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Editorial

The Cultural Sensitivity of Grounded Theory

Fall 2000

Recently, I have received several nice articles, all using grounded theory. These were international submissions—which I welcome—and the research in these articles was conducted in various places: Taiwan, Hong Kong, Sweden, Turkey. The topics for these studies were typically suited to grounded theory: responses of parents of terminally ill children, of those recovering from breast cancer, and so forth.

But as I was reading these studies, I was struck by the total absence of any description of culture. These studies could have been conducted right here in Alberta, Canada.

I do not have any answers, but because this is a very important matter that will not go away, questions keep forming. Perhaps by voicing these concerns, a methodologist somewhere will be able to modify our methods or researchers will modify their focus and return the cultural context to our work.

Where is culture?

• Is grounded theory, as a method, insensitive to cultural nuances and description?
• Does grounded theory enable the researcher to get to the core of the human experience, describing something that lies beneath the veneer of culture?
• Or does grounded theory, as a method, ignore (and simply not report) cultural dimensions of experience? By not providing the researcher with strategies to elicit cultural description, are cultural nuances omitted? Does this mean that by using grounded theory, we could conduct a cross-cultural study and elicit emotional responses common to and consistent with all cultures? Basically, we would be describing the essence of being human.
• When I use grounded theory, where am I describing my culture? Am I being ethnocentric, demanding cultural description from others and not providing it myself?

My anthropological training emerges, and my editor’s hat feels tight. I return the articles to the authors for revision.

January 2001

I continue to worry about grounded theory and culture as a predoctoral student, Betty Wills, begins planning her dissertation. She has chosen to use grounded theory to explore elderly Chinese immigrants’ experiences in seeking health care. To overcome my worries, we have developed a design that incorporates ethnographic strategies to elicit supplemental information about culture into the grounded theory. From this distance, it appears that it will work. We present it at the February
2001 *Advances in Qualitative Methods Conference* (Wills & Morse, 2001). It did not raise any hackles.

**June 2001**

I find a stunning article in *Health Care for Women International* describing American Muslims’ experiences (see Hassouneh-Phillips, 2001). Culture has not been sanitized from the experience; rather, it is there providing explanation, just as I think it should—there is even a category “Getting *Khula*.”

And I realized the problem. At one point, Glaser (1978) said, “I can tell you if it is grounded theory by looking at the categories” (p. 6). If grounded theory has category labels that explain the identified processes, then they should be used. Once a process is labeled, then the label must be used. But if the process has not been labeled, then the limitation imposed by the selection available forces the theory into an ethnocentric mold. It is the method, or our interpretation of how the methods should be used, that has been ethnocentric.

Use additional ethnographic strategies if you wish. The real power of the method lies with the researcher, not the method, not the strategies. It is the researcher’s ability to sensitively perceive and conceptualize, balancing the grounding in the literature, the data, and the cultural context, that ultimately produces an excellent study.

JANICE M. MORSE  
Editor

**REFERENCES**

Letters to the Editor

To the Editor:

Reflections on Deconstructing Harry,
or When Is Good Art Bad Science?

Having sat through the Brad Trilogy and its aftermath at the recent Advances in Qualitative Methods Conference sponsored by the International Institute for Qualitative Methodology, we remain troubled by what unfolded. As a piece of art, the Brad Trilogy has considerable merit: It is a strong dramatic piece about the tragedy of a love relationship between Harry, a “researcher” (quotes used intentionally), and Brad, a young man who has taken up residence on the property of the researcher. What is presented is the moral demise of both characters, for quite different reasons. What began as an intimate relationship and developed into a quasi-case study ended in a violent scene in which the researcher’s home is burned to the ground. Brad sinks into the world of forensic psychiatry, and the academic researcher feels hurt and betrayed, stating he “can only feel safe when Brad is in jail.” The author (Johnny Saldana) and Harry Wolcott, on whose writing the play is based, view the play as explicating an issue of queer politics, period. They do not, apparently, see anything problematic in presenting the play’s content as research.

Like many other researchers attending the recent Advances in Qualitative Methods Conference in Edmonton, Canada, at which the play was presented, we view the play somewhat differently. What we experienced is a descriptive presentation of some unexamined, unethical behavior on the part of Dr. Wolcott that is being passed off as research. Apparently, for Wolcott there is nothing wrong with

- sleeping with a research participant (regardless of who initiated it) or
- identifying as a case study participant an individual who is 20 to 30 years younger and dependent on Wolcott’s largesse for his very survival. Brad is someone (a) with whom Wolcott has a preexisting sexual relationship, (b) who is given money “for doing chores” and in compensation for interviews, and (c) whom Wolcott allows to camp out on his property (what does this also say about the validity of the data or the findings?).

In the play, Brad is presented as a slick, seductive predator, whereas Wolcott is the victim of this drama. Nowhere, either in the play itself or in the public discussions with Wolcott, is there an acknowledgement that there might have been something wrong in his own judgment or use of power. This is contrary to the widely accepted codes of ethics for research. For example, the American Anthropological Association Code of Ethics (Wolcott is an anthropologist) dictates that an anthropologist has an obligation to “avoid harm or wrong, understanding that the development of knowledge can lead to change which may be positive or negative for the people . . . studied” and to work toward a goal “of establishing a working relation-
ship that can be beneficial to all parties involved.” It is difficult to see how this relationship could even be construed as beneficial to Brad. On the contrary, we would argue that it was exploitative and that in allowing this production to be presented, Wolcott continues to benefit.

Now, Wolcott has made a significant and valuable contribution to the literature and knowledge about education in North America. Does this unethical behavior diminish that contribution? Heidegger’s contribution to inquiry is still respected in spite of the fact he was an avowed Nazi collaborator. Few would doubt Heidegger’s scholarship. We would argue that the situation is not paralleled by Wolcott in that rather than distancing himself from his mistake, he continues to repeat it by exploiting Brad through presentation of this drama. Would Heidegger, were he alive today, publicly and repeatedly support a dramatic presentation of his heroic role in Hitler’s Germany? Would we as researchers tolerate such behavior?

Finally, we are concerned that the Brad Trilogy was even presented at the International Institute for Qualitative Methodology Advances in Qualitative Methodology Conference. Such conferences are important public venues for the dissemination of theory, debate of methodology and methods, and discussion of ethical issues in research. By not preplanning a critical debate to accompany the presentation of the Brad Trilogy, we believe that the conference organizers inadvertently sanctioned Wolcott’s actions as a researcher. We are not against freedom of artistic expression, but we want to point out that the Brad Trilogy was profiled as an exemplar of “ethnodrama.” Surely codes of research ethics apply to ethnodrama just as much as they apply to other methodological ventures.

RITA SCHREIBER
PATRICIA (PADDY) RODNEY
HELEN BROWN
COLLEEN VARCOE
University of Victoria

EDITOR’S NOTE

A discussion period (preplanned) was held both after the Brad Trilogy and in a session the next day. Apart from the abstract, I did not preview the play prior to the conference (neither did I preview any another presentation) and would consider such vetting, feasibility issues aside, not as a form of review but of censorship. My role as conference coordinator is not to shield but rather to provide the forum and then to let such corrective discussions as this occur.

JANICE M. MORSE
Editor and Conference Coordinator

NOTE

1. Performance, “Finding My Place—The Brad Trilogy,” presented by Johnny Saldana, Lori Hager, David Vining, Charles Banaszewski, and Harry Wolcott on Friday, February 23, 2001, with discussions immediately following, and on Saturday, February 24, at the Second Advances in Qualitative Methods Conference, Edmonton, Alberta, Canada.
To the Editor:

Comments on the Brad Trilogy

This year, the annual conference hosted by the International Institute of Qualitative Methodology included an unusual ethnodrama and workshop. In this letter, we (two Ph.D. students from Sweden who participated in the conference) wish to communicate our experiences as drama spectators and workshop participants. The drama had its starting point in an article from 1983 by Professor Harry F. Wolcott, published in a journal for which he, at that time, was the editor. In collaboration with the author, Johnny Saldana had, for the conference, adapted this article to a play. Parts of the drama narrative can be found in the article. However, a central discrepancy between the drama and the article was the description of the relationship between a researcher and an informant (19 years old). It was the progress of their relationship into one of sexual and economic imbalance resulting in tragic consequences that constituted the intrigue in the drama. The play was professionally performed and was entertaining, but we had difficulties in identifying its scientific value. The article, on the other hand, is clearly focused on educational matters, and to us, it seems to be serving its scientific purpose well.

With this contribution, we want to discuss some ethical issues related to qualitative research. The workshop that followed up the drama the next day was rather short, so only a few persons got the opportunity to speak up. Upon Janice Morse’s request, we therefore communicate our views with an invitation to a broad discussion among senior and junior qualitative researchers.

AT THE PLAY

In the conference program, the purposes of the project were declared as follows: (a) to recognize the contribution of the trilogy to ethnography and the anthropological life history and (b) to experiment with research representation of previously published work.

On entering the room in which the play was presented, we received a program in which the primary ambitions of the drama were expressed as providing an experience that was “enlightening and entertaining and arriving at a new or deeper understanding of human social life.” The program also warned that the performance contained “smoking, profanity, and graphic sexual images.” The drama was going to tell a true story from the private life of a senior researcher attending the conference. The article, which the drama was based on, was not fully cited in the program text. Maybe researchers from North America were aware of the Wolcott story, but we were not.

We have to admit that from our perspective, the drama producers reached some of their goals. If it had been an ordinary play, the action on stage would have been
elegant and clever. We now know more about tragedies in human social life than before. However, as Ph.D. students, we also need guidelines for how to perform good qualitative research and examples of high-quality science in general.

ABSENCE OF CRITICAL ETHICAL QUESTIONS

Research ethics were never discussed by those responsible for the play, neither during the drama session nor at the workshop. However, ethics still became the central theme for the discussion that took place at the workshop the following day. Note that it was the spectators who turned the discussion in that direction. At the workshop, we would have appreciated a discussion by the drama producers of their ethical responsibility during the collection of data and the preparation and presentation of the play and, thereafter, a discussion of what it involves to turn facts into fiction in a scientific sense. In fact, without this discussion, the drama had no real purpose being part of a qualitative methodology conference. The conference would have been better served if the drama had been framed explicitly so as to raise fundamental ethical questions. Bringing up these questions would have helped us to relate our experiences to science. This not having been done, we were left with our ambivalence regarding whether this ethnodrama met the ethical demands to the degree one would expect of a contribution to a conference on qualitative methods.

RESEARCH, THERAPY . . . OR MARKETING?

In most professions, there is an ethical code that each professional is supposed to follow. According to most or all of these codes, professionals must not have a sexual relationship with an informant or client, and if they have, they are supposed to conclude the professional relationship. In Sweden, we also have restrictions when it comes to economic transactions. We assume that in research settings, no monetary gifts, which may be mistaken for bribes, are exchanged. Still, of course, the informant should be reimbursed for any expenses he or she has paid. We do not believe that there exist totally different interpretations of what constitutes ethical behavior among scientists throughout the world. Therefore, we assume that the senior researchers involved in the production of the ethnodrama were well aware of the ethical issues involved. Taking this line of reasoning further, we are unable to avoid the suspicion that there was a hidden agenda defined for the drama sessions at the conference beyond reaching “a new or deeper understanding of human social life.” What the agenda contained can only be a matter of speculation. We offer here some “sneaky” possibilities: The sessions were part of a marketing ability test of the drama, the drama was arranged as collective therapy sessions for the research community involved, or the sessions were a marketing arrangement for recently released publications.

At this time, we find any of these alternatives just as possible, credible, and comprehensible as the motives provided in the drama and conference programs. Accordingly, we feel uneasy about the way the audience might have been used for
the above alternative purposes, and we feel uneasy about the prospect of belonging to a community that seems to tolerate oppression in the name of science. However, we do appreciate that Wolcott was attending the conference after the drama and that he took part in the discussions with upset conference participants.

MARLENE OCKANDER
GUNNEL ÖSTLUND
Social Medicine and Public Health Science
Linköping University, Sweden

REFERENCE

Working With Women’s Groups to Promote Health in the Community Using the Health Analysis and Action Cycle Within Nepal

Marion Gibbon
Isabelle Cazottes

The Health Analysis and Action Cycle was conceived as an empowering approach that enables women to review their health and environmental situation. It considers health in its socioenvironmental context and does not focus only on the biomedical dimension. The women are able to consider their own beliefs surrounding health and illness in a nonthreatening way and to plan and take action for themselves. The approach was first developed for use in Nepal among literate women’s groups; later, a more visual approach was adapted from this for nonliterate groups. This second step was felt necessary due to the high level of illiteracy (75%) among women. This article will provide information on the steps involved in the Health Analysis and Action Cycle and some of the outcomes of this approach.

Nepal is a small country (140,797 sq km) that lies in the central Himalayas and is sandwiched between India and China. The population (19,143,000) (World Health Organization [WHO], 1993) is very unevenly distributed, with the most densely populated area being the lowland (Terai) along the border with India.

The population is composed of approximately 75 ethnic groups, and more than 30 languages are spoken in Nepal. Officially, Nepal is a Hindu kingdom; however, the country is characterized by religious diversity, with substantial Buddhist and Muslim minorities in certain areas. This study took place in the eastern hills of two districts (Dhankuta and Sankhuwasabha). However, the findings presented in this article focus on a Pelangma women’s group (Sankhuwasabha district).

In Nepal, female illiteracy is at 75%, whereas that of males is 55.5%. Over the past three decades, the male literacy rate has increased faster than the female one. Literacy levels in turn reflect the school enrollment ratio, with 36 girls for every 64 boys at primary school level. Enrollment rates decrease further for secondary and again for tertiary education (Shrtii Shakti, 1995).

There is a preponderance of males versus females, with the sex ratio being 105.4 males per 100 females (WHO, 1993), which can be accounted for by the exceptionally high maternal mortality rate of 515 per 100,000 live births (United Nations Children’s Fund, 1996). Life expectancy has increased but still remains very low at 52 years for males and 51 for females. This again underlies the disadvantage of being female in Nepal. The lower life expectancy of women is in opposition to the

AUTHORS’ NOTE: We would like to acknowledge the advice of Professors Ann Taket, Leroy White, and Rayah Feldman and the anonymous reviewers who helped prepare this article for publication.

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female biological advantage. Teenage brides are common and, therefore, so is teenage sex and pregnancy. The average age at first marriage for girls is 17.9 years, whereas the average age for first marriage among males is 21.5 years (WHO, 1993).

Women’s role in the procurement of water and fuel wood has a direct impact on their domestic workload. Lack of safe water and sanitation facilities plays a major role in ill health. In Nepal, 30% of urban areas and 75% of rural areas have no access to safe water. In terms of sanitation facilities, the situation is worse: 83% of urban areas and 100% of rural areas are without sanitation facilities (WHO, 1993). Health statistics in Nepal are among the worst-case scenario in Asia (see Table 1). There are a few pit latrines in the rural areas, but they are extremely rare. Health care provision is also limited. There are 2.4 hospital beds per 10,000 people, which is the lowest ratio in the South Asian region. The health budget was 4.6% of the total budget in the Eighth Plan period (1992-1997). Health is a neglected sector in Nepal, and the government does not appear to consider the health situation within the country as particularly important (Dixit, 1996). Justice (1996) stated, “Rural health facilities were generally understaffed, under-supplied, and under-utilized” (p. 9).

There is a lack of quality primary health care services. The health statistics of the country reflect the poor services offered. The infant mortality rate is 165 deaths per 1,000 live births (United Nations Children’s Fund, 1996). Many maternal and child deaths are preventable. Diarrheal disease is the biggest killer among children younger than age 5. Several studies depict a scenario of underuse of the existing health care services (Justice, 1996; Sigdel, 1998). Among the reasons suggested are paucity of medicines, inconvenient location of the health posts, and the rudeness of the medical personnel. Others comment on the lack of awareness surrounding health issues and health being a low priority for village people.

With such a poor situation within the government health sector, many organizations are considering how to improve the overall health situation of people at the local level, and it is for this reason that the study aimed to improve health by working with women’s groups. It was with this in mind that we set about developing an alternative model: a health action approach used with women’s groups, which we called the Health Analysis and Action Cycle (HAAC). We were also concerned with using an approach that involves the community, and therefore, we will look at what the term community means.

### TABLE 1: A Comparison of Development Statistics for Asia

<table>
<thead>
<tr>
<th>Country</th>
<th>IMR</th>
<th>U5MR</th>
<th>MMR</th>
<th>Primary School Completion Rates</th>
<th>Access to Safe (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nepal</td>
<td>107</td>
<td>165</td>
<td>850</td>
<td>27</td>
<td>37</td>
</tr>
<tr>
<td>Bangladesh</td>
<td>110</td>
<td>184</td>
<td>700</td>
<td>35</td>
<td>80</td>
</tr>
<tr>
<td>Bhutan</td>
<td>125</td>
<td>195</td>
<td>770</td>
<td>35</td>
<td>25</td>
</tr>
<tr>
<td>India</td>
<td>80</td>
<td>146</td>
<td>400</td>
<td>49</td>
<td>84</td>
</tr>
<tr>
<td>Maldives</td>
<td>38</td>
<td>55</td>
<td>400</td>
<td>95</td>
<td>50</td>
</tr>
<tr>
<td>Pakistan</td>
<td>113</td>
<td>162</td>
<td>500</td>
<td>50</td>
<td>64</td>
</tr>
<tr>
<td>Sri Lanka</td>
<td>19</td>
<td>35</td>
<td>50</td>
<td>89</td>
<td>67</td>
</tr>
</tbody>
</table>

NOTE: IMR = infant mortality rate; U5MR = Under 5 mortality rate; MMR = maternal mortality rate.
Community

Frequently, the word community is attached to participation. Stone (1986) saw “community participation” (p. 223) as a sound development strategy but one that rarely occurs in practice. Jewkes and Murcott (1998) argued that “experience supports the widely held belief that lay involvement in health decision-making is beneficial; that some forms of popular action can be very effective in promoting health” (p. 857). However, they also pointed out difficulties that donors and policy makers involved in the design of projects have with identifying people who are representative of the community. Another problem arises in the beginning of the participatory process in the establishment of community needs. Before needs analysis is carried out, the program planners have already defined the scope and content of the program and outlined budgets and job descriptions. Primary health care has defined community needs, which included the rhetoric of community participation. However, it is doubtful that any community would define its needs in the same ways as the program planners define them. “In the Nepal program, a high level of community involvement, a level that matches the highest ideals of participatory development is specified on paper” (Stone, 1986, p. 223). Stone went on to quote from a government paper that the village health committee “should identify the local health needs, mobilize local resources, design plans, carry out and evaluate them, and again, identifying further needs, continue the process as an indispensable part of village life” (p. 299).

We see communities as being diverse in terms of the people that make them up, but in the context of this article, we are also considering geographically based communities. Encouraging community participation has often been viewed as a possibility for bringing about change, although what is meant by the term change is often less clear.

Participation

Participation is often seen as central to development and has different meanings depending on the context. Oakely (1991) wrote that “in terms of thinking and practice about development, we are currently in the age of ‘participation’” (p. vii). Its meaning implies giving a voice to the underprivileged, and yet in reality, projects find that the elite groups still tend to dominate and improve their economic situation. In the weakest and poorest sectors of society, at best nothing changes and in some situations conditions worsen. Another factor in the use of the word participation is the notion of “democratic empowerment” (Chambers, 1994), which is meant to incorporate reversal or neutralization of domination and bring about liberation and freedom for all relationships. This is supposedly said to restore a proper balance of power between the government and the people. In the context of development, beneficiary involvement is thought to improve the quality of decisions and thereby increase the commitment to implementation.

Theories of participation in development have often depended on the popular approach of Freire’s (1976) work in education and the failure of the “blueprint” approach or “magic bullet.” Friere’s belief was that the exploited can and should be enabled to develop the capacity to analyze situations, identify, prioritize, and plan for action. Rifkin (1990) wrote of “levels of participation,” and Arnstein (1969) wrote
of a “ladder of participation.” Both these concepts consider levels of participation from a passive acceptance of benefits—that is, “they” participate in “our” project—to more active participation in the management of program activities, monitoring, and evaluation (see Table 2).

Although there is no single interpretation of the concept of community participation (Oakley, 1989), it is clear that initiatives involving resources and responsibilities from within the community are important. From this it follows that an organization cannot unilaterally decide that it is going to carry out a program based on community participation; the will for such a program must come from the community itself. The example used in this article will attempt to show the feasibility of this in practice. The research process involved the use of participatory action research (PAR), and we will now consider what this means.

### PAR

The distinction between PAR methods and other methods is a philosophical distinction (Tolley & Bentley, 1996) between the roles played by the researcher and the researched. In conventional empirical research, the two roles are distinct. The researcher defines the questions for the research and determines how data collection is to proceed. Both the research problem and the methodological tools are predetermined. The informants provide information but are seldom involved in the collection or analysis of data. In PAR, however, the outsiders (researchers) and insiders (respondents) are partners, sharing and learning together (Cornwall & Jewkes, 1995). In participatory rural appraisal (PRA), as noted by Chambers (1983), “outsiders are convenors, catalysts and facilitators” (p. 2).

PAR is a process in which the participatory researcher is able to help develop a research capacity in others. It is therefore essential for teaching and learning to
occur in this context. To enable these activities to take place, there has to be a balance between safety versus risk taking (Meulenberg-Buskens, 1996) and an atmosphere of critical reflection versus confidence building. The main mode of learning is experiential. PAR involves participants working together with facilitators as researchers who bring their own knowledge to the process. Facilitators need to be able to understand the dynamics of group processes and the ways to encourage visualization and critical self-awareness among the group. The ability to embrace error and to adapt and share without boundaries are some of the characteristics that facilitators need to have.

Outsiders and researchers can often persuade local people to give their time to answer questions and carry out different PRA activities, and it is mainly the researcher who will benefit. The villagers in the process may enjoy themselves and gain empowerment by discovering their own abilities and knowledge. However, it is important to consider the cost of local people’s time and the ethical consideration of unequal relationships. PAR methods and processes can engage people for long periods in intense activity. Often, these lead to expectations of future projects, especially where appraisal and planning are involved (Chambers, 1994). As Chambers stated,

Again and again, outsiders and outside agencies have been unable to respond, or have failed to honor their pledges. While this is not a new experience to most communities, and not peculiar to PRA, it remains an issue for serious concern and self-questioning among facilitators. (p. 10)

PAR is not without its own limitations, one of these being the process of writing up.

**Criticisms of PRA Approaches That Led to Participatory Appraisal of Needs and Development of Action**

PRA is derived from rapid rural appraisal (RRA). RRA is an extractive form of research that attempts to rapidly assess an environment for development of programs that are based on local needs. RRA has often been criticized because it does not go beyond appraisal to enable analysis, planning, prioritization of possible solutions, and finally a commitment to act. It has a good set of tools for data collection, but it does not always fully explore the issues and assess different options and choices for action. It tends to simplify and overlook the inherent problems in developing a plan of action. What does one do when there are conflicts of opinions or different parties pursuing their own interests? It is apparent that there is a need for a further step. Participatory Appraisal of Needs and Development of Action (PANDA) takes on these tensions by incorporating tools from management sciences and operational research. These methods have been seen to be useful in Belize, where the participatory and transparent nature of the techniques and the process facilitated learning.

The project aimed at helping the participants to visualize and structure the issues in terms of how they saw them, and ensuring that their main concerns were being aired. During the project, the incorporation of participative aids for decision-
making helped the participants to consolidate what they learnt about their problems with what feasible options they could explore. (White, 1994, p. 461)

PANDA and its associated methodologies are being increasingly used in the field of health (de Koning & Martin, 1996; Nichter, 1984; Ong, 1996; Ong, Humphris, Annett, & Rifkin, 1991; White & Taken, 1997). Our justification for using this approach for carrying out research is to be found in the description of PRA as “a growing family of approaches and methods to enable local people to share, enhance and analyze their knowledge of life and conditions to plan and to act” (Guijit & Kisadha, 1994, p. 171).

PANDA is an innovative approach to rural social change that does not consider institutional boundaries but actively involves people in generating knowledge about their own condition and how it can be changed. PANDA is not static and fixed but a dynamic process that can change with time as the situation deems necessary.

The growing popularity of participatory approaches is due to several factors. The first is a recognition of the gap between the concepts and models professionals use to understand and interpret reality and those of different groups in the community (de Koning & Martin, 1996). The biomedical understanding of disease is often very different from its understanding in the local culture. This implies that communication strategies need to be far more carefully considered than many health workers have previously perceived. Secondly, many factors—cultural, historical, environmental, socioeconomic, and political—have crucial impact on the outcomes of interventions and the efforts to improve the health of rural people.

Participatory approaches try to avoid survey biases and quantitative questionnaire failures by getting outsiders to think more and learn more about the reality of the local people who live in a changing world. The use of both participatory research and action research methods allows a more meaningful understanding of development needs and processes. The approaches were developed to attempt to give depth traditionally achieved by in-depth anthropological studies more quickly. The use of PAR leads to a better understanding of what is going on; programs are designed with local people in a more appropriate fashion, and more pragmatic solutions to local problems are provided.

PRA methods provide the first steps in a process. They do not constitute a participatory process in themselves. What currently passes as participatory projects involves local people taking part in other people’s projects. The different modes of participation are characterized by what the ends users intend to pursue (see Table 2).

We have focused on the potential for colearning within a process that aims towards the goal of collective action. Colearning refers to the way in which the facilitators and participants learn from each other. In our project, exchange of information was a two-way process whereby participants learned from facilitators and the facilitators learned from participants. Through collective participation in seeking new knowledge and synergistic experiences, strategies for action were devised that were then implemented. The study tried to go beyond PRA, which focuses on appraisal toward an active implementation of activities by the groups involved. In our research, we drew on personal reflections and experiences that were shared with the people we worked with in different settings to explore ways in which these methods can be used to initiate a participatory process.
The HAAC

This section presents the steps involved in the piloting of the HAAC with women’s groups and describes the process in detail. The HAAC was developed in the very specific context of the Community Health Development Program (CHDP) of the Britain Nepal Medical Trust (BNMT) (Gibbon & Cazottes, 1997). The HAAC is an approach that is primarily concerned about action.

The research process recognizes the position of women’s group members within a particular cultural context and helps them to plan projects that are within their capabilities. There is a major concern to enable an empowerment process to take shape. The HAAC uses participatory methods to raise the awareness of community and women’s groups to analyze their health situation and to be able to take action for improving their health.

HAAC as a Process Leading to Action

The major dimension to the HAAC (see Figure 1) is the approach it takes to working in the community. Tones and Tilford (1994) outlined an approach to working with communities that is based on the conviction that the facilitators should work with the community and seek to facilitate the achievement of the health goals that the community itself has identified. CHDP has the same philosophical basis and uses a broad, holistic approach to health. Tones and Tilford used a model known as the health action model to explain the community-based approach. Efficient decision making requires conscious calculations of the costs and benefits of actions. Decisions are influenced by beliefs, motives, and social pressures that enable action to occur if and when the appropriate circumstances arise. The HAAC aims to enhance efficient decision making and conscious analysis and is an empowering approach to health education.

The provision of support to facilitate genuine decision making is a necessary component in an empowering process. It was therefore felt essential to take into account the constraints and facilitating factors interposed between intention and action. The facilitating factors are a necessary prerequisite for effective health promotion.

The HAAC steps allow the groups to discuss and visualize several aspects of health:

- the effects of good health and bad health in their daily lives,
- the relationships between their environment and its effects on health,
- the mechanisms within their body through their own interpretation,
- the possible preventive measures to the health issues discussed, and
- the attitude to adopt for each discussed health issue.

The input of external knowledge is limited as much as possible (although not entirely excluded), and the emphasis is put on facilitating the discussion and the exchange of knowledge between the participants. The external knowledge that is introduced is not imposed on the group members but is discussed, and it allows them to make decisions about incorporating it into their worldview. The closeness to the problem created by the use of participatory tools seems to increase the participants’ ownership of the action to be taken. In the piloting phase, we observed that
most of the time the decisions taken by the groups were followed by actions. The HAAC approach was devised by the two authors of the article together with the staff of CHDP. Marion Gibbon (the researcher) was working on her doctoral thesis (Gibbon, 1999), and Isabelle Cazottes was the coordinator of CHDP.

The entry point of CHDP’s work with local communities was through provision of literacy classes to women. Literacy rates among women in Nepal are 17%, whereas those of men are much higher. After the completion of 6 months of classes, groups were formed to implement development projects within their communities based on a management planning cycle. The groups were not necessarily representative of the community, because only those women whose families supported them could attend classes. Poorer women could not afford the time required for attendance of meetings with no financial benefits due to their workloads (Gibbon, 1998). Projects that arose through the management planning cycle did not necessarily focus on health issues. Later, the work of CHDP was reviewed, and it was felt that CHDP needed to focus more specifically on health-related issues, and it was with this in mind that the HAAC approach was first devised and then piloted.
The projects used the HAAC approach with seven groups of women. Of these, the findings of six were analyzed in depth. Each group had a maximum of 20 (more usually between 10 and 15) participants, because more than this meant everyone was not able to contribute and participate in a meaningful way. The steps were facilitated by a project worker external to the group itself. Steps 1 through 6 were worked through within a 2-day workshop in Sankhuwasabha and a 3-day workshop in Dhankuta where groups had not been previously formed. The Dhankuta groups had not had previous literacy classes, and therefore, consideration of how the approach could be used with illiterate groups was incorporated and the time taken was a day longer.

The research undertaken took place in two district locations. In Sankhuwasabha, four of the groups were in areas where there was predominantly one ethnic group—Rai. In Dhankuta there was one group that was entirely composed of Rai women and two others that were mixed with Rai as well as those from Brahm and Chettri castes.

Facilitation of groups was done by Nepalese men and women. This did pose problems at times, as the Rai women did not always speak Nepali even though they usually understood it. This difficulty was overcome through some young Rai men who were interested in being involved helping in translation and cross-cultural communication. The women’s group members were happy to have the men take part in the discussions and help with translation when necessary.

The pilot in Sankhuwasabha used lists and flow charts that involved written Nepali that the researcher felt would not be useful when working with illiterate women. The researcher decided to work with a local artist to develop the approach for use in nonliterate groups. This process took place during a 3-day workshop, and the artist worked together with local women to draw picture codes to enable discussion of what is meant by good health and bad health. Codes were also devised for discussion of a healthy environment and a nonhealthy environment. Pictures were used to represent each of the main health problems within their community, the months of the year, and solutions to the health problems that they faced, for example, latrine, a rubbish pit, a clean water source, and covered water pots. The groups then implemented projects that were monitored by the facilitators and the researcher. The pilot was then evaluated in a CHDP review that took place in 1999.

Before the research process was able to commence, discussions were held with the BNMT. The outline for the proposed process was presented, and permission was obtained to undertake the pilot phase. A preliminary study was undertaken to determine the main health problems in the Sankhuwasabha district. This study was short-term and used two methods: focus group discussions with women’s groups and visits to health posts to investigate why people were using the health posts. The BNMT training unit then gave the CHDP facilitators training in the main health problems identified. The initial training focused on diarrhea, malnutrition, respiratory infections, and hygiene-related skin problems. We then involved the field staff in the design of the health analysis cycle to help them shape the process. The whole process was continually revised, and changes were made through feedback when specific methods were found to have limited utility for encouraging discussion.

We reported progress periodically and made sure that the work remained visible and open to suggestions so that unforeseen ramifications could be taken into account. We made sure that any problems and issues raised by the participants or facilitators could be discussed and resolved. In this way, when facilitators came up
against issues that they felt unable to tackle, they were able to discuss them with colleagues and gain insights to enable beneficial changes to be made.

The Steps in the HAAC

The HAAC allows the women’s group members to reflect on their perceptions and understanding of health. The cycle uses a process that provides an opportunity to exchange knowledge through dialogue between the facilitators and participants.

This section will illustrate the use of several tools that come from PRA. The tools include health mapping, seasonal calendar, body map, and cause tree. Some of the health problems mentioned by the groups are seasonal. For this reason, we decided to include a seasonal calendar to consider seasonal illnesses in relation to seasonal attributes and to examine if any of the causes defined in the discussion around the health map have a seasonal dimension.

STEP 1: CONCEPT OF HEALTH

Step 1a: Preliminary Discussion Regarding Health

To determine the participants’ understanding of health and the implications of good and bad health, the group used a brainstorming technique. The topic for the brainstorming was the group understanding of health in terms of good and bad health. Table 3 shows an example that one of the groups came up with. The groups enjoyed discussing their perceptions of health. They mentioned that very often their views were not given any credence when visiting modern health practitioners.

The women conceived good health mainly in terms of their ability to work. All the groups where the HAAC were tested (six were analyzed in total) mentioned this point. Good health was also thought of in terms of healthiness, being fat or plump, and being clean. Half the groups mentioned being able to walk, which is essential given the terrain in the hill regions of Nepal where everyone has to walk to get from

<table>
<thead>
<tr>
<th>Good Health</th>
<th>Poor Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can work</td>
<td>Cannot work</td>
</tr>
<tr>
<td>Feel like working</td>
<td>Cannot eat</td>
</tr>
<tr>
<td>Good appetite</td>
<td>Cannot earn money</td>
</tr>
<tr>
<td>Can walk</td>
<td>Unable to carry loads</td>
</tr>
<tr>
<td>Fat</td>
<td>Problems for family</td>
</tr>
<tr>
<td>Can cut a lot of wood</td>
<td>Cannot send children to school</td>
</tr>
<tr>
<td>Can work quickly and then rest</td>
<td>Clothes not good and cannot buy more</td>
</tr>
<tr>
<td>Family is happy</td>
<td>Cannot travel to other places</td>
</tr>
<tr>
<td>All the tasks can be done</td>
<td>Not enough food</td>
</tr>
<tr>
<td>The children can go to school</td>
<td>Body becomes weak</td>
</tr>
<tr>
<td>Can cultivate, have a good harvest, and have money</td>
<td>Body becomes thin</td>
</tr>
<tr>
<td>Can carry loads</td>
<td>Can get other diseases</td>
</tr>
<tr>
<td></td>
<td>Can die</td>
</tr>
</tbody>
</table>
one place to another. Other considerations were strength, appetite, and the type of food one eats. Two groups of the Rai ethnic group also attributed happiness to being in good health. The Pelangma group also included the ability to send their children to school.

There were a few difficulties encountered with the brainstorming session on health. Half the groups had Nepali as a second language, and they preferred to use their mother tongue. The facilitators all spoke Nepali by preference. To overcome this difficulty, the facilitator relied on the young men of the community who were able to speak both Nepali and the local dialect fluently, and they helped with the translation. The women were quite happy with the young men being present in their group.

**Step 1b: Tole’ Health Map**

The second part of Step 1 is for the participants to draw a health map of their village or tole (see Figure 2). This is meant to enable the participants to visualize the causes of their health problems and those aspects of their environment that contribute to positive health.

They mark the factors attributing to bad health in red (e.g., shown by a box on the diagram). The factors that contribute to good health and hygiene are shown in green (e.g., shown by a dotted lined box).
Latrines were included as a factor contributing to good health in their village. Vegetable gardens, clean water, the presence of a traditional healer, and a health volunteer were also given prominence.

The points the Pelangma group mentioned in relation to poor health were using a pigpen as a toilet, having hens in the house, too many flies, absence of latrines, and the presence of a polluted stream.

STEP 2: LISTING, IDENTIFYING, AND PRIORITIZING HEALTH PROBLEMS

Step 2a: Listing and Identification of Health Problems

Step 2 involves listing and identifying the health problems in the community. The objective of this step is to identify the main illnesses in the community as seen by the women. The Pelangma group mentioned abdominal pain, flu, toothache, body pains, poor eyesight, cold with headache, scabies, diarrhea, joint pains, migraine, handicap, dysentery, broken leg, coughing blood (probably tuberculosis), pneumonia, and cough.

The six groups mentioned 41 different health problems. All the groups mentioned diarrhea as a health problem. This exercise was found useful in starting a discussion about community health. It was, however, necessary to use other methods, such as the cause trees used in Step 4, to encourage a greater depth of discussion. There were also a few language limitations, but these were overcome as mentioned previously.

Step 2b: Prioritization of Problems

The second part of Step 2 is to prioritize the problems listed. The prioritization takes place according to the criteria devised by the participants. They use a health-matrix ranking process to determine the most important health-related problems in their community and end with a decision on the health problem that they want to focus on. Table 4 shows the health matrix of the Pelangma group.

This particular group used the criteria “causes weakness,” the “illness spreads quickly and easily,” “the illness causes fatality,” and the “illness causes the inability to work.” They then ranked the seven illnesses using these criteria and decided that diarrheal disease was the most important illness to tackle in their community.

This tool allows for the groups to choose criteria that they feel are most important. It is therefore flexible and does not constrain them. This tool was seen to help the groups think through issues and share their ideas. Some of the groups found it difficult to choose criteria and spent much longer on this section of the HAAC. However, once criteria were agreed on, the ranking process proceeded quickly.

STEP 3: IDENTIFICATION OF EFFECTS

Step 3 involves identifying the effects of their specific health problem. Community, household, and individual-level effects are discussed in the group. The Pelangma
group mentioned five effects of diarrhea: It can spread to others, people can die from having diarrheal disease, one cannot travel with it, one cannot work, and one gets old before one’s time.

Discussing the effects of the health problem allowed sharing of knowledge between the group members. Some of the criteria used in the ranking exercise were also seen to be effects. This discussion also allowed the group to decide whether the effects of their chosen health problem warranted a project to try and improve their health situation.

STEP 4: CAUSES AND MECHANISMS

Step 4 is broken down into several parts to determine the perceived causes and mechanisms of their selected health problem.

Step 4a: Discussion of the Tole Health Map

The first part uses the initially drawn health map to discuss in more detail the causes for ill health that women can see. Through this process, they are able to visualize the relationship between the selected health problem and the environment. For example, the Pelangma group mentioned how chickens running in and out of the house unchecked could contribute to diarrheal disease. They also discussed how cow dung was polluting the streams where they draw drinking water.

Step 4b: Seasonal Calendar

The second part considers the seasonal dimension to their health problem through the process of drawing a seasonal calendar (see Table 5).

The months with spots in Table 5 refer to those where there is high incidence of diarrhea; the greater the number of spots, the greater the significance of that particular factor. The groups used maize kernels to show the incidence of the illness and to indicate when that particular cause was the most important over the course of the year.
## TABLE 5: Diagrammatic Seasonal Calendar of Pelangma

<table>
<thead>
<tr>
<th></th>
<th>April</th>
<th>May</th>
<th>June</th>
<th>July</th>
<th>August</th>
<th>September</th>
<th>October</th>
<th>November</th>
<th>December</th>
<th>January</th>
<th>February</th>
<th>March</th>
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</thead>
<tbody>
<tr>
<td>Diarrhea and dysentery</td>
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<td>••</td>
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<tr>
<td>Flies</td>
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<td>••••••••</td>
<td>••••••••</td>
<td>•••••</td>
</tr>
<tr>
<td>Eating new maize</td>
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<td>••••••</td>
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</tr>
<tr>
<td>Dirty compounds</td>
<td>••••••</td>
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<td>•••••</td>
</tr>
<tr>
<td>Cold and wet weather</td>
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<td>••••••</td>
<td>••••••</td>
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</tr>
<tr>
<td>Water in well is dirty</td>
<td>••••••</td>
<td>••••••</td>
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**NOTE:** • = Low incidence. ••••••• = High incidence.
Step 4c: Body Mapping of an Illness

The third part consists of the participants drawing a body map of their prioritized illness. This allows them to visualize their health problem and helps the facilitator to understand how the participants perceive the transmission route of the causal agent. It also allows for an understanding of how the participants view the mechanism of the illness selected. Probes are used to determine how the body becomes sick, the effect the illness has on the body, and how they perceive the illness to travel through the body.

The photograph of the Pelangma group’s body map (see Figure 3) is particularly interesting in the considerable amount of detail that it entails. The rings around the eyes were to “show the sunken eyes of dehydration.” The arms and the body were redrawn with further lines to show how the body wastes away with chronic diarrhea. The ribs are also shown as they “protrude as the body gets thinner.” They also showed how the body gets diarrhea from dirty water and flies that land on their rice. They also showed how not washing hands and cleaning your nails could lead to “dirt getting inside the body,” which in turn caused diarrhea.
The women also tried to depict pain, shown as lines on the face and red squiggles in the stomach area. I feel this visual representation shows a sophisticated understanding of the causation and effects of diarrhea on the body, evidenced by the immense detail they included in their body map. Body mapping was found to be a very useful method to understand how a group viewed a particular illness gaining entry to the body and the route and effects it had on the body.

**Step 4d: Identification of Causes**

The fourth part is for the participants to draw a cause tree to identify the causes of their health problem (see Figure 4). It is important to probe for root causes, because this will help to indicate possible solutions.

Analysis of the cause trees found four major themes concerned with the following:

1. Water
2. Food and eating habits
3. Defecation practices
4. Domestic environment

All the groups mentioned dirty water as a cause of diarrheal disease during the drawing of their cause trees, and this agrees with the findings from the health maps, seasonal calendars, and the body maps. There were two aspects to water: One was concerned with water practices such as covering water pots and with how water is used. The second was concerned with animals being free to roam and their excreta acting as a water contaminant.

The food and eating habits were concerned with leaving food uncovered and, as a result, flies being able to land on it, thereby bringing contamination from elsewhere. Defecation practices were a theme throughout all the cause trees relating to diarrhea. There is a good understanding of how poor hygienic practices can lead to
diarrhea. The fourth theme of domestic environment relates to environmental hygiene. The groups mentioned concerns such as animals being free to roam everywhere and dirty compounds.

**STEP 5: POSSIBLE SOLUTIONS**

The fifth step involves defining possible solutions for each of the root causes identified. The group members consider which solutions they can address locally as individuals and as a community and those that require outside intervention and support. The solutions should be prioritized according to group capacity and resources. The participants also need to consider the solutions they can deal with immediately, those they would deal with soon, and those they would tackle at a later date. Table 6 shows the solutions that the Pelangma women's group discussed.

**STEP 6: ACTION PLAN**

The sixth step involves drawing up an action plan to implement the solutions from the previous step. The action planning process involves preparing detailed lists of tasks and determining roles and responsibilities of the group members and the project staff. Finally, a time frame for implementation is worked out and decisions are taken regarding how and who will monitor different activities. Table 7 shows the action plan of the Pelangma women's group.

**STEP 7: IMPLEMENTATION**

Step 7 follows on from the action plan and involves its implementation. In the regular meetings of the group, the facilitator helps the group to assess whether the tasks were performed according to the action plan. Where the action plan has not been followed, the group looks for the causes and tries to find alternatives. Accordingly, the action plan may need revising periodically.

In all the groups that have considered diarrheal disease, members have all started covering their water pots but in most cases have not dealt with the wider
community issues of animals being free to roam. They have dealt with flies contaminating their food by using lids and nanglo to cover their food.

The Pelangma group has already built latrines and has been concerned with community awareness raising and ensuring all their members have latrines. They have not had a wider community discussion regarding the environment. Such discussion has taken place in the Dhankuta groups, and wider community members have commented on the cleaner environment that has resulted from the group activities.

All the groups have decided on activities that try to prevent diarrhea in their communities. At present, these issues have only been dealt with on a group member basis, with the exception of group situations near towns and the Pelangma group, where some effort has been made to increase awareness about the environmental causes of diarrheal disease.

STEP 8: MONITORING

Monitoring is an integral part of the implementation of the action plan. The group is responsible for drawing up how it will monitor its plans of action. In drawing up the action plans, the group members also state who is responsible for supervision at each stage. The group discusses what progress they have made in their meetings. Monitoring is therefore an ongoing process and not a distinct step. The BNMT staff is also involved in monitoring progress of the group. At a later stage, the group is able to evaluate its success in dealing with the chosen problem.

STEP 9: EVALUATION

The objective of this step is that the participants in the whole process and possibly the beneficiaries evaluate the impact of the project once it is completed as well as the process itself. At a later stage, the group is able to evaluate its success in dealing with the chosen problem. This then takes the participants on to reviewing their problems
and determining what other problems they want to try and tackle, and the HAAC is once more revisited.

The facilitator first helps the group to describe what was achieved and what the process involved. The action plan is the basis for discussion to review the different actors involved and the resources used for the completion of the project. The group also comments on the difficulties met during the realization of the project and the way they were addressed.

The group reviews the benefits brought by the project and the number of people who benefit from it. They then discuss their expectations of how the long-term changes can be brought about by the project and the way to sustain these changes. They may draw a new action plan to sustain these long-term benefits, for example, maintenance of water tap or sustained hygiene practices.

Assessing the impact allows the group to measure the success and the benefits of its actions and to increase members’ confidence in their own abilities to deal with health issues. Reviewing the process helps them to ensure that they are familiar with the various steps and to identify the difficulties in carrying out the process so that they will be able to anticipate them and to better solve them in the future.

This step is documented and integrated into the monitoring system of the project. It is part of the monitoring of outcomes as well as monitoring of impact if repeated later on. Immediate changes in behavior are tracked through this step, but the assessment of these changes also requires cross-checking through observation by project staff. Long-term impact is defined as sustained changes in behavior and is measured after 1 year. The health benefits of the approach are measured through assessing the participants’ perceptions in regard to improvements in their health. Other measurements such as health facilities data are not accurate enough and present too many confounding factors to be a reliable indicator.

Summary of the Findings From the Pelangma Women’s Group

1. There are 14 members in the group. During the first cycle, they identified diarrhea as the health problem that they wanted to tackle in their group. They decided to implement a household hygiene program and ensure that all their group members had built latrines. During a monitoring visit, the researcher found that there are five remaining members who have not yet built their latrines. One said, “They’re not so difficult to build, it doesn’t need so much time.” They then proceeded to go through all the different farming activities that needed to be finished before they could build their latrines. They were extremely realistic in setting their time frames. They aimed to finish in 2 months. They then decided among them who could monitor progress on the basis of who lived closest to a particular member. The focus on diarrhea also led to a discussion about what to do in the case of diarrhea. Members were able to learn from each other about where to go for jeevan jal (oral rehydration salts). One group member knew they were available from the female community health volunteer. Another member mentioned that it is necessary to feed a child more after a case of diarrhea and also gave the others some dietary advice. They then decided to try and tackle the problem on a community basis and not only at the group level. It was decided that the group members would attend the next village development meeting.

2. The women’s group members attended a village development committee meeting to discuss the drinking water problem in their village. They presented the need for pipes
and other materials to protect their water source. The village development committee then agreed to help in the construction of a protected water source.

3. The next problems the group tackled were pneumonia and, following that, scabies. To tackle pneumonia, group members wanted to consider how to improve their cooking facilities. Suggestions were made for having external cooking facilities. For scabies, they recognized through discussions that they needed to improve their hygiene.

4. Home visits by the CHDP staff allowed for observations of the individual practices being put into effect. Nine home visits were made. Of those, only one had a dirty interior to her home; all the others were clean and tidy. All the women with one exception were covering their drinking water pots. We saw two of the women lipnu their houses during our visit. All the group members were keeping chickens from entering their homes. We saw one member together with her husband building a new latrine to replace their previous one. Nearly all the activities they had agreed to carry out had been implemented.

5. In the following meeting, one member reported that two households that were not part of the group have now built their own latrines. Only one member has not built hers, and one other is in the process of rebuilding.

DISCUSSION AND CONCLUSION

The experience of CHDP has found that the HAAC is a process that allows women’s group members to take action in addressing health issues that they perceive as important. However, it should be noted that in the CHDP context, the HAAC comes at a later stage in the whole process, which aims to develop women’s abilities to solve their problems independently. The building of rapport and capacity is an essential preliminary part. We cannot stress sufficiently the crucial role of appropriate facilitation.

The HAAC builds group capacity and raises awareness about health issues among the group and later to the community. The HAAC takes the group through a cyclical process that enables members to prioritize the issues, determine the causes and effects of their main health concern, identify solutions, plan a course of action, and then implement, monitor, and evaluate their project.

The HAAC has used a PAR approach to explore the possibilities of women’s groups to bring about improvements in community health. The theory has provided a basis to consider if active participation is possible, and the practice describes how women’s groups can actively plan and implement action plans that will eventually lead to improvements in well-being. This all takes place within a community setting, which leads to a greater sense of unity and enhances group capacity. Gradually, the groups were able to influence the community through planning projects that would improve the quality of life of the overall community. An example of this was in the provision of clean water through construction of a tank and water pipes.

Strengths of the approach lie in the enhancement of social ties within a group, increased feelings of self-confidence and esteem, and an overall improvement in health status. The planning and implementation of small projects led to feelings of group achievement and satisfaction. The participatory health analysis and action process is owned and shared by all the participants. It has generated far more than research data and brought about positive changes among individuals and groups as a whole.
Through this process, the information, knowledge, and confidence gained enabled participants to show their capabilities in planning and making decisions regarding how projects were to be implemented. Women who had been involved in the projects reported that prior to being involved, nobody had ever wanted to listen to what they had to say. Now they could be heard. To this extent, the research process gave voice to a silent group.

However, this article presents the process as being simple when in fact PAR is very complex. There were issues of ethnicity, caste, power, and status differences. Oakley (1991) argued that the researcher and researched both share a subordinate position by virtue of their gender, and therefore, power relations are equalized. My experience suggests that gender alone is not enough to create shared understandings or eradicate power differentials between women. Ethnicity and caste are added dimensions that contribute to the process. Analysis needs to consider many social characteristics (ethnicity, class, caste, and culture) to enable us to be aware of commonalities and differences and to acknowledge the differences between women and not underestimate them. The Rai women found it easier to attend meetings than the Brahmin and Chettri women because Rai men and women are more equal in status. On the other hand, the Brahmin and Chettri women were able to build latrines because they tended to be more socioeconomically advantaged; however, they were more subservient to men, and unless their families could determine an advantage from their involvement in groups, they were not given the same support. The time commitment required was at times a barrier to women. Women’s workloads in Nepal are very high, and juggling multiple roles often limits their involvement in community activities unless a benefit for them can be seen.

The convergence between the solutions generated by the women’s groups and those that a health educator might want to hear may seem surprising. This can be explained through the dialogical process: past experiences gained by the group through the management planning cycle phase and through media influences. Many rural families in Nepal listen to community development messages via radio programs, many of which are now being broadcast in mother tongues and focus on issues such as hygiene and sanitation. At the same time, there were differences in understanding, such as the women’s group members seeing respiratory infections being caused by bad air. However, if beliefs did not have negative effects on health, they were not necessarily challenged immediately, but facilitators would note them for future discussions.

An awareness of the theory has enabled an interactive cyclical process to be developed that was then assessed in terms of its effectiveness in bringing about change. The HAAC has been found to be useful in raising awareness, increasing women’s empowerment, and bringing about action to improve health. It helped in the enhancement of group capacity, planning, and ability to make decisions and bring about action to improve health. The process led to increases in individual confidence and self-esteem within the women’s group members.

The limitations of the approach can be brought down to the following factors: It takes a long time to undertake the projects, differences in understanding sometimes were difficult to resolve, and women’s position in society remains unchanged.

Finally, we would be happy to hear how this approach has been replicated in other contexts, but we would like to remind you of the importance of making adjustments according to differing environments.
NOTES

1. A tolé is equivalent to a hamlet.
2. A nanglo is a large flat circular woven bamboo effect used to sort rice.
3. Lipnu refers to the practice of smearing the floor with mud and cow dung to reduce dust.

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Marion Gibbon is currently a research fellow at South Bank University. She has worked in Asia and Africa for various development agencies, including the Department for International Development. She has worked overseas for the past 10 years in the field of nutrition and community health and is now working on an action research project with Black and minority ethnic groups in the United Kingdom. She has published in the areas of women’s health and development.

Isabelle Cazottes worked for Britain Nepal Medical Trust as a coordinator for the Community Health Development Program. She has worked in Nepal extensively over a period of more than 10 years. She now works for Save the Children Fund UK in Tibet.
Productive Readings: The Portrayal of Health “Experts” in Women’s Magazines

Allison Kirkman

This article illustrates how health practitioners are portrayed through advice columns, articles, personal accounts, and advertisements in women’s magazines. Magazines provide a valuable source of information about health services and also influence lay knowledge about health and illness. A wide variety of health practitioners provide information and advice in women’s magazines, ranging from orthodox medical practitioners to alternative practitioners. However, there is a blurring of boundaries between these, with orthodox practitioners sometimes including alternative therapies in their practice and alternative therapists sometimes encompassing a number of orthodox therapies within their practice. The way health practitioners are represented in the media has implications for how their expertise in health issues is evaluated and used by consumers of health care services.

In this article, I explore women’s popular magazines as a productive source of health information and, in particular, information about health practitioners. Health columns and reports have become staples in newspapers, lifestyle, and women’s magazines (Chew, Palmer, & Kim, 1995). Indeed, all issues of women’s magazines usually contain at least four varieties of health coverage. The first is medical advice pieces where specific diseases (such as breast cancer or heart disease) are discussed in terms of warning signs, treatment, and prognosis. The second is the letter or advice columns where questions about particular conditions are asked and answered, and the third form is the human interest story or personal narrative based on women’s own experiences with illness (McKay & Bonner, 1999). In addition to these three forms are advertisements, which frequently include health products and services.

In this article, I argue that women’s magazines, along with other forms of media, have an influence in shaping views about health and health services. As Williams and Calnan (1996) convincingly argued, “The media play a powerful role not only in the shaping of lay views and evaluations of modern medicine, but also in the profiling of risks in contemporary society” (p. 259). Accordingly, the media may play both a mystificatory and a demystificatory role, highlighting not only the positive aspects of modern health care but also the atrocity tales of medical misadventure. Williams and Calnan suggested that in this sense, the media may both create and

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convey lay views concerning a wide range of medical and social issues, located as
they are at the critical juncture between social and scientific rationality.

The media are thus a major unofficial source of health information (Rogers,
Hassell, & Nicolaas, 1999) and are important in shaping people’s actions and
knowledge about health care and expectations about service provision. This also
influences directly the development of demand for all health services. The media,
along with friends and relatives, are sometimes the main source of health informa-
tion and an important adjunct to official information and advice from professionals.

However, the influence is not all one directional, and popular books, newspa-
pers, and magazines may also influence both lay and professional providers of care.
New ideas about acceptable and controversial treatment have been found to reach
the layperson before the professional and to act as a source of information via
laypeople to professionals (Rogers et al., 1999).

Women’s popular magazines are one form of media situated at the juncture
between social and scientific rationality referred to by Williams and Calnan (1996)
and, as such, are worthy of critical analysis. Women’s magazines have received
attention from feminist writers (Budgeon & Currie, 1995; Hermes, 1995; McCracken,
1993); however, there has also been a shift in the ways of thinking about the impact
of media images. The academic writing that accompanied the feminist movement
of the 1960s onward emphasized how media depictions played a role in the social-
ization process of young men and women. It was asserted that the ways in which
women continued to be portrayed in a two-dimensional manner, as housewives
and mothers on one hand and sexual objects on the other, served to further women’s
oppression. In particular, through the 1980s, feminist sociologists characterized
the advertisements, feature articles, and stories appearing in women’s magazines as
vehicles of women’s socialization into subordinate roles. Currie (1997) contended
that in keeping with sex role theory, much of this work takes the view that women,
as readers of social texts, internalize messages that represent the “scripts” (p. 456) of
femininity. More recently, the question has again been focused on how the link
between media images might be implicated in the constructions of masculinity and
femininity, but this is now seen as a more complex issue than the earlier formulation
(see McRobbie, 1997).

Another more recent focus of research on magazines has been on the way in
which we read magazines. Hermes (1995) suggested that women’s magazines con-
stitute a genre that does not make demands, and “since, as readers, we know maga-
zines will not capture us totally or carry us off, they are safe to read” (p. 34). Her-
mes’s research involved interviewing women and men about reading women’s
magazines and identified a number of repertoires for reading magazines. For exam-
ple, women readers used the repertoires of magazines as “easily put down,” read
for “relaxation” and for “practical knowledge.” Men readers, even more than
women, read them “because they are available” within the house. Hermes’s work is
an important development because it illustrated “the move towards the reader” in
popular media research. It also points out the different reading practices of those of
us reading and writing about the media and those of us reading the media. This
present study does not claim to make the move toward the reader but instead is an
exploratory study to establish issues that can then be tested with actual readers in
future studies.
The examples used in this study come from the main women’s popular magazines available in New Zealand, covering the period from November 1997 to November 1999. However, these magazines constitute a genre that is found in all other Western societies, and the findings have broader pertinence than for New Zealand alone. There are, of course, some aspects that are specific to New Zealand, and these are made clear during the discussion.

The sample for this study was determined by two main factors: the circulation figures of the magazines and the selection of magazines from various price ranges (see Table 1). All the major women’s magazines in New Zealand, in terms of circulation figures, were included, and a number of smaller circulation magazines were included to provide a range of more expensive magazines. On the basis of this sample, 12 magazines were available for detailed analysis. Some of these magazines are weekly, whereas others are monthly or quarterly. Women’s popular magazines can be broadly divided into a number of subgenres. The first would be the domestic weekly magazines (also called service weeklies), which have a strong emphasis on practical advice and come in a moderate price range (e.g., Woman’s Weekly, New Idea, and Woman’s Day). There are also more highly priced monthly or quarterly magazines (frequently called “glossies”) of which Style and Fashion Quarterly are examples. Between these are a number of magazines that are published monthly. One of these, the Australian Women’s Weekly, has much in common with the domestic weeklies and, as its name indicates, originated as a weekly magazine. Another group of monthly New Zealand magazines that are a combination of the glossies and the domestic weeklies claim to be marketed for a specific audience, for example, She, More, (now She and More), Lifestyle, and Next. These, along with the monthly Australian magazines Cleo and Cosmopolitan, all claim to be for the younger modern woman.

A range of more expensive imported glossy fashion magazines are also available in New Zealand either monthly or quarterly, for example Vogue, Elle, Harpers

### TABLE 1: Examples of Magazine Circulations and Pricing in New Zealand in 1999

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Cost</th>
<th>Circulation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Weekly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Woman’s Day</td>
<td>3.10</td>
<td>165,914</td>
</tr>
<tr>
<td>Woman’s Weekly</td>
<td>3.10</td>
<td>126,640</td>
</tr>
<tr>
<td>New Idea</td>
<td>3.10</td>
<td>67,070</td>
</tr>
<tr>
<td>Monthly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Australian Women’s Weekly</td>
<td>5.20</td>
<td>80,045</td>
</tr>
<tr>
<td>Next</td>
<td>5.95</td>
<td>62,255</td>
</tr>
<tr>
<td>She</td>
<td>5.95</td>
<td>27,137</td>
</tr>
<tr>
<td>Grace</td>
<td>7.95</td>
<td>19,124</td>
</tr>
<tr>
<td>Quarterly</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fashion Quarterly</td>
<td>8.50</td>
<td>22,463</td>
</tr>
<tr>
<td>Style</td>
<td>8.95</td>
<td>11,032</td>
</tr>
</tbody>
</table>

a. In New Zealand dollars.
and Queen, and Marie Claire, but they were not included in this study because of its focus on New Zealand-or Australian-produced magazines. No specifically teenage magazines (e.g., Dolly) have been included in this study. Although the codes in teenage magazines are important because of the way in which gender identities develop in teenage years (Currie, 1997; McRobbie, 1997), it is felt that this is an area worthy of a separate study.

Although these broad subgenres can be identified, and I am aware that commercial market research would suggest that certain categories of women (e.g., career women, young women, women in unpaid work) would read a particular kind of magazine, Hermes’s (1995) research did not support this marketing assertion. It is also worthwhile pointing out that not all magazines we read were purchased by us, for example, magazines in waiting rooms, cafés, and other people’s homes.

A feature of the magazine market both in New Zealand and other Western societies is the changing array of magazines (McCracken, 1993). When this study was commenced, More and She were separate magazines, but they combined into She and More—“the magazine for the woman who knows what she wants”—in 1997. And in 1998, there was the emergence of a new glossy, Grace, on the magazine racks. The 2-year time period for this study provided sufficient data for analysis, and indeed, saturation was achieved with no new themes being identified in the final months of the study. However, this time length was also to take into account the potential skewing influence of any health panics that may have occurred during the research period, and although these in themselves are worthy of analysis, they were not the main focus of this study.

The study involved three main stages: The first was deciding on the sample, and the second involved categorizing all the material relating to health according to whether it constituted an article, advice column, advertisement, or personal story. The items in these groups that included reference to health professionals or health practitioners were then identified. The third stage was the analysis using an interpretive approach (Lupton, 1999) that focused on the use of language, particularly in headlines; visual imagery; and the major topics and actors receiving attention. Lupton (1999) suggested that this approach “sees the news media as the sites of discourses, or recurring patterns of representation and meaning” (p. 40). Whereas Lupton was concerned with news media, my purpose was to determine whether a similar approach had utility when applied to women’s popular magazines.

A number of authors (e.g., Fairclough, 1992; Wetherell, 1999) are in agreement that there is no specific method for undertaking discourse analysis of the media and have stressed the importance of developing a method that is specific to the particular project being undertaken (Grace, 1998). However, in doing this, I paid attention to Fairclough and Wodak (1997), who noted that critical discourse analysis aims to “make more visible the ideological loading of ways of using language, and the underlying relations of power (as these are often unclear to people)” (p. 258). Recognition of relations of power is particularly applicable to the representations of health professionals, and an analysis that revealed these dimensions was essential in this project. The method adopted was therefore concerned with these social relations rather than involving a detailed linguistic analysis of discourse.

I was also able to draw on a number of other studies that have examined the way in which the media represent certain topic areas in health, and these also
provided guidelines on how to approach this project. In relation to women’s health, reproductive issues have been the most closely examined in studies dealing with menstruation (Coutts & Berg, 1993; Kalbfleisch, Bonnell, & Harris, 1996; Oinas, 1998), hysterectomy (Sefcovic, 1996), and new reproductive technologies (Albury, 1987; Condit, 1996). The ways in which life-threatening diseases are covered in the media have also received attention in studies examining breast cancer (McKay & Bonner, 1999), toxic shock syndrome (Cheek, 1997), and HIV/AIDS (Lichtenstein, 1996; Lupton, 1994). Men’s health issues are also increasingly appearing in women’s magazines (Lyons & Willott, 1999), and studies of these identify a similar focus on diseases of the reproductive system, with testicular cancer and prostatic cancer featuring prominently (Clarke & Robinson, 1999).

In this article, rather than focusing on one specific disease, I explore the way in which health professionals are represented. To do this entails identifying some of the differing discourses in the types of magazines included in this study, followed by an analysis of the portrayal of health practitioners in these magazines.

SOME DIFFERENCES BETWEEN DOMESTIC WEEKLIES AND GLOSSIES

The initial analysis revealed a qualitative distinction between domestic or service magazines and the glossies, and this has implications for the way in which health professionals are represented and is discussed here before proceeding with the analysis of representations of health practitioners. Two central discourses around health and illness were evident: These involved either the female body or the family. Discourses about body projects (Turner, 1992) emphasize the reshaping and autonomy of the individual woman’s body and are particularly evident in the glossies. Thus, along with exercise regimes, dietary regimes, and cosmetic surgery, there is also a focus on reproductive and sexual health. These magazines are likely to have reporting on health rather than illness, in particular, sexual health. Sexual health is presented as something that you might find difficult discussing with your doctors, and in “Health News by Kendra Smith,” there is the regular “Embarrassing Question of the Month” (Cosmopolitan, December 1997, p. 244).

By way of contrast, family discourses emphasize reproductive health as well as family health. But in this case, it is not just women’s individual health that is of concern but also their children’s and husbands’ health and well-being. The Woman’s Weekly has a column “Weekly Help for Mums and Dads by Sally Woodfield,” which states, “Each week we run questions from mothers and fathers about pregnancy, childbirth and childcare” (Woman’s Weekly, December 1997, p. 62). However, fathers have disappeared somewhat in the instructions for submission of questions that state “Write to: Mother’s Helpers,” and this confirms the view that it is mothers who do the caring. This looking after extends to looking after men, and frequent references are made in relation to how women can assist with the health of the men in their lives. For example, “Did you know? Men who bottle up their feelings increase their risk of developing heart disease by up to 75 percent. So try to get the blokes in your life to talk about what is bothering them” (Lifestyle, February/March 1998, p. 80). Thus, in this situation lay knowledge and action is seen as preferable, at least in the first instance, to expert knowledge.
These examples illustrate the argument by some (e.g., Calnan & Gabe, 1991) that there is a closing of the “knowledge gap” between medical and health practitioners and the consumer of their services, and this reduces the consumer’s unquestioning trust. In this context, consumers, armed with increased knowledge, have become more ready “to shop around for medical services, as they do for other commodities in the marketplace” (Tully & Mortlock, 1999, p. 169). Magazine articles encourage this shopping around with examples that exhort one to construct one’s family health tree and assess one’s risk of developing certain diseases. For instance, in “Your Family Tree and Your Health,” the reader is asked, “Are you aware of any patterns of disease or conditions occurring within your family?” (Lifestyle, February/March 1998, p. 82). The object of constructing a family health tree is “to examine your lifestyle and implement changes to minimize your risk of contracting disease where a pattern emerges, not to become paranoid” (Lifestyle, February/March 1998, p. 82). Once one has done one’s research, it is suggested that one share this information with one’s doctor and “if they do not take you seriously—find another who will” (Lifestyle, February/March 1998, p. 83). The next section moves on to examine who, apart from doctors, provides information on health issues and what differences and similarities emerge within the different magazines.

PORTRAILS OF HEALTH PRACTITIONERS

The question of who holds the main expertise within medicine has been well debated in the sociological literature. Within the sociology of professions, the traditional dominance of the medical profession (Willis, 1983) has been recognized as coming under challenge from a number of quarters in recent years. Included in these challenges are the growth of complementary or alternative therapies or medicine (Willis, 1994), the opposition from the women’s health movement (Coney, 1991; Coney & Else, 1999), the professionalization efforts by other health care workers such as nurses and midwives (Tully & Mortlock, 1999), and the rise of managerialism in health care.

In this study, it is the first of these challenges, the growth of alternative or complementary therapies, that is particularly evident in women’s magazines. An ever increasing array of experts in health matters is now presented in women’s magazines. These include medical practitioners, allied health practitioners (e.g., pharmacists, physiotherapists, occupational therapists), and alternative or complementary practitioners (e.g., naturopaths, osteopaths, chiropractors, herbalists, aromatherapists, iridologists). A major occupational group that receives less coverage is nurses and midwives. Nurses, for example, appeared only in advertisements for hospital services or were mentioned as one of the qualifications of a person claiming other health qualifications, especially alternative health practitioners.

Thus, the dominance of the medical profession is no longer uniform, and in a number of magazines, alternative health practitioners are gaining equal recognition. This increase in the range of practitioners was apparent across all the magazines; however, there were some variations that can be illustrated by a detailed examination of a column “For Your Good Health” in the weekly magazine Woman’s Day. This column has a similar format in every issue and commences with the posing of a question, which is in turn answered by three health practitioners. Among the three answers is what it calls the “traditional approach,” and examples of what
constitutes this approach have been provided by medical doctors from a number of specialties (dermatologist, immunologist, respiratory physician), a psychologist, and a physiotherapist. In the December 15, 1997, issue, the question asked is “How can I stop feeling tired?” (Woman’s Day, December 15, 1997, p. 46). The traditional approach is given first and is presented by Gail Ratcliffe, who is a registered psychologist and the author of Take Control of Your Life: The Five Step Stress Management Plan. After providing a number of ways of combating tiredness, she ended with the suggestion that “if you know that your tiredness is caused by depression or stress, a psychologist may be able to help, but if you are not sure of the reasons for your fatigue, it is probably best to consult a doctor” (Woman’s Day, December 15, 1997, p. 46).

The second approach is the iridology approach, and the representative of this is Leanne James, who is defined as a natural health practitioner with her own practice. Leanne began her answer with a definition of iridology—“the science of diagnosis from the iris”—and suggested nutritional and herbal remedies for tiredness. She also appeared to specifically direct her answer at the potential readers of the magazine when she wrote “tiredness is caused by many, many things but is often triggered by nutrient deficiencies—particularly for women who have had children” (Woman’s Day, December 15, 1997, p. 46).

The final answer to the question is the aromatherapy approach. Janet Southern is introduced as an aromatherapist at Aromatics and a professional member of the New Zealand Register of Holistic Aromatherapists. She suggested that “using aromatherapy oils is a great way to beat tiredness” (Woman’s Day, December 15, 1997, p. 46) and then provided a number of combinations of essential oils.

In further columns, the same format is repeated, which provides a sense of familiarity for readers of this magazine. In reply to the question “What can I do about my hay fever?” the traditional approach is given by Dr. Richard Douglas, a clinical immunologist at a city hospital. He began by defining hay fever—“the technical name for hay fever is seasonal allergic rhinitis”—and then went through symptoms and treatment. He ended with a caution: “Finally, not all runny noses are allergic rhinitis. It might be worth a visit to your doctor to check there isn’t an underlying condition causing your sneezing” (Woman’s Day, December 27, 1997, p. 43). His reply is followed by the homoeopathy approach by Christina Van Den Berg, who is described as “a classical homoeopath with a naturopathic and nursing background.” Like the iridologist, she commenced with definitions—“homoeopathy is the medical practice which treats like with like” (Woman’s Day, December 27, 1997, p. 43). And the third approach is the aromatherapy approach, which is again represented by Janet Southern.

In all the examples examined in the columns “For Your Good Health,” those practitioners who claim to represent the traditional approach usually make reference to seeking further medical advice if the problem is not resolved by the suggestions given. This occurred when medical practitioners gave the response but also when other allied health practitioners were respondents, for example, psychologists and physiotherapists. In the case of the practitioners who are not allied to orthodox medicine, there is never reference to seeking other forms of therapy or medical intervention. These practitioners are never called alternative or complementary but are referred to by the name of their specific practice, for example, chiropractic, naturopathy, osteopathy, or homeopathy.
Another feature in these examples is the way the alternative practitioners initially spend time defining what their practice entails, whereas with the medical practitioners, it seems to be taken for granted that their practice is understood and their approach is to commence by defining the disorder and identifying the signs and symptoms. This approach conforms to the biomedical model of illness and often includes diagnosis, signs and symptoms, treatment, and prognosis.

The reference to a range of practitioners other than medical or paramedical appears in all the women's magazines examined, with aromatherapy the most often cited alternative to conventional therapies. Aromatherapy features in the advice columns, in articles, and in advertisements. Within the range of alternative therapies, there are varying degrees of recognition from the state, with some (e.g., chiropractic) being regulated by specific acts. As a consequence, practitioners covered by these acts have access to certain forms of state funding. Aromatherapy is not covered by any regulatory framework, and as such, it is possibly not surprising that it has such a wide coverage in magazines. In addition, there is a market associated with aromatherapy products, and it could be seen as a self-help option, whereas other practices often rely on the expertise of the practitioner.

I am suggesting here that there exist hierarchies amongst alternative therapies as well as between orthodox and alternative therapies. One means by which this hierarchy is established is the way in which certain therapies are seen as warranting regulation to govern their practice (e.g., chiropractic), whereas for some this is seen as unnecessary (e.g., aromatherapy). The existence of a regulatory framework suggests that there is potential for harm if the practitioner is not competent in the practice, and this is a major difference between chiropractic and aromatherapy, the two examples being discussed here.

**DEFERENCE TO DOCTORS?**

A further difference detected between alternative practitioners and medical practitioners is the greater deference that is sometimes accorded to medical practitioners. For example, in the article “Keeping Your Breasts in Good Shape” (*Lifestyle*, December/January 1998, p. 62), the surgeon is referred to the first time as Colin Calcinaia and thereafter as Mr. Calcinaia for the remainder of the article. Other people interviewed in this magazine are all referred to by their first names.

The other distinguishing feature between medical practitioners and other health practitioners are the photos that continue to show some doctors with stethoscopes around their necks. In *New Idea*, an advice column “On Call” is hosted by Dr. Wendy Fisher, who is described as a general practitioner (GP) and whose photograph appears at the top of the column. In this head-and-shoulders shot, Dr. Fisher appears to be holding case notes, and she has the ubiquitous stethoscope around her neck. In addition, the columns hosted by medical practitioners usually have a statement requesting letters but also stating that the doctor cannot make individual replies (*New Idea*, December 2, 1997, p. 28). Some of the domestic weekly magazines (e.g., *Woman’s Day*, *Woman’s Weekly*, and *New Idea*) have continued to include advice columns fronted by doctors, whereas the glossies are now more likely to have a health column as opposed to advice about illness (e.g., *Next*, *She and More*, *Grace*).

One such doctor in a domestic weekly is the *Australian Women’s Weekly* columnist, Dr. Kerryn Phelps, who in the 1997 issues is referred to as Kerryn Phelps but by
late 1998 is being termed “our Weekly doctor,” Dr. Kerryn Phelps. What regular readers of women’s magazines would know is that Dr. Phelps married her female partner in New York during the year (a story covered widely by the tabloid press), and although female doctors may be desired in women’s magazines, female lesbian doctors may not be the ideal. By referring to her as “Dr.,” the emphasis is now on her medical expertise as opposed to the previous emphasis on her being just like the woman next door. This outing of her sexuality does not appear to have impeded Dr. Phelps’s career, and in 1999, she was elected president of the New South Wales (NSW) branch of the Australian Medical Association (AMA). Indeed, according to members of the NSW Council of the AMA, she has cited her experience within the media as a reason for why she was ideal for the position of president.

THE BLURRING OF DISCIPLINARY BOUNDARIES

Whereas the presentation of specific therapies by name may be an attempt to define disciplinary boundaries, there is also a blurring of disciplinary boundaries, with some practitioners claiming to represent a number of therapies. For example, Bo Hendgen is described as a qualified aromatherapist, naturopath, osteopath, and director/founder of Absolute Essential Ltd (*Lifestyle*, February/March 1998, p. 40). Apart from being an author of an article on aromatic medicine, Hendgen also featured in an advertisement for courses in aromatherapy. “Choose a career in one of the fastest growing industries, Natural Health, and open your doors to a successful future” with “Your tutor: Bo Hendgen qualified Aromatherapist, Naturopath, Osteopath and director/founder of Absolute Essential Ltd” (*Lifestyle*, February/March 1998, p. 40).

This boundary blurring also occurs between more orthodox medicine and other therapies, with some medical practitioners using both conventional and alternative therapies, acupuncture being a specific example. However, the incorporation of some alternative practices within orthodox practice is usually portrayed as a more controversial combination. For example, Dr. Tessa Jones (*Next*, May 1999, p. 52) is heralded on the magazine cover as “True Grit: A GP takes a stand for complementary medicine.” In the features index, the article about her practice is listed under “Burning Issue: Meet a controversial GP who combines orthodox and nutritional medicine,” and on page 52 the headline reads,

> The best of both worlds. Little Liam Williams-Holloway’s story brought into focus the deep divide between the medical profession and practitioners of so-called alternative therapies. Can the two work together? Meet a controversial GP who combines orthodox and scientifically based complementary medicine. (*Next*, May 1999, p. 52)

This article deals with Dr. Jones’s combination of orthodox medicine with nutritional medicine and her practice of selling nutritional supplements. She said, “If doctors don’t supply them, patients will go to naturopaths and they will become the doctors of the future.” “Indeed, Tessa believes,” continued the article, “doctors run a real risk of losing patients to health food stores, pharmacists and naturopaths” (*Next*, May 1999, p. 55). Throughout the article, Dr. Jones continually referred to the scientific basis of her nutritional analysis and diagnosis, and this emphasis is
reflected in the article heading above. This claim of a scientific basis can be seen as an attempt to differentiate oneself from those alternative therapies that make no such claim.

OTHER HEALTH EXPERTS? MEDICAL NEWS IN WOMEN’S MAGAZINES

The rhetoric of science distinguishes another group of experts appearing within magazines. “Research news” is now a regular feature within the health sections of many magazines. However, this news is never supported by actual sources but relies heavily on numbers for the illusion of scientific legitimacy. An example below demonstrates this point with a focus on nutritional health and reference to omega-3 polyunsaturated fatty acids.

Under the heading “Happy Talk” is the statement that it may be possible to keep depression at bay by eating more oily fish. Research shows that omega-3 polyunsaturated fatty acids may help the nervous system to function well. The studies show that a dietary deficiency of omega-3 reduces levels of a substance that is linked to depression and hostility. (Woman’s Day, December 27, 1997, p. 43)

What is significant about this and other research reports is that no reference to the actual research studies is provided, and this is the rule rather than the exception when research is cited in women’s magazines. If a reference is cited, it is likely to be from a source such as the Cancer Society rather than a scientific publication. This type of citing is also more likely to occur in one of the glossy magazines rather than the domestic weeklies. As Petersen and Lupton (1996) pointed out, “Many of the medical and epidemiological ‘facts’ presented as ‘truth’ to the lay public are not as free from controversy as they tend to be portrayed” (p. 43). Thus, although scientists may provide a cautious interpretation in their scientific reports, this is often not translated into the media accounts. This has implications for the lay reader as the following example in a column headed “Health With Nicky Pellegrino” demonstrates:

If you’re pregnant you should think twice before slipping into a piping hot bath and enjoying a long soak. Scientists say it can harm your unborn baby. It’s thought sitting in hot water for a long time may heat the baby’s brain, which will not as yet have developed an effective cooling system . . . This theory is currently being tested and, until we get the final results, the best advice for women is to stay cool at bathtime. (Woman’s Weekly, April 19, 1999, p. 72)

From the information provided here, it would be difficult for any pregnant woman to find the source of this research, and in the meantime, they are supposed to stay “cool at bathtime,” a rather vague and possibly anxiety-producing suggestion.

In this section on research and expert knowledge, it is possible to point to a further dilution of the sources with reference to health writers rather than researchers. An example of this is in an advertisement with the heading “Natural Bodies”; it is an advertisement for Menopace. “With an effective combination of 22 nutrients it
comes highly recommended by health writers” (Next, April 1999, p. 56). What is deceptive about this advertisement is its placement in the middle of an article on nutritional medicine, which ensures that it blends in with the editorial copy. It is also difficult to assess the credibility and legitimacy of health writers even more so than researchers.

Up to this point, the examples discussed in this article have included health articles, health and advice columns, and advertisements. In the next section, I move on to examine real-life stories and personal narratives and what they may reveal about health practitioners.

REAL LIFE STORIES AND “ATROCITY TALES”

McKay and Bonner (1999) asserted that in the past 15 years, Australian women’s magazines have altered substantially in tone and content to become the most tabloid of all Australian media. They suggested that the three leading women’s magazines have shifted noticeably away from the three Rs of royalty, recipes, and romance into “salacious gossip and scandal more reminiscent of tabloid magazines” (p. 563). In content terms, “tabloids have the same characteristics: emphases on celebrities, tragedy, sensationalism, coincidence, medical (mis)adventures, sex, romance and the supernatural” (Bird, 1992, cited in McKay & Bonner, 1999, p. 563). Because many New Zealand magazines are the local editions of Australian magazines (e.g., New Idea, Woman’s Day), it is not surprising that this format applies also to many of the magazines discussed here.

There are many examples of the medical problems of celebrities in women’s magazines, but equally noticeable is the growing use of first-person accounts of people who are not celebrities but supposedly ordinary people like you and me. Sometimes this will be in the form of a full-page article, or in other cases, it will be in the Letters to the Editor. An example of both the former and the latter is demonstrated in the following letter titled “Incorrect Scan.”

I’m writing in regard to the article about the incorrect ultrasound scan (Woman’s Weekly 11.1.99). I’ve had a similar experience. Pregnant with my second child I went for a scan at 31 weeks. A specialist later told us our baby had some abnormalities and may not live or, if so could be disabled. There was no mention that they could be wrong. We planned to go to Auckland to establish the severity of the abnormalities but due to all the stress created our baby had to be delivered eight weeks early by emergency caesarean. Further scans were taken and no abnormalities were present, except for a small hole in the heart, which is common in eight-weeks-premature babies and has now closed over. Apparently, there’d been a few people before me who had been given wrong scan details. No one has apologized. Instead, I feel as if we are made out to be the ones with the problem. It’s like they are saying “What are you complaining about—the baby’s okay.” I nearly lost my life and also our baby. It’s lucky that we are here at all. It’s this fact which is taking a long time to deal with. I get sick of medical professionals sticking up for the radiologists. Why can’t someone just admit, “Yes we got it wrong. Sorry you went through what you did.” It was all so unnecessary. Name and address supplied (Woman’s Weekly, 19 April, 1999, p. 44).

Real-life stories have become a feature in all media forms, and the expectation is that we will be able to identify with at least some of the experiences, as the woman in
the Letter to the Editor does above. In women’s magazines, many of these real-life stories relate to medical problems or experiences. Rogers et al. (1999, p. 195) suggested that information from magazines also acts as a check on the knowledge and the actions taken by health professionals and indirectly provides a resource for negotiating and managing a response from the health care system. Indeed, they claimed that “it seems that magazines and other sources may for the most of the time be the only source of evidence-based medicine available to the public” (Rogers et al., 1999, p. 195).

This example can also be used to return us to the earlier discussion of experts and the suggestion that the dominance of the medical profession has been challenged in recent years. An example of this challenge is seen in the media’s denouncement of doctors who make mistakes or are found guilty of negligent practice or professional misconduct (Bradby, Gabe, & Bury, 1995). As Bury and Gabe (1994) suggested, in the case of television reports on medical situations, there is the occurrence of “trial by media” rather than medical dominance. This is a feature of the first-person accounts of medical problems that appear in women’s magazines in which the person has an issue to air concerning the competence of the medical practitioner. In the letter above, the writer referred to collusion between practitioners when she wrote, “I get sick of medical professionals sticking up for the radiologists” (Woman’s Weekly, April 19, 1999, p. 44).

DISCUSSION

The media examples cited in this article reflect the changes that have occurred in the provision of health care in New Zealand and many other Western societies (Davis & Dew, 1999; Willis, 1994). They also reflect changing expectations of consumers in relation to the role of health care practitioners and the provision of services. I have argued here that advice or health information that cites medical practitioners as the experts now coexist alongside advice that is provided by a range of health practitioners. However, there are differences in the way these practitioners are presented. In advice columns within the service weekly women’s magazines, medical practitioners are signified as experts in the area of health. This is done with the taken-for-granted expectation that the reader will know what to expect from these practitioners, whereas in the case of alternative practitioners their range of practice or expertise is frequently defined in the column or article. This reflects the existence of shared cultural knowledge about the role of doctors that is sustained by media. In the examples discussed in this article, this sustenance takes place through the portrayal of doctors in women’s magazines, but this influence is also achieved in a range of media—for example, the multiple television stories based in medical settings (see Karpf, 1988). Whereas Willis (1994), on the basis of Australian studies, argued that alternative medicine has shown a significant growth in popularity through the 1970s and 1980s, and New Zealand studies (Dew, 1998) show a similar trend, the wider cultural understandings of many alternative therapies is more recent and not as widespread as medicine; thus, it is essential for these therapists to define their area of expertise within the media if they are to attract a clientele.

However, I have also pointed to the blurring of boundaries between orthodox practitioners and alternative practitioners; a number of alternative therapies are used by medical practitioners, with one example being acupuncture. In this way,
alternative therapies may gain legitimacy by being associated with medical practice. Within the alternative therapies, there is also boundary blurring with a number of therapists claiming to use a range of alternative therapies, for example, naturopathy, aromatherapy, and homeopathy. As mentioned already, although many alternative therapies have a long history (Dew, 1998), many appear in these magazines as more recent and therefore in need of explanation.

The way the media portray health practitioners has implications for all health practitioners and the people who use their services. In the case of the women’s magazines analyzed in this study, medical practitioners and a range of alternative therapists gain exposure as holders of expert knowledge. The coverage of practitioners and services within women’s magazines means that readers of these magazines gain both positive and negative information about a range of practitioners and services. It also supports the contention that the gap between expertise knowledge and lay knowledge will continue to narrow, and all health practitioners need to heed this when considering how to present their services.

A final point to note in this discussion is that for readers of these magazines, there is the surfeit of information on health practitioners as well as health issues. Some of this information is contradictory, and research that assesses how magazine readers make selections from the available sources is now needed.

NOTES

1. For example, a situation currently receiving media attention in New Zealand is the deaths of at least seven women from blood clots as a consequence of taking the third generation oral contraceptive pill. The media coverage of this situation warrants a complete study.

2. Liam Williams-Holloway is a small boy with cancer. He became the focus of media attention over January/February 1999, when his parents chose to seek alternative treatment for his illness. A court order was obtained by the Children and Young Persons Service (a government agency) to ensure that he received treatment from oncologists where he had already had some treatment. However, his parents took him into hiding, and for several days, their photos appeared on the front pages of newspapers and television news programs asking the public to let the police know of their whereabouts. At the time of this writing, it has been reported that they are in West Germany, with Liam undergoing chemotherapy after unsuccessful alternative therapies in Mexico.

REFERENCES


Allison Kirkman is a senior lecturer in the School of Social and Cultural Studies at Victoria University of Wellington, New Zealand. Her initial interest in health stemmed from her experience as a nurse and midwife in New Zealand and Australia. Her current research interests are the relationship between gender, sexuality, and health.
Conceptualizing Sports Medicine as Occupational Health Care: Illustrations From Professional Rodeo and Wrestling

Joseph A. Kotarba

In this article, I propose a sociological model of sports medicine that conceptualizes it as occupational health care. The term occupational health care refers to the delivery of health services to workers who occupy the role of patient. Historically, there have been three stages in the evolution of this practice. First, medical services were delivered to workers injured on the job. These services became economically viable during the expansion of industrialization during the 19th century due to the concentration of workers in the urban factory system and the rapid improvement in the quality of medical and hospital care. Second, preventive health care services were delivered to a wider range of workers beginning in the mid-20th century, as managers realized the economic value of a healthy and productive workforce. An example of this trend was the movement, largely in concert with the union movement, to create safe and hygienic workplace. Third, in the late 20th century, a vastly expanded range of workers began receiving comprehensive curative and preventive care as the medicalization of workers’ physical, affective, and cognitive problems became nearly complete. Examples of this trend include extensive application of the social security system to an increasingly liberally defined population of disabled workers and the spread of employee assistance programs (Conrad & Schneider, 1992). I am not arguing, however, that this expansion has resulted either in an

_The purpose of this article is to propose a sociological model of sports medicine that conceptualizes it as occupational health care. All occupational health care systems can be summarized according to three types: elite, managed, and primitive. These types reflect the quality of health care provided, the social class membership of workers, and workers’ value to employers. The author presents ethnographic data to illustrate the social dynamics of primitive occupational health care delivered to rodeo cowboys and local professional wrestlers. This care is primitive because these athletes have relatively low economic value as workers, and the rugged individualism of their sports’ subcultures supports a system of health care that is inexpensive, nonmedical in its philosophy, personalistic in the structure of its practitioner-patient relationship, and incidental in its delivery._
overall improvement in health status among workers or in an overall increase in health care opportunities for them (see Navarro, 1981). Again, the expansion of the scope of occupational health care reflects a growing conceptualization of health as a work and employment issue rather than as a personal issue, as most recently exemplified by the Clinton administration’s efforts to link health care reform to mandated employer financial support.

The numerous styles of occupational health care provided to workers today reflect the variety and complexity of work in our postindustrial society. Specifically, there are two principles—based on structural and cultural characteristics of work—that largely determine the configuration of any occupational health program.

Structurally, the quality and complexity of occupational health care is a function of the relative value of the worker to the employer. The recent emergence of wellness-in-the-workplace programs demonstrates how the most highly valued employees (e.g., executives and managers) receive the highest quality, individualized preventive health care services (e.g., health and country club memberships) in contrast to lower status employees (e.g., line and staff employees), who are offered group services at the work site (e.g., aerobics and smoking cessation classes) (Conrad, 1988; Kotarba & Bentley, 1988).

The style, tone, and meaning of occupational health care delivery (e.g., practitioner-patient interaction and ongoing relationships) are largely a function of the work culture. For example, the delivery of comprehensive health care to astronauts by National Aeronautics and Space Administration flight surgeons is only partially shaped by the requirements and stressors of space flight. The flight surgeon–astronaut relationship is also a function of the more general culture of flying, with its attendant values on individuality, adventure, mastery of the environment, and optimal work performance (Kotarba, 1983b).

For analytical purposes, however, I will summarize the variety of occupational health care systems according to three types: elite, managed, and primitive. Elite occupational health care is delivered to the most highly valued workers in an organization. Structurally, elite health care is the most expensive and medically sophisticated care corporate or governmental money can buy. Culturally, elite health care is framed in the value of individuality, because the most highly valued workers are perceived as special and often difficult to replace. The modal health care worker in elite health care is the medical specialist.

Managed occupational health care is delivered to typical workers in an organization. Structurally, managed health care must be responsive to economic contingencies, because employers constantly seek ways to control the ever-rising costs of health care for the bulk of their employees. Culturally, managed health care is framed in the value of rationality, most commonly in terms of managed care. The modal health care worker in managed health care is the general practitioner (family practitioner or sports medicine specialist) who serves as much as bureaucratic gatekeeper for health maintenance organization or preferred provider organization services as he or she does as healer.

Primitive occupational health care (POHC) is delivered to the most marginal or least valuable workers. Structurally, POHC is low-quality and low-cost health care because the employer has very little invested in the worker. The worker can be easily replaced given low skill requirements or abundance of potential alternative workers. Culturally, primitive health care is framed in the value of benevolence.
Healthcare is given either as charity or for extraproductivity objectives such as public relations or employer image. No real effort is made to achieve optimal health or productivity. Instead, the goal is at best to patch up the worker in an incidental manner—when care is available and when there is an immediate need for care. The modal health care worker is the allied or ancillary health care practitioner who patches up the worker but who also conveys the conservative ideological belief that good health (or poor health) is primarily the responsibility of the worker.

This three-category model applies to occupational health care delivered to professional athletes, or sports medicine. Major league players (i.e., National Basketball Association [NBA], National Football League [NFL], National Hockey League, and Major League Baseball) receive elite health care. For example, it is now common practice for NFL teams to station orthopedic physicians on the sidelines during a game in addition to the traditional team trainers and physicians. Moreover, professional athletes competing and achieving in individual sports (e.g., golf and tennis) can afford to take the best care of themselves. Pro-Pop players (e.g., Continental Indoor Soccer League, the Arena Football League, and the Women’s NBA) receive care delivered on managed care contract from providers such as HealthSouth, Inc.¹ The least valuable and most easily replaceable professional athletes receive primitive health care.

In the remainder of this article, I examine the delivery of POHC to two types of professional athletes: rodeo cowboys and wrestlers. After describing the ethnographic methods used to conduct this study, I present separate descriptions of the worlds of the rodeo cowboy and wrestler. I conceptualize them as professional athletes who make very little money and regularly and predictably get hurt. I also examine the occupational roles and everyday tasks of the health care workers who work most with these athletes. These workers include athletic trainers, physical therapists, and chiropractors. I describe the health care workers’ common tasks and activities as well as the practical knowledge needed to accomplish this work. I conclude with a discussion of the cultural and economic benefits of integrating health care delivery to these athletes into the popular concept of sports medicine, and I speculate why this integration occurs in rodeo and not in wrestling.

METHOD

There were two stages to this study. First, I investigated professional rodeo in two settings. The first setting was the Houston Livestock Show and Rodeo in 1997 and 1998. I spent a total of 20 days over 2 years hanging out with and observing two “Justin heelers” at work, both in their trailers and on the floor of the rodeo arena. Justin Sportsmedicine is a health care program funded by the Justin Boot Company that employs an athletic trainer who delivers on-site care to rodeo cowboys at no charge. I conducted both formal interviews and conversational interviews with them, discussing their careers and the nature of their work. I also conducted conversational interviews with 15 cowboys who used the heelers’ services. These interviews focused on the cowboys’ work and injury careers.

The second setting was a small rodeo that was part of a county fair near Houston. I had the opportunity to interview and observe a chiropractor working with the cowboys. These data allowed me to compare the two major healing modalities offered to cowboys: medically informed athletic training and chiropractic care.
I supplemented these data with official documents obtained from the Professional Rodeo Cowboys Association (PRCA) and information posted on the PRCA Internet home page.

The second stage of the study consisted of a similar series of interviews and observations at five local professional wrestling training sessions and three events in the east Texas region. I conducted interviews with approximately 20 members of two of the four wrestling groups or associations in the region. My focus here was on the physical therapists and chiropractors who are the primary actors in the delivery of care to wrestlers.

This study adhered to all regulations established by the Committee for the Protection of Human Subjects at the University of Houston.

THE RODEO COWBOY’S WORK AND WORK-RELATED INJURIES

In their definitive study of rodeo in the United States, Wooden and Ehringer (1996) described the way professional rodeo has emerged to become a great national pastime. Rodeo originated in the common work needed to operate cattle ranches in America. Professional rodeo now involves more than $22 million in annual prize money and nearly 20 million spectators in attendance. Professional rodeo cowboys freely admit that rodeo is as much a lifestyle as it is a professional, potentially lucrative, and dangerous sport. Among professional athletes, cowboys are unusual because they do not get paid to compete. The rodeo contestant must pay an entrance fee that allows him the opportunity to compete for a share of the purse. If the cowboy’s animal must be “turned out” because the cowboy is too ill to compete or if the cowboy is injured in a preliminary event or even if there is a foul-up in travel plans, he forfeits the entrance fee.

The cowboys who follow the circuit full time may be entered in 100 rodeos or more each year held all over the United States and Canada. The PRCA, the major rodeo promotions organization, sanctions approximately 720 rodeos per year. Due to both the expenses of traveling to events and the small winnings, many professional rodeo cowboys compete part time and hold other, typically manual labor or blue (denim), jobs to support themselves.

Professional rodeo cowboys ordinarily do not have sponsors to help cover their expenses. They may have patch sponsors (similar to the advertisements posted on race cars), and they may make a few personal appearances at local western boot and hat stores, but they cannot live on these sources of income.

In 1998, the PRCA-sanctioned rodeos awarded total prize money of $21,290,343, and the 1998 world champion all-around cowboy has accumulated career earnings of $1,195,707. Given the fact that so many of the cowboys compete only part time and may compete only in limited geographical regions of the country, it is difficult to estimate the average winnings. The issue is further obscured by the fact that a given cowboy may compete in events sanctioned by other associations, such as the Professional Bull Riders Association or one of the other specialty associations. One can safely assume that the vast majority of contestants are in rodeo for the sport, because they simply do not earn any money at it. Some cowboys even lose money by failing to win back their entrance fees.
The PRC does not keep systematic records of all performance injuries. From all indications, however, the injury rate is very high. Nebergall, Bauer, and Eiman (1992) reported an injury rate of 12% among professional rodeo cowboys. The majority of these injuries were sustained in bull riding, bronc riding, and steer wrestling—otherwise referred to as “rough stock events.” Aspegren and Hyde (1993) monitored injuries treated by chiropractors in the Mountain States ProRodeo circuit. Data were collected on injuries incurred during one day of “rough stock only” competition. There were 12 reported injuries among the 84 contestants (14.3%). Ten injuries occurred in bull-riding events, and two occurred in bareback bronc-riding events. Injuries ranged from broken limbs (2) and dislocations (2) to sprains and strains (4) and lacerations and contusions (4). In addition, self-reported medical histories on these 12 athletes indicate that many of these contestants had one or more chronic injuries, that is, those existing for more than 3 months. The rate of chronic conditions reported (33%) is likely to be an underestimate, because this event was held early in the season and contestants had the off season to heal.

The Justin Sportsmedicine Program, in collaboration with the PRCA, has compiled extensive data on the relationship of specific rodeo events to specific injuries. From 1983 to 1998, the percentages of injuries by specialties were as follows: 46% in bull riding, 24% in bareback riding, 17% in saddle bronc riding, and 13% in various timed events. Major location of injuries include spine injuries (20%); hand, wrist, and elbow injuries (17%); knee injuries (13%); foot, ankle, and leg injuries (13%); shoulder injuries (11%); groin or hamstring injuries (10%); head or face injuries (9%); and miscellaneous injuries (7%) (Justin Sportsmedicine Program, 1999).

Because injuries are a common and expected risk in professional rodeo, they have become a common feature of rodeo culture. For example, the most dramatic examples of contestants being bucked off the animals or missing the catch in some timed event are replayed for the entire audience on the giant TV screens at the end of each day’s competition at the Houston Livestock Show and Rodeo. By the volume of their applause, the audience selects the cowboy to receive the “Hard Luck Award,” which in recent years has been a round-trip airplane ticket. The applause reaches a crescendo at the sight of life-threatening events, such as a bull stomping on a thrown cowboy’s head. Conversely, the audience has been known to boo minor events, such as a saddle bronc rider merely being thrown from a horse.

The PRCA has recently instituted a feature on its Internet home page called the Justin Sportsmedicine Injury Report. This link lists cowboys’ recent injuries, location of the rodeo, medical or surgical response, and prognosis. The following statement from an injured cowboy’s at-home media coverage illustrates that cowboys’ injuries are taken for granted:

National Finals Rodeo [NFR] qualifier Glen O’Neill of Water Valley, Alberta, sustained a broken tibia and fibula in his right leg at the first performance of the Canadian Finals Rodeo when the horse he was riding ran O’Neill’s leg down the fence. O’Neill was taken by ambulance to University Hospital in Edmonton, Alberta, where he underwent surgery to put a rod and plate in the leg. He qualified in the fourth slot of the NFR saddle bronc riding, but is expected to miss that event and all other competition for three to four months, according to his wife, Jennifer O’Neill. (Justin Sportsmedicine Program, 1999)
Taking Care of Rodeo Cowboys’ Injuries

In her anthropological analysis, Lawrence (1982, p. 65) noted that the term individualism most forcefully marks the identity of the rodeo cowboy. This identity is a residue of the image of the traditional cowboy who worked on ranches. When we think of the rodeo cowboy as a professional athlete, this identity is dramatic. The rodeo cowboy is an individual participant in his sport. No one is there to carry an injured cowboy or substitute for him when he is injured, as is the case in team sports. Rodeo cowboys commonly help each other out on the circuit, sharing a truck or a room at night. There is, however, little one’s friend or buddy can do when for another when one is injured—he is likely to be hurt himself.

The essence of healthcare for rodeo cowboys is last resort, charity-like services offered more for catastrophic injuries than for routine injury management or prevention. These services address public relations at least as much as healing functions. The Justin Boot Company supports the Justin Cowboy Crisis Fund (JCCF), established in 1989 through a cooperative effort with the PRCA. The overall purpose of the fund is to provide need-based financial assistance to persons injured through their participation in the sport of professional rodeo. Since its inception, the JCCF has provided more than $1.4 million in financial help to approximately 180 individuals in need. A board of directors consisting of celebrities from other sports and the music industry administers this fund. An award may be used for rehabilitation expenses or, as one official from Justin put it, “to help an injured cowboy make his truck payment.”

There are medical insurance policies available. These policies are very expensive for most cowboys, and the cowboys may have too many preexisting conditions to qualify.

The Justin Sportsmedicine Program

In 1981, a noted orthopedic surgeon and a professional athletic trainer established what has come to be known as the Justin Sportsmedicine Program (1999). This program wanted to take into account the nomadic nature of rodeo and the rather independent and solitary lifestyle of rodeo cowboys. The program was able to persuade a manufacturer of western wear products, the Justin Boot Company, to underwrite an innovative system of health care for cowboys. An elaborately equipped truck-trailer unit was furnished and stocked with state-of-the-art equipment and supplies and over-the-counter medications for the on-site care of rodeo injuries. This trailer is staffed by a health care worker who is not only knowledgeable about the nature of the rodeo events and the appropriate measures necessary to prevent and treat rodeo injuries but also familiar with the behavior of the livestock involved. This knowledge makes it possible for him to enter the arena before the action has ended to help extricate injured contestants and do triage: either signal for the emergency medical technicians provided by the local rodeo promoter or assist the cowboy from the arena area himself.

The Justin Sportsmedicine Program has grown to seven full-time staff members, two mobile centers, and permanent facilities in Guthrie, Oklahoma, and
Mesquite, Texas. The program maintains an elaborate referral system of experts on rodeo athlete injuries throughout most of North America. There are four men, with backgrounds as athletic trainers, who work as the Justin heelers. Each Justin heeler treats, on average, approximately 70 cowboys during a typical rodeo and provides education, preventive information, and precompetition preparation to a great many more over the course of the season. In addition, they coordinate back-up services with local physicians, athletic trainers, and physical therapists. Coordinating activities serves to educate local health workers about rodeo injury care while ensuring their ready availability if serious injuries should occur.

The Justin Heelers at Work

Justin heelers find themselves at the intersection of two cultures. One world is that of sophisticated health care workers who use their training and expertise to get young athletes back into competition as quickly as possible. The second world is that of the nomadic cowboy, traveling around the rodeo circuit and enjoying the excitement and atmosphere of the rodeo world. The Justin heelers share the personality and persona of their clients. Their work uniform consists of traditional cowboy attire (i.e., pressed Wrangler jeans, crisp western-cut shirt, a pair of Justin boots, large silver belt buckle, seasonally appropriate hat, and above all else, a jacket or vest with the logo of the sponsoring corporation emblazoned on the back). Their hair is always closely cropped and freshly trimmed. They chew and spit.

The Justin heelers work at different types of locations, depending on where the rodeo is held. They set up shop in the formal team training rooms of professional sports arenas, such as the Compaq Center in Houston where the National Bull Riding Finals are held. They also set their equipment bags down on the ground next to the livestock stalls at open-air, county rodeos. One Justin heeler noted their two main logistical concerns: “We’ll work about anywhere. All we demand is a clean and secure work environment, with running water, and a convenient location near the rodeo floor, so we can get to an injured cowboy as fast as possible.” At major events such as the rodeos in Denver, San Antonio, or Houston, the Justin heelers work out of one of two fully equipped, mobile sports medicine units. These bright-red semi–trailer trucks are parked near the rear entrance of the rodeo arena. The interior of the remarkably roomy, air-conditioned trailer is divided into three areas. The front consists of a bunk area where cowboys can lie down when waiting to be served. The rear area contains the isokinetic and nautilus-type equipment for muscle strengthening and testing and two examination and treatment tables. The center is the busiest and most elaborately equipped portion of the unit. The entrance to the trailer is in this middle portion. Both walls are covered with cabinets that contain supplies and materials, such as dozens of roles of tape of all types and widths; over-the-counter medications, such as anti-inflammatory, analgesic, antacid, and antidiarrhea products, liniments, adhesive release sprays, and various topical products; and several instruments, such as those that are used to measure joint flexibility and reflexes. Other equipment include Staodyn PGS (DC) and TENS (AC) stimulator units, a microwave/convection oven to prepare special casting and padding materials, and an intermittent compression unit.

The Justin heelers’ work day begins approximately 2 hours before the rodeo begins. Cowboys start trickling in not only to get their wrists, ankles, and knees
wrapped but also to talk to health care workers with whom they feel very comfortable. The Justin heelers’ style of work follows from their very personalistic relationship with the cowboys. One stock handler stated, “If a cowboy gets bucked off and lands hard, the first face he sees when he opens his eyes is usually Bill’s” (Kotarba & Haney, 1995, p. 16).3 Much of the Justin heelers’ credibility and effectiveness derive from their direct, pragmatic, and holistic style of healing. Many cowboys come to the trailer to receive some good, practical health and career advice. The lasting value of any information or advice offered by the Justin healer is that it may be the last health and/or injury intervention the cowboy may get for a while. As Joe Baumgartner, six-time National Finals bull rider stated,

> When I’ve got to go to some rodeos they’re not going to be at, they make little care packages; they’ll give me some extra rolls of tape and some prewrap and stuff like that—usually whatever I need until I get to see them next time. (Justin Sportsmedicine Program, 1999)

As rodeo time approaches, the trailer gets congested. Ironically, the flood of volunteer help is a mixed blessing. On one hand, the Justin Sportsmedicine Program depends on local physicians and athletic trainers for help, especially at the larger events. Yet health care volunteers who come around specifically to vicariously share in the rodeo mystique can get in the way.

Once the rodeo begins, the Justin heelers stay by the gate leading to the rodeo floor. They will occasionally remain inside the arena. When a cowboy is thrown from a bull or horse, is trampled by a bull, or simply limps away from a successful ride, the heelers enter the arena on foot to provide assistance. If an injury appears severe, they will signal for the paramedics, provided by the local promoter, to take over and transport the cowboy to a local hospital for emergency medical attention. If the injury does not appear to be serious or if the cowboy resists emergency medical care, the heelers will patch him up the best they can.

Clearly, the Justin Sportsmedicine Program offers battlefield-style health care (i.e., designed to treat acute injuries and get the cowboy back to work as soon as possible). Long-term care is still a problem, and the establishment of viable long-term care for cowboys is an organizational goal. The Justin heelers have access to and increasingly make use of the North American Sports Medicine Referral System, which is an Internet-based network of physicians and specialists throughout Canada and the United States. The problem is, however, whether the rodeo cowboy has the time to take care of himself, given the constant travel of the circuit, and whether he has the money to pay for health care services on his own.

### The Wrangler Chiropractic Sports Medicine Program

The Wrangler Chiropractic Sports Medicine Program is a second, albeit smaller, system of health care available to professional rodeo cowboys. The Wrangler Company sponsors the program by providing promotional materials and supplies. The program is staffed locally by chiropractors who volunteer their services. In tune with the culture of their profession, the chiropractors set up adjustment tables in the open areas behind the actual floor of the rodeo where the cowboys queue for their events. Cowboys seek a preventive spinal adjustment before their events. The chiropractors
do not respond to injured cowboys during or after the actual events. Unlike the Justin heelers, who organize their work in terms of their employment by the Justin Sportsmedicine Program, the chiropractors promote their local private practice quite heavily with business cards and brochures on chiropractic stamped with their name and office information.

The presence of the medically oriented Justin heeler and a chiropractor in the same rodeo functions as a microcosm of the larger professional relationship between medicine and chiropractics. Privately, each practitioner acknowledges the potential value of the other’s work but publicly ignores the other’s existence and does not ever refer cowboys to him or her (see Kotarba, 1983a, p. 96).

THE PROFESSIONAL WRESTLER’S WORK AND WORK-RELATED INJURIES

Professional wrestling is a remarkable phenomenon in the world of entertainment. The World Wrestling Federation’s (WWF’s) Monday evening television program, RAW, routinely outdraws Monday Night Football for viewers and is the highest rated TV show on U.S. cable (Gray, 1999). The almost monthly pay-per-view programs offered by the WWF and its main competition, World Championship Wrestling, are viewed by millions, at a typical cost of $35 per cable event. Celebrities ranging from Arnold Schwarzenegger and Dennis Rodman to Jay Leno lend their personae to pro wrestling. Professional wrestling has moved way beyond the old “Is it fake?” debate of the 1970s and 1980s. A former professional wrestler, Jessie “The Body” Ventura, is the governor of Minnesota, and a monster/mutant named Mankind had an autobiography sitting not at ringside but at the top of The New York Times Book Review bestseller list in December 1999. One fact is clear, however, about the role of the professional wrestler: He (or, increasingly, she) is an athlete who will be injured during the course of training or performance.

The world of local professional wrestling is a far cry from its nationwide counterpart. There are approximately 100 local wrestling organizations stretching across the United States. The southern states seem to be the mainstay of local wrestling, with four organizations in the Houston, Texas, area alone. Local professional wrestling is a low-profit venture. Events are typically held in Bingo halls, Veterans of Foreign Wars clubhouses, or community centers. Crowd sizes typically range from a few dozen to 300 or 400. Tickets are very inexpensive: $9.00 for general admission (rows 4 to 7) and $10 for reserved seats (rows 1 to 3). It appears that most income is derived from snack stand sales of nachos, sausage on a stick, and beer.

Local professional wrestlers’ remuneration ranges from nothing to several hundred dollars per match. Most maintain day jobs or other sources of income to support their major love and thrill in life: beating up each other with open fists or folding chairs. Typical day jobs range from nightclub bouncer and construction worker to loan shark collector and bodyguard. Those wrestlers who do not work can be found taking college courses or working out in the gym. Local professional wrestlers are young men in their 20s whose athletic careers typically include a little high school football, perhaps some high school wrestling, and considerable fighting, playful or otherwise. They love physical contact; they love to hit and be hit.
I raised the following question in numerous interviews and casual conversations with professional wrestlers: Have you been injured while wrestling? The responses have been uniform. Wrestler after wrestler will, with the pride of a seasoned warrior, quickly point out black and blue badges of courage: broken fingers permanently bent, locations of head concussions, scars, knee surgeries, locations of steel plates that mend broken limbs, and broken ribs.

Training and the Prevention of Injuries: Protecting One’s Opponent

Injuries are a common and expected feature of professional wrestling, as is the case in professional rodeo. The types of traumatic moves that comprise a wrestler’s repertoire result in a certain pattern of injuries. For example, the body slam is a mainstay move, resulting in back and shoulder strains. Being thrown from the ring to a concrete floor results in ankle and knee twists. Having one’s head smashed against the turnbuckle or the opponent’s knee results in concussions, cuts, and bruises.

The first principle of injury management is the need to choreograph one’s ring performance in concert with one’s opponent. A move is successfully and safely accomplished when both wrestlers understand the dynamics of the move and cooperate to accomplish it. For example, a body slam is most successful when the recipient subtly jumps to lighten his opponent’s effort.

In terms of injury prevention, a wrestler’s first responsibility is to protect his or her opponent. Both wrestlers must have faith that their opponent will control each move to avoid injury. A wrestler must stop a few millimeters short of contact when punching an opponent in the face. A wrestler must allow his opponent to breathe during a choke hold. A wrestler must keep the belt loose and avoid snapping the belt when whipping an opponent. A close look during a match will often show one wrestler verbally, albeit very quietly, disclosing an impending move to his opponent. A wrestler who does not protect his opponent quickly achieves the reputation of a wrestler to avoid.

The Commish: A Role Cluster in the Wrestling World

The major structural principle organizing health care in professional wrestling is that the promoter assumes no responsibility either for injury or the provision of injury care. Local wrestlers sign standardized waivers by which they assume all the responsibility for injuries. The revenues produced by professional wrestling are simply too low and unpredictable to support regular provision of health care. Furthermore, most local wrestlers do not have contracts with promoters, so that any sort of work-related health insurance would be prohibitively expensive.

That does not mean, however, that health care is not available. There are, in fact, four typical sources of care. First, some wrestlers who hold day jobs have medical insurance through work. They can receive care for wrestling injuries if they either claim that the injuries occurred at their day jobs or if they claim that the injuries occurred during leisure time. Second, those younger wrestlers who are full-time college students or are dependents of their parents can file insurance claims based on these statuses. Third, injuries that require immediate medical care are taken to
local hospital emergency rooms, where stitches and X rays are paid for out of pocket. Fourth, the promoter can offer injury care directly. For example, the “Commish” is the owner and manager of a physical therapy clinic. He provides chiropractic services to wrestlers either in the backstage area during an event or at his clinic after an event. He does not charge for these services, which are very useful for managing separated shoulders, back sprains, and other problems commonly addressed by chiropractic care (Kotarba, 1983a). The Commish’s role in local wrestling is typical insofar as he wears several hats at different times. He has been a wrestler. He occupies the role of commissioner of wrestling for his association, a role that is most visible during dramatic interludes between wrestling matches. His essential tie, however, is to the scene itself:

I love wrestling, always have. I guess it’s the action. We like to hit and get hit. I watched wrestling on television ever since I was a kid. Now, I can be a face (i.e., good guy) or a heel (i.e., a bad guy), and that’s fun. My son is now wrestling for (the association), so I guess it’s a family affair for us.

Providing chiropractic care and physical therapy to wrestlers also has its marketing and public relations value. Fans are told at every event that the Commish’s clinic provides these services to wrestlers without charge.

The major cultural principle organizing health care in professional wrestling is that the provision of injury care fits the local wrestling subculture. The wrestlers conceive of themselves as very physical, manly, and tough. They crave the action in the ring and use pain and injuries as signs of both their dedication to and success in the ring. Like professional rodeo cowboys, professional wrestlers seek health care less to verify disability than to get them back into the ring as soon as possible. Thus, the pragmatic approach of chiropractic fits in well. Furthermore, the small scope of local professional wrestling requires participants to act out multiple identities at different times. Wrestlers can, for example, serve as referees. Similarly, if not ironically, the Commish gets involved in the creation of injuries. For example, at a recent event, the Commish was chastising the wrestler who broke his son’s arm. The Commish threatened revenge. During the ensuing match, the wrestler was thrown from the ring. The Commish ran over to him and proceeded to bite the wrestler on the head, drawing (possibly if not probably fake) blood.

Interestingly, local wrestling fans are confederates in the staging of wrestling and wrestling injuries. They contribute to the mass illusion of pain and suffering with their “oohs” and “aahs” when a wrestler is punished. Yet, one event illustrates the limits to the fantasy mutually created during a wrestling event. During one recent match, a manager, who was standing just outside the ring, handed his wrestler what appeared to be a beer bottle. (I later discovered that the bottle was made of a soft, sugary material.) When the wrestler hit his opponent with the bottle, it shattered all over the ring. Several fans at ringside, who are typically the most vocal and obnoxious of all fans, immediately shouted to the referee and pointed out the sharp-edged broken glass littering the ring. The referee ignored their cries and, consequently, placed the combatants at great risk of head and facial cuts as they dragged each other across the canvas. Two ring attendants/guards/crowd control agents eventually swept the ring during the following intermission. This event illustrates that the fans really do not enjoy or favor real injuries to their heroes in the ring.
DISCUSSION AND CONCLUSION

There are a number of structural similarities in health care delivery between the professional rodeo cowboy and the wrestler. Athletes in both sports occupy positions very marginal to professional sports, both in terms of their value to promoters as workers and their status in the eyes of fans. Therefore, they are not provided high-quality health care. They can too easily be replaced if incapacitated. Both make very little money at their craft so that they usually cannot afford either health insurance or health care on their own. Both engage in work activities that may appear irrational to the outside observer yet are highly valued by the athletes and their subcultural peers.

Culturally, both kinds of athletes operate within subcultures that value highly the ability to live with pain, to perform in spite of injuries, and to respond to injuries in stoic fashion. The most prominent health care workers in both worlds share in the athlete’s culture and shape the actual delivery of health care accordingly.

At the same time, the rodeo cowboy and wrestler differ in certain critical ways. First, rodeo cowboys deal with injuries as predictable risks of their work. Wrestlers, on the contrary, seek out injuries, or at least the appearances of injury, as signs of competence and status. Whereas an injury can restrict a rodeo cowboy’s ability to work, an injury—real or faked—can in fact enhance a wrestler’s ability to work by enhancing his persona and providing material for dramatic interludes during events.

Perhaps the most sociologically relevant feature shared by the professional rodeo cowboy and the professional wrestler is their membership in the working class. They cannot afford to dwell on their afflictions, which include the wrestlers’ real injuries (Curry, 1992). Thus, rodeo cowboys approach job injuries pragmatically like other members of the working class who work hard for a living and do not get paid if they do not work (cf. Kotarba, 1983a; Smith, 1981). This commonsense philosophy helps explain the increasing popularity of chiropractors in these sports—with their pragmatic, get-em-back-to-work-as-quickly-as-possible method of healing. This approach contrasts with the health care given to middle-class athletes (managed care for Pro-Pop athletes) and the comprehensive, specialized, medically based, and individualized health care given to upper-class athletes (elite care for major league athletes).

One final sociological issue is the relationship of these primitive forms of occupational health care to the concept of sports medicine. Members of professional rodeo have been successful in locating their health care system under the rubric of sports medicine, whereas members of professional wrestling have not. Historically, the concept of the Justin heeler emerged in the early 1980s, at the same time that the concept of sports medicine was gaining currency both in the medical literature and the common culture. The traditional role of the trainer—with its corresponding cultural image of a swarthy, middle-aged, pot-bellied, cigar-chomping denizen of sweaty locker rooms—gave way to the professionalized, college-trained paramedic. As the concept of sports medicine gained legitimacy in team sports (e.g., football and baseball) as well as individual sports (e.g., running), promoters of less fashionable sports such as professional rodeo could readily claim legitimacy by displaying to their audiences and critics, in effect, “Y’all might think that rodeo is pretty old fashioned, but we’ve made progress just like the other sports... We even
have sports medicine for our cowboys.” Thus, the Justin heeler joined the instant-replay screen and indoor fireworks as ways of modernizing rodeo to meet mass media–driven audience expectations.

Sports medicine has served one other function for professional rodeo as a social institution: It has helped reframe the cowboy’s image as an athlete. The concept athlete is highly esteemed in our culture. The introduction of sports medicine helped restore the image of the cowboy at a time when the mass media (e.g., films and television) were ignoring him or relegating him to folk history. All of this has been accomplished at the minimal cost of creating a system not dependent on expensive physicians for staffing or administration. The introduction of the concept of sports medicine, however, does not mean that the long-term health care needs of rodeo cowboys are yet adequately addressed.

There are at least two reasons why professional wrestling has not sought to locate its health care system under the rubric of sports medicine. First, from a structural perspective, it lacks the kind of corporate sponsorship that would see public relations value in supporting a program like the Justin heelers for wrestlers. Second, from a cultural perspective, professional rodeo operates within a theatrical, romanticized, and fictionalized world in which the stark realities of injury and disability simply do not fit. A parallel phenomenon would be the imposition of the reality of emergency health care for a twisted ankle at a performance of the Swan Lake ballet.

In conclusion, changes are taking place rapidly in the world of professional sports that should be monitored in the development of a sociology of occupational health care. Rodeo promoters are proposing new and increasingly comprehensive insurance coverage for cowboys. Female wrestlers are becoming increasingly visible, accompanied by their gender-specific health care needs. New styles of wrestling, including Extreme Championship Wrestling, are integrating traditional theatrical wrestling with martial arts, boxing, and street fighting. The level of injury and the resultant need for additional health care services are likely to increase.

NOTES

1. The term Pro-Pop sports refers to professional team sports whose status is lower than that of major league sports in terms of overall popularity, fan attendance, level of remuneration to players, and so forth. Unlike minor league sports, such as the Continental Basketball Association and Minor League Baseball, Pro-Pop sports do not ordinarily serve as training grounds for future major league stars. Instead, Pro-Pop sports teams function to (a) provide arena business when the major league sport is not in season and (b) attract families and other budget-conscious entertainment consumers who have been priced out of the major leagues.

2. The word heeler is only partially a play of words. Although it implies a deliverer of health care, it also refers literally to a member of a calf-ripping team. The heeler is the cowboy who ropes the calf’s rear legs.

3. See Kotarba and Haney (1995) for a detailed, case-study, biographical description of the original Justin heeler, Bill Ziegler.

4. I will not engage in the commonsense and sociologically dysfunctional issue of whether professional wrestling is fixed. Like other forms of artistic performance, professional wrestling is obviously choreographed. Furthermore, fans apparently are less and less concerned with this question, as the issue of who wins and loses is less relevant than the dramatic and theatrical context of the matches and the wrestlers’ personae (see also Mazer, 1998).
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Joseph A. Kotarba, Ph.D., is professor of sociology at the University of Houston. He has conducted extensive research on chronic pain, alternative health care, wellness, and HIV/AIDS. He is currently writing a general theory of sports medicine as occupational health care and studying inner strength among persons living with HIV/AIDS.
Tell Me What You Mean by “Sí”: Perceptions of Quality of Prenatal Care Among Immigrant Latina Women

Deborah E. Bender
Catherine Harbour
John Thorp
Peter Morris

Individual perceptions form the basis of many health research reports related to access, utilization, continuity, and quality. Many health care providers are not well equipped for designing studies or collecting data with immigrant populations. In this article, the authors examine issues in data collection on topics related to perceptions of quality of prenatal care among immigrant Latino populations. The conceptual model is Donabedian’s framework for quality. Two instruments—a qualitative interview with photographs representing components of quality and a questionnaire—were used for data collection. Examples of narrative responses given by women in response to the photo-narrative prompts are presented and compared to shorter survey responses. The authors emphasize the importance of designing research instruments that reflect the perceptions of the research subjects rather than simply those of the investigators.

Assessing client perceptions of quality of care is often a low priority for health service providers. This may be so because of the difficulty of obtaining objective, verifiable information. For example, a researcher who asks a respondent how she feels about the prenatal care she has received cannot independently verify her answer (McNabb, 1990). Still, there is an increasing call for understanding quality from the perspective of the client, perhaps precisely because these perceptions do form the basis for judgements of quality of health care. This is especially important in prenatal care in which values and practices passed from one generation to another may be inconsistent with advances in technical quality of care or in which clients and providers are members of different cultural and/or linguistic backgrounds. In this article, we examine issues in data collection on topics related to perceptions of quality of prenatal care among recent immigrant Latino populations.

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© 2001 Sage Publications
Many health care service providers may not be well equipped for designing studies and collecting data with recent immigrant populations because they lack experience and preparation in cross-cultural research (Hong, 1998). Research instruments reflect the perspectives of the investigators. These perspectives may not reflect the perceptions of the research participants. “Whenever instruments are selected and used, innate influences that are, in part, a result of the researcher’s worldview of the universe of interest may be in operation” (Ferketich, Phillips, & Verran, 1993, p. 227). This difference in worldview between researcher and participant can affect the validity and, ultimately, the applicability of research results to service delivery.

Several previous studies have combined qualitative and quantitative methods of data collection for health care research, and this type of combined methodology may be especially appropriate in a cross-cultural research situation. To incorporate cultural concerns in public health research, Carey (1993) supported the use of qualitative methods in combination with quantitative methods: “Because culture is largely a qualitative phenomenon necessitating at least some qualitative methods, cultural factors will not be adequately integrated into public health unless greater effort is made to use both approaches” (p. 315).

McVey (1997) used qualitative and quantitative methods to study vitamin and antibiotic injection practices among migrant Latino farmworkers in North Carolina. The practice is of concern because of the risk of HIV transmission through shared needles. Investigators combined qualitative data from the semistructured interviews with quantitative survey data to further health service providers’ knowledge of lay injection practice. In this study, the qualitative data enriched quantitative data by adding context and narrative to reported statistics. “This study illustrates the need for a culturally sensitive approach to HIV education. In the case of migrant farmworkers, merely translating material developed for U.S. populations inadequately deals with their life experiences” (McVey, 1997, p. 97). By using a combined methodology, this study was able to ascertain some of the cultural significance of the practice of lay injections as well as their prevalence.

Several studies have considered the challenges of collecting data in a cross-cultural context. Discussing recruitment for a multicultural survey on mammography, Zapka, Chasan-Taber, Bigelow, and Hurley (1994) found that “many low-income women had little experience with such surveys—many seemed perplexed about why we would want their opinions” (p. 492). Investigators found that a substantial effort was required through telephone contact and mailed information to garner participation in the study.

In a study of an arthritis self-management program for Spanish speakers, Lorig, Gonzalez, Ritter, and Nacif de Brey (1997) compared three methods of data collection (face-to-face interviews; telephone interviews; and mailed, self-administered questionnaires). The investigators found differences among the three types of data collection methods in the self-efficacy evaluations (a perceptual assessment). Self-efficacy scores were “significantly lower in the group that reported through the mail,” which the authors attribute to “a tendency to present a ‘good’ or more positive self-image during a face-to-face or telephone interaction with an interviewer” or “socially desirable” bias (Lorig et al., 1997, p. 233). The bias may also result from interviewees being more confident in their abilities when talking with an interviewer than when answering a questionnaire in writing (Lorig et al., 1997).
McNabb (1990) examined the use of self-reported data when investigators come from a culture different from that of study participants. His study of Alaskan Native Americans found that cultural convention about disclosure of information hinders data interpretation. “The collection and analysis of subjective self-reports under these circumstances may provide good data regarding cultural differences but poor data about perceived life quality” (McNabb, 1990, p. 291). Normally, researchers develop questionnaires to be independent of context and to “evoke entirely common features of real human discourse and interaction” (McNabb, 1990, p. 296). McNabb found that investigators’ attempts to remove context in measurements of subjective states are ultimately futile. “Despite efforts to eliminate context and create perfectly lexicalized items, conventions of expression establish an inescapable context for questionnaires” (McNabb, 1990, p. 296). Thus, attempts at assessing subjective elements of quality of care, such as satisfaction, must take into account the context in which the question is asked and answered.

A Likert-type scale question format, which uses many different categories and is often used in social science research, has been found to be difficult to use with certain populations (Giachello, 1996, p. 242). Saint-Germain, Bassford, and Montano (1993) examined the use of preventive health care by older Hispanic women in the southwestern United States. They found that the Likert-type scale caused problems with subjective questions because it imposed a decontextualized response frame on a contextualized situation. Not wishing to be discourteous, the respondent will simply opt for the least contentious response, which in this case is usually very satisfied or somewhat satisfied. The way the question was framed forced respondents into a restricted way of thinking about their health care that conformed to the restricted choice of responses.

In summary, select characteristics, recognized as being intrinsic to Latino culture, make it more difficult to collect reliable information using traditional closed-ended questions or Likert-type scales. The Latino preference for presenting a good self-image and the way in which health and illness are contextualized in the complex fabric of life argue for a more open-ended format for data collection. Such formats do pose a challenge for health professionals in their analysis and presentation, but the dilemma is not insuperable. Narrative responses can be decontextualized and coded like other data during analysis and then recontextualized in the presentation of findings and recommendations. If these steps are carefully executed, the research has the potential to enrich as well as inform.

Bender, Baker, Dusch, and McCann (1997) nested a focus group study within a cross-sectional design in their study of periurban Bolivian women’s knowledge of exclusive breast-feeding as an early method of family planning. Their objective was to gain a more in-depth understanding of women’s knowledge and experiences with lactational amenorrhea antecedent to the design of an intervention to promote method use. The authors compared findings of the focus groups and questionnaire and found that the more complete narrative responses of the focused group discussions clarified the noncommital responses to the questionnaire. The results gave further direction to the design of educational messages for the intervention.

Data collection methods that employ photography or prompts may be useful in cross-cultural research settings to overcome certain linguistic barriers. In these settings, the researcher is “a joint participant who encourages study participants from
cultural backgrounds different from his or her own to express themselves through whatever interpersonal communication media are useful and contextually appropriate” (Hong, 1998, p. 86). Participants can talk about a picture using their own vocabulary; they are not restricted to scales or other types of closed-ended responses.

Photography is a powerful tool that can be used to provoke emotion and stimulate memory. Early documentary photographers used their visual images as a means of presenting the inner lives of culturally distinct individuals or communities to a broader audience (Allard, 1989; Collier & Collier 1986). More recently, documentary photographers, including Ewald (1985, 1994) and Wang and Burris (1994, 1997), have placed cameras in the hands of members of disadvantaged groups (inner-city school children in Durham, North Carolina, and peasant women in China, respectively). The subjects turned photographers are encouraged to document their lives, identify strengths and needs, and generate solutions to their own most pressing problems. The picture-based medium appears to have high effectiveness in low-literacy environments or in locations where print-medium materials are not readily available.

Others have asked participants to take photographs to illustrate a particular concept. Hanna, Jacobs, and Guthrie (1995) used photography to study the subjective topic of adolescent diabetics’ conception of health. Adolescents were given Polaroid cameras and asked to photograph situations of health, then asked to write how the photographs demonstrated health. Investigators then content analyzed the written descriptions for the elements of the meaning of health. The authors noted that photography is a way for “children and adolescents to communicate feelings and ideas” (Hanna et al., 1995, p. 322).

Bender and Castro (2000) have given immigrant Latina women cameras and asked them to photograph themes—persons, places, and things—that are important in helping them to maintain their health and well-being (see also Bender, Castro, & O’Donnell, 1999). After the photographs were developed, the women were asked to tell the story of the photograph. Using photographic prompts also allowed the interviewee to talk about herself in the third person by projecting her own experiences and opinions that may not be “socially desirable” onto the subject in the photograph.

A second recent study reporting on Latina preferences explored the relation between prenatal characteristics and satisfaction among Medicaid recipients (Handler, Rosenberg, Raube, & Kelley, 1998). Satisfaction included reference to access, availability, and efficacy; technical quality; and the art of care. Results were reported for 75 African American and 26 Mexican American nonadolescent primiparous pregnant women who had had at least three prenatal care visits. For both groups, whether the provider explained procedures was the most important determinant of satisfaction.

The above reviewed outlines a set of research-based precedents; they are presented as the foundations of the study, whose findings are reported here. In this study, we report on immigrant Latina women’s perceptions of quality of prenatal care. We emphasize the additional depth of understanding gained from listening to women’s stories about the photo-narrative prompts as compared to responses given on the questionnaire.
METHOD

The study sought to assess Latinas’ perceptions of quality of care and personal values that influence care-seeking behavior. Donabedian’s (1988) model of quality served as the conceptual framework for the study. The investigators chose to organize data collection using the four components of health care: access, continuity, technical management, and interpersonal relations (Donabedian, 1966, 1988; see Table 1). Access and continuity of care address provider and consumer concerns with the quality of care received by the community as a whole rather than that received solely by individuals. The quality of technical performance depends largely on the knowledge, judgments used in selecting strategies for care, and skill in application held by the provider (Donabedian, 1988). Interpersonal relations, a component of quality that providers find very subjective, may be key to judging quality on the part of recent Latina immigrant women. For recently arrived Mexican women, accustomed to confiding only in their mothers, the interest on the part of doctors and clinic staff helped them alleviate their sense of loneliness and distance from extended family members (Bender & Castro, 2000). The interpersonal process is also essential to high-quality health care and is the face and hands of technical care. The quality of the interpersonal process may be judged relative to dominant social preferences, norms, and expectations. These expectations may vary widely as a result of differences in birthplace, education, social class, occupation, and culture.

### TABLE 1: Dimensions of Quality: Concepts and Perceptions

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<th>Access</th>
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<th>Technical management</th>
<th>Interpersonal processes</th>
<th>Continuity</th>
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<td>Personal accessibility</td>
<td>Convenience of locations</td>
<td>Availability of resources</td>
<td>Personal acceptability of care</td>
<td>Continuity of care/follow-up appointments</td>
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<tr>
<td>Convenience of locations</td>
<td>Transportation types</td>
<td>Ability of providers to elicit and respond to questions</td>
<td>Language spoken/interpreter</td>
<td>Perception of improvement/protection of health</td>
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<td>Transportation types</td>
<td>Travel time, costs</td>
<td>Treatment/advice is provided according to professional standards of care</td>
<td>Humanness</td>
<td>Finances</td>
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<tr>
<td>Travel time, costs</td>
<td>Hours/days of service delivery</td>
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<td>Information gathering</td>
<td>Efficacy/outcomes of care</td>
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<td>Technical management</td>
<td>Availability of resources</td>
<td>Pleasantness of surroundings and staff</td>
<td>Humanness</td>
<td>Referral as appropriate to standards</td>
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<td>Availability of resources</td>
<td>Ability of providers to elicit and respond to questions</td>
<td>Information giving</td>
<td>Personal acceptability of care</td>
<td>Continuity of care/follow-up appointments</td>
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<td>Ability of providers to elicit and respond to questions</td>
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SOURCE: Adapted from Donabedian (1988), Linder-Pelz (1982), Myers (1965), and other expert reports of the literature, providers, and managers of services.
Data were collected from immigrant Latina women attending two prenatal clinics, the University of North Carolina Ambulatory Care Center (UNC-ACC) in Chapel Hill, North Carolina, and the Wake County Health Department in Raleigh, North Carolina. This study used two data collection instruments: a quantitative survey and a qualitative interview with photographic prompts (see Figure 1). Both instruments reflected concern for the four components of Donabedian’s (1988) quality framework. The survey sought to assess women’s perception of the four components of quality, using questions with Likert-type scale answers. The survey also included sociodemographic questions, such as level of formal education, current residence, fertility history, and prior use of health services. Items for this
questionnaire were selected from among those used for a demographic and health survey, originally designed for use with Third World populations (Gutierrez, Ochoa, & Raggers, 1994). Data were also collected on place of birth, place of residence at 12 years of age, and length of time in North Carolina, which are variables recognized as markers of acculturation (Bender, Rivera, & Madonna, 1993; Giachello, 1996). The questionnaire took about 30 minutes to administer.

The photographs were taken with the assistance of staff at the UNC-ACC, who suggested stages of the prenatal care appointment and posed in the pictures as nurse, doctor, receptionist, and so forth. They were selected by the authors from among 30 photographs taken as representative of the components of Donabedian’s framework. The interview guide for the photographic prompts asked women to first describe the photograph, including how the woman in the photograph was feeling. Then each woman was asked if the photograph reminded her of an experience she or a family member had had. If so, she was asked to tell the story of that experience. The photo-narrative interview took about 15 minutes to administer.

Because the investigators wanted to test the photographic prompt instrument and compare responses to the standard questionnaire, they intended that one of every four women who answered the questionnaire also respond to the photographic prompts. However, the women preferred to talk about their own experiences in relation to images presented in the photographs. As a result, more women responded to the visual instrument than had been anticipated.

Interviews were held with participants following a prenatal care visit at one of the two sites named above. Participants were given an appreciation gift (a gender- and language-neutral baby toy) to thank them for participating in the study. The study was approved by the University of North Carolina School of Public Health Institutional Review Board on Research Involving Human Subjects.

Data from the survey were coded in Epi Info 6.0 then transferred to Statistical Analysis System for analysis. Qualitative data from the interview with photo prompts were typed into Microsoft Word. Two investigators read each of the interviews and coded the text using induced codes in Spanish. The comments made by the women were then grouped under one of Donabedian’s (1988) components of care by the two investigators. As a next step, the investigators compared groupings, discussed differences, and agreed on a primary assignment of a woman’s comment to one quality component. The photo prompts themselves are sequenced so as to elicit experiences related to access, technical management, interpersonal relations, and continuity, so the majority of the women’s responses fit neatly with a component. Sometimes, however, stories pursued a tangent, and a reassignment to another component was necessary. Data from quantitative and qualitative sources were used together to generate study results.

RESULTS

Ninety-seven women responded to the questionnaire; 45% of these were at the UNC-ACC and 55% were at Wake County Health Department. Forty-five women responded to the photo narrative: 44% of these women were at the Ambulatory Care Setting; the remaining 56% were at the Wake County setting. The data from the two samples were compared at the outset. No differences in patterns of education, birthplace (rural vs. urban), and residence at 12 years of age were found between
participants from the two sites. In the paragraphs that follow, we present results related to access and interpersonal processes, two components from the Donabedian (1988) framework. The combined use of qualitative and quantitative methods gives the reader greater depth of understanding while placing the qualitative results in the context of responses to a larger, more generalizable sample.

The questionnaire asked the respondent about two characteristics of access: mode of transportation and ease of getting to the clinic. Women were asked to choose their response from among those listed on a 5-point Likert-type scale. Three quarters of the women used some form of private transportation—the family car, a borrowed car, or a ride from a friend. Interestingly, only 28.2% of the women reported having a driver’s license. Slightly more than half of the women said that it was easy to get to the clinic; the remainder reported that it was neither easy nor hard (14.1%), difficult (25.6%), or very difficult (5.1%) to get there. Furthermore, even among those who used public transportation (bus or taxi) to get to either of the clinics, responses were evenly divided as to the ease of arrival at the clinic. Travel time to the clinic was 30 minutes or more for 50% of the women. There were no differences by site.

The photo-narrative interview added more telling detail to the transportation picture sketched by the quantitative survey results. The women’s responses give the reader an indication of the effort involved in keeping scheduled appointments. One photograph depicted a woman sitting next to the door of the clinic, with a child in a stroller and another woman at her side (see Photo Prompt 7).

Of the seven pictures, Photo Prompt 7 elicited the most animated responses, even from women who drove themselves to appointments. In responding to the photograph, women often switched from talking about the woman in the photograph (“She looks like . . .”) to talking about themselves (“I had to . . .”).

Pero son muy apagadas. Ellas tienen que venirse, si sus esposos las traen está bien. Cuando no sabía manejar esperé mucho—esperaba el bus público. [They look really worn out. They have to get here themselves; if their husbands bring them, it’s OK . . .] When I didn’t know how to drive, I waited a long time—I waited for the public bus.

Hasta ahora, yo no manejo. Me hace esperar 3-4 horas hasta que llega mi esposo del trabajo para recogerme. [I don’t drive yet. I had to wait 3 to 4 hours until my husband came from work to pick me up.]

Para mí es difícil arreglar el ride porque está lejos . . . consigo ride y pues me espera hasta que salgo . . . [I ask] a cousin or friends or people from church.

Me trajo un primo . . . cualquier persona me trae. [My cousin brought me . . . someone always brings me.]

The women’s responses to this photograph were consistent with those in the questionnaire but provide more detail about the types of hurdles women face in getting to clinic appointments at the time requested. Many Latinas have never driven or owned a car prior to their arrival in the United States. Getting a driver’s license affords one a greater degree of freedom, especially in a locale where public transportation is inadequate. Arranging rides, coordinating schedules with working family members or friends, and waiting make scheduled appointments more difficult to meet.
Waiting time to see the doctor at the clinic was another topic that provoked much comment from the women. The questionnaire asked, “How long did you wait here in the waiting room before seeing the doctor?” Almost two thirds of the women reported having waited 30 minutes or less, but the remaining third of women said that they had waited 60 minutes or more for their most recent appointment. Differences between the two sites were not significant. However, a greater percentage of women at UNC (25.9%) waited more than an hour and a half as compared to Wake County (19.4%).

Two of the photographs addressed waiting; one depicted the waiting room (Photo Prompt 1), and the other depicted a woman waiting in the consultation room (Photo Prompt 4).

Although some participants did not seem to mind waiting outside for a while, others were less patient. Although waiting is an accepted part of the process, it is interesting to note the differences in waiting time based on having or not having an appointment. In a similar study conducted in Bolivia, the respondents suggested that more educational materials should be made available or videos shown during the wait to help patients learn more about prenatal care and family planning and to reduce the boredom of the wait.

In the questionnaire and in the photo-narrative interviews, women were asked about two aspects of interpersonal relations: the way they were treated by the doctor or nurse (Photo Prompts 2, 3, and 5) and their experience with interpreters. Of the women responding, 90% said that they had been treated respectfully or very respectfully by the doctor and nurse. In the narrative responses, the women indicated more clearly how they perceived respect.

In each of these phrases, women use the verb platicar (to chat) rather than other synonyms. The repeated use of the more informal verb suggests the value that
Latinawomenplaceonhavingtimetotalkthingsover,tospendalittletimewiththedocotoralkingaboutchildrenorotherfamilymembers,literally,tochat(PhotoPrompt5).Forthesewomen,chattingoffersreassurancelandisavaluedpartofhigh-qualitycare.

Womenwerealsoaskedabouttheirexperienceswithinterpreters.InasettingwheretheimmigrantLatinapopulationisarecentoccurrenceandrelativelyfewprovidersspeakSpanish,theroleplayedbyinterpretershasthecapacitytoexertastronginfluenceoninterpersonalrelations.Ofthewomenwhorespondedtothequestiononinterpretation,63%hadusedclinicinterpretduringthemostrecentvisit.Twowomenhadbroughtachildalongtointerpret;30%ofwomenreportednotneedinganinterpreterbecausethedoctorspokeSpanishor“Spanglish”wellenoughtocommunicate.

Thephotonarrativeinterviewsyieldedmoredetailedandpersonalexperiencesofinterpretation.MostrespondentsidentifiedthewomanwhoaccompaniedtheLatinainthephotographasaninterpreter(PhotoPrompts2and5),whetherfromtheclinicorsomeonethepatientbroughtwithher.Respondentshadmixedopinionsabouttheinterpreters.

Sentir a una persona cómoda, tener siempre a una persona interpretando... por lo regular cuando tiene interprete, bien, okay—“tengo alguien conmigo.” Si tiene preguntas, puedes preguntar. De nuevo se siente [señalando a la foto] bien por que puede entender lo que está pasando. [You feel comfortable always having someone interpreting. ... Usually when you have an interpreter, it’s good, it’s OK—“I have someone with me.” If you have questions, you can ask them. Again, she {pointing to the picture} feels good because she can understand what’s going on.]

Untilrecently,oneclinicdidnothaveafull-timeinterpreter. One woman at that clinic said,

[Cuando vení con el embarazo de mi hija], traía mi niño, a mi niño le traje [para interpretar]. [[When I came with the pregnancy of my daughter], I would bring my son, I made him come (to interpret].

Stillotherwomenpreferrednottouseaninterpreterbecauseofaperceptionthatinterpretersarenotveryhelpful.

No quiero. No me gusta verlas. Son muy malas. Prefiero entender lo que puedo. [I don’t like them. I don’t like to see them. They’re very mean. I prefer to understand what I can.]

Interpretersrepresentmanymakes to the Latina respondents. They are neutral. Women who are uncertain about the circumstances of care tend to rely on the interpreter as a friend. The use of a child as an interpreter is an indication of the urgency a woman feels to understand the context of prenatal care. Providers agree that children should not be used as interpreters, but sometimes circumstances make it necessary. In some clinic settings, there may be both paid and volunteer interpreters. The latter may be well intentioned but not have the requisite skill to serve as a qualified interpreter. Women with some English vocabulary are likely to discern errors and misinterpreted passages.
Because of the Latino cultural preference for appearing to agree with persons in authority—including interviewers, as in this case—direct questions would have been less likely than the photographs to elicit such a frank response as this one. Even in the other two examples, the respondent was free in the photo-narrative interview to attribute a role to the third person in the photograph and to answer based on that decision. The same flexibility of format does not occur in a questionnaire format.

CONCLUSIONS

Many challenges face researchers who seek to gather data in populations of different national or ethnic origins. The most obvious challenge is the language barrier that often exists between researchers and participants. However, other more subtle differences between researcher and participant may be just as important: literacy levels, interviewer-interviewee rapport, cultural backgrounds, social desirability, and the lack of suitable background data.

Literacy levels can affect both recruitment and data collection. Posters and flyers advertising studies may be inaccessible to Latinos with low-literacy skills, especially if they are written in English. Literacy may affect the style of data collection as well. Investigators may need to administer questionnaires if wording is ambiguous or if the study population is not highly literate. Mailed questionnaires are another option. Participants may be unwilling to be tape-recorded, which can complicate data collection.

The rapport or lack thereof between a participant and a researcher may also affect the quality and validity of data collected. Two important considerations when working with Latinos are confianza (trust) and personalismo (personal character). When working with Latinos, it is often important to chat (charlar) or engage in small talk about personal lives before beginning to talk (hablar) about the purpose of the business or medical visit to establish trust and a friendly, communicative environment (Torres & Aponte, 1999). Data collection protocols that do not encourage the researcher to establish this rapport through small talk or other means may collect answers that are more guarded, particularly about sensitive topics such as reproductive health care.

For many types of research, a bias toward social desirability limits the quality of data collected. Aday, Chiu, and Andersen (1980) noted that a “yea-saying” bias in Spanish-heritage respondents was significantly higher than in other respondents. During data collection in the study described above, one of the investigators (Harbour) interviewed a woman in a late stage of pregnancy in a very full waiting room. The participant and the investigator were standing against the door to the clinic waiting room because there was no place to sit while children and their parents went in and out of the door. The investigator asked, “How comfortable is the waiting room: very uncomfortable, uncomfortable, neither comfortable nor uncomfortable, comfortable, or very comfortable?” The Latina woman shrugged her shoulders and said “comfortable,” although to the investigator, the waiting room seemed just the opposite.

Social desirability is difficult to assess, and indeed, the concept of comfort may mean something different to the interviewer and to the interviewee (Leung & Van de Vijver, 1996). In this situation, the respondent may have compared the waiting
room to others she had been to and judged this one to be more comfortable. Or she
may have considered the waiting room to be comfortable in general, although she
recognized that at the time of the interview, there were an unusual number of peo-
ple waiting, which temporarily made it uncomfortable. At a minimum, to be acces-
sible, data collection instruments to be used with speakers of another language
must be accurately translated into the other language. Instruments should also be
culturally sensitive and use appropriate vocabulary for the research participants
(depending on region, ethnicity, gender, etc.). For Latinos, “the data collection pro-
cess is impeded by research instruments that are neither designed nor sensitive to
the cultural contexts of the diversity of Hispanic/Latino population” (Giachello,

Another challenge in designing instruments is to overcome investigators’ own
cultural and professional backgrounds. Asking interviewers to work in another lan-
guage can also be problematic and can compromise their data collection skills (Van
de Vijver & Leung, 1997). In selecting the items to be included in and excluded from
data collection, researchers’ own socializations and biases of gender, race, class, and
so forth come into play. The differences between investigators and participants can
have linguistic ramifications as well. Researchers, particularly those with a strong
medical background, may speak more “medicalese” than their research partici-
pants (e.g., “contusion” for bruise or “MI” for heart attack). “Practitioners adhere to
the standards of communication set down by the ‘medical culture’ even when they
may conflict with the goal of reaching the client” (Meadows, 1991, p. 39). Questions
may be written using vocabulary that is too technical or wording that is difficult for
respondents to understand in the way intended by the researcher.

Closely related to the use of medicalese is the paired issue of educational level
and socioeconomic levels of researchers and research participants. Researchers and
participants may have very different levels of education and come from different
socioeconomic levels. These disparities can have an impact on how instruments are
designed and delivered and how well respondents actually understand them. Dis-
cussing instruments available for health outcomes research on Latinos, Giachello
(1996) wrote that “the available instruments are most likely to be biased along racial
and ethnic, socioeconomic and/or gender lines and are often difficult to adapt to
populations with low levels of education” (p. 242). Researchers may design instru-
ments laden with “survey-ese” that is difficult for some participants to understand,
or participants may be unfamiliar with the purposes of surveys and interviews.

This study minimized many of the barriers to data collection related to percep-
tions in a cross-cultural context. Using both quantitative and qualitative instru-
ments yielded more in-depth information than either method alone would have
yielded. The paired methodology sets in place a number of checks and balances
with respect to the reliability and validity of the data. The use of the questionnaire
with a larger sample provides information on the reliability of responses. The in-
depth responses of women to the photographic prompts enabled the women to
speak about their concerns and frustrations in ways that a questionnaire does not
invite. Because these frustrations have the potential to influence future care-seeking
behaviors, a better understanding of the women’s perspectives can lead to improve-
ments in service delivery.

Because prenatal care appointments follow a routine procedure, which research
participants in the study easily recognized, the photographic prompts facilitated
women’s responses. Other health care situations may follow less standard
procedures, and it could be more difficult for a research participant to see his or her own experiences in a set of photographs. One useful modification to data collection would have been to conduct focus groups with women attending the clinics. These might have been done prior to asking about photographs, or the photographs themselves could be the center of the focus group discussion. Previous research has shown that focus groups can be very informative with some populations. Saint-Germain and colleagues (1993) found that focus group interviews “may be a better way than surveys of making persons with limited education feel that their words and ideas are important” (p. 347). The format allows participants to brainstorm together and draws on oral traditions to seek out and examine information and perceptions (Saint-Germain et al., 1993, p. 363). “Often, members can trigger ideas from each other, and views may be expressed that would take much longer to elicit in the context of an individual interview” (Proctor, 1998, p. 86). Saint-Germain et al.’s (1993) study of Latinos found a difference in respondents’ satisfaction with health care between individual survey respondents, who were highly satisfied, and focus group respondents, who were less satisfied.

The combined use of questionnaire and photographic prompts has the potential to elicit responses that are representative and valid. Quantitative data collection can be used for statistical analysis or to enhance previously collected data, but its uses for asking about perceptions are limited. It has an accepted structure, and its closed-ended responses can be rendered descriptively or analytically, depending on the needs of the investigators. The use of photographs, however, allows a respondent greater freedom of expression than does a questionnaire. In the photographic interview, respondents can answer in their own language using their own vocabulary and avoid problems of survey-ese, medicales, and the imposed language of a closed-ended question. Focusing the discussion on the photographic prompts allows the respondent to tell a story about a third party rather than trying to recapture and describe an experience that only the participant understands. Although many of the women’s responses to the photographs were similar to the responses made in the questionnaire, photographs did evoke different (and often more compelling) stories than those elicited by the survey instrument.

In this study, photographs were used as prompts to elicit women’s stories about their own and other family member’s experiences. The stories draw on the respondents’ visual memories of past health care encounters. Their responses may not be accurate, for many reasons, including time-lagged recall bias. However, the stories that each woman chose to tell convey certain recollections of their experiences. And these stories appear to play a role with respect to the respondents’ perception of the quality of care received.

REFERENCES

Deborah E. Bender, Ph.D., M.P.H., is a clinical professor at the University of North Carolina School of Public Health. Her research interests focus on quality of health services for migrant women and children and the integrated use of qualitative and quantitative data collection methodologies.

Catherine Harbour, M.P.H., worked with Deborah Bender interviewing Latina women about perceptions of quality of prenatal health care. She currently works in multimedia documentary research and production for health education at State of the Art, Inc., in Washington, D.C.

John Thorp, M.D., is codirector of the North Carolina Program for Women’s Health Research and faculty in the School of Medicine at the University of North Carolina.

Peter Morris, M.D., M.P.H., is medical director and policy director for Wake County Human Services in Raleigh, North Carolina. He also serves as chair of the North Carolina Farmworker Health Alliance, an organization dedicated to improving the health and well-being of the state’s immigrant Latino population.
Components of Quality of Life for Persons With a Quadriplegic and Paraplegic Spinal Cord Injury

Patricia J. Manns
Karen E. Chad

This investigation determined the themes that represented quality of life for persons with a spinal cord injury. Fifteen people (6 females, 9 males; 7 persons with quadriplegia, 8 with paraplegia) participated in this study, which used naturalistic inquiry methodologies. Results showed that quality of life for this population, regardless of severity of impairment, consisted of nine themes: (a) physical function and independence, (b) accessibility, (c) emotional well-being, (d) stigma, (e) spontaneity, (f) relationships and social function, (g) occupation, (h) finances, and (i) physical well-being. The themes of life quality were similar for quadriplegics and paraplegics; however, physical function and independence and physical well-being affected the quality of life of persons with a quadriplegic injury to a greater extent. These findings may provide health professionals with information necessary to assist in the development of programs to enhance quality of life.

Health care professionals have traditionally focused on disability assessment and management when working with persons with a spinal cord injury (Whiteneck, 1994). Much less attention has been directed to the evaluation of life quality, even though it has been suggested that the overall goal of most rehabilitation professionals is to assist patients to improve the quality of their own lives (Wood-Dauphinee & Kuchler, 1992). Raeburn and Rootman (1996) have stated that quality of life is a representation of how good life is for a person. Thus, a change in life quality for a person with a spinal cord injury should be viewed as an important indicator of the effectiveness of health promotion strategies (Lanig, Chase, Butt, Hulse, & Johnson, 1996).

The direct assessment of quality of life has been done infrequently in a rehabilitation setting. To date, quality of life has been routinely inferred from general measures of a person’s health or functional status (Renwick & Friefeld, 1996), and it has been assumed that an improvement in an individual’s health or functional status results in a direct improvement in his or her quality of life. However, this is not necessarily a correct assumption because health and functional measures are not based on well-developed conceptual frameworks of quality of life (Renwick & Friefeld, 1996). In addition, other tools that have purported to directly measure the quality of life of a person with a spinal cord injury have frequently been adapted from measures for able-bodied persons, without specific input from those with a spinal cord injury (Schulz & Decker, 1985). Thus, the validity of these measures in assessing life quality in the spinal cord–injured population may be questionable. To improve the
validity of such instruments, researchers need to gain a better understanding from individuals with a spinal cord injury of the various themes that should be included in the measurement of their life quality. Day and Jankey (1996) suggested it is essential that individuals who are being assessed have greater input into the determination of which aspects of their lives will be considered relevant to the ultimate representation of their quality of life. This statement is further supported by the work of Dijkers (1997), who suggested that “only the perspective of the patients/clients themselves is a useful guide to where resources can be utilized most effectively” (p. 839).

Two notable studies have used naturalistic inquiry methodologies to address some of the past concerns about measurement validity and to improve our understanding of quality of life issues with groups of physically disabled persons (Bach & McDaniel, 1993; Renwick & Brown, 1996). The findings from Renwick and Brown, who interviewed nondisabled persons as well as persons with various physical disabilities, showed that the components representing life quality were similar for all persons, regardless of a physical disability. In contrast, Bach and McDaniel (1993) found that some life quality themes, such as assertiveness and dependence/independence, were only important for individuals with a quadriplegic injury. These investigations provide preliminary information for the rehabilitation professional whose goal is to assist persons with spinal cord injury in improving the quality of their lives. However, further research may be warranted to attempt to replicate these findings and to investigate whether the issues related to quality of life for persons with a spinal cord injury vary according to the level of the impairment. Therefore, the purpose of this investigation was to determine the themes that represent quality of life for persons with a spinal cord injury. In addition, we examined whether there were differences between persons with quadriplegia and paraplegia in terms of the representation of their quality of life.

METHOD

Design

This investigation was a focused ethnographic study that examined the concept and experience of quality of life for a group of persons with a spinal cord injury. Ethnography is a “generalized approach to the developing of concepts and understanding human behaviors from the insider’s point of view” (Morse & Field, 1995, p. 26). As an ethnographer, the researcher sets out to learn from people, as opposed to going out to study people (Morse & Field, 1995). In contrast to traditional ethnography, focused ethnography concentrates on a specific area of inquiry (Sabari, Meisler, & Silver, 2000), such as quality of life, and can be used to improve practice in health science settings (Morse & Field, 1995).

Participants

Purposive sampling technique was used in this investigation because it increased the range of data that could be uncovered (Lincoln & Guba, 1985). The sample was
TABLE 1: Semi-Structured Interview Guide

1. What things are important to your life (your quality of life [QOL])?
2. How does the spinal cord injury (SCI) affect these things?
3. What are the things or aspects of your life that are affected by a SCI?
4. How do these things affect how good your life is?
5. Does the SCI prevent you from complete satisfaction in these areas (the areas they discussed that are important to their life)?
6. Does a SCI affect how good your life can be? (Either negatively or positively.) How (in what ways)?
7. What do you think QOL means?
8. Does a SCI change what is important in your life?

selected from a list of persons with a complete spinal cord injury, between 3 to 30 years post injury, living within a 150-mile radius of the research institution (150 persons in total). This list was generated from the Canadian Paraplegic Association (CPA) database. The research assistant and an individual from the CPA examined the list and selected individuals who were representative of different age groups, duration of injuries, gender, and level of injury. These individuals were then telephoned by a representative of the CPA and asked if they would consider volunteering for a study. If consent was given, the research assistant for this investigation contacted the individuals and interview times were arranged.

Nine males and 6 females volunteered to be interviewed. They ranged in age from 22 to 63 years and were a mean of 13 years post–spinal cord injury. Seven persons had complete quadriplegic injuries (1 female, 6 males), and 8 persons had complete paraplegic injuries (5 females, 3 males). Four of these persons lived in a rural setting, and the remaining 11 lived in an urban setting. Five participants were employed at least half-time, 2 were in school full time, and 8 were unemployed.

Procedure

The method of data collection in this study was semistructured interviews. Each person was interviewed on one occasion. The interviews were conducted by one of the authors, a researcher with 6 years of experience working with the spinal cord–injured population as a physical therapist. Prior to the interviews, the procedures were explained to each participant and a consent form was signed. Participants were interviewed individually in a quiet setting of their choice. The interviews were audiotaped and lasted approximately 45 to 60 minutes. The semistructured format of the interviews allowed the researchers to use predetermined open-ended questions that introduced the topic under study. These questions focused on what was important to our participant’s lives, how the spinal cord injury may or may not have affected what was important, and finally how the participants would define the term quality of life. Examples of key questions used during the interview are provided in Table 1. Data collection was terminated after 15 complete interviews, because there was saturation of information and an “emergence of regularities” in the data (Lincoln & Guba, 1985, p. 350). Saturation of information is when the interviewer begins to hear the same information reported and hence is no longer learning anything new (Douglas, 1976; Lincoln & Guba, 1985; Rubin & Rubin, 1995).
Data Analysis

Data analysis was an ongoing process from the initiation of data collection to the completion of the study. The data obtained during the project were interpreted and analyzed using strategies suggested in the qualitative literature (Guba & Lincoln, 1981). The goal of data analysis in qualitative inquiry is to find emerging themes in the data. This is achieved by identifying, coding, and categorizing patterns in the data.

At the conclusion of each interview, the notes made during the interview were reviewed to determine emerging ideas and preliminary categories. These were recorded in the researcher’s reflexive journal, a diary suggested by Lincoln and Guba (1985). The interviews were then transcribed verbatim from the audiotapes, and the manuscripts were reviewed several times by the research assistant and the principal investigator. While scanning the data, notes and comments were written on the manuscripts of the interviews to identify recurring thoughts and ideas of the participants. This information was cross-referenced with the notes made in the researcher’s reflexive journal. The process of unitizing was then performed, which involved working with the data to find units of information that came directly from the transcripts and included phrases, sentences, or entire paragraphs.

The next stage of data analysis involved the formation of categories. The units of information gathered from the unitizing process were grouped into provisional categories when the units seemed to relate to the same or similar content (Lincoln & Guba, 1985). In this investigation, the file folder method was used (Bogdan & Biklen, 1982); following placement of the similar units of information into the file folders, researchers began to look for themes, concepts, or recurring messages that emerged from the data. The process of collapsing the categories into themes involved reading the content of the file folders and finding common ideas and concepts as well as the overall messages that were emerging.

Following preliminary identification of the quality of life themes, member checks were carried out. Lincoln and Guba (1985) stated that in naturalistic inquiry, member checks are “the most crucial technique for establishing credibility” (p. 314). Member checks consisted of distribution of a document that outlined the quality of life themes to persons who had been interviewed and to other stakeholders (i.e., employees at the CPA). Respondents were asked whether the documented themes captured what was discussed in the interviews. Also, they were questioned about whether they felt the components of their quality of life were represented by the themes. Some participants responded in writing, whereas other member checks were accomplished through discussion. Following the member checks and suggestions from the respondents, minor revisions and modifications to the quality of life themes were made.

Throughout the process of data analysis, a “critical friend” or external auditor was used to independently examine the product, data findings, and interpretations (Humbert, 1995). This person performs the audit by following the data trail from the interpretations of the themes back to the raw data, forming an opinion about whether methodological decisions and themes are logical and appropriate. The auditor also looks at researcher bias, completeness of data collected, and the sampling process (Lincoln & Guba, 1985). This individual is an important part of data analysis because he or she serves to enhance the validity and dependability of the analysis (Lincoln & Guba, 1985).
RESULTS

All of the participants in the study stated that quality of life was a subjective construct and that the only one who could comment on an individual’s life quality was the person himself or herself. The respondents indicated that quality of life was what the spinal cord–injured person perceived it to be. For example, one respondent described quality of life as

basically doing what you want to do and enjoying it. I was thinking about quality of life, and you know it might look to a lot of people that there’s not much going on in my life, but I like it.

Quality of Life Themes

Data analysis led to the establishment of nine themes that this group of persons with spinal cord injury felt composed their quality of life. These themes included (a) physical function and independence, (b) accessibility, (c) emotional well-being, (d) stigma, (e) spontaneity, (f) relationships and social function, (g) occupation, (h) financial stability, and (i) physical well-being.

Physical Function and Independence

Physical function and independence in this investigation represented a person’s physical ability within his or her present limitations (i.e., level of injury). It consisted of the participant’s ability to transfer and perform bed mobility and wheelchair mobility as well as his or her independence with activities of daily living. In general, the participants stated that it was very important to their quality of life to be as physically independent as possible within their limitations. One woman with a paraplegic injury stated,

I try to be as independent as I can. My husband fixed up the lawn mower for me so I was able to cut the grass. This thing about having to wait on people to do it for you is really a burden. It really doesn’t go well with me. So I try to find a way to do it myself.

An important aspect of physical function and independence was energy expenditure for everyday activities, and it was mentioned frequently by the participants as something that affected their quality of life. The respondents stated that if a person could perform an activity independently yet expended so much energy that he or she unable to do anything else for the rest of the day, then that activity would not be functional for that person and satisfaction in this domain would decrease. One participant discussed energy expenditure for daily activities in this way:

After all these years, I still find it very frustrating to do some of the things that should be so simple yet they take so much energy. An incline that is a little too steep is just hard, hard work to get up to the top. And yet if you’re walking, you’d take the stairs or the incline, I mean there is just nothing to it. I think a person in a wheelchair or whatever disability expends a whole lot more energy, in relation to somebody who can just jump up and do whatever.
Physical function and independence was one of two themes (the other being physical well-being) that affected the quality of life of persons with quadriplegia to a greater extent than those with paraplegia. Hand function was specifically identified as decreasing physical function for quadriplegic persons. This limited function had implications for (a) writing in school and work settings, (b) mobility in terms of opening doors and wheeling, and (c) activities of daily living such as eating and grooming. Respondents with a quadriplegic injury stated that they frequently required adaptive equipment and that tasks usually took more time and effort than for a person with a paraplegic injury. One man with quadriplegia discussed some of these issues:

I’ve often thought how much easier things would be, even if I were a para. Even if I had use of my hands… How useful they are, they’re great, everyone should have working hands.

Accessibility

The theme of accessibility refers to the physical accessibility or inaccessibility of the environment (i.e., at home, work, or leisure facilities) and the effect that it has on quality of life. Accessibility affected the quality of life for many of the participants. One respondent with quadriplegia stated, “The environment is your barrier. If everything was set up for me perfectly, then my quality of life would be absolutely wonderful. You know I could go anywhere I wanted, and everything would be just perfect for me.”

Seasonal accessibility was an issue for all of the participants in the present study. The respondents reported that cold temperatures and snowy sidewalks in winter made mobility and accessibility very difficult. One individual reported, “It’s almost like come spring, I get out of jail and I’ve been in jail for the last 7 months, and I haven’t done a damn thing to be in jail, but I have been.” Another participant discussed the difficulties related to accessibility that a person with spinal cord injury faces when deciding whether to live in an urban or rural setting:

It’s something that I still struggle with—how long I want to stay here [in the city]. But then I look at the issues that I think a lot of people with spinal cord injury look at, as far as being able to get out and get around independently. You don’t have a choice. If I want to access a gym that’s accessible with equipment, then I have to live in the city. If I want to go for a wheel at night, I have to live in the city. I can’t go wheeling down a gravel road, it’s just not practical. So it’s kind of a toss up.

All participants felt that physical accessibility was becoming less of an issue in recent years, although it still continued to be a factor that affected their quality of life. Throughout the interviews, the participants reported that there were still many places an able-bodied person could access that they could not. For example, one woman discussed how she was unable to get into the post office in her town because even though there was a ramp to the door, she could not open it without help.

The respondents also mentioned that ease of accessibility was a concern for them. They suggested that there was a difference (although not always recognized by the general population) between something being technically accessible and something being realistically and easily physically accessible to the majority of persons in a wheelchair.
Emotional Well-Being

The theme of emotional well-being was represented by two subcategories: (a) the participants’ emotional health and (b) the behaviors the participants engaged in that enhanced or detracted from their emotional health. The first subcategory represented the respondent’s actual state of emotional health, which included self-esteem, self-image, and self-confidence. Most participants reported that these issues affected their quality of life at some point in their adjustment to the spinal cord injury. As one individual stated, “You just don’t feel whole sometimes.”

Respondents also reported that at one time or another, they had varying degrees of depression following their spinal cord injury, which had affected their quality of life. One man talked about how he continued to feel depressed at times.

You dream. There are nights when I don’t sleep good. I still fight depression sometimes, not every time but sometimes. It’s not as often as it was, but there are bouts of it that are just as bad as if it [the injury] just happened.

Some of the participants stated that depression negatively affected their quality of life by making it difficult to get up in the morning and to find something to look forward to. Others, however, reported that although they may have been depressed following the injury, depression or depressive feelings were no longer as common or did not affect them at all. One young man who was injured when he was 15 years old reported that he now was just like everyone else: “You feel pretty down sometimes, but pretty much like everybody else. You get a bad day and you sit there and kind of mope. I don’t really get depressed about anything any more.” Another participant stated, “I’ll tell you, I had good days and bad days when I was walking, and I have good days and bad days now.”

The second subcategory of emotional well-being was made up of behaviors that had an impact on the emotional well-being of the participants. In the present study, these behaviors were related to coping, adjustment, and outlook following a spinal cord injury. This area was very important to the participant’s quality of life and was discussed frequently during the interviews. Many individuals were proud of how they had survived and enjoyed discussing their methods of coping. Examples of coping methods included possessing a sense of humor, not worrying about the things that cannot be controlled, and being able to recognize individual strengths and abilities. One respondent stated, “Yes, there are certain things that I know I just can’t do and, it just comes to a point that it just doesn’t bother you. You just can’t let it bother you; that’s the main thing, acceptance.” Although the ability to accept one’s injury was expressed by some of the participants, other persons reported that coping with the spinal cord injury was more of an adjustment to the disability as opposed to acceptance of that disability. This was expressed by one respondent who stated,

It’s not that you accept it. People say you sure accept your disability, but you know, it’s not that I accept it, it’s that I live with it and I do the best with what I have. I wouldn’t say that I will ever accept it.

The persons who felt they were coping well stated that they were able to do so because of their efforts to adjust to the changes caused by a spinal cord injury. They
reported that they had found a way to appreciate what they were still able to do. One respondent who had a quadriplegic injury discussed how he coped with the spinal cord injury and overcame depression by recognizing that there were others who were worse off than he was.

There was a woman who had a heart attack or a stroke. She used to really make me so mad when I was in the hospital. My door was right at the buzzer, and she’d drive her wheelchair up there and make that buzzer squawk, and she’d just sit there and they’d go and get her and bring her back, and she’d drag that chair up there again and sit there and make that buzzer squawk. And after about 2 weeks of that I thought, I can’t walk and I can’t do a heck of a lot but at least I ain’t that mixed up, sitting there and making that buzzer squawk. And that really helped. She was kind of my savior as far as my head because before that I was really depressed.

Other individuals who appeared to be having some difficulty coping with their injury frequently compared themselves to nondisabled persons or to where they thought they should have been had they remained nondisabled. For example, one respondent stated, “I really would have gone nuts if I couldn’t drive. That’s one thing I can do almost equivalent to anybody else . . . and in most circumstances, it’s pretty clear cut that you’re not [equivalent].”

The respondents also stated that one’s attitude and outlook were important factors related to a spinal cord–injured person’s quality of life. One participant demonstrated his positive attitude toward his injury when he said,

My thing is, it’s about 5 minutes slower than what I would be doing if I was walking. Like to go somewhere, it would take me 5 minutes longer. So it’s not a huge change, I just get around with wheels. That’s about it. Don’t get the old feet working.

One respondent further stated, “I’m the same person that I was before the accident except that now I have to get around a little bit differently.”

The majority of the participants also reported that they had somehow found the strength to find reason and purpose in their lives. Some individuals stated that their quality of life had actually improved since the spinal cord injury, as was evident in this quote:

The injury makes you think about what’s important and what’s not important. Before my injury, a lot of things just really didn’t concern me or I didn’t think of them as big issues. Whereas after my injury, all of a sudden you had to, you learn to appreciate a lot of different things. It [the injury] tested me as a person. It makes you a little bit stronger, I guess.

Many participants said that they had no choice but to adjust and carry on. A number of persons talked about how the spinal cord injury forced them into a personal growth they would not otherwise have achieved. It was apparent that emotional well-being and the behaviors that one used to maintain or enhance it were very important to overall quality of life.

Stigma

The theme of stigma represented the perception that persons with a spinal cord injury have of other’s attitudes toward them as people with spinal cord injury. The
respondents stated that if stigma was present or was perceived to be present, it had a
degative effect on quality of life. The participants reported that stigma affected them
to the greatest extent in the first 2 to 3 years after their injury. It then generally less-
ened over the years as they adjusted. One participant stated,

I really had a problem with that [stigma] when I was first injured. It’s not so bad now
that I had a baby because people don’t look at me as being disabled. You know, she
can have a baby or she can keep up her yard. People don’t look at me like that
around here because they know that I can do things and try before I’ll say, “No, you
better do it.”

The spinal cord–injured person’s reaction to stigma determined to a large extent
how it affected his or her quality of life. One woman discussed people’s attitudes
and her changing reactions to them over the years:

It’s really interesting, other people’s perspectives. And I must admit, early on once I
was back to work, I found it very frustrating and quite demoralizing in that lots of
people seem to almost dismiss you. In that, oh, well, if you’re legs are paralyzed,
your brain must be too. That sort of thing drove me crazy... It doesn’t happen
nearly as often anymore, probably because people are a lot more educated or what-
ever. But it was really tough to begin with. Like, you just wanted to go somewhere
and cry. So it’s interesting, that whole transition. Now I think, well, all people make
mistakes. If some people haven’t been around a person in a wheelchair, what do
they know?

Some respondents also commented that they had to overcome not only the percep-
tions of others but also their own perception of people in wheelchairs, the percep-
tion that they held when they were nondisabled. One respondent commented, “I
don’t seem to notice people notice the chair now. I mean, I’m just who I am. It was
probably that way 10 years ago, except I perceived it to be different.”

**Spontaneity**

Spontaneity (or lack of it) in all daily activities was frequently reported as some-
thing that affected the quality of life of the participants. The respondents stated that
it took longer to do things and that much more planning was needed for all activi-
ties. One individual, when asked about how the spinal cord injury affected his life,
summed up the group’s feelings about spontaneity when he stated,

Spontaneity. You have to plan a lot more. You can’t just up and go wherever with
whoever, whenever. There’s gotta be some routine. Whether it’s for personal care,
whether it’s for accessibility, whatever. I mean, you might not be able to just up and
go to the lake for the weekend if you need personal care, if you’ve got personal care
staff coming in, or if it’s not accessible and you don’t have the transportation.

**Relationships and Socialization**

The theme of relationships and socialization included relationships with family,
friends, and significant others. Some of the participants reported that their relation-
ships with family actually improved following the spinal cord injury, because they
no longer took them for granted. They came to recognize the importance of their
relationships and cultivated them to a greater extent.
My family is a lot more important than they were. I mean, they were always important, but I depend on them more. Not as much as I did in the beginning, but just to know that I always know they’re there. I just feel like they’re more important.

The respondents, however, reported that forming new friendships and relationships with potential partners was more difficult now with a spinal cord injury. Some of the respondents made successful adjustments in this area, whereas for others this difficulty negatively affected their quality of life. One man discussed his lack of a relationship and how he felt it stemmed solely from the spinal cord injury.

I guess I can compare the situation I’m in now with where I should have been if I wouldn’t have ended up in this thing [the wheelchair]. I would have been married, I would have had three kids and a dog or two. Things would have just been totally different than they are now.

Peer support was also identified as an important factor in the quality of life of a number of the participants in the sample. The respondents identified the National Paraplegic Association and friends and associates in wheelchairs as being the major sources of peer support. One participant talked of the importance of support from peers and how it was easier for her to find such individuals in a bigger center.

Actually, I think the one thing I find about being in a smaller center is I’m not around other people that are spinal cord injured, and that’s really hard. I mean, it’s not that they don’t try to understand, but they can’t. I think that’s hard. Why I really like living in a larger center is that, like, I’m around my friends and stuff, because they know what it’s like. If you have a bladder or bowel accident, you don’t have to explain it, they know. It’s a comfort zone. They also know if you’re out of shape what that means to your whole life. Whereas if you get out of shape if you’re not disabled, you can still walk. So I think that being around people that understand or can relate to you is a really big part of it.

Occupation

Another quality of life theme that arose from the interviews was the importance of having an occupation. This included not only paid employment but volunteer work, school, and housework. One respondent described the importance of having a job in this way:

I don’t know if having a job is more for financial reasons or if it’s just something to get you up and going. I was off [work] for about 13 months, and I just kind of hung around the house. You get pretty bored when you don’t have much—you just get up and do nothing again all day. At least having a job makes you get up and gives you something to look forward to—even if you don’t really like it some days.

Other participants felt that having an occupation was important because it had a positive effect on self-worth and self-esteem. One respondent reported that the sole reason she was looking for a job was her self-esteem. Because she did not have a job like a lot of other women her age, she felt it negatively affected feelings of self-worth. The persons who were able to go back into the working environment they were in prior to their injury seemed to have an easier time adjusting than those who had to change their vocation in addition to all the other changes caused by spinal cord injury.
**Finances**

All persons interviewed reported that their financial situation affected their quality of life. The respondents stated that health care costs and the price of equipment and services, such as home care or housekeeping, were substantial. One participant discussed the issue of driving and how for some people it just was not an option because of the cost of the equipment needed:

> Finances play a big part, especially when you need a vehicle that’s equipped. All that stuff costs money.... I’ve talked to a lot of people who say, “Well, I would go and get my license, but I can’t afford the vehicle and all that equipment.” It’s the same for me. But having a vehicle makes you so much more independent. I would sell my left leg for that van.

The need for outside help to assist in the care of a person with a spinal cord injury can be costly in many situations. One man described one of the common problems a lot of families face when one member has a spinal cord injury. He discussed why his wife no longer worked: “She did for a while, but that didn’t make any sense. She was getting paid less than what we were paying them to look after me. What the hell’s going on here?”

Lack of finances or financial difficulties were also noted to have an impact on leisure activities or simply the option to be involved in those health-promoting activities. Respondents stated that for someone with a spinal cord injury, playing a sport or participating in a recreational activity was no longer simply a case of buying a pair of running shoes. One participant discussed these issues:

> That’s the thing with sports and stuff. I play in this chair [her everyday chair], but it gets banged up and bumped out of whack, and plus it’s just not set up to be a sports chair. Everyone else on my team has a rugby chair. I mean, it’s like you can’t do the stuff you want to do without that modified equipment that costs much. So that’s a big thing.

**Physical Well-Being**

This theme encompassed two aspects of physical well-being: (a) the participant’s physical health and (b) the behaviors and actions of the participants that promoted their health or detracted from it. The first subcategory of this theme, physical health, represented the presence or absence of physical symptoms, including physical illness, obesity, or physical injury. The respondents reported that pain, spasticity, urinary tract infections, and pressure sores were common health problems that had negatively affected their quality of life.

Health behaviors, in contrast to actual health, referred to what the respondents did to enhance their health or detract from it. Participants discussed health behaviors such as eating a healthy diet, physical activity and recreation, and adequate rest as having a positive effect on their quality of life. They also discussed the importance of being proactive with regard to common health problems related to spinal cord injury. Some of these behaviors included pressure relief while up in the chair to avoid pressure sores and maintenance of a regular bowel and bladder regime so that infections could be prevented. One respondent also talked about physical
activity as a health behavior that played an important role in the prevention of obesity and in his quality of life.

I gain weight if I haven’t been doing things, and that tires me out more, I know it does. I get more sluggish and transfers get harder and I think it’s harder on the shoulders when I’m at a stage where I’m not doing things [exercising]. Yeah, I just feel better [with activity].

Another respondent talked about lifestyle choices and health behaviors, commenting on the potential they have to affect a person’s physical health and function and, in turn, their quality of life.

Mostly I think it’s lifestyle things that impact our health. And so it pays to pay attention to your lifestyle because you’re gonna pay for it sooner or later. So, I mean, eat properly so you don’t get high cholesterol. Don’t gain pounds and pounds and pounds, ‘cause I know it would tire me out. I’ve seen quite obese people, and I have no idea how they would get in and out of the wheelchair by themselves or in and out of a vehicle.

Physical well-being was the other domain that affected those with a quadriplegic spinal cord injury more so than the paraplegic group. Primarily, the differences seem to reflect the belief of many of the participants that persons with quadriplegic injuries had to work harder at the health-promoting behaviors to maintain their physical health. The most common example was in relation to body weight. The importance of maintaining an optimal body weight was frequently discussed by both persons with quadriplegia and persons with paraplegia with respect to the effect it could have on a person’s overall health and function. However, it was apparent that the persons with quadriplegia had to work harder in terms of nutrition and physical activity (health-promoting behaviors) to maintain an optimal body weight.

Physical well-being was frequently discussed during the interviews, and all participants felt that it had a big impact on their quality of life. Physical well-being was something that they were no longer able to take for granted, and as a result, many were very cognizant of it and anxious to learn more about the positive behaviors that may enhance their health.

**Impact of Quality of Life Themes on Each Other**

All of the themes discussed in the previous section directly affected the participants’ overall quality of life. However, the findings also showed that satisfaction (or lack of satisfaction) in one or more of the quality of life themes often had an effect on other themes. Figure 1 illustrates the potential crossover effects, both negative and positive, from the themes exclusive to persons with disability to the quality of life themes that are frequently described in the literature as being common to all people. With the exception of the physical well-being theme, crossover effects within the themes typically described for nondisabled persons will only be discussed briefly. Physical well-being, for our participants with spinal cord injury, affected or was affected by a number of quality of life themes. Good health allowed opportunities for maximization of functional potential and for relationships and social function. A number of our participants indicated that health also had an impact on their
ability to work. One person spoke of a pressure sore she had at one time that made it impossible for her to work for 6 months. Poor physical well-being also crossed over and had negative effects on physical function and independence. Persons who were less healthy indicated that they had more difficulty completing their functional tasks (as compared to when they were healthier). Other crossover effects more obviously affect all people, both disabled and nondisabled. For example, a person’s occupation often has an effect on finances and thus on quality of life. Emotional and physical well-being likely have an impact on each other and affect quality of life both directly and indirectly through their effect on each other.

Of particular interest in this article are the quality of life themes that are exclusive to persons with disability and the way these themes affect the quality of life themes that are more typically representative of all people. For example, stigma, an aspect of life that many nondisabled persons do not deal with on a day-to-day basis, had both negative and positive crossover effects on emotional well-being and relationships and socialization. If participants perceived that they were coping well with the stigma society places on persons with disability, emotional well-being was positively affected. For others, stigma was difficult to overcome and negatively affected their emotional well-being, their relationships, and thus their quality of life. Participants also reported that inadequate accessibility restricted opportunities for physical health (not able to access a gymnasium or appropriate place to wheel), occupation, and relationships. Many disabled persons face obstacles related to accessibility when considering a job. Participants indicated that these obstacles can
be overcome with work and perseverance, but nonetheless, they are obstacles that are not necessarily present for a nondisabled person pursuing a career. In addition, one man talked about how he missed social opportunities because he could not access his friends’ houses. Many of the participants indicated that spontaneity (or lack thereof) had crossover effects to relationships, especially sexual relationships. Persons participating in health-promoting behaviors such as healthy eating or exercise reported that those activities had a positive effect on physical well-being and ultimately on their quality of life. Healthy eating and exercise also affected physical function and independence because persons were stronger and less obese and thus able to carry out their functional activities with less effort and greater independence. These examples illustrate that the quality of life themes do not necessarily represent themselves in isolation but may have a significant indirect impact on overall quality of life through crossover effects to other themes.

**DISCUSSION**

The objective of this study was to determine the themes that represented quality of life for persons with a spinal cord injury. The results showed that regardless of the severity of the impairment, life quality encompassed nine areas: physical function and independence, accessibility, emotional well-being, stigma, spontaneity, relationships and socialization, occupation, finances, and physical well-being. It is not unexpected that these quality of life themes were similar between quadriplegics and paraplegics, because both groups live their life from a wheelchair and, as a result, deal with common issues. Although all of the participants identified the same parameters encompassing quality of life, the themes of physical function and independence and physical well-being had a greater impact on the life quality of persons with a quadriplegic injury. This finding is not surprising, because research has shown that a quadriplegic injury has more serious implications for a person’s health and function than does a paraplegic injury (Bauman & Spungen, 1994; Noreau, Shephard, Simard, Pare, & Pomerleau, 1993). In addition, because a person with a quadriplegic injury will typically expend more energy performing activities of daily living than a person with a paraplegic injury (Janssen, Van Oers, Van Der Woude, & Hollander, 1994), this may also impact their physical function to a greater extent.

Previous qualitative investigations have reported mixed results when determining whether similar quality of life parameters apply for all populations. Renwick and Brown (1996) found that quality of life for an individual with a spinal cord injury could be evaluated using the same conceptual framework used for all people, disabled and nondisabled. The work by Bach and McDaniel (1993), however, showed that some quality of life themes were exclusive to the spinal cord injured population, indicating that using measures based on other populations may not be valid. In the present study, the themes of emotional and physical well-being, relationships and socialization, occupation, physical function/independence, and finances were also identified by Renwick and Brown (1996) and Bach and McDaniel (1993) as factors important to the life quality of physically disabled persons. These themes have also been found to be significant factors in the representation of quality of life for nondisabled populations (Flanagan, 1982). Although there has been general consensus in the literature that these themes are important to quality of life for
all persons, satisfaction in areas associated with work, finances, health, and social relationships has generally been lower for the spinal cord–injured population (Dijkers, 1997). This may be due in part to the stigma and problems associated with mobility and accessibility that were evident in the present study. Overcoming the real or perceived barriers of stigma as well as the limitations of accessibility and mobility may make it difficult to find employment and to be proactive with regard to health concerns related to the physical disability. In addition, even in a country with a universal health care system, there are financial burdens that are incurred by the person with the spinal cord injury and their family in order to fulfill the health needs of the person with spinal cord injury. This suggests that even though there are several quality of life themes that are similar between nondisabled and spinal cord–injured persons, some of these may have a greater impact on the quality of life of the spinal cord–injured population.

The results from the present investigation also identified four themes of quality of life (accessibility, stigma, spontaneity, and health-promoting behaviors) for the spinal cord–injured population that have not typically been included as components for nondisabled persons (Flanagan, 1982). In addition, these themes have not been previously identified in the literature as quality of life themes for persons with a spinal cord injury (Bach & McDaniel, 1993; Renwick & Brown, 1996). Renwick and Brown (1996), however, did identify the issue of accessibility as an important part of an individual’s physical belonging within the environment and with others. Even though most participants in the current study agreed that accessibility was improving and that stigma was decreasing, the respondents reported that these issues continued to affect their quality of life. This finding was reinforced by Renwick and Friefeld (1996), who stated that “environmental factors (e.g., social, political, cultural, and physical) continue to pose significant obstacles to their [persons with disabilities] opportunities for participating in and contributing to society” (pp. 28-29).

Spontaneity was another quality of life theme that was frequently discussed by our participants. Stensman (1994) similarly reported that one of the negative effects of a spinal cord injury was “not being able to do things ‘at once’” (p. 420). Adjustment to this change determined to a large extent how quality of life was affected for the participants in the present study. Some were well adjusted and reported that lack of spontaneity was just a “fact of life.”

Health-promoting activities or behaviors can be defined as “activities directed toward increasing the level of well being and actualizing the health potential of individuals” (Stuifbergen & Rogers, 1997, p. 2). Although this theme has not been specifically identified in the past as an important quality of life theme for nondisabled persons (Flanagan, 1982) or for those with a spinal cord injury (Bach & McDaniel, 1993; Clayton & Chubon, 1994), Flanagan (1982) and Renwick and Brown (1996) do recognize recreation and leisure as an important part of quality of life. A recent qualitative investigation with persons with multiple sclerosis also identified physical and emotional health-promoting behaviors as important to that population’s representation of quality of life (Stuifbergen & Rogers, 1997). Participants in that investigation reported that they needed to be more careful in order to maximize their physical and mental capabilities because their health status was already vulnerable (Stuifbergen & Rogers, 1997). The participants in the present study expressed similar sentiments when discussing why health-promoting behaviors, both physical and emotional, were important to their quality of life.
The findings from this investigation reinforce the theory that quality of life should be represented by subjective measures, if not totally, at least in combination with objective measures (Rapheal, 1996). Direct input from persons with spinal cord injury about what is important to their quality of life can assist in the appropriate selection of a quality of life measurement tool and help establish the validity of that chosen measure. By increasing our knowledge about what is important to the quality of life of a person with a spinal cord injury, the results of this investigation may provide a basis for the development and implementation of programs for persons with spinal cord injury that are aimed at enhancing quality of life.

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Patricia J. Manns, M.S., P.T., is currently a doctoral candidate at Oregon State University, studying in the area of movement studies in disability. She worked as a rehabilitation physical therapist before going back to school. This article is based on the work that was done during the completion of her master’s degree at the University of Saskatchewan in Canada.

Karen E. Chad, Ph.D., is an associate professor in the College of Kinesiology at the University of Saskatchewan in Canada. Her research interests include program evaluation, issues around metabolism, nutrition, and physical activity, with a focus on populations such as children and adolescents, females, and persons with disabilities.
Feeling Healthy: So Why Should Mexican-Descent Women Screen for Breast Cancer?

Evelinn A. Borrayo
Sharon Rae Jenkins

Mexican-descent women are at particular risk of late-stage breast cancer diagnosis by being the least likely of the major U.S. Hispanic subgroups to undergo breast cancer screening. This grounded theory study investigated how cultural health beliefs regarding the causes and nature of breast cancer influence women’s decision to participate in screening. Thirty-four women (age 49 to 81) were interviewed in five focus groups using theoretical sampling across levels of acculturation and socioeconomic status. Analysis of the most prevalent cultural health beliefs led to a discovery that the core problem Mexican-descent women face is that they perceive there is no reason to participate in breast cancer screening when they are “feeling healthy.” In addition, women who subjectively and cognitively feel healthy and otherwise have no evidence of illness according to their cultural health beliefs are unlikely to risk feeling ill rather than healthy by seeking to discover breast cancer through screening.

Hispanic women are not at greater risk for breast cancer development due to ethnicity per se, but they are more likely to die from the disease than are non-Hispanic women (Ramirez, Villareal, Suarez, & Flores, 1995). High mortality rates from breast cancer among Hispanic women are largely due to the late diagnosis of this cancer (Richardson, Langholz, Bernstein, Burciaga, & Ross, 1992). Late diagnosis is directly related to the underutilization of screening techniques such as breast self-exam (BSE), clinical breast exam (CBE), and mammography (Fox & Roetzheim, 1994). Hispanic women of Mexican descent are at particular risk of late-stage diagnosis because they are the least likely of the major U.S. Hispanic subgroups to undergo breast cancer screening (Suarez, Lloyd, Weiss, Rainbolt, & Pulley, 1994).

Crucial to changing this trend is to understand the factors that affect the breast cancer screening behaviors of these women. Low socioeconomic status (SES) and less access to health care are among the factors most strongly related to their low screening rates (Farley & Flannery, 1989). However, social and cultural factors also influence the decision of ethnic minority women to engage in breast cancer screening (Rajaram & Rashidi, 1998). In particular, social class and acculturation are cultural change processes (Berry, 1980) that have been linked to Hispanic women’s health protective attitudes and behaviors relative to cancer (Harmon, Castro, & Coe, 1996). Interventions that effectively promote screening must reflect an understanding of sociocultural factors.
This study was undertaken to gain understanding of how cultural beliefs about breast cancer influence the screening behaviors of Mexican-descent women across various levels of acculturation and education. In the course of the study, we explored the most prevalent cultural beliefs women hold regarding the cause and nature of breast cancer. More important, we organized women’s cultural beliefs using psychological constructs and dynamics that explain how their beliefs may influence their process of deciding whether to participate in breast cancer screening.

METHOD

Participants

The focus group sample included 34 women of Mexican descent living in the cities of Dallas and Fort Worth, Texas, in the United States. The participating women had an average age of 62 years (range = 49-81). There was considerable variation in level of education (range = 2-17+ years); whereas 19 (56%) women did not have a high school education, 15 (44%) reported a high school education or higher college degrees. The women’s personal annual incomes ranged from less than $5,000 to more than $40,000. The average annual income was approximately $10,000, with 17 (50%) participants living below the federal poverty level. As measured by the Acculturation Rating Scale for Mexican Americans (ARSMA) (Cuellar, Harris, & Jasso, 1980), acculturation was positively correlated with education ($r = .78$, $p < .01$) and income ($r = .57$, $p < .01$). That is, more acculturated women were likely to have higher levels of education and income and vice versa.

Of the 34 women interviewed, only 8 (23%) reported doing a BSE 12 times a year, and only 19 (56%) reported obtaining a mammogram within the past year. Moreover, 4 (12%) women reported that they had not performed a BSE at least once during the past year, and 4 (12%) reported never having had a mammogram. With respect to obtaining a CBE when they have a pap smear test, 22 (64%) reported obtaining a CBE within the past year, and only 1 (3%) reported that she had never obtained a CBE in her lifetime.

Data Collection

Prior to data collection, a university Institutional Review Board for the Protection of Human Subjects approved the study. Data were obtained through five successive focus group interviews (FGIs). Community gatekeepers were consulted to obtain the names of women who met the selection criteria for each of the groups. The FGIs were conducted at senior centers, health centers, and churches that could be accessed easily and where women would feel more comfortable. A team of researchers who conducted the FGIs consisted of Hispanic females fluent in Spanish and English, because the FGIs were conducted in either language.

The participants initially provided their informed consent. Then they completed a written survey in Spanish or English that asked for information on demographics, acculturation, and breast cancer screening habits (BSE, CBE, and mammography). To measure acculturation, the survey included a shorter version of the
ARSMA (Elder et al., 1991). The interviews were conducted following a series of predetermined open-ended questions. Each of the FGIs lasted approximately 90 minutes and was recorded and transcribed in the language of the originally collected data.

Data Analyses

Grounded theory methods of analysis, as developed by Glaser and Strauss (1967) and Strauss and Corbin (1990), were used for this study. As appropriate in grounded theory, data analysis was initiated when the first interviews were conducted and continued until conceptually dense theory was derived from the data through the process of theoretical sampling. We approached theoretical sampling in a twofold way: first, by considering the choice of questions for each group’s protocol and, second, by selecting participants according to their acculturation and education. First, each FGI transcript was analyzed to yield questions to be pursued in the following group. Thus, the questions differed across groups, becoming increasingly specific as the concepts needed for the theory became clearer. Second, women were sampled according to the differences in levels of education and acculturation (preference for English or Spanish language), which were two moderating variables used as an index of SES for U.S. Hispanics (Balcazar, Castro, & Krull, 1995).

Theory was further generated using the constant comparison method (Glaser, 1992). In the comparative analysis, rigorous coding techniques (called open coding, axial coding, and selective coding; see Strauss & Corbin, 1990) were used to test whether and how new pieces of data both do and do not fit into an emerging hypothetical framework of plausible relationships between theoretical concepts. Spread sheets and matrices were used to assist in sorting, organizing, and visualizing the data.

The analyses began with open coding to fracture the data into discrete concepts that could be easily labeled and sorted (first-line codes). This level of coding involves analyzing every word and sentence to generate as many discrete concepts as possible. For instance, one participant stated, “When I had that burning sensation, I went to the doctor, specially because I thought that it was cancer.” A burning sensation became a discrete concept labeled breast cancer symptom. Discrete concepts that were related to the same phenomena were grouped under conceptual labels or categories (second-line coding). The conceptual categories (e.g., symptomatic illness) were at a higher level of abstraction than the discrete concepts. Second-line coding also involves identifying each conceptual category along its respective properties and dimensions. The concept of symptomatic illness has the property of presenting sudden symptoms, such as finding a lump, or progressive symptoms, such as feeling increasing pain. These properties can be manifested in various dimensions that range from mild or small, such as feeling “a little knot . . . like a seed,” to severe or big, such as feeling “a knot . . . like a potato.”

Axial coding, a more intense level of analysis, was carried out to formulate plausible relationships within and among the categories. This level of analysis used the coding paradigm developed by Strauss (1987) and Strauss and Corbin (1990). The coding paradigm aids in specifying a category in the following terms: the conditions that give rise to it (causal conditions), the context (the specific set of conditions) in which it was embedded, the action/interaction strategies by which it was
managed, the intervening conditions that appeared to facilitate or constrain strategies, and the consequences or outcomes of those strategies. In the case of symptomatic illness, a coding paradigm was used to analyze this category’s relationship to screening behavior:

I go [obtain a mammogram] because I have to [action strategy—breast cancer screening], because I have this cyst [intervening condition—symptomatic illness], and if I don’t go get it checked [causal condition] then it [breast cancer] can develop [consequence—breast cancer development].

The process of selective coding achieved theoretical integration. At this level of analysis, the relationships among the distinct categories were established at a higher, more abstract level and validated by returning to the data and looking for evidence that supported or refuted those relationships. Cultural health beliefs were compared with each other, as were their relationships to acculturation and education differences. It also required reexamination of the FGI data and listening to the tapes again for further details on specifically what women said they believed. As the relationships became clearer, two main categories (causes and nature of breast cancer) and a core category (feeling healthy) emerged around a basic social-psychological problem that women face when deciding whether to participate in breast cancer screening. Although in grounded theory there is no predetermined sample size or definite point when a theory is finalized, the final phase in this analysis occurred when no new ideas appeared in additional data.

RESULTS

This study found that the basic social-psychological problem (Hutchinson, 1986) of Mexican-descent women is that they generally perceive that there is no reason to participate in breast cancer screening when they are “feeling healthy.” In addition, for asymptomatic women, screening presents the risk of losing their internal sense of feeling healthy. Feeling healthy involves subjective feelings of well-being and a cognitive perception that they are not at risk for the development of breast cancer. Women judge their vulnerability by the presence or absence of any indicators or conditions (e.g., causes) that according to their cultural health beliefs point to the possibility of having or developing breast cancer. Accordingly, their judgment of whether they are healthy becomes one of the most influential factors in their decision to participate or not to participate in screening. However, unlike other basic social processes (Hutchinson, 1986) that move progressively, these women’s decision-making process is nonprogressive in that it “does not necessarily occur in stages or phases” (Strauss & Corbin, 1990, p. 152). Instead, the process and its outcome vary depending on the conditions that trigger the process, the context in which it takes place, the strategies women use, and most important, the type and strength of the cultural beliefs women hold. One woman summarized how feeling healthy influences women’s decision to participate in screening:

In Mexico, it’s not like here [United States]. In Mexico, they [women] don’t make it a habit to go [for breast cancer screening] every year to the doctor. If you are not sick, you don’t go see a doctor [avoid detection strategy]. I don’t know why, if it is because they don’t have the money to pay for a doctor or because they feel healthy.
This may suggest that in Mexico, at least, the habit of going to the doctor may be in part determined by whether women are feeling healthy or not. A woman may be more likely to go to the doctor for screening services if she does not feel healthy or is cognitively aware of her objective risks (e.g., genetic) to develop cancer. In contrast, a woman who feels healthy and perceives no reasons that suggest otherwise is less likely to risk losing this feeling by participating in breast cancer screening. Feeling healthy is a psychological construct that is mostly influenced by cultural beliefs regarding the causes and nature of breast cancer illness.

The Role of Health Beliefs About the Causes of Breast Cancer

Women’s subjective feelings and cognitive awareness of their susceptibility to breast cancer come from their interpretation of what they believe are four major causes of breast cancer: physical predetermination, detrimental external sources, breast-feeding, and divine predestination. How beliefs in these causes influence women’s assessment of whether they are healthy or at risk for breast cancer appears to be moderated by women’s knowledge about breast cancer and their overall level of formal education and acculturation. Women who are less knowledgeable are usually more likely to rely on their cultural beliefs regarding the causes of breast cancer and are more likely to decide to take or to avoid certain cultural preventive measures and detection strategies to maintain their sense of feeling healthy.

Briefly, the cultural measures some women take to prevent getting breast cancer are breast-feeding correctly, avoiding detrimental sources such as bumping their breast, and praying for divine protection. Cognitive awareness that they have adhered to these strategies results in feeling healthy, which further influences women’s decision not to undertake medical detection strategies. Accordingly, screening is more common among women who believe that they are predisposed to develop breast cancer and perceive that they have failed to take preventive measures—that is, among women who might feel potentially unhealthy but who might be also less knowledgeable about breast cancer causes.

Physical predetermination. The belief that heredity causes cancer is the most influential of the physical predetermination beliefs across women of various levels of acculturation and education. A cognitive awareness of a predisposing family history of cancer makes women less likely to feel healthy and consequently more likely to screen. The opposite is true for women without a family history of cancer; they are less likely to screen because they are aware of being less susceptible to breast cancer and are more likely to feel healthy. Thus, screening is a detection strategy to be used when women are cognitively aware of the possibility of not being healthy or is an unnecessary strategy to take when they are subjectively feeling healthy.

The formulation of how physical predetermination belief influences screening behaviors across women is illustrated by the following quote from a woman with a high level of education and acculturation. The quote is structured as a paradigm statement.

The reason I don’t go [to obtain a mammogram] more often [avoiding detection strategies] is because it [breast cancer] is not in my family [intervening condition—
belief in physical predetermination. If it was like ya’ll or some of you that has it in the family, then I probably would go more [detection strategy]. But it’s not in my genes.

In the same context, women who are less educated and acculturated to the mainstream society expressed a similar position: “Like the other lady said, I think it [breast cancer] is hereditary.”

**Detrimental external sources.** To a lesser extent, beliefs in detrimental external sources as causes of cancer also influence women’s assessment of their health status or risk of developing breast cancer, especially the assessment of Mexican-descent women who are not knowledgeable about risk factors that have been scientifically linked to breast cancer. Less knowledgeable women also tend to have lower levels of education and acculturation. Such women are more likely to express the belief that exposure to detrimental external sources such as caffeine or trauma to the breast (un golpe) can jeopardize a woman’s good health and put her at risk of developing breast cancer. To maintain their health or their sense of feeling healthy and to avoid breast cancer risk, women may take corresponding oral measures, such as eliminating coffee and nicotine, and behavioral measures, such as avoiding physical trauma to the breast. Women who fail to take such cultural preventive strategies cognitively perceive that they are vulnerable to breast cancer and are more likely to consider breast cancer detection strategies.

I heard that if you drink a lot of coffee [intervening variable—belief in detrimental sources] you get all these little tumors in your breast and they can develop into malignant tumors. That’s why I have cut down on my coffee [prevention strategy]... that is why I have a mammogram every year... I examine myself [BSE] even more often [detection strategies].

Middle-class women and women of higher SES levels also express the belief that detrimental external sources cause breast cancer; however, what varies from lower SES women is the type of detrimental external sources believed to be causal agents. Middle and higher SES women believe that “if you take hormone pills, you are more apt to get breast cancer.” They are also more likely to be informed about recent but inconclusive research findings, such as the possible link between exposure to agricultural pesticides (e.g., DDT) and cancer development.

**Breast-feeding.** Feeding breast milk to one’s baby is believed to be both a cause and a preventive measure of breast cancer, especially among women who hold more traditional or folk health beliefs. The interesting paradox refers mostly to whether the milk is extracted from the breast, because stagnated milk is believed to cause breast cancer. The belief that breast-feeding is a cause of cancer comes mostly from hearing older women of Mexican descent say that if the baby burps air into the breast, the air causes the breast milk to become stagnated and eventually the milk develops into cancer. Women who breast-fed may think that they can develop breast cancer if they did not take certain measures to breast-feed correctly, such as positioning the baby correctly during breast-feeding or draining the milk out of the breast if the baby burped into the breast. If women perceive that they have taken these preventive measures, they are more likely to feel healthy and less likely to engage in screening, particularly if they are uneducated about breast cancer causes.
The belief that breast-feeding can prevent breast cancer comes mostly from hearing health care providers indicate that it is a preventive agent. However, it seems that women use their own interpretation of how breast-feeding might prevent breast cancer. Women reconcile the information they receive about breast-feeding as a preventive source by explaining that breast-feeding drains the milk out of the breast. If a mother does not breast-feed, the breast milk becomes stagnated and then becomes cancerous. Thus, women evaluate their breast cancer risks according to the extent of correctness of their breast-feeding practice. Women who believe they have taken preventive measures and therefore feel healthy may be less likely to screen.

My friend who had breast surgery asked the doctor and he told her that women who do not breast-feed are more susceptible to cancer [intervening condition—breast-feeding as a preventive measure]. But to the one that breast-fed the baby and [the baby] burped air, this will complicate things. When the baby burps, it’s when the baby has to be very close [to the breast] so that with [his or her] hot breath can take out that air. That complicates things, because if the air stays there and the milk becomes stagnated and turns bad, it is then that it [cancer] develops [intervening condition—breast-feeding as a cancer cause].

Less traditional middle-class women suggested that they were aware of cultural beliefs about breast-feeding as a causal breast cancer agent but indicated that they did not embrace this belief: “As far as I’m concerned, that is an old wives’ tale.” In contrast, highly educated and acculturated women were unaware of the paradoxical beliefs about breast-feeding in relation to breast cancer. Interestingly, they did not mention having learned about the importance of breast-feeding through a health care provider or other educational sources about breast cancer risk factors.

Divine predestination. This is another belief that most women provided to explain developing breast cancer, which may reflect the strong religious, mostly Catholic background that Mexican-descent women tend to share. This is the belief that God’s will or fate has destined certain individuals in advance to develop an illness such as breast cancer. Accordingly, some of the prevention strategies mentioned were of a religious nature. Mostly, women who lack financial resources or health insurance tend to use religious strategies that include “faith in and prayer to God” for protection and healing from breast cancer to restore the feeling of being healthy, as illustrated by the following statement:

I ask God [intervening condition—belief in divine predestination] to help me and to protect me from all illnesses and to protect my health [preventive religious strategy] because I don’t have insurance to go to the doctors. I ask God for the healing of all my body [religious strategy to restore feeling healthy].

Theoretically, beliefs in divine predestination at best seem to serve as barriers to breast cancer screening. Because beliefs in divine predestination encourage thinking that an illness is beyond one’s control and that one should adjust to an inevitable illness, the likelihood that women with these beliefs will take breast cancer detection strategies or treatment strategies appears to be minimal, even among middle-class women.
I think that if I were to get breast cancer, I wouldn’t be surprised because when it is your turn, is your turn, and you place everything in the hands of God [intervening condition—divine predestination] and accept [avoid detection and treatment strategies].

Although highly acculturated and educated women recognized embracing religious beliefs, they said that the more traditional women in their family were the ones who used religious coping strategies.

The Role of Health Beliefs About the Nature of Breast Cancer

Women of Mexican descent attribute certain characteristics or qualities to breast cancer. The most salient health beliefs, particularly among more traditional women, are that breast cancer is a symptomatic, fatal, and/or shameful illness. These qualities are based mostly on what they perceive are their culture’s health beliefs about the nature of similar terminal illnesses and less on the breast as a specific location. The condition under which these beliefs are less influential is when women are highly educated about breast cancer. In addition, as observed for other health beliefs among women in our sample, women who hold more traditional beliefs about the nature of breast cancer are also the least acculturated and educated.

Symptomatic illness. The cultural belief that breast cancer is a symptomatic illness is the most influential belief among women across the acculturation and SES spectrum. More than for any other health belief, women recognize the strong influence of the belief that one must feel a symptom in order to be ill. The absence of symptoms also reinforces the subjective and cognitive perception that women are healthy because they feel healthy.

For the most part, women who believe that breast cancer is symptomatic tend to wait until they feel what they perceive to be a breast cancer symptom (e.g., pain, lump) to perform detection procedures such as BSE, CBE, and/or mammography. Otherwise, women who do not perceive any symptoms and thus feel healthy are likely to participate in breast cancer screening.

I feel fine [feeling healthy], nothing hurts me [intervening condition—belief in symptomatic illness], thanks God, and that is why I say why should I go see the doctor to check me [CBE] [avoid detection strategies]?

On the other hand, women do not feel healthy if they perceive certain symptoms that they believe are indicative of breast cancer. Women who no longer feel healthy and become cognitively aware of the possibility that they could have breast cancer are more likely to take detection strategies not to prevent breast cancer but to prevent or avoid death:

You just have to wait [delay detection strategies]; sometimes you have something that you don’t even know about . . . but it doesn’t hurt [intervening condition—symptomatic illness]. One time when taking a shower, I touched it [breast] and I felt something [lump], so then I began to do it [BSE] [engage in detection strategies].
**Fatal illness.** To a lesser extent, the cultural health belief that breast cancer is a fatal illness also influences women's decision to screen. The belief that breast cancer is by nature fatal refers to the belief that cancer inevitably brings death. Thus, women may not engage in breast cancer detection strategies because of the potential risk of being diagnosed with such a fatal illness. If women develop breast cancer, they are likely to believe that engaging in treatment strategies to heal or treat breast cancer to restore feeling healthy is also futile, especially if women lack health insurance or the financial resources to pay for treatment.

“If you [doctor] are going to operate and to subtract what I have and if it’s cancer, I do not want you to cut it [the breast].” So no, I said, “if I will die anyway and it will continue to advance, what’s the point of having it cut? That is better, if my time has come.” … It was all I thought that I was not going to live very long [intervening condition—fatal illness] . . . that is how I reacted.

Women who are more educated about how early detection could prevent breast cancer death are more likely to screen regularly. In a group of women of low SES, one woman in response to hearing another woman say that breast cancer is fatal said, “That’s if you don’t do it on time. . . . I have a mammogram every year.”

**Shameful illness.** Breast cancer is believed to bring shame and dishonor to oneself and to one’s family, whereas feeling healthy is associated with positive regard from others. Women of Mexican descent who hold more traditional or folk beliefs are more likely to believe that any cancer is a shameful illness. In an attempt to avoid the diagnosis of a shameful illness and the negative reactions it would bring, women may be less likely to participate in breast cancer screening. This belief is recognized as a strong screening barrier even among women who are highly acculturated. However, the highly acculturated women suggest that the belief is less likely to influence their behavior compared to how strongly it influences the behavior of traditional women.

I know a family just like this, *Mejicano*, oh, yeah, but they were born here [United States]. Then one lady will tell the other, “Oh, there is always something wrong with you” [illness]. You are always looking for trouble [consequence—blame]. Stop looking [discourage detection strategies]. You should be ashamed of yourself [intervening condition—shameful illness]. Is almost like a pride thing, like, “I am going to be better than her and I better not go see the doctor” [avoid detection strategies] . . . . It’s a dishonor if you are not good and healthy but ill; if you come out ill [e.g., breast cancer], then is like you are no good, you are useless. And that does exist.

**DISCUSSION**

This study is an initial effort to understand in an articulated conceptual framework how a cultural explanatory model (CEM) about breast cancer might influence the breast cancer screening behaviors of Mexican-descent women. This was achieved by eliciting the elements of women's breast cancer CEM from an emic perspective (Rajaram & Rashidi, 1998). We began by obtaining a detailed description of the most prevalent cultural health beliefs women hold regarding the causes and nature of breast cancer. We then organized women's beliefs around one core
variable (feeling healthy) that appeared to account for the pattern of problematic behavior, the low rates of breast cancer screening of Mexican-descent women.

We propose that the core problem Mexican-descent women face is that they generally perceive that there is no reason to participate in breast cancer screening when they are feeling healthy. Women do not engage in screening because they rely on their subjective sense of feeling healthy more than on epidemiological risk factors (e.g., age, weight) to evaluate their susceptibility to develop breast cancer. That is, the CEM of health and illness of Mexican-descent women is not congruent with Western health beliefs regarding the prevention of a probability illness (Rajaram & Rashidi, 1998). According to Western or biomedical CEMs, preventive health behavior refers to any behavior directed to the prevention or detection of an illness at the asymptomatic stage (Kasl & Cobb, 1966). Instead, the CEMs of Hispanic women generally reflect a lack of belief in the detection of an unfelt illness, such as breast cancer.

In addition, women do not engage in screening regularly in part because they risk losing their sense of feeling healthy. In other words, not perceiving a reason to screen but considering the possibility of detecting cancer through screening puts women at risk of feeling that they might be ill rather than healthy. Such perceptions may originate from the fact that feeling healthy or healthiness, as initially identified by Rose (1978), is seen as a sign of strength, “good fortune, luck, or a gift from God” (Saint-Germain & Longman, 1993). Illness is seen as a sign of weakness (Rose, 1978) and as punishment from God (Kosko & Flaskerud, 1987). In an attempt to maintain their sense of feeling healthy, women may avoid screening because of the potential of finding breast cancer, a fatal and shameful illness.

Certainly, other studies have discovered similar relationships between cultural beliefs and preventive health behaviors among other ethnic minority women (e.g., Wardlow & Curry, 1996). Differences in cultural beliefs have been observed also across ethnic groups (Frank-Stromborg & Olsen, 1993) and found to depend on levels of acculturation and SES (Stein, Fox, & Murata, 1991). Of importance is that our study contributes to this literature by providing evidence that some of these findings extend in particular to women of Mexican descent. It is important to provide this type of specific subgroup information rather than generalize some study’s findings to all people who fall under the umbrella of Hispanic (e.g., Mexican, Puerto Rican, Cuban). There is increasing evidence of subgroup differences in important variables such as SES and acculturation experiences (Muñoz & Ortega, 1997), which may differentially influence preventive health behaviors (Schur, Bernstein, & Berk, 1987).

Women of Mexican descent differ from other ethnic women and even from other Hispanic women in that they are at higher risk of failing to comply with breast cancer screening guidelines, which has been further associated with higher incidence of late diagnoses and higher mortality rates. Thus, more systematic efforts are needed to understand the sociocultural factors that influence and facilitate Mexican-descent women’s participation in breast cancer screening procedures.

We investigated cultural health beliefs in the context of acculturation and SES factors. Because these factors represent processes of cultural change (Berry, 1980), we used them as the major dimensions of range and variation in cultural beliefs among this changing population of Mexican-descent women. We mostly pointed to how the impact of the CEM about breast cancer on women’s screening behaviors varied based on differences in their levels of acculturation and SES. In this
sociocultural context, our main observation was that cultural health beliefs about cancer appear to be more related to actual breast cancer screening behavior than are general acculturation dimensions or SES among more traditional immigrant women. Thus, future research should quantitatively measure the elements of these women’s cancer-relevant CEM in their sociocultural context (e.g., Borrayo & Jenkins, 2001). Meanwhile, it is important to include women’s specific CEMs in the framing of persuasive messages that are intended to increase breast cancer screening rates among women of Mexican descent.

NOTE

1. In the quotes used as paradigm statements, two types of brackets are used: [] contain implied information, and {} indicate coding labels for identified strategies, intervening conditions, and so forth.

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Evelinn A. Borrayo is an assistant professor in the Department of Psychology at Colorado State University. She holds a Ph.D. in clinical psychology with specialization in health psychology. She teaches courses in health psychology. Her areas of research include cultural health beliefs, women’s health, and psychosocial oncology, using quantitative and qualitative methods.

Sharon Rae Jenkins is a University of North Texas associate professor of clinical psychology. She holds a Ph.D. (personality psychology, Boston University), postdoctoral certificate (clinical psychology, California School of Professional Psychology, Berkeley/Alameda), and Texas license. She was an National Institute of Mental Health postdoctoral fellow at University of California, Berkeley’s Institute of Human Development.
Women’s Lived Experiences of Pregnancy: A Tapestry of Joy and Suffering

Terese Bondas
Katie Eriksson

The phenomenological study of the lived experiences of pregnancy described in this article is part of a Finnish caring science research program. Eighty interviews with 40 women combined with nonparticipant observation were analyzed according to Colaizzi. Pregnant women wishing for a perfect child want to promote the health of their unborn baby, no longer take health for granted, and try to change their health behavior. Their altered mode of being involves body changes, variations in mood, and worries. The striving to achieve family communion is seen in the evolving significance of the baby; in dreams, hopes, and plans; and in changing relationships. In relation to Eriksson’s ontological health model, the joy and suffering in pregnancy are based on being there for another. Taking seriously the women’s experiences and the hidden questions that reveal suffering in both lay and professional caring might prevent the serious postpartum misery of motherhood.

Evolving societal myths and rituals and technological and scientific development surround pregnancy. Culture provides a mirror for pregnant women’s experiences. Today, women have more possibilities of choosing motherhood (Bergum, 1989; Mercer, 1986; Sandelowski & Black, 1994). From a historical point of view, Höjeberg (1985) described lay traditions that were aimed at teaching and warning the woman, helping her leave her previous life behind, and providing guidance for the new life as a mother. Pregnancy and the structure and content of perinatal care in the culture of Western health care have changed and become a biomedicaleventthatisp athologicalinspiteofitsexperientialnondisease nature (cf. Graham & Oakley, 1986; Hillan, 1992; Oakley, 1980).

Pregnancy also has been conceptualized within a psychological framework of crisis theory. Emotional maladjustment continues into motherhood, with negative consequences for the woman’s health and for child care if the crisis is not worked out successfully (Bibring, 1959; Breen, 1975; Chertok, 1969; Shereshefsky & Yarrow, 1973). The maternal role and identity are notions in the sociologically and psychoanalytically oriented research of Rubin (1976, 1984). Rubin, supported by Stainton, McNeil, and Harvey (1992), stated that every pregnancy implies the following tasks: ensuring safe passage, bonding with the unborn child, and learning to give. Sandelowski and Black (1994) analytically distinguished the fetal acquain-

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tanceship. Mercer (1986) found that women dealt with conflicting internal drives to achieve or excel in different roles.

In the area of stress and social support, there are findings that pertain to pregnancy. Cranley (1981) focused on maternal-fetal attachment, and Tilden (1983) focused on emotional disequilibrium during pregnancy. Cronenwett (1985) discussed positive psychological and physical effects on pregnancy outcomes and predicted satisfaction with the maternal role and child care. Brown (1986) elaborated on the prediction of health, Aaronson (1989) on positive health behaviors, and Tarkka and Paunonen (1996) on network size. Violation of support expectations was correlated with decline in satisfaction with partner relationship (Coffman, Levitt, & Brown, 1994). Stress during pregnancy had an indirect effect on the woman’s report on family functioning postpartum (Mercer & Ferketich, 1990). A review of randomized controlled trials of social support shows that support may also extend the length of gestation and reduce interventions during labor (Bryce, 1991). Gottlieb and Mendelson (1995) stressed the importance of listening carefully to pregnant women to determine their need for support. The support must fit the mothers’ needs and is most effective when it is perceived to be available because of the limited carry-over effect (Mercer & Ferketich, 1990). Childbirth preparation groups are a source of social support, although they are criticized for not preparing the women adequately for the labor experience, changes in family relations, or child care (Beaton & Gupton, 1990; Hallgren, Kihlgren, Norberg, & Forslin, 1995; Nolan, 1997; Vehviläinen-Julkunen, 1995).

In pregnancy, increased urination needs, fatigue, increased appetite, sweating, heartburn, morning sickness, edema, backache, body image concerns, and vulnerability are reported (Drake, Verhulst, & Fawcett, 1988; Mercer, 1986; Patterson, Douglas, Patterson, & Bradle, 1992). Motherhood might develop into misery (Barclay & Lloyd, 1996) and tensions (Sethi, 1995) and result in a decrease in self-esteem (Mercer, 1986) or even ill health, conceptualized as postpartum depression (Beck, 1992, 1993; McIntosh, 1993a, 1993b). Beck (1992) described postpartum depression as a living nightmare filled with uncontrollable anxiety attacks, consuming guilt, and women’s obsessive thoughts about harming themselves as well as the baby. Even if depression has not been focused in some studies of new motherhood, loss of freedom and all-consuming responsibility, loneliness and isolation, and absence of support are related to becoming a mother. The majority of women suffered in silence, ashamed to talk even to their next of kin about what they regarded as a sign of personal inadequacy and failure (Barclay, Everitt, Rogan, Schmied, & Wyllie, 1997; Rogan, Schmied, Barclay, Everitt, & Wyllie, 1997). Thus, women experience suffering as a result of childbirth and child care, and it is important to try to prevent and alleviate this suffering. The focus in previous pregnancy-related research has been on delimited aspects of motherhood, childbirth preparation and symptoms during pregnancy using crisis, developmental, psychoanalytical, biomedical, and/or role theories as a starting point. Therefore, the aim of the study was to explore the lived experiences of pregnancy from the women’s perspective. The perceived knowledge will be discussed in relation to Eriksson’s (1997; Eriksson, Bondas-Salonen, Herber, Lindholm, & Matilainen, 1995) ontological health model to facilitate further insights into the Western maternity care culture (cf. Bondas, 2000; Bondas-Salonen, 1998a, 1998b).
THEORETICAL PERSPECTIVE

There are different interpretations of the meaning of theory in phenomenological research (Giorgi, 1985; Mitchell & Cody, 1993; Moustakas, 1994). The theoretical perspective must not be seen as a testable frame of reference that deductively would lead to hypotheses. In this study, it was assumed that the perspective has to be explicated in relation to the validity of the findings. The theory is used to discuss the emerging essential structure. The human being is seen as an entity of body, soul, and spirit (Eriksson, 1992, 1994, 1997; Eriksson et al., 1995). The most important human endeavor is to shape one’s life with a sense of inner freedom and responsibility for oneself and other people. This is expressed as the concept of human dignity. Dignity is accorded to be there for the other person in both lay care and in professional care and is grounded in caritas, an agape form of love and mercy. Human beings have a view of the world and themselves that is partly connected with their culture and partly unique. Health concerns a person’s growth toward uniqueness, wholeness, and integration in his or her movement between the dimensions of doing, being, and becoming. Health and suffering are two poles of human life. Health can be connected to endurable suffering. A prerequisite for growth is a person’s understanding of the contrasts of health and suffering. Human beings experience suffering and health in relation to their living conditions, their will to live, and their endeavor to find meaning in life. Human beings strive for joy and health, although they experience strain and suffering (Eriksson et al., 1995). Suffering presupposes caring, and the basic structure for caring is the relationship between the patient and the caregiver. Health can be developed and suffering alleviated by touching the human being’s health potential through caring, an ethical way of being there for the other (Eriksson, 1997).

METHOD

The method described by Colaizzi (1978) was chosen for the entire research program. The aim is to understand pregnancy from an insider lived perspective, which will also be shared in part by others in the same culture. Phenomenological research pursues not only the sense people make of things but what they are making sense of (Crotty, 1996). The reality is seen as complex and constructed, and the research process is an interactive, descriptive, and explorative process (cf. Giorgi, 1985; Morse, 1991). The ethical committees of two health care centers and a health care district approved this study. Forty women, both primigravidae and multigravidae, participated in this study. The sample was purposeful (Morse, 1991). Saturation was accomplished through a triangulation of different data collection techniques, periods, places, and participants. The researcher also participated in some of the respondents’ health care visits for sensitization. The women were interviewed in early and late pregnancy and during and after the birth. A group of 9 women were interviewed in the 36th week of their pregnancy and 3 weeks, 3 months, and 2 years after giving birth. Each woman was asked to describe her lived experiences of pregnancy in detail. The dialogical interviews (Colaizzi, 1978) focused on the present moment at the time of the interview, but the women were also asked to recall their
earlier experiences as well as their thoughts, dreams, and plans for the future in relation to the birth of their child.

Phenomenological studies are conducted in a manner as free as possible from unexamined presuppositions (Moustakas, 1994; Spiegelberg, 1975). This is called bracketing and helps ensure that the phenomena are being studied as they are experienced. Bracketing was performed consciously in all stages of the research process. The researcher (T. Bondas) held her theoretical knowledge, personal experiences of her own three pregnancies, and professional knowledge as a public health nurse and nurse executive in maternal care in abeyance. Time creates distance, and her own personal and professional experiences are mainly from the 1980s. She continually wrote down thoughts and reflections that also helped her accomplish the bracketing. She attempted to question her knowledge and really listen to what the women told her. Developing trust was important, and the researcher also felt that the women disclosed more of their experiences with each interview. Many of them also said that they reflected on their experiences as a result of the interviews. Moral responsibility and human dignity were acknowledged as important ethical prerequisites throughout the study as well as anonymity, voluntary participation, and process-oriented informed consent. The names in this article are pseudonyms.

Colaizzi’s (1978) phenomenological method was also used for data analysis. The participants’ descriptions were transcribed verbatim. Significant statements pertaining to the phenomena in the study were extracted. Meanings were formulated and organized into themes, which were clustered in categories and integrated into an exhaustive description of the phenomenon. An essential structure was derived. The structure is discussed in relation to the theoretical perspective of the research program. This means going further than Colaizzi’s phenomenological method presupposes. The motive for this is related to the theoretical development that this might enhance the insider perspective (cf. Morse, 1997) while still maintaining the richness and vividness that a phenomenological approach can provide.

RESULTS

Ten emerging themes were clustered in three comprehensive categories: the perfect child, an altered mode of being, and striving for family communion (see Table 1). Some quotations were chosen for illustration. The exhaustive description ends with an essential structure of the phenomenon, followed by a discussion related to
Eriksson’s (1994, 1997; Eriksson et al., 1995) ontological health and suffering model and to previous research that examined the experiences of pregnancy.

The Perfect Baby

There were three themes that captured the wish and strivings for a perfect baby: promoting the health of the unborn baby, health as no longer taken for granted, and changing health behavior.

**Promoting the health of the unborn baby.** Especially in planned pregnancy, the women in this study were motivated to lead a healthy, sound, and regular life by the desire to safeguard the health of the wished-for baby. This included harmony and balance, good nutrition and exercise, a nonsmoking and drug-free lifestyle, and economical stability, including an acceptable and satisfying job and good housing. There were peak experiences of health, which included emotional as well as physical events such as enjoying a free warm summer day or a sauna. The movements of the baby were a source of well-being, because they showed that the child was alive and well. Multiparous women emphasized the quality of their relationships with others. They appreciated time for the family to be together, time to be with their partner, and also time to be alone.

**Health as no longer taken for granted.** Most of the primigravidae women in this study had not had any major health problems, and they had not experienced pain and suffering to any large extent. But even if the woman was a health professional, she had hardly thought of what health meant to her before her pregnancy. Such women may have thought of their healthy state with a general sense of gratitude, but their pregnancy meant a heightened consciousness about their health. Sick or malformed children and other people’s misery touched them deeply, and they thought that such suffering could affect their own family. Very few women tried to prevent disease if they had not experienced ill health. Pregnant women were sensitive to a lot of internal and external factors affecting their health, such as hot summer weather, spicy or fatty food, or too little or too much food. They compared their present experience to how it had been earlier in their pregnancy or how they were before it. Although Lisa was only 21 years old, she was pregnant for the fifth time and stated, “With my third pregnancy, I had to admit that I don’t have the same strength as earlier. This is actually my fifth pregnancy, one each year, and I’ve had two miscarriages, so I feel that I have the right to be tired.” The multiparous women also remembered their first pregnancy when they had time to rest and had their partner’s sole attention.

**Changing health behavior.** All the participating women consciously and some almost constantly thought about how their health habits would affect the baby’s health. They changed their health behavior and became more health conscious as their baby grew and began to move. They ate regular nourishing meals and avoided junk food, coffee, sweets, and salty and fatty products. The women also complained about a too small or a too big weight gain, were eager to weigh themselves, and yet were afraid of doing so. Many women also felt that they should exercise in some way, but they were uncertain about what they could do because they were afraid of
harming the baby. They thought that the delivery would be easier for them and the baby if they were fit. Most women tried to take long walks but were more cautious about riding a bicycle or doing a workout. Backache prevented them from exercising. For those women who had been interested in sports, pregnancy meant a break in training. After the birth of the baby, healthy food and exercise were mentioned more as an ideal. The baby occupied the women’s time, and those who had problems with breast-feeding, fatigue, and ill health after the birth complained about lack of sleep, fresh air, and exercise and about not having time to make nutritious meals. Most women thought they would harm their baby if they used tobacco, alcohol, or drugs. They felt both an internal urge and external pressure from the health care staff, friends, and colleagues at work to stop, but many were ashamed because they could not stop and tried to hide or cut down on their use.

An Altered Mode of Being

The themes in the category named an altered mode of being are as follows: the changing body, variations in mood, ill health as part of being pregnant, and worries.

The changing body. The enlarging belly was the visible sign of pregnancy for the women in this study, and it evoked many feelings, from happiness and wonder to disgust and annoyance. The big body might also lead to a sense of being handicapped when the woman had a lot of work to do and was used to moving around easily. Clumsiness was considered part of being pregnant. At the end of their pregnancy, the women grew tired of their body and longed to be their normal selves again. The way the pregnant women felt about their body was also a consequence of how other people treated them. Women felt annoyed and embarrassed when people looked, tapped on the belly, and made comments. They easily thought that something was wrong with them compared to other women, as Britt did: “I’ve heard that I’m not becoming bigger and that the pregnancy does not show. I began to think that maybe things are not right, maybe I’m too small, maybe the baby is not healthy, and maybe something’s wrong.” There were women who did not buy maternity clothes because they did not want to show their pregnancy, and they thought that their big belly made them look fat and ugly. They used metaphors of animals such as toads and elephants to describe how they felt about their body. Cherry, a 22-year-old student, only admitted this in her third interview, 3 months after her first pregnancy:

I hated to be pregnant, ugh. I thought it was disgusting, and I still think so. I was so mad when someone told me I was big. I hated my belly, and I would do almost anything so that people wouldn’t see that I had that big belly. I could cover it, and I wouldn’t like it today, either.

There were women who took minute care of their body, rubbing creams into their skin every day. They wanted to avoid liver spots and striae, but they postponed the thoughts of the changes that they knew that the end of the pregnancy would involve.

Variations in mood. Many of the participating women described rapid variations in their mood and characterized them as a sign of pregnancy. Periods of strength
and easy living might suddenly change to feelings of being weak and weary. Many women described sensitiveness and a longing for peace and quiet, and they did not laugh as easily as they cried. There were women who felt calm during their pregnancy, and their mood changes were not as rough as they had expected. In late pregnancy, when the woman felt she had enough of her pregnant state, she became impatient and eager to end the pregnancy and finally see her baby. Joyous expectations altered with dark premonitions.

Ill health as part of being pregnant. Paradoxically, some of the women emphasized that pregnancy was not a disease, although they experienced all kinds of discomfort. The signs of ill health were then seen as part of being pregnant. Many women had experienced morning sickness in early pregnancy. They even expected sickness to occur, and they would hardly believe that they were pregnant if they felt good. In the middle of the pregnancy, most pregnant women felt better and more brisk. Many of the women complained about fatigue and strain, which they felt was a part of being pregnant and also due to sleeping problems. They said they tossed and turned, were more sensitive to noises, found it difficult to fall asleep, and often had the urge to visit the toilet during the night. The women wanted to take naps and were especially tired after work. The multiparous women who already had a family to take care of at home could not just lie down when they felt tired. Pains in the back, headache, dizziness, and muscle cramps were also common. The early contractions were either viewed as part of being pregnant or as threatening signs of premature birth. The pregnancy complications were difficult to understand for the pregnant women because they were not always associated with experiences of ill health. Ann described her experience of toxemia 3 months after the birth:

At the beginning, I felt so sick, and at the end, it was very hard because of the poisoning. I was forbidden to do anything that would make the blood pressure go up. I was 3 weeks in the hospital, and then I thought it was unnecessary, but afterwards I’ve read about it and understood why. I felt healthy and it was a wonderful summer and I had to lie in bed.

Women asked what other pregnant women had done to avoid or alleviate their ill health, and they wanted the best possible care. When women talked about the cause of their ill health, they used humor and tenderness, as Sandra did: “I talk and sing to the baby. Why are you making me feel this way?”

Worries. Pregnant women worried about their health, the baby’s health, the family’s health, the delivery, and their future life. It was a question of new things and events in their lives and things that were taken for granted earlier. Some women lived through their pregnancy in a state of ongoing worry and therefore regretted it. Even when everything had turned out fine, they thought that there might be problems ahead. They needed to talk to a professional caregiver who they trusted about the worries, which they thought nobody else had and which they did not want even their partner or close friends to know about. This was the fear of becoming a mother and wondering about how there would be room in their hearts and lives for this new child, especially if it was disabled, colicky, or ill because of their unhealthy habits. They were afraid of being reproved or of being unable to understand the information they were given. There were women in this study who suffered alone and
tried to get information from friends or literature. There were also women who wanted to visit the health center every day for a checkup. Multiparous women worried about the development of their other children when they did not have the patience and strength to take care of them. This was especially common with those who carried their second child. But they also clung to their experience and thought that child care will now be easier. These women wanted to prepare their other children for the birth of the new baby. Carol, whose firstborn was 4 years old, said,

We talk almost daily with our boy about the baby. He is sad about my stay in the hospital. I think he’s jealous when he has to share his position in the family with somebody else. He is such a big part of me. He means so much to me because I was able to enjoy him and I was ready to give him everything.

Being pregnant and doing hard work was seldom a good combination, and women worried about the effects stress had on the baby. Few primigravidae women wanted to be at home because they did not have enough to do there to fill their day and then they would worry. They tried to take care of themselves at work by having regular meals and breaks. Paradoxically, they felt that they should be as effective as their colleagues but also felt that they should take it easy. Most of the women in this study thought they could get sick leave when they needed it, and pregnancy was also an accepted reason for sick leave. All of the women felt relieved when they went on maternity leave 4 weeks before their due date, which the Finnish social security system allows. Those women whose delivery was overdue felt imprisoned and restless and tried to get the delivery started by cleaning the house and taking hot baths. The women were worried about their performance, the pain, the health of the baby, the staff, and the use of technology at the delivery. They described their pain threshold as low or high depending on their experiences of menstrual discomforts or headaches. As the time of delivery drew near, women wanted detailed information about the delivery and the hospital care. They thought they had to be prepared for a long, painful, and complicated delivery, as Ann did, who had read a lot about alternative natural childbirth: “All the things might happen that you don’t want to go through, a Cesarean, an episiotomy, and you’ll be chained to machines.” There were women who were afraid of the hospital because of the sterile surroundings and the lack of privacy. They thought that a visit to the hospital and seeing the staff might be helpful, but most of all, they hoped that their partner would be there. They thought that they ought to prepare themselves by practicing special breathing and relaxation techniques, but without guidance, they easily postponed it. Fears and worries were not alleviated only by knowledge, although most women actively searched for information. It was not easy for them to apply general knowledge to their own situation, and it could cause more anxiety when the woman thought of all the things that might happen.

Striving for Family Communion

The pregnant women’s striving for family communion is pictured as an outcome of the following themes: the evolving significance of the baby; dreams, hopes, and planning; and changing relationships.
The evolving significance of the baby. Most of the women in this study claimed that the child was welcome into their lives, although the importance of the baby for them and their family evolved gradually. Even if a woman had planned her pregnancy, the unreality of having a baby was described as a shock. In early pregnancy, the general attitude to the pregnancy was related to how well the pregnancy was planned and whether the family wanted a child. There were women who wanted a child of their own when they had a peaceful, sheltered, and economically and emotionally satisfying way of life. Multiparous women wanted to give their other children a sibling and a playmate and strengthen the ties within their family. Women pondered and weighed their presumed losses, such as their interests in life, traveling, and their career. Having a newborn baby also causes a loss of the freedom that has occurred when the other children do not need their mother’s full-time attention. Even so, there are considerable advantages for those who appreciate the possibility of a break in their career and want to be at home with their other small children. The primigravidae especially longed for a change in daily routines, and they longed for family communion and the closeness to their partner that can result from the birth of the baby. It may also be a positive thing to move to a bigger apartment or a place that is more suitable for children, which many of the participating women did. The women who had reached 35 years of age or more thought that it was now or never. They feared that they would not have the strength to bear a child later, or they were afraid of the risk of having a child with Down’s syndrome. Women in this study described that it was the health of the child that was important, not whether it was a boy or a girl. There were women who have had major problems in getting pregnant. Many women said that they had a premonition of the pregnancy before they had the test at home or at the maternity center. It was a wonderful experience if the women really had wished for the pregnancy. The worry and the problems were postponed at this moment, and they wanted to share the joy with their partner.

The pregnant women described how the baby had already affected their lives in terms of heightened responsibility and maturity. Many women described an awareness of their development in late pregnancy. They felt privileged, proud, and happy about their pregnancy and compared themselves with others who complained. The experience of being privileged was related to the women’s earlier experiences of losses through miscarriages and a feeling of now having accomplished something that increased their self-esteem. They wished that other women could have the same special experience. However, this special privileged sense of being might also become a feeling of being lonely and deprived, of having lost their freedom because of the restrictions, and of not being understood. They reflected on how motherhood will change them. There was not enough time to enjoy pregnancies after the first one, such as preparing for the baby. The birth of the baby and living with the child occupied the women so much that they seldom spontaneously talked about their pregnancy in the interviews after the birth. They felt that they had forgotten some of the difficulties, and the pregnancy remained a strange, confused, and unreal period of their lives.

Dreams, expectations, and planning. The fear that there will be no baby changes into the happiness of knowing because of the symptoms of ill health, the baby’s movements, hearing the baby’s heartbeat, and the ultrasound examination. The ultrasound was an anticipated screening for them, important also as an experience of communion for the woman and the attending partner. They hoped to get a
picture to show to friends and relatives. The women trusted the technology, and none of them doubted the usefulness of the screenings. They were not afraid that screenings could be harmful, nor was such information given to them.

Dreams and expectations with moments of joy and planning characterized the pregnancy from the day the women actually started to wish for a child. This is what Britt said in her late pregnancy, although her pregnancy was not planned: “I have plans for the future. I have so many plans, and there is much to put in order. I really enjoy it.” The pregnant women prepared for their baby by making clothes and buying equipment. The women thought that life would change, but they could not imagine how. Life changed slowly from a concentration on work, leisure, and hobbies and a self-centered way of life to a more family-centered lifestyle. The multiparous women were even more aware of their wish for a healthy, perfect child because they had experienced how demanding child care could be. They had seldom thought about children before they began to wish for a child of their own. Karen, a social worker, said,

I developed a lively interest in children and a lively feeling for children when we had our first child. Earlier, I had neither understood how to take care of children nor honestly liked children. I just feel that I now like other children in a completely different way.

For the primigravidae women, there was hope that they will be able to care for their child because they had been able to care for other children. They wanted to do the best they could to care for and nurture their baby, but they knew it would require strength. They thought that they were able to care automatically and intuitively and that everything would turn out right, and they felt they were best for their children. Everything need not be perfect; they hoped they would gradually learn. There were women who felt very embarrassed about breast-feeding and thought that it would affect the relationship with their partner. The women also wondered if their milk would be enough for the baby. The multigravida women had wishes about breast-feeding depending on their experiences with the other children, and they wanted to succeed as well or even better now.

Changing relationships. Pregnancy brought forth changes in relationships and new acquaintances. Women described these in relation to their partner, children, parents and parents-in-law, friends, and professional caregivers. Women expressed the importance of sharing the pregnancy with their partner. He put his hands on the woman’s belly and felt the baby’s movements, and he was with her sometimes in prenatal care. It was a way of getting closer to each other and strengthening the family bonds. The woman wanted her partner to show interest in the baby’s health and development. Those who were eligible for free genetic screening wanted to share the difficult decisions, but as Anne said, “I have to take the child as it is, even if it is ill.” They thought that they could love a child with health problems and care for it but that their partner would have difficulties. The young primigravidae women said that their partner would not leave them because of their pregnancy. Many women worried about the loss of interest in their sex life because they were afraid of harming the baby and tried to compensate for it by tenderness. The women expected the partner to take part in the child care and the housework without being asked, but not many women mentioned their expectations to their partner. The
women had few wishes about the partner’s participation in the delivery. Here are Pat’s words in the 36th week of her first pregnancy:

He’ll be there. We’ve planned it from the first day we knew about the baby that he’ll be there at the delivery. He doesn’t want to miss such an experience. I know it’s hard for him to experience the pregnancy the way I do.

The women wanted to feel that the whole family wanted the child as much as they did. There were presumed pros and cons for most women as far as their other children were concerned. They did not think that the siblings would react in a positive way at first, and they wondered how the relationship would change. They thought it would be valuable for the child to have a sibling.

The women’s parents and parents-in-law often supported them and shared the worries and joy of the pregnancy, and the bonds would become stronger during pregnancy. They helped with the child care so that the mother-to-be could get some rest. The woman’s own parents are a source of security if something happens in the relationship with her partner. They took care of the other children when she was in the hospital. The woman also felt that she would be able to give her parents and parents-in-law something valuable because they would become grandparents. The woman’s own mother was especially important to her, and she needed her approval.

Many a pregnant woman was afraid of becoming isolated and hoped there would be friends in the same situation who could support her and whom she also would like to support. If the woman had friends who had had problems during pregnancy, she was on her guard, and the worst thing was the risk of losing her baby. This also worked the other way around. Women were more confident if they knew others who had had positive experiences related to pregnancy. The young primigravida lost some of her friends because her life situation changed and she no longer went to discotheques or pubs. Her interests also changed from a school world to a world filled with her pregnancy and dreams about a future including the child. Caroline, a 22-year-old student, said, “Now I know who my real friends are, although this is not a life crisis.” Many of the women were eager to join in small groups of other pregnant women, regardless of educational and vocational differences. The preparation courses were criticized both during pregnancy and after delivery because they offered the women unrealistic knowledge and the big groups and lectures did not offer discussion. The women had suggestions about how the maternity center could help the women get acquainted with each other.

The nurse and the doctor were mostly new and important people to the pregnant woman. The nurse was needed as a supporter, someone to talk to about her life and worries, and someone who can provide solutions to different problems. The pregnant woman wanted to know that everything was the way it should be through the screening and measuring, and she needed information about the delivery and life with the child. Pregnant women flourished when the caregiver told them that everything was fine. Sensitivity was also essential in prenatal care, for women easily felt hurt: “You pay a control visit and they screen and measure you and then you leave. I felt so disappointed.” Pregnant women who have been satisfied with the care at the maternity center hoped that the same caregiver will take care of them at the delivery in the hospital.
THE ESSENTIAL STRUCTURE OF THE LIVED EXPERIENCE OF PREGNANCY

The essential structure based on the exhaustive description tries to capture the lived experience of pregnancy from the perspective of those who live or have lived through it. The essence is the invariant meaning that emerged in this cultural context (cf. Colaizzi, 1978; Giorgi, 1985; Spiegelberg, 1975). It is formulated as follows: The pregnant women wished for a perfect baby in an altered mode of being while striving for family communion. The women tried to promote the health of their unborn babies, no longer took health for granted, and tried to change their health behavior to match differing ideals. Pregnancy is experienced as an altered mode of being when the women’s bodies change; they experience variations in mood and worries related to their own health as well as the baby’s and the family’s health, the delivery, and the future. The women strive for family communion, which is seen in terms of the evolving significance of the baby, dreams, hopes and plans, and changing relationships.

DISCUSSION

The exhaustive description and the structure of the lived experience of pregnancy provide an understanding of the women’s wish for a perfect child, their altered mode of being, and a striving for family communion. There is deep joy as well as suffering to show the beginning of a major change in their lives. The validity is related to the phenomenological requirements of bracketing previous knowledge. Another criterion is the richness of the data from different participants collected using both semistructured and unstructured interviews. This was accomplished during different periods combined with the researcher’s participation in the women’s visits to health centers and the hospital to achieve sensitiveness and depth (cf. Giorgi, 1985; Morse, 1997; Moustakas, 1994; Spiegelberg, 1975; Van Manen, 1997).

The findings of this study support previous research on various aspects of pregnancy, for example, pregnancy tasks (Rubin, 1976, 1984), body changes (Mercer, 1986; Rubin, 1984), variations in mood and worries (Bibring, 1959; Breen, 1975; Chertok, 1969; Mercer, 1986; Rubin, 1984; Shereshefsky & Yarrow, 1973), and changing relationships (Coffman et al., 1994; Rubin, 1984). The classic crisis, role, and stress paradigms focusing on negative and pathological versus external societal perspectives might no longer provide a full understanding of the experience of pregnant woman in the Western world. The cultural changes imply planned and even induced pregnancies in which motherhood and womanhood are separated in an urban lifestyle with working careers, personal interests, and the nuclear family in transition (cf. Graham & Oakley, 1986; Hillan, 1992; Oakley, 1980). Women in the Western world are used to planning their lives, but it is not possible for them to plan childbearing, the birth, and the relationship with the baby in every respect. The existential questions seem to be neglected in Western cultures and, naturally, also in the maternal care organizations. We will concentrate on discussing study findings of an existential nature that have not attracted very much attention in previous research.
Eriksson’s ontological health model (Eriksson, 1994, 1997; Eriksson et al., 1995) can shed further light on the essential structure. In the ontological health model, a person’s conception of health is connected with suffering. Eriksson argued that a human being reaches a higher level of integration through crucial experiences. In pregnancy, there are underlying existential questions about health and suffering and life and death that are related to the woman, the baby, and the future family. The ontological health model is conceptualized as becoming, as a movement in three dimensions: doing, being, and becoming in relation to health and suffering.

The first dimension, doing, is characterized by problem orientation, health connected to behavior, living a healthy life, preventing disease, and escaping suffering (Eriksson 1994, 1997; Eriksson et al., 1995). In early pregnancy, the woman asks, “Is there really a child growing within me?” The second set of questions emerges when the woman recognizes that there is a baby inside her, and these questions are related to the baby’s health. She also asks, “Can I provide health for the baby?” The woman desires answers, ideals, completeness, and being like her peers. She feels that she should follow the often culturally determined opinions regarding food, exercise, alcohol, smoking, appearance, and clothing. This may create a positive circle of well-being and increased self-esteem when her own resources and knowledge increase. It may also lead to the opposite, a negative circle of failures and suffering, when her pregnancy is not accepted and she does not act according to her culture’s rules. After the birth, health behavior is not meaningful in the same way. Pregnancy assigns a special meaning to health promotion. The woman exists not only for herself but also for the baby. An interesting cue to health promotion research is that healthy behavior seems to persist if the woman holds on to the physically based relationship with the baby through breast-feeding.

The second dimension of being is a state of health with a striving for well-being, balance, and harmony in relationships and life situation (Eriksson, 1994, 1997; Eriksson et al., 1995). The behavioral aspects and focusing on her body might be an attempt on the part of the woman to avoid thinking about the meaning of the baby or the changes in her life after it is born. The rosy dreams about the perfect child and family prevail, and she thinks everything will be so good when the baby is born. Women look on their pregnancy and their symptoms as a natural state of health that is part of the experience of being pregnant. This attitude may create problems if the women do not consult the maternity center, and this also makes preventative screenings important (cf. Patterson et al., 1992). As time goes on, the mother-to-be dares to ask, “What will the delivery be like for me, my partner, and our baby? Can I do it right? How much pain and suffering will there be? What will the child be like?” At the end of the pregnancy, she may still feel that the child is not real and the time of delivery will never come. The woman has wishes mixed with fears, but she seldom admits this even to herself or her partner. The questions often hidden from the outside world are “What will it look like? Will it be a boy or a girl?” The woman and her partner are ashamed of wishing for a boy or a girl, which is something that they admit only after the baby is born. However, it is culturally permissible to wish for a healthy child. The woman tries to steer clear of the worst things that can happen: a malformed or dead child, a family that is not complete.

The third dimension of becoming has its starting point in the assumption that a human being is in continuous movement and will never fulfill himself or herself. Movement alternates between integration and disintegration and is driven by internal or external forces. Anxiety drives a human being into the drama of unendurable
suffering, which alternates between hope and hopelessness (Eriksson, 1994, 1997; Eriksson et al., 1995). In the study discussed in this article, it is accentuated in women who live their pregnancy in a state of worry. Many women have an inner yearning to become mothers, to love and be loved by the child and their partner in an ideal family (named family communion in this study). The profound changes are not yet visible to pregnant women. Most first-time mothers in their well-planned and ego-centered lives do not seem to be prepared for restricted routines and at the same time a floating family-oriented life (cf. Barclay et al., 1997; Rogan et al., 1997). Multiparous women encounter the paradox of both joy and suffering in being needed by their whole family and living a life of continuous prioritizing, which tends to put their own needs last. Tilden (1983) stated that pregnancy is an unforgettable and intensive experience. The findings of this study support this idea, but it seems that the pregnancy experience is overshadowed by the experience of childbirth and the massive amount of energy that is required to incorporate the baby into the family (cf. Beck, 1992, 1993; Bondas-Salonen, 1998a, 1998b; McIntosh, 1993a, 1993b; Mercer, 1986; Rubin, 1984; Sethi, 1995). It is not only a question of the care the child will need but also a matter of coming to terms with oneself as a mother and, most of all, as a human being, both good and evil. Caring originates from motherliness or spontaneous love, which can be regarded as natural care (Eriksson, 1997). This is required when the woman takes care of herself, her family, and the newborn baby, whose needs are absolute and can seldom wait.

The suffering created by the worries of pregnancy continue if the woman does not have the strength and support necessary for her to lead a satisfying way of life together with her family. She suffers in silence to maintain her own dignity as the ideal good mother. The woman’s development will be interrupted, and the victim is not only the woman but also her baby and her family. Joy and desire seem to be completely gone even if the pregnancy was a good experience and in spite of the presence of the wished-for child. Findings from this study highlight Eriksson’s (1994, 1997) assertion that suffering and health belong together. Suffering as well as joy, such as a pregnancy in this study, might lead to a better understanding of the terms of human existence and health (Eriksson, 1994). For the women in this study, the meaning of health deepened and changed.

Health as integration (Eriksson, 1994, 1997; Eriksson et al., 1995) requires that all three dimensions of doing, being, and becoming are present in the pregnant woman’s life. This implies an active attitude toward one’s own health. This is evident in the findings of this study but not always encouraged by the paternalized, medicalized, and stereotyped health care culture (cf. Graham & Oakley, 1986; Oakley, 1980). The pregnant woman needs to be surrounded by a caring culture. In this deepest sense, the meaning of life is to be able to minister, to exist for another person (Eriksson, 1992, 1994). The need to exist for another person is fulfilled by pregnancy and childbirth. Providing the best health through one’s own body and person is a way to this ministering.

The woman wants to be seen as a unique person and not as an object, a womb. She knows that all her questions cannot be answered. She grieves the loss of her earlier life (cf. Mercer, 1986; Rubin, 1984). Still, she hopes to be seen and taken care of in the best possible way, and she wants to tell her story of joy and suffering and to share her experiences of earlier pregnancies, deliveries, child care, breast-feeding, and her family (cf. Eriksson, 1992). This goes beyond wishing for the best possible care, because the woman wants the caregiver to get to know her and confirm her dignity.
and uniqueness and alleviate her suffering. A suffering person often seeks caring in a symbolical or metaphorical form (Eriksson, 1997), and it is important to listen to what lies behind the words, because women may joke about things that hurt them the most. Listening is caring in itself, which was reported by the women in this study, and not only a way of assessing the need for support, as Gottlieb and Mendelson (1995) asserted. The woman may need help to find the peace and quiet to establish a relationship with the child. She may even need help to create family communion and feel the joy of pregnancy and parenthood (cf. Eriksson 1994, 1997). Thus, new rites of passages are needed (cf. Höjeberg, 1985). In light of this study, there is a need to incorporate the women’s experiences as a basis for perinatal care and to include the women as well as their families as active participants in care. Even though the woman carries the baby, the whole family experiences the pregnancy and will be there when the child is born (cf. Hallgren et al., 1995). The family cannot be known only through one of its members.

Women also desire to share their experiences with other pregnant women and women with newborns because they might help alleviate their worries (cf. Hallgren et al., 1995; Hillan, 1992; Mercer, 1986; Nolan, 1997; Vehviläinen-Julkunen, 1995). The women also need compassion and want to show compassion to other women who are in the same situation. But “artificially constructed” social support cannot mimic natural support within families and other networks (Bryce, 1991), as this study also shows. This phenomenological caring science research program (cf. Bondas, 2000; Bondas-Salonen, 1998a, 1998b) continues to focus on the substance of the maternity care culture, which maintains and enhances human dignity in lay care as well as in professional health care.

NOTE

1. The first author, Bondas, has conducted the data collection, the transcriptions of data, and the phenomenological analysis.

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Terese Bondas, R.N., LicNSc, is a doctoral student in caring science and a lecturer in caring science and health care administration at Åbo Akademi University in Vasa, Finland.

Katie Eriksson, R.N., Ph.D., is director of nursing at Helsinki Central University Hospital and a professor of caring science at Åbo Akademi University in Vasa, Finland.
Exploring the Technical Aspects of “Fit” in Qualitative Research

Janice M. Morse
Joanne Singleton

The concept of fit and processes of fitting have been largely ignored in qualitative inquiry. In this article, the authors address the technical significance of fit as an analytic process for both data and concepts in the process of theory construction. The ramifications of violating processes of fit and examples of misfits are discussed. Finally, the procedural components and fit as a method of validation are presented.

Although fit, both as an analytic process and a research procedure, is a crucial component in qualitative inquiry, scant attention has been paid to the actual nature, mechanisms, and implications of the concept. Yet fit is essential to qualitative inquiry: Fit is the means by which processes of synthesizing are achieved, the validity of data and the credibility of the study are ensured, theories are constructed, and findings are recontextualized for application, allowing them to be placed within the broader context of knowledge. Thus, the concept of fit is central to data analysis, theory construction, the validation of results, and the generalization and utilization of qualitative research.

Fit refers to the process of identifying characteristics of one entity and comparing them with the characteristics of another entity to see if similar characteristics are present. Fit may also refer to complementary relationships, as in fitting pieces of a jigsaw puzzle. Fit is therefore the process of examining two entities and identifying their similarities or compatibilities along some identifiable dimensions.

Given the centrality of fit to all stages of the qualitative research process, it is astonishing that so little emphasis has been placed on the concept of fit itself. It is probable that the silence regarding fit stems from the more general lack of explication of methodological detail in qualitative inquiry and, in part, from the lack of knowledge regarding the general principles of qualitative research. In this article, we explore the processes and procedures of determining fit in various stages of the research process and discuss appropriate and inappropriate uses of fit.
FIT AS AN ANALYTIC PROCESS

In the process of data analysis, determining fit of each datum is the most basic of all operations in qualitative inquiry. By examining data, piece by piece, the investigator ascertains if the qualities or dimensions of interest of the two bits of data are in accordance or if a datum is similar to data within a category. In other words, fit has occurred when it is established that two entities have characteristics, qualities, or dimensions in common. Even when these characteristics, qualities, or dimensions are not actually identical but similar, fit allows these data to be associated, to be placed within the same class or category, or to be linked with one another. In this way, determining fit enables data to be sorted and subsequently reduced. As data cluster, the dimensions that the researcher is using to determine the similarities between them allow the salient characteristics of the category or the concept to be identified and explicated. Analytic processes become more formal as series of questions are developed about the nature and dimensions of the fittingness. The process becomes an interplay between the analytic uncovering of potential for fit and the questioning that facilitates establishing the datum as a part of the group or category. Thus, fit is a term that is used to ascertain if one entity is a part of the same group (i.e., deciding if a piece of data may be considered a part of a larger category or, in the case of a concept, part of a theory). Fit has occurred if the researcher is able to describe the commonalities of the entities, whether they are a part of a whole (as the relationship of a datum to a category or concept) or whether they are equivalent in meaning (e.g., as when a researcher compares one datum to another).

An example of the importance of determining fit inductively occurred in a study in gift giving in hospitals (Morse, 1991b). In this study, Morse argued that gift giving was a reciprocal act, an acknowledgement of care received. But are sabotage and lawsuits a part of gift giving in hospitals? Nurses argued that patients gave back for poor or incompetent care, just as they gave carefully chosen gifts for excellent care. Thus, retaliatory acts fit into the taxonomy explicating types of gifts.

Thus, analytic fit may be considered to have occurred when one unit (datum) is determined to be a member of a data set or class (category). By determining fit, data are synthesized; concepts are delineated, described, and linked; and theories are constructed.

Fitting Concepts

As qualitative models are constructed and the pertinent concepts in the model or theory are identified, it becomes evident that when concepts fit ideally, the boundaries of the two concepts should butt (with minimal overlap) like two pieces of a jigsaw puzzle. The linkage between the concepts must be sensible, logical, and verifiable in both exemplars (obtained from the data) and must be supported by (or at least not seriously contradict) the literature. When the developing model is a process, concepts may appear within the theory at different times. Concepts may parallel each other, thus changing the nature of one or both concepts, or they may transect or intercept one another.

Determining the fit of one concept to another is achieved by using the same processes as determining analytic fit. First, the dominant concept is identified, and this
concept forms the base into which the second concept is fit. It may be necessary to open both concepts and explore each for common characteristics or components, and once identified, these shared components will indicate where the two concepts merge. Once the fit of the two concepts is understood, other concepts may be similarly brought into the model, and in this way, qualitatively derived theory is constructed.

An example of linking concepts using the principles of fit appears in the work of Morse and Penrod (1999), who explored the relationship between suffering and hope. The dominant concept was suffering, the point of interception was despair, and through the interaction of the two concepts, Morse and Penrod were able to show how hope enables those who are suffering to emerge from suffering. Qualitatively derived theories may, therefore, be systematically constructed by determining fit between categories and concepts, between emerging concepts and theory, and between emerging theory and the literature. The processes are the same as in fitting data, regardless of the level of abstraction of analysis.

The Ramifications of Violating Processes of Analytical Fit

What is wrong with forcing analytic fit? Glaser (1992) noted that “if you torture data enough, it will give up!” and that forcing “by preconception constantly derails it [theory] from its relevance” (p. 123). Forcing destroys the inductive thrust, so the emerging results are not data driven but rather deductively driven from the researcher’s own agenda or from a preadopted theoretical framework. In this case, the fit of two data, or the data and the category, is determined by the investigator’s own agenda rather than by comparing the two pieces of data for compatible properties. Unfortunately, this process most frequently occurs at a subconscious level, resulting from the inability of the researchers to bracket the literature and their research agenda and maintain the sanctity of data.

PROCEDURAL COMPONENTS OF FIT

The concept of fit is also used in qualitative inquiry as an important procedure for determining internal and external validity. When exploring internal validity, methodological fit may be considered to have occurred when the assumptions underlying the phenomenon being examined, the emerging research question and the method selected, including the type of data collected and the analytic procedures used, are congruent.

In other words, the methods used must be able to provide the best answer to the research question; data collected and the analytic strategies inherent in the method selected must be able to yield results that will optimally answer the research question. This internal consistency is not always present in qualitative inquiry. Researchers may lack flexibility in their knowledge and use of qualitative methods and, therefore, be forced to use a single method, regardless of the nature of the question and the type of knowledge required to answer it. For instance, grounded theory (or phenomenology) is used to answer a question that would be better answered using another qualitative method, such as ethnography. Another example from
within a project is the use of incorrect analytic methods. For instance, constant comparison, normally used in a grounded theory study, may be erroneously used to identify themes for a phenomenological study.

External validity of a study is demonstrated by assessing pragmatic fit. Pragmatic fit occurs when the results of one qualitative study are applied to another setting or context. Thus, pragmatic fit is the basis for generalization and utilization of qualitative studies.

Principles for applying fit may be identified: First, the larger the unit, the more difficult it is to determine fit. For example, in the case of a high-level concept, there will be a greater number of contexts to which the concept may be applied. However, if the concept is more abstract, the likelihood of a good fit to a particular situation is lost. Second, implementing a smaller, less abstract study in a single context carries less risk. Thus, the lower the level of abstraction (i.e., the less conceptual it is), the fewer the contexts to which the concept may be applied. When it does fit, the fit will be more obvious, the information transferred will be more concrete, and the process of application is eased.

**Fit as a Means of Generalization**

Analytic generalization “involves a reasoned judgment about the extent to which the findings from one study can be used as a guide to what might occur in another situation” (Kvale, 1996, p. 233). Fit is determined by “assertational logic” (p. 233). By making the similarities and differences of the two problems explicit, the determination of fit may be evaluated, and if appropriate, transference of findings may occur.

**Fit as a Method of Validation**

One way to verify or confirm an emerging model is to check it with the participants. Once the results have been relatively finalized, investigators take the results back to participants for their comment and validation. Participants are asked to compare the theory with their own experiences—in other words, to fit the theory with their reality (Miles & Huberman, 1994). Elsewhere, Morse (1998) has criticized this practice because it only validates the participants’ experiences if the theory is relatively low level. The legitimacy of these criticisms aside, this is a relatively common use of fit in qualitative inquiry.

**Triangulation**

Triangulation is the fitting of complementary findings from studies that have sequentially or simultaneously explored the same topic (Morse, 1991a). Studies may explore the topic at different level of inquiry: For example, one study might explore touch microanalytically using videotaped data, whereas another might explore the meaning of touch to nurses and patients using interviews. Logically, these two studies should yield complementary results, with the meaning of touch linked with the duration and intensity of touch from the observational study.
Mis-Fits

Misapplications of fit can occur, and fit may be inappropriately used when the wrong dimensions are used for comparison. Below we will first discuss the demographic composition used for selection of sample (rather than using a theoretical sample) and second sampling by matching research topic (rather than selecting a problem).

Demographic fit. In quantitative research, generalization is achieved by determining the similarities between the study populations and the population to which the results are to be generalized. This approach is not pertinent with qualitative methods; in fact, sole reliance on fit of demographic dimensions of the sample population and the study sample may invalidate the transference of results.

The reason is that similarity of population composition in itself is an inadequate rationale for ensuring that the results will be applicable to the setting. Rather, the researcher should compare problems. If these are similar and the concept is pertinent to the new setting, then the theory will have meaning (application) to the setting and be generalizable. Recall that in qualitative research, it is the theory that is transferred, and if the theory is adequately developed, the processes of decontextualization and abstraction will get rid of any data that link the theory to the context from which the theory was derived. As stated previously, the problem and the concept must be appropriate for the setting, not similarities in demographic composition.

A study conducted by Applegate and Morse (1994) provides an example. The study focused on privacy maintenance in the nursing home and revealed that the respect for privacy was closely associated with how residents and staff regarded and treated each other. If persons responded to each other as though the other were an object, then privacy norms were violated; if they treated one another as a stranger or a friend, then privacy norms were respected. Now, these results were obtained from a sample of elderly men living in a nursing home. Would these results be useful to me if I were working in a unit that treats women with breast and ovarian cancer? The answer is as follows: If the problem fits, then the theory should fit any situation that has a problem with privacy maintenance. That is, the results are not particular to elderly veterans. In fact, the issue that the theory was developed with elderly men and the new unit contained young and middle-aged women should not inhibit the process of generalization.

Firestone (1993) noted that in such generalization or transference from sample to population, extrapolation is “not likely to be.” The important point that it is not a matter of demographic comparison is missed by Miles and Huberman (1994). In their discussion of external validity, transferability, and fittingness, their first relevant query urged the reader to explore similarity of the sample. We repeat: Such comparison is not pertinent or relevant. Furthermore, Lincoln and Guba (1985) also missed this point, and they confused things further by comparing contexts, suggesting that the researcher must indicate “the range of contexts to which there might be some transferability” (p. 124) of findings and that adequate thick description of the context is needed “so that anyone else interested in the transferability has a base of information appropriate to the judgment” (pp. 124-125).
Matching by topic. Inappropriate fit occurs when the researcher is limited by subject area rather than by research problem. That is, the researcher restricts the literature review to similar populations rather than reviewing all of the literature pertaining to the concept concerned. For instance, a researcher studying hope in breast cancer patients might be tempted to disregard another qualitative study addressing hope because it was conducted with an AIDS population rather than with those with breast cancer. Again, the researcher must look beyond the population and the context in which the study was conducted and consider whether the concept (in this case, hope) is relevant and will fit the present inquiry. To insist that studies are only pertinent to one’s research if they have been conducted with similar populations or in similar contexts diminishes the contribution of others’ research at the conceptual level. Concepts, by definition, are abstract and not context bound.

SUMMARY

Determining fit begins with an analytic process, which requires abstract thinking. This conceptual thinking involves the identification of the criteria that justify the decisions that form the basis for determining the fit. These are followed, as the process continues, with more overt criteria or procedural thinking. That is, as the process of determining fit continues, the procedures become more apparent. Questions about the characteristics of the categories become clearer. Thus, criteria used to determine the fit must be identified before applying or generalizing the results or before results can be used in another context. In this way, fit precedes function.

All qualitative analysis is based on the appropriate application of the concept of fit. Fit is pertinent to data analysis, synthesis, and summarization; to the development of categories and themes; and to theory construction, triangulation, utilization, and application. Given the centrality of the concept to qualitative inquiry, it is important that fit be appropriately addressed in methodological texts.

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Announcement

I am delighted to announce that starting with Volume 12, Number 1 (2002), *Qualitative Health Research* will be published 10 times per year. Issues will appear in January, February, March, April, May, July, September, October, November, and December. The numbers of pages in each issue will remain unchanged. A new section will be added—“End Notes”—which will contain brief hints on qualitative methods or discussion points. These will be reviewed and will contain short comments that are important but do not require a context of a full-length article. Please see “Instructions for Authors” in Volume 12 or our Web site, http://www.ualberta.ca/~iiqm/, for further information.

JANICE M. MORSE
Editor

With the expanding use of focus groups in health studies and the paucity of guidance of their use for rigorous research, I eagerly delved into this book, whose goals are “to cast a critical eye” on the formulaic approach and “suggest ways to develop the full potential” of this method. Unfortunately, the breadth of this cast is too limited, and the book does not live up to the title’s potential. The premise that researchers are in danger of “uncritically adopting the market researchers’ models” (p. 1) is contrary to volumes of peer-reviewed, published studies that document the appropriate uses of this method.

The intended audience is not clear. Some basics of the focus group technique and its development are briefly reviewed in the Introduction. This material is not comprehensive enough to be useful to a researcher new to this technique, and the interested reader is not referred to standard sources for further information. Across the chapters, the definition of this technique varies or is not defined. For research purposes, it would have been helpful to state an operational definition that is appropriate to research, not merely “any group discussion . . . as long as the researcher is encouraging of, and attentive to, group interaction” (pp. 4-5).

Some of the statements are not accurate, such as the claim that market researchers use a positivist paradigm and view participants as passive subjects (p. 188). Although my experience and understanding of market research is primarily limited to North American literature, I believe that this general statement is in error. Also, to criticize a survey for only obtaining a snapshot and not rich data and for not allowing survey respondents to continue involvement in the research process is to rebuke inappropriately the survey technique for purposes it was never intended to provide. The instances of statements that I consider in error, or at least not in accord with general consensus, are too numerous to address in this review. My concern is the confusion that may arise when readers new to this technique compare this book with other publications, many of which are cited.

The studies described are very interesting; some address very challenging work with children, health issues for lesbians, participation of ethnic minorities, and other sensitive topics. The authors come from varied backgrounds and have experience working in social settings in Great Britain. There are some practical comments, for example, on running sessions with children. One chapter focuses on discussion groups, as contrasted with more traditional focus groups, described as naturally occurring groups in which the study of the development of knowledge is examined. Chapter 6 provides a particularly detailed description of the participatory action research process and clearly delineates the different goals of research and development. However, this chapter recommends the use of focus groups “to carry out action research” (p. 126). As a data collection technique, focus groups cannot be used for this purpose; rather, they can be used to generate data that are needed for
such work. Chapters focusing on transcript analysis, data analysis, and the impact of context on data are interesting to read but provide little new insights.

Most of the studies are concerned with particular uses of focus groups, for example, empowerment and participatory studies. Appropriate use of focus groups and research in general is broader than empowerment and changing power relations between researchers and the participants. Drs. Kitzinger and Barbour’s assumption (p. 18) that the focus group technique is inherently able to accomplish this is in error. In past and recent literature reviews, I have not come across this assumption.

In sum, this book will not be added to the short list of references I recommend on focus groups. Although it will not advance our understanding of this technique, it is worthwhile to read the studies, and I could suggest it for researchers interested in working with special populations.

MARTHA ANN CAREY
National Institute of Mental Health
Transdisciplinarity and the New Production of Knowledge

Max van Manen

It appears that university- and discipline-based forms of inquiry are giving way to new modes of knowledge generation. In The New Production of Knowledge: The Dynamics of Science and Research in Contemporary Societies, Michael Gibbons and his international group of colleagues (1999) argued that transdisciplinarity is a term of the discourse that describes changes in the way that research is increasingly practiced in contemporary societies. Whereas traditionally knowledge is developed in the scholarly context of academic disciplines, the new knowledge production is carried out within a context of application. The authors—Gibbons, Limoges, Nowotny, Schwartzman, Scott, and Trow—showed at the hand of many examples that the new scientists are less often occupied with basic or first principle research and more often with direct applications of knowledge to problems arising in technological, commercial, industrial, economic, communicational, and governmental sectors.

The argument about the “new mode of knowledge production” is provocative because this new mode is not the result of simple borrowings, importations, and accumulations of existent disciplinary perspectives, concepts, and methodologies. Rather, the new mode of knowledge production transcends the disciplinary theories and paradigms from which it is in part derived. Gibbons et al. (1999) call this “mode 2 knowledge production.” What distinguishes this new epistemology of transdisciplinary and application is that it is more context sensitive, eclectic, transient, and inventive than traditional (or mode 1) interdisciplinary and cross-disciplinary research practices and methodologies. Gibbons et al. (1999) suggested that their examples and models are problem-solution oriented and often driven by considerations of marketability, social policy, and practical use. Yet they also see similar trends of transdisciplinarity and context-sensitive inquiry occurring in the humanities and the arts. For example, they cite the new uses of information technologies and computer science in qualitative research (see Table 1).

Gibbons and colleagues described and advocated a way of thinking about knowledge and knowledge production that is quite reductionist and problematic from the perspective of the ethical value of human understanding. But it is important to be aware of the global trends to conceptualize knowledge in management and marketplace terms. In a sequel study Rethinking Science: Knowledge and the Public in an Age of Uncertainty, Nowotny, Scott, and Gibbons (2001) explored how the re-
The interaction between scientific research and society has changed into a more reciprocal dynamic process. Coevolutionary movements and changes between society and science require a more or less complete rethinking of the basis on which new social contracts between science and society are to be constructed (Nowotny et al., 2001). And in this evolutionary process more open and more dynamic frameworks for “doing” science are emerging.

Whether the social and epistemological analyses of Gibbons et al. (1999) and Nowotny et al. (2001) are valid, it seems undeniable that new modes of knowledge generation may be observed in the professional fields such as nursing, medicine, health science, clinical psychology, education, and the new information and communication technologies. These are, of course, domains of inquiry that maintain relations of application with the human sciences, the arts, and the humanities and that distinguish more differentiated conceptualizations of the theory-practice relation, and more complex philosophies of knowledge and human understanding. The theory-practice conceptualizations of Gibbons and colleagues appear surprisingly simplistic and technocratic from a human science and philosophic point of view.

Indeed, professional fields tend to be less amenable to the language of production discourses and problem-solving technologies. And yet, here too, we seem to see an emergence of transcendent knowledge modes as well as an emphasis on problem-based practices and inquiries. In particular, the human science epistemologies of the professional fields are becoming more sensitive to the particular ecological, subjective, moral, emotional, personal, and interactional dimensions of the ordinary lifeworld. Perhaps the notion of transdisciplinarity is important here too, but in a different manner.

Qualitative researchers now employ methods and approaches that have moved far beyond traditional discipline-based methodologies and methods. This can be observed in comparing the works of traditional phenomenological philosophy with the work of phenomenological research in the professional fields.
phenomenological philosophers rarely conduct research interviews; they seldom conduct on-site observations; they rarely employ allusive logics; and they typically distrust artistic, fictional, noncognitive, and nonrational epistemologies. But to inquire into topics that are of concern to professional practitioners, contemporary phenomenological researchers may need to step outside the accepted limits of disciplinary methodologies. They may turn to literature and art, to ordinary language sources and voices from the street, and yes, also to the relevant social science and philosophical disciplines to explore sources of meaning that evoke new and practical understandings and that resonate with the emergent legitimating priorities of local and global contexts of contemporary societies.

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Max van Manen is a professor in the Department of Secondary Education at the University of Alberta, Edmonton, Canada.
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