THE SIDS CARE-WORKERS STUDY:
PERCEPTIONS OF THE EXPERIENCE OF MĀORI SIDS FAMILIES

Tim McCreanor
Whariki Research Group
Massey University, Auckland[1]

David Tipene Leach
Sally Abel
National Māori SIDS Prevention Unit
University of Auckland

Abstract

Sudden Infant Death Syndrome (SIDS) continues as a significant cause of death of infants, particularly among Māori. While much attention has been focused through biomedical research on causation, little attention has been paid to the social and contextual issues surrounding these tragedies and their consequences among families. This paper reports on a qualitative scoping study with members of the national Māori SIDS Prevention Unit, drawing upon their cumulative knowledge and expertise to shed light on the fraught interfaces between families and institutions that follow SIDS. A thematic analysis presents the main issues, and the discussion considers their significance for the grieving of the bereaved parents, and the social practices of service institutions that deal with SIDS.

INTRODUCTION

In New Zealand, research on Sudden Infant Death Syndrome (SIDS) has concentrated on the quantitative analysis of data from the New Zealand Cot Death Study, a case control study that measured the risk associated with certain parental behaviours and characteristics of the social situation or family environment. There is as yet no published research in New Zealand that explores, in a qualitative fashion, the experience that SIDS families endure. This paper reports on an exploratory process that was undertaken in order to delineate the important issues that might be relevant in proposed subsequent interviewing of families for an in-depth study on the experiences and perceptions of grief among Māori SIDS families. Its findings were such that we felt it was deserving of publication in its own right and would address, in some small way, the absence of such studies in the literature.

---

1   **Correspondence**
    Tim McCreanor, email: t.n.mccreanor@massey.ac.nz

BACKGROUND

In the early 1980s New Zealand had a higher rate of SIDS than other comparable Western countries (Mitchell 1990). A Cot Death Study from 1987 to 1990 identified a number of risk factors and a national SIDS prevention programme followed in 1991. The campaign significantly decreased the national SIDS rates but Māori SIDS rates decreased only minimally (Mitchell et al. 1994). Subsequently, the Public Health Commission funded a Māori-specific SIDS prevention coordinator who, with a Māori public health physician (David Tipene Leach), consulted extensively in Māori communities about the experiences of SIDS families in order to develop an appropriate health promotion programme. Māori SIDS rates have fallen steadily during the period following the implementation of the programme (New Zealand Health Information Service 2004), but Māori deaths are currently six times the Pākehā rate and the loss of Māori babies to this condition remains as part of the bleak catalogue of indicators of Māori health disparities (Ajwani et al. 2003).

The grief within these Māori families seemed inextricably entwined with the social conditions of the community, and criticism was voiced about the way in which families were dealt with by professional services and the lack of support they received. The trauma of post-mortem examination came in for particular scrutiny (Tipene Leach et al. 2000b).

In the development of the Māori SIDS programme, the need for dedicated SIDS care-workers quickly became clear. Māori women with strong iwi networks and the ability to work well with local health services were employed to cover defined geographical regions throughout the country, the first ones beginning in 1996. These care-workers provided education, training and resources to a range of child health care providers and Māori community health workers alongside the development of the health promotion programme. Making use of their special involvement in the community, their role was soon extended to include case work; that is, the support of Māori families in the throes of a SIDS death and during the months that followed it (Tipene Leach et al. 2000b).

In 1996/97, a parallel but independent programme was funded to service SIDS issues in the Pacific community and the Māori and Pacific SIDS Coordinators worked side by side. The Pacific programme, however, was unable to provide dedicated full-time care-workers because the lower SIDS rates in these communities attracted far less funding. The large number of Pacific ethnic groups and their multiple language needs saw the development of a team of part-time Pacific SIDS educators from a number of Pacific communities and a less comprehensive ability to attend to the acute needs of bereaved families.

The close involvement with SIDS families by the care-workers led to an acutely attuned awareness of the context of events around a SIDS death from the perspective of the parents. In the care-workers' assessment, there was a need for better coordination of the agencies that respond to SIDS deaths, and for greater cultural sensitivity in the highly forensic coronial investigation process. They also highlighted the difficult social and economic circumstances of these families (Tipene Leach et al. 2000a).

Recognition of the importance of sound research for effective advocacy led the Māori and Pacific SIDS teams into the New Zealand SIDS Study Group, a multi-centre team investigating the feasibility of a second New Zealand SIDS case control study. This project included a qualitative study of Māori, Pacific and Pākehā infant care practices (Abel et al. 2001) and the development of a set of best practice guidelines for SIDS death scene investigation, including autopsy protocols for infants. In addition, a study of Māori families' experiences of grief following a SIDS death was developed. This included a preliminary protocol that would delineate the likely issues surrounding SIDS families and add a client safety aspect to the interviewing. This involved a single focus group with members of the Māori and Pacific SIDS teams that encompassed a range of topics concerning the impacts of SIDS and its sequelae on parents and families. This paper reports on key outcomes of this latter process.

METHODOLOGICAL APPROACH AND RATIONALE

This study used a standard focus group methodology (Wilkinson 1998) to gather data from the participants.[2] The participants, all women, were drawn from the Māori and the Pacific SIDS programmes: three Māori women and one Pākehā woman from the Māori SIDS prevention programme, and a Tongan woman and a Samoan woman from the Pacific programme. The inclusion of Pacific SIDS workers in a process scoping the situation for Māori families was an effort to approach the topic in a less insular fashion.

The workers from the Māori programme were the most experienced. Two had three years, one had six years and one had more than 10 years of field experience, mostly with the families of Māori babies who died unexpectedly. As such they had been witness to the aftermath of over 100 Māori SIDS deaths and so had an enormous wealth of knowledge to draw upon.

---

2   Focus groups are an increasingly utilised data-gathering method in the social sciences and are widely used in the area of health research (Carey 1995). They are a recommended tool for exploratory research for scoping new research areas, and for providing richness and depth to such investigations (Wilkinson 1998) and are therefore particularly appropriate to this study. They are especially valuable to social action research for the grounding of projects in participants' experience, giving voice to otherwise marginalised knowledge (Fine 1992) and promoting social change (Johnstone 1996).

We regarded these six workers as key informants on the topic of SIDS grief and the complex of pressures and tensions that pervade the lives of those who experience the unexplained death of an infant. The agreement of these care-workers to be interviewed allowed the researchers on the subsequent Māori SIDS Grief Study to approach, albeit from a distance, the experience of the bereaved family in an ethical but thoroughly authentic manner.

The data collection was mutually agreed to and arranged by the participants and was facilitated by Dr Louise Webster, a psychiatrist attached to the broader SIDS Research Project. The session itself was conducted in the workplace of the Māori and Pacific SIDS Prevention Programme teams and took the form of an extended group discussion, with Dr Webster putting only the occasional prompt for clarification or continuity. The session was not time limited and ran out at approximately three hours of recorded data. These were transcribed verbatim and checked with the participants, and so constituted the database for the project.

DATA AND ANALYSIS

The database consists of the audiotape of the interview and the transcript. A technique called discourse analysis (Potter and Wetherell 1987, Wetherell et al. 2001) which has evolved within social psychology, was used to evaluate and describe these data. Discourse analysis is based upon multiple, detailed readings of the body of data in order to develop a systematic and comprehensive description of the patterns and variations in the talk on a topic, and the ways in which language is deployed to establish and defend various discursive positions (McCreanor 1996, McCreanor and Nairn 2002).

This style of analysis evolves through awareness of the interpretative resources drawn upon for the description of the diverse themes that are used in the transcript. Verbatim texts or sections of text that use such themes (at first rather loosely defined) are collated into files. The patterns of ideas, images, linguistic and rhetorical forms are clarified by further intensive reading of the files, allowing the researcher to describe and illustrate the content and function of the themes and their facets (McCreanor and Nairn 2002).

Like other forms of qualitative research, discourse analysis operates outside of the protective cloak of objectivity. The selections, interpretations and descriptions the researcher makes in working with data of the kind available here depend upon the sensitivity, experience and orientation of the researcher (Patton 1990, Taylor 2001). The rigour and discipline involved are complemented by an openness of reporting, which allows readers to judge for themselves the appropriateness of the descriptions that emerge. Unfortunately, limitations of space mean that only illustrative segments of text can be made available in this context, but we note that each of the themes described here was drawn from coded material running to several pages of data.

The five themes presented here are descriptions of participants' talk around the topics they covered in the discussion. Each is a distillation and a collage of the actual usages in the data coded from the focus group transcript, and a construction in the sense that participants do not speak the forms or necessarily even the terms of the various outlines. The inclusion of illustrative quotes from the data is intended to give a feel for the natural forms in which the participants represented their ideas.

The Process Around Grieving

Although issues are recognised to be different for care-workers and families, process was seen to be crucial to grief outcomes for those experiencing a SIDS death. For families, the period immediately following the death was one of sensitivity and vulnerability in which experiences were heightened in a nightmare-like fashion, and pressures around incidents were greatly enlarged.

> "I think that working in this job you realise that the point when a child dies... for the family everything suddenly magnifies, it's huge and even as a worker you have this … you know that when you go in there you're going to make an impression on this family's life forever, they're gonna remember you." (Māori SIDS care-worker)

Participants indicated that in such contexts, a seemingly minor or mundane action or comment was able to take on a profound significance and have enormous impact.

A fundamental need for the bereaved was to be able to set aside the questions and feelings of guilt that attach to unexplained death in order to be able to talk, to weep, to express emotion and to let the grief run its course.

> "So sometimes they just need to talk … it's one of the main things … until you come out with it you know … well they can feel it I suppose... and they open up and they cry and then I feel good and sometimes I cry with them." (Pacific SIDS worker)

To achieve this, supportive partners and family were crucial. SIDS care-workers felt that they provided a more independent and detached support that could also be useful.

In many instances the bereaved expressed to the SIDS care-workers that they felt guilty. The loss for mothers was often described as a physical ache, consistent with the carrying and the bearing of the child, and the physical holding of the infant's body became an important part of coming to terms with the death. Care-workers commented that unreconciled grief was sometimes manifest in behaviour such as fixation on the dead child's clothes or bedding, talking as if the baby was still alive, or carrying items related to the baby. The sense of loss and of the baby as a person in its own right

frequently persisted in the long term. Although well-meaning family, friends and often partners might see it as such, the idea of "replacement" of the baby with another child was not immediately comforting.

SIDS care-workers were committed to facilitating normal, healthy grieving in this inherently abnormal situation, often acting as a buffer between the family and various institutions. Following the leads of the bereaved, they at one time both support the family and encourage an appropriate grieving process.

> "As workers we want to stop the hurt, we don't want to hinder their grief process and all that other stuff, psychological gobbledegook as D said once, we just wanna help and we just wanna stop the hurt." (Mäori SIDS care-worker)

This involves the workers in listening to the family and answering questions as fully and openly as possible. There was often a need to alleviate the sense of guilt that could distract the bereaved from grieving. Working in groups and teams offered the possibility of matching workers and the bereaved families, thereby improving communication and supporting the facilitation of the process.

The Cultural Context

The cultural context in which SIDS occurs had diverse positive and negative impacts on grieving processes for bereaved families. For example, extended Māori and Pacific family offered resources, the support of relatives and elders, culturally focused explanations and might even lay blame for the death.

> "It's like the Pacific culture and Mäori culture, we believe that things that we do in the past come back to haunt you by way of your children, or otherwise … and I don't not believe that, as westernised or colonised as I am, I don't not believe that that there are things that come back from the past and events like this when you have unexplained deaths … these are just classic avenues when you can start to place some of the outcomes of your actions in the past, it happens … we call it *mate Mäori*." (Mäori SIDS care-worker)

Such close-knit family structures could facilitate the spread of rumour and distortion, but could also provide access to power hierarchies, laying speculation to rest. This contrast was illustrated when culture was described both as a storehouse of remembered feud and curse, and a source of atonement and defusing of tensions.

In culturally mixed marriages the already complex situation was intensified with many new sources of misunderstanding, from simple language barriers to differing cultural practices, which emerge to interfere with healthy grieving processes.

> "And it was like when you make your bed you lie in it. Any problems arise from this union we will forever remind you. So a baby's death from that kind of union you see, I told you not to marry that Samoan. And what would the Samoans say? I suppose you shouldn't have married the Cook Islander." (Pacific SIDS worker)

Interlocking socio-economic dimensions also had a major impact. Poverty might entail anything from substandard dwellings, to the shame of being unable to afford funeral costs.

Police Actions

The behaviour of the police was identified as a major influence on outcomes for families dealing with SIDS. The police were involved because SIDS – by definition unexplained death – inevitably required a police response. Because they were among the first to respond to the situation, they tended to arrive when turmoil and distress were very high for the bereaved. The care-workers said that unless the police behaved with exceptional sensitivity, there were many points at which their activities could have a profound negative impact. They were always in danger of being seen as blaming or judgemental, so over-reaction to the call-out, pursuing peripheral or irrelevant inquiries on the scene and explaining the need for autopsy in terms of implied guilt on the part of parents were examples of behaviours that needed to be avoided.[3]

> "In one instance, the police went in and said to the family – in no way related to the death of the baby – but said to the father, 'Well how long have you been in a gang?' And the father was dealing with the shock of his child having died and then the shock of his child being taken from the house. He said to the police, 'What has that got, what has that got to do with anything?' [The police officer] said, 'Because we want to know, we want to know sonny'." (Māori SIDS care-worker)

The care-workers found that the particular vulnerability of the bereaved at this stage of grief meant that seemingly minor inputs could be devastating and leave ongoing or unresolved issues with parents for the rest of their lives. Responding police officers needed to be mature and aware of the cultural and psychological aspects of the situation. However, in the SIDS care-workers' experience, many officers did not have these qualities (some young officers were described as "terrified") and they were unable to deal adequately with the situations they faced in cot death cases.

---

3   The Police have since developed a partnership protocol "Mate Tarāwhare", which includes a set of operational procedures for dealing with all deaths of tangata whenua.

> "By not sending older police officers [we get] a lot of comments from the families that he or she was a young police officer … there aren't any Mäori police officers around are there you know … I just remembered [an example] where the family asked about an autopsy and that and the officer said – it's so we know that you didn't poison your baby … and you know those kind of comments stick in their heads … Oh my God they think I poisoned my baby." (Mäori SIDS care-worker)

In this highly charged context, the care-workers found that the responding police officer could either ameliorate the difficulties or worsen them. One very positive example was given of an officer who offered simple and genuine support as he carried out his investigations. His task may have been made easier by the content of his message, which settled the cause of death as accidental.

The Post-Mortem

The process of autopsy is of great significance and impact and it can be either constructive or destructive. While it is true that the autopsy findings can be a relief to families, the uncertainty, alongside the unfamiliarity and unpleasantness of the forensic protocols, can cause extreme distress.

> "Yeah I think that a lot of people question why does my baby have to have an autopsy but I think when they don't know and they are given information like they can actually determine why baby passed away, it starts to clear a little bit … the fear is more how baby will come back from the post-mortem." (Mäori SIDS care-worker)

This is particularly so for Māori where remaining with the body at all times is central to the protocol of tangi (funeral). The mandatory removal of the body (sometimes without appropriate ceremony or respect) for an undefined period to unfamiliar premises for unknown practices to be carried out to establish cause of death is extremely difficult. Care-workers have recommended a system where better contact with the body could be maintained and better liaison established between families and authorities involved in the autopsy.

Poor process on the part of officials could be disastrous, resulting in perceptions such as the autopsy being about establishing parental guilt. Good process, on the other hand, made the outcomes valuable for families by dispelling fear and uncertainty, thereby facilitating the grieving process.

> "There is one thing that I have noticed with some of the families that I have supported that if there is an inquest hanging over this baby's death … often families are not given a date of when the actual inquest is going to be … there is not very much description of what [post-mortem] really is and the process and prolonged fear of being found guilty has a big impact I think." (Mäori SIDS care-worker)

Fathers

The role and experience of men in SIDS cases prompted many questions from these female SIDS care-workers. While they felt that they could reach bereaved women, men presented an enormous problems. The gender difference meant that men often behaved in ways that were hard for loved ones to understand, negative for families and sometimes self-destructive. In particular, the younger, less mature fathers who had less power, status, financial security and self-worth, and fewer life skills, had limited capacity to provide for the family in this demanding situation. The problems for such bereaved fathers were often complicated by involvement with drugs and alcohol, and with attendant violence, crime and sometimes imprisonment.

> "You get them drinking, not able to deal with anger, expressing their grief by beating up their wife." (Pacific SIDS worker)

Such difficulties aside, men were perceived to have very different styles of grieving from women, and diverse patterns were also observed within the gender.

> "A society it has certain expectations of male and female roles and from my experience it's been that the father is just as lost as the mum but trying very much to have the stiff upper lip and kind of look after and take care of business." (Mäori SIDS care-worker)

Men were seen to have difficulty in expressing their feelings and experiences, which they internalised. The resultant turmoil emerged as anger or violence (sometimes directed at their partner or family), stoic pragmatism (for example, supporting their partner, caring for the children but not dealing with their own pain), bewildered questioning of their role in the death, or combinations of the above.

These behaviours were seen to arise from male socialisation, social expectations, an alienation from mother and child (not having "carried the baby") and lack of supportive networks.

"I find that if my dad or my uncle comes with me the men relax because there is a male that they can talk to and the connections happen … they may know my family or they may have been to school with one of their kids or they went to the freezing works together … and that starts to work and where my dad or my uncle can sit there and talk with the men, if that's what the men want to do … and normally my dad will get out information that I know I wouldn't be able to." (Mäori SIDS care-worker)

It seems that having male SIDS care-workers makes a crucial difference to outcomes for men, a fact that our informants (all women) were at a loss to explain beyond assertions that men needed to develop their own awareness as to exactly what would be most useful for them. This resulted in a challenge to men working in the area to focus on developing strategies to fill the gap.

DISCUSSION

As SIDS care-workers in a mainly Māori context, the participants in this study present a particular set of viewpoints. They spoke from the perspective of those whose primary responsibilities lie with the bereaved family. They spoke, as it were, for the family; they were their advocates. They did not, for example, speak as priests, police, coroners or ambulance staff, but rather, about them and their behaviour in this particular context.

The commonalities of experiences and issues faced by this group of SIDS care-workers, and by implication, SIDS families, have been revealed. This new body of "legitimised knowledge" has greatly informed the practices and policies of the Māori SIDS Prevention team in its responses to families in the field, in the nature and direction of its national advocacy with other occupational groups involved in the death scene and in the training programmes it provides for other health workers. The information has also been made available to SIDS parents, thereby reducing the sense of isolation and distress that arises for a family feeling that they alone have endured the despair and chaos of the SIDS death.

The main themes discussed were extremely useful in the stated objective of informing the subsequent in-depth qualitative Māori SIDS Grief Study (Edwards et al. in press). Māori researchers without field experience in SIDS were able, by these insights, to approach highly sensitive areas with some degree of sensitivity and safety. In addition, the ongoing analyses in the Māori SIDS Grief Study (Clarke et al. forthcoming), have been strongly shaped by the insights generated from the analyses reported in this exploratory project. However, in the context of the skeletal nature of study, the small size and spread of the sample of informants and the limitation of the topic to "grief in SIDS", the findings call for further research into discourses on the topic.

The five themes by no means exhaustively cover the diversity and complexity of the topic being explored. In part this is because a generalising, reductionist approach drives this stage of discourse analysis. Later stages can use findings such as these as aids to analysis of further examples of text on the topic, highlighting the variations and distinctions that are gathered together in the search for pattern here. Although mindful of these limitations, we suggest that for the data available, the themes described amount to a significant proportion of the discursive resources available for talk on the topic of grieving in SIDS. We argue that they raise important issues on a number of different levels, within the broad concern about grieving the loss of a baby to SIDS.

At the human level of the needs of the bereaved parents, the findings assert the value of supportive families in facilitating and encompassing the extreme emotion and behaviour that comes with this form of loss. In the absence of such support, and in acknowledgement of the overwhelming disempowerment engendered by the forensic process, the data strongly endorse the importance of outside support of the kind provided by the Māori SIDS care-workers.

There are other striking features, such as the inability of many fathers to cope with the loss of a baby to SIDS, as illustrated by their physical or emotional absence. It is also clear that guilt in its many and diverse forms plays a central role in the unwinding of people's grief at the death of a baby.

In cultural terms our participants repeatedly emphasised the different ways of coping they had observed in different cultural groups and argued the need to allow and develop these culturally appropriate expressions. The stark reality is that these differences are manifested as the tangi collides with the post-mortem, and the needs of crime detection challenge the practices of awhi and manaakitanga (cherishing and kindness).

Finally, this small study has implications for the institutional and statutory processes and functionaries who impact upon the grief that attends a SIDS death. The participants identified that the agendas, protocols and practices of the external agencies are frequently ad hoc, rigid, callous, suspicious and blaming. When carried out by personnel with inadequate training, sensitivity or caring, the added distress was seen to impact on the grieving processes of the bereaved in the years that followed. In that they represent at least one side of several significant issues that relate to a sensitive death scene environment, these themes could usefully facilitate dialogue with various agencies and authorities in order to improve practice and service.

More extensive enquiry would doubtless reveal diverse new dimensions not raised here. Nevertheless we note that this small exploratory study, in utilising the qualitative focus group methodology and a discourse analysis, has provided useful insights into

this distressing phenomenon, forewarned the Māori SIDS Grief Study researchers of substantive issues to be faced, highlighted new and marginalised knowledge from a hitherto little acknowledged group of workers, and lent credibility to the discounted experiential understandings available from parents. Such work is at once a way of understanding existing practices and of searching out or foregrounding possible improvements, not only in relation to grief, but also to our knowledge of the SIDS phenomenon as a whole.

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.

Carey, Martha Ann (ed.) (1995) *Issues and Applications of Focus Groups, Special Issue Qualitative Health Research*, 5(4).

Clarke, E., T. McCreanor and R. Haretuku (forthcoming) *The Māori SIDS Grief Study*, Tomaiora, University of Auckland, Auckland.

Edwards, S., V. McManus and T. McCreanor (forthcoming) "Collaborative research with Māori on sensitive issues: The application of tikanga and kaupapa in research around Māori Sudden Infant Death Syndrome (SIDS)" *Social Policy Journal of New Zealand*.

Fine, M. (1992) "Passion, power and politics: Feminist research possibilities" in M. Fine (ed.) *Disruptive Voices: The Possibilities of Feminist Research*, University of Michigan Press, Ann Arbor.

Johnstone, A. (1996) "'It's good to talk': The focus group and the sociological imagination" *Sociological Review*, 44(3):517-538.

McCreanor, T. (1996) "'Why strengthen the city wall when the enemy has poisoned the well?': An assay of anti-homosexual discourse in New Zealand" *Journal of Homosexuality*, 31(4):75-106.

McCreanor, T. and R. Nairn (2002) "Tauiwi general practitioners' explanations of Māori health: Colonial relations in primary healthcare in Aotearoa / New Zealand?" *Journal of Health Psychology*, 7(5):509-518.

Mitchell, E.A. (1990) "International trends in post-neonatal mortality" *Archives of Disease in Childhood*, 65:607-9.

Mitchell, E.A., J.M. Brunt and C. Everard (1994) "Reduction in mortality from sudden infant death syndrome in New Zealand: 1986-92" *Archives of Disease in Childhood*, 70:291-4.

New Zealand Health Information Service (2004) *Fetal and Infant Deaths 2000*, Ministry of Health, Wellington.

Patton, M.Q. (1990) *Qualitative Evaluation and Research Methods*, 2nd edition, Sage Publications, Newbury Park, California.

Potter, J. and M. Wetherell (1987) *Discourse and Social Psychology*, Sage, London.

Taylor, S. (2001) "Locating and conducting discourse analytic research" in M. Wetherell, S. Taylor and S.J. Yates (eds.) *Discourse as Data: A Guide for Analysis*, Sage, London.

Tipene Leach, D., S. Abel, C. Everard and R. Haretuku (2000a) "Reorienting family services: The professional response to sudden unexpected deaths in infancy – issues and protocols" *Social Policy Journal of New Zealand*, 15:27-40.

Tipene Leach, D., S. Abel, R. Haretuku and C. Everard (2000b) "The Māori SIDS Prevention Programme: Challenges and implications for Māori health service development" *Social Policy Journal of New Zealand*, 14:65-77.

Wetherell, M., S. Taylor and S.J. Yates (eds.) (2001) *Discourse as Data: A Guide for Analysis*, Sage, London.

Wilkinson, S. (1998) "Focus group methodology: A review" *International Journal of Social Research Methodology*, 1(3):181-203.