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United Kingdom

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Contents

Foreword <i>Janet Lewis</i>	1
Introduction <i>Linda Bell - Issue Editor</i>	3
Ethical considerations in planning a research project <i>Paula McGee</i>	5
Researching hard-to-access, culturally insular populations: Methodological and ethical challenges <i>Kate Coleman</i>	11
Researching the sacred: Reflections on the challenges and ethics of data collection <i>Farida Pirani & Irena Papadopoulos</i>	19
Acute Poisoning and suicides in rural Sri Lanka <i>Neil Jaysinghe & John H Foster</i>	27
An evaluation of the practice assessment tool used to assess clinical practice in the pre-qualifying and undergraduate nursing programme <i>Chrysi Leliopoulou, Kathy Wilson, Kathy Markey & Angela Rawnsley</i>	33
Book review: Mauthner M, Birch M, Jessop J and Miller T (Editors) (2002) Ethics in Qualitative Research. London: Sage. (ISBN 0761973095) <i>Theresa Bourne</i>	41
Conference report: IX World Congress of Psychosocial Rehabilitation Conference title: 'Psychosocial Rehabilitation Coming of Age in a Globalized World' 12th- 15th October 2006 Athens, Greece <i>Christopher Griffiths</i>	43
Guidelines for Authors	45



Foreword

Janet Lewis

PhD, MA, Dip Soc Admin, Acss, Chair of the Middlesex University
Ethics Committee, Visiting Professor at Middlesex University

The importance of research being carried out in an ethical way is generally accepted and is reinforced by government regulation and professional codes of practice. This does not mean that putting the intention into effect is easy. The articles in this issue demonstrate the way that judgement has to be exercised so that the general principles, such as informed consent, confidentiality and treating people with respect, can be put into effect in a way that is appropriate to the context. Properly to fulfil its responsibilities of ensuring that research is carried out ethically by its staff and students, a University has to know that appropriate information about ethical standards is available; have review mechanisms in place to make sure that projects will be carried out ethically, before they begin; and provide opportunities for researchers to get help and advice when faced with a difficult judgement.

The Middlesex University Ethics Committee, which I chair, is examining the procedures and mechanisms that are in place within the different Schools to make sure that they are providing what is needed to inform and support individual researchers. We are also looking to see the extent to which there can be a common University-wide system which also allows flexibility for different Schools to modify the arrangements to suit their particular circumstances. Thus we may identify a Code of Conduct or Ethical Guidelines that we think to be most appropriate, or suggest different ones for different disciplines (the one with which I am familiar is the Social Research Association's Ethical Guidelines – see www.the-sra.org.uk); we are looking at Ethical Review process to see if we can agree a standard approach; and we are examining ways of providing advice and support.

But “Ethics” and behaving ethically is not just an issue for research, it is something that has to underpin all of the University's activities. The Ethics Committee is therefore also looking at a considerable number of the University's policies, procedures and guidelines in relation to teaching, administration and organisation's practices as a whole. We are keen to make sure that these have covered any ethical issues in an appropriate way. Among the policies we have looked at have been conflicts of interests and their disclosure; freedom of information; fundraising; and computer use. But to be coherent, the individual policies need to be underpinned by the university's values so we are trying to make sure that these connections are made.

However, as with research, there are ethical dilemmas in all areas of the University's work for which there is no ‘right’ or ‘wrong’ answer and a judgement has to be made. The University therefore has to be clear about who can make that judgement and in what circumstances. But ideally everyone in the organisation, from first year student and part-time employees through to the Vice Chancellor would have an awareness of the ethical dimension to the decisions that they made. The right conditions therefore need to be created to develop what might be called ‘ethical literacy’ – an understanding of the issues and how they might be resolved. Training and opportunities for discussion are a key to developing this and the Ethics Committee is seeking ways to give ‘ethics’ a higher profile. People doing research within the University are in a good position to contribute to this, as they will have had to have given some thought to ethical issues and dilemmas in the course of doing their work. We need to build on this and the articles that follow are an excellent beginning.

Contact details:

Janet Lewis
Chair of the Middlesex University Ethics Committee
Via Teresa Kelly, Middlesex University, Trent Park.

Tel: +44 (0)20 8411 6018
Email: T.Kelly@mdx.ac.uk

Introduction: Ethics and Research

Linda Bell

PhD, BSc, Principal Lecturer in Research Methods, School of Health & Social Sciences, Issue editor



We may think we know what ethical research practice 'is', and what it 'isn't', but if presented with examples of 'real world research' it becomes obvious that making this distinction is often no easy matter. Issues of ethics are always bound up in practice with other matters and in terms of research, they are embedded in research methodology. As Janet Lewis indicates in her Foreword to this journal issue, universities need to consider ethics widely if they are to fulfil their aims. This includes giving appropriate attention to policies and procedures, but also to encouraging those of us who carry out research to do so with full regard to the implications of our research practices. We have responsibilities to exercise good judgement about how we work with people, rather than simply allowing ethics committees to shoulder these responsibilities for us (Truman, 2003)ⁱ. We are therefore all involved when considering ethics. It was this sense of a need for involvement which prompted me to suggest that a special issue of the Journal raising issues relevant to research ethics could be useful and timely. The papers in this issue therefore all take up this theme in various ways.

In her paper *Ethical considerations in planning a research project* Paula McGee offers some extremely useful advice for students and novice researchers working in the fields of health or social care, which are now covered by the Department of Health's Research Governance Strategy. Paula focuses on what Research Ethics Committees (RECs) are likely to be most concerned about and offers guidance when negotiating this 'complex and bureaucratic set of procedures'. She outlines key ethical issues underlying work with research

participants, based on the principles identified by Beauchamp and Childress (2001)ⁱⁱ.

Kate Coleman's paper focuses on a specific research example. It is relevant to broader discussions around accessing hard to reach participants and the ways in which these processes link to ethical concerns about cultural sensitivity, confidentiality and informed consent. She suggests, for example, that we may need to modify standard ethical practices in some circumstances, to avoid having the opposite effect to that intended.

Farida Pirani and Irena Papadopoulos's paper presents a very interesting example concerned with researching the sacred. This paper explores a number of issues relating to participant observation in unfamiliar cultural settings. These issues connect with various ethical considerations requiring the researcher to work with "empathy, a non judgemental approach, and reflective research [which] can assist in maintaining ethical practice among researchers".

Neil Jaysinghe & John H Foster present their work on *Acute poisoning and suicides in rural Sri Lanka*. This paper raises a number of concerns relating to working with incomplete datasets and tackling sensitive topics, especially in cross-cultural contexts. In the research areas discussed they suggest that efforts need to be directed towards providing culturally sensitive interventions.

ⁱ Truman, C (2003) Ethics and the Ruling Relations of Research Production *Sociological Research Online*, 8, (1), <http://www.socresonline.org.uk/8/1/truman.html>

ⁱⁱ Beauchamp, T & Childress, J (2001) *Principles of biomedical ethics*. 5th edition. Oxford: Oxford University Press

Chrysi Leliopoulou, Kathy Wilson, Kathy Markey & Angela Rawnsley present a paper concerning development of a Practice Assessment Tool (PAT) as a mode of assessing clinical competence for pre-registration nurses. In presenting their research material these authors demonstrate the need for sensitivity and reflection in handling research data, as well as in the use of the tool itself.

Theresa Bourne reviews a recent edited book on ethics and qualitative research and suggests some of the ways in which researchers and publishers can explore these issues (one of which is how far a potentially misleading title can detract from what a book contains).

Finally Chris Griffiths presents a conference report from the IX World Congress of Psychosocial Rehabilitation held in Athens, Greece, which he attended as a member of the Empowerment of Mental Illness Service Users: Lifelong Learning and Action (EMILIA) project.

I would like to thank Professor Irena Papadopoulos (editor-in-chief) and Chris Constantinou (administrator) for all their support in preparing this issue of the journal, in a spirit of team-working which is entirely appropriate for our current theme.

Contact details:

Dr Linda Bell
Principal Lecturer in Research Methods
Middlesex University
School of Health & Social Sciences
The Archway Campus
Highgate Hill
London
N19 5LW

Tel: +44 (0)20 8411 5476
Fax: +44 (0)20 8411 5276
Email: L.Bell@mdx.ac.uk

Ethical considerations in planning a research project

Paula McGee

RN, RNT, PhD, MA, BA, Cert. Ed. Professor of Nursing, Faculty of Health & Community Care, University of Central England, Birmingham

Abstract

Preparing a research proposal for review by a Research Ethics Committee can be a daunting task for students and novice researchers in the health and social care fields. This paper is intended to help them to identify and address ethical issues in their research proposals and prepare sound applications for ethical review. The paper draws on key documents such as the Research Governance Strategy issued by the UK Department of Health and the philosophical ideas of Beauchamp and Childress are used to provide structure.

Key words

Ethical review; ethical issues in health and social care research; planning research.

Introduction

The publication of the Research Governance Strategy (DH 2001, DH 2005) by the UK Department of Health has brought about a profound change in the ways in which researchers now think about their work particularly with regard to human participants. These are no longer to be regarded merely as subjects, the passive objects of the researcher's investigation, but as people who have rights and responsibilities. The most important message contained in the Research Governance Strategy is that the 'considerations related to the well-being of the human subject should take precedence over the interests of science and society' (WMA Declaration of Helsinki 2000, section 5). The Strategy therefore represents a major philosophical shift from doing research *on/about* others to doing research *with* others because it requires researchers to take full account of factors such as ethnicity, gender, disability, age, sexual orientation in all aspects of the investigation. It also requires researchers to involve participants in the design, conduct, analysis and reporting of the research wherever possible.

Unfortunately, this change of emphasis has been obscured by the introduction of a complex and bureaucratic set of procedures, intended, primarily, to govern the conduct of pharmaceutical and medical

research (European Parliament 2001). These procedures require the researcher to identify and address not only ethical issues but also a wide range of other matters concerning the scientific basis of the study, health and safety, financial governance, all of which are essential to the conduct of good quality research. To a novice researcher, this can seem a daunting prospect. Nevertheless, it is important to remember that ethical considerations lie at the heart of these procedures and that the system is intended to protect both participants from ill-prepared researchers and researchers from themselves. This paper is intended as a guide, for novice researchers in health and social care, to help them in preparing an application for review by a Research Ethics Committee. It begins with a short explanation of the nature of ethics and how these relate to research. This is followed by a discussion which outlines the ethical issues that are likely to be considered by a Research Ethics Committee.

Creating an ethical environment for research

Ethics is 'a branch of philosophy concerned with the systematic study of human values and the principles and methods for distinguishing right from wrong and good from bad' (Eby 2000, p120). Inherent in these values and principles is our view of other people; how we behave towards them and what we regard as acceptable behaviour towards ourselves. In everyday life we often do not think consciously about these things unless something goes wrong and we are alerted by a sense of injustice. Learning about ethics helps us to become more conscious about how we relate to others; they are valuable; they matter (Benner and Wrubel 1989). The relationships that we have with them counterbalance our preoccupations with ourselves and can bring rewards through, for example, offering new perspectives. This is an important point for researchers. Research can be a solitary business in which individuals can become so engrossed in their investigations that they lose sight of the implications of their activities. Engagement with others can enable researchers to appreciate the possible consequences of their work. In this context, an

application to a Research Ethics Committee can be seen as a valuable opportunity to gain an independent, disinterested opinion about a proposed investigation.

This opinion is particularly pertinent in health and social care because the complexity of work in these fields requires constant collaboration between professionals; no discipline or practitioner can act alone. Ethical dilemmas are frequent events; two or more courses of action are morally right and acceptable but only one is possible (Eby 2000). Such dilemmas may arise because of difficulties in communication between the parties concerned; interdisciplinary conflict; intrapersonal conflict in situations in which personal values and beliefs clash with those of the professional sphere or the need to balance commitments and act fairly (Hamric and Reigle 2005). It is inevitable that research in health and social care will reflect the same challenges. Researchers and practitioners alike need to develop ways of working in which ethical issues and dilemmas are clearly identified and openly discussed. Senior practitioners, experienced researchers and academic supervisors are in positions to provide leadership through the application of ethical theories in the everyday worlds of practice and research. This leadership involves helping colleagues to identify and address ethical concerns within contexts in which many diverse opinions are expressed and in which there may, sometimes, be considerable conflict (Hamric and Reigle 2005). Ethically competent leaders are able to promote open and constructive discussion about ethical issues and enable those involved reach ethically sound resolutions (box 1). In so doing leaders are instrumental in creating ethical environments for research.

Box 1: Skills needed for ethical competence in research

The ability to identify a problem clearly
separate feelings from events but recognising both as valid;
gather relevant information;

Conflict resolution –
acting as broker so that all parties can hear and try to understand each other;
identifying and dealing with unhelpful/resistant behaviour/positions;
building consensus;
achieving a plan for resolution/compromise.

(Summarised from Hamric and Reigle 2005)

Preparing an ethically competent investigation

Ethics are not peripheral to the conduct of research but an integral part of planning and undertaking any investigation. However, identifying and resolving ethical concerns is not always a straightforward matter. Ethics

are not concerned with providing a set of rules or prohibitions to be followed in any situation; nor are they necessarily concerned with matters of law or religious belief (Seedhouse 1998). What ethics are concerned about is the premise that other people matter; that they are equal to oneself and should thus be treated as ends in themselves rather than as a means to the ends of others. Moreover, if others are equal to oneself, then they are as equally capable of moral reasoning. The United Nations Declaration of Human Rights (UN 1948), and the European Charter of Fundamental Rights (EU 2000), plainly state all people are born equal and that each has the right to make decisions, for themselves, without duress or coercion from others. These ideas are upheld in the UK Human Rights Act 1998 and are particularly relevant to researchers, reminding them that people whom they wish to study are free, autonomous individuals even if the exercise of that autonomy means that they refuse to take part in a study. Planning ethically competent research requires researchers to take account of individual freedom and autonomy. This means using ethical theory to identify concerns and develop appropriate ways of addressing them. There are many theoretical perspectives to choose from; this article is based on the ideas of Beauchamp and Childress (2001) which has been selected here as one of the most frequently used theories in health and social care. Beauchamp and Childress (2001) propose some guiding principles for practitioners that can be used to inform the development of the research proposal.

Beneficence

The principle of *beneficence* refers to the duty to do good and avoid harm (Beauchamp and Childress 2001). This applies first to the research itself in that it should be worthwhile and aim to promote goodness rather than evil. Researchers are, therefore, asked to justify their choice of research topic in the light of previous studies, explain who is likely to benefit and in what ways they might do so. This can be a difficult. First, there are issues about who decides that a particular topic is worthy of investigation. Researchers, academics, senior practitioners may all have their own agendas about what should be researched and why. The users of health and social care services may have quite different views and be distrustful of what they perceive as authorities making decisions *about* rather than with them especially where previous studies have failed to produce promised improvements (see, for example, Whitmore 1994). Current research policy is directed towards a more inclusive approach in which service users and anyone else, for example carers, for whom the research may be of direct concern, are actively involved in all aspects of the design and conduct of the study (DH 2005).

Second, some forms of research may not produce any tangible results for many years if at all but can still, nevertheless, be directed overall towards achieving beneficial outcomes. Similarly, students who are embarking on a research project primarily in order to gain a qualification, may have difficulties in applying the

principle of *beneficence* with regard to others. Nevertheless, they should be encouraged to consider the application of their findings and the ways in which it may be beneficial, perhaps by helping them to improve their own practice.

If research is to comply with the principle of *beneficence* then it should be scientifically sound (DH 2005). This means that the methodology should be appropriate for the topic under study and that the researcher has the expertise required to use the chosen methods and the research tools. Poorly designed research may be considered unethical since it is unlikely to yield any reliable findings; it may even cause harm by raising unrealistic expectations and by producing inaccurate outcomes. Similarly, a lack of expertise in conducting some or all aspects of a study may undermine the principle of *beneficence*. Thus it is essential that everyone involved in a project receives adequate training and that additional expertise, such as advice about statistical analysis is co-opted when needed. Evidence of training and the co-opting of expertise should be presented as part of the application to the Research Ethics Committee.

Non-maleficence

The principle of *non-maleficence* refers to the duty of the researcher to ensure that those who participate in the project are not exposed to unnecessary harm or risk (Seedhouse 1998, Sieber 1992). There are several ways in which harm may arise either immediately or at a later date, which may be years after the point at which the individual took part in the research.

i) physical harm to participants arising

Taking part in research can sometimes involve physical procedures that are high risk. One example of this type of risk is pharmaceutical research in which a new substance is tested in humans for the first time.

ii) psychological harm to participants

Psychological harm may result from asking participants to undergo or recall distressing experiences. For example, the research may focus on participants' experiences of a particular illness or maybe some earlier unpleasant event such as an assault. They may become distressed whilst talking about such experiences or, later on, feel very unhappy or depressed as a result.

iii) social harm to participants

Additional harm may arise through the ways in which data are collected and used (DH 2005). In everyday life there is widespread concern about the ways in which personal data about each person is collected, who has access to it and how it is used. The same applies in research and the principles outlined in the Data Protection Act 1998 apply not only to businesses and services but also to research activities. Thus it is not enough for researchers to blithely assure participants that the information they provide will be treated in confidence and anonymised; they must now state how they propose to achieve this (box 2).

Box 2: Data management and protection

What information will you collect, why do you need it?
Do you require permission to access this data as part of your project rather than your work? If so then get this permission in writing.
Where and how will you store this data?
How will you anonymise the data?
Who will have access to this data and under what conditions?
How long will you keep this data and under what conditions?
When and how will the data be destroyed?

iv) harm to researchers/research assistants

Those engaged in data collection or analysis may be harmed physically or psychologically by the procedures they are asked to carry out. For example, the research requires a researcher to undertake interviews, in participants' own homes, about coming to the UK as a refugee and which reveal experiences of torture before arrival. In this example, those involved in data collection may be physically at risk and the researcher would be asked to demonstrate how this risk might be minimised by, for example, applying the guidance given by the Suzy Lamplugh Trust at <http://www.suzylamplugh.org> In addition, there may be a need for debriefing and counselling support in collecting and handling data of a distressing nature.

Observing the principle of *non-maleficence* requires researchers to be open and honest, in both the research proposal and the participant information material, about the nature of participation, the types and levels of risks entailed and the steps taken to minimise each of these. Researchers should also ensure that indemnity insurance is in place to pay compensation to anyone harmed as a result of their involvement in the investigation. Failure to pay attention to these issues may render the research unethical since it exposes people to an unacceptable level of

risk, in effect treating them only as a means of achieving the researcher's goals rather than as ends in themselves.

Respect for autonomy

The principle of *respect for autonomy* refers to the individual's capacity to take charge of his/her own life and the ability to freely choose a course of action without the permission of others. It requires researchers to respect an individual's decision, even though they may disagree with it, and even though that individual may have limited ability in the exercise of autonomy (Beauchamp and Childress 2001, Runeson *et al.* 2001, Seedhouse 1998, Sieber 1992). In the context of research, *respect for autonomy* begins with the recognition that researching human beings is a privilege and not a right and the central feature of demonstrating that respect lies in the concept of informed consent. Obtaining this consent first involves presenting information in a permanent form that individuals can keep and which they can access easily and repeatedly. A useful model for participant information is available at www.corec.org.uk

Second, they should have the option of discussing that information with others, at home, and with professionals who are knowledgeable about, but not involved in, the research in which they have been invited to take part. Researchers must, therefore, be genuine and open in dealing with people, making every effort to ensure that they have a thorough understanding of what they are being asked to do. The researcher must also acknowledge that consent is not a binding, once-and-for-all decision; people are free to change their minds and that decisions about whether or not to take part have no bearing on treatment, care, education, employment or any other aspect of their lives (McGee and Notter 1995).

Justice

The principle of *justice* refers to the notions of fairness and equality (Beauchamp and Childress 2001). In health care, justice requires professionals to treat people equally (Seedhouse 1998). In the context of research, the principle of *justice* requires the researcher to ensure that all participants are treated fairly and that individuals are not exploited (Sieber 1992). For example, in a diverse society such as that of the UK, it is reasonable to expect that research will be inclusive, taking full account of factors such as ethnicity, gender, disability, age and sexual orientation unless the topic under investigations specifically limits the focus to one section of the population only (DH 2005). However, *justice* can be a difficult principle to apply since it can be argued that all research on human beings involves some form of exploitation in that participants may receive little or nothing in return for their efforts (Hammersley and Atkinson 1995). It is, therefore, advisable to explore ways in which reciprocity can be established by, for example, anticipating participants' need for health information (Ehtisham, *et al.* 1991, McGee 2000).

Conclusion

This paper is intended as a guide for novice researchers who are preparing an application for ethical review. It has outlined the main points with which a Research Ethics Committee is likely to be concerned. Such committees provide independent opinions about research which, despite the attendant bureaucracy, remain one of the most valuable sources of advice for researchers, enabling them to refine their ideas and thus produce better quality research (Box 3).

Box 3: Outcomes of an ethical review issued by the Research Ethics Committee

Final opinion. The Committee may reach a final opinion on the application at the meeting. This opinion may be either:

(a) favourable

(b) unfavourable.

(ii) Provisional opinion with request for further information. The Committee may decide that an opinion cannot be issued until further information or clarification has been received from the applicant (see paragraph 3.8-3.9). It should indicate a provisional opinion at the meeting.

(iii) No opinion. The Committee may decide that no opinion can be given until a referee has been consulted.

Extract from Central Office for Research Ethics Committees (2006) Standard Operating Procedures for Research Ethics Committees version 3.1 available at <http://www.corec.org.uk/rece>

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Contact details:

Professor Paula McGee
AESU, Faculty of Health
University of Central England
Perry Barr
Birmingham
B41 2SU

Tel: +44 (0)121 331 5340

Email: paula.mcgee@uce.ac.uk

Researching hard-to-access, culturally insular populations: Methodological and ethical challenges

Kate Coleman

MSc, BSc, PhD Student at Centre for Behavioural and Social Science in Medicine, University College, London, Research Assistant, Institute of Nursing & Midwifery, Middlesex University.

Abstract

This paper addresses methodological challenges and ethical considerations that may present when conducting research with members of hard-to-access, culturally insular communities. These are illustrated by describing the challenges that arose during research undertaken by the author with haredi Jewish breast cancer patients in London. Haredi Jews are strictly orthodox in their religious beliefs and practice. They live in tightly-knit and highly integrated communities functioning in self-imposed cultural insularity and hold negative attitudes towards many aspects of the secular world. In keeping with this insularity, a prominent feature of charedi communities is the tendency towards self-sufficiency, whenever possible.

Specific ethical considerations addressed concern anonymisation procedures and participant after care. Negative cultural attitudes towards counselling and psychotherapeutic interventions may disqualify aftercare leaflets outlining sources of support available should participants experience undue distress post-interview. Alternative support strategies may need to be put in place. In closely-knit and relatively small communities, such as the London haredi community, community members may be able to recognise each other from relatively few identifying facts, compromising participant confidentiality. Hence, anonymisation procedures may need to include changes to seemingly innocuous personal information, in addition to the usual practice of using pseudonyms.

Methodological considerations addressed concern whether matching interviewers and respondents from the same ethnic group achieves or impedes effective communication. Whilst this has been common practice, it does not necessarily lead to 'better' data. Interview and survey research with haredi communities has typically used interviewers from inside the community. However, their attitudes towards discussing personal matter with fellow community members are conflicted. Gate keeping is often an inevitable feature of conducting research with hard-to-access communities. The final section of the paper concerns the role of the gate keeper, the advantages this individual brings to the research, as well as some of the limitations this method of recruitment involves.

Key words

Research methodology; research ethics; qualitative research; Jews, cancer.

Author affiliation

Kate Coleman is a PhD Student at the Centre for Behavioural and Social Sciences in Medicine at University College London. She is also a research assistant in nursing and midwifery at the School of Health and Social Sciences at Middlesex University.

Research ethics committee approval

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Introduction

This paper addresses methodological challenges and ethical considerations that may present when conducting research with members of hard-to-access, culturally insular communities. To illustrate these I shall describe the challenges that arose during my own research investigating medical decision-making by haredi (strictly orthodox) Jewish breast cancer patients (Coleman, in press; Coleman *et al*, in press). I shall argue that although methodological and ethical issues require consideration when conducting research with any vulnerable population, such as cancer patients, additional challenges present when study participants come from tightly-knit communities and are hard-to-access due to their cultural insularity.

Background

The study participants

The participants belonged to the strictly orthodox, or haredi, Jewish communities of North London. There are several major divisions in the modern Jewish world couched principally in terms of a spectrum of outlook ranging from the secular to the strictly orthodox (Longman & Coleman, 2006). Jewish orthodoxy can be measured according to two criteria: the extent to which adherents view religious laws and practices as God-given

and unchangeable, and the degree of adherents' immersion in the values and activities of the secular world.

Haredi (literally 'one who trembles') Jews are located at the strictly orthodox end of this spectrum. Central to the haredi belief and value system is the Halacha; the collective corpus of Jewish law that regulates all aspects of behaviour for Orthodox Jews. The Halacha comprises laws of both Biblical and Rabbinic origin. The binding source of authority for the entire system is Divine revelation through Moses at Mount Sinai. Haredi Jews believe that Jewish law is of Divine origin and the observance of all Biblical and Rabbinic laws is obligatory. The Halacha (literally, 'the way') comprises both laws applicable between man and man, and the precepts concerning the relationship between man and God. Matters covered include details of ritual religious observance, civil law, criminal law, and ethical requirements. Medical treatment is subject to Halachic guidelines and, in line with medical advances, modern medical ethics has developed into a specialised and complex area of Halacha (Jakobovits, 1975; Rosner, 1991; Tendler, 1996).

Rabbinic authorities have a prominent role in establishing and maintaining guidelines for behaviour, issuing both public statements with general applicability to haredi Jews and personal responsa answering specific questions posed by individuals. In this way, haredi Jews aim to ensure that their behaviour, both individually and collectively, will be in accordance with the Halacha, and hence with God's will.

Haredi life is structured around comprehensive religious obligations and prescribed behaviour including, strict observance of the Sabbath and festivals, strict adherence to dietary laws, modesty in personal behaviour and dress, separation of men and women in public domains and, for men, ongoing religious study and thrice daily prayer.

Haredi Jews live in tightly-knit and highly integrated communities functioning in self-imposed cultural insularity. The very wealthy and the economically impoverished live side by side, forming a heterogeneous community. Many features of the secular world are perceived as detracting from God's sanctity. They hold negative attitudes towards the secular media and, although religious academic ability is highly prized, the study of secular, non-religious subjects may be actively discouraged. In keeping with this insularity, a prominent feature of charedi communities is the tendency towards self-sufficiency, whenever possible.

The study

The study investigated the process of medical decision-making in a group of haredi breast cancer patients (Coleman, in press; Coleman *et al*, in press). Semi-structured interviews were conducted with a purposive sample of five haredi breast cancer patients in London. The interview questions related to:

- participants' needs for information about their illness;
- which issues would be important when thinking about further treatment if the prognosis was terminal;
- which groups of people participants had spoken to about their cancer and the issues they had discussed;
- how participants believed the strictly orthodox Jewish community reacted towards cancer patients;
- whether participants had been able to make sense of having cancer.

The full interview transcripts were analysed using interpretative phenomenological analysis (Smith, 1996; Smith *et al*, 1999). Demographic and personal data were collected using a structured questionnaire.

The participants were aged between 39 and 58 years with a mean of 50 years. Date of diagnosis ranged from 1998 to the end of 2004; the majority (n=4) were diagnosed during 2004.

Participants expressed a clearly articulated need for medical information in relation to their diagnosis, treatment and prognosis. Their motivations behind this included, wanting to understand what was happening to them and needing to be able to educate their families.

Participants' views concerning medical treatment were largely directed towards active treatment and negative views were expressed concerning hospice and palliative care. These views were rooted in the belief that it is a religious obligation to preserve life for as long as possible.

Participants discussed their illness and its treatment with a variety of people including friends, fellow patients, and family members. All participants had consulted a Rabbi, with the majority (n=4) asking for assistance with making decisions to do with medical treatment. In adopting this approach, participants were strongly influenced by a wish to act in accordance with God's will, believing that the Rabbi, with his expertise in Jewish law and his experience in interpreting the Torah, would be able to provide an answer that conformed to God's will.

Participants made sense of their illness in a variety of ways, although two common themes emerged. The women believed, firstly, that the cancer came from God as part of a pre-determined and meaningful plan, and, secondly, that the disease took the form of a test. The interpretations of their illness accorded with their existing religious beliefs where virtually every event ultimately is understood with reference to the Divine. These interpretations brought the occurrence of cancer within the scope of their existing cognitive schemas, making the diagnosis religiously logical and causing minimal disruption to participants' belief systems (Pargament, 1997).

Participants believed that cancer was stigmatised in the haredi community. This had implications for personal identity and social status. Participants believed that the stigma would devolve onto their children making it difficult for them to find marriage partners. A highly regulated and controlled method of arranging marriages occupies a central position in the haredi framework of beliefs and practices. Hence, it becomes both a focal point and a stimulus for negative perceptions of cancer.

Ethical considerations

Clearly, ethical considerations should be uppermost when conducting research with a vulnerable patient population (Addington-Hall, 2002). Such considerations include appropriate recruitment of volunteers, appropriate acknowledgement of costs to the individual participant, strict standards of informed consent, safeguards against coercion or manipulation, and careful monitoring of research procedures including data storage, protection and access, and anonymisation procedures.¹ In addition to these general requirements, additional 'population specific' ethical considerations may arise.

Anonymisation

In the research I conducted, I believed that the closely-knit nature of the haredi community meant that standard practices of anonymisation where fictitious names are substituted for participants' real names would be insufficient to ensure participant anonymity. In closely-knit and relatively small communities, such as the London haredi community, it is common for community members to be aware of the details of each others' lives to a greater extent than is usual in the wider community. As result of this, community members may be able to recognise each other from comparatively few identifying facts, and confidentiality may be compromised. Indeed, other researchers working with the London haredi community have reported that their anonymisation procedures that consisted of the substitution of pseudonyms occasionally proved inadequate with the result that participants could identify each other (Holman, personal communication 2005, concerning Holman & Holman, 2002).

My intention from the outset was to disseminate the results to health and social care organisations based within the haredi community, as well as within the wider academic community.² The participants were aware of this before they consented. Hence, it was important to strive to ensure participant anonymity. The anonymisation techniques I used involved changing names and ages of participants, numbers, ages and gender of children and other named relatives, and in one case country of origin.

Participant after care

The participant information sheet and consent form should provide adequate information to enable potential participants to decide whether or not they are emotionally and psychologically able to deal with the issues the research will raise. However, responsible researchers intending to ask vulnerable individuals sensitive questions may wish to consider adopting additional measures to ensure participant well-being.

A measure that is commonly adopted is to provide participants with a leaflet outlining the sources of support that are available to them should they experience an unacceptable level of distress after the interview. Typically these sources of support include the General Practitioner, and the counselling and psychotherapeutic services that can be accessed via General Practitioner referral. Counselling provided by the relevant disease-specific support networks may also be described.

After careful consideration and discussion with health care professionals working with haredi communities, I decided that such a leaflet was culturally inappropriate and may cause more distress than its provision is intended to relieve. Typically, the haredi community holds negative attitudes towards psychological and psychiatric treatment (Greenberg & Witztum, 2001). The reasons for this are several and centre around three main concerns: firstly, that the vulnerable patient will be exposed to 'dangerous' ideas and concepts alien to haredi beliefs and values; secondly, that the therapist will endorse behaviour proscribed by Jewish Law (e.g. homosexuality, extra- or pre-marital sexual relations); thirdly, that haredi religious practices will be

¹ Grimley Evans (1997) goes further and argues that the first ethical questions that should be asked in respect of a proposed research project include, whether the research question is sufficiently important, the research team sufficiently competent, and the methodology sufficiently rigorous to produce a report of a study that is of a high enough standard and clinically significant enough to justify requests for patient involvement.

² Rabbinically approved organisations, run by members of the haredi community, provide a range of health and social care services. The motivation behind this in part stems from the wish to remain as culturally separate from the secular majority community as possible; by managing their own health and social care haredi Jews can ensure that the services offered do not conflict with their religious values and beliefs. Another strong motivation is the value of 'gemilas chasadim' (literally, 'dispensing kindnesses') which exhorts members of the community to care for one another through good deeds and acts of charity. These organisations provide services either in cases of general ill health or to meet the needs of specific medical conditions and diagnoses including depression and other mental health problems, child-birth, infertility, and learning disabilities. Services provided include hospital transportation, medical equipment, kosher meals-on-wheels, nursing volunteers, counselling, residential nursing care and day centres (Loewenthal & Rogers, 2004).

pathologised and viewed as indicative of mental ill health.³

I believed it to be culturally insensitive and potentially distressing to participants to provide them with a leaflet suggesting that they may require psychological treatment as a result of participating in this research. Furthermore, I believed that the suggestion that such treatment may be necessary could pose a serious obstacle to obtaining consent. No suitable alternative leaflet was found and, after discussion with the aforementioned health care professionals working with the haredi community, the decision was made to proceed regardless.⁴ We felt comfortable with this decision because the participants were recruited through a member of the haredi community with whom they each had a good relationship (see *Access and gate keeping*, on page 9). This individual was willing to offer informal support should participants require it.

Methodological issues

'Race-of-interviewer effects'

In the 1950s and 1960s, survey researchers in the USA became increasingly interested in the concept of 'race-of-interviewer' effects (RIE). This concept refers to the response 'bias' and measurement 'error' recorded reflecting the adjustment interviewees made to their expressed opinions and attitudes when questioned by an interviewer from a different racial or ethnic group.

The area of inter-racial and inter-ethnic research has continued to be the focus of methodological anxiety to researchers (Montero, 1977; Myers, 1977). Gunaratnam (2003) argues that RIE serves to justify these anxieties by appearing to provide evidence about the potential difficulties and barriers to inter-ethnic and inter-racial communication and research. Phoenix (1995) suggests that matching interviewers and respondents from the same ethnic group does not necessarily lead to 'better' data; other markers of identity, including age, gender and social class, may be influential in achieving or impeding effective communication. Furthermore, RIE is small in comparison to other response effects in survey research (Sudman and Bradburn, 1982).

Interview and survey research with haredi communities has tended to use interviewers from inside the community (Albert *et al*, 2004; Cinnirella and Loewenthal, 1999; Holman and Holman, 2002; Loewenthal and Rogers, 2004). However the findings from these studies suggest that haredi Jews view discussing sensitive issues with fellow community-members as a double-edged sword. Typically, they believe that someone who does not share their belief-system will misunderstand them. However, they also express concerns about breaches of confidentiality that may arise from talking to a member of the same community. It has not been reported whether this disquiet does indeed lead to bias.

I came to this study as a practicing orthodox Jew. In broad terms, I resemble participants in that I share their beliefs concerning the Divine origin of the Torah and the obligatory nature of its laws. I use the same religious concepts and terminology. I differ from participants in that their adherence to Jewish Law may be stricter than my own. Furthermore, whilst they shun the secular world, I choose to move in both secular and religious circles. The participants and I belong to different religious and social communities. This puts me in the position of being neither an insider, nor a complete outsider. My hope was that this status would be advantageous. As someone who shares their belief-system, I hoped that I would be perceived as likely to appreciate the issues they face and that this would facilitate communication. As someone who is outside their community, I hoped that concerns over confidentiality would be reduced.

Access and gate keeping

'Gate keeping' is often an inevitable feature of conducting research with vulnerable populations, with the researcher having to negotiate access via health care providers. This can have both positive and negative effects: gate keeping can play an important role in facilitating research by enabling access and providing a measure of protection to vulnerable potential participants. However, overly paternalistic health care providers can take away from patients the opportunity to make autonomous informed decisions about research participation (Addington-Hall, 2002).

³ In recent years communal leaders, Rabbis and haredi health care professionals have made moves to change these negative attitudes. Public meetings and discussions concerning mental health issues have been held in the community: these have been publicized in the haredi owned press. Other initiatives include Chizuk (literally 'encouragement', 'support'). This community-based mental health organization offers support to haredi Jews suffering from mental illness and their families. Services include support groups, drop-in services, creative therapy groups, counseling and hospital visiting. Separate sessions for men and for women are held. The Nefesh (literally 'soul') network of orthodox mental health care providers is another initiative. The activity of both these organizations receive coverage in the haredi press, however, the stigma attaching both to mental health and to undergoing psychiatric or psychotherapeutic treatment endures (Jewish Tribune, 2004).

⁴ We felt that a leaflet issue by the Jewish cancer support organization, Chai (literally 'life') Cancer Care, was unsuitable, because, although Jewish, this is not a haredi organization and does not reflect haredi values. Indeed, my own research found that participants believed that Chai Cancer Care could not meet their needs. The reasons given centered firstly around the inclusion of non-haredi practices that participants felt uncomfortable exposing themselves to, e.g. women working in and using the centre would likely wear trousers and short-sleeved low cut blouses, the centre hosts events with mixed male and female audiences. Secondly, participants believed that the cross-denominational nature of Chai meant that their values, beliefs and practices were likely to be misunderstood and possibly perceived in a negative light (Coleman, 2006). See also 'Race-of-interviewer effects' and footnote 2, on page 7.

With hard-to-access communities, gate keeping may 'make or break' a research project: without a sympathetic gate keeper access may prove impossible. The haredi community is both tightly-knit and relatively closed. As discussed previously, although I am an orthodox Jew, I am not haredi: if pressed to provide a self-definition, I would describe myself as modern orthodox (Longman & Coleman, 2006). Although my religious beliefs and practices mean that I am not a complete outsider, I can in no way be described as an insider. Breaking into this community, making contacts, identifying and recruiting participants, and establishing credibility both as an individual and as a researcher, presented a challenge.

My contact who acted as a gate keeper was the 'culture broker' to the haredi community. Culture brokers are haredi Jews who bridge the gap between the community and the medical profession. They advise members of the community concerning their health problems including life-threatening illnesses, facilitate medical referrals and second opinions, accompany patients to appointments, and assist in discussions of diagnosis, prognosis and treatment options (Westermeyer, 1987; Greenberg and Witztum, 2001; Lightman and Shor, 2002; Coleman, 2006). Culture brokers enable the haredi community to benefit from the health and social care services provided by the majority secular community, whilst maintaining the preferred level of cultural insularity. By operating through the culture broker, a member of the haredi community can feel secure that any health or social care professional he or she consults will be 'haredi friendly', that is, understanding of haredi religious beliefs, practices and values, and how these may influence treatment preferences. Greenberg and Witztum (2001) describe the benefits to health and social care professionals that involvement of a culture broker offers. These benefits may include gaining credibility in the eyes of the patient, their family and the community as a whole, maximising patient attendance and treatment compliance, and giving the patient 'permission' to engage with the therapist and with treatment (Coleman, 2006). In these respects, the culture broker may act as a valuable co-therapist.

The involvement of communal figures as a bridge between a community and the medical profession is not exclusive to haredi communities. The phenomenon has also been reported in indigenous aboriginal communities in North America (Heilman and Witztum, 1994). Intermediaries serve a not dissimilar role to better enable deaf clients to access mainstream mental health services (Wax, 1996; Lightman and Shor, 2002).

My initial meeting with the culture broker only took place after several long telephone calls. During the meeting and these telephone conversations he informally 'interviewed' me to assess my intentions, level of knowledge about both the haredi community and my area of academic interest, and my character. I provided him with a copy of the research proposal and all other

research documentation including the participant information sheet, consent form, and interview guide.

He was sympathetic to the aims of the research and we formed a friendly working relationship. He agreed to recruit research participants. Purposive sampling techniques were used: we discussed at length the inclusion and exclusion criteria. He was provided with copies of the participant information sheet and gave these to potential participants. With permission, he passed their contact details to me so I could discuss the study with them and answer any questions.

The culture broker enabled access and established my credibility and the credibility of the research project. It is also possible that the involvement of this highly respected individual gave my participants 'permission' to speak to me.

Gate keeping: the impact of gender

The researcher must be aware of the potential impact on recruitment of the gate keeper's gender. Gender issues may work to facilitate recruitment by better enabling communication with potential research participants. Alternatively they may bias the recruitment process: in this research project the gender imbalance between the male culture broker and the female target population may have meant that some potential participants were reluctant to consider participation as they did not wish to be in contact with a man. The researcher may be able to do little when faced with a possibly unfavourable situation, other than acknowledge any limitations inherent in the method of recruitment and consider how a biased sample will impact upon the generalisability of the results.

Although there is scant research investigating the phenomenon of the culture broker in haredi communities, it seems that generally culture brokers are male (Greenberg and Witztum, 2001). This is not unexpected; large families are the norm in haredi communities (Holman and Holman, 2002) and the demands these place upon women may leave them with little time to devote to other roles. Therefore the situation I was faced with, working with a male culture broker/gate keeper seems typical of the norm. Reaching hard-to-access communities is rarely perfect and the limitations methods of access via gate keepers involve may have to be accepted along with the benefits they offer.

Conclusion

Whilst many ethical and methodological considerations apply across populations, different measures may be required with specific populations. In some cases the standard methods may prove insufficient and additional measures may need to be implemented, as was the case with the anonymisation procedures described above. In others standard ethical practices may have the opposite

effect to that intended and may need to be modified or rejected. Similarly, methodological issues may be population specific.

This paper is not intended as an exhaustive account and analysis of all methodological and ethical issues that arise when conducting research with members of hard-to-access populations. Different considerations may apply to different populations and each population should be assessed on its own terms. In order to do this, the researcher must be sensitive to and familiar with the beliefs, values, practices and needs of the community their intended research participants belong to.

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Contact Details:

Kate Coleman
Research Assistant
Institute of Nursing and Midwifery
School of Health & Social Sciences
Middlesex University
Highgate Hill
London
N19 3UA

Tel: +44 (0)20 8411 5188
e-mail: K.Coleman@mdx.ac.uk

Researching the sacred: Reflections on the challenges and ethics of data collection

Farida Pirani

RMN, MSc Mental Health, Research Student, Research Centre for Transcultural Studies in Health, School of Health & Social Sciences, Middlesex University

Irena Papadopoulos

PhD, MA(Ed), BA, RGN, RM, Head of Research Centre for Transcultural Studies in Health

Abstract

The paper describes the process of data collection and the challenges encountered during a study carried out at a religiously sacred site, that is, a Muslim shrine in Pakistan. Conducting research in a Pakistani cultural setting, using a research process and ethical framework derived from a Western world perspective presented a series of challenges. These included issues arising from working in an environment closely related to a particular religious value and belief system and a lack of basic infrastructure and privacy when conversing with people who were vulnerable and unacquainted with the concept of this type of research. Cultural awareness, empathy, a non judgemental approach, and reflective research can assist in maintaining ethical practice among researchers.

Keywords

Research ethics; Pakistan challenges; qualitative interviews; participant observation; religious shrine.

Introduction

This paper outlines the progress made so far in a qualitative, ethnographic research study entitled 'Pathways to healing: Explanatory models of mental distress and help seeking among attendees at a Muslim shrine in Pakistan'. It highlights the need for the study, the methods employed to address research questions and the experience of data collection in a naturalistic setting - a religious Sufi shrine in Pakistan. The paper will also attempt to reflect on the process of the research, ethical issues arising from being in the field and outline some of the challenges encountered, both methodological and personal.

Rationale and background for the current study

Research shows that many people use religion as a coping mechanism to deal with mental distress

(Pargament, 2004; Koenig, 2001) and ill health and misfortune may be understood in religious or spiritual terms (Kleinman & Good 1985). In Pakistan and other non western societies, where many aspects of life are organised around religious beliefs and activities, religion may become very important when ill health is encountered. Help seeking from faith healers and going to religious venues for a variety of health issues is common practice.

Presently mental health care services in Pakistan rely heavily on the use of medication and physical therapy, such as electroconvulsive therapy, to treat mental distress. It is common for families to bring religious healers to hospital wards in order to carry out religious rituals or sometimes patients are removed from hospital in order to visit these healers. While the majority of people simultaneously use medical and religious healing, some choose to give up psychiatric interventions completely and seek healing purely from religious sources such as the shrines of dead Sufi saints.

I have always found the whole social phenomenon of seeking healing at a shrine for what is commonly considered a 'mental health problem' intriguing. My professional training has been strongly influenced by western bio-medical models of distress and illness. While training, it became essential for me to evaluate behaviour in the light of Western classification systems [*Diagnostic and Statistical Manual of Mental Disorders (DSM)* or *the International Statistical Classification of Diseases and Related Health Problems (ICD)*]. However, during my work, I witnessed large numbers of people seeking healing at shrines. Although I have always perceived religion and religious activity in a positive light, the sufferer's isolation from their family and society as a whole and spending weeks, months, or even years in a shrine in the absence of any certainty of healing is behaviour which raised many questions in me. I therefore embarked upon this project in order to gain a deeper understanding of insiders' perspectives on this social phenomenon.

In many Muslim countries, especially in the Indian Subcontinent, shrines of many Sufi saints serve as sources of help and healing. Thousands of people visit the shrines and pray for healing. Many of them stay for short or long periods of time and carry out religious rituals. However, how people conceptualise their problem and what factors lie behind this type of help seeking behaviour remains largely unresearched. What role shrines play in addressing people's problems and illnesses and what routines/rituals are carried out at these shrines and what it means to them are areas in need of exploration.

Mental health services in Pakistan

There is little data available about the utilization of mental health services in Pakistan and its outcome in terms of effectiveness. Mirza & Jenkins (2004) conducted a thorough systematic review of the studies from Pakistan and found no study addressing the effectiveness of treatment or the prevention of anxiety and depression. Primary care services are mostly clinic based and referral is from rural health centre to district hospital. The services offered at either venue are very limited. Specialist care is often based in private hospitals and is very expensive. Diagnostic interventions such as psychometric testing, Electroencephalography, and brain scan and treatments such as psychotherapy, individual/family/couple therapy, and ECT are sometimes available but are largely affordable only to those from higher socio-economic groups (Karim *et al*, 2004). Limited financial resources often leads to a reliance on psychotropic medications, and prescribing trends are strongly influenced by socio-economic factors, the availability of drugs, safety and cost factors (Gadit, 2003).

Healing by faith healers and at religious shrines

Many faith healers are accessible and available to all sections of the community. Their approach to addressing illness includes attending to the social and religious needs of clients and involving the whole family in care. These resources are well used not only because of the unavailability or inaccessibility of western model psychiatric services but because of their 'fit' with the explanatory models of people experiencing mental distress. Faith healers or religious leaders are often a first line of contact when an individual or family experiences mental distress (Mubbashar & Saeed, 2001). Places of religious worship for Muslim, Hindu or Christian, all serve as mental health resource for the general community. Many of these places including 'dharamshaalas' (religious convents), temples, and shrines play a significant role in offering non-medical treatment options aimed at enhancing overall well-being.

Shrines are places where Sufi saints are buried and are sacred to the followers of Islam, especially Sufism. The shrines are centres for religious education and resources

for physical, mental, and spiritual well being for people in various Muslim cultures. The healing rituals offered at the dargah (shrines) are often compared to psychotherapy due to its impact on the person's psychological health (Pfleiderer, 1988).

Kleinman places crucial importance on the sick person's judgement of how illness can be coped with best, how problems of daily living can be overcome, what lifestyle changes need to be initiated or outside help consulted in order to deal with the problems being experienced. Illness perceptions and behaviour tend to be shaped by local traditions and cultural orientation. Similarly, symptoms of any illness have cultural meanings attached to them. The cultural meaning reflects what is generally considered as normal, abnormal, desirable, undesirable, and its associated causative theories (Kleinman, 1988).

Aims of the study

Thousands of people in Muslim societies visit shrines in search of help and healing in times of need. These needs may include better health outcomes, fulfilment of wishes concerning wealth, beauty and success, or the elimination of perceived threats from others. The area I chose to explore concerns help seeking for mental distress at Muslim shrines in Pakistan. From the review of literature, it is obvious that the nature of problems people take to the shrines are ones that are commonly labelled as mental disorder by health professionals. However, this labelling represents the views or perspectives of health professionals, and not those of the participants actually engaged in the help seeking process. The current research hopes to shed light on questions such as how sickness or mental distress is perceived and described by an individual or families in Pakistan, and how their explanations in regard to sickness relate to their decision to seek help at a religious shrine. It also aims to illuminate the role a shrine plays in changing the problem or the appraisal of the problem by an individual or a family; and what treatment or help a shrine offers to mentally distressed attendees and how this may affect either a reappraisal or resolution of the problem with which they presented.

The aims of the study are to

- Investigate the explanatory models of sickness among attendees at the shrine particularly in relation to their reasons for visiting the shrine and choosing this particular method of help seeking
- Explore individuals' perceptions and experiences regarding the role a Muslim shrine plays in alleviating or curing their perceived sickness and mental distress

It is only really possible to understand a phenomenon or particular set of circumstances and behaviours by developing understanding of the beliefs and thought processes of those taking part in the experience and the

factors that affect their choices and decision-making. How individuals and families experience illness, distress and healing, arrive at decisions, and choose a particular course of action is essential knowledge if health practitioners are to be able to respond appropriately and effectively and provide culturally competent care. Setting aims and objectives for this study meant determining what to look for, what epistemological position to assume when conducting the research and how broad a focus to take. I wanted my work to be able to contribute towards policies around health care delivery in Pakistan and in western countries with Muslim populations.

It is hoped that the results from the study will highlight the significance of explanatory models in decision-making and choice of pathways to healing. The knowledge generated through this study can assist health professionals in becoming more culturally competent when dealing with clients from diverse backgrounds. It will also enable health services whether in Pakistan or in Muslim settings to become more able to embrace popular healing traditions and integrate its principles into the practice and delivery of health care services.

Methodological considerations in qualitative designs

A review of studies from Pakistan and India in the area of shrines and mental healing showed that researchers frequently took a western psychiatric perspective when examining the subject. The description of the problems experienced by the participants were often analysed against set psychiatric diagnostic criteria (DSM or ICD) used for classifying mental illness (Saeed *et al*, 2000; Malik & Bokhari, 2003; Hussain *et al*, 2003). These studies have focussed on measuring the prevalence of mental illness in a community group or estimating the effectiveness of a healer or healing venue in terms of the clinical improvement of patients, using mental health rating scales and clinical interviews (Raguram *et al*, 2002).

There are only a few mental health screening tools, which have been translated into the main Pakistani language (Urdu), and they require administration as an interview due to low literacy levels amongst the population. How depression or anxiety is conceptualised and measured in different cultures is also widely debated in international psychiatry. Some of the issues involved in this type of transcultural research include linguistic and transcultural translations of the mental health tool used, cultural definitions of what is labelled normal or abnormal, idioms of distress and attitudes towards sickness/illness.

I decided to use an ethnographic approach, which provided me with an opportunity to listen to people's stories regarding how they perceived their problems and why they had come to the shrine. This method offers more control to the participants in explaining their experience, perceptions, opinions, and ideas rather than

imposing the researcher's frame of reference or world view. The experience of the participants in using a religious venue for healing makes them experts on how it works for them rather than seeing the mechanism from the view of practitioners who may generally have a Eurocentric perspective.

Kleinman's explanatory model framework for describing sickness and its treatment (1980) provided an ideal way of bringing structure and direction to this research topic. The framework focuses on eliciting participant's emic perspective on social phenomena. Eight questions that can be used in eliciting explanatory models are: What do you think has caused the problem? Why do you think it started when it did? What do you think the sickness does? How does it work? How severe is the sickness? Will it have a short or long course? What kind of treatment do you think the patient should receive? What are the most important results you hope to receive from this treatment? What are the chief problems the sickness has caused? What do you fear most about the sickness?

This framework allowed me to gather in-depth 'emic perspectives' of those who experienced the phenomenon of healing at the shrine. Although shrine healing is a common cultural practice in Pakistan, many health professionals do not see it favourably. The presence of this phenomenon and its popular use is acknowledged but there is resistance to understanding the deeper social processes, which promote or prevent recovery. Lack of monitoring and governance for religious healers has allowed quackery and abuse to flourish and often health professionals are on the receiving end when a person's condition deteriorates as a result.

Conducted in a naturalistic setting, ethnographic research allows the capture of original social phenomena without inducing any manipulation or control to bias the findings. Semi structured interviews and participant observation reduce potential bias by allowing in-depth exploration and immersion in personal perspectives and experience therefore limiting faulty cultural and social assumptions. The ethnographic approach offers a very appropriate method of inquiry when there is a dearth of literature on the topic under study.

Participant observation - observer as participant

Hammersley & Atkinson (1983) describe four levels of participant observation in the field. These are 'complete participant', 'participant as observer', 'observer as participant' and 'complete observer'. Becoming a complete participant is possible when the research is carried out in a group setting where the researcher becomes a member and while in that role, carries out observation. Issues around deception, secrecy, and subjective bias are significant and limit use of this method. Becoming a complete observer on the other hand provides detachment from the social phenomena and reduces bias. However, it is then almost impossible

for the researcher to engage in interviewing participants. It also makes it harder for the parties to develop rapport, as the participant feels observed and examined.

In the current study, being a complete participant or observer was not appropriate. I was an outsider and could not share the perspective, which operates at an experiential level. As I was also using interviews as a method for data collection, it was not possible for me to be a complete observer. Being a complete observer in this situation may have limited possibilities for exploring the practices or rituals, which were carried out as part of seeking healing. Being an 'observer as participant' therefore was the most appropriate approach, which allowed me to remain detached from the social phenomena in terms on 'not being native' but also enabled me to participate in some activities, build rapport, and explore issues needing clarification.

The research process

Obtaining permission

As I am currently resident in the UK, planning to conduct research in Pakistan required long distance correspondence involving social and professional networks to assist in obtaining the necessary permission. Many months before I was to begin my data collection, I started inquiring about the channels of authority that I would need to navigate in order to access the shrine attendees. It is especially true when dealing with the public sector in Pakistan, that quite often, permission to undertake work of this type will require contacting a variety of departments in order to determine who is actually able to grant the necessary permission to proceed.

Therefore, my limited exposure to the workings of the public sector made it difficult to know how to proceed. Two months before the data collection was due to begin, I was told that I would need permission from a particular department in the Ministry of Religious Affairs. The most effective way of pursuing this was to prepare a detailed document outlining my intentions and the process of the research and present it directly to the authorities. The chances of the proposal being rejected were very high if the purpose, process, and scope of the research were not communicated in a manner, which was clear and understandable.

With help from a colleague in Karachi, who agreed to act as my proxy and meet with the government official, I was able to send a detailed research proposal. In the first meeting, my colleague received verbal agreement for the study to proceed as planned; however, it was made clear that the proposal would be sent to higher authorities in the Ministry and their further approval would be needed before data collection could proceed. Several telephone calls followed and the letter of permission finally came through 7 weeks after the first contact was made.

Being in the field

For the current study the shrine of Hazrat Abdullah Shah

Ashabi was the field site. The shrine is located near the small city of Thatta. Thatta is in the province of Sindh, Pakistan, located about 98 km east of Karachi. Hazrat Abdullah Shah Ashabi was a popular Muslim missionary and performer of miracles in the 14th Century. When alive he was consulted over health matters and is said to have restored the sight of a blind man (Ahmed, 2001).

The shrine of Hazrat Abdullah Shah Ashabi is surrounded by graves and mausoleums. Upon entrance, one can see an area allotted to keep visitors' shoes in return of small amount of money. Wearing shoes in the shrine, especially near prayer areas or graves is considered disrespectful. Practices which are not acceptable in the shrine may not be clearly communicated to attendees, however the expectation is that one should understand and offer optimal respect to the shrine and its practices.

A team of people are employed by the Auqaaf Department (part of the Ministry of Religious Affairs) to care for and manage the shrine. The work of these people includes the cleaning and maintenance of the shrine, safeguarding property, collection, and disposal of donations from the followers/attendees, overseeing the issues around the resident attendees, housekeeping, and activities related to running the attached mosque. I use the term caretaker to refer to one male and one female, live-in worker who are employed to oversee the residence halls. These employees, by virtue of their position, hold great power over the attendees as they decide who can stay and how much space they can take up. Displeasing these employees can lead to negative consequences for the attendees especially those residing there for a period. One caretaker was seen swearing at attendees who did not abide by the rules at the residence hall. Distressed attendees kept to themselves and appeared to engage in minimal interaction with the caretakers.

How was I perceived?

My repeated journeys from Karachi to the shrine and back made me a familiar face on local transport. While some drivers reserved seats for me, others referred me to other shrines or healers, which they thought may be useful in finding healing for my 'problem' (I was perceived to be a person seeking healing from the shrine). In a culture and environment where females without a male escort do not generally use public transport, my travel arrangements invited curious glances, stares, and at times harassment from males.

The majority of attendees reflected the national population profile, i.e. low literacy rates, poor socio-economic groups and more traditional views about the specific gender roles in society. I made special efforts to dress according to local norms and pay respect to the shrine setting. With time, I became familiar with some individuals who introduced me to other attendees. Being a female gave me easier access to the female residence hall. However, there were those who disapproved of my presence and discouraged other women from participating.

My presence at the shrine as an unescorted female (not escorted by a male but accompanied by a fellow colleague), not wearing a veil, and talking to male attendees, raised concerns, suspicions, and questions from some attendees. It was a challenge to those who held traditional expectations of the roles women should adopt in a male dominated society. While some people wondered whether I represented the media doing a story about the shrine, others showed resentment, anger, and hostility, possibly condemning me as a woman of loose character and moral values. These negative feelings reflected their disapproval of seeing women in a non-traditional role. Some attendees also disapproved of my presence for study purposes, seeing it as a 'western influence', which encouraged women to step outside of their traditional culturally assigned roles. While some attendees and their families were happy to share their stories others were disappointed that I needed 'evidence' that their beliefs were true rather than just accepting its truth on face value. Although I travelled on public transport and spent my days in public places, it was still necessary for me to have a female colleague with me at all times. This gave me a greater air of respectability than if I had been alone.

The attendees who were long term residents at the shrine and who came from very poor socio-economic backgrounds perceived my presence in terms of resources. They asked me questions about what I had in my bag, whether I had any food to share with them, whether I could give them money to help solve the never-ending problems in their lives. There was often silent communication and pleading in their eyes, seeking help to find a source of income so that they could feed themselves and their children. The children who were living at the shrine with their mothers often played in the shrine compound with soil or plastic toys, bought from local shops by visitors. Many of them were malnourished, actively looking for any one who could give them something to eat. They would often run after the visitors begging for money or offering to clean their shoes or carry their bags so that they could receive some money in return for their services.

While it was extremely difficult and sometimes painful for me to witness such levels of poverty and deprivation, it was equally important for me to draw clear boundaries around the purpose of my presence and not encourage or develop any dependency or raise expectations, which I could not meet. I avoided eating anything within the shrine compound as it caused children to come and beg for food I was eating. I also did not offer any money for charity or make donations, as there was no end to people in need of money or food. Drawing a line under what I was or was not prepared to offer was difficult. There are no philanthropic organisations working in the shrines aimed at supporting attendees or finding them jobs or other sources of income. Each mentally distressed individual or their family members required long term

and consistent social work. Unfortunately very few resources for help were available for them, most of them lived in the city of Karachi which is about 100 Km from the shrine and a long way for relatives to travel on regular basis.

Recognising and accepting my limitations, as a researcher was crucial for me as it kept me focussed on the task in hand. It did, however, raise a number of questions for me that I discussed in my supervision, regarding social justice, human rights, the meeting of basic needs and poverty in Pakistan.

Data collection methods

The most appropriate method of collecting data in ethnographic research is through participant observation and dialogue with participants in semi structured interviews. Initially it was important to determine which people were attending the shrine to seek healing for their mental distress rather than solely to carry out their religious rituals. The presence of mental distress and the intention to seek healing became the criteria that guided the process for inclusion in the study. To determine the presence of mental distress, possible participants were asked to complete a mental health questionnaire – Self Reporting Questionnaire (SRQ) by Harding *et al* (1980) that has been translated into a variety of different languages including Urdu.

Recruitment of participants

Participation in this study was completely voluntary without incentive or coercion. The nature of the research setting was such that the attendees were resting, praying, talking with their family/relatives, having their meals, or sleeping. It was not always very easy to recruit participants for the study as it meant crossing their personal boundaries. I therefore approached the potential participants and explained the purpose of the research project. This included briefing them about completing the questionnaire about their health status and if they met the criteria, their willingness to share their experience at the shrine. I used a participant information sheet to explain the purpose and nature of the study and assured participants that confidentiality would be maintained. A copy of the participant information sheet was given and it was emphasised that the participants could withdraw from the study at any time without giving any reason.

Many attendees, regardless of their eligibility for inclusion in the study questioned me about my background and my purpose of being there. The most common assumption made was that the interview was for the purpose of publication in a national or local newspaper or magazine. Some people said that they felt wary of anybody with a cassette recorder or note book as in the past, practices at the shrine have been a target for ridicule by the media. On the other hand, some long-

term residents at the shrine hoped that the media would be interested in their stories so that they could be paid for their interview. I repeatedly explained that I was studying and researching a topic related to healing at the shrine and therefore would like to listen to people's stories in order to gain an accurate understanding of this phenomenon.

The consent form

The participants who showed a willingness to participate in the study were asked to sign their name or put their thumb impression on the consent form [Urdu translation]. For those willing to participate in the study but not willing to sign the consent form, verbal consent was sought and tape-recorded when appropriate. It was, however, apparent that some participants showed a level of discomfort in signing or putting their thumbprint on the document and questioned whether their words were not adequate to assure me of their willingness to participate.

Although I was able to explain that this was a measure to ensure that the participant had fully understood the task and was willing to participate, some attendees perceived it as a sign of distrust and refused to continue the process. One woman expressed this by saying '*do you not trust me when I say that I am willing to participate, is it not enough?*' Other participants argued that their continuing with the interview should be considered as a form of consent as it showed their willingness to participate. This situation demanded flexibility and modification in documentation to make the research process culturally appropriate and acceptable to those participating. What seemed most acceptable and inoffensive to the participants was that I read the consent form out loud and they confirmed their willingness verbally prior to the start of the interview. The process of signing a written consent form as a sign of willingness to participate in the interview process is a western tradition. Questions are raised concerning its appropriateness for use in cultures with oral traditions and low levels of literacy.

Tape recording

Just over a quarter of those willing to be interviewed refused audio recording for a variety of reasons including keeping 'purda' (a veil) for their voices, and maintaining respect for the shrine. Some women believed that it is part of their religious duty to have no interaction (seeing, hearing or touching) with males outside their own families. The request to record the interview caused them anxiety and uncertainty about who would listen to their voices on tape, and resulted in a refusal to be taped. They did, however, permit the taking of notes by a colleague during the interview. Some people also believed that religious matters should not be talked about with anybody else as it is a private and personal communication between an individual and the higher being. Talking about it to others may mean disrespecting their own developed code of practice at the shrine.

Those who agreed to have their interviews tape-recorded also insisted that we sit far from public places to avoid disapproving glances from others in the surrounding areas. Some women, conversely, did show their excitement while taking part in the recording of their interview stating that this is first time that they had felt valued for what they could offer.

Privacy (individual or group interview)

Many times other women joined us during the interview and just sat and observed. I attempted to discourage them from doing so but was not always successful. Sometimes participants stopped me from discouraging other women from sitting close by. It appeared that each of them knew the story of the other and did not mind if they heard it again. The rest of the participants, who did not want their interviews tape recorded, agreed that my colleague could take notes throughout and I would also make reminders and memos during the process. These interviews were transcribed in Urdu, verbatim, within 24 hours to prevent any errors due to memory lapse.

Some challenges

(a) *Research in a religious place*: Some people strongly believe that religious places are sacred places and should not serve as research sites. I experienced a level of resistance and disapproval for initiating such an endeavour. This was further complicated by my gender as a woman and how this is traditionally seen in the light of Islamic principles, as interpreted and practiced by the general population in Pakistan.

(b) *Language*: each culture has its system of communicating subtle messages using a combination of facial expressions, body gestures, and turns of phrase. Many times, when I needed greater exploration of a topic, these messages were given. Failure to respond appropriately to these cues at times ended the interview. A balance between exploring and respecting remained crucial in the data collection process.

(c) *'Being from the same culture'*: being from the same culture was in some ways helpful for me, but it also posed additional challenges. I was expected to understand hidden messages and subtle cues and hints. Although taking the approach of being naïve or unaware has been suggested by qualitative researchers in understanding perspectives from participants, it often caused irritation among participants in this study as they felt having to verbalise their thoughts in detail. This in turn brought ambivalence and contradiction in their beliefs and behaviour in light, which was often uncomfortable and caused defensiveness.

(d) Researching in my own culture on one hand gave me an advantage of understanding the emic point of view, but it was also a constant struggle to maintain a distance between my own thoughts and feelings and those of participants. My exposure to higher education, the

mental health field, and a broader understanding of different cultures increased my scepticism in regard to the reasons or logic behind participants' decisions. However, questioning had to be done in a very sensitive manner to avoid offending or patronising, which was not easy.

Conclusion

Conducting research in an environment that is sacred and significantly relates to a groups' particular and strict value and belief system raises many ethical questions and creates situations that require an ethically competent approach, a situation frequently experienced by transcultural researchers. Although I am from the same culture as the participants, the data collection process in the research opened up a series of complex situations for me, all requiring careful evaluation, and challenging me to maintain ethical practice principles. The power imbalance between the researcher and those researched in regard to health status, the availability of the means of basic living, education, and apparent control over immediate surrounding played a significant role. Having a basic understanding of the culture, empathy, a non judgemental and respectful approach, acceptance of others' as unique individuals and reflective practice are essential for the transcultural researcher if ethical research practice is to be established.

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Contact details:

Farida Pirani
Research Student, Research Centre for Transcultural Studies in Health
School of Health & Social Sciences,
Middlesex University
10 Highgate Hill
London N19 5LW

Tel: +44 (0)208 411 5476
Email: F.Pirani@mdx.ac.uk

Professor Irena Papadopoulous
Head of Research for Transcultural Studies in Health
School of Health & Social Sciences,
Middlesex University
10 Highgate Hill
London N19 5LW

Tel: +44 (0)208 411 6626
Fax: +44 (0)208 411 6106
Email: R.Papadopoulos@mdx.ac.uk

Acute poisoning and suicides in rural Sri Lanka

Neil Jaysinghe

MD, MScPH, Research Assistant, School of Health & Social Sciences, Middlesex University

John H Foster

PhD, MSc, BA, RMN, Senior Lecturer in Mental Health, School of Health & Social Sciences, Middlesex University

Abstract

Introduction: Sri Lanka has one of the highest rates of acute poisoning cases and deaths in the world and this is mainly due to deliberate self-harm which causes many deaths by the toxicity of the poisons.

Method: Primary data were collected from the base and general hospitals and the national poisons information centre in Sri Lanka.

Results: Suicide and poisoning rates are increasing throughout Sri Lanka and particularly prevalent in rural areas. Snake bites are common but the highest case fatality rates are presented by pesticides most notably organophosphates. Once again the problem is at its' most acute in rural areas. Of particular concern are number of episodes of poisonings for young men in the 15-44 year age range.

Conclusion: The increasing suicide and poisoning rates caused by organophosphates in Sri Lanka (most marked in rural areas) are caused by a combination of availability of organophosphates and inadequate medical facilities. Research efforts need to be directed towards providing culturally sensitive interventions and the development effective of antidotes and activated charcoal.

Key words

Acute Poisoning; Suicide; Rural; Urban; Agrochemicals; Organophosphate (OP); Paraquat; Pesticides; Sri Lanka; Death.

Introduction

Poisoning is a clinical disease or other adverse health effects suffered by an individual by the action of poison. A poison is a substance that when introduced into or absorbed by a living organism causes death or injury, especially one that kills by rapid action even in a small quantity (This is dependent upon the type of poison).

According to WHO Suicide is the result of an act deliberately initiated and performed by a person in the full knowledge or expectation of its fatal outcome http://w3.whosea.org/en/section1174/section1199/section1567_6745.htm (2006).

Suicide today is defined differently depending on the purpose of the definition-medical, legal, administrative, etc. In most countries reporting to the WHO, suicide is defined as one of four possible modes of death. An acronym for the four modes of death is NASH: natural, accidental, suicidal, and homicidal.

In many countries in South-East Asia and the Western Pacific, the death rates for deliberate self-poisoning can be 40% of the total mortality. The huge disparity lies not with differences in healthcare systems, although these do play a part, but with the extreme toxicity of the poisons most commonly taken in South-East Asia – pesticides such as organophosphates and herbicides such as paraquat. Even small doses can be lethal within hours http://www.wellcome.ac.uk/doc_WTD006147.html (2005).

Pesticide poisoning is an important cause of morbidity and mortality in the world. It has been estimated that 95% of fatal pesticide poisonings occur in developing countries, many of which are in the Asia Pacific region (Jayasinghe, 2003). Furthermore pesticides poisoning from occupational, accidental and intentional exposure is a major developing world public health problem (Eddleston, 2000). The high rate of suicides in rural areas is associated with the availability of these chemicals.

Organophosphate (OP) pesticides are the predominant problem worldwide, being responsible for many cases of self-poisoning and the majority of deaths, particularly those who from rural areas. The reported fatality rate due to organophosphate (OP) pesticides in hospital-based surveys was as high as 46% of total self-poisoning deaths. This has recently become an important cause of deaths in parts of South Asia (Eddleston *et al.*, 1998). An estimated 1 million serious accidental poisonings and Two millions suicide attempts involving organophosphorus compounds occur each year worldwide (Kipling, 1985).

The other most dangerous agrochemical is paraquat. The dipyrindyl herbicides paraquat is highly toxic compound for humans and animals and many cases of acute poisoning and death have been reported over the past few decades. So far, no standard treatment exists (Jayasinghe, 2003).

A large proportion of the acute poisoning deaths in Sri Lanka are by ingestion of pesticides, insecticides and

herbicides (Eddleston, 2000). Acute poisoning cases tend to be fatal, especially in the rural areas, because rescue facilities are seldom available. Most victims poison themselves with pesticides and herbicides, which are frequently on hand; because they are widely used on plantations and no protective measures are taken.

Pesticides, as would be expected, are particular problems in rural areas where they are freely available. Small quantities of pesticides are even being added to illicitly distilled moonshine called **Kasippu*. **(Kasippu is distilled by coconut flowers which are an illegal alcohol drink in Sri Lanka However; this is a popular alcohol in rural areas.)* Poisoning is the main cause of death in Sri Lanka, even outnumbering the casualties of the civil war (Bolz, 1998).

During the past 22 years, it is estimated that nearly 50,000 persons have been killed by war while deaths due to suicide, in the same period, are estimated to be 106,000 twice the number due to war. Nevertheless, as late as the 1950s, Sri Lanka had a low suicide rate of 6 per 100,000. The official estimates for 1996 are 37 per 100,000, making Sri Lanka one of the countries with the highest number of suicides per unit of population. However, in 2005 rates are estimated to be 44-50 per 100,000 http://w3.whosea.org/en/Section1174/Section1199/Section11567/Section1824_8078.htm (2005).

Aims

The main purpose of this paper is by drawing upon national data and relevant hospital databases to determine the major public health impact of acute poisoning and its close relationship with suicide in Sri Lanka.

Material and methods

Data were collected from the base hospitals in Negombo and Gampaha. (Both based in the Western province) the General Hospital Anuradhapura, (Central Province) during the period of 1995-2002, from the hospital registers.

The poisoning information data were collected from the national poisons information centre register, Sri Lanka during the period of 1991-2001.

The population statistics were collected from the Sri Lankan National Registry, the Department of Census and Statistic Centre, Sri Lanka from 1981-2001.

Table 2: Type of Poisoning Agents According to Some Urban/Rural/or Mixed Regions, 2000.

Areas	Toxic effects of All kind of Agro Chemicals			Poisoning by Drugs Medicaments And Biological Substance			Snake Bites			Toxic effects of othersubstance chiefly non Medical as to Source			Total	
	Cases	Deaths	CFR*	Cases	Deaths	CFR*	CFR*	Deaths	CFR	Cases	Deaths	CFR	Cases	Deaths
Sri- Lanka	20326	1843	9%	14288	301	2%	37081	194	0.5%	15641	328	2%	87336	2666
Urban	4640	560	12%	4479	60	1%	11360	35	0.3%	3996	113	3%	21233	676
Mixed	4683	376	8%	2264	46	2%	5149	31	0.6%	2346	17	0.7%	14484	528
Rural	6887	579	8.5%	3705	56	1.5%	14003	52	0.4%	5574	168	3%	30207	852

The source for this data is the Sri Lankan National Poison Information Centre *CFR- Case Fatality Rate

Results

This paper presents the following data.

- i) Prevalence of suicide for the whole of Sri Lanka in 1994.
- ii) National data relating to types of poisonings.
- iii) Changes in Poisoning Rates from 1990-2000 in selected urban and rural districts.
- iv) Prevalence of Hospital Admissions and deaths for all Sri Lanka in 1996.
- v) A case study of in one rural hospital.
- vi) The spread of suicide rates across different age groups.

Table 1: Suicide and Acute Poisoning Distribution According to Some Urban/ Rural/or Mixed Regions, 1994.

Provinces With Districts	Estimated Population 1994	Number of Suicides	Swicide rate Per 100,000	Number of Acute Poisoning 1994		Acute Poisoning Per 100,000 1994	
			1994	1994	Cases	Deaths	Cases
Urban	7,129,669	2830	78	7364	465	214	13
Mixed	3,354,021	1806	96	5982	563	350	34
Rural	3,015,031	1961	150	8267	648	662	52

Data showing suicide and acute poisoning rates are shown in table 1. There are clear differences between suicides and acute poisoning rates across urban/ rural/ or mixed regions. The highest rates were found in rural areas, followed by the “mixed” areas and thereafter urban areas.

Table 2 shows the total number and type of poisoning agents in urban/rural/or mixed regions. The majority of deaths in all three regions are caused by Argo-Chemicals. The higher case fatality rate (CFR) is present in urban areas. The next highest category is non-medical substances. On this occasion the CFR is identical in urban and rural areas. Drug medicaments and biological substances are the third most prevalent category of poisoning agents. The highest CFR are in mixed areas. The least common category is for snake bites; again these are more prevalent in mixed areas.

Table 3: Acute Poisoning Rates According to Urban and Rural Districts, 1990/2000.

Districts Urban	Toxic Effects of all kind of Agrochemicals				Poisoning by Drugs Medicaments and Biological Substance			
	1990 (Rate per 100,000)		2000 (Rate per 100,000)		1990 (Rate per 100,000)		2000 (Rate per 100,000)	
	Cases	Deaths	Cases	Deaths	Cases	Deaths	Cases	Deaths
1.Colombo	11	02	45	06	39	01	46	01
2.Kandy	64	04	94	10	12	00	65	01
3.Galle	24	03	55	09	13	00	77	01
Districts Rural								
1.Anuradhapura	143	18	323	30	08	00	138	01
2.Polonnaruwa	217	14	285	28	14	00	244	01
3.Kurunegala	127	22	211	16	14	01	105	01
Sri-Lanka	57	08	110	10	13	00	77	02

The source for this data is the Sri Lankan National Poison Information Centre Jayasinghe (2003).

In table, 3 poisoning rates in three urban districts and three rural districts are displayed comparing differences between 1990 and 2000 (Jayasinghe, 2003). All six districts are the capital cities of their wider provinces. In all districts there has been an increase in acute poisoning rates over the survey period but the greater rates of cases and death are present in the rural districts. There have also been increases in poisonings by “drugs medicaments and biological substances. On this occasion there has been a much larger increase in rural districts. However the death rate is comparatively low throughout.

According to table, 3 there are clear differences between the urban and rural districts and type of toxic agents used over the period from 1990 to 2000. The mortality rate in urban areas, where pesticides are relatively uncommon, tends to be lower. Drugs, medicaments and biological substances are most commonly used. Fortunately, the majority of these poisons are less toxic than pesticides.

Table 4: Hospital Admission and Deaths from Poisoning in All Sri Lanka, 1996.

Poisoning Agents	Total hospital admissions	Hospital deaths	Case fatality rate
1. Organophosphates & Carbanates.	14 894	1327	9.0%
2. Other pesticides.	6 235	523	8.4%
3. Medical agents.	8977	145	1.6%
4. Snake bites.	27 251	164	0.6%
5. Other poisoning & toxic effects.	13 566	343	2.5%
Total	70 923	2502	3.5%

The source for this data is the Sri Lankan National Poison Information Centre.

In table, 4 hospital admission and deaths from poisoning in all Sri Lanka (1996) are displayed. The highest numbers of hospital admissions were for snake bites however these had the lowest CFR. These were followed by Organophosphates & Carbonates and other Pesticides (All kind of Pesticides) - both of these had a CFR > 8%.

There were 13566 admissions were “Other poisonings & toxic effects” but the CFR was lower at 2.5%. Medical agents also produced a CFR of 1.6%.

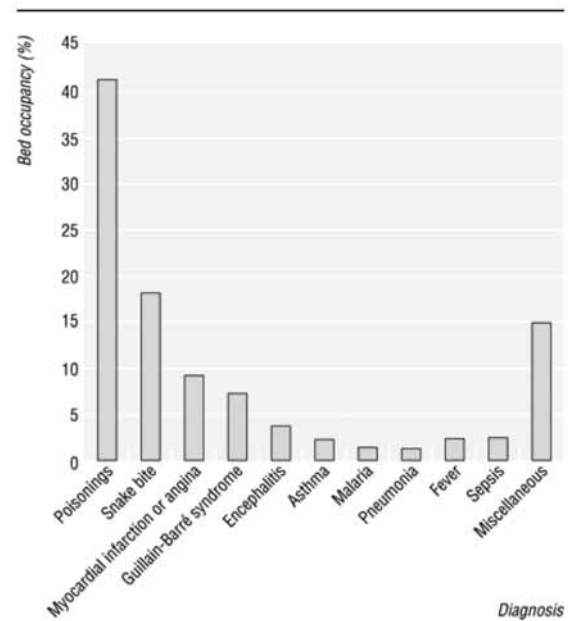


Figure 1: Bed occupancy in relation to diagnosis in the medical intensive care unit of Anuradhapura General Hospital, Sri Lanka, 1995-6.

Finally a rural hospital has been chosen as a case study. The Anuradhapura General Hospital is a secondary referral centre for 900,000 people living in the North Central province. The relevant data relating to bed occupancy (intensive care) in 1995 and 1996 is shown in figure 1. During 1995 and 1996, 2559 adults (age range 12-73 years; 1443 men and 1116 women) were admitted to the hospital with acute poisoning. Altogether 325 (12.7%) died in the hospital 246 men and 79 women (17.0% and 7.1% of admissions, respectively).

By far the greatest cause of bed occupancy was poisoning (41%) followed by snake bites (17%). Other than a miscellaneous category all the other categories are communicable diseases with a bed occupancy rate of < 9%.

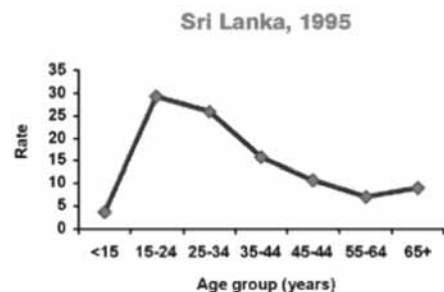


Figure 2: Age variation in Suicide Rates, Sri Lanka (%), 1995. http://w3.whosea.org/en/Section1174/Section1199/Section11567/Section1824_8079.htm at Accessed [20 Oct 05].

There is also a difference in the occurrence of suicides among various age groups. According to the figure 2, the 15-34 years age group has had the highest rates of suicide

mortality (30-60%) and from age 35, rates are decreasing gradually while the rates are increased again at the age of 60 years and above. However, figure 2 indicates that in Sri Lanka more than 60% of suicides have occurred in the 15-44 year age group. Information from the World Health Organisation for 1991 report show the following Sri Lankan suicide rates per 100,000- 44.6 (male), 16.8 (female). http://www.who.int/mental_health/prevention/suicide/suiciderates/en/print.html (2006). Equivalent figures from the UK for 1992 are 17 (male) and 6 (female). http://www.samaritans.org.uk/know/suicide_stats.shtm (2006).

Discussion

By using a series of different datasets this paper confirms that there is an increasing problem of poisonings and suicides in Sri Lanka. Although poisoning by snake-bites are common, death rates are comparatively rare as medical resources and serums are available to tackle this problem. The main difficulty is presented by pesticides in particular organophosphates. These have a high and rising case fatality rate. Although poisonings through organophosphates presents a problem throughout Sri Lanka it is particularly marked in rural areas.

Fernando (2002) and Eddleston *et al.*, (1998) point out that Sri Lanka has a particularly high acute poisoning rate compared to other countries in the Indian sub-continent. National data has confirmed this and shown that there are differences across urban, mixed and rural areas. The highest rates of acute poisoning were found in rural areas followed by mixed areas and finally urban areas. However an examination of the types of poisoning agents using data collected in 2000 shows a more contradictory picture. The highest case fatality rates are for agro-chemicals and these are markedly greater than those for all other causes shown in table 2. Furthermore the highest CFR for Argo-chemicals is found in urban areas. The author postulates two possible explanations for these somewhat contradictory findings. Firstly it is possible that rural hospitals may transfer acute poisoning cases to urban settings because of the lack of facilities and lack of qualified doctors or the relatives may take the patient directly to an urban hospital. A second possibility relates to the Sri Lankan urban lifestyle whereby fruit and vegetables are frequently grown with the aid of pesticides and other forms of Argo-chemicals. There are observations of the first author who has practised as medical doctor in a Sri Lankan hospital.

Interestingly the highest number of poisonings is through snake bites and yet these carry the lowest CFR. This suggests that Sri Lankan hospitals are more equipped to deal with snake bites rather than other forms of poisoning.

The data of greatest concern is shown in table 3. This clearly shows that other than one rural district (Kurunegala) poisoning and deaths due to agrochemicals have increased markedly (1990-2000) in both urban and

rural areas. Although there has been a similar increase in poisoning rates over the same period for “drug medicaments and biological substances” (particularly marked in rural districts) there has been very little change in fatality rates. National data from 1996 confirm the importance of pesticides/agrochemicals in national fatalities.

The data confirms a higher suicide rate in rural areas. Furthermore information collected in 1995 by WHO confirms that the greatest number are by males and occur in the 15-44 age groups.

Prevention and treatment

Eddleston (2000) believes that three factors are interacting to explain the high rates of suicide and deliberate self-harm in Sri Lanka particularly in rural areas. These are a lack of medical facilities, easily availability of organophosphates and a lack of cheap antidotes. A long-term civil war and the precariousness of subsistence farming in the developing world exacerbate this. A quote from Eddleston (2000) encapsulates this very well- “In a moment of extreme stress- when crops fail- when losses imposed by the war seem insurmountable- there are enough reasons at times- people just grab the nearest thing and drink it.”

Reducing deaths from self-poisoning will require multiple approaches. One-way of reducing deliberate self-harm would be to limit access to poisons (Jayasinghe, 2003). This will not be easy because the availability of pesticides is fuelled by sales promotion activities and easy credit facilities designed to promote pesticide use.

There are now series programs that promote the safe use of pesticides through education and training of farmers (Fernando, 1997). To date these have not been evaluated. In time to reduce deliberate self-harm the Sri Lanka community will have to develop an awareness of lethality of these substances and the some of the inherently unsafe practices currently employed by them. For example pesticides are often not locked away safely in rural areas where farmers live in huts without a bed, furniture, or cupboards. Furthermore education initiatives should be aimed at the farmers concerning proper storage and disposal of agrochemicals (Jayasinghe, 2003). At a policy level stricter legislation is required regarding their sale and distribution of pesticides- notably organophosphates. An improved agricultural extension service to promote alternative non-chemical methods of pest control is the most important strategy, in the long term, to prevent acute pesticide poisoning.

Banning common poisons, such as particular pesticides, maybe effective. However it is difficult to predict the long-term outcome, since the picture is never constant and new poisons become popular, replacing others. Also for some farmers, farming at subsistence level means that all measures need to be employed to ensure crops do

not fail. So the workability of bans must be questioned. Long-term improvement will come from reducing the incidence of harmful behaviour and improving medical management.

Unfortunately the frequent presence of pesticides is accompanied by a lack of mechanical ventilators and shortage of drugs and related facilities (Van der Hook *et al.*, 1998). The management of the forms of poisoning seen in the tropics is not well developed, with few specific antidotes and few evidence-based protocols (Eddleston *et al.*, 1998). Therefore, protocols need to be developed for better management of these poisonings, particularly for use in rural areas where medical services are at their most inadequate.

The available treatments also need to be subjected to rigorous trials. The importance of establishing whether cheap non-specific therapies such as multiple-dose activated charcoal regimens can save many lives (Fernando, 2002). The debate surrounding the efficacy of activated charcoal has ranged for decades with little change (Van der Hook *et al.*, 1998).

All these factors have to be put in the context of deliberate self-harm occurring in an area where poverty and inequality is rife. One of the particularly concerning aspects of the Sri Lankan situation is the number of young people dying as a result of deliberate self harm. Ultimately such solutions have to be found that are working with and respecting the existing culture, helping the indigenous population arrive at their own solutions. This should be carried out in combination with cross-national measures aimed at reducing inequalities that force poverty-stricken farmers to use such dangerous chemicals with few safeguards.

Limitations

This study if assessed by scientific criteria would be described as being piece meal. However it has attempted to collect the most recent data from Sri Lanka from a variety of sources and reflects the fact that this is not systematically collected. There is minimal contemporary data relating to suicides in Sri Lanka as there are no statutory centres or organizations regarding suicide prevention. However, better data for poisoning are available as there is a National Poison Information Centre. According to those data, cases and deaths due to acute poisoning are listed together for accidental and suicidal intent. Therefore, it is impossible to know how many of these cases have a suicidal intent. Furthermore, there is limited information collected relating to age and gender. In this paper the authors are dependent upon national and local data and subject to the deficiencies inherent in how these have been collected.

Ethical issues

As this study did not require taking samples from or the interviewing of human beings on the face of it there

might appear to be no ethical issues involved in this study. This was not the case; ethical issues surround the problems inherent in conducting work focused upon areas where record keeping facilities are not widespread and systematic. As mentioned above by scientific standards the data collected is not systematic. However some data exists and presumably was used for making decisions concerning resource allocation.

This raises the question of what is our role as academics and researchers. The purpose of this study was to raise awareness of a problem that is arguably of epidemic proportions. On some occasions the only evidence of hidden problems is anecdotal. The data collected in this study is far more than that but probably by positivistic standards would not be regarded as acceptable evidence. Surely it is part of our role to develop more insights into why the data collected in certain circumstances is haphazard. There are a number of possibilities that present possible future research opportunities.

- The data was not collected in a systematic manner because there is not the manpower nor software facilities to do so.
- The issue of suicide is likely to be stigmatised within Sri Lankan society and therefore it may be too sensitive for funding bodies to finance data collection in this area.

Conclusions

This paper has used a variety of data sources to confirm the high rates of deliberate of self harm and suicide resulting from the use of organophosphates in Sri Lanka. This is most marked in rural areas. The main reasons for this are the high prevalence of organophosphates and lack of adequate medical facilities and antidotes. Further research is required develop antidotes to the poisons and produce culturally sensitive interventions to alleviate this problem.

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Contact details:

Dr. Neil Jaysinghe
Research Assistant
Middlesex University
School of Health and Social Sciences
The Archway Campus
Highgate Hill
London N19 5LW
United Kingdom

Tel: +44 (0)20 8411 5814
Fax: +44 (0)20 8411 5276
Email: N.Jayasinghe@mdx.ac.uk

Dr. John H Foster
Senior Lecturer in Mental Health
Middlesex University
School of Health and Social Sciences
The Archway Campus
Highgate Hill
London N19 5LW
United Kingdom

Tel: +44 (0)20 8411 2656
Fax: +44 (0)20 8411 5276
Email: J.Foster@mdx.ac.uk

An evaluation of the practice assessment tool used to assess clinical practice in the pre-qualifying and undergraduate nursing programme

Chrysi Leliopoulou
Kathy Wilson

MSc, BSc, RNT, RN, Senior Lecturer, Health & Social Sciences, Middlesex University
MSc, BSc (Hons), Cert Ed. Dip.N, RGN, Principal Lecturer/Head of Practice Based Learning, Health & Social Sciences, Middlesex University

Kathy Markey

MSc, PGCHE, BSc, RN, LPE, Senior Lecturer, Health & Social Sciences, Middlesex University

Angela Rawnsley

MSc, BA (Hons), RNT, PGCEA, RCNT, RGN, RM, Senior Lecturer, Health & Social Sciences, Middlesex University

The following paper reports on an evaluation of the practice assessment tool used within the pre-qualifying and undergraduate nursing programme, to assess competence of clinical practice. A qualitative approach was used. Focus groups with; nursing students (n – 20), mentors who support learning and assess practice (n – 20) and nurse lecturers (n- 20) was used to collect the data. The key findings suggest that there are many benefits to the structure and function of the current practice assessment tool, but highlight that further amendments are required. The findings highlight that skills development and progression were not explicit within the assessment tool, students and mentors reported that they felt unprepared to use the tool confidently, strengths and challenges associated with reflection were reported and there were communication problems highlighted in the student-mentor relationship. Recommendations focus on; maintaining the positive aspects of the tool, making skills assessment more explicit within the tool, implementing strategies to provide greater preparation for students and mentors to use the tool, refining the student reflective accounts required and incorporating strategies that further promote continuity of learning and assessment in practice.

Key words

Practice assessment; Pre-registration nursing programme; Competence; Practice learning.

Introduction

As nursing is a practice based profession, practice learning is central to the student experience. The pre-qualifying and undergraduate nursing programme of study is directed towards the achievement of professional proficiencies, with a requirement that students complete fifty per cent of their programme in practice settings. Students are required to demonstrate their achievement of “standards of proficiency” as outlined by the Nursing

and Midwifery Council (NMC, 2004). As a mechanism of demonstrating the achievement of these standards, students are summatively assessed on each practice experience, with the use of an assessment tool. Assessment tools are central to nursing education as they are used to assess the level of competence or proficiency of nursing practice. However, there remains an ongoing debate within the nursing literature regarding their reliability and validity (Benner 1982; Redfern *et al* 2001) and as a result practice assessment continues to present as a challenge for students, mentors and lecturers (Jackson and Mannix, 2001; Carlisle *et al* 1999; Dolan 2003).

Since September 2000, the practice assessment tool (PAT) is the tool used to assess practice on the pre-qualifying and undergraduate nursing programme, at Middlesex University. Prior to the PAT the modified nursing competency scale (commonly referred to as the Slater tool) had been used as the method of clinical assessment for the Dip HE Nursing programme, first validated in 1991. The programme was revalidated in 1996 and a requirement of that validation was that the use of the Slater tool be reviewed (Gordon and Brown, 1999). Several publications were taken into account in the process of reviewing this assessment tool, including Making a Difference (DoH, 1999) and Fitness for Practice (UKCC, 1999). These documents recommended that practice assessments in pre-registration nursing programmes should be competency based and reflect the holistic nature of nursing, whilst carrying a skills focus. The United Kingdom Central Council (UKCC) had at the time recently issued further statutory competencies that students must achieve at the end of the first year, approximately mid-way and at the point of registration and these were reflected, where appropriate to clinically based assessment in the assessment documentation.

Within the PAT, the learning outcomes are set within seven nursing practice domains, as guided by the Nursing and Midwifery Council (NMC). Each domain

consists of a general learning outcome and several associated specific learning outcomes, the achievement of which underpins the meeting of the general learning outcome. These outcomes are designed to guide the assessor and the student towards the types of activities the student should gain competence in and are based on the first three levels of performance by Benner (1984). Within the pre-registration programme there are separate PATs for novice level (year 1), advanced beginner level (year 2) and competent level (year 3) which indicate the learning outcomes to be achieved by the end of each year of the students programme.

At the beginning of this study the PAT had been in use for almost three years and in line with the overall curriculum evaluation, it was felt appropriate to formally review its effectiveness. The aim of this study therefore was to increase our understanding as to how student nurses, their mentors and nurse lecturers viewed the tool by exploring how it was being used in practice and whether or not it was supporting the development of clinical competence.

Background

Assessment is widely recognised as one of the most powerful influences on learning approaches and behaviour adopted by students. A number of studies have highlighted the fact that many practice assessment tools give little attention to psychomotor nursing skills, leaving students anxious about their ability to perform certain skills and in effect students have been reporting to feel uneasy and unprepared to give holistic care to their patients (Calman *et al* 2002; Dolan 2003).

There are a number of arguments for and against various assessment methods and tools used in the assessment of nursing practice, which includes the assessment of nursing skills. Studies by Neary (1997) and Calman *et al* (2002) have shown that both students and mentors do favour the use of a structured assessment for the development of their practical skills and progress. Calman *et al* (2002) highlighted that students felt that assessment tools need to be more skills specific, although they acknowledged that nursing and midwifery practice was more than a collection of tasks; nevertheless, they felt they needed to learn how to do a range of tasks essential to practice.

Similarly, Cheek and Jones (2003) emphasised the need for the development of greater clinical skills in pre-registration nursing programmes, although it was clear that this did not only mean practising of tasks in traditional settings. Understanding oneself and the wider context in which one works was recognised as much a part of the development of clinical skills, as the performance of certain tasks. However, if clinical skills are not made explicit within assessment documents, the risk is that they will not be assessed (Scholes and Endacott 2002).

Reflective practice is deemed to be an important facet in the development of clinical competence and there has been an increasing emphasis on students providing written reflective accounts or supporting evidence to demonstrate achievement of competence (Runciman 1990; Chambers 1998). However, reflection is a difficult concept and in a study by Limatainen *et al* (2001) which describes reflective learning for student nurses, it was found that only 50% of the students reached the level of critical consciousness by the end of the programme; the others remained at the level of consciousness. It was deduced from this study that in order to support students' reflection, clinical mentors and lecturers need to be committed to reflective practice and to be sensitive to their students' learning needs.

Scholes *et al* (2002) also undertook a study exploring the use of portfolios to assess competence of practice and this included the submission of reflective accounts and other sources of written evidence by students to support performance. Within this study it was found that the portfolio approach seemed to enable some students to develop literacy and analytical skills but left others struggling to make connections between theory and practice. Students in this study commented that they had at times made naïve statements. They also found it difficult to identify their learning needs and at the beginning of a placement did not know what they needed to find out. Findings similar to these were duplicated in a number of other studies (Carlisle *et al* 1999; Jackson and Mannix, 2001; Clarke, 2002; Dolan 2003). It is against this background of policy, practice and research that this small scale evaluative study is set.

Sample

A purposive sample was used to recruit students, mentors and lecturers to participate in this small scale study. All participants were invited to take part via global emails, where some preliminary information on the study was given. In total, sixty (n=60) participants volunteered to take part in focus group discussions on the PAT. It must however be acknowledged that it is possible that participants who had particular strong views about the PAT volunteered to participate in the focus groups. This suggests the potential need for further research to explore in more detail approaches to practice assessment, using a larger sample size and incorporating strategies to focus on recruiting participants who may have less strong views about the PAT.

Three student nurse focus groups were facilitated, consisting of students from the adult, mental health and child branch, from year 1, 2 and 3 of the undergraduate nursing programme (20 students in total). Mentors (who are qualified practitioners who support and assess learning in practice) from the main hospitals affiliated to the University, participated in three mentor focus groups (in total 20 mentors). There were also three focus groups consisting of lecturers who support student learning on

the pre-registration nursing programme (in total 20 lecturers), to further complement the overall discussions on the practice assessment tool. An informed consent and a participant information sheet were given to all students, mentors and lecturers who volunteered to participate, prior to the focus groups along with a demographic questionnaire.

The focus groups took place in the hospital sites to make it easier for travel arrangements for participants. The focus groups represented as far as possible the gender and the ethnic background of the University and the NHS Trusts who participate in facilitating student learning and assessment. Equally, the student groups were an adequate representation of all levels and branches, ethnic and gender mix of the overall student population.

Ethical considerations

Ethical approval was obtained from the Health Ethics sub – committee of the School of Health and Social Sciences. Consideration was given to protecting the confidentiality of participants and obtaining consent to collection, recording and subsequent use of data. It was envisaged that students or mentors might be reluctant to identify examples of bad practice for fear of creating problems for colleagues. Participants were encouraged to contribute within the focus group but would not be pressurised if they felt reluctant to discuss any particular issue.

Data collection

As indicated, focus group interviews were used to collect data. During the focus group discussion, one of the two researchers led the discussion and the other researcher took detailed field notes to support the tape recordings of the interviews. All researchers took part in facilitating a focus group and each focus group discussion lasted approximately 1.5-2 hours.

Data analysis

Consistent with grounded theory, analysis of data generated from the focus groups took place alongside data collection. Within this study all focus group discussions were audio taped and transcribed verbatim. Data analysis was conducted using the constant comparison technique (Strauss and Corbin 1990). Data were also re-analysed by a member of the broader research team to ensure all aspects of the discussion were fully captured and understood for content validity.

Findings

The following four themes emerged from the data collected:

- Students' progression in clinical skills development
- Student and mentor preparation

- Students' reflective skills
- Achievement and progression

Students' progression in clinical skills development

Evidence of progression in skills development was one of the main themes that emerged from the findings of the focus groups. Although, it was recognised by the lecturers and some mentors, that skills such as the administration of medicines, communication, empathy and organisational skills were identified amongst the student learning outcomes within the PAT, there was a general consensus that psychomotor nursing skills needed to be more explicit so that they could be specifically assessed. Students from all levels, but in particular those students at competent level (year 3), voiced their concern over skills development and progression, to date. Students feared they had not progressed at the level they were required to be at by the end of their programme and that they had not achieved what they felt they should have. The following statements reflect the majority of comments made.

Students' comments included:

"It (PAT) offers good guidance on setting clinical learning objectives; however it is not specific enough when it comes to skills"

"Many students go through 3 years on nurse training without having the opportunity to pass even an NG tube and potentially if the domains were specific enough to certain key skills then these would be addressed"

"A skills checklist would be very useful so that by the end of 3 years you would be assessed carrying out pertinent nursing skills"

Mentors' comments included:

"The PAT is not skills focused enough, which is what is required as many senior students are not able to carry out crucial skills such as blood pressure monitoring"

"Some students lack basic skills even at the end of their 2nd and 3rd year placements. It is hard to know the sort of skills they should be practicing by the end of their placement"

"It does not focus on skills assessment and really does not allow mentors to assess the level of skills competencies"

"There is a need for a skills list or checklist so that we can sign off that students have completed the necessary skills"

Lecturers' comments included:

"Concerns have been raised about the level of clinical skills some students have and so my link wards are listing skills that students should achieve within their placement. It would be helpful to have something like this included in the PAT".

"...possibly the development of a list of skills the mentor has to sign off if he assesses the student as being competent...not a checklist as such but it does not have to have a great volume of information that is needed either".

Student and mentor preparation

Students reported having some preparation in how to use the tool at the beginning of their programme, but in terms of content delivered, this appeared inconsistent and some of these students reported having had no further structured guidance until year 3 of their programme. The majority of mentors on the other hand acknowledged attending some initial workshops on the PAT and having attended sessions with their link lecturers. Lecturers also highlighted their role in preparing mentors to use the PAT and identified a range of strategies used to facilitate this. However, the consensus from all focus groups emphasise that greater preparation is required for students and mentors, to ensure that the PAT is used appropriately and effectively to support learning and assessment in practice.

Students' comments included:

"Mentors do not appear to understand their role or have a clear idea about what the students should be doing and rely on the students to guide them"

"I only understood what to do with the PAT in my second year as I had a 2 hour session with a practice facilitator and I never had any other preparation"

"Although we had a session in our first year and there is information in our handbooks we do need more guidance and support on how to complete the PAT because different mentors seem to want different things from us"

Mentors comments included:

"I think the expectations of students and mentors and what is being assessed is not always clear"

"Students struggle with the PAT and do not always appear to understand the relevance of completing it. I think the language is difficult for them also"

"...some students do not know what to write but then others surprise you with lots of very relevant information"

Lecturers' comments included:

"I have had mixed experiences but overall I would say that students are not using the PAT well and need more help in completing it"

"There is a section within the PAT which addresses professional accountability and mentors can use it to log lateness and absence but they do not always seem to understand this though I must say there has been some improvement recently"

Students' reflective skills

Students are required to reflect on their learning within each of the domains within the PAT, to provide evidence of how they have met their learning outcomes and identify future learning needs. Within the focus groups, whilst students, mentors and lecturers highlighted the importance of reflection in the PAT, a great deal of

discussion ensued regarding the completion of this section of the document and the students' ability to reflect. It was felt by both the students and mentors that reflective accounts as sources of evidence of achievement of the learning outcomes were insufficient, as the written accounts were not always reflective in nature. Novice students in particular struggled to grasp this concept. It was felt that other forms of evidence were also required.

Students' comments included:

"I find the PAT very useful to aid reflection and it also encourages critical analysis, though I am not always sure that I am completing it correctly"

"When writing up my reflection I am very aware that a mentor is going to read it and so I write what I think they want to hear as opposed to writing about bad practices"

"I find it very repetitive and you end up copying what you had written earlier. I do not think it is actually read by anyone, mentors very rarely look at it and I do not think it is ever read by the university"

Mentors comments included:

"The reflection component is very important but there is no evidence that students are building or developing on their skills"

"What students write in their PAT is not always valuable and some students just write down any old thing and seem to get away with it"

"I do not actually pay a lot of attention to the reflective accounts but just make a judgement based on how the student is performing for their level of training"

Lecturers' comments included:

"I have seen some excellent examples where students have reflected well but I do think it is quite a 'grown up' tool and difficult for some students to use. For me one of the problems is that students describe rather than reflect and because of this the student is not able to analyse what it is they know and do not know"

"I think students really need quite a bit of help and guidance on how to complete this section. I have seen examples from third year students who have stated that their communication skills have improved and they need to learn more anatomy and physiology which is meaningless. They should be very specific about precisely what they have learned and what they need to do to progress"

"I do not actually think that at novice level that students recognised what they have learnt to be able to reflect on it as it takes experience to do that. So, I think they need more guidance at novice level"

Achievement and progression

Within the focus groups it became clear that mentors in particular, did not feel confident with what students should be achieving at the different levels of their programme.

Students commented that mentors at times did not read

their reflections within the PAT and relied on them to tell them what they were required to achieve. Some of the issues raised highlighted communications problems in the student-mentor relationship where students felt unsupported by mentors in developing the required levels of knowledge and skills with poor feedback or feedback only on negative performance being cited as examples of this.

Examples of where the student – mentor relationship worked positively were cited by all parties though one of the issues that mentors felt restricted their ability to effectively support students was a lack of awareness of how a student performed on a previous placement. They felt this would be invaluable in their ongoing support.

Students' comments included:

"It does make it better when the mentor reads and goes through what has been written but this does not occur very often and mentors do not always take it seriously. Some do not read it at all and just sign it"

"Because you have to demonstrate how you have met the learning outcomes it does encourage us to read more and gain more knowledge but the structure does not allow me to write down all the things I have learnt"

"I'm not sure if I am doing well or not on a ward and sometimes all we hear is the negative comments. It would be better to have weekly evaluations that are formal with the mentor to ensure progress is being monitored appropriately"

Mentors' comments included:

"The PAT is a good guide and prompts the mentor to ask the right questions, however the tool does not give me information on students previous experience and skills and this would be useful for us so we could set the right learning objectives and support them to achieve this".

"The PAT does not tell me the students' skills and abilities up to the point when they enter your ward; therefore it is hard to know the sort of skills they still need to gain to develop further"

"I do always make sure that I arrange a mid-term interview with a weak student but I have to admit that I do not always do it with the better ones"

Lecturers' comments included:

"I think it is important for the clinicians to know what the students have learnt before they come to their area. I know they could ask the student but for some reason this still causes difficulty as they do not always communicate well enough"

"The PAT is an excellent tool and has a lot of potential if used properly. I think we need to take it one step further to enable mentors to see what happened to the student before they came to them to ensure continuity"

"It needs to be clearer from the guidelines what you want from comments. At present mentors can make very general comments such as 'this is a hard working student' though no mention is made of their learning

and development in practice. Mentors do need more support with giving feedback"

Discussion

The development of the Practice Assessment Tool (PAT) as a mode of assessing clinical competence for pre-registration nurses reflected a significant change in the assessment approach used for nursing students within the University. Overwhelmingly, both lecturers and mentors felt the PAT was a positive development and much favoured it over the 'Modified Slater Tool' that had been used in the previous curriculum. The findings from this study however, point to the need for further refinement and development in a number of areas including, skill acquisition, preparation and support of all participants and general layout and presentation of the tool.

It was evident from the focus groups that the majority of participants were in support of a greater skills focussed assessment tool, with emphasis on a skills checklist approach. There was a significant appeal for a more robust and transparent assessment of skills, within the PAT. This request was particularly vocal from the student and mentor focus groups, though also identified as important by the lecturers who participated in the study. This finding is supported by a range of other studies including the work of Fergusson and Hope, (1999) and Calman *et al* (2002), where it was highlighted that students felt particularly anxious about their ability to perform certain skills because of the limited attention to psychomotor skills within their practice assessment tools. Through the discussions within the focus groups, it was interesting to note that many participants were focussing on the more technical practical nursing skills such as administration of medicines, vital signs, catheterisation and injections. There appeared to be limited acknowledgement to the more holistic or humanistic skills required for professional practice, as participants appeared to gloss over the caring and interpersonal skills that were clearly identified within the PAT. Mentors' concentration on psychomotor skills may have been influenced by the ongoing debate about graduates' practical skills, when newly qualified. Another possible explanation for this may be offered by McAlister (1998) who claims that humanistic aspects of practice assessment do become de-emphasised because it is easier to value and measure scientific and technical aspects of care that can be repeatedly demonstrated. Although not explored, it may be suggested that those humanistic aspects that McAlister refers to may be well enough addressed within the PAT as mentors and students did not appear to raise this as an area of concern, suggesting that this is an area that we would hope to strengthen rather than lessen.

It is clear that all participants felt the need for practical nursing skills to be more explicit within the practice

assessment tool, to ensure these skills were developed and assessed throughout the programme. The adoption of skills assessments, however, have been criticised for their lack of objectivity and for fostering a reductionist approach to assessment of nursing practice. Redfern *et al* (2001) claims such approaches can lead to fragmented care as nursing attributes such as attitude, intuition and empathy are often ignored. It is therefore, important to prepare students who not only have the psychomotor skills required to practice but also an underpinning knowledge base which will equip them to cope with the complex nature of practice (Cope *et al* 2000).

Mentors reported that although some preparation was received, they did not always feel confident in using the PAT, to assess students' level of competence in practice. Since professional judgement is at the heart of any assessment the reliability factor depends upon the perspective and training of the assessor. No assessment schedule is assessor proof. It is therefore, important that in order to enhance the reliability of the practice assessment, appropriate professional development, support and continuing education of assessors is essential. This finding of this study is consistent with findings of other studies, reinforcing the importance of preparing and supporting the mentors to assess practice (Percival *et al* 1994; McMullan *et al* 2003; Duffy, 2004).

Whilst a number of initiatives are in place for the education and support of mentors including the mentorship preparation programmes, assessor updates and local workshops; however, it is still evident that a gap remains in ensuring mentors are comfortable with their knowledge and understanding of the assessment tool. With fifty percent of the student's programme taking place in practice, mentors have a high degree of responsibility and if we wish our mentors to aspire to this level of clinical support for our future professionals then we must provide them with education, training and ongoing facilitation that allows them to function in this demanding role effectively (Cope *et al*, 2000; Watson, 2002)

Students also reported that although some preparation was received to use the PAT, they still felt that further preparation specific to the use of the PAT is required. Third year students had felt that they had developed the skills necessary to complete the PAT but that this was through trial and error, though novice students still found it difficult and frustrating. The findings from this study support the fact that the amount of preparation and support for assessment of practice can not be underestimated and strategies must be put in place to meet this need. Similarly, Neary (2000) in an exploration of students and practitioners views about the process of their assessment noted that students and staff rarely knew the assessment criteria and how to interpret them.

The use of the PAT as a means to promote reflection and self-assessment of learning to underpin life long learning and continuing professional development have been recognised as positive attributes within this study,

however inconsistencies did occur. Some mentors claimed they had little time and on occasions did not fully read the reflective accounts that the student had written. One mentor admits to never reading what the student has written. This latter comment has been supported by discussions that occurred during the student focus groups. Whilst it is accepted that mentors do have competing demands and require extra support there is also a grave concern that students are moving from placement to placement having being deemed as meeting the required proficiencies without being effectively assessed.

Watson (1999) reported that student nurses were being allowed to pass clinical assessments without having demonstrated sufficient competence to practice, a finding that prompted Duffy to undertake her study 'failing to fail' (Duffy 2004). Although failing to fail was not explicitly explored in this study it is obvious that mentors who do not understand or who are using the tool inappropriately will fail to identify students who are not progressing at the required level and there is certainly anecdotal evidence to support this. There is a need to refine the approach to assessment to enable mentors and lecturers to see progress to date within one document. Equally, the findings of this study emphasise the need to monitor assessment processes and quality of written feedback that is offered to the students, on their practice. Many authors highlight the professional responsibility and accountability that mentors have during assessment of practice but also suggest that mentors also have a moral obligation to assess accurately and objectively. (Melia, 1995; Chambers 1998; Duffy, 2004).

Conclusion

There appear to be consistent views from all participants acknowledging that the PAT is a potentially valid practice assessment tool however would necessitate amendments.

It is evident from the data analysis that the learning outcomes need to reflect key nursing skills and show students' progression throughout the three years. This is a view supported by all participants of the study. It is recommended that there needs to be specific skills assessments which focus on psychomotor skills across the three years of the programme and these need to be explicitly assessed as a component of the assessment tool, in order to assist mentors to progress students in terms of skills and attitudes.

The educational needs of students from a diverse social and economic background who mainly come from non-traditional educational backgrounds, do not perhaps initially possess all of the educational skills that would enable them to work through a tool such as the PAT appropriately (Gerish 1993, Snadden and Thomas 1998), suggesting the need for more guidance within the PAT.

It is recommended that the PAT becomes part of a more comprehensive portfolio of evidence and be tailored to the

levels of achievement required by the student. A practice assessment tool that could perhaps be used across the year as opposed to each practice experience in isolation could provide greater continuity between placements. This approach would also enable the mentor to refer to the student's previous performance to further facilitate development of knowledge and skills, as required.

Equally important is the need to review and develop current strategies that are used to prepare students and mentors to use the practice assessment tool and monitor assessment processes in practice and quality of written feedback offered to the students.

The need to review the current assessment processes against pedagogic research, which includes reviewing the structure of the tool and incorporating formative and summative assessments of practice has also been highlighted.

Overall, whilst this study has identified many positive aspects to the PAT it has also laid the foundations for the development of an effective assessment strategy to support learning and progression and facilitate appropriate assessment of competence.

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Contact details:

Chrysi Leliopoulou
Senior Lecturer
School of Health and Social Sciences
Middlesex University
Royal Free Campus
Pond Street
NW3 2QG

Tel: +44 (0)207 830 2659
Email: c.leliopoulou@mdx.ac.uk

Kathy Wilson
Principal Lecturer/Head of Practice Based Learning
School of Health and Social Sciences
Middlesex University
Archway Campus
Highgate Hill
Archway
EN52LU

Tel: +44 (0)208 411 6676
Email: k.wilson@mdx.ac.uk

Kathy Markey
Senior Lecturer
School of Health and Social Sciences
Middlesex University
Queensway
Enfield
Middlesex
EN3 4SA

Tel: +44 (0)208 411 6504
Email: k.markey@mdx.ac.uk

Angela Rawnsley
Senior Lecturer
School of Health and Social Sciences
Middlesex University
Royal Free Campus
Pond Street
NW3 2QG

Tel: +44 (0)207 830 2692
Email: a.rawnsley@mdx.ac.uk

BOOK REVIEW:

Mauthner M, Birch M, Jessop J and Miller T (Editors) (2002) *Ethics in Qualitative Research*. London: Sage. (ISBN 0761973095)

Theresa Bourne

MSc, PGCCCE, DPSM, RM, RGN. Principal lecturer, School of Health and Social Sciences, Middlesex University.

There is a tendency amongst researchers to focus on the practicalities of ethics in the development of research. This is evident also in many of the research texts with the spotlight resting mainly on the issues involved around gaining consent from an ethical body rather than the principles and dilemmas that may exist for some researchers as they design their study.

This book tries to move the reader beyond that of 'ethical guidelines' and 'frameworks' to consider some of the ethical dilemmas that co-exist with the politics and philosophies that underpin the epistemological and ontological standpoints of various research methodologies. Although the title of the book would suggest consideration of a wide range of qualitative methodologies, its focus appears mainly from the feminist perspective.

I recognise that this is the background of the editors and even the development of this book. Yet I feel the strong focus around women detracts from many of the issues that most qualitative researchers are challenged with when dealing with any potentially vulnerable or disadvantaged group. It is not that the book concentrates only on these issues but it retains a strong flavour in many of the areas that the authors explore. There are other texts that consider the problems of feminist research and it is disappointing perhaps that the editors have not promoted a more generic viewpoint, in considering more powerfully some of the other philosophical standpoints where the literature and discussion is not always so strong. Nevertheless, many of the points are salient in a variety of qualitative frameworks.

This is a useful text in widening the discussion into these issues, themes that are perhaps briefly highlighted and discussed in the classroom rather than fully in the research arena. It is not unusual to discover articles around some philosophical viewpoint or argument around research and research is richer for this discussion. It is less common to see the same level of consideration to how the researchers' philosophy or political standpoints might impact on their interpretation of some of the ethical dilemmas of consent

for example (consenting to what?), or confidentiality (divided loyalties, divided expectations).

There is the perception that we can glibly address these issues within our proposals with a tick box mentality. However, the challenge is to consider these ethical concerns in keeping with the reasons that we are choosing to undertake qualitative research. The voice of qualitative research is much stronger for a variety of reasons, surely one reason is the rigour in which we design and evaluate our projects. However, just as the qualitative researcher examines his or her research using different tools from the 'traditionalist', our application of ethical principles needs also a different perspective. These tools have been designed from years of discussions and arguments about what makes 'good' qualitative research rather than conforming to the positivist paradigm. Now is the time to begin this process more fully as to what makes ethical qualitative research, with full and frank discussion on some of the ethical dilemmas within research and the apparent trade offs we are sometimes feel expected to make (knowing responsibly).

This is a useful text for researchers, academics and students, not perhaps as a definitive text but one that initiates discussion. This book does not provide the answers only the questions. I hope all will take the opportunity to read some of the chapters, including those indicated above within brackets, and contribute to the future dialogue around this important area of research.

Contact details:

Theresa Bourne,
School of Health and Social Sciences
Middlesex University
Archway Campus,
Highgate Hill,
London.
N19 3UA

Tel: +44 (0)20 8411 5058
E-mail: t.bourne@mdx.ac.uk

CONFERENCE REPORT:

IX World Congress of Psychosocial Rehabilitation

Conference title: 'Psychosocial Rehabilitation Coming of Age in a Globalized World'

12th- 15th October 2006 Athens, Greece

Christopher A. Griffiths *BSc (Hons), Researcher, School of Arts and Education, Middlesex University*

The IX World Congress of Psychosocial Rehabilitation, sponsored by W.H.O, took place in the Greek city of Athens. The conference was attended by 1000+ delegates from over 50 countries. According to the organisers the congress included over 400 oral paper presentations, 27 key lectures, 160 posters, 48 'meet the experts' sessions, 15 practical workshops, three special sessions with artistic performances and video projection, and an art exhibition by artist-users. The conference was aimed at all of those who have an interest in the rehabilitation of those impaired or disabled by a mental disorder. The main themes of the congress included: the phenomenon of globalization; promoting and securing the rights of the mentally ill; the implementation of mental health networks and services in developing countries; the role and inclusion of mental health service users in their own rehabilitation; immigration and mental health; vocational rehabilitation; attitudes, stigma and rehabilitation; and prisons and mental health issues.

I attended the conference as part of my role in the Empowerment of Mental Illness Service Users: Lifelong Learning and Action (EMILIA) project. This is a Framework 6 European Union project, funded at €3.4 million over a four and a half year period involving 14 European countries in the thematic area of lifelong learning. One of the major innovations of the EMILIA project is in utilising a lifelong learning process to facilitate the social inclusion of mental health service users. This project seeks to empower mental health service users and encourages mental health services to maximise service user involvement in the training for, and delivery of, new and innovative services.

The conference provided a bewildering selection of presentation topics in a packed and well organised schedule. Key speakers included eminent figures from the field of psychosocial rehabilitation such as Robert Liberman and Larry Davidson. As a taster of what was on offer I describe two presentations which, for me, stood out in terms of the quality of the presentation and the importance of the issues described.

In his presentation 'Physical illness and access to medical services in people with schizophrenia' Dr. M. Maj stated that people diagnosed with schizophrenia have twice the mortality rate for physical illness of that of the general population, and that this group of individuals have not benefited from the trends of lower mortality and improved health that have been seen in the general population. Whilst suicide is often thought of by many as the biggest killer of those diagnosed with schizophrenia this is in fact not the case, it is cardiovascular disease. Dr. Maj revealed that those diagnosed with schizophrenia are much less likely to receive treatment for any physical health problem they might have. In addition, research shows that the treatment these individuals receive is of comparably lower quality. This highlights discrimination within the physical healthcare system on the basis of a mental illness diagnosis. Dr. Maj stated that "the neglect of physical health in schizophrenia should be regarded as an expression of discrimination and disregard for their rights as human beings and citizens." He explained that a lack of attendance to physical illnesses of those diagnosed with schizophrenia can reduce quality of life by exacerbating psychopathological magnifications and by impairing the individual's ability to adhere to treatment. Those who provide care for individuals with a diagnosis of schizophrenia need to be aware, for example, of the inability by some to describe the nature of the pain of a physical illness. Research findings suggest that the threshold of pain of those with a schizophrenia diagnosis is increased. To help improve the quality of life and mortality rates of those with a diagnosis of schizophrenia Dr. Maj recommended the imbedded systematic employment of basic physical health screening that takes into account this group's specific problems and needs.

Dr. P. Sidandi spoke about 'HIV/AIDS and mental illness, the Southern African experience'. This presentation highlighted the gulf between first world and third world healthcare, as exemplified by the statement that many people in Botswana, where Dr. Sidandi works, have little or no access to modern healthcare. It came as

a surprise to hear that despite the huge stigma associated with HIV/AIDS, in Botswana having mental illness had more stigma than having HIV/AIDS. This stigma had appalling negative health implications for individuals as many of those with mental illness were cast out from society and left to fend for themselves. He explained that in sub-Saharan Africa HIV/AIDS is a huge problem and that while this area contained only 10% of the world's population it had 60% of the world's HIV infected population. He detailed some mental health problems that can result from a diagnosis of HIV/AIDS such as depression, anxiety and suicidal ideation, and conveyed the importance of treating these conditions, as treatment increases adherence to anti-viral medication and helps to prevent suicide. He explained that HIV/AIDS associated dementia can cause behavioural changes, memory deficiencies and motor impairment. With a lack of money for the most effective drugs to deal with HIV/AIDS and associated mental illness, Dr. Sidandi stressed the need to develop psychosocial services within sub-Saharan Africa that can facilitate medication adherence, coping ability, improvements in nutrition, and higher levels of physical health care.

EMILIA representatives held a symposium at the conference entitled: 'User's empowerment and participation in the mental health services system: A European perspective.' Within this symposium there were five presentations by representatives of organisations involved in the project. As a representative of Middlesex University and the lifelong learning work package of EMILIA, I presented under the title 'Lifelong learning: Applications and benefits for mental health service users'. I presented the details of our literature review into lifelong learning for mental health service users and the beneficial effects that can result, describing the links between social inclusion, empowerment, and lifelong learning. I presented the results of our European survey carried for the EMILIA project to find out what lifelong learning provision exists for service users. This presentation speculated as to the potential benefits for mental health service users of participating in the EMILIA project and it made suggestions for how lifelong learning provision for service users can be improved. Further details of the EMILIA project and our work within Middlesex University can be obtained by writing to me via the email address provided.

Overall, I found this conference very informative and rewarding and it provided many opportunities for networking. The work that the World Association of Psychosocial Rehabilitation does is of vital importance in providing a platform for the presentation of research that can benefit those who are impaired or disabled by a mental disorder. I would dearly love to attend the next WARP conference but unfortunately it is in Bangalore, India, and the travelling budget won't stretch that far.

Contact details:

Christopher A. Griffiths
Researcher
School of Arts & Education
Middlesex University
Trent Park Campus
Bramley Rd
London
N14 4YZ

Tel: +44 (0)20 8411 6349
E-mail: c.griffiths@mdx.ac.uk

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**Please contact Chris Constantinou
or Rena Papadopoulos regarding
this and/or future issues:**

Chris Constantinou (Secretary)

Middlesex University
School of Health and Social Sciences
Queensway
Enfield
Middlesex
EN3 4SA
UK

Tel +44 (0)20 8411 5192
Email: c.constantinou@mdx.ac.uk

Irena Papadopoulos (Chair & Editor-in-Chief)

Middlesex University
School of Health and Social Sciences
Charterhouse
The Archway Campus
2-10 Highgate Hill
London
N19 5LW
UK

Tel +44(0)20 8411 6626
Email: r.papadopoulos@mdx.ac.uk