COLLABORATIVE RESEARCH WITH MĀORI ON SENSITIVE ISSUES: THE APPLICATION OF TIKANGA AND KAUPAPA IN RESEARCH ON MĀORI SUDDEN INFANT DEATH SYNDROME

Shane Edwards¹ Verne McManus Tim McCreanor Whariki Research Group, Massey University

Abstract

This paper describes research practices and experiences employed by Māori field researchers within the context of a current research project that investigates the knowledge and insights of Māori families that have lost a child to Sudden Infant Death Syndrome (SIDS). The research process devised by the Māori research team made innovative use of Māori community and care worker networks in order to investigate a deeply sensitive issue and to enhance our understanding of Māori SIDS. We contextualise our commentary within tikanga and kaupapa Māori research frames. We hope that the use of diary annotations will illuminate points made in the discussion and will be of use and inspiration to researchers working with Māori on issues that would ordinarily be difficult to approach and which would therefore require measures of sensitivity and caution.

INTRODUCTION

In Aotearoa New Zealand Māori continue to experience disproportionately high SIDS rates. This is one of the primary reasons for research in this area. A key aim of the Māori SIDS project was to design and develop research processes and practices that anticipate and deal with the cultural aspects of Māori SIDS in culturally appropriate ways. The sudden and unexpected loss of an infant is a devastating experience for people of all ethnic and cultural backgrounds, and all ethnicities experience and respond to the SIDS experience in unique and culturally specific ways. We argue that Māori, therefore, utilise specific cultural beliefs and values as valid ways for understanding Māori cultural sensitivities to SIDS events. This discussion employs and discusses some of these beliefs and values in ways that enable us to examine the understandings more closely. The principles of tapu and mana in particular are explored as a means of

¹ The research was hosted by the national Māori SIDS Prevention Team at the University of Auckland and funded by the Health Research Council of New Zealand, grant 01/268. Tim McCreanor provided guidance and editorial advice on the writing of the paper. Special thanks to David Tipene Leach and Fiona Cram, who provided constructive criticisms of earlier drafts of this paper.

developing understandings. These principles are also used to articulate how SIDS and other sensitive research with Māori might be undertaken in ways that are culturally appropriate. Of particular significance here is the relationship between life and death within a Māori world-view that supports the uniqueness of different groups and their approaches to sensitive issues and research.

Research processes involved in qualitative social science investigation are integral to both the direction and dynamics (Cram 1997, Pyett 2001) of research projects in terms of their impact on participants and on the eventual outcomes and findings of the study. Indigenous communities the world over have long been belittled by research done "on" them rather than with or for the benefit of these communities (Smith 1999). Too often Māori have been researched by those who view their subjects with the "colonial gaze" (Paraha 1992, Pihama 1994). The results of the research have been used to define and further malign Māori politically, spiritually, culturally, economically and socially (Stokes 1992). This has led to a negative stance towards research and researchers in many indigenous settings (Cram 1997, Humphery 2001, Jahnke and Taiapa 2003, Smith 1999).

One result of the negative stance, particularly in the investigation of sensitive topics, has been non-involvement by these communities, and in many cases this has served to further disadvantage them (Abel et al. 2001, Kearns and Dyck 2005, Smith 1999, Spoonley 2003). Disadvantages include isolation, reduced access to resources and services, and continued mistrust of and resistance to research and researchers, including Māori. While there are many success stories and some evidence of improvements in Māori wellbeing, it is often the case that the issues and concerns that affect Māori communities either continue to be dealt with ineffectively, in ad hoc ways that produce inaccurate findings, or they simply remain unaddressed. To take but one relevant example, health disparities between Māori and Pākehā have continued to grow, especially since the mid-1980s, despite decades of research and intervention (Ajwani et al. 2003).

Kaupapa Māori is a research paradigm that recognises and accommodates the unique requirements of this project. As a response to traditional Western research paradigms it acknowledges the historical experiences that Māori have had with research. It goes further to provide possibilities for creativity and innovation within a framework that is responsive, reflective and accountable.

This paper was written as part of the project Experiences of Māori SIDS Parents, Caregivers and Whānau, funded by the Health Research Council. The project investigated the contextual processes and practices within which SIDS is experienced by parents and caregivers. The aim of this discussion is to highlight interesting and valuable innovations in the research process that we used in order to ensure the

effectiveness and integrity of our approach in an area that is at once very difficult to access and of great concern to Māori communities. We explore the influences of tikanga and kaupapa Māori on the research to contextualise our examination of the delicate balance among the aims and needs of the project, the role of the national Māori SIDS prevention (MSP) team, the safety of the interviewees, and how the research demonstrates sensitivity towards that complex relationship. The research is both conceptual and experiential, and this discussion has been freely and liberally interspersed with excerpts from our field notes about our own experiences in this project.

WHAT MIGHT BE CONSIDERED SENSITIVE

Defining the sensitivity of a research topic is complicated by the norms of groups; what might constitute a sensitive issue varies with cultural and other contextual factors. In research around loss and grief, Māori life principles provide some guidance as to areas of high sensitivity, normalising Māori world views into design, process (Jahnke and Taiapa 2003, Smith 1999) and research frame.

Two Māori principles that have provided Māori society with rules for living are the principles of *tapu* and *mana*. Although these concepts are widely used by Māori and others, there is a considerable variability and nuance, which make definition difficult beyond the general. In its very broadest sense tapu refers to the sanctity (or restriction) of something or someone, and mana refers to the inherent power of something or someone. With the concept of tapu it is possible to talk of *tapu o* and *tapu i*. Our understanding is that *tapu o* refers to the sanctity of someone or something that stems from the divine or spiritual realm – a faithfulness – and *tapu i* refers to a sanctity that has been grown over time (Shirres 1997). This same principle can be applied to mana, where *mana o* is derived from mana atua and *mana i* is derived from mana tangata. Those things or people that have mana or tapu atua are created or born with this, while mana tangata and tapu tangata are strengthened or weakened depending on the acts of the various parties (Barlow 1991).

Māori generally acknowledge that human beings are born with te ira atua, divine spirit that endows them with tapu. People also have mana atua, and this "power" stems from this divine spirit that is in each of us. We therefore have tapu atua, which is the precursor to mana atua. Based on our actions or those of our relations our tapu tangata and mana tangata is enhanced or reduced depending on our activities. Based on this it is apparent that, in relation to people, sensitivity can be considered anything that deals with the tapu and mana of something, but most commonly with people. If research activity is likely to have effect on a person's tapu or mana, whether this person is living or dead, then this should be considered sensitive.

Another principle that guides many Māori researchers is the relationship between life and death. Life is a matter of extreme sanctity within Māori society and death is an integral part of life. In matters of death, health and the human body, the researcher will encounter important issues around tapu and mana. When a baby dies suddenly without apparent cause, as is the case in SIDS (which is in effect a default diagnosis that accounts for unexplained death), all of these factors converge to create situations of the highest sensitivity.

Over recent years appropriate ways to conduct research with Māori and within Māori communities have been developed. Approaches such as "involving Māori," "employing Māori," "research by and for Māori" (Bishop 1996, Cram 1997) are some examples that build on the pioneering work of Linda and Graham Smith in developing Kaupapa Māori research as a valid research methodology. Such approaches (Smith, 1993, Smith and Pihama 1995) are based on Māori epistemology and pedagogy, which are concerned with positive social transformation through the application of research methodology (McManus 1997). Kaupapa Māori research is the notion that indigenous approaches to research seek positive and improved outcomes for the participants and their wider communities. Smith (1999) says that Kaupapa Māori approaches to research are based on the assumption that research that involves Māori people, as individuals or as communities, should set out to make a positive difference for the researched. She adds that historically, indigenous peoples have not seen the positive benefits of research, and that this naming of research has provided a focus through which Māori people, as communities of the researched and as new communities as the researchers, have been able to engage in a dialogue about setting new directions for the priorities, policies and practices of research for, by and with Māori.

Many Māori are now much more aware of the effects of research and its potential to empower or disempower different groups (Cram 2001, Edwards 1999). Māori are becoming more aware of culturally appropriate practices for meeting and interacting in ways that are uniquely Māori as Māori researchers redefine best Māori practice and thus construct difference positively for the benefit of Māori. Māori practices and principles are becoming normalised as "good research practice" in working for and with Māori in diverse fields (Royal-Tangaere 1997) of social action. As fields of inquiry have grown there has been increased involvement by Māori at various levels in research, with a resultant flowering of information and knowledge that is sensitive to Māori needs. These changes are underpinned and enhanced by theoretical frameworks such as Whare Tapa Wha and Te Pae Mahutonga (Durie 1994, 1999), and Smith's (1999) decolonising work, which emphasise the rigour and creativity of good practice.

Our research draws distinctly on Māori world views, especially that of mana tangata, the acknowledgement of the human being, her families and the cultural precedents for interpersonal relationship borne out in contact between peoples. In the general

sensitivity to the power of knowledge that research history has fostered among Māori, SIDS represents a particularly important case. Not only does it evoke the sacred territory of death but it is also particularly poignant for its implications for the living and future generations. Mikaere (2002) has written that whare ngaro, loss or absence of children in a family, as a loss of potential and inheritance, represents a "terrible tragedy" for the entire whānau and wider tribal grouping of the bereaved. These cultural imperatives, along with the troubled history of medico-legal interventions in Māori SIDS (Everard 1997, McCreanor et al. 2004), undoubtedly contribute to the complex mix of emotions and feeling that attend SIDS in Māori families. With these understandings to hand, especially through our relationship with the Māori National SIDS Prevention Team, it was clear that particular care would be needed to build a research project that was safe and sensitive to the needs of all involved.

RESEARCH BACKGROUND

Our investigation into the experiences and insights of Māori SIDS parents, care-givers and whānau was a collaborative, qualitative approach undertaken by the MSP team and Māori academic researchers based at Auckland University. The common goal of these two groups – to improve the wellbeing of Māori whānau and communities – has provided distinct advantages that have combined to positively influence the direction and the dynamic of the project. Kaupapa Māori principles and beliefs shared by the team members have served to mitigate the tensions and conflict that can characterise collaborations that lack this cultural match. The project arose in the late 1990s within the national Māori SIDS Prevention programme at the University of Auckland. Concerns with lack of progress in reducing Māori SIDS rates led to the initiation of Māori-led research. In particular, it was felt that Māori processes and experiences around childrearing, grief and life course were not attended to and yet had considerable potential for advancing understanding and therefore prevention of SIDS (McCreanor et al. 2004).

The research processes that were adopted feature a close collaboration among MSP field and academic research staff. The design was developed in consultation among the parties and implemented by the research team paying close attention to both the cultural and emotional aspects of conducting research in a sensitive area such as the unexplained death of an infant. The project sought to gather life story narratives from Māori parents (primarily mothers) as neglected holders of experiential data on the contexts within which Māori SIDS has occurred, privileging the oral accounts as testimony that gives voice to marginalised experiences (McManus 1997). In this way the mana is with the participants, while the validity of the project and the insights it has gathered are enhanced and authenticated (Cram 1993).

Discussion among the academic researchers supported the development of a grant application to the Health Research Council that was duly framed and once funded was brought to a meeting of the entire MSP team, where it was endorsed for action. While the MSP team was constituted as a service organisation with a national network of regional coordinators and care workers to ameliorate Māori SIDS trauma, in this context these workers are regarded as co-researchers with recognised roles and responsibilities within the project. From earlier investigations (McCreanor et al. 2004) it was realised that very little was known about the experiences of Māori fathers in relation to loss of this kind and it was resolved to include a Māori male database complementary study.

At an MSP team quarterly meeting, a project overview and guidelines in draft form were presented so that protocols covering selection, recruitment and support of participants could be negotiated. The interview model, support services to the participants during and after the interviews, koha to the participants for their time and contribution to the research, and the contributions of research team members were discussed and agreed upon. A key feature was the sharing of research roles between the MSP researchers and the academics, such that the former managed all aspects of participant involvement on the basis of ongoing care relations while the academic researchers gathered and analysed the data. The entire team collaborated in the interpretation of findings through the circulation of draft papers and discussion at two research hui. Dissemination activities were also shared, with presentations at the Public Health Association conferences in Ngaruawahia (2003) and Christchurch (2004), the Society of Australasian Social Psychologists conference in Auckland (2004).

The relationships and networks established by the MSP care workers within the context of their professional practice and the services they deliver to SIDS families were paramount to the effectiveness of the recruitment and data collection processes. The research could not have proceeded without this commitment and support from the MSP.

The remaining sections of the paper report on some key themes, drawn from research diaries kept by the interviewers, that came to structure our experience of carrying out the research project within the framework outlined above. The data that were originally conceived of as personalised reflections came to provide a useful reflexive tool for the research process, contributing to the ability of the research team to keep both researchers and participants safe and to monitor aspects of our research approach. The use of field notes has allowed us to describe and elaborate on some of the more subtle nuances, cultural and otherwise, and the contexts within which some of these themes occur. This focus enables the reader to differentiate what might easily be considered intrinsic, but not culturally exclusive (to Māori), aspects of the findings.

THE INDIVIDUAL AS PART OF THE COLLECTIVE – THE NOTION OF WHĀNAU

Many research participants are often part of larger collectives or whānau groupings. These whānau groupings are not only based on blood connections but can be conceptualised as whānau based on history, experience, the context or the kaupapa, or connected through association constituting a whānau relationship as determined by the participants (Durie 2004, Walker 1990). For us this meant that we were not only working with individual participants but with whānau members as well, and thinking about our own families and the impacts of the research in these circles.

"Note to self: This research will be very draining on me as the researcher, it is dealing with very sensitive issues, I've got two infant children myself! Why am I agreeing to do this? ... maybe it's because it provides the opportunity for difference, to make a difference for our people. Although this will be challenging emotionally it is positive with potential to be positive for our people. I am also in the privileged position of having the skills and training to make a difference where others may not, the iwi is bigger than the individual." (male interviewer)

In the initial stages of getting the project off the ground, another whānau, that of the MSP care workers, had to be satisfied with our intentions as researchers and with the benefits, the costs and the effects of the research for the participant members of their clients and whānau, before access was permitted. The first steps were through the mihimihi process at a critical first meeting and formed the basis for positive outcomes, but we needed to show the MSP team who we were and what we had to offer.

"It is important that I meet these people, they have to trust me and I need to trust them if we are all going to do credit to the research planned and ultimately the participants and their families. The ancestors of those people that we are travelling to meet and mine will possibly reunite through our meeting today. If they trust me this will enhance our relationship and this will also enhance the activities that may stem from a positive first encounter." (male interviewer)

It was essential that as Māori researchers we were "seen by the people" of the communities in which we worked and in practical terms the MSP team carried this function for the research team as a whole. Knowledge of tikanga and te reo was very valuable in these situations, as was maintaining awareness of the tapu and mana of the whānau or group and that of the researcher.

"We arrive at the hotel for the meeting. We enter the room where we will start our hui. I am conscious of my behaviour as the encounter process begins. I am conscious that my behaviour will be assessed and that I represent my whānau, hapū and iwi also, the institution that pays me fails to register in my The Application of Tikanga and Kaupapa in Research on Māori Sudden Infant Death Syndrome

thoughts in this area, the faces of my elders are vivid. I begin to prepare, will there be a kaumātua, is there going to be mihi, is it pseudo-Māori? I meet the coordinators and prepare to say the standard, 'kia ora' and kiss. I am conscious to wait until they approach me. I am the quest and the first move rests with them, the home people. I am conscious that kia ora is an informal greeting for people who are acquainted with each other. Consequently I say, 'tenā koe'. We are offered a cup of tea. Again, I wonder should we acknowledge and greet each other first and thus negotiate the ritual of encounter before eating or drinking, as is practice in Maori society? We have come into contact and so we are still in a state of tapu until the ritual has finished and this tapu is lifted by kai so that we become noa. I don't have a cup of tea. We all sit. Of our team of four we sit together in pairs but separated. There is no paepae, or speaking platform, I wonder would it have been tika to all sit together as visitors? The hui starts. There are no males from the home people. One of the females gets up and welcomes us in Māori. I listen for a sharing of information, I am hopeful to be 'fed information' from the 'kai korero,' key names of people and places that I may be required to acknowledge if required to respond. I feel comfortable. There is a good feeling, it is welcoming and inclusive, it is Māori. This is a good start. We respond to the mihi." (male interviewer)

While the MSP whānau were asking questions of us and we were responding, there was a reciprocal judging of the propriety and possibilities that each group represented. The dynamics of whanaungatanga came into play as access to communities was negotiated.

"In the breaks in the meeting I interact with people individually and we 'find joins' between us and connect some more. Joins are formed around families we know predominantly based on our ancestral blood lines and the geographic locations that we derive much of our uniquely Māori identity from; some joins will stem from the ability to speak Māori. The joins are important for the whänau to know us and for me to know the whānau/liaison people to know that we and those we represent are safe and that further interactions will be positive ones. I get a better sense of what my role will involve and I am conscious that my interaction with the participants and coordinators will leave me touched by the research and that these relationships will have effects in and on my life. I make a mental note that I will have karakia both before and after the project for my personal safety. These karakia are karakia kaupare, or karakia to protect myself from being 'touched' from anything. Another name for these forms known to me is 'takutaku'. Again, these are karakia to protect oneself when coming into contact with things, including people that have the potential to influence the health of the individual." (male interviewer)

Researchers need to be happy with the project and the people with whom they will be working in order for the research to be successful and beneficial to the stakeholder groups. It is not only about participants' possible uncertainty about "research vampires" but acknowledgement also that the researcher has personal tapu and mana that could be affected; as such, a researcher needs to be aware and acknowledge this, both as an individual and as a member of other collective groups as there is the potential to be "touched" by the research itself or the participants themselves.

These connections can leave indelible marks on some researchers. For many Māori researchers karakia plays a central part of research pedagogy. In traditional times all activity took place with karakia present throughout. The effect of successive colonial acts to limit connectedness to Māori spirituality meant that karakia did not and continues not to play as central a role in the everyday lives of Māori as previously experienced. This is still the case in the majority of situations today. Nevertheless, karakia is still a powerful force in preparing a researcher for activity (Shirres 1997). This is especially so when coming into contact with other people and heightened when the purpose is of a sensitive nature. Some researchers are known to do their own karakia before they engage in activity; others have a member of their whānau do karakia for them before they engage in research activity. They also repeat this process in situations that call for it and at the completion of activity. Following interviews and field research many researchers will often find places to wash their hands with water to lift the tapu associated with human encounter.

WORKING WITH KEY PEOPLE

The appropriate selection of participants as well as invitations to key support people in their whānau was a process carefully guided, region by region, by the MSP care worker, confirming the importance and value of this interface. The procurement and provision of vital details and background information was a crucial element in supporting high-quality research. The MSP care workers were able to coordinate activities that supported and nurtured this process. Therefore, maintaining the flow of information was important, letting them know where things were at and keeping them in the loop.

"I've just finished an interview, I need to ring the Regional Coordinator and report how the interview went, any issues or not, need to maintain the trust." (male interviewer)

In this project the dependence of the academic researchers on the care workers for contacts, interview support and overall safety in data gathering for researchers and participants has given rise to regular team meetings. The quarterly gatherings allowed the team to maintain accountability and engagement, and ensured that the research knowledge remained close to where it was needed as well as making it available to broader scrutiny and to other groups who may value it.

LIFE STORY INTERVIEWS

Our chosen data collection method, known as focused life story interviews, sits comfortably within qualitative social science investigation. This method is based on the life story model discussed by Olson and Shopes (1991) and Anae (1998). Focused life story interviews are very appropriate for sensitive topics as they encourage a reflective, narrative style where the interviewee sets the pace and the interviewer listens, clarifies, probes and possibly brings up topics which need to be covered in the interview that have not arisen spontaneously in the course of the conversation. This particular style allows for a relaxed, almost conversational, approach to data interview. The hope was that the participants would feel safe and supported enough to talk through the very difficult circumstances surrounding the loss of their baby. The MSP care worker was the key to our highly positive experiences and most certainly enhanced the participant's appreciation of the sessions. This interview method is also consistent with the principles that underpin a Kaupapa Māori research framework within which the mana of the participants and the information that has been shared is upheld, and our respect and appreciation for the contribution are conveyed.

"When I explained the aims and objectives and scope of the project to the participants I wanted to give them some idea of the profound impact and value their stories will have in the planning and development of strategies for reducing and preventing SIDS. I wanted them to know that wherever possible there would be increased effectiveness and improvement in the delivery of services to whänau who experience SIDS. Responses were often emotional expressions of appreciation and gratitude for being given the opportunity to tell their stories and most importantly to have the chance to help other whānau cope with or avoid this tragic experience. At the conclusion of each interview the sense of relief from most of the participants was so palpable I got the feeling that a major milestone had been achieved. What became abundantly clear is that this type of grief is an ongoing process, which is at times extremely difficult. This reality was made heart-wrenchingly apparent throughout the personal testimony given by each of the participants." (female interviewer)

The experience of story gathering has been both humbling and gratifying. Being a guest in their homes and listening to some of the participants' most personal thoughts has been an honour and a privilege. They were able to give expression to their thoughts and feelings in a way that allowed them to control the flow and direction of the interview as was intended. The resultant high quality of data is affirmation of the appropriateness of the selected method. According to Bishop (1996), storytelling is a useful and culturally appropriate way of representing the "diversities of truth" within which the storyteller rather than the researcher retains control. Bishop (1996) and Olson and Shopes (1991) promote storytelling and life story interviews, respectively, as not not only culturally appropriate but also as empowering for interviewees. Importantly, this method encouraged the participants to reflect upon and talk about their experiences in a biographical manner, a novel and often amusing experience.

To start the interviews the participants were asked to construct an outline of their life, paying special attention to those aspects (themes) that relate to whakapapa, relationships, family structure, economic/employment issues, education, identity, sense of belonging, access to amenities and other aspects of community that impact on the health and wellbeing of whānau. Multiple themes evolved and arose spontaneously through the course of interviews and these have added to the richness and diversity of the data. At times, when it appeared that an interview had gone "off-track," with gentle guidance the participants were able to continue with their story. They were encouraged to expand on ideas, elaborating and providing detail wherever this was possible and appropriate.

The interview process highlighted the importance of the relationship that is created between the participant and the researcher. The relative strength of this relationship will determine the quality of outcomes. You can feel if the "vibe" is good and that all people are comfortable with each other.

"My first interview, I need to be aware not to talk above or below the participant; it is my responsibility to meet them at their comfort level, both in dress, appearance and language. Take your time, don't try and fluff round the reason that you're here, they know why, it will only make people uncomfortable, never turn down a coffee or kai. Remember names, they have meaning and are important, maintain eye contact (but not direct eye contact for extended periods) to show respect and acknowledge that you are listening and that their words are valuable as is their story and them and their whānau." (male interviewer)

Many of our research participants occupy New Zealand's lower socio-economic grouping and this was a key consideration for us. Other considerations included some of the more subtle aspects such as clothing and vehicle choice and appropriate pitching of language. These seemingly mundane things tell a lot about us as researchers as they are ways of representing relative wealth, financial, economic, social and cultural milieux. The aim is to encourage participants to feel comfortable by de-emphasising difference, a subtle process that can easily degenerate into perceived patronising that can then lead to distrust. We found that the giving of koha was appreciated as we were essentially being hosted; Māori principles of reciprocity require that a koha be provided. Many researchers give a koha at the beginning of the interview, some do so afterwards.

"Diary reflection – just finished an interview on a SIDS incident. The young Māori male and his partner had made a huge effort; they had cleaned their house and were both there to meet me, before we entered the house they had apologised for their house being messy, you could tell that they were nervous. We talked about their ethnic background and made connections based on family surnames and then through people or areas we knew. The whakawhanaungatanga enabled us to connect. I talked about what the research was about and gave the participant the koha in an envelope. He said thank you and neither of us mentioned it again; he pushed the envelope to one side of the table not looking at it in my presence." (male interviewer)

This experience emphasises the need for the researcher to maintain flexibility and remain responsive to the reactions of participants during the encounter.

Most of the participants said that they valued doing the interview. Throughout their interviews many of them realised that a lot of the events and happenings that they were recalling from their history, especially in relation to schooling and whānau dynamics, had been all but forgotten. It was therefore with combinations of amazement and amusement that many of these recollections were made and recounted. As has been found elsewhere (Dyregov 2004), the opportunity to speak to a respectful, professional stranger (in this case strongly linked with the well-trusted MSP team) appeared to be of significant benefit to the participants. Additionally, all participants expressed a strong desire to help other whānau to deal with SIDS and related issues.

SAFETY ISSUES

Having the MSP care workers present during the interviews meant that appropriate support strategies were immediately available in the event of issues arising during or after the interview. The risk-laden nature of the research made this a very important aspect of the process and was the result of strategic risk management and forward planning to ensure that field crises would be kept to a minimum and managed efficiently. In most instances the researchers had to rely on basic instinct as well as expertise, making very fine and delicate judgement calls. This was crucial as often participants would break down while recalling and describing their experiences, especially those aspects closely related to the SIDS event.

"It's late in the avo, I've just finished a gut-wrenching interview, we both ended up sitting there bawling. Research training 101 never prepared me for this, you're supposed to be unbiased, unobtrusive... man that don't work in indigenous communities. I think of my own children, the participant and I connected with each other and the topic, I've been touched. I ring my partner, I talk to our infant children, I can't wait to get home and hold them." (male interviewer) Although most participants were reasonably composed throughout their interviews, it was the presence of the care workers that provided that extra reassurance. Knowing their ability to offer expert support and comfort, both immediately and afterwards if necessary, was a crucial factor. This kind of support epitomised the role of the care worker; it also served to highlight the need that many SIDS whānau have for ongoing specialised support and assistance.

"She sobbed gently and softly, from the beginning of the interview, to its conclusion, almost three hours later... this sorrowful weeping was such a natural reaction and after my initial thought I no longer felt a compulsion to stop the interview... it was entirely appropriate for her to be expressing her emotions while sharing this painful experience... by the end of the interview she was so happy and peaceful she seemed to beam; thank goodness I had resisted the urge to postpone... and I couldn't imagine it having gone any other way." (female interviewer)

"It was critical that as a researcher and (maybe more importantly) as a mother and a Māori woman that when I completed an interview, I was able to depart with the knowledge that the care worker and I had appropriately and adequately expressed our respect and appreciation and care for the participant and the precious information that had been shared. I made sure to emphasise my availability, I am happy to come back, I am only a phone call away. This was very important to me." (female interviewer)

The advisory arm of the research team was another safety mechanism that was on hand offering interventionist support and assistance. The confidence gained from knowing that we had immediate access to such a high level of support was another key factor providing reassurance throughout the interviews.

INFORMALITIES

The interview included having kai, or sharing food, which we considered as part of the informal "icebreaking", but which in this context is also properly regarded as a formal aspect of Māori research conduct, to lift the tapu between people having met. This activity provided more opportunity for rapport building and was therefore an important part of the process where connections were made and trust was further developed.

"Munching out on KFC with a participant, he gives me his name, my mind automatically searches the genealogical archive in my head for the name, I inquire, are you part of the whānau from the West Coast? I get an affirmative, we lock in on whakapapa and people, we have a laugh and a join is affirmed. We will return to this after the interview and connect some more." (male interviewer) The importance of being able to work with Māori participants when and where it is appropriate to them is an essential part of recognising and acknowledging our diverse realities as well as the knowledge we carry.

CONCLUSION

This paper has outlined the method and process required for investigating aspects around the very sensitive topic of the unexplained death of an infant among Māori. As Māori researchers collaborating with a Māori service organisation and its field workers, we were able to maintain a modicum of control over the design and implementation of innovative research practice in order to expose the depth of those experiences in a safe environment. This is particularly relevant when conducting research in a culturally fraught and emotionally charged area, and one in which there is huge potential for victim blame at the hands of a hostile press and public.

Acting collectively is a common feature of Māori society and, among other things, includes the whānau, hapū, iwi and waka contexts. Māori frequently unite under a single banner, either to answer and resist colonial impositions, or to work for the common good. As researchers we are conscious that our actions reflect on the members of the other groups with which we have worked and that we are part of a collaborative approach that acknowledges and values the contribution each individual makes to the project. In our context, attending to the process of the research takes on a double importance in terms of accountability, as well as ensuring the quality of the eventual findings of the research.

Participant research (McManus 1997) is a model that enables Māori to include, incorporate and uphold, through the voices of the participants, oral and cultural traditions (see Cox 1993, Jackson 1975, Jenkins 1991, Havelock 1991). Through the transcripts, the use of quotes and diary excerpts, marginalised voices have been privileged. The diary materials in particular allowed us to reflect on our process and practice in ways that assisted our ability to keep both participants and researchers safe and to continuously improve the research approach needed to address a highly sensitive issue for Māori communities.

SUMMARY

- The imperative of the safety of the interview structure for the families (and for the researchers) was recognised by the Māori SIDS research group at an early stage.
- The "bridging" role of the service care workers was utilised in order to allow the researchers a "highly privileged" place from which to conduct their research activity.

- This strategy was highly successful, as reflected in the ease of access and the reports (both direct and indirect) of the positive experience of participants completing the interviews.
- The dimensions of "sensitivity" articulated in this paper are not prescriptive or exhaustive, but illustrative of the range of issues that arose in our research.

We have highlighted the centrality of Māori ways of knowing and being as appropriate ways for working with Māori in sensitive areas such as SIDS. Our research process is inspired and informed by the methodological literature of Māori research, and it is our hope that detailing our practice as we have elaborates and contributes to the scope of Māori-oriented research. We hope that it can provide other researchers, particularly those with an indigenous focus and especially those working in sensitive areas, with an indication of the complexities inherent in the conduct of qualitative social science inquiry.

The aim of the research project and the approach taken was to collect data that illuminate the environmental, contextual and process variables within which the SIDS event has occurred. Papers reporting on these findings are currently in preparation.

REFERENCES

- Abel, S., M. Lennan, J. Park, D. Tipene-Leach and S. Finau (2001) "Infant care practices in New Zealand: A cross-cultural qualitative study" *Social Science and Medicine*, 53(9):1135-1148.
- Ajwani, S., T. Blakely, B. Robson, M. Tobias and M. Bonne (2003) *Decades of Disparity: Ethnic Mortality Trends in New Zealand 1980–1999*, Ministry of Health and University of Otago, Wellington.
- Anae, M. (1998) *Fofoa-I-voa-'ese: The Identity Journeys of NZ-Born Samoans*, PhD thesis, University of Auckland.
- Barlow, C. (1991) *Tikanga Whakaaro: Key Concepts in Māori Culture*, Oxford University Press, Auckland.
- Bishop, R. (1996) *Whakawhanaungatanga: Collaborative Research Stories*, Dunmore Press, Palmerston North.
- Cox, L. (1993) *Kotahitanga: The Search for Māori Political Unity,* Oxford University Press, Auckland.
- Cram, F. (1993) "Ethics in Māori research" in L.W. Nikora (ed.) *Cultural Justice and Ethics*, proceedings of a symposium held at the Annual Conference of the New Zealand Psychological Society, University of Victoria, Wellington.
- Cram, F. (1997) "Developing partnerships in research: Pākehā researchers and Māori research" *Sites*, 35:44-63.

- Cram, F. (2001) "Rangahau Māori: Tona tika, tona pono The validity and integrity of Māori research" in M. Tolich (ed.) *Research Ethics in Aotearoa New Zealand*, Pearson Education, Auckland.
- Durie, M. (1994) Whaiora: Māori Health Development, Oxford University Press, Melbourne.
- Durie, M. (1999) "Te Pae Mahutonga: A model for Māori health promotion" keynote presentation at the Health Promotion Forum Conference: Health Promotion on the Move, Napier.
- Durie, M. (2004) "Effective interventions with young Māori: The Aotearoa reality" Compass Seminar, Hamilton.
- Dyregov, K. (2004) "Bereaved parents' experiences of research participation" *Social Science and Medicine*, 58(2):391-400.
- Edwards, S. (1999) Hokia ki nga Maunga kia Purea koe e nga Hau o Tawhirimatea: Māori Identity Reclamation, Empowerment Through Identity, MA thesis, University of Auckland.
- Everard, C. (1997) "Managing the New Zealand cot death study: Lessons from between the rock and a hard place" *Journal of Community Health and Clinical Medicine for the Pacific*, 4(2):146-152.
- Havelock, E. (1991) "The oral literature equation: A formula for the modern mind" in D.R. Olsen and N. Torrance (eds.) *Literacy and Orality*, Cambridge University Press, Cambridge.
- Humphrey, K. (2001) *Indigenous Health and "Western Research"*, VICHEALTH Koori Health Research & Community Development Unit, University of Melbourne.
- Jackson, M. (1975) "Literacy, communications and social change" in I.H. Kawharu (ed.) Conflict and Compromise: Essays on the Māori Since Colonisation, A.H. & A.W. Reed, Wellington.
- Jahnke, H. and J. Taiapa (2003) "Māori research" in C. Davidson and M. Tolich (eds.) Social Science Research in New Zealand: Many Paths to Understanding, Pearson, Auckland.
- Jenkins, K. (1991) Te Ihi, Te Mana, Te Wehi o Te Ao Tuhi: Māori Print Literacy from 1814–1855: Literacy, Power and Colonisation, MA thesis, University of Auckland, Auckland.
- Kearns, R. and I. Dyck (2005) "Culturally safe research" in D. Wepa (ed.) *Cultural Safety in Aotearoa New Zealand*, Pearson, Auckland.
- McCreanor, T., D. Tipene-Leach and S. Abel (2004) "The SIDS Careworkers Study: Perceptions of the experience of Māori SIDS families" *Social Policy Journal of New Zealand*, 23:154-166.
- McManus, V. (1997) *Crisis or Cartharsis? Integration and Re-establishment at Hukarere,* MA thesis, University of Auckland, Auckland.
- Mikaere, A. (2002) "Māori concepts of guardianship, custody and access: A literature review" in D. Pitama, G. Ririnui and A. Mikaere (eds.) *Guardianship, Custody and Access: Māori Perspectives and Experiences,* Ministry of Justice, Wellington.

- Olson, K. and L. Shopes (1991) "Crossing boundaries, building bridges: Doing oral history among working class women and men" in S. Gluck and D. Patai (eds.) *Women's Words: The Feminist Practice of Oral History, Routledge*, New York.
- Paraha, G. (1992) *He Pounamau Kakano Rua: Construction of Māori Woman*, MA thesis, University of Auckland, Auckland.
- Pihama, L. (1994) "Are films dangerous? A Māori woman's perspective on The Piano" Hecate, 20(2):239.
- Pyett, P. (2002) "Working together to reduce health inequalities: Reflections on a collaborative participatory approach to health research" *Australian and New Zealand Journal of Public Health*, 26:332-336.
- Royal-Tangaere, A. (1997) "Māori human development learning theory" in P. Te Whaiti, M. McCarthy and A. Durie (eds.) *Mai i Rangiatea: Māori Wellbeing and Development*, Auckland University Press / Bridget Williams Books, Auckland.
- Shirres, M. (1997) Te Tangata: The Human Person, Accent Publications, Auckland.
- Smith, G. (1993) "Tane-nui-a-Rangi's legacy...propping up the sky: Kaupapa Māori as resistance and intervention" presented at the NZARE/AARE Joint Conference, Deakin University, Australia.
- Smith, G. and L. Pihama (1995) *Kaupapa Māori Lecture Series*, Education Department, University of Auckland, Auckland.
- Smith, L. (1999) *Decolonizing Methodologies: Research and Indigenous Peoples,* Zed Books Ltd, New York.
- Spoonley, P. (2003) "The challenge of cross cultural research" in C. Davidson and M. Tolich (eds.) Social Science Research in New Zealand: Many Paths to Understanding, Pearson, Auckland.
- Stokes, E. (1992) "Māori research and development" in M. Hohepa and G. Smith (eds.) The Issue of Research and Māori, Research Unit for Māori Education, University of Auckland.
- Walker, R. (1990) Ka Whawhai Tonu Matou: Struggle Without End, Penguin Books, Auckland.