

Brief

Dilemmas of Difference and the Politics of Comparison: Cross-Cultural Research on Dementia

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L'article traite de quelques-unes des questions théoriques et méthodologiques apparues lors de la recherche inter-culturelle de l'auteure consacrée à la démence. Son souci principal est la difficulté de représentation au sein des groupes culturels. L'article sous-tend que, tandis que la représentation induit une perception d'homogénéité du groupe, elle estompe ainsi les différences en son sein. Il est parfois opportun d'employer cette méthode pour faire avancer la cause du groupe en question. L'auteure propose une façon de présenter les résultats qui, tout en atteignant les objectifs de la recherche, ne compromet ni les participants ni le chercheur. Cette recherche montre l'arbre de décisions qu'elle a suivi durant la réalisations de son étude.

This paper examines some of the theoretical and methodological issues that were raised when I undertook cross-cultural research on dementia. The main concern addressed in this paper is the difficulty of representation within cultural groups. The paper contends that whilst representation can lead to perceived homogenization of a group, thus blurring intragroup differences, it is at times expedient to use this method in order to further the cause of that group. This paper proposes a way of presenting findings that, whilst meeting the aims of the research, compromises neither the participants nor the researcher. This paper also represents part of the decision trail the author left while carrying out the research.

Introduction

Recently I was asked by the Chief Executive Officer of a major public-care facility for the aged to prepare a report on understandings of dementia from various cultural perspectives. Thus began a preliminary foray into the cultural beliefs of dementia found among Mediterranean, Asian, and Arabic communities. The aim of the project was to formu-

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late recommendations for enhancing the "cultural sensitivity" of nursing care at the facility.

This request was premised on an understanding that the work would be stereotypical. It was acknowledged that the project would uncover only "flavours" of cultural understandings of dementia. However, it was argued that this would be appropriate to the trans-cultural nursing practice already established at the facility.

I used a qualitative method for my data collection and conducted interviews with nine bilingual employees. My reason for choosing these particular people for the project was that they almost all worked with older people who spoke the same language as they did. In this regard I felt that these employees would have an insight into the cultural background of the people with whom they were working and thus would be able to articulate various cultural understandings of dementia.

Although the process of data collection posed no problems and the participants were all very willing to share their understandings of dementia, it became apparent that theoretical and methodological dilemmas had to be addressed. The remainder of this paper will first examine some of the dilemmas I discovered whilst undertaking cross-cultural research, then propose a way in which to manage data in order to best help resolve those dilemmas.

The Slippery Concept of Culture

The first difficulty I encountered when I undertook the project was how to manage the huge concept called *culture*. Australia is very proud of its multiculturalism and its concomitant policies that try to ensure equity and equal access for all Australians. It is acknowledged, however, that there are real political and philosophical problems in trying to define culture, because of the inherent complexity and multiplicity of meanings of the term (Wallerstein, 1990). Clearly, however, an operational definition of the concept of culture is a prerequisite to its having the potential to inform policy development or research.

In Australia, policy reflects the notion that different language groupings connote different cultural groupings. People who speak Italian, for example, would be perceived as belonging to the Italian community and sharing the values of that community. Conversely, people who are seen as not part of the Italian community do not speak Italian and therefore do not share the values of that community. So it can be argued that concepts of language, culture, and community can be used interchangeably.

I argued that basic concepts such as caring and health were culturally specific and socially constructed, and that they can vary with each cultural group. I also argued that dementia had only recently been constructed as a biomedical condition within the Anglo-Celtic culture (Hernandez, 1991; Lyman, 1989). The normative nature of such basic concepts, however, means that often the issue that they are culturally constructed is rendered invisible (Ferguson, 1990), and this can be very powerful for the dominant or host culture.

Employing the above notions of culture, I assumed that the participants – because of their language – belonged to a particular community and therefore had an insight into the beliefs and values of that community. I also assumed that the participants would have an understanding of the Anglo-Celtic construction of dementia as a pathological manifestation.

The Problem of Representation

I then encountered another problem. Whilst I (and the funding body) realized that the research would be stereotypical, I had not envisaged the power of the proviso of almost all the participants that whilst they would share their understandings of dementia constructed out of their own cultural experiences, I was not to interpret their comments as representational. This posed theoretical problems in terms of the definition of culture I had used and methodological problems in terms of how I would write up my findings.

Once we see groups as representative, particularly because there is a shared language, then the complex intragroup dynamics tend to be blurred and obscured (Higgenbotham, 1992), masking difference, rendering issues such as class and gender invisible, and ignoring power relations. Moreover, homogeneity lends itself to essentialism, which represents "the community" as sealed, static, integrated, and enduring.

The participants and I agreed that seeing their contribution to the research as representative would suggest homogeneity, and thus render invisible certain aspects of that community. Given that the aim was to improve health-care delivery to people of non-English-speaking backgrounds, the challenge was to find a method of data analysis that could lend itself to informing nursing care whilst not falling into the trap of false representation.

Highlighting the problem was the fact that representations of cultural groups lend themselves to cross-cultural comparisons, which can be seen as compounding the issue of homogeneity and which can also

run the risk of being labelled racist and thus political. Additionally, making comparisons of stereotypical representations seems a somewhat fruitless exercise. Pearson (1987) sums up this dilemma:

To ignore differences is seen by some as egalitarian, treating all people the same, but by others as evidence of colour blindness. To emphasize difference within a racist ideology is to reinforce and emphasize notions of alienness, whilst within an anti-racist perspective, recognition of difference is a prerequisite for a positive and sensitive awareness, a welcome departure from ethnocentrism. (p. 44)

This expresses exactly the dilemma faced by me, as the researcher, and by those who participated. Cultural research can lead to a greater understanding of cultural differences; however, it can also lend itself to cross-cultural comparison. This comparison, as the data analysis was to suggest, has the potential to reinforce negative, racist stereotypes.

Another problem that became apparent was that the participants, all of whom worked in health or welfare using their bilingual skills, wanted more funding, improved access, and cultural equity for the groups with whom they worked. Clearly, it became politically expedient for participants in this research to offer as much cultural information as possible in the hope that the research recommendations would benefit older people from non-English-speaking backgrounds. Therefore, while it is culturally insensitive and inappropriate to represent groups in a way that assumes homogeneity, it is politically expedient, given finite health-care resources, for the participants to speak in representational tones if they perceive a benefit.

The Politics of Comparison

Considering the potential for conflict between highlighting difference and the politics of comparison, the researcher can find herself in a very powerful and thus political position. Given that cross-cultural comparisons can lend themselves to racist interpretations, the researcher must make some very clear, principled and ethical, methodological decisions about data interpretation.

I realized that my data represented some powerful beliefs and emotions. Clearly, dementia was a very evocative subject for all people in this research. However, the cultural constructions of dementia varied considerably across the sample of people interviewed. Dementia was variously articulated as "dotage," "madness," "payback," "craziness," and "second childhood." Those who spoke of dementia in a negative

sense articulated a complex web of emotions and actions that manifested in various notions of shame.

Another notion that demonstrated cultural specificity was that of caring. For some groups, "caring" was the hands-on, day-to-day physical care carried out almost exclusively by women. Others stated that the men do the caring. When I delved into this subject it became obvious that caring by men was synonymous with making decisions on behalf of another, such as a parent making a decision on behalf of a child. When the participants were questioned further, they stated that the women do the hands-on work but did not articulate this as "caring."

The two above examples, outlining conflicting cultural constructions of dementia and caring, point to the potential for difficulties inherent in cross-cultural comparative research. Where there exists the possibility of perceiving something in a negative light – for example, dementia as madness associated with shame and stigma – the researcher must address the issue in a way that does not reinforce old stereotypes or create new ones.

Towards a Pragmatic Approach

A possible solution to my methodological problem was discovered in a rereading of my original aims and objectives. The principal aim of the project was to recommend ways to enhance culturally sensitive nursing care. To do so I would have to look for common themes or convergences in the data, which could be possible sites of service provision. Differences would not need to be highlighted; thus the possibility of harmful comparison would be reduced.

I arranged my findings under two broad headings: "benign" and "malign" constructions of dementia. As is normal in qualitative research, I included quotes from the transcripts to help to clarify the findings. However, I omitted the source of the quote. The reader therefore had no knowledge of the cultural origins of the speaker and thus could not attribute either benign or malign constructions of dementia to any one group of people. The decision to present data in this way was supported by the finding that all groups, however they constructed dementia, experienced great difficulty in relinquishing care of their loved one.

In choosing to arrange my data in this way I realized that one aspect of rigour in qualitative research, that of external validity, would be compromised. However, although the reader would not be able to

identify the speaker, data was presented in such a way that the speaker could immediately identify his or her own comments. This notion of subjects being able to find themselves in a final report enhances the credibility of the research. Credibility is also enhanced if the reader can identify real issues raised in the report and follow the decision trail made by the researcher (Koch, 1994).

By approaching the research findings in this way, I deliberately chose to forsake reader interest in the specific details of the findings for a more general overview. In making this decision I realized that I would not be able to use a large amount of the data that I had collected. However, I felt that I could still fulfil the aims of the project, maintaining some of the aspects of rigour involved in qualitative research yet knowing that I was not personally compromised and that I had not compromised the integrity of the participants in any way.

Conclusion

This paper has presented some of the dilemmas I encountered when I set out to do cross-cultural research on dementia. The major difficulty for me has been how to acknowledge difference while at the same time being aware of the politics of comparison. This work has shown that findings do not have to be written up in a comparative way. Nurse researchers can find alternative ways to present findings.

The research process is an inherently political one. All research is culturally specific (King, 1994). We must therefore acknowledge methodology and process as cultural constructions, with all their implications for cultural regulation and control. It is thus imperative that the research agenda acknowledge the political nature of the research, particularly if, as I have demonstrated, the research is cross-cultural.

The outcomes of this project highlight the inadequacy of the operational definition of culture with which I started and which guides policy. It has become obvious that if culture is seen as synonymous with language then the way to break down cross-cultural barriers is to use interpreters. A possible outcome of such an argument is that a language problem has the potential to be interpreted as a cultural problem. The conclusion to such an argument is that a person's culture is to blame for any misunderstanding.

Finally, I suggest that there exists a hegemonic culture to which both I as the researcher and all the participants alluded. Although all participants did express particular cultural views of dementia, they simultaneously acknowledged the Anglo-Celtic view as the dominant

view, and the view that attracted government funding. It was therefore expedient for them to participate in the research process – so that their communities would benefit from funding.

This paper hints at just some of the ideological and conceptual difficulties that confront any person wishing to undertake cross-cultural research. I have proposed one way of writing up research findings that is sensitive to the wishes of the participants whilst simultaneously fulfilling the aims of the funding body. The challenge in cross-cultural research lies in acknowledging the fact that research is political, and then using data in a way that can produce benefits whilst not compromising the cultural integrity of the participants.

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