the experience of developing weight - related concerns. Specifically, we discuss issues such as engaging gatekeepers, using cultural insiders, developing culturally - sensitive recruitment materials, offering payment, and developing trust with participants and their communities. We conclude the article by presenting practical strategies for addressing these issues based on our experience and the available literature on the recruitment of non - dominant research participants

Keywords

Recruitment, Non - Dominant Ethnic Groups, Qualitative Research, Health Research

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Recruiting Ethnically Diverse Participants into Qualitative Health Research: Lessons Learned

Hagar Renert, Shelly Russell-Mayhew, and Nancy Arthur

Educational Studies in Counselling Psychology, University of Calgary, Alberta Canada

The inclusion of ethnically diverse populations in health research is crucial for addressing ethnic disparities in health status and care. Despite this need, non-dominant ethnic groups continue to be under-represented in health studies. The reasons may be at least partly due to the difficulties inherent in recruiting such groups for research. In this article, we attempt to assist researchers, who are seeking to conduct inclusive qualitative health research, by sharing some of the lessons we learned in the process of recruiting ethnically diverse immigrant women for a qualitative study on the experience of developing weight-related concerns. Specifically, we discuss issues such as engaging gatekeepers, using cultural insiders, developing culturally-sensitive recruitment materials, offering payment, and developing trust with participants and their communities. We conclude the article by presenting practical strategies for addressing these issues based on our experience and the available literature on the recruitment of non-dominant research participants. Keywords: Recruitment, Non-Dominant Ethnic Groups, Qualitative Research, Health Research

The importance of including ethnically diverse populations in health research is now widely recognized (Herman, Tucker, Ferdinand, Hasan, & Beato, 2007; Knobf, Juarez, Shiu-Yu, Sun, & Haozous, 2007; Ogilvie, Burgess-Pinto, & Caufield, 2008; Robinson & Trochim, 2007; Yancey, Ortega, & Kumanyika, 2006). The growing diversity of the North American population, coupled with ethnic disparities in health status and health care (Centers for Disease Control and Prevention, 2011; Institute of Medicine, 2002; Lasser, Himmelstein, & Woolhandler, 2006; Williams & Mohammed, 2009), constitute compelling reasons for their inclusion (Arthur & Collins, 2010). However, non-dominant ethnic groups continue to be under-represented in research studies (Killien et al., 2000; Mak, Law, Alvidrez, & Perez-Stable, 2007), particularly eating disorder research, in part due to the difficulty inherent in obtaining ethnically diverse samples. The risk is that the voices of individuals from non-dominant groups are often not included. Alternatively, research that was obtained in small samples is often used to represent the experiences of entire groups (D'Andrea & Heckman, 2008).

The recruitment of non-dominant ethnic groups into research is complicated by many of the same barriers that contribute to health disparities among ethnic groups (i.e., fear of stigma and discrimination, mistrust of research and/or health professionals, lack of awareness of the problem, language barriers, financial difficulties, limited health insurance, lack of transportation and/or childcare, and competing priorities) (Knobf et al., 2007; Ogilvie et al., 2008; Robinson & Trochim, 2007; Russell Maraj, Wilson, Shedd-Steele, & Champion, 2008). There are few resources available to address these barriers (Robinson & Trochim, 2007; Yancey et al., 2006), and there is little practical guidance for researchers seeking to include participants from non-dominant ethnic groups in their studies. In writing the article, we sought to move beyond debates about which method is best to a focus on what helps to support the success of research with individuals from non-dominant ethnic groups. Based on our supervisory relationships between researchers and graduate students, we found that there

were few articles that offered practical considerations. We greatly benefitted from hearing about the experiences of other researchers and hope that by adding to the knowledge base that other researchers may also benefit from our experiences.

The purpose of this article is to advance inclusive qualitative health research through sharing some of the lessons we learned in the process of recruiting ethnically diverse immigrant women for a qualitative community-based study on the development of weight-related concerns. Although the experiences of newcomer populations are not necessarily the same as those of all members of non-dominant ethnic groups (Birman, 2005), there is overlap in recruitment issues found in these populations, and it is this overlap that we focus on in this article. We begin the article by briefly describing the purpose and methodology of our study. We then discuss some of the challenges we encountered in recruiting participants and the strategies we used to overcome these challenges. We conclude the article by offering some recommendations for future recruiting practices, based on our experiences and a review of the existing literature.

Research Context

Historically, eating disorders and related weight preoccupation were conceptualized as Western culture-bound syndromes, with the result that most eating disorder research has been carried out with White, middle-class women (Smolak & Striegel-Moore, 2001). Although there is emerging evidence that eating disorders occur in ethnically diverse groups (for reviews see Becker & Fay, 2006; Crago, Shisslak, & Estes, 1996; Marques, Alegria, Becker, Chen, Fang, Chosak, & Diniz, 2011; Smolak & Striegel-Moore, 2001), women from non-dominant ethnic groups continue to be under-represented in eating disorder research (Becker, Franko, Speck, & Herzog, 2003; Cachelin & Striegel-Moore, 2006), as in other areas of mental health research (Kessler et al., 2005). Consequently, there has been little information about their experiences to guide treatment, prevention, and research efforts (Gilbert, 2003; Marques et al., 2011; Smolak & Striegel-Moore, 2001).

The purpose of this study was to address the ethnicity gap in the eating disorder literature by exploring, describing, and understanding the experience of developing weight-related concerns among ethnically diverse immigrant women who reside in Canada. Given the important role that culture is believed to play in the development of weight-related disorders in women, we chose to focus specifically on the cultural dimensions of the participants' experience. By interviewing women who were both first generation immigrants to Canada and members of visible non-dominant ethnic groups, we hoped to shed light on various cultural risk factors hypothesized to be associated with non-dominant ethnic group status, including racism, immigration, acculturation, and poverty.

We recruited participants through multiple strategies, including direct contact, word of mouth, and advertisements at multicultural centres, on college and university campuses, in student newspapers, and in online communities featuring free classified advertisements. A total of six women participated in the study, representing the following Canadian non-dominant ethnic groups: East Indian, Vietnamese, Colombian, Brazilian, Somali, and Filipino. Seidman's (2006) in-depth phenomenological interviewing method, which combines phenomenological interviewing and life history research techniques, was used to obtain descriptions of the participants' experiences in their life contexts. Two interviews of 1.5 to 2 hours duration were held with each participant. The first was a life history interview that explored childhood experiences that shaped the participant's relationship with food and her body, and the second was a phenomenological interview that examined the participant's experiences of developing weight-related concerns while residing in Canada. Thematic analysis was used to identify the broad cultural themes connecting individual experiences.

Thematic results of the interviews have been published (Renert & Russell-Mayhew, 2012). The focus of this article is on the recruitment issues and challenges that cut across the content focus (i.e., eating disorders) of research when seeking participation from non-dominant ethnic groups.

Lessons Learned

When we began the study, we were familiar with the literature on recruiting culturally diverse participants for health research and cognizant of some of the challenges involved in the process. We anticipated that we would need to modify our recruitment efforts as the study progressed. Although we did not have a formal evaluation process built into the study to address methodological concerns, we informally assessed and addressed these concerns as they arose. We kept a reflective journal in which we documented the outcome of various recruitment strategies, and when necessary, met to brainstorm potential solutions to the problems we faced. The lessons described in this section were gleaned from this informal evaluation process.

Engaging Gatekeepers

Accessing non-dominant ethnic groups for research typically entails working with community gatekeepers, individuals occupying formal or informal leadership positions in immigrant-serving and community agencies, churches, and neighbourhood associations (Dennis & Neese, 2000; Eide & Allen, 2005; Knobf et al., 2007; Neufeld, Harrison, Hughes, Spitzer, & Stewart, 2001; Ogilvie et al., 2008; Russell et al., 2008). Our initial recruitment strategy was to contact such individuals and inform them about the study, requesting their permission to post our recruitment notices in their agencies, churches, and community centers. This strategy proved to be largely unsuccessful, as most gatekeepers were reluctant to assist us. As we soon discovered, lack of awareness of women's susceptibility to eating disorders was not only prevalent among health care providers, as suggested by the eating disorder literature, but also extended to community gatekeepers. For example, when we approached the leaders of one ethnic community, we learned that they considered eating disorders and weight-related concerns to be non-existent in their community. They expressed the view that women in their community were protected from experiencing such problems by virtue of their culture's acceptance of diverse body shapes, echoing the stereotyping of eating disorders as "White women's diseases". Other gatekeepers, like the director of a large community agency serving ethnically diverse women, were open to the possibility that eating disorders existed among women from non-dominant ethnic groups but did not believe that our study would elicit much interest among their clients, who were struggling with more pressing survival issues such as homelessness, unemployment, poverty, and domestic violence.

These experiences taught us that while community gatekeepers can facilitate recruitment of non-dominant ethnic groups into research, they can also hinder it based on their own perceptions of the relevance and importance of particular studies. In order to obtain gatekeepers' support in this case, we would have likely needed to invest considerable time in the pre-recruitment phase networking with community gatekeepers, educating them about the existence of eating issues in ethnically diverse communities, and possibly involving them in an advisory capacity in the recruitment process (Knobf et al., 2007; Russell et al., 2008). Due to the relatively short time period allocated to this project, however, we could not realistically accomplish these goals. To address these limitations, we revised our letter to gatekeepers to include information about the existence of eating disorders in ethnically diverse women and

relied on multiple recruitment strategies. This remedy proved to be crucial, as we did not ultimately obtain any of our participants through community agencies.

Contacting Cultural Insiders

In addition to engaging the support of community gatekeepers, a common strategy for encouraging the participation of non-dominant ethnic groups in research is to recruit using cultural insiders, defined as individuals who share the same cultural background as the target population (Birman, 2005; Eide & Allen, 2005; Knobf et al., 2007; Neufeld et al., 2001; Ogilvie et al., 2008; Yancey et al., 2006). Cultural insiders can bolster the credibility of the research in their ethnic communities and increase the likelihood that potential participants will feel comfortable participating in the study (Knobf et al., 2007; Neufeld et al., 2001). Although we did not formally retain cultural insiders as research assistants, we asked our contacts in various ethnic communities to spread word about the study to potential participants. Although our cultural insiders initially agreed to assist us, this strategy proved to be ineffective, likely due to the private and sensitive nature of the research topic. After taking some time to consider the nature of the task, some of contacts returned to us and advised that they felt uncomfortable intruding on the participants' privacy concerning their weight issues by providing them with information about the study. They suspected that potential participants would be equally reluctant to divulge their interest in the study for fear that the cultural insiders would subsequently gossip about them in their community. This finding is consistent with Neufeld et al.'s (2001) observation that while cultural insiders were helpful for identifying potential participants for their ethnographic study on the experience of immigrant caregivers, some of these potential participants later declined to participate because of privacy and confidentiality issues. Approaching potential participants directly, or through intermediaries who were not affiliated with their ethnic communities, achieved a better response rate; in fact, we were able to recruit four out of our six participants using this strategy.

Developing Culturally-Sensitive Recruitment Materials

The use of culturally-sensitive recruitment materials has been identified as being a facilitating factor in the recruitment of non-dominant ethnic groups into research (Knobf et al., 2007). Our original recruitment notice (Appendix A) was similar in appearance and content to posters typically found on university and college campuses, and employed language consistent with the sensitivity requirements of the American Psychological Association's Publication Manual (2009). We assumed that women meeting our selection criterion of fluency in spoken English would be able to easily read and comprehend the notice, and would be unlikely to be offended by any of our terminology.

When we consulted our contacts in the ethnic communities about our recruitment notice, they informed us that it was problematic for at least two reasons. First, the contacts stated that the notice was potentially too long and complicated to effectively target women for whom English was a second language. Our contact in the Filipino community pointed out that spoken fluency did not guarantee reading fluency, and that while some potential participants might be able to understand the notice if they took the time to read it carefully, many likely would not invest the time and effort required to do so. Second, our contacts stated that the terminology had the potential to alienate prospective participants. Our contact in the Sudanese community remarked that our use of the term "eating problems" to refer to the range of disordered eating behaviours occurring among ethnically diverse women could be construed as pathologizing them, since it suggested a medical problem. Similarly, she was

concerned that our use of the term “women from visible minority groups” could be regarded as patronizing, as it implied a power differential between the dominant culture and non-dominant ethnic cultures.

To address these limitations, we modified the format and content of our original recruitment notice considerably (Appendix B). We shortened and simplified the notice, as well as changed the terms “women from visible minority groups” and “eating problems” to “women who are members of ethnic communities” and “concerns about eating, weight, or body image” respectively. Although these changes ultimately broadened our conceptualization of the phenomenon from “eating problems” to “weight-related concerns” and resulted in our being contacted by some immigrant women who were not members of the visible non-dominant ethnic groups we hoped to target, our contacts in the ethnic communities advised us that our revised notice appeared less threatening and more culturally-sensitive.

Offering Payment

Offering payment has been found to be effective for promoting the participation of non-dominant ethnic groups in research (Preloran, Browner, & Lieber, 2001; Yancey et al., 2006). However, paying participants also raises concerns about the potential for undue influence and misrepresentation (Grady, 2005), particularly when the participants are from low-income backgrounds (Ogilvie et al., 2008). Initially, we proposed to provide participants with a \$20 honorarium as a way of thanking them for their time. We assumed that such a token amount would be less likely to raise any ethical issues, as higher payment for participation in research studies has been controversial, there are variations between academic disciplines, and we could find no standard guidelines. In the course of our recruitment efforts, however, we learned that this amount was insufficient. One of the immigrant-serving agencies from which we hoped to recruit some or all of our participants required us to provide reasonable compensation for participants’ time as well as to compensate them for any parking, travel, and babysitting expenses prior to allowing us to advertise the study in the agency. Many of their clients were unemployed mothers who were struggling financially and lacked their own transportation. Consequently, we needed to increase our honorarium to \$50, and be prepared to interview the women in their homes, if necessary. This revision to the amount of honorarium was approved without question through the Ethics Board of our university and seemed to be a more reasonable amount to compensate for the expenses incurred from participation.

Developing Trust in the Research Relationship

Mistrust of research has been identified as being one of the central barriers to successful recruitment of non-dominant ethnic groups for research, particularly among those who have historically been subject to oppression, discrimination, or exploitation (Barata, Gucciardi, Ahmad, & Stewart, 2006; Corbie-Smith, Thomas, & St. George, 2002; Eide & Allen, 2005; Knobf et al., 2007; Offet-Gartner, 2010; Shavers, Lynch, & Burmeister, 2002; Yancey et al., 2006). Although mistrust is expected to be less problematic in a descriptive qualitative study as compared to a clinical intervention trial (Knobf et al., 2007), we found that it still impacted our recruitment efforts. As White academics seeking to interview women from non-dominant ethnic groups, we often sensed that community gatekeepers and potential participants were suspicious of our motives and concerned that the study would be used to further stigmatize their communities. Consequently, developing trust became an important aspect of our recruitment process.

In addition to seeking community gatekeepers' endorsement of the study and using cultural insiders as recruiters, we attempted to foster trust by making the research process as transparent as possible. Our informed consent form provided detailed information about the purpose and procedures of the study, the rights and obligations of participants, and the risks and benefits of participation. Prior to providing the informed consent form to potential participants for signature, we scheduled an initial contact meeting during which we explained the study verbally to them in non-technical terms. Since English was their second language, we felt that obtaining their informed consent both verbally and in writing was essential. During the initial contact meeting, we also took the opportunity to address any concerns or reservations the potential participants had about the research procedures. For example, one participant, an East Indian Canadian woman, was concerned that despite the confidentiality provisions, the researchers might still gossip about her to mutual acquaintances, jeopardizing her job prospects. She explained that in her culture, there was no such thing as "confidentiality." Taking the time to explain the researchers' ethical requirement of confidentiality, the sanctions that would follow breach of confidentiality, and the specific steps that would be taken to protect her anonymity, appeared to help alleviate her concerns and make her feel more comfortable about participating. While such informed consent procedures necessitate a considerable investment of time and effort, they have been demonstrated to positively impact the willingness of non-dominant ethnic groups to participate in research (Barata et al., 2006; Birman, 2005; Dennis & Neese, 2000; Norton & Manson, 1996).

Research involves relationships with the people who are invited into the project as participants. In those relationships, it is prudent to remember that the researcher is the instrument of the research project (Lincoln & Cannella, 2009). We also sought to increase trust by establishing a respectful and equitable relationship with participants. For instance, in describing the study to participants, we disclosed that we had worked with clients with eating disorders in our counselling practice and that one of us was herself an immigrant who had struggled with an eating disorder after coming to Canada. Such interviewer self-disclosure has been advocated as an approach for empowering participants, encouraging reciprocal sharing of intimate experiences, and overcoming barriers related to race and culture (Oakely, 1981; Reinharz & Chase, 2003; Song & Parker, 1995). Such disclosure needs to be guided by researcher reflection about the impact of such experiences and the personal motivations for pursuing research (Offet-Gartner, 2010).

We attempted to accommodate participants' preferences with respect to the time and location of the interviews as much as reasonably possible, in order to minimize the burden associated with participation. Although our preference was to conduct two separate interviews spaced 1-2 weeks apart, we recognized that we needed to be flexible in this regard. In some cases, to accommodate participants' scheduling conflicts, we agreed to conduct both interviews on the same day, and in another instance, 3 weeks apart. We also agreed to interview some of the participants in their home. Conducting interviews in their natural setting seemed to make these participants feel more in control and comfortable with the research process.

Finally, we attempted to build trust by undertaking to make our best efforts to ensure that the study would be used to benefit the participants and their ethnic communities. Avoiding the "helicopter" approach to cross-cultural research where researchers appear at the research site only to collect information and disappear, without giving back to the participants or the studied community, has been identified as being important to fostering trust in the research project (Dennis & Neese, 2000; Eide & Allen, 2005; Knobf et al., 2007) and is considered by some to be an ethical imperative (e.g., Ponterotto & Grieger, 2008). Since we did not target a specific ethnic community for our study but rather, sought to recruit women

from diverse non-dominant ethnic groups, we could not use the results to directly benefit any one community. However, we undertook to endeavour to advance health professionals' understanding of the experiences of women from non-dominant ethnic groups by publishing the study results in health related journals and by sharing them at professional conferences and with community agencies serving ethnically diverse clients. We also undertook to provide our participants with a copy of the final research report and encouraged them to contact us with any questions or comments they had concerning our findings or interpretations. These undertakings appear to have been influential in persuading the participants to participate in the study. During the interviews, some of the participants commented that they agreed to participate because they felt we were doing "good work" and hoped that their stories would be used to benefit other women from non-dominant ethnic groups. Other participants indicated that they participated because they hoped to develop a better understanding of their experience, an opportunity made possible by the provision of the full report.

Conclusions and Recommendations for Future Recruitment Practice

Given well-documented ethnic disparities in health status and health care, adequate representation of non-dominant ethnic groups in health research is crucial for better understanding these disparities and for improving services through research-informed practices. Notwithstanding the widespread recognition of the need to include ethnically diverse groups in health research, however, diverse samples are difficult to obtain, as many of the challenges that contribute to health disparities among non-dominant ethnic groups also arise during the recruitment process. In this article, we attempted to provide some practical tips to researchers seeking to recruit ethnically diverse populations for their studies by discussing some of the strategies we used in our study, evaluating the relative success of these strategies, and suggesting ways of overcoming obstacles to recruitment. Although our study involved recruiting ethnically diverse immigrant women for qualitative interviews about the development of weight-related concerns, we believe that the lessons we derived can also be used to inform other studies addressing a variety of health issues relevant to ethnically diverse groups.

From our recruitment experience and the limited available literature on recruiting ethnically diverse groups for health research, it is evident that recruitment of such groups is possible; however, researchers must be prepared to invest significant time, effort, and resources in the process and to be flexible and adaptable in their approach. Specifically, researchers need to spend time prior to the commencement of the project developing an alliance with community gatekeepers (Corbie-Smith et al., 2002; Knobf et al., 2007; Russell et al., 2008). In addition to promoting community members' trust in the research, gatekeepers can help researchers better understand cultural norms and specific concerns of the target community and plan their recruitment efforts accordingly (Corbie-Smith et al.; Knobf et al.; Russell et al.).

Since the effectiveness of particular recruitment strategies may vary depending on the nature of the research topic and the characteristics of the targeted communities, researchers cannot rely solely on community gatekeeper endorsement to recruit participants (Knobf et al., 2007). Multiple strategies should be employed, including contacting potential participants directly, using cultural insiders and/or unaffiliated intermediaries as recruiters, and advertising the research in various venues accessed by ethnically diverse populations (Knobf et al., 2007; Ogilvie et al., 2008). Recruitment materials should be written in a culturally-sensitive manner, and consultation with cultural insiders can be invaluable for accomplishing this objective (Knobf et al., 2007). Offering payment that reasonably compensates participants for

their time and lessens the burden of participation may also enhance recruitment (Preloran et al., 2001; Russell et al., 2008; Yancey et al., 2006). Finally, given the significant role that trust plays in non-dominant ethnic groups' decision to participate in research, researchers should endeavour to foster trust in the study by (a) ensuring that consent is truly informed and (b) developing respectful and reciprocal relationships with participants and their communities (Barata et al., 2006; Birman, 2005; Dennis & Neese, 2000; Knobf et al., 2007). By being sensitive not only to the cultural context of non-dominant research participants, but also to the kinds of working relationships that will support their participation and retention, researchers may be able to address ethnic disparities in health status and health care research.

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Author Note

Hagar Renert, M.Sc., is a registered counselling psychologist in private practice in Calgary, Alberta, with special interest in anxiety, depression, and eating disorder treatment. Contact information: hagar.renert@gmail.com

Dr. Shelly Russell-Mayhew is a registered psychologist and Associate Professor, Educational Studies in Counselling Psychology, Faculty of Education, University of Calgary, specializing in weight and eating-related issues. Contact information: mkrussel@ucalgary.ca

Dr. Nancy Arthur is a registered psychologist and Professor, Educational Studies in Counselling Psychology, Faculty of Education, University of Calgary, specializing in professional education for cultural diversity and social justice. Contact information: narthur@ucalgary.ca

Correspondence concerning this article should be addressed to Dr. Nancy Arthur, Professor, Educational Studies in Counselling Psychology, Faculty of Education, University of Calgary; E-mail: narthur@ucalgary.ca

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Article Citation

Renert, H., Russell-Mayhew, S., & Arthur, N. (2013). Recruiting ethnically diverse participants into qualitative health research: Lessons learned. *The Qualitative Report*, 18(Art. 23), 1-23. Retrieved from <http://www.nova.edu/ssss/QR/QR18/renert23.pdf>

Appendix A



Name of Researcher, Faculty, Department, Telephone & E-mail:

Hagar Renert, M.Sc. Student, Faculty of Education, Division of Applied Psychology
Telephone 288-2848, E-mail: hrenert@hotmail.com

Supervisor:

Dr. Shelly Russell-Mayhew, Ph.D.
Telephone 220-8375, E-mail: mkrussell@ucalgary.ca

Title of Project:

The Experience of Eating Problems among Women from Visible Minority Groups

PARTICIPANTS NEEDED FOR RESEARCH EXPLORING THE EXPERIENCE OF EATING PROBLEMS AMONG WOMEN FROM VISIBLE MINORITY GROUPS

Although culture is believed to play an important role in the development of eating problems, the impact of specific cultural factors remains incompletely understood. Feminist research has shown that eating problems are gendered, however, little is known about the roles of race/ethnicity, immigration, and acculturation. To shed light on the roles of these additional factors, I am interested in speaking with women who:

- (a) are between the ages of 18-40;
- (b) are members of a visible minority group;
- (c) are first generation immigrants;
- (d) are fluent in spoken English; and
- (e) identify themselves as currently experiencing an eating problem that developed during the time that they have resided in Canada.

As participants in this study, you will be asked to take part in two 1.5-2 hour confidential interviews, scheduled 1-2 weeks apart. The first interview will focus on your life history up to the time that you became aware that you have an eating problem, and the second interview will focus on the details of your eating problem experience and its meaning for you. In appreciation of your time, you will receive a \$20 honorarium.

For more information, or to volunteer for this study, please contact:
[researcher's phone number and email address]

*This study has been reviewed by, and received ethics clearance through,
the University of Calgary Conjoint Faculties Research Ethics Board*

Appendix B

VOLUNTEERS NEEDED FOR STUDY ON EATING AND BODY IMAGE CONCERNS IN ETHNICALLY DIVERSE WOMEN

- Are you a woman from an ethnic community?
- Have you ever been concerned about your eating, weight, or body image while living in Canada?

If so, you may qualify to participate in a study exploring how immigration and culture impact eating and body image in women

As a participant, you will be asked to take part in ~3 hours of confidential interviewing and will receive \$50 in appreciation of your time

For more information or to volunteer, please contact:
Hagar Renert, M.Sc. in Counselling Psychology,
University of Calgary
[researcher's phone number and email address]

*This study has been approved by, and has received ethics clearance from,
the University of Calgary Conjoint Faculties Research Ethics Board*
