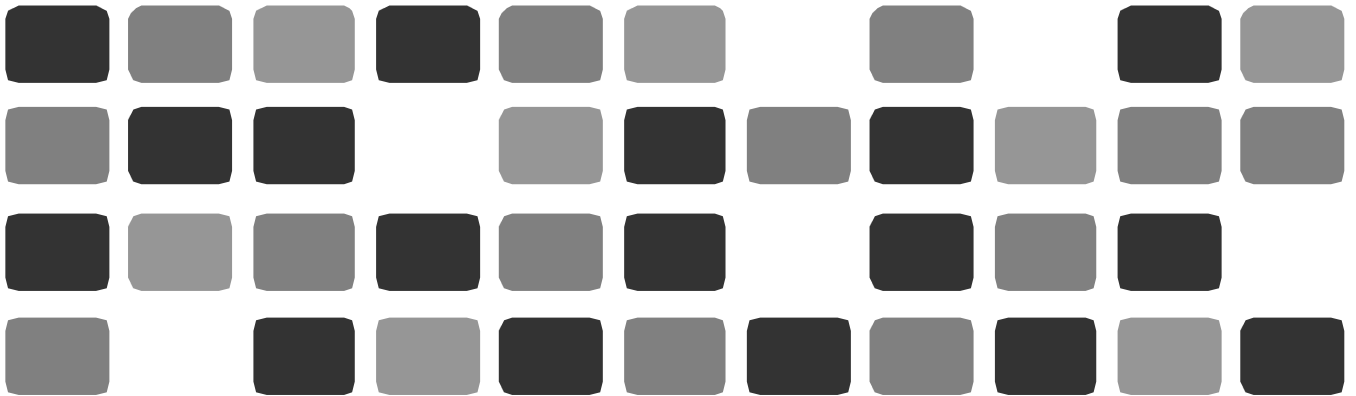# Qualitative research: a vital resource for ethical healthcare

Proceedings of the conference organized by the UK Forum for Health Care, Law and Ethics and sponsored by the Wellcome Trust Biomedical Ethics Programme 20 October 1999, London

Volume 2

The Wellcome Trust

Foreword

This report is the outcome of a meeting which arose when Professor Jonathan Glover contacted Dr Priscilla Alderson. Each had been awarded project grant funding by the Wellcome Trust under its newly established Biomedical Ethics Programme. Both research projects involved using qualitative methods to help inform healthcare ethics. Professor Glover, a philosopher, wanted to learn more about qualitative approaches from experienced practitioners. Rather than hold a one-to-one meeting, it was felt that there might be a general interest in this topic and so the idea of the meeting was born.

The report does not seek to present the definitive story on qualitative research. As the following pages make clear, the very idea of a definitive account is problematic, for qualitative research, its benefits and limits and the choice of most appropriate methods, are the subject of lively debate within and outside the social sciences. We hope it will stimulate further development of qualitative approaches and a wider understanding of them.

The report has been subject to the normal process of peer review. The views expressed in this publication are those of the authors and do not represent those of the Wellcome Trust or any of its affiliates. The Wellcome Trust takes no responsibility for any factual errors in this document.

Information about the Wellcome Trust's Biomedical Ethics Programme and about the awards made under this programme can be found on the Wellcome Trust website: www.wellcome.ac.uk/en/1/mismisethres.html

Introduction

The Wellcome Trust's Biomedical Ethics Programme funds research into social, ethical and public policy implications of scientific and medical advances. The initiative especially funds multidisciplinary research which involves thinking across traditional boundaries between the natural, medical and social sciences and the humanities. In their collaborative work, researchers are examining knowledge from other disciplines and, perhaps more importantly, learning about different ways of collecting and understanding that knowledge. This involves working across further boundaries between pure and applied ideas and evidence, and between research directed towards abstract theorizing and that directed towards informing policy and practice.

One example is the work by the philosopher Jonathan Glover and the psychiatrist Gwynnyth Adshead about the nature of evil and the experiences of people in Broadmoor special hospital. Another example is the research which Clare Williams and I, as sociologists, are conducting with the philosopher Bobbie Farsides on the impact of the new genetics on prenatal and neonatal services around the millennium. We gain immensely from Bobbie's understanding of how our complex and sometimes overwhelming amounts of data can be clarified into philosophical patterns, and Bobbie welcomes the evidence about busy, daily hospital life and dilemmas that we collect.

The aim of the conference reported in this volume was to explore how qualitative social research can be useful in these multidisciplinary initiatives, intended to inform ethical healthcare, and how people who are highly expert in their own discipline might embark on collecting qualitative evidence to complement their theoretical work. Some of the conference papers review theories and methods in social research, but this is not a beginner's guide for social researchers, rather, we aim to assist people who already know a great deal about theories and policies in research. We also hope that the report will be of interest to policy makers, medical journal editors and to people who review qualitative protocols and papers which are submitted to funding bodies, ethics committees and to journals. Some criteria for planning and assessing qualitative research differ from those applied to quantitative research, as discussed in this report.

The conference was organized by the UK Forum for Health Care, Law and Ethics which promotes multidisciplinary discussions. Besides the reviews about ethical research methods, the meeting was intended to interest people who usually do 'straight' ethics or clinical research, to see what qualitative research can offer in terms of opening up new perspectives on their work, and in thinking about the methods and potential problems to avoid. We hope the report will encourage readers to approach qualitative social scientists, to plan joint work which balances and does justice to each of the disciplines involved, and to feel confident that they know enough about key issues in social research to be able to negotiate and achieve this balance.

These conference proceedings are complemented by a shorter exposition of the main issues with additional sections on doing and evaluating qualitative research, also published by the Wellcome Trust. I am grateful to all the conference speakers and attenders, to Bobbie Farsides and Heather Draper of the UK Forum, and Patricia Spallone of the Wellcome Trust Biomedical Ethics Programme for help with holding the conference and producing this report.

Priscilla Alderson

Ethical issues in the teaching of qualitative research method

Mildred Blaxter

I feel a little diffident about speaking today, because I am certainly no ethicist – I do, however, have a long experience of teaching behavioural sciences and their methods to medical and other health professional students, beginning as long ago as the early 1970s, and I thought it might be of interest to consider some ethical problems of qualitative method from this point of view.

It is generally thought that medical and other professional students get a very inadequate amount of teaching about qualitative method, though of course it is increasingly being introduced. In preparation for this talk, I did a survey (neither quantitatively nor qualitatively acceptable!) among the people I knew in medical schools and obtained details from some eight or ten: I was going to provide a quantitative table, but it would really be meaningless since it would neither be complete nor using clearly defined categories.

I will summarize by saying that most undergraduate medical students nowadays are exposed to something called behavioural sciences, or medical sociology, or health and society, or whatever, where they are certainly introduced to qualitative studies – but usually without any methodological or theoretical backup. There is a general view that teaching of qualitative method may be better among nursing or therapy students. In several medical undergraduate courses they do have attachments in the community, or small projects which are likely to be qualitative. However, several of my colleagues suggested that new problems have been raised by problem-based learning methods.

Qualitative methods are, however, very often a part, either as a core methods course or as an elective module, of BSc Med.Sci. courses, or of MSc or MA postgraduate courses in Medicine, Medical Science, General Practice, Primary and Community Care, Health Promotion, Applied Health Studies, Public Health, Research in Healthcare, Sociology of Health and Healthcare. There is an amazing plethora of courses, for which the student groups usually include both doctors and other healthcare professionals. The amount of time devoted specifically to qualitative method teaching in a typical two-year course ranges from two or three hours of lectures to a whole term's course, with compulsory projects. In the MSc or MA courses I myself teach, the student groups include doctors, nurses, therapists, administrators, and people from social science and social policy. I should add that such groups are a delight to teach.

However, the topic here is qualitative method and ethics. It occurred to me that it might be of interest to use my own experience to ask what ethical dimensions there are in the teaching of qualitative method to professional students. It seems possible that the problems which the students have about the method might just have some lessons for qualitative research in general. The first thing that must be said, of course, is that on the whole medical students are interested in, and receptive to, qualitative method. Qualitative method is usually about people, and most medical students see themselves as interested in people. People almost inevitably involve ethical issues. As Williams said in the *Journal of Medical Ethics*:

> 'Students enter the medical course hungry for ethical meat. We give them (in most cases) anatomy, physiology and biochemistry.'
>
> (Williams, 1996)

The attraction of qualitative method applies even more strongly to many experienced medical and other health professionals. Most practice is about talking, listening, understanding; most professionals are happy to say that though their practice is based on and guided by science it is more than that – on the whole they are well aware of the importance of context, the problematic nature of rigid definitions, the importance of exceptions to the rule and the complications that human behaviour and attitudes and beliefs can give rise to.

Tell them about qualitative method and they are delighted to find that like M Jourdain, they 'have been speaking prose all their life without knowing it':

> 'On entering the MSc course, doctors are frequently surprised to find how deeply rooted they remain in the biomedical model they encountered in medical school. Whereas many have intuitively embraced a more bio-psychosocial approach through their working experiences as GPs, they discover with some enthusiasm its theoretical foundations through engagement with the literature of medical sociology and psychology.'
>
> (Calvert and Britten, 1999)

So I suggest that there are really no difficulties in persuading medical students, on the whole, of the interest and importance of qualitative method. However, this is not to say that they have no problems with it. Their problems, where there are any ethical implications, may be a useful way of thinking about qualitative research in general.

Informed consent

A first problem is not really theirs, but mine as a teacher, and it arises precisely out of their professional experience. Let us be generous, and say that most professionals, especially in the health field, honestly and truly have the interests of their patients or clients at heart. They feel responsible for them; they have a special relationship with them. This wholly admirable attitude is precisely why there may be a problem at the very beginning of guiding them into qualitative research projects – a problem in persuading them of the true nature of informed consent, and the necessity for obtaining it when, as is quite likely with these students, they are proposing to do a study among their own patients. The trouble is that they know what the rules are for, say, a drug randomized control trial. The requirements are laid down, codified, enforced. But in qualitative research one is only, they say, talking to people, or observing them, or using written material they have provided. Talking to people can do no harm – have no side-effects. It is no different to what they do across a consulting desk every day. And, more aggressively, these are their patients: in a sense they own them and their records; they already know all manner of confidential things about them; no-one can be forced to talk unless they positively wish to and research nurses or other workers are employed under their direction. The replies we would make to this are probably similar – that 'only' talking may have more effects than they suppose; that the ethics of consent do not simply relate to the legal dangers of being sued for physical harm; that people have rights over their own lives and beliefs and actions and the use that is made of information about them. But the idea that formal informed consent is required from their 'own' patients for a qualitative research study is very foreign to many professionals.

What I tell them – and I am honestly seeking advice about this (am I right?) – is that anything that is done for research purposes rather than in an explicitly therapeutic relationship between individual professional and client, requires informed consent, involving the giving of clear information about what the research is for and how it will be used.

A similar problem, which applies to much student project work even if it is not conducted in their own practices, relates to their customary practice of exchanging information among their own professional group. Thus, I commonly find, they see no ethical or confidentiality relevance in obtaining clinical records before there has ever been a chance to seek consent; in discussing their research subjects with fellow doctors, nurses or therapists; in feeding back information to a colleague general practitioner; or even in being provided with the name and diagnosis or other details of lists of patients. Am I being over scrupulous here in believing that the names of girls who have had a termination, or patients with, say, MS (realizing that I am choosing emotive issues) should not be given out for research purposes without consent, and the fact that the researcher is medically qualified is irrelevant? Of course this position runs me into political difficulties, since it is the senior people giving out the names whom I am really criticizing. Still, I believe students should be

clearly introduced to the standard methods of getting around this, and should be encouraged to consider exactly what rights to information without consent a professional qualification bestows on them.

The professional responsibility

The professional ethos leads to a second area of problems which students have. What should a researcher do if their subjects are distressed, in risk of danger, or need – by their professional standards – some immediate action to be taken? What if they ask for professional advice? After all, much qualitative research is undertaken among people who are ill, in crisis, or in distress. Because it is difficult or impossible to do quantitative, large-sample research among, say, the terminally ill, those with AIDS, or the stigmatized, qualitative research is specially favoured. What should the observer do if situations are seen to be dangerous, services acting in a way which is careless of ethics, or behaviour illegal? Many such problems arose in AIDS research. Qualitative research implies empathy; it is difficult at the same time to stand back with scientific detachment. Where, students ask, does my Hippocratic obligation take over?

My reply to this – and again, I should like to know if it is the correct reply – is that professionals are in fact no different from any other researcher. All of us who have done qualitative research have met situations where, as human beings, we could not stand by, where the risks of not referring someone for some professional action were too great. We do not write about them because of confidentiality. And we are all asked for advice, when the actual giving of advice might ruin the research design and in any case we would wish to avoid being placed in or seen as in the role of the expert.

What I say to students is that on the question of emergency situations, there is no research project that is worth more than a risk to one subject's life or fundamental wellbeing – there is really no contest. If it is necessary, one takes action, and may well as a consequence have to delete that case from the research. Too bad. In cases of lesser importance, compromises may be possible. The intervention can be built in to the research. Or, I remember one study I was involved in concerning the needs of disabled people and service response to them over time, where I made the contract with myself that I would not interfere for six months, except in an emergency, but at the end of that period I would go round every case acting as an adviser and referral agent.

Nevertheless there is a special problem here for professional students of research method. Not only do they have difficulties in shedding their professional skin, they have ethical problems about not advising and interfering. There are, again, routine answers for RCTs (randomly controlled trials). If there are more than trivial side-effects the patient is withdrawn from the trial: ethical actions are codified and built in to the research design. In qualitative research it is more difficult, because there is less risk of actually causing harm, yet by the nature of the research one is more likely to know when individuals are experiencing neglect, distress, deprivation. I am not sure that I am satisfied with my own answers.

Confidentiality and reporting

Other practical problems relate to issues of confidentiality and the writing-up of research. There is a tradition of the case history in clinical and psychiatric work where it is considered quite proper to describe one individual in very great detail. I suppose the position would be that this is usually addressed to colleagues, or printed in the professional press where lay people are unlikely to see it, and (in the medical case at least) objectifies the subject in terms of symptoms, measures, tests, a body rather than a full social being. Anyway, people appear to have no problems about the rules for clinical case studies. On the other hand, in relation to quantitative or experimental research, they are used to standard information and consent documents which offer complete confidentiality: data will be used only in aggregate form, no individuals identified, and so on.

As a result of these two rather contradictory practices, students either tend to be very careless or else over-

anxious about confidentiality. For example, with a small sample, they may want in their write-up to give a table listing all the relevant social and medical characteristics of each subject, which even if no names are given makes them instantly identifiable to their doctor or anyone else involved with them. Alternatively, students may go to the other extreme and worry about qualitative research being impossible because of confidentiality problems. Again, my own practice is to emphasize that the researcher had a contract with subjects. Absolute confidentiality, that is that no subject would ever be written about in a way recognizable to their family, colleagues, doctor – or to themselves – is rarely a possibility. Verbatim passages are often being used, and of course people can recognize their own words. To say that the material is being printed only in confidential reports or in academic journals which subjects are unlikely to see is to my mind not enough: there is some sod's law, of which I could give endless personal examples, which ensures that the secretary who types the paper recognizes her aunty, or the voluntary group with an interest in the topic gets hold of the academic paper and circulates it to their members. One way in which it is quite common for sociological work to cope with this – if it matters – is to alter unimportant details of research subjects. This, I find, is a problem for professional students, brought up in scientific method to believe that altering the data is a mortal sin.

I said 'if it matters', and there are situations where one would not wish subjects to read what one has said about them, or what their doctors or spouses or colleagues have said. The ethics of using potentially harmful or distressing data is tricky. But on the whole I believe that professional students should be told that one would have to have very strong reasons indeed for using any data that you would not want the subjects to see.

The approved way of dealing both with the confidentiality question and offering evidence of the validity of the analysis is respondent validation. One is not of course suggesting that the analysis is to be fed back to respondents in exactly the same form that one would finally use for reporting or publishing, but at least they are given the opportunity to correct the researcher's mistakes or misinterpretations. Any of us who has seen a verbatim transcript of our own contribution to an interview or discussion will be aware of how entirely possible it is to say things one does not mean, give a quite false impression, and so on.

I find this is problematic for professional students. Altering data posthoc is to them an ethical question. Trying to represent truly what the subjects of research want to say is also, to me, an ethical question. Of course, subject validation is not always possible, and it depends on the type of research: in conversational analysis, looking at every word of taped interactions, the words are objective data and cannot be changed. And in other types of research, one might be interested precisely in what was at the front of people's minds, what their instinctive expressions and situated opinions were rather than their considered thoughts. Much of focus group work is of this sort, though the method is often used improperly. However, some sort of subject validation of the actual analysis is usually still profitable.

Evidence and subjectivity

This raises the last problem I discuss: issues of evidence and what we mean by the truth of data. The subjectivity of qualitative data gives rise to contradictory responses among professional students. Some say there is no proof that this is really what people think, or do, or that the researcher's analysis is correct: the whole enterprise is 'only' subjective. Others assume there are methods of analysis which enable us somehow to know what is the 'truth', that there are equivalent, though different, methods to those of scientific measures.

One of the colleagues I surveyed noted that in his experience students tend to select for their projects the qualitative method they feel most at home with – face-to-face interviews or focus groups – and then run a computer package over the data set and produce an answer. The whole process of doing research thus seems to be little different from doing a quantitative survey, running SPSS and producing the answers.

I have said that health as a state of subjectivity, rather than an observable condition of the body, is not a terribly foreign notion to most health practitioners. Yet, when they come to think about research rather than practice, their education in scientific method tends to take over. I would not wish to get too precious about this: as Harding and Gantley suggested, it is arguable whether health service researchers could, or even should, adopt the same epistemologically informed approach to qualitative research as, say, sociologists. But, they suggested, they should at least be taught to avoid too simplistic an approach:

> 'To treat what people do and say as self-evident, without a theoretical framework in which to interpret facts/descriptions, reduces the power of subsequent analysis to little more than accumulated accounts of common sense...the question becomes, not simply what pattern can be discerned from people's narratives, but why this pattern and not others?'
>
> (Harding and Gantley, 1998)

Another aspect of this problem is the definition of research, in quantitative/scientific mode, as something which is done by the expert to a passive or objectified subject. It requires a shift of perspective to acknowledge that the participants in an organization being studied, the authors of documents being analysed, the lay people, whose attitudes or experiences being described, may be experts in the data and their own knowledge, and may be able to offer corrections.

Evidence-based medicine is not something I would wish to say much about, since it is going to be more expertly discussed later. However, the idea that what qualitative research can show about what people know, think, or experience is also evidence, is something I and others have argued for years. But if we have not yet been able altogether to persuade 'nice' people of this, it is not surprising that professional students sometimes have difficulties. Not always, though – once one has got over to them the idea that qualitative research is always context specific, and simply a different way of getting at a different truth. As Judith Green noted in a case study of Accident Alliances:

> 'The only participants to unequivocally regard RCTs as good evidence of effectiveness were academic researchers and public health professionals.'
>
> (Green, 1998)

Conclusion

What I have been doing here is really just airing my own problems, and I am sure others will have their own solutions. I hope at least that some topics for discussion have been raised. I should really like to conclude with a plea for some sort of formal document or protocol about ethics in qualitative research. Of course it should not be, could not be, too rigid or prescriptive. But the fact that there are such rules laid down for experimental or biomedical research is part of its legitimacy. The fact that rules may apply in different ways in qualitative research, but there is no formal agreement about them, harms the legitimacy of the method and makes teaching it more difficult.

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Discussion

Comment There are many kinds of participation and sometimes there is no proper participation by research subjects, such as in covert research. Today, we would not accept covert research as ethical, but that would rule out a lot of important anthropology and ethnographic research, in remote villages in Africa, for example, about having a village meeting and crossing cultures. Surely covert research is all right if it adds to knowledge and does no harm? How can we convince people that no harm would come to the subjects?

Response Presumably, they know they are being studied and questioned. I think this kind of observational research is a little different from ethnographic research on, say, the cultures of drug users, when it is extremely important to get informed consent. It is also useful in such circumstances to have a third party to request the consent or to act as witness.

Comment A bigger problem in healthcare is incompetent patients, when you want their views for research. How to get round that one?

Response If they have intelligible views, then presumably they can give consent, including children, and researchers need not rely on proxy consent.

Comment With research in psychiatric settings, such as about how people react to the staff, some of them might not be aware enough to give consent.

Response As far as is humanly possible, we should be seeking consent. We might be finding things of great value on occasions when we are not able to gain full consent, but we must assure full confidentiality. Is there a way of drawing a boundary and balancing the interests of the subjects and of the research? One way is through contact with the subjects so that they know about the use that is being made of the research. In organizational research, people may eventually veto your reports, and you have to respect that decision, although you may try to re-negotiate it. This is politics rather than ethics. Top people in organizations give permission for the research, and they may tell the lower people, and may inform them but not ask for their consent. So is it necessary to try to get consent from everyone, all the way down the hierarchy, and at every meeting or observation. This may be impossible. I find this troubling. Yes, probably everyone knows at one level that you are researchers, but are they aware of what you are researching and about your aims and intentions? There are so many partly conflicting pressures in research.

Comment Can we hear more about formal documents and guidelines about ethics and standards in qualitative research?

Response The British Sociological Association (BSA) asked me to convene a Working Group which produced criteria for assessing qualitative research. It took two years to do, for it was hard to get researchers to agree. Everyone has different ideas. Each person feels strongly from their own position, and they may have no idea about what other people believe the rules are. The position is different in medical research where the ethical codes for RCTs are clearly agreed.

Comment Don't other codes already cater for qualitative research? Is it so different in its ethical rules and principles? Qualitative and quantitative research overlap, so should research ethics committees apply different rules?

Response Yes, but research ethics committees may try to apply RCT rules to qualitative research, and they are not the same. The Economic and Social Research Council (ESRC) now have a qualidata archive, which raises questions about how we can get the consent of people not only to take part in our research but also for their verbatim histories and responses to be archived for other researchers to use in future. There are three

levels of consent here: to take part in the research; for the data they give to be published; and consent to secondary analysis. This is very different from the archiving of statistical data.

Comment There is also the problem of over-rigorous ethical standards, so that researchers are unable to collect or publish evidence, and people cannot or will not agree to be observed. There are the further questions about evidence and trust. Do you impose or project a pattern, as a researcher, or see one that is already there, when you analyse interviews? Could you give us some instances?

Response There are all sorts of methods of showing that you are approximating to a truth, but the essential point is that there are many truths. When I am introducing medical students to qualitative research, I talk about Derek Jarman's film *Blue* and I show them a blue acetate, and another acetate with the simple wavelength for the colour blue. I ask them which of these two is the true description of the phenomenon, and it seems to be a good way of getting the point over to them: they agree that both are 'true', and neither is the whole truth. Understanding of reality has to be linked to some kind of theoretical analysis. The theory you draw on can differ, but within that framework you can justify whatever pattern that is there. You must also point to negative examples, to show how reality is contingent. As far as students go, and in health services research, we don't need to be too esoteric about trying to find some absolute definitions of truth, as long as research is more than just picking pebbles off the beach.

Chair There are also differences between objective criteria and measures of colour. I'm slightly colour blind and I agree there is no one way of measuring it. But, for example, I am trying to find in people with antisocial personality disorder whether they lack moral capacities, such as empathy. I worry that I may not be getting even to the level of one of the state of affairs of truth, but I'm just imposing my own views.

Response You could get more than one person to check the data.

Chair Then that might just be two inter-subjective views. Thank you for raising these important issues.

Changing perceptions on the politics and ethics of qualitative research

Paul Atkinson

My credentials are that I trained as a social anthropologist. Then, instead of travelling to somewhere exotic, I spent two years with medical students at Edinburgh University, observing them in teaching and clinical areas. Since then, I have conducted qualitative studies of haematologists in the United States and the United Kingdom and of British geneticists. With Angus Clarke, a clinical geneticist, I am working on one of the Wellcome Trust Bioethics and Genetics projects. I am also carrying out an ethnographic study of the Welsh National Opera Company.

I have a friend who used to live in Florence – lots of friends would visit him and say, 'Can we do Florence in a day?' He would say, 'Yes.' 'Can we do Florence in a week?' 'Yes.' 'You've been here for ten years, so you know it very well?' 'No, I don't know it very well at all yet.' We know things at different levels. So in the course of this brief presentation it will be necessary for me to make a number of assertions rather than engaging in detailed argument. I'll assert some ideas, and over-simplify them rather than demonstrate their meaning.

I will talk about two things which I hope are of relevance to qualitative research and to beliefs, values and ethics. First, I shall make some brief suggestions concerning the relevance of contemporary qualitative research for the investigation of beliefs, values, rules and ethics. Secondly, I shall say something about the ethical perspective of qualitative research itself. And I shall preface both these with some very general remarks about qualitative research. I hope to reinforce rather than reiterate what Mildred Blaxter has said.

Qualitative research

The growth and spread of qualitative research is gratifying and intriguing to those of us who work in ethnographic and cognitive approaches. From their origins among sociologists and social anthropologists, ethnography and cognate research approaches have spread into many disciplines and substantive domains: human geography; discursive psychology; oral history and life history; cultural analysis; health research; nursing research; evaluation studies; organization and human resource studies. These and others like them have benefited from the incursion of qualitative research over the past two decades. Those of us who have had some role in these developments can only welcome them – if only because they create for us new audiences, new partners and new readers for our publications. But we need to be cautious. This is a gift horse that repays some inspection.

I think that there is a danger of treating qualitative research as a substitute for disciplinary knowledge and understanding. Qualitative research – for all the enthusiasm of some converts and proselytisers – is not a self-justifying activity. In and of itself, it is not a research paradigm. It does not substitute for disciplinary or theoretical ideas. I don't think this means that only paid-up sociologists and time-served anthropologists should be let loose to do the research. But I do think that research methods are empty in and of themselves. Without productive and appropriate ideas and theoretical perspectives to drive them, no particular research methods alone will support or sustain significant research programmes, nor will they generate systematic, cumulative knowledge about the social world.

The use of qualitative research methods can often include the collection and interpretation of language and the use of language data, for instance: in primary care consultations or presentations; in multidisciplinary team meetings; in clinical case conferences and rounds; in counselling or therapeutic encounters; in emergency room settings. The list can be expanded to include any and every form of social encounter. To

study language in a hospital, you need several weeks to look at lots of qualitative research which includes tape or video recordings of social interventions in naturally occurring settings, team meetings, case conferences, ward rounds, counselling, and clinical sessions. And the search for these cannot be approached naïvely, although it often is. Understanding the context and organization of, for example, the clinical encounter is important. Now language has its own intrinsic forms and organizational features. These are not learned simply through a lecture on conversation analysis. In the absence of systematic knowledge, the collection and inspection of language data can be quite futile. Of course, there are different analyses to be performed – conversation analysis, discourse analysis and narrative analysis being among them – but these are well understood methods. In the total absence of disciplinary and methodological expertise, the naïve researcher is likely to produce nonsense from the data. Researchers who come to qualitative research are short circuiting it if they don't know how to analyse language. They will reinvent the wheel, but not properly. It is no use adopting a method without understanding the background. It is like my saying to Angus Clarke (a clinical geneticist), 'I'll just do a bit of DNA sequencing using some kitchen equipment.'

The same is true of the collection of data from interviews, and the way people think that doing an ethnography means doing interviews. A great deal of qualitative research is based on a restricted palette of methods and data, and much is based on interviewing. A lot of what passes for cultural understanding does not allow for how complicated it is to collect and analyse interview data. It isn't just about getting people to talk about their experiences or their beliefs or attitudes. It certainly isn't self-evident that you can or should treat interview data as unproblematic, as transparent productions of informants' private experiences, or as proxies for what informants and others actually do. You can't get direct naïve access to people's private thoughts in an unmediated way. You have to analyse interviews as speech acts, to see how people enact memory and accomplish performance. I don't think interviews can give you access to people's private inner thoughts.

Equally, uninformed observation of social settings is useless. It is important to document how the ordinary and the mundane are sustained by social actors. For example, I just love watching what people do at opera rehearsals. Sometimes I get comments about my research being a convenient excuse for enjoying opera without having to pay! Yet, without a theoretical interest and a disciplinary view, without guiding ideas, I'm wasting my time; nothing is likely to come of it. Researchers are expected to be enquiring and open-minded. But there is a world of difference between an open mind (which I regard as a good thing) and an empty mind (which I don't). With the latter, you are likely to end up with an empty notebook.

So, if some disciplined understanding is vital, what does that amount to? Well, clearly I am not about to recapitulate all of sociology, anthropology and linguistics here, and it gets very hard to distil a single set of guiding principles. But I think that a rough approximation can be made, which simultaneously sets the agenda for qualitative research, and for the systematic study of practical ethics.

I therefore take it that the following propositions are in some ways foundational or axiomatic.

The commitments of interpretive social science

Though by no means random, the ordering of the following propositions is not intended to imply any strong patterning, and no priority or logical entailment is intended.

- Social life is possible because it is meaningful. Social actors engage in their everyday lives and interact with one another in the light of those shared meanings.

- Social life is symbolic, in that it is conducted through language and other systems of conventional representation.

- Cultures are highly variable, and are locally produced through the varying knowledge and skills of social actors. We all produce and reproduce our social lives. You can't just read off culture in a

general way.

- Social actors are highly knowledgeable and skilful. They have extensive repertoires of practical, often tacit, understanding, and practical methods to get things done.

- The moral order is pervasive. While we are not mechanistically rule-governed, we orient our actions to shared systems of rules to ensure that everything is done in accordance with rules and conventions. We justify action through appeals to rules. These are enforced in many ways, through sanctions, and through the repair of rule breaking. For example, to save face, we are constantly constructing ourselves as moral agents who are more or less competent. We demonstrate how we are in control of our self and our body. An example is a man who suddenly remembers that he has left something at home and turns back to fetch it. To demonstrate that he is rational, and not randomly changing direction, he will go through certain behaviours such as clutching his head to indicate having a new thought or memory. (The point was illustrated dramatically.)

- Selves and identities are socially, collectively, and continually shaped and reshaped. Institutionalized rites of passage shape and mark actors' moral careers.

- Social life is a matter of process rather than of fixed, determined entities and structures. Meanings and identities are in constant flux, constantly re-defined and re-understood.

- Natural and cultural phenomena are interpreted in the light of cultural categories, which are themselves under-determined by the natural world.

I think these are the kinds of ideas and commitments that should inform qualitative research. Clearly, one can go on modifying or adding to or arguing about any of these. Nevertheless they give us a start. I think that they imply the following kinds of methodological commitments. We need to treat seriously the knowledge and skills of ordinary social actors, and examine their everyday commonsense knowledge and beliefs, which are recipes for action – their methods for getting things done. These constitute the primary subject matter for sociological or anthropological research. Here, of course, 'treating seriously' does not necessarily involve subscribing to them, or being persuaded by them, or 'going native'. Equally, however, it does mean avoiding an interpretation of everyday practical reasoning about people's accounts which searches for deficit. Analytically, we need to use the principle of symmetry, which means analyzing medical, 'official' or 'expert' knowledge and 'lay' knowledge equally attentively, and not denigrating either. We cannot exempt, say, 'scientific' knowledge from social analysis, and regard it as 'given' or unquestionable, while devoting analysis to the social contexts of 'lay' knowledge. Too often, accounts of public understanding of science are presented as public misunderstanding, for instance. To contrast 'expert' professional knowledge with 'lay' belief is to bypass the analytic issues about what counts as knowledge and how it is produced.

Equally, we need to pay close attention to the ways in which social actors accomplish and perform their selves and their collective actions. This requires close attention to the local production of culture and social organization. Social contexts, and the study of social action *in situ* are of fundamental importance. The close observation and documentation of local action is a *sine qua non.*

Now it seems to me, therefore, that it isn't just the methods of data collection that render them significant for social research in general, or for research on healthcare and bioethics in particular. The broader commitments and the intellectual traditions that underlie them provide the major impetus.

And they are significant. For a programme of empirical research on medicine and society, with a major emphasis on bioethics, the issues I have summarized are entirely appropriate. The issues include understanding the processes of practical decision making and practical reasoning in context; the use of medical technologies in diagnostic inference; lay reasoning and practical action; the division of labour within and between other specialisms; the rhetoric of persuasion and legitimation; the discourse of clinical encounters; the micro-politics of professional work; the social production of expert knowledge and how it is used and understood. All these can be explicated through empirical research.

The ethics of qualitative research

If we believe that qualitative research methods, and the intent behind them, are of profound value in researching everyday life, practical reasoning and practical ethics, then the ethics of qualitative research also deserve some attention. Please note that I make no special plea to the effect that qualitative methods are in themselves especially ethical, or politically more desirable than any others. Indeed, they can clearly pose their own problems of access and consent. Rather, I want to make some brief observations about changing emphases in the ethics of qualitative research.

At one time, the ethics of field research could be regarded as fairly straightforward in principle, if sometimes hard to practice. For instance, in 1967 Howard Becker asked rhetorically, 'Whose side are we on?' His interest was about 'taking sides' not just in terms of crude partisanship in research, although his work has been read in that way too. Becker was – quite reasonably – referring to the methodological need to apply the principle of symmetry between all the actors' perspectives. The perspective of the 'underdog' should be respected and treated with the same analytic seriousness as the 'official' or 'mainstream' culture. Shirley and Edwin Ardener (1972) proposed a similar view. They drew attention to the significance of what they called 'muted groups', saying that the majority of anthropological accounts were implicitly reflections of dominant models and perspectives, constructing an unduly homogenous view of cultures. We need to identify muted groups, to note their models and the way they can transform mainstream culture.

Worries about the legitimacy of covert research have been mentioned. It is extremely difficult to know, during research processes, what issues are going to occur. The ethnographer is often in a subservient position. I have done research, which in retrospect seems deeply unethical, when I was the tool of other people. Sometimes I could obtain informed consent from clinicians and medical students but not from patients. If you're walking along with students and a surgeon, and you all go into the ward, the surgeon says, 'Good morning,' and pulls back the bed clothes, adding, 'What is your opinion of this scar?' You can either stay, or leave and not do the research data collection. You cannot say, 'Wait a minute, I've just got to ask for this patient's informed consent to my presence here.' Relations with people when you have the time and opportunity to inform them are relatively unproblematic.

These kinds of views have been given further and renewed currency in recent years. Numerous political, cultural and ideological influences are transforming the very nature of qualitative research and how we think about research itself. Edward Said (1978) said that Orientalism and western science appropriate and interpret other cultures and see the 'other' as exotic and alien. In this time of post-colonial scholarship, we're crucially aware of the relationships of domination and subordination that lie at the heart of traditional research between anthropologists and sociologists and the objects of their observations: post-colonial scholarship has called into question the relationship between the observer and the observed.

Likewise, feminist scholarship has helped to transform fundamental ideas about the complications of the nature of authority in relationships between the researcher and the 'other' who is the subject/object of research. In the United Kingdom, Liz Stanley and Sue Wise (1983) have captured and informed this strand of methodological and ideological awareness. More recently still, a broader agenda of gender studies has raised questions about theories we once took for granted, and I think more attention is paid now to the ethical and political relations between researchers and subjects.

There is also the rediscovery of rhetoric in the human sciences. It is no longer seen as mere rhetoric but as a powerful way of understanding how we persuade one another of what we do. This has made a profound impact. Analysis of rhetoric shows how scientists and social researchers construct cultures, social settings, social actors, texts and accounts. With considerable impetus from cultural anthropologists in the United States, many scholars have contributed to a so-called 'crisis of reproduction'. The text embodying a single authoritative voice, and reflecting a single perspective or gaze has increasingly been seen as problematic. It is a revolution, with powerful implications about how we research the social world and how we write about it. The descriptions and accounts we present are not just about studying language, but are about critical reflexive understanding of our own use of language.

Traditional polarities between researcher and researched, between observer and observed have been thrown into sharp relief. They have also been undermined to some extent, by anthropologists working 'at home' rather than among overseas and exotic societies, and by the activities of 'native' or indigenous anthropologists. This newer knowledge is more complicated than common understanding when Becker was writing about power relationships. The conduct of research and its representation could be treated then as relatively unproblematic. Ethical dilemmas in fieldwork, enshrined in standard works about methodology, were certainly identified. But they were couched primarily in terms of covert versus overt research, the ethics of access to research settings, or when one's problems and findings were emergent phenomena. Once access was granted, once consent was negotiated – however provisionally or precariously – then the conduct of research, the analysis, and the written monograph could all be regarded as more or less straightforward.

The crucial difference between a generation ago and now is that the methods, the analyses, the construction of research texts are all subject to critical scrutiny and moral reflection, in the world where researcher contact with our research hosts is morally more complex than we recognized decades ago. There is no homogenous field of culture. There are different meanings and degrees of power, multiple voices and fragmented perspectives, each clamouring for attention. The researcher's formerly privileged enquiry has been replaced by a more tentative series of dialogues with others. We can no longer speak for an entire field with one voice. If we are not to be discredited, then we have a highly problematic obligation to negotiate between different perspectives, aware of changing moral and political contexts. The texts we write may become more 'messy' and multi-layered. By no means all research has become so muddled and complex: many people proceed with little or no reflection about anything, of course. But one cannot embark on a consideration of qualitative methods for social research without some awareness of the changing ethical and moral contexts of that research tradition itself.

Finally, some of these issues are conventionally ascribed to 'postmodernism'. In some ways this is a handy label for them, but it is quite misleading in a more profound sense. I don't think that postmodernism adds anything to what we have talked about. It is a slack way of alluding to these ideas which have already been well discussed at the heart of many ethnographic and other qualitative research texts for nearly a century, though they have been given renewed force and currency in recent years. The very best practitioners always knew what they were doing – the intellectual elite. To some extent, literary interpretation has been similarly hard disciplined, but social enquiry is more complicated than literary analysis. It is important to recognize that qualitative research is not a set of off-the-peg methods. The methods have long traditions and changing insights, although these are not impenetrable or secret or arcane, and they are worth engaging with.

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Discussion

Chair You leave us slightly daunted by the complexity of qualitative research.

Comment Your lecture was incredibly interesting. As a philosopher I am working in partnership with sociologists on ethical quests to explore inter-connections between disciplines. But a problem with the context you speak of is how we can understand representations, interpretations and constructions. What about moral truths? Can we fit a bioethics approach with skilled qualitative research, or is that just a mismatch?

Response Interdisciplinary work isn't easy. A BSA and health economists joint conference years ago was a nasty business. I gave the opening keynote address for the sociologists, and an economist gave another keynote address. It was a non meeting of minds. Were we all charlatans? We criticized their nonsense dummy models, and they could criticize us similarly. But instead of this negative interaction, we could look at how we engaged with one another, at the processes of reading and misreading. We would start with the same empirical phenomena, and end up with different perspectives. I have no problems with this kind of dialogue. It is not a question of 'keep off my patch'. But if a philosopher wants to say there are moral absolutes that would be difficult. But if you want to see how notions of moral absolutes are played out in a clinic or a rationing meeting, and how these are not done in clear actuarial way then, for example, we can see how people talk and persuade each other about what is the truth, what is proper and reasonable. Philosophers have interesting things to say about all these issues, and about epistemology. A radically different vocabulary is not necessarily a barrier, as long as we can share discussions.

Chair Some social science reports are a bit subversive about the belief systems of the people being studied. For example, researchers who went into psychiatric hospitals with false diagnoses and pretended to be patients. That study is likely to call into question professional psychiatrists' belief systems.

Response I can't comment on that example because it is too long since I've read it. What do you mean by subversive? If you start by assuming scientific discoveries are special, and then you demonstrate that they are subject to the same arguments and challenges that other knowledge is subjected to, then you could look subversive. But you could start by thinking that social and scientific discovery are themselves social processes which are culturally influenced. For example, replicability is taken as a sign of scientific rigour. Yet you can see in detail how each replication of certain experiments is subject to interpretation and argument as to whether it counts as genuine replication. An example is Henry Collins' work on gravity waves. Collins shows how the research community originally tried to test Webber's claim to have detected gravity waves. They didn't believe in gravity waves and interpreted their failure to detect them as undermining Webber's claim. He, on the other hand, claimed that they hadn't performed these experiments adequately. After all, you would normally know if equipment was sensitive enough or well enough calibrated if it successfully detected or measured something. If you don't believe the phenomenon exists then it becomes very tricky. Now, people do expect to detect gravity waves and are genuinely trying to replicate

the original experiment. But the point is that the logic of scientific discovery is actually dependent on scientists' expectations, matters of trust and plausibility. In this case, replication means 'when enough serious people agree that it has been done' and not that the same results are obtained every time. This is like any other human activity and can be observed as a process of belief and disbelief and persuasion, out of which comes useful knowledge. There are similar social influences on qualitative and quantitative research methods, but you don't seem to have the same critical challenges to social and health economics research methods. Perhaps I was rather over-stating the point, but yes, I would treat social, scientific and medical knowledge as symmetrically as I could. I have, for instance, written on the rhetoric of ethnography and how we construct our own discipline (e.g. Atkinson 1990, 1992).

Comment I'm a medical researcher. Why don't patients make the decisions we think they should make? But that means we want to change their behaviour, so they do what we think is best for them.

Response I'm not involved in that kind of policy therapeutic intervention. You want to find out why people don't do what you want them to do. If you start from asking, 'Why do they do what they do?' then it is possible to establish a sounder dialogue with social researchers and a basis to understand the patients' rationality. It is too easy to slip into the deficit model and to assume that patients are ignorant or irrational.

Comment Yes, it worries me that we try to change them by using our research about them.

Response Qualitative research is not an argument for letting people just get on with things in any random way. I think you have to crack the assumption that you know what they want to do. There are rich folk anatomies, physiology, oncology, mathematics, probability understanding, risk assessments and so on. They need to be taken seriously.

Comment Well informed people with high risks still refuse certain treatment. We want to see why, to persuade them to have this test.

Response If you are a geneticist, I think you have a perfectly legitimate desire to change people's behaviour. But in a research context, we, the lay public, can be well informed although we may use our information and beliefs and feelings in different ways. Evelyn Parsons found that women's understanding of genetics risks translates percentages into categorical and not ordinal data. The women were given interval data to translate into ordinal – high and low – risks. They turned these into categorical ones, such as 'I can't have children' or 'I can't have boys'. Misunderstandings can arise when doctors and patients each assume that the other shares their own understanding.

Chair It is good that the Wellcome Trust has this new interest in biomedical ethics, and is drawing disciplines together. Patricia Spallone is going to tell us about the new Biomedical Ethics Programme.

The Wellcome Trust programme and 'evidence-based' ethics

Patricia Spallone

The aim of this talk is to set out some ideas about the value of qualitative research in the context of the Wellcome Trust's Biomedical Ethics Programme. I will have to cover many issues briefly, and this talk will be like seeing Florence in an hour. I will first talk about the scope of the Trust's programme, and then raise some points about qualitative research based on our experience over the past year and a half, and talking to researchers such as yourselves.

New directions in social, ethics and public policy research
The Governors of the Wellcome Trust decided in June 1997 to fund a programme to support research into the social, ethics, and public policy aspects of biomedical science, principally in two areas – neurosciences and genetics. This represents a new area of research funding for the Trust: part of its response to the wide recognition over recent years that advances in biomedical science raise questions of ethics and of social import which require careful examination, and in some cases, suitable regulatory supervision.

With this in mind, the objectives of the programme are:

- to support research of timeliness and quality;

- to enhance national research capacity;

- to ensure, so far as is possible, that research is relevant to public policy and that the results of research are efficiently communicated to those making public policy.

I will return to the point about relevance to public policy later in this talk.

The components of the programme are a scheme of research grants, studentships and fellowships, and other activities to support researchers. It became clear during the planning of the programme that research funding alone in this emerging area of work was not sufficient. Researchers need other kinds of support to ensure that networks of information and people are created. This conference is one such effort.

One of the underlying assumptions was that some lines of research are already well covered by medical ethics, health services research, and health economics. The programme aims to go wider, to include concerns of social cost and cultural impact, particularly for problems which arise from high specialization in science and in medicine. One example is 'genetics and intelligence'. Research might rightly approach the issue by examining potential harms to specific individuals who are immediately and directly affected by the research and practices which might arise from it. But there are also wider concerns about how such developments change society and relationships, or affect children's lives, and what uses are made of them. Social sciences offer methods of tackling the social context of biomedical advance. This isn't to say that there is a stark contrast between methods which tackle the individual and the social. (Meg Stacey and colleagues eloquently characterize how social science is concerned with both individuals and society in the introduction to *Changing human reproduction*.)

The research effort which the Trust is trying to encourage does not define the disciplines and methodologies to be employed in advance. The field of study is by definition multidisciplinary. It benefits from employing approaches and concepts from disciplines ranging from law, through philosophy to medical sociology and social anthropology; also incorporating social studies of science, technology and policy. Thus the programme places priority on:

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- multidisciplinary research in this multidisciplinary area, and;
- factual investigations and qualitative research.

I should stress that while collaborative work is encouraged, it is not an essential prerequisite of funding. The crucial point is to increase mutual trust and understanding among disciplines: the medical, scientific and social sciences; the humanities; also of the perspectives of patients and their supporters, the many 'publics'. Genetics and neuroscience are changing, and society is changing, and researchers need to be cognisant of these.

Emphasis is placed on research which is practical and empirical; not least because this kind of work may speak to public policy considerations. In other words, the gold standard is not the randomized controlled clinical trial. This is reflected in the membership of the independent panel of experts who consider the grant proposals, none of whom comes from the medical or physical sciences.

The members of the panel (called the Medicine in Society Panel) are:*

- Arthur Lucas, (Education) Principal, King's College, London, Chair

- Anthony Tomei, Director, Nuffield Foundation

- Albert Weale, (Political Theory) University of Essex

- Marilyn Strathern, (Social Anthropology) University of Cambridge

- Steve Yearley, (Sociology) University of York

- Sandy McCall-Smith, (Medical Law) University of Edinburgh

- John Durant, (Public Understanding of Science) Imperial College, London

- Mike Kenward, (Science Journalism) The *Independent*

The Medicine in Society Panel represents expertise in the social sciences and humanities disciplines. It specifically includes public understanding of science because the Panel considers grant proposals for social and ethics research as well as applications for funding of activities and grants in the public understanding of science. Support for social and ethics research is part of the Trust's wider Medicine in Society Programme. The Biomedical Ethics Programme works alongside Consultation and Education, which is involved in broadening out the debate to the public.

Grant proposals are considered in the usual way. They are sent to referees in the academic community for review, and then to the independent Medicine in Society Panel.

The role of qualitative research: issues and examples

Crucial to the Trust's programme is its interest in supporting high quality empirical research which identifies real problems and poses practical research questions. Some of the public policy debates recently have tended to focus on broad issues, declarations of principles, and anecdotal evidence (as happened with cloning).

In some cases, advisers themselves are calling for empirical evidence to inform their decision making. An example is in the Department of Health's recent report *Surrogacy: review for health ministers of current arrangements for payments and regulation*. Their final report raised the issue of the lack of social research to aid policy makers: the review team said that they encountered a problem in the 'relatively limited amount of hard evidence about the incidence and nature of surrogacy arrangements'.

* Members of the Medicine in Society Panel at the time of the conference (membership has changed since this paper was delivered). Members normally serve for three years.

Similar comments have been made in the report *Human genetics* by the House of Commons Science and Technology Committee in 1995; by the Human Genetics Advisory Commission in its report on insurance, and by individual members of the Commission in lectures and public presentations.

Awareness of the value of empirical work is occurring in academic work devoted to ethics applied to medicine. Tony Hope, in an article in *Journal of Medical Ethics* (1999: 25), makes a case for empirical medical ethics, arguing that medical ethics is sympathetic to empirical issues, and acknowledging that medical ethics has been shaped by empirical facts. So does Dan Callahan, 1999. This marks a different approach to the earlier Warnock Committee of Inquiry into Human Fertilization and Embryology (1982–1984), which relied on responses to its own consultations and philosophical argument. The general point is that there are social and political dimensions to medicine, science and morals. This may sound obvious or even mundane to this audience but much of policy making and decision making has relied hitherto on universal or unsubstantiated claims.

The question that remains is: How do you 'get' from such evidence to policy? The Trust's support for social and ethics research on biomedical science emphasizes relevance to public policy, including empirical research relevant to policy considerations. But what does this mean? What is social evidence? What does public policy need to know from research? What kind of research is relevant?

The insistence on relevance recently has led to some vapid research. Certainly, there is a sense that the emphasis on relevant research in the natural sciences has distracted science policy researchers, politicians, and commercial companies for the past two decades. We do not expect to produce a neat and tidy definition of relevance for social and policy research on biomedical science. What I would like to do is to use two illustrative examples of excellent empirical research which demonstrate different kinds of relevance.

Can policy relevance ever be asked for? Priscilla Alderson's work on children's consent to surgery, and on proxy consent, is a notable example of where relevance can be asked for. The work is described and designed to have relevance to a particular policy question, or more accurately, a set of questions about consent. In *Choosing for children* (1990), the result of research into parents' experiences of giving consent to high-risk medical treatment on behalf of their children, she writes:

> 'Instead of starting with a theory or history of consent, or a model drawn from law or ethics, I tried to see the families' experiences through their eyes. It soon became clear that some of their concerns are missing from the consent literature, such as how families come to terms with painful realities, how they connect medical decisions with their daily lives, how they cope together during surgery and with whatever the future might bring, and how they give voluntary and proxy consent.' (p.11)

Besides interviewing parents and the medical professionals, Priscilla Alderson looked at the consent process – the procedures in place in the wards and the professional team work. She found that parents' ability to give consent is affected by the way hospitals are organized, and by hidden factors such as accommodation – or lack of adequate accommodation – for parents whose children are staying in hospitals far from home. At the same time, she revisited issues debated in medical ethics: information, voluntariness, trust; writing in language which everyone can use. The results of the research were written for a wide audience: medical professionals, medical ethicists, parents, anyone wanting to engage in debate and discussion.

Relevance can be asked for, as with this work, where the field is small, well defined and self referential, as Marilyn Strathern (personal conversation, 1998) pointed out to me. One of the things which the Medicine in Society Panel has been finding over the course of the funding programme is that research questions in grant proposals were much too broad in an attempt 'to try to fix the world', and they made inappropriate claims to

policy relevance. Good empirical research is small scale and builds up over time.

My contrasting example is the work that began in 1983 (in the USA) of the social anthropologist Rayna Rapp on antenatal genetic counselling. Rapp was interested in the social impact and cultural meaning of antenatal testing, and set out on an anthropological analysis of antenatal diagnosis. She wanted to query the experience of pregnant women from diverse backgrounds: what they do and don't want from genetics tests; how they and their supporters understand childhood disability; what a fetus is, and what might be the worth of abortion. At that time, voices of professionals dominated.

One group she became interested in is the women who refuse amniocentesis, whom she saw as a pivot around which to view the problems arising out of new technology which is increasingly put forward as safe and rational. She found that the women and men involved contextualize their choices from many and varied locations. In one example, a black woman, whom she calls Catherine Judd, had decided to go ahead with the amniocentesis. She had been through the initial counselling session, and seemed enthusiastic and positive. Catherine Judd then changed her mind, and when Rapp talked to her about that decision, it became clear that the decision was taken in the context of opposition from close kin. Further talk brought out an important aspect of the decision. Catherine Judd decided against the test after she and her husband read and discussed the consent form. She told Rapp that her husband was particularly concerned about the question asking for consent to experimentation. Rapp explained that this did not mean that she or her baby were going to be subject to experimentation, but that leftover fluid would be used for research; and she explained the particulars of what that research might be. She added that the couple could consent to the amniocentesis without giving consent to the use of the fluid sample for research. Judd explained that her husband was thinking about past unethical experimentation on black people. Rapp realized that they were talking about biomedical experimentation in a much wider context, with sensitivity and knowledge about the role which the black community played as guinea pigs in biomedical research. Rapp recognized that she herself was wholly focused on the medical scientific terms of the situation, but this couple made their decision from another location. For Rapp, this raised questions about personal choice, volition, and collective position.

Rapp came to the view that every pregnant woman is interpolated into the role of moral philosopher. 'One cannot confront the issue of "quality control" of fetuses without wondering whose standards for entry into the human community will prevail and what the limits of voluntary parenthood might be' (Rapp, 1998). She acknowledges that she benefited from the scholarship of history, the sociology of science and technology, and from learning about medical genetics and cytogenetics. But as a field-working ethnographer, she was committed to breaching the boundaries of disciplines. Her field work includes participant observation – a messy methodology, she says – and interviews.

This work is held up today as a fine example of relevant research. But it was not understood so clearly as that when she set about it. It has taken 15 years to build up the work and to come to the understanding that is appreciated today.

This work is complemented by that of other researchers: psychologists and sociologists such as Theresa Marteau and Martin Richards (1996), historians such as Barbara Dudan (1993), and clinical geneticists such as Angus Clarke (1991). Together the work has demonstrated that failure of communication in genetic counselling comes not solely from the basic misunderstanding of technical terms, but from those involved bringing different assumptions and values to the matter; and the difficulty, if not impossibility, of providing truly non-directional counselling in genetics. Problems cannot be solved simply by training genetic counsellors better. Empirical research has helped to elucidate this knowledge, but not in one take. Good empirical research is small scale and builds up over time, as with Rapp's work.

'Practical ethics'

I would like to say something about ethics, even with Jonathan Glover in earshot. Rapp might not frame her work as policy relevant or addressing ethical issues. Nevertheless, this kind of research illumines 'the practical ethical work being undertaken through the day-to-day choices, priorities, decisions, and actions taken by [people]'. Qualitative research can hope to provide 'a unique illumination of the problems and issues that will need to be addressed by any attempt to regulate these matters by legal mechanisms, professional self-regulation or ethical guidelines' (Nik Rose, personal communication, 1999).

In our area of work, what might 'evidence-based policy' or 'evidence-based ethics' require?

- Empirical basis for moral reflections

- Qualitative, ethnographic, anthropological investigations

- Not randomized control trials as gold standard

Relevance

As the Wellcome Trust enters its second year of administering grants for research into the social, ethical and public policy considerations raised by biomedical science, we have come to the conclusion that relevance in research quite simply is having a sense of a wider audience than one's academic peers, as my colleague Tom Wilkie puts it. Both Alderson's work and Rapp's work have this characteristic, reflected in the questions they ask, and appreciation of the expertise which patients and their supporters bring to bear. But of course they are more than that. They identify researchable questions, are theoretically informed and framed, imaginatively designed, and were rigorously researched. They have, no doubt, contributed to the fields of sociology and anthropology, but they do not assume that existing fields – methodologies and disciplines – are unproblematic or sovereign. They offer, too, reliable knowledge about what happens in the process of specialized biomedical practice. Priscilla Alderson's study can be framed in conventional sociological terms of inequities in power relations, for example. And it does contribute to the sociology of medicine. But it is also more than that, it is a contribution to the literature on consent. Rayna Rapp, on the other hand, does not explicitly engage in a policy issue as such, but she makes the point that an aim of her work is to help to wrest undo control of the discourse from medical authorities; to illumine the expert knowledge that the women themselves bring to decision making; and help put control in their hands.

To take the point further into the policy making arena, let me paraphrase the House of Commons Science and Technology Committee's Third Report, *Human genetics: the science and its consequences*. It rightly recognized that the dilemmas that genetics poses will not be resolved by academics alone, but need to be resolved by public and parliamentary debate, although that debate must be well informed, both about the science and about its ethical, legal and social implications.

In thinking about relevance to public policy, we have identified areas which the Trust's programme needs to take account of and which researchers may, as appropriate, take account of:

- social values as a component of assessment;

- noting public concerns;

- reviewing the work of policy-making bodies;

- following advances in biomedicine: identifying high priority issues;

- effective communication to those making public policy, and others who need to know the results of research.

An aim of the Wellcome Trust's Biomedical Ethics Programme supporting social, ethics and public policy research on biomedical science is to make research findings accessible to various users including policy makers. This aim of course has been actively pursued by other organizations such as CERES (Consumers for Ethics in Research); by other funding bodies such as the Joseph Rowntree Foundation, and by individual researchers. Still, unfortunately, much research remains lodged within scholarly journals or PhD dissertations sitting on library shelves.

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Discussion

Chair The emphasis on current scientific development is very valuable, but are there other things to look at? For example, there is the role of institutional factors such as on whistle blowing, and the possibility in the Bristol case that the person who brought this to light is alleged to have lost his career in Britain. There is the worry about professional codes of behaviour in how much experts and others give information to the public.

Response Certainly those kinds of institutional issues and questions are important. In defining priorities of a social and ethics research programme, the Trust decided that it should not be a general funding programme, but limited. The focus on biomedicine, particularly genetics and neuroscience, reflects the Trust's scientific interests.

Comment In a few weeks' time, the ESRC will call for research about new medical technologies. Will there be any dialogue between the two programmes?

Response Yes, we have been talking to the ESRC. We see the two programmes as broadly complementary. Trust staff liaise with other funders too, but the ESRC's emphasis on social science research is close to our own interest in supporting empirical work. But the Wellcome Trust does not define social and ethics research by discipline, but rather emphasizes multidisciplinary research shared between philosophers, scientists, geneticists and many others, so we are in a slightly different arena.

Comment Is there a danger of funders such as Wellcome being stuck while waiting for the ESRC to prepare their innovative health technologies programme? Might there be interference between funders about what research to commission?

Response I agree that it is difficult for researchers to assess the overall picture to know how to plan their submissions. (That is one reason why are talking to one another.)

Comment Why should people take any notice of qualitative research evidence if, as today, it is presented as just one truth among others?

Response There are specific things one can do to promote the value of good work (Priscilla Alderson's work which I described is an example of this). Do researchers like yourselves think that your research is relevant? [Several people said 'yes'.]

Comment Is Wellcome interested in survey and normative studies and other methods, as well as qualitative research?

Response Yes. The programme is interested in a range of methods, but the early emphasis has been on qualitative research which has been neglected. We don't rule out research that might need archive work, for example. In any case, there are difficulties in distinguishing between normative and descriptive research. The example of research in this area I mentioned earlier was the broad topic of 'genetics and intelligence'. I wanted to avoid people asking about narrow topics (and avoid sending the wrong message about the relative importance of different topics).

Comment What if someone wanted to think out fundamental moral issues, such as what are the criteria we seem to be setting for allowing a fetus to become a human being?

Response For the Trust's programme, there is the question of eligibility (does the project fit the remit and priorities of the programme?). There is a question about what counts as research and as scholarship (what is funding needed for?). It is not always clear where that line is drawn. The Trust's support for social and ethics research is a new programme, and there are not hard and fast rules – we are still working these questions out.

Research with men who have cancer

Clare Moynihan

Introduction

The session began with a videoed interview with Sean talking about his treatment for testicular cancer. He wanted to have his own name used. Sean began by describing how the diagnosis was given to him, and how it felt a very numbing experience. He had thought that having his testicle removed would be the end of the treatment, and that he would be able to get back to work, a theme he repeatedly referred to. He began to realize something was wrong, and that more was involved, when he saw the sombre looks on the faces of his family. He described the next stage, of coming to terms with the fact that he had to have drugs. He apologised, saying, 'Don't get me wrong. I was only 17 and I was mischievious [*sic*], so I thought that going on drugs would be a real good party; being on a high.' When he started the treatment, he realized that he was 'in for a fight' which he found 'really very difficult'. Then he began to describe how the young men in the cancer ward supported each other, and not in a competitive way. 'Testosterone was flying around,' Sean said. He implied that sexual aspects of life had not gone out of his head. The young men were very aware of the young nurses, and Sean liked the nurses being so respectful and kind. Throughout his interview, Sean raised themes which many other young men who have been treated for testicular cancer also raised. Sean was absorbed in his account, and my questions as interviewer tended to be made in response to his comments, rather than to introduce new topics myself.

Sean went on to talk about how he was treated, and how the young doctors were 'just cold, like robots – they treated me like a machine'. The older doctors were nicer, and Sean felt this was because 'they'd come to terms with themselves'. He thought that the younger men and women doctors had become 'very aware of themselves', through knowing Sean, of their own mortality, and of masculinity and health. 'I was much stronger than they were before the chemo, more vibrant and virile; I scratched their identity.' Sean saw a power game going on, with the doctors treating him simply 'as a body because they couldn't face the man. They were thinking about my testicles [Sean gestured to them] and I was concerned about the whole king caboodle'. The other parts of him that should also have been attended to were left out. Then he went on to talk about his life and work and how difficult it was for him to talk with his work colleagues about his cancer. In doing so, he introduced the whole panoply of masculinity very starkly, saying that if he had worked amongst women he would have had much care and attention. Yet in the very male orientated work of building he only met with a kind of blank wall. One or two people wanted to know, but they could hardly bear to face what he told them. Sean spoke of being very isolated and said his friends treated him like a leper, they would cross the road to avoid him, and ignore and ostracise him. Sean became very aggressive, as if he was winding a cocoon of armour around himself. He then talked about relationships. He and his girlfriend got married after the chemotherapy was over, and everything seemed to be on an even keel, until I interviewed him about five years later, for my research. Sean said during this videoed interview that the earlier interview had absolutely broken him down. It was 'as if part of my brain had been opened up', indicating that Sean had shelved his emotions during the five years since his treatment. He believes now that he was going through a mourning process. We can do harm with our interviews and counselling, although Sean turned this into a positive experience. After containing his feelings, he felt that then I had opened them up, and slowly he found that was a way of coming to terms with having the cancer and treatment. It took more than another five years, but now he feels that he is beginning to come to terms with his experiences.

During this turmoil, his marriage failed partly, he thought, because he couldn't have children as a result of the chemotherapy. He added, 'It may sound selfish, but I'd rather have my life than have children.' Sean now lives with another partner and her child. He talked about becoming 'more himself' – being much less aggressive. He has also become very insightful, seeing himself as part of the reason why his marriage broke

up and accepting responsibility for himself, instead of blaming all the problems on to the cancer. He changed from being an angry man who quarrelled with everyone, and is now a full-time student having completed a first degree and now doing a further degree. Sean's example suggests that surgery and other cancer treatments do not resolve all the problems of having cancer. There may be an overwhelming aftermath. Even if people look as if they are doing very well, they may feel in turmoil years later, with disrupted relationships, infertility problems, employment difficulties and a personal identity crisis. Long-term after care should take account of these problems. Sean wanted doctors to acknowledge these possibilities. Some men want counselling, and appreciate practical help from doctors such as supporting letters to employers.

Being a man and being masculine

I want to talk about concepts of masculinity, cancer and genetics in relation to qualitative methodology. In doing so I want to distinguish between sex and gender and theories of masculinity and how they affect men when they are going through a cancer experience. Both quantitative and qualitative methods share many of the same problems: for example, both have to face up to questions surrounding validity, generalization and reliability. I want to emphasize here the importance of fitting the method to the question that is being asked. If we are trying to explain something in terms of meanings, I don't think that it is scientifically or ethically viable to use a quantitative methodology, and likewise, if we want to know how many men brush their teeth at night, for example, a qualitative approach is not appropriate. If we want to know why they do so, qualitative methodology may provide an answer.

My work at the Institute of Cancer Research is with men who have a diagnosis of testicular or prostate disease. The former appears in younger men, usually between the ages of 20 and 35 years, and involves aggressive treatment procedures, sometimes resulting in infertility. The overall survival rate is over 97%. Prostate cancer is a disease of older men, usually in their 60s and over. Management is uncertain, sometimes involving surgery and hormone therapy. Although the disease is often controllable, rates of survival in men with metastatic disease (secondary spreading cancer) are low. My research has involved both qualitative and quantitative methods and my remit is to carry out research that will enable health professionals working with men with cancer to give optimal care, and to disseminate the results.

In Western medicine, sexual anatomy equates with sexual destiny. Anatomy is proof of being a man. The concept of masculinity will be entwined with a man's sexual function as will his levels of testosterone, measured and quantitatively analysed. Masculinity here refers by and large to those who are white, middle class and heterosexual but being a man takes on a universal status, generalizable and immutable. Success, aggression, reason, a need to control, competitiveness and emotional reticence are thought to be some of the few natural male attributes. Contradiction or ambiguity is anathema to a man. This is strange, because medicine recognizes sexual ambiguity in anatomical states, but it seldom recognizes the complex social issue of gender.

> **Examples of indicators of masculinity**
>
> Please write in a number on the following scale
>
> 1 = strongly disagree 2 = disagree 3 = undecided 4 = agree 5 = strongly agree
>
> * A man should not cry in front of his friends
>
> * It's better if a man can avoid getting too emotional in public
>
> * A man who shows it publicly whenever he's upset or depressed should try to learn to control his emotions
>
> * I might find it a little silly or embarrassing if a male friend of mine cried over a sad love scene in a movie   (Brannon, 1984)
>
>
> How desirable is it for men to be assertive/unyielding/strong/masterful?
>
> very desirable
>
> desirable
>
> undecided
>
> undesirable
>
> very undesirable   (BEM, 1974)

These stereotypes of masculinity inform research in all of its aspects. Self reports that measure masculinity may be hugely biased. Men who present themselves as highly masculine have been shown to under report medical and psychological symptoms such as pain, swelling and emotional distress. Motives and feelings are hidden when men report on the emotions they feel they ought to have according to oppressive stereotypical myths of masculinity. Questionnaires are devised without actual observation of possible behaviours and the contradictions that undoubtedly exist. Instead, men are asked to rate their personality characteristics on a scale in answer to questions such as, how desirable is it for a man to be assertive/yielding? (see box). Cultural mores and expectations built into the questionnaire will shape (limited) static responses, only perpetuating the myth of what it means to be masculine and 'proving' that men behave in certain ways. This tells us more about the researchers than it does about the men. (And by adhering to these stereotypes men will find it difficult to reveal their sadness, as they hide behind a facade of stoicism.)

When men are closely observed, masculinity can no longer be perceived as a single variable but as a highly complex state of being.

> 'My worries never stayed in one place if you see what I mean. They changed from diagnosis time to the present day. I thought I'd die when I was told. Then I worried about the treatment because it was that, that made me ill, not the cancer and now it's the thing like relapse. I think about that a lot...when I think about having a child, it will be whether my sperm is up to it...I expect you wanted one worst worry, but I can't give you that so I'm worrying about that now.' (Sean laughs)

Sean highlights many aspects of being a young man with cancer. Nothing is static; ambiguities and contradictions run right throughout his story. Never can he be viewed as a single variable but as a highly complex being whose responses would, I think, lose that richness through turning a conversion into numbers. How would you, for example, capture his anger, his sanguinity, joyfulness, sadness, strength, frailty, wisdom, uncertainty, playfulness, seriousness and articulateness? And even within these nebulous boundaries, nuances abound. He has told his story in the context of his own social world in a truly unique way. And while men will speak with different voices, his story mirrors those of others I have talked to and serves to build on theories about masculinity in the fluid and ever changing contexts of men's experience.

Other men reflect Sean's talk, showing how impossible it is to squeeze their stories into single variables. Infertility may be a problem at the time of treatment or later on, or they may eventually come to terms with infertility by rationalizing the loss through juxtaposing it with the importance of survival. Sean brackets out his childlessness. He is trying hard to avoid letting this uncertainty permeate his thoughts and later his identity as a man, or the man he was. This glossing over of uncertainty runs through many of the men's stories and serves to minimize the pain. It can of course also raise identity problems. The cost of trying to maintain past identity may actually jeopardize his grieving process – Sean explained that well in the video.

Sean's most important point was the fact that any interview of any kind, whether it is in depth, or a questionnaire, is an intervention that may be damaging and even irreparably so. This raises ethical questions that need to be thought through across the entire spectrum of research with people.

Theories of masculinity

Interestingly, there is a paucity of theory regarding masculinity that addresses men who are ill. Yet, certainly the work of, for example, Seidler (1995), Kimmel (1988), Hearn (1994), and many others serves to guide the interpretations and theory building that we may arrive at through an analysis of our data. They have shown, for example, how masculinity is identified with reason, morality and progress, but at the same time dictates the invisibility of men from their very selves. Their reasoning powers are played out in the public spaces of their lives, while their needs and feelings are hidden as signs of weakness and given no place in the public realm. Men become estranged not only from the personal aspects of their experience but also from their somatic selves as they learn to think and rethink in terms of neutral standards of reason (Moynihan, 1998).

The body is written about as a crucial locus for men's sense of themselves as men. Physical injury transforms the body which men may have perceived as previously healthy and capable of defending space in a masculine order, to the body of what has been termed the 'lesser man'. Masculinity is shown to prize the external rather than the internal world, predisposing men to controlling their emotional states by controlling the external environment. For example, men with cancer are shown to try to ignore the pain they may have experienced, instead, focusing on work and the ways that the experience may impinge on the external and material aspects of their lives. The consequences for men of the oppressive concepts of masculinity as a result of socialization are not only alienation from meaningful intimacy but the restricted entitlement to experiencing and/or expressing emotions.

Theories about friendship and intimacy revolve around a consensus that while women are said to have deep, intimate, meaningful and lasting friendships, men have a number of shallow, superficial and unsatisfying acquaintances. Sometimes this is credited to the fact that men tend to be highly homophobic, emotionally inexpressive and competitive. Men tend to distance themselves from each other by organizing themselves around activity that is external to themselves, rendering them to becoming emotionally impoverished. Other theories suggest that 'bonding with intimacy' is a distorted notion. Social conceptions of love and intimacy have become feminised since the time of the industrial revolution – thus it is wrong to judge men's friendships against the standard of the type of intimate relationships that women tend to develop. Men's friendships are characterized by what one theorist suggests is a 'covert style of intimacy' – women and men experience and define intimate friendships in different ways and neither should be judged by the standard of the other (Rubin, 1983).

The whole concept of identity in chronic illness as it relates to masculinity has been theorized. The work of Kathy Charmaz (1998) is particularly useful here as she looks at the processes that men with chronic illnesses experience. She describes the ways in which men accommodate to uncertainty as they realize that the crisis of illness has lasting consequences, in their efforts to preserve the self and to maintain a sense of coherence while experiencing loss and change.

Follow up and research

In 1987 I researched the concept of cure with a random sample of testicular cancer patients who had been treated one to five years previously. At that time nothing was known about how young men felt as a consequence of their cancer. Against the wishes of many of the clinicians who wanted a quick quantitative answer regarding psychological morbidity, I carried out a qualitative study and included the partners and friends of the men in order to capture as full a picture as was possible. We did use, however, a measure of anxiety and depression that had been validated in a cancer population as was being used in other work, mostly with women. Men were interviewed in their own homes where they said they felt that they would be able to reveal aspects of themselves that many men admitted they had not voiced before. In that study I found that cure, as Sean put it, was not 'a bed of roses'. Like Sean, men were constantly aware of the (unlikely) possibilities of relapse. Many felt that cancer had changed their lives (some for the better). Many had had difficult relationships with friends, partners and parents. But most interestingly, no one had sought formal counselling, suggesting that it was crucial for men to be controlled and silent about their emotional life. This reflects the theory that men tend to be reticent and unable to voice emotional feelings and needs. And yet they were talking to me an outsider, although, only in a context of trust and flexibility.

Part of qualitative research is to be reflexive and to consider how the responses might be influenced or constructed through the nature of the particular research question. Could young men have been so forthcoming because I was detached from the clinical team and was someone old enough to be their mother? Did these men see me as a middle class expert? And were they responding to me in the way that they did because I was a woman? Was I responding towards them in the way that I did because I am a mother of a grown up son? All these aspects of me were possibly playing into the conversations I was having with these men and they with me. But rather than push this bias away as if it didn't exist, I have used it as a subject of enquiry in its own right.

> 'Every time I want to cry I get into my car, drive down the road and blubber...it always makes me feel much better, and nobody knows. That way I don't bother them.'

The themes of self control and stereotypical masculine identity where constantly re-enacted in the face of their illness as men described how they wept in private, far away from their families, and often in their cars where they felt enclosed and safe.

A few men told me of their covert manifestations of loss and pain, their reliance on being allowed to engage with their innermost fears and fantasies, but always recounting a need to do this alone, away from the watchful eye of family and friends. Men's stories illuminated contradiction and ambiguity, mirroring the reality of our lives. I have observed men crying in one encounter and stoically withdrawing in another, or doing both. I have seen a man holding a toy for comfort while refusing psychotropic drugs for fear of losing control, and I have seen a weight lifter who was capable of lifting 180 kg in health but was unable to lift a spoon in illness.

Like Sean, many men talked about cancer as the enemy. Some saw cancer as an opportunity to change – to reconstruct the self. Some would talk of both reactions at differing moments in their narratives. As Kathy Charmaz suggests, both responses reveal the connectedness between body and self. Viewing the cancer as the enemy, objectifies and externalizes it and thus distances and separates it from both personal and social

identities; it testifies to a man's continuity of self – he is the same but his body is different. Sean spoke about illness as an intrusive presence as if it was an unwelcome stranger to the body. But this distancing helped him perhaps to maintain a sense of his masculine self, left to fight the battle and win – it was a competition, not between others but between the cancer and himself.

Again, like Sean, many men spoke of their need to reclaim the past when they had cancer by leading what they called 'normal lives': going back to work, making up for lost time as it were, as they spoke about their sexual conquests. And like Sean, by doing so they marginalized the effects of illness and maintained continuity, but often at an enormous personal cost. Men appeared to be drawing upon the existing cultural definitions of masculinity as they tried to make sense of their altered selves. When a penetrative sexual act, for example, forms the foundation of their conception of masculinity, anything less will undermine their image of themselves as men. As men spoke of their sexual performance (some focus entirely on it) it was always in the context of their desirability as if they relied on their partners to treat them as desirable sexual beings. Many indicated this and one man said, 'My wife has never been phased by the loss of my testicle, and she says that our love making is just as good as it ever was if not better. She is having a baby soon and I truly believe I'm cured.' Interestingly, and it is not unique to our study, men never questioned the idea of masculinity as such. It seems that to explore these areas may be too painful in the light of a broken gender identity; that a stereotypical masculinity may be compromised in facing up to such revelations.

Silence and avoidance

The need for silence both on the part of doctors and patients, and a seeming need to maintain identity through silence was reinforced by the ways doctors expected the patient to achieve a mode of masculinity. Men told me how male clinicians often attempted to 'smooth troubled waters' in trying to articulate the possibility of dramatic existential crises; how they would talk of 'firing blanks' when referring to possible or real infertility; and how the loss of a testicle and the fear of potential sexual problems were referred to as 'a plane flying on one engine and landing safely,' or that 'one cylinder is as good as two.' This kind of language reinforces the way in which many men think about their bodies as machines, controllable and controlled. It highlights the way that a Cartesian dualism between mind and body is recreated, leaving men feeling separate and estranged from their somatic experiences. During the video, Sean in no uncertain terms talked about the way doctors 'treated him like a robot.' He sounded angry at this and it has never left his mind, it rankles, even 18 years after he was given his diagnosis. He is able to express his feelings now, but at the time, the doctor's seemingly insensitive approach may have blocked him from moving forward, as it did many men in my study. On the other hand that way of curtailing a patient's possible need to explore further may also have served to reinforce an armour that many men need to weave around themselves, as is so obvious in Sean's story and in many others. In any case, by approaching the research question in a way that enables meanings and ambiguous feelings to emerge through a qualitative analysis, we can begin to suggest practical changes in doctor patient interactions, and illuminate problems in medical research and practice that need further investigation.

Genetics and cancer

The need for control and silence emerges again in a study that I am currently involved in and I think gives us even more insight into how men may cope with the issues that concern disease and in ways that illuminate traditional masculine definitions. We want to know what men know and think about the concept of genetic cancer. Much work has been carried out in this area of cancer medicine, almost exclusively with women. Most research has been carried out from the point of view of the service provider. Anxiety, perceptions of risk and interest in genetic testing are measured quantitatively and dealt with through genetic or psychological counselling. Investigators have been surprised by the differences in response regarding, for example, high reported interest in genetic testing and lower actual uptake rates. They are surprised when quantitative methods that depicted a static picture of anxiety in women in high risk groups are complicated by temporal factors. Qualitative research has shown that women at high risk of breast and ovarian cancer are

anxious intermittently, and especially at various meaningful times such as an anniversary of a mother's death of the disease in question. Other qualitative work has shown women to be the main information seekers and givers within families and this is reiterated in our work with men and genetic disease.

Research also illuminated a mismatch between theories of Mendelian genetics and people's beliefs and needs (Richards, 1996). In our own research, we asked three groups of men to agree to be researched in a venue of their own choice: a) Men without the disease but who have a relative with prostate or testicular cancer, who is known to be in a higher risk group because there is a family history; b) Men with a relative with either disease who is not in a high risk group because there is no obvious family link, and c) Men who have no cancer in the close family. Ninety nine index cases (men with the disease) were asked to contact a relative and in turn ask him to contact me. No further contact would be made, unless a man voluntarily opted in. Twenty five men with no cancer in the family were asked by a GP practice nurse to contact me if they were interested in joining the study. Thirty, well, largely middle class men from all parts of England have agreed to talk to me, 24% of the original total approached.

The research topic was wide. For example these men have been asked to tell me what they know about cancer and its causes. They were also asked to refrain from seeking information regarding genetics between our initial conversation and the interview.

We had already entered a space of mutual trust, as it were, as they would tell me they were clueless when it came to the research question, making sure that I knew that they had not 'gened up on genetics' as more than one man put it. And I believed them. I think they believed me when I assured them of confidentiality, and a chance to see their transcripts and a final report, so that they too could have a say as to how I had interpreted their talk, using the respondents' validation Mildred Blaxter has mentioned.

It very soon became obvious than men who contacted me had not necessarily spoken to their diseased relatives, to the extent that I would have to telephone the index case to ascertain that I was not breaking confidentiality. Invariably the women in the family had passed on my message to the possible participant. I was always given the go ahead, 'Just fine,' said one index case, 'you can talk about my illness, it's just that I can't.'

This silence is interesting in any context but in the context of genetic disease it is a crucial factor when we consider how the mapping of genes in their initial stages relies solely on communication between and within families. Noncommunication became a research topic in its own right and revealed many interesting facets of men's need to keep silent in the context of disease, but for reasons other than what you may imagine.

This reticence did not always appear to follow stereotypical notions that men are unable to speak about emotional and personal matters, although the perceptions of cancer as being a taboo subject is evident. This is not new. The medical profession itself was, until relatively recently, extremely reluctant to communicate truthfully with patients and some doctors still are, where cancer at least is concerned. The men in this sample saw no reason to talk of illness and especially cancer, amongst friends, although there were at times exceptions, usually when they or someone else close to them had the disease or when, in other words, it had direct relevance. Otherwise, talk about health and illness was often perceived as peripheral to men's lives. Most importantly, the concepts of respect, intrusion, and privacy were very clearly evoked in the men's accounts.

Talk about health and illness was felt to disrupt the fabric of relationships both within and outside the family, causing worry and taking up precious time. This need to protect family involvement would often be talked about in the context of men's lives and in the lives of others.

One man refused to take part in research because he mistakenly thought that blood testing would take place at weekends. His response may be interpreted as a need to get on with his life – he may change his mind (an important factor, never captured in fixed questionnaires) – but nevertheless he has other things to do and he doesn't want to disrupt the lives of others.

That men did not talk about their illness was reflected in their self-confessed, so-called, ignorance concerning cancer. This finding was reiterated in a Mori poll. Eight thousand men were questioned and the findings provoked the media into questioning how men could and must be made to talk, as if it would solve all problems. Talking or counselling is of course, the panacea of good medical practice, and has been for some time in the world of cancer. My colleagues and I are tentative, but we feel, having carried out these studies, that men have their own reasons for silence and/or maintaining traditional masculine ideals at a time when a young man's sense of himself is possibly shaken to the core by experiencing cancer. We want to respect them. We have gone as far as instigating a policy (that may change over time) that men are not routinely offered counselling soon after diagnosis. We feel that they should be able to wrap a cocoon of masculinity around them at this particularly difficult time, if that is what they wish to do. Similarly we need to be thinking about their need for privacy and respect in the context of genetic disease. Appropriate, clear information, may respect their autonomy, as may changes in the way clinicians and other health professionals talk to their patients.

Some of the findings I have presented here on our work with men with cancer give just one example of the kinds of counter intuitive evidence which qualitative research can provide. This work has spanned many years and we are constantly in the process of building on a theory of masculinity with men who are experiencing a serious disease. In addition we hope that our work that spans both qualitative and quantitative approaches will assist in providing optimal patient care.

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Research about children and ethical healthcare

Priscilla Alderson

Introduction

Examples from research about child health vividly illustrate links between research methods and theories about childhood and children's best interests. This paper traces some of these links, and shows how qualitative research about children can provide evidence and insights into their health and welfare to inform ethical healthcare policies and practices. Generalizability is discussed and there is a brief historical review of research about children and of ways of addressing theories about childhood through qualitative research. The theories include the deficit model of childhood, concepts of children as active contributors to their healthcare, research which searches for causes or for motives to explain children's responses, age and stage theories, and childhood as a biological or a social state. Later sections consider research methods, including research about complex interactions, conversation analysis, and combining observations with interviews in research with disabled children.

From many possible definitions of ethical healthcare, this paper mainly considers how healthcarers can attend to the ethics of respect and justice by listening to children's own views, and by balancing the protection of children with respectfully shared decision making with them. The 1989 United Nations Convention on the Rights of the Child enshrines children's rights to express their views in all matters affecting the child, and to have account taken of their views according to their age and ability (UN 1989, article 12). All governments except the United States and Somalia have ratified the Convention, although they vary in how much they honour it. English law goes beyond the Convention in acknowledging that children of any age can be the main decider about proposed treatment, and can give valid consent to healthcare interventions, provided that the doctor treating them believes that they are competent to do so (*Gillick v West Norfolk & Wisbech AHA* 1985, and research on this topic is reported in Alderson, 1993).

Combining qualitative with quantitative methods

The gold standard research method is not necessarily either quantitative or qualitative, but is the most appropriate method to answer the research question. Each approach has strengths and limitations. Quantitative surveys can provide a statistical background to qualitative reports about children's experiences and views, in showing how commonly or exceptionally the issues discussed occur, although qualitative research alone can provide certain kinds of evidence to inform the planning and provision of ethical healthcare, at local, national and international levels, as later examples will illustrate.

The questions 'How rarely or commonly does this example occur? Is it unique or typical?', which are raised by all research reports, are dealt with more directly and systematically in quantitative work. For anyone wanting to apply research findings to healthcare, these questions about frequency involve further ones: 'How transferable or generalizable are the research findings to other similar instances? How valid or strong are the links between the researchers' evidence, the conclusions, and their general applicability? And, therefore, how justifiable or ethical will it be to apply the findings generally?'

Answers to these questions include the following. Exact, replicable measurements of people's reported views or activities are often not possible because, as free agents, people change over time and situation. Relative, approximate terms, such as 'more' or 'less', 'most' or 'few', which describe rather than measure precisely, may therefore more realistically report social responses than quoting percentages. Some features will be more broadly generalizable than others. An example is people's general optimism about a form of treatment, though they will report different, individualized reasons for being hopeful. The main use of valid generalizations is to be able to identify types of patients and to predict their likely responses. This is vital to

scientific medicine when prescribing appropriate medication or surgery, but is not necessarily useful in social aspects of medicine. For example, a paediatrician was frequently told by parents of one-year-old children with a congenital condition that his colleague had given them pessimistic prognoses a year earlier.

> 'I estimate that half the parents said they didn't really mind and they were relieved that things were not nearly as bad as they expected, and the other half were upset and said they had not enjoyed anything throughout the first year, they were so anxious waiting for awful things to happen. Maybe we need to be able to predict which type the parents are and treat them differently.'

There are problems in this solution. It may never be possible to develop rapid and very accurate methods for identifying which of the two types each parent belongs to. Even if it were possible, what should be done when a child's mother and father are in different groups, or when parents' attitudes change? Is it ethical to give one group radically different information about, say, spina bifida from another group, unless they request this? And what would be the policy about answering questions, especially from parents who ask why they were told more or less than another parent? Instead of using quantitative methods to measure reactions in order to classify and predict reactions, it could be more useful to try qualitative research. There could be observations of the early and follow-up consultations; interviews with the doctors on their views about the information they give and how they audit its accuracy, relevance and effects; and observations and interviews with the families through the first year on how the children progress, on what information they find helpful or unhelpful, and how and why the parents hold their views. This in-depth tracing of the babies' growth and the interactions between the doctors and families could lead to the doctors gaining more knowledge about the range of children's abilities and difficulties, and how to inform parents about these possibilities.

The research might follow up suggestions about alternative types of support, and evaluate these with the help of the people concerned. Parents are likely to give a range of mixed responses, not a simple binary format which they can be slotted into quickly. Instead of searching for methods to generalize and predict (and possibly stereotype) types of parents, the doctors could become more aware of the types of prognoses which various parents find realistic and helpful; these may not clearly correlate with the degree of difficulty the child experiences. The doctors could also use clinical approaches similar to qualitative research interview methods which explore (fairly briefly) with the parents which 'type' they belong to and which approach appears to be the best for them as the child grows. Thus, more flexible and helpful information and support might be provided. Research results showing that 48% of parents in the sample come into one group and 22% into another, linked to a few demographic variables, will not help doctors to classify parents into certain groups, though used as rough guides to 'more and less likely' responses, the percentages can help clinicians to know which is the most likely reaction to check for first. One danger of percentages is that, say, 52% may be seen as 'most patients' and may then filter into practice as the preferred treatment for all patients. So, in summary, exact quantitative assessments are valuable for the more standardized physiological reactions to a treatment, and descriptive qualitative methods are valuable for people's variable and changeable psychological and social experiences of health and illness.

Research about childhood in the past

There is a long history of observations, anecdotes and theories about the nature and management of childhood. The seventeenth-century philosopher-physician John Locke is one example from many doctors, past and present, who have published their views about how children should be reared. These manuals show wide swings of fashion, from indulgent to very harsh methods of childcare (Hardyment, 1985). Darwin was a founder of the child study movement observation methods which are recorded in his notes and drawings of his own children (Morss, 1990) and he was followed by numerous other parents including Watson, Skinner and Piaget (Bradley, 1989). Skinner was among the psychologists to develop standardized laboratory-based research on children, and his daughter lived for months in a large incubator where her environment could be 'totally controlled' by her carers, as Skinner described in a novel (Skinner 1946; and see Bradley, 1989:

36–44). Historical examples of childcare practices and experiments which are now regarded as harmful or misinformed might be taken as evidence of the need for researchers to move away from small-scale investigation towards quantitative research. Then, in systematic comparisons the benefits and risks of favoured childcare methods might be more clearly demonstrated, and children could be protected from adverse interventions through objective scientific knowledge. However, quantitative methods alone have not guaranteed sound knowledge or benign policies (Cooter, 1992). Truby King's experiments with calves, for example, led to decades of inappropriate baby feeding regimes (Stainton Rogers and Stainton Rogers, 1992). Cyril Burt's extensive surveys of intelligence and of criminal tendencies (Burt, 1947/1962) led to self-fulfilling predictions and to segregating and labelling education policies which policy makers, teachers and parents continue to try to reform.

Theories of childhood
Splitting positive and deficit characteristics

All research is founded on theories, and valid research involves clarifying and questioning the underlying theories or models of thinking. What are the main theoretical assumptions? Where are they derived from? How sound are they? How do the theories affect the research process in the collection and analysis of data, and in the way research findings are understood, and accepted, attacked or ignored. For example, traditional medical and psychological research tend to assume a certain model of childhood as factual, a biological state in which the mind develops, like the body, through a universal series of age-related steps up from the low point of babyhood towards a supposed end point of adulthood. Researchers chart the stages of physical, cognitive and emotional growth, to identify abnormalities against identified norms, and to assess the most effective means of promoting healthy development. The stages may be broken down into detailed 'milestones', which have been repeatedly identified through decades of surveys and experiments. These child development theories dominate professional and public understanding of modern American-European childhood, to the extent that they tend to be taken as universal facts and no longer as hypotheses or beliefs. Examples of how the theories are popularized are given by many texts for student teachers, nurses and other child workers. In a widely used and recently reprinted text, students are asked to observe a child and to note how the child fits the recorded milestones. For instance, here are 'key features of 9–18 months'.

> 'Growing independence can lead to rage when thwarted. Shows anxiety when left alone. Emotionally more stable but can be jealous of adults' attention to other children. Can be defiant – learns NO.'
>
> (Sharman, Cross and Vennis 1995/2000)

There are problems in this approach for research and childcare as growing numbers of psychologists point out (Dunn, 1993; Penn, 1998; Woodhead, 1999). The examples given are all negative and the many positive experiences and characteristics of young children are omitted. The 'key features' imply that the features are specific to, or especially dominant at, this age group, whereas they are found at every age group in some circumstances. The context and relationships with other people involved are crucial in how each person reacts, whereas the key features are shown in isolation, as if they are intrinsic to the child. This can dangerously mislead adults into assuming that in any differences or rows they have with a young child, the adult's view will be mature and the child's will be instinctive and irrational, in need of firm management rather than, possibly, negotiation.

Underlying these notions is a deeper and one-sided theory of human nature which ascribes the positive qualities to one group and the negative ones to the other group (figure 1).

Figure 1 Human dichotomies

Type 1	Type 2
inexperienced	experienced
ignorant	informed
volatile	stable
vulnerable	protective
developing	mature
dependent	providing
egotistic	altruistic
foolish	wise
unreliable	reliable
incompetent	competent

In the past, women and non-Europeans have often been assigned to type 1. Today, type 1 is mainly identified with children and teenagers. Figure 1 is a classic example of splitting and projection, the common and powerfully emotional process in which we assign good qualities and trust to our own group, and project the opposite qualities onto outsiders. Whereas in reality most people, at times, combine all these qualities at every age.

A second way in which children tend to be stereotyped is in assumptions about giving and taking. On seeing an image of a tall adult standing near a small child with their hands almost touching, it would usually be assumed in the richer minority world that the adult was giving and the child taking. Media and popular views tend to see children demanding goods and services, and requiring constant protection from risks, neglect and abuse. Among the majority world, the 83% of people who live in poorer countries, a different image is often seen of the child also giving, helping with housework, care of the other children or animals, or with street work. Research reports in mainstream medical and psychology journals often present a one-way model of adults assessing, treating and providing for needy children. Children are seldom seen as contributing views or helping themselves or others. *Archives of Disease in Childhood,* the leading paediatric journal about children's bodies and behaviour, only exceptionally refers to children's views. Yet this one-way model of healthcare provided by professionals to passive patients, which is implicit in many surveys and trials, does not fit the reality: children provide much of their own self healthcare, and treatment of their illnesses usually depends on their active cooperation, not simply their passive compliance. These processes and partnerships of shared care can be accurately researched through qualitative observations, talking, gaining their confidence and sharing in their daily activities with children.

Causes or motives

The assumed dichotomies in Figure 1 have deterred researchers from asking children, when they are regarded as inadequate and unreliable, directly about their views and motives. Instead, researchers have tended to observe children's behaviours and experiment on them using methods derived from physiological and behavioural animal research. As a result, we know a great deal about children's physical growth, functioning and optimal care such as healthy diets. A second quantitative approach has been to survey parents' and professionals' views about children's learning or behaviour (Rutter, 1988). Demographic and behavioural variables can be used towards making predictions about how identified groups of children are likely to react to certain conditions. This cause-and-effect model of research is valuable in identifying general positive or negative influences in childhood. However, as mentioned earlier, it cannot identify precisely which children

will react in predicted ways, or why they do so, or their own understandings about influences on them and their responses. Cause-and-effect based research assumes a rather passive, reactive, predictable concept of human beings, whereas even young children have motives, they actively and purposefully influence the people and things around them, exercise their will, make choices, and make sense of experiences by reasoning about them, in many ways as adults do (Dunn, 1993; Alderson, 2000). Qualitative research allows for more detailed study of the subtle and varying processes through which individuals feel and think about and cope with a condition such as cancer or epilepsy.

Age and stage theories

Widespread beliefs that children develop slowly through age-related intellectual and moral stages are influenced by Piaget's studies. For example, he showed children a model of mountains and asked them to choose from ten photographs the one which matched the viewpoint from which a doll would be hidden behind the mountains (Piaget and Inhelder, 1956). Most children under seven years chose the photograph matching their own viewpoint. Piaget deduced that they were egotistical, and unable to appreciate another person's point of view. Researchers have refuted Piaget's theories, and shown how when the mountain test is rephrased, three-year-olds can solve it, and versions twice as hard, or that when a 'naughty teddy' asks Piaget's repeated questions, the children laugh and give more consistent replies (Donaldson, 1978: 19–23, 64–5). Microtechnology now shows that babies aged only six months appear to think in sophisticated terms, such as widening their eyes in surprise when they see an 'effect' shown before a 'cause' (Siegal, 1990). These findings challenge the age-linked milestones of development.

Qualitative analysis helps to explain why some of Piaget's central views, despite being refuted, continue to dominate western theories of children's gradual development. It seems so obvious that children's bodies grow up gradually towards adulthood, and therefore their minds do too. At first it can be hard to question this seemingly obvious fact and to perceive it as a theory, which is challenged by the way people of every age can become competent and experienced in some matters and not in others. Historical reviews of the misleading pre-Darwinian notions of child development criticize the 'biologising' of childhood, which sees children as nearer to animals than to human beings (Morss, 1990). There are psychoanalytical studies, showing how Piaget, Bowlby and others interpreted their data to fit their preconceptions of the child – as a lonely scientist, or as needing an ever-attendant-wife-mother figure (Bradley, 1989). Piaget's theories lend scientific support to the splitting in figure 1, which is popular and convenient for adults, when it appears to justify their unquestionable authority over children and to dismiss children's different views as irrational. Many adults are irritated or troubled by the notion that children may in some ways be equal with them. Yet rigorous research involves thinking through uncomfortable and counter-intuitive ideas, and letting go of misleading assumptions rather than trying to justify them. Qualitative researchers are increasingly aware of how they have subconsciously talked down to young children and constructed them as less mature than the children were (Solberg,1993), in a different version of the 'moral accounts' structuring mentioned by Paul Atkinson. During my research, I asked Amy, aged ten, 'So you are having your legs made longer?' She replied with dignity, 'I suffer from achondroplasia and I am having my femurs lengthened.' In this way she reset the conversation at a more 'adult' level, although since this was also Amy's level, it is misleading to label certain levels 'adult' when children can engage in them equally well (Alderson 1993: 7). Childhood, like masculinity, is constantly constructed and reconstructed through such countless daily interactions (James and Prout, 1997).

Building on Aries' (1962) accounts of the vast range of childhoods through the centuries, historians, anthropologists, sociologists and social psychologists have compared differing childhoods around the world. Eight-year-olds behave like adults in one society and like infants in another (James and Prout, 1990; Stainton Rogers and Stainton Rogers, 1992; Burman, 1994; Johnson *et al.*, 1995; Jenks, 1997). Children aged under eight years wander alone all day with their goats in extremely hot or cold temperatures in Outer Mongolia (Penn, 1998). Detailed qualitative studies of young children have shown how they can be

intensely aware of other people's feelings, of morality and of appropriate behaviour (Dunn, 1993; Mayall, 1994; Hutchby and Moran Ellis, 1996; Alderson, 2000) in ways which challenge traditional age-stage assumptions.

Researching children's competence

Running through research about childhood, implicitly or explicitly, is the question: exactly which characteristics, such as those in figure 1, are exclusive to childhood or adulthood? General competence is assumed to be a key distinguishing feature of adulthood. However, children who are regarded as disadvantaged, such as those with chronic illness or disability, refugees, stigmatized or street children, may have opportunities to show their courage and maturity, in ways which sheltered children do not experience (Alderson, 1993; Ennew, 1996; Butler, 1998). Disadvantaged but competent children are not necessarily exceptional, rather, they live in exceptionally challenging circumstances, with opportunities to reveal capacities that are probably latent in most children.

Qualitative interviews and observations can address children's competencies which may not be immediately obvious: by asking open questions, rephrasing and dwelling on them, and approaching a topic from different angles; by encouraging extended replies during which people may arrive at new insights while they talk; by exploring examples through narrative during which people voluntarily introduce rich examples and incidentally make passing comments that might not occur to them while quickly working through a questionnaire; by examining ambiguities and uncertainties, and reasons for holding stated beliefs; by exploring people's views and experiences through a range of research methods; and by understanding people's responses through the meanings invested in them by the context of their daily lives. For example, children who have had recent surgery will know far more about that than average children do, and standardized tests tend to miss this kind of specialized knowledge, with the risk of concluding that children do not and even cannot possess it. Qualitative interviews can reach a level of truth when children talk about their understanding of the nature, purpose and effects of their treatment, demonstrating a competence which cannot be expressed unless it is possessed.

I observed the power of beliefs about age-related competence over actual practice while researching children's consent to surgery. During an interview, when asked the age at which he thought children could be the 'main decider' about whether to accept recommended surgery, one surgeon replied, 'Help! [long pause] I suppose basically when the child becomes an adult...when they're 16 I suppose, when legally they're allowed to make their own decisions' (Alderson 1993:147). A little earlier during his outpatient clinic, the surgeon had seen a girl aged 14 whose legs were different lengths; a four-centimetre difference which is on the borderline to be considered for surgery. He had advised her to consider the options and write to let him know her decision. We talked about the girl, and the surgeon agreed that he would operate only if she wanted surgery, not simply with her parents' consent. 'Unless they're very keen, they're unlikely to carry [the treatment] through to completion...yes, children are allowed to refuse...there's no point in starting leg lengthening unless the child's willing to go through with it.' The varied qualitative research methods illuminated the mismatch between the surgeon's conservative beliefs and his more liberal practices. This dissonance is quite common between concepts of childhood as a biological and inevitably dependent state or childhood as a social status variously constructed in different societies through numerous interlocking beliefs and practices. How children live their lives dependently or independently, passively or actively is partly determined by the self-fulfilling beliefs about 'normal' childhood held by children and adults.

People tend to assume that their own society has the best understanding of childhood and childcare and to worry when these are questioned, in case children are allowed to be a danger to themselves or to others, if they are not firmly 'kept in place' as not yet competent. Many health staff respect young patients, but they are concerned about the risks of litigation if they overrule a competent child or accept the refusal of treatment from a child who may not be competent. Each case is so individual, that research about the elusive processes

of children's competent decision making is understood more clearly through qualitative case studies rather than through standardized questionnaires. Competence can then be seen as a variable construct rather than a fact, and is heavily influenced by the types of information, support and respect which the adults give to the child. Understandably, busy practitioners prefer definitive, unequivocal research findings. 'So if 16 or 18 is no longer the age of competence, what age shall I look for now?' doctors have frequently asked me. There is no simple answer, which is why I wrote a book about the variety of children having surgery whom I interviewed and their varying circumstances (Alderson, 1993). The examples showed how a child's (in)competence might reside in the eye of the assessor. Part of ethical healthcare is that health professionals work out with each child how able and willing the child is to share in being informed and involved in decision making, instead of making ageist assumptions. I summarized some of the 120 children's views and experiences in graphs, while emphasizing that they could not be taken as representative because they were unusually experienced and knowledgeable about their elective orthopaedic surgery, on average having already had four or five operations. Children being treated for other conditions, or in emergencies, would probably give very different replies. Yet medical reviews of the book treat it as a quantitative report and talk of the research reporting a 'mean age' of consent (Foreman, 1999). A report was rejected by the *British Medical Journal (BMJ)* as too 'soft' in 1992, although the *BMJ* now regularly publishes qualitative reports.

Some methods of research with children
Researching complex interactions

Primary care and community healthcare practitioners spend much time on advising young families about behaviour problems. Rates of diagnosed mental ill health among young people are shown to be rising and earlier preventive interventions are recommended (Rutter and Smith, 1995). Quantitative and qualitative research can support such interventions in differing ways. For example, a quantitative survey might measure parents' views on how often their two-year-olds have 'tantrums'. The results might be used to reassure parents that their tempestuous child is fairly normal, and thus help the parents to 'cope better with a difficult stage'. This could be seen as ethical and supportive family healthcare. In contrast, qualitative observations and interviews might examine: how disagreements arise; how and why the children and adults behave as they do within certain interactions; how each person concerned perceives the 'tantrum' which they may not define as such; and how, if they are unhappy about the episodes, they try to prevent or resolve them.

Research which examines how people share in constructing behaviours and beliefs about one another can help to increase adults' and children's awareness and, potentially, their control over their interactions. They may move from angry confrontation to reasoned negotiation. Intrinsic to such research are theories of young children as agents who can reason and reflect and act consciously (Mayall 1994; Miller 1997). The research could be said to support ethical healthcare by respecting both adults and children as moral agents (people who are aware of moral values and actively try to respect them) and who affect one another's mental health. Blame no longer rests solely on the child's developmental stage, and responsibility to understand and look for resolutions is shared, albeit unevenly, between adults and children, such as by showing young children how to use mediation skills (Highfield, 1997). These types of qualitative or quantitative research findings will be accepted or rejected by practitioners and families partly depending on whether they agree with the underlying theories about childhood and competence.

Another example of how exploratory descriptive research might support ethical healthcare would be in detailed studies with children who have, say, cystic fibrosis. The research could examine how children share in managing their arduous daily healthcare routines, what problems they experience and try to overcome, and what works well. Starting from a basis of family health, the research could then report models of effective care, for other families to select from and adapt. From their earliest years, children have to cooperate with gruelling physiotherapy and unpleasant diets and, if stress and resistance are to be reduced, the children have to understand the reasons for the treatment and why treatment is preferable to the untreated disease. Two-year-olds have been found to have sophisticated knowledge about their cancer treatment (Kendrick *et al.,*

1986) and children were found to protect their parents from realizing and worrying about how much the children knew (Bluebond-Langner, 1978), yet research about young children's responsible self healthcare is seldom conducted.

The Wellcome Trust has recently funded a qualitative project among East Londoners originally from Bangladesh who have type 2 diabetes (Greenhalgh, 1999). Many speak a dialect which has no written form. Researchers found that the people had gained most of their knowledge about good management from their friends, not from health professionals, and through telling stories, an activity they valued highly. Much useful knowledge was gained from the research about the problems people experienced, and the story medium through which they enjoyed communicating. A two-year development project currently involves introducing story telling as an integral part of 'empowering' healthcare, and is training advocates in story telling skills to work with individuals and groups to increase ways they can help one another. This is an example of how the ethos and methods, as well as the findings, of qualitative research can inform healthcare practices. These methods are also useful in research with children.

Conversation analysis

An example from qualitative conversation analysis illustrates how aware young children can be and how their viewpoints can be revealed through research. In an example of therapy, Stuart, aged four, and his speech therapist look at a picture of a spotty face, to start talking about 'sp'.

Therapist	S:pots
Stuart:	Bots (looking at picture).
Therapist:	Pots?
Stuart:	Bots (looking at therapist then away).
Therapist:	Are they pots?
Stuart	(Looks to therapist again and shakes head.)
Therapist	Let's hear the Sammy snake sound at the beginning then. (Pause) .h s:pot.
Stuart:	Bots.

(Gardner 1998)

The speech therapist wants Stuart to realize his pronunciation errors and learn to correct them spontaneously. To achieve this, she tends to suggest corrections implicitly and does not tell Stuart exactly what she wants him to do and why, as if she thinks that if Stuart becomes conscious of the problem and the correction he will not be able to do this spontaneously, and almost subconsciously. The main topic of her conversation is sounds, but Stuart assumes that, as in ordinary conversation, the main issue is the sense and meaning of the words, not their sounds, and that the aim is to check whether the things in the picture actually are spots. It is not that Stuart is too limited to understand the therapist's rules, but that she does not explain them. Stuart is skilful in the ordinary rules of conversation and keeps trying to apply them here, although his efforts are not seen by the therapist as sense (trying to follow the usual rules), but as non-sense (not following any rules) and as a failure to understand sounds and 'repair errors'.

It could be helpful for the therapist to treat Stuart more as an informed partner. She could look at why Stuart's responses make sense to him, and explain to him her agenda. Before being able to correct himself spontaneously, Stuart has to understand her aim of teaching him a new skill (pronouncing 'sp'), and how and when to use it. This would involve moving from a rather behaviourist-training approach to a closer partnership, an explicitly discussed and shared agenda, spending more time on consulting and appealing to his informed cooperation, and less on instruction.

Combining observation and interviews: theory and method

With this kind of detailed observation obtained through conversation analysis, it is usually only possible to collect relatively few examples, although Dunn (1993), for example, has combined qualitative work involving many children with quantitative analysis. Yet the scale, standardized methods and necessary speed of much quantitative research tend to limit people's responses, partly by fitting brief replies into pre-ordained categories, rather than considering each person's distinctive perceptions at some length.

Qualitative case studies, by showing the interactions and cross-effects between variables within each example, can unravel complex ways in which disability, like childhood, is socially constructed. Disability researchers distinguish between the 'medical model' of disability which emphasizes individuals' physical impairments, and the 'social model' of disability which examines how people are disabled by social attitudes and barriers (Oliver, 1996). Research which reveals these detailed construction processes involves spending time with children at home and school. One study of disabled children's views of their special or integrated schools began by talking with them and their parents at home and later, with their permission, at their schools. The children's social integration or exclusion was clearly shown by their local friendship patterns. Those who travelled long distances to special school tend to be isolated and lonely at home. Those who attended local mainstream schools tended to have more confidence, like Michael, aged 11, who was playing outside in the street in his wheelchair before his interview. Later, his mother mentioned how a market trader had asked 'What's he got a wheelchair for?' Michael replied, 'Wass he think? It's an early Christmas present?' (Alderson and Goodey, 1998: 156). Siobhan, whose mother fought for her to go to mainstream nursery and school, was similarly streetwise when she continued the fight at her new secondary school. She commented:

> 'Well, that was hard work, because there weren't no lift, and for the first year I was there lots of teachers had to come to me. First I had no lessons. I was sitting in reception and everything; some teachers came downstairs, some didn't. And I wasn't getting no lessons, but eventually a lift came in. [It was] kind of horrible, 'cos you see I wasn't mixing with friends. First thing, I had no friends, 'cos they was all going to their lessons, so it kind of built a barrier a bit, 'cos I could only go to lessons which was on the ground floor. In the end they was rescheduling the lessons...when the lift was built it was much better.'
>
> (Alderson and Goodey, 1998: 143)

Siobhan summarizes here many of the themes of socially constructed disability: her hard work to avoid being excluded; other people's relative indifference; the way the lessons could have been rescheduled earlier; and how the teachers tended to think in terms of needing equipment, a lift, instead of also reviewing their own attitudes and practices.

Linda, aged nine, talked enthusiastically about playing with her friends, and enjoying swimming, brownies and playing football using her crutches. At the end of her interview I asked if she had anything to add, and she replied that when things are hard, 'I don't give up. I try, but if it's too much I give up', mentioning how she tried hard at recorder, choir and chess (Alderson and Goodey, 1998: 132–3). When we walked to her school she pointed out the houses where her friends lived, reinforcing her interviews about her sense of social inclusion. In contrast, students at special schools who tended to have few friends at school and none at home, usually spoke less about activities, and more about their anxieties, short-comings and loneliness. Interviews included observations especially with children who did not speak and who communicated with signing and other body language.

During my research about children's consent to surgery, interactions between children and parents illustrated how they shared the medical decision making. John created an exhibition for me of his false legs he had collected over 16 years. His own and his family's hilarity reflected the humorous and determined way they

described having coped with the many difficulties they encountered. In another example, Tina, aged 12, told me she wanted to be involved in decisions: 'Most of the doctors I go to talk over my shoulder to my Mum and I don't like that. I'd rather they talk to me, 'cos I think, "Cor, well, I'm having the operation, why are you talking to Mummy?"' During her interview, Tina had a heated argument with her mother and aunt about an experimental growth treatment she wanted to refuse. She ran through her arguments fluently, showing her clear understanding of the harms and benefits of research, potential conflicts between her present and future interests, how new social arrangements had made her restricted mobility much easier to cope with, and her determination to be accepted for herself, 'I'd rather stay like me'. During the argument, Tina spontaneously made comments which showed her ability to weigh decisions and accept the risk that, 'If I make the wrong decision, it's my own fault, not my Mum's' (Alderson, 1993: 37–9). Her comments, through being volunteered, could be seen as having greater validity, being closer to her actual feelings, than if she had been replying to sets of specific questions.

Research theories about childhood and disability as social constructions are linked to research methods intended to be as inclusive as possible, such as by using plain language, and making time for children to talk about their own concerns in open-ended interviews and through shared activities. Interviews with children, or with adults who have learning difficulty, about their understanding of consent to health treatment and their competence to make decisions, go beyond being simply research accounts. They are similar to clinical interviews between patients and practitioners who are trying to assess competence. The research method and 'raw data' are like the clinical method and data. Clinicians checking whether the child can 'really' understand rely on flexible interviews when through the conversation they discover whether children are simply repeating phrases, or are speaking with understanding and intention.

Working out shared priorities

The 1989 UN Convention on the Rights of the Child article 12, on the child's right to express a view on all matters which affect the child (UN 1989), influences Non-Governmental Organizations (NGOs). They have developed research with and by children in accordance with it. The following example shows how even the poorest of poor children can understand and undertake research (Khan, 1997). Eleven Bangladeshi street children aged 10–15 years, five girls and six boys, interviewed 51 other street children aged 7–15 years in Dhaka. The research team held 16 meetings. They chose the topics and questions, the methods and the interviewees. They did one or two interviews each morning and, as they were unschooled, they dictated all they could remember to adult scribes in the afternoon. The team then listened to every transcript and argued about the 11 priorities they wanted to report, which they identified after comparing and synthesizing many issues. They eventually decided that the greatest difficulties reported in the interviews were the following:

1. torture by police;

2. torture by muscle men (who force children to smuggle arms, deal drugs, do sex work);

3. misbehaviour by adults (who call children bad names, never use the child's own name, chase them away, and accuse them of being bad);

4. dislike present job;

5. do not get job without guardian (to be an advocate in an adult-run society);

6. marriage problems of girls (even slum girls can get a husband even street boys would not marry bad, dirty street girls);

7. uncertain future (as they get older girls cannot stay on the street but have no where else to go);

8. poor income, cheated by adult traders when pick rags, have to find dirty rotten food;

9. street girls are hated as they are involved in bad things (adults force children to do bad things then punish and blame even the innocent ones);

10. cannot protest against injustice without adult relatives to help, hopeless to try to get help from police without an adult guardian;

11. no access to education (though they want vocational training more than years of schooling).

It is rare for organizations like governments and the World Bank to listen to children. Yet if global policies about child health are to be informed and effective, it is essential to discover first what children as intended beneficiaries think that they need. The assumption that adults know best is challenged by numerous global problems of war and want. These young researchers dictated, and had read back to them, three reports in Bangla, one in English, and a leaflet in both languages. They were very keen to publish their views and to write for specific influential groups, and they also did radio and television broadcasts, illustrating their main points with details from the interviews. Their conclusions challenge the international aid policies in their emphasis on health and education programmes which, in effect, can mean paying Western agencies and commercial companies to provide services. Only two of the Bangladeshi child researchers' 11 points refer to material needs (poor income and rotten food). Instead, they said they wanted social change to help them to gain access to justice, to reasonable protection from assault, and to better work, creating a society where adults listen and are not violent or abusive, and where policy makers rethink the world from the viewpoints of children and young people.

Linking qualitative research to ethical healthcare

Qualitative and quantitative approaches tend to be linked to different implicit concepts of ethical healthcare. Surveys and trials tend to emphasize expert services which protect and support relatively passive patients. Qualitative interviews, by allowing time for patients to give their detailed views, can treat them more fully as morally aware actors. They can also demonstrate respect for children, and justice in (re)balancing relationships between children and adults. There are risks in any research of being over-intrusive, and of supplying misleading evidence which might, for example, lead to children being over-loaded with responsibilities, guilt and anxiety they would prefer adults to bear for them. These serious dangers require careful discussion and reporting throughout the research process and, as far as possible, when the research is disseminated, interpreted and applied. Yet because the whole area of how parents and children can and could share in the daily management of behavioural difficulties or of chronic illness or disability is under-researched, little is known about whether children feel over-burdened or too excluded from taking responsibility. How their early experiences affect their self care later in the teenage and adult years is also unclear. A vision of young children not needing to have any responsibility is unrealistic since such high levels of their cooperation with unpleasant procedures are essential with some chronic conditions. Yet funding for such research is unlikely to be granted until funders, and society generally, acquire more realistic views about children's actual and latent capacities.

In research about issues such as children's competence, representativeness need not be very important. This is because the question for ethical healthcare is not 'How *many* children of a certain age are competent to give consent to surgery?' but 'Are *any* children, perhaps exceptional ones, competent at this age?' Even if only a few children aged four years show that they are able to make serious decisions, this can be valid reliable evidence, supporting a recommendation that clinicians should check this possibility with each young patient.

Qualitative research is less concerned with providing standardized evidence to inform fast, mass healthcare, than with reminding clinicians of the uniqueness of each patient. Instead of giving generalizable, predictable standards, such as to look for competence in children aged over eight, or over 14, qualitative evidence suggests: Look for emerging competence in every child. Work out with each child how much information

and shared decision making seems to be in the child's best interests. Apply the exploratory methods of qualitative research to clinical practice. Respectful listening can help to avoid doing harm, the first principle in ethical healthcare.

Commenting on a collection of social research projects with children in hospital, about their distress at being away from home and being treated like 'work objects', Margaret Stacey wrote about differences between biological-medical research and social research.

> 'In our acceptance of medical practice we have accorded doctors the right to inflict pain. Our concern therefore has to be to see that...health workers do not inflict pain unnecessarily; we believe our skills as social scientists make it possible for us to point out the unintended suffering inflicted, suffering which is unrecognized and which may perhaps be unnecessary or avoidable. Our claim...is to be able to observe and analyse such sufferings in dimensions where doctors and nurses are unsighted by virtue of their training. Their gaze is directed to the mysteries of physiology and anatomy...our gaze has been trained to look at the workings of the mind and of society...to look below the surface of the commonsensical and see the deeper implications.'

(Stacey, 1979: 186–7)

Besides looking below the surface at implicit theories, unspoken experiences and underlying patterns and structures in healthcare, qualitative research can help to unpack misleading and oppressive stereotypes about childhood and disability, and to obtain more accurate accounts of children's experiences and views. Reflexive researchers also acknowledge that all research, like all human interactions, inevitably constructs and reconstructs our experiences and perceptions to some extent.

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Discussion

Comment We have heard today about the difficulty of knowing what people think from what they say. How do you think you can know what the men with cancer are saying to you?

Response (CM) People say the same things to me over the 15 years I have been working at the Marsden Hospital. They say these things in different ways, but they are saying the same thing.

Comment How do you negotiate access for these very sensitive interviews? How do you inform and warn people about what the sessions might be like so that they can make an informed decision about whether to talk to you?

Response (CM) I have sent the questionnaire to the men before I ask for their consent, so that they can look through it before they decide. I think this is one way of getting over the huge problems which this kind of qualitative and quantitative work presents. We also have back up for everyone, we have a geneticist on hand and we also always offer follow-up counselling.

Comment I was very interested in your book on consent, but the children were very highly informed indeed, and surely they were not typical. So that you could not generalize from them about the competence of every

child to consent to surgery.

Response (PA) Yes I agree with you, and with the importance of being cautious about the risks of over-generalizing from any group. The 120 children were deliberately chosen because they were unusually well informed and we wanted to know how much they would be able to understand, their potential capacity, given the best possible information and support and circumstances. A study of 120 children having emergency treatment would give very different responses, and they would be no more representative of all children. The danger with an emergency group would be of mistaking children's lack of opportunity to learn and understand with an inability to do so, and of concluding that all children or average children are equally ignorant and frightened as people in an emergency tend to be.

Comment So the ones in your book were more typical of all children?

Response (PA) In some ways they were typical, for example there was a range of ability including six of them who attended special schools for physical or learning difficulties. But in important ways they were very unusual. This was not because of their inner characteristics, but because they had exceptional experiences, of very serious illness or disability and surgery. These experiences, though very unfortunate, gave many of the children the opportunity to demonstrate and become aware of their great capacities, such as their understanding and moral courage. I believe that typical children have these strengths which often go unrecognized because (fortunately) most children do not have the adverse experience which reveal these capacities. They live such safe, protected lives that their potential and capacities tend to be underestimated.

Comment Professionals tend to uphold children's right to consent but not to refuse. Did you find that in your research?

Response (PA) Yes, for example, Tina who refused hormonal treatment did not have that in the end. It was partly due to the timing of the research, 1989–1991. 1989 was the year of the Children Act and the UN Convention on the Rights of the Child with children's rights coming to the fore. From 1991 there was the controversial series of High Court cases which retracted on children's rights up to this year. It is worrying that now doctors seem afraid to accept the child's refusal and this uncertainty in the law needs clarifying.

Comment Is qualitative research mainly done by women or do men do it much?

Response (PA) Contract research is mainly done by women because it is such insecure work without a career structure. Some research is directed by men but still mainly carried out by women.

Comment I was wondering whether women had particular skills that were useful in qualitative research.

Response (PA) I think women have advantages when researching families and children, especially as 'parents' in research are usually mothers. It is probably easier as a woman to slip into homes and talk to families there perhaps less obtrusively. One nine-year-old wanted to talk, without being interrupted by her brother, in her bedroom and that might have been more awkward if I was a man.

Comment I thought the interview with Sean was fantastic and I wondered how that would have gone with a male interviewer.

Response (CM) I'm not sure if it had been with a man it would have been different or any better. It would inevitably be biased because I am a woman and because of my age, though I don't need to push that away. But the men I talk to say they are threatened by other men, and by ways some of the doctors talk, and in a sense by the masculinity. There are a lot of things about me that I think have a bad effect on what I am

doing. But also there are some things about me that lend themselves to these men. One is my children, who teach me the language which younger people use.

Comment One thing that is reverberating and I find rather hard to grasp exactly what you mean. You say that being a woman and your age and having children inevitably biases the interview, but you said that it was possible to 'not push it away'. Do you make use of it? Can you say more about that?

Response (CM) I use Jocelyn Cornwell's book and her writing about getting past people's formal 'public' accounts to their intimate private deeper thought. She writes about sitting and waiting for people to speak which will alter their way of talking to you. And the way they talk will change over time. She is a middle class woman, like myself, though in time she was able to talk with people in East London in this more private way. In one study, I interviewed people in their homes and away from the hospital because they felt more comfortable at home and I would say to them 'this is not going to go back, it is between you and me'. When I interviewed the men without cancer who were in the genetic study, almost all of them wanted to be interviewed at work, in their offices. And I would always be sat at a table with the man always sitting in the chairman's seat. There was a change in the balance of power and I would use that, although there is not time to talk here about how I would do that.

Comment I was fascinated by Sean and Tina, but it strikes me that the strengths of this interview, video or book is that it is rather like a novel, you hear a voice that rings home and is very real. At the same time one has this nagging doubt, perhaps an academic concern for truth, which asks how far can one generalize. One could come to qualitative research because of one's own views or concerns or one could come to it because of a question, a genuine wish to know. You could come either from complete ignorance or from a desire to prove something. In writing up qualitative research, how would one guard against the accusation that one was being highly selective?

Response (PA) All research inevitably involves selection and therefore potential problems of bias to guard against. There are methods of managing this, for example, asking a balanced range of questions, checking through all the data for how typical or exceptional each kind of response is, examining the important unusual cases as to how and why they might be unusual, trying to be aware of one's own prejudices and how they might be affecting the way the data are collected and interpreted. Selecting a broad sample of different types, for example from among the rich variety of children in the orthopaedic wards, is also important. Having researched parents' consent, I was interested in the question 'at what age do children begin to be able to be competent?' and I did not expect to find competence at such young ages. At a recent day of lectures about *David Copperfield*, I was reminded of the depth and range of social evidence, analysis and commentary in great novels, and their powerful impact on public policy. These are achieved through different methods from social scientific research, they are different genre, but they both address truths. Our theoretical work and selection are in another dimension. For example, children's ability or inability to understand can be considered against many aspects of their own characteristics or their circumstances, in systematic ways that show you are working with non fiction in the research.

Response (CM) I think another difference is our analysis. We are not just telling a story. My theories lend themselves to illuminating what people say. But my main answer is that this is an area where we are always learning. People come to us, the men with cancer, and they are all telling us something. Other people will do more work in the area and increase our knowledge, but it must all be theory based and carefully analysed.

Response (PA) To continue on the point of asking a question or setting out to prove a point, I'm not sure that being in 'complete ignorance' is helpful, or that it ensures open-mindedness or lack of bias. It sounds more like the 'empty mind' Paul Atkinson mentioned. Before beginning the research you have to review the literature, find out what is already known and where the gaps are, and possibly why there are these particular

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gaps. The gaps in knowledge about children's consent follow dominant traditional theories which assumed children's inabilities and inevitable incompetence, and in order to recognize their competence it is necessary to question and analyse and test these theories first. Surely research is about discovering surprises, the unexpected and counter-intuitive, and being prepared for these. Although qualitative research cannot make generalizations, it can challenge them. You only need two or three detailed examples of ordinary three-year-olds explaining their understanding of their cancer and treatment to refute generalization that they cannot understand to that level until they are seven years old. Paul Atkinson said that research cannot give you access to people's private inner thoughts, but how does he know? Research can't prove a negative. Young children and people with Down's syndrome provide very interesting examples which challenge this denial about the possibility of talking about deep and original thoughts. In some interviews, they express profound ideas too clearly to be imitating or parroting other people's speech, and also in too unusual and idiosyncratic a way.

Comment Are you saying that men don't seem to want to have counselling and therefore that it probably won't do them any good and it shouldn't be offered to them?

Response (CM) I want to see what those men's voices are, what they are saying. I then go with the answer to my colleague and we discuss this many times. We don't change our policies quickly. The change has come through years of research on one topic, masculinity. It has taken 12 years to come to this conclusion against the huge cry for counselling, and say look, we think we are doing more harm than good.

Comment I am interested you can say that you have been able to do years and years of research when funding now tends to be so short-term and hard to raise.

Response (CM) Yes, and it was only after we did our latest trial which was quantitative. If we had done it qualitatively we would have got a different answer. We found that the men who were counselled did worse than the control. We looked at who said yes to counselling, who said no and why. And after all this time we have agreed that we don't think that this particular type of counselling, with this particular set of cancer patients, needs to be given routinely. We've been very careful about the words we've chosen.

Comment You said that the qualitative and quantitative research would have resulted in different conclusions, so shouldn't you have to take the quantitative results as more reliable?

Response (CM) With both kinds of research, conclusions depend on the types of questions you ask, the sample selected, the method and analysis, one is not necessarily more valid or reliable than the other. Quantitative research, however immaculately it is designed, does not necessarily yield definitive results. I have seen statisticians wringing their hands as to how they should interpret something when the results are not clear cut. We are also relying on theory. I don't think we can come to any conclusion about theory.

Response (PA) Every researcher has to worry about fairness and accuracy all the time and in the end all you can do is try to do your best.

Comment I think Paul Atkinson was talking about not going in with preconceptions, about letting people tell their own stories and looking at how they tell them, generating hypotheses from that, and then going to have conversations with more people that will test that hypothesis. When you use the word theory it is not always obvious what you are saying.

Response (CM) Yes, I'm talking about my work and also about other people's work, and about a whole body of work.

Response (PA) Some examples of theory are the social construction of masculinity and the social construction of childhood and the work by many researchers to unpack traditional assumptions and how they colour our beliefs and behaviours so that we construct and reconstruct, for example, the macho man or the vulnerable child through the way we interact. Then we can see more clearly what is going on and how we as researchers are also drawn into and repeat these patterns – or critically examine them. There are many levels of theories, including for instance, beliefs about what is truth and how do we know what we know. This is slightly easier in medicine which gazes on the sick body. In social research we examine meanings and experiences of illness which are more elusive and shifting. Theories deal with different kinds of knowledge and different ways of apprehending them.

Comment The video was so rich, for example in Sean's body language and the directions in which he looked at various times. There are so many ways in which it could be analysed. What main theories and methods did you use for doing this, grounded theory for example?

Response (CM) I should have explained that this video was made and will be edited for a lecture I have to give in December, it was not a research interview. In my research, yes I use grounded theory.

Comment Yes, I think as qualitative researchers we need to make clear that there are conventions and agreed methods and ways of doing our work, a whole body of knowledge which is very fully developed and debated, and is not pie in the sky. We might talk about the transferability rather than the generalizability of qualitative research.

Comment As a philosopher I know we could argue about method all night. I'm more interested in how hard you have succeeded in getting your work taken up into policy in local hospitals and also nationally and how we can learn to do that using these kinds of methods, how can we sell this research?

Response (PA) The children's consent to surgery work published in 1993 does seem to have had a national impact. Many nurses have done follow-up studies. At medical and nursing conferences now, not only parents' consent but also informing children, listening to them and involving them in decisions about treatment seems to be taken seriously by many people. The great worry is uncertainty in current law. Last July, three High Court cases overruled children's views, to the extent of authorizing that a heart transplant might be enforced on a 15-year-old girl. In 1996, lawyer Jonathan Montgomery and I published a book recommending that the law was too blunt an instrument to promote clinical standards of good practice – a Code of Practice would be more effective, and the BMA now has a group working on guidelines which could help practitioners to have more confidence in respecting children's views*. It is a very slow process, but fortunately very many people are engaged in it.

* The report is now published: Romano-Critchley, G and Sommerville, A *Consent, rights and choices in healthcare for children and young people* (BMA, 2001).

Overview of the conference

Conference Chair: Jonathan Glover

The English are reputed to have a genius for compromise, and perhaps one example of this is to arrange a one-day conference on so complex a topic as qualitative research. During the day, we have considered the relevance of qualitative research to policy, and to matters which we hope to have some influence in changing. As a philosopher, I have recently begun research with a psychiatrist in a special psychiatric hospital, and to ask, how do I begin to do qualitative research? We have held this conference in the belief that replies to this question would interest many people working in health research or planning to do so.

Our first speaker, Professor Blaxter, spoke about how policy in the broader sense needs to be informed by qualitative research that should have a wider audience. Yet the average academic paper is read by only three people. I welcome the idea of expanding the audience for qualitative research, for extending its links with evidence-based medicine, and with ethics and multidisciplinary research. I would add a plea for moral reflection itself during the research process. It is a pity that no philosopher is involved with drawing up the ethics guidance on qualitative research. I will briefly review some of the main themes of the day.

Ethics

Qualitative and quantitative research raise many ethical issues and deep methodological problems throughout their processes. It is wrong to suppose that talking cannot have any benign or adverse effect on people. Just as much a matter of potential concern, are questionnaires. There is also no absolute guarantee of confidentiality, and we ought to think pretty hard about what standards of confidentiality we are going to agree on. The ethical problems raised by research have been made clear, and I don't have obvious answers to them.

Methods

Professor Atkinson pointed out, regarding methods, that qualitative research is not a discipline in itself. Researchers working in specific disciplines need to bring their discipline to it, with sharply focused questions from our own discipline and our human experience. We have to ask why have this pattern and method and not others? How can we avoid bias in selection? These are very real problems, but almost any human study is going to have this problem.

History

Because qualitative research is a fairly recent phenomenon, people tend to think these points are new. But we would say that history should not be done because it is inevitably selective. If you ask what are the dates for the second world war, you would get very different replies from the UK, the US, Japan and Russia, because they joined at different times. Yet that doesn't discredit the whole subject of history.

Principles and communication

Atkinson talked about principles, and he thought we would accept his analysis of the social shaping of identities and the pervasiveness of the moral order which constructs our identities. I thoroughly enjoyed his splendid take-off of a person walking along and changing direction. It seems to have a ring of truth, but you don't need to be a social scientist to know this. Novelists can write about it too, as Alan Bennet has done when describing being in a doctor's waiting room. When his suit against the sofa made a fart-like noise, he moved about a lot on the sofa, to make clear to everyone else there that the noise was not what they thought it was.

But I wondered about these principles of moral display, as if we have to see people's beliefs and categories in a slightly detached way, as a product of their circumstances. Do we really see other people's principles in this way and, if so, what do we make of Paul Atkinson's own principles and account? Nietzsche said that there are no truths, only perspectives. Yet is this point also only a perspective, and if so, how can it

ultimately deny truth? Nietzsche's point applies to some of these highly debatable points in social science. This morning, we were presented with very different ethical and methodological issues, which made me wonder if I'd made a wrong move into qualitative research, it seems so enormously difficult. This afternoon, there were quite a few impressive grounds for hope, especially in cases of a degree of intuitive interpretation that doesn't exactly look like science.

Intuition

Do we too often dismiss human intuitive knowledge of each other as not rigorously scientific enough? Science must be as rigorous as possible, but Aristotle advises us to have the right degree of position that is appropriate to the subject matter. Human beings are pretty well equipped to understand each other's behaviour intuitively. This shows in novels. We understand each other very well, although we are open to different interpretations.

For example, in *Anna Karenina* two people were widely expected to get married. They both thought they would, and all their friends thought so too. They went to look for mushrooms in the birch woods and each thought this was the right moment. He was a bit nervous and he walked off to prepare what to say to Varenka. When he returned and began to speak to her, she blurted out a question about mushrooms. He was thrown, and they both felt the momentum dying away, and they didn't get married after all. Intuitively, we understand that kind of story very well. We all have failed to say things because of social awkwardness, and so on.

As far as possible, we must subject our interpretations to rigorous scrutiny in social science research. Yet because there are very many things that could be said about Sean's account, we don't need to say that Clare's interpretation is implausible. Nick Humphrey's psychological work suggests that on evolutionary grounds, we would expect humans to understand each other fairly clearly, unless someone has a psychological disorder. And when this happens, one way we identify and define certain types of psychological disorder is to say that the complex sophisticated mutual understanding we expect is not happening. But we see this as 'disorder', not as a usual state of affairs. Part of the human brain is devoted to the interpretation of faces. We are highly programmed, it seems, to interpret other people's beliefs and attitudes.

Paul and Priscilla spoke about getting through to other people's deep beliefs. We can get people to talk about deep beliefs, and there is respectable evidence that people will do this, though I agree with being alert to stereotypes when interviewing – our own and other people's. I am concerned about this in my future interviews with people with neuro and psychiatric conditions, and I do not want to say 'don't let's worry about the science, let's just get as close as we can.' I do also want to explore intuition, how we gauge and relate to one another. I was in the hospital sitting room when a woman with a trolley came up and shouted at me, 'Would you like a milky drink?' I said, 'No, thanks.' On hearing my voice, she said, 'I'm terribly sorry I thought you were a patient.'

We have heard about qualitative papers being turned down by the *British Medical Journal* because they were 'too soft'. Should we question the categories of hard and soft? Otherwise an enormous amount of human material of vital importance will simply slip through the net of published research that might influence policy.

Dr Bobbie Farsides
Chair of the UK Forum for Health Care, Law and Ethics

We know, through the Forum which has organized this conference, that more teachers in law and philosophy are making links with people in social science and doing multidisciplinary research, including that which Wellcome is sponsoring. Thank you Jonathan, for chairing this conference and to all the speakers, and everyone who shared in the day.

Dr Bobbie Farsides
Chair of the UK Forum for Health Care, Law and Ethics

APPENDIX

Criteria for the evaluation of qualitative research papers

Adopted by the Medical Sociology Group of the British Sociological Association, 1996

1   Are the methods of the research appropriate to the nature of the question being asked?

- Does the research seek to understand processes or structures, or illuminate subjective experiences or meanings?

- Are the categories or groups being examined of a type which cannot be preselected, or the possible outcomes cannot be specified in advance?

- Could a quantitative approach have addressed the issue better?

2   Is the connection to an existing body of knowledge or theory clear?

- Is there adequate reference to the literature?

- Does the work cohere with, or critically address, existing theory?

Methods

3   Are there clear accounts of the criteria used for the selection of subjects for study, and of the data collection and analysis?

4   Is the selection of cases or participants theoretically justified?

- The unit of research may be people, or events, institutions, samples of natural behaviour, conversations, written material, etc. In any case, while random sampling may not be appropriate, is it nevertheless clear what population the sample refers to?

- Is consideration given to whether the units chosen were unusual in some important way?

5   Does the sensitivity of the methods match the needs of the research questions?

- Does the method accept the implications of an approach which respects the perceptions of those being studied?

- To what extent are any definitions or agendas taken for granted, rather than being critically examined or left open?

- Are the limitations of any structured interview method considered?

6   Has the relationship between field workers and subjects been considered, and is there evidence about how the research was presented and explained to its subjects?

- If more than one worker was involved, has comparability been considered?

- Is there evidence about how the subjects perceived the research?

- Is there evidence about how any group processes were conducted?

7 Was the data collection and record keeping systematic?

- Were careful records kept?

- Is the evidence available for independent examination?

- Were full records or transcripts of conversations used if appropriate?

Analysis

8 Is reference made to accepted procedures for analysis?

- Is it clear how the analysis is done? (Detailed repetition of how to perform standard procedures ought not to be expected.)

- Has its reliability been considered, ideally by independent repetition?

9 How systematic is the analysis?

- What steps were taken to guard against selectivity in the use of data?

- In research with individuals, is it clear that there has not been selection of some cases and ignoring of less interesting ones? In group research, are all categories of opinion taken into account?

10 Is there adequate discussion of how themes, concepts and categories were derived from the data?

- It is sometimes inevitable that externally given or predetermined descriptive categories are used, but have they been examined for their real meaning or any possible ambiguities?

11 Is there adequate discussion of the evidence both for and against the researcher's arguments?

- Are negative data given? Has there been any search for cases which might refute the conclusions?

12 Have measures been taken to test the validity of the findings?

- For instance, have methods such as feeding findings back to the respondents, triangulation, or procedures such as grounded theory been used?

13 Have any steps been taken to see whether the analysis would be comprehensible to the participants, if this is possible and relevant?

- Has the meaning of their accounts been explored with respondents? Have apparent anomalies and contradictions been discussed with them, rather than assumptions being made?

Presentation

14 Is the research clearly contextualized?

- Is all the relevant information about the setting and subjects supplied?

- Are the cases or variables which are being studied integrated in their social context, rather than being abstracted and decontexualized?

15 Are the data presented systematically?

- Are quotations, field notes, etc. identified in a way which enables the reader to judge the range of evidence being used?

16 Is a clear distinction made between the data and its interpretation?

- Do the conclusions follow from the data? (It should be noted that the phases of research – data collection, analysis, discussion – are not usually separate and papers do not necessarily follow the quantitative pattern of methods, results, discussion.)

- **Is sufficient of the original evidence presented to satisfy the reader of the relationship between the evidence and the conclusions?**

- Though the presentation of discursive data is always going to require more space than numerical data, is the paper as concise as possible?

18 Is the author's own position clearly stated?

- Is the researcher's perspective described?

- Has the researcher examined their own role, possible bias, and influence on the research?

19 Are the results credible and appropriate?

- Do they address the research question(s)?

- Are they plausible and coherent?

- Are they important, either theoretically or practically, or trivial?

Ethics

20 Have ethical issues been adequately considered?

- Is the issue of confidentiality (often particularly difficult in qualitative work) been adequately dealt with?

- Have the consequences of the research – including establishing relationships with the subjects, raising expectations, changing behaviour, etc. – been considered?