

University of Warwick institutional repository: <http://go.warwick.ac.uk/wrap>

This paper is made available online in accordance with publisher policies. Please scroll down to view the document itself. Please refer to the repository record for this item and our policy information available from the repository home page for further information.

To see the final version of this paper please visit the publisher's website. Access to the published version may require a subscription.

Author(s): F. Griffiths, E. Green and G. Bendelow

Article Title: Health professionals, their medical interventions and uncertainty: A study focusing on women at midlife

Year of publication: 2006

Link to published version:

<http://dx.doi.org/10.1016/j.socscimed.2005.07.027>

Publisher statement: None

Health professionals, their medical interventions and uncertainty: a study focusing on women at midlife

Authors:

Frances Griffiths - University of Warwick

Eileen Green - University of Teesside

Gillian Bendelow - University of Sussex

Abstract

Health professionals face a tension between focusing on the individual and attending to health issues for the population as a whole. This tension is intrinsic to medicine and gives rise to medical uncertainty, which here is explored through accounts of three medical interventions focused on women at midlife: breast screening, hormone replacement therapy and bone densitometry. The accounts come from interviews with UK health professionals using these medical interventions in their daily work. Drawing on the analysis of Fox (2002) we distinguish three aspects of medical uncertainty and explore each one of them in relation to one of the interventions. First is uncertainty about the balance between the individual and distributive ethic of medicine, explored in relation to breast screening. Second is the dilemma faced by health professionals when using medical evidence generated through studies of populations and applying this to individuals. We explore this dilemma for hormone replacement therapy. Thirdly there is uncertainty because of the lack of a conceptual framework for understanding how new micro knowledge, such as human genetic information, can be combined with knowledge of other biological and social dimensions of health. The accounts from the bone densitometry clinic indicate the beginnings of an understanding of the need for such a framework, which would acknowledge complexity, recognising that factors from many different levels of analysis, from heredity through to social factors, interact with each other and influence the individual and their health. However, our analysis suggests biomedicine continues to be dominated by an individualised, context free, concept of health and health risk with individuals alone responsible for their own health and for the health of the population. This may continue to dominate how we perceive responsibilities for health until we establish a conceptual framework that recognises the complex interaction of many factors at macro and micro level affecting health.

Abstract word count: 302

Key words: uncertainty; women's health; medical interventions; complexity; health professionals

Full word count:

Introduction

Medical uncertainty, a term thought to be initiated by Parsons (1951), and developed further by Fox (1999, 2002) has become a key aspect in understandings of contemporary interactions between health professionals and patients (Gabe et al 2004) as modern society is increasingly characterised as one in which individuals seek to reduce anxiety and powerlessness by pursuing rational choices and no longer passively accepting their fate (Giddens 1991, Alaszweski and Harvey 2001). The rhetorical nature of such individual choice has however been problematised (Lippman 1999, Alaszweski and Harvey 2001) as, certainly in the case of technological medical interventions, doctors remain the key decision-makers in their deployment. Foucault (Foucault, 1976) has argued that medical power is maintained through the operationalisation of the medical discourse. Using data collected from an ESRC funded study {Griffiths, 2003 #411}, this paper examines issues of uncertainty and medical interventions for women in mid-life in order to contribute to understanding how medical power is currently being maintained through these discourses and the potential for change in the discourse of medical uncertainty.

The study focuses on three medical interventions focused on women at midlife: breast screening with mammography, screening for risk of osteoporosis (brittle bones) using bone densitometry and hormone replacement therapy (HRT), used for the relief of symptoms of the menopause and, until recently, widely used for the prevention of osteoporosis. The medicalisation of women's bodies at midlife, at least in part through the use of these technologies, has been debated over the past 20 or more years. It has long been argued that HRT can be seen as a form of social control imposed on women to keep their pathological bodies under control and to conform to societal expectations which value women in terms of youth and beauty (Oakley 1984 Martin 1987 Greer Klein & Dumble, 1994). However, more recently it has also been argued that women engage with medicalisation (Denny 1996, Griffiths, 1999; Williams & Calnan, 1996) and may even see HRT as a lifestyle choice to help cope with the effects of ageing and to reinvent themselves (Fairhurst, 1998). Roberts argues that sociological theory needs to allow for the possibility of HRT working to the benefit of some women (Roberts, 2002:). However, the literature has not examined the discourse used by health professionals about the medical interventions they use and about medical uncertainty, a missing element in understanding the dynamics of the power relationship between midlife women and health professionals.

Screening forms part of what has become known as surveillance medicine (Armstrong, 1995) which, it is argued, has become a major part of health care. (Nettleton, 1996) has pointed to potential negative consequences of screening for women. For mammography screening this can include the anxiety engendered by false positive results and the false reassurance of false negatives (Gigerenzer, 2002). Medical interventions such as screening can produce specific measurements, the interpretation of which may be perceived as a threat to the individual (Lauritzen and Sachs, 2001). Although aware of the potential negative consequences of screening for women, Nettleton points to paradoxes embedded in prevention where the health of the community is the aim, commenting 'all citizens have a right and a duty to maintain, contribute to and ensure... their health status' (Nettleton, 1997). Women at midlife recognise this responsibility as one factor in their decision making about screening for osteoporosis (Griffiths & Green, 2003a). (Mant, 1994) has suggested that doctors, who are normally focused on diagnosis and treatment of individual patient's illness, are willing to take on a role in screening aimed at the whole population, as they feel a responsibility for patients who develop a disease that they consider could have been prevented through screening, despite evidence questioning the usefulness of some screening. These commentaries on both women and health professional's approach to screening alerts us to the uncertainty for individuals within any screening: how can we know that a particular individual was better off for being screened? Screening is based on

estimates of probability so we cannot know for certain. Gigerenzer (2002) in his commentary on breast cancer with mammography, suggests that many doctors over interpret the possible benefit of breast screening because they do not sufficiently understand the probability, and that this contributes to the perpetuation of an illusion of harm-free benefit for women. The medical profession are beginning to learn how communication about risk can be improved (Edwards, Elwyn, & Mulley, 2002). However, the uncertainty implicit in risk remains. Writing in the Lancet about the use of medical evidence in consultations Sullivan and MacNaughton (Sullivan & MacNaughton, 1996) talk of doctors taking an interpreted and individualized approach, in which the doctor acts ‘wisely in the face of inevitable uncertainty’ (page 941)

The inevitable uncertainty in medicine, in particular in relation to technological interventions, is the focus of this paper. As we have discussed, this is an issue for those using the intervention, here the midlife women and those deploying it. We focus on health professional discourse on uncertainty, a missing element in the current literature. Other papers from the same project examine how doctors talk to women about uncertainty (Griffiths, Green, & Tsouroufli, 2005) and what women hear from their health professionals about uncertainty (Green, Thompson and Griffiths in preparation). Renée C Fox has developed the most extensive framework for understanding the different types of medical uncertainty (Fox, 2002). This paper uses her framework in the analysis of interviews with health professionals talking about the three medical interventions focused on women at midlife. Fox (ibid) suggests that medicine and its relationship with uncertainty is an indicator of more general social and cultural trends. This paper aims to explore the ‘social and cultural’ implications of the discourse of health professionals about medical uncertainty.

The idiosyncratic and the generalising in medicine

Rosenburg ((Rosenburg, 1998) explores the tension in medicine between a desire to attend primarily to the individual patient and a need to attend to the health issues for the population as a whole:

‘The conflict between idiosyncrasy as opposed to the...generalising – tendency is central to medicine’s history... Although there is an essential tension between the two ways of understanding medicine, they are, in practice, mutually constitutive. Diseases must always manifest themselves in the bodies and minds of individual patients. And – reciprocally – a focus on the individual and the idiosyncratic leads the physician towards the general and the schematic as he or she seeks to treat and predict. (page 349)

This account from Rosenberg clarifies that the tension integral to medicine between the idiosyncratic and the generalising is here to stay. Medicine will always face the tension between giving priority to the needs of the individual patient and giving priority to population health needs. Medicine also faces tensions about what is good medical evidence, based on studies of populations or individual patients. These tensions are explored for mammography screening, HRT and bone densitometry.

We chose to investigate these three interventions as they are focused on one stage in women’s lifecourse, and are often used by healthy women. This allows exploration of the issue of uncertainty in relation to medical interventions without needing to pay careful attention to other issues such as age, gender and also types of illness and suffering, particularly the vulnerability of those receiving a medical intervention. The three forms of intervention are interrelated through their use and side effects. Mammography is used for breast cancer screening. HRT was used for

the prevention of osteoporosis, the latter being detected through the use of bone densitometry. There is evidence that HRT use increases the incidence of breast cancer (Million Women Study Collaborators, 2003; Writing Group for the Women's Health Initiative Investigators, 2002).

Drawing on the analysis of (Fox, 2002) we distinguish three aspects of medical uncertainty that arise from the tension between the ideosyncratic and the generalising in medicine. Firstly, there is uncertainty about the balance between the individual and distributive ethic of medicine. For example, what is the appropriate balance between attending to individual's health needs and attending to health needs of a population and what benefits and disbenefits does attending to the one have for the other? For example, attending to population health needs may cause disruption for some individuals. Likewise, attending to individual needs may use resources that could have been used for the needs of the population. Secondly, there is the dilemma faced by health professionals when using medical evidence generated through studies of populations, such as clinical trials and epidemiology, and applying this evidence to individual patients. For example, we know that smoking causes cancer but a doctor does not know if the patient sitting in front of them will get cancer or not. This Fox calls 'epistemological uncertainty' (ibid). Thirdly there is uncertainty because of a lack of a conceptual framework for our understanding. For example how can the new knowledge about the human genome (our genetic make up), be combined with knowledge about other biological and social dimensions of medicine and health to be of use to the practice of medicine? Medicine does not have a conceptual framework for linking up the different levels of understanding related to health from genes through physiology, psychology, family, community and society. These three aspects of uncertainty will be explored below. Accounts of each of the health care interventions, breast screening using mammography, hormone replacement therapy and bone densitometry, will assist in exploring the three types of uncertainty.

The study

This paper considers data collected as part of an ESRC funded research project (Griffiths, Green, Bendelow, & Backett-Milburn, 2003) which was part of the Innovative Health Technology programme (Webster, 2004). The project, undertaken in the UK, involved interviews with 98 women aged 45-64 years sampled from both community groups and health care sites, interviews with 58 health professionals sampled from both primary care and specialist health care sites and 109 recordings of health care consultations (Griffiths, Green, Bendelow et al., 2003). This paper reports on semi-structured interviews with the health professionals working in specialist clinics sited in hospital outpatient facilities: a breast screening and follow up clinic, a bone clinic including bone densitometry and a HRT clinic which also sometimes included bone densitometry. Seven nurses, seven doctors and two radiographers were interviewed individually.

At interview the health professionals were asked their views on health priorities for women at midlife in general, their own knowledge of all three medical interventions and how they discussed them with women in the clinic. The interviews did not ask about specific patients but about their clinical practice in general. This paper focuses on what they said about the technology with which they worked.

Analysis of the project data was undertaken by the project team through a process of reading the data, identifying key themes, relating the themes to social science literature and then going back to the data. The theme of 'medical uncertainty' was identified as a strong theme across the data set at an early stage of analysis. Another paper (Griffiths, Green, & Tsouroufli, 2005) reports on how it was dealt with in health care consultations. For this paper the team undertook a

comparative analysis of each health professional's account of the technology with which they worked. The analysis presented is based on the whole account from each interview, but for reasons of space is only illustrated with selected data. These health professionals provide what could be considered an 'expert' view of the medical interventions from within the health professions generally. Fox (2002) identifies that one uncertainty for the individual doctor (or nurse) is the impossibility of knowing all that is known related to medicine and health. The health professionals interviewed for this paper were likely to have a high degree of knowledge about the specific medical intervention with which they worked, and much more than those working in general medical or nursing practice, or lay individuals.

The accounts of the use of the health technologies by the health professionals were analysed in relation to literature on medical uncertainty. This led to the alignment of the different interventions with the three types of medical uncertainty described in the previous section. This analysis is presented below.

The individual and distributive ethic: the example of breast screening with mammography.

Mammography is X-ray of the breast used to detect breast lumps that cannot be felt (screening) or to help with diagnosis when women feel a breast lump. This paper only considers its use for screening when the aim is to reduce the number of deaths from breast cancer in the population as a whole. Its use for screening follows a distributive ethic and in the UK the breast screening service is led by doctors (Cancer Research UK, 2004). However, these same doctors also undertake individual assessments of women asked to attend follow up clinics after screening. In these clinics the focus is on the individual so the individual ethic is to the fore.

In the UK, breast screening with mammography was established following a report based evidence from epidemiology and clinical trials, that early detection and treatment would reduce the rate of early death from breast cancer (Forrest, 1986). Policy makers judge the effectiveness of breast screening in terms of its contribution to population health. An epidemiological study using data from 1990-1998 in England and Wales has shown that the total reduction in mortality from breast cancer for women aged 55-69 years was 21.3% compared to the predicted mortality based on the previous decades increasing mortality. Not all of this change in mortality rate can be attributed to the breast screening programme, although it is estimated that about one third of the reduction is a direct effect of screening (Quinn, 2004). The reduction in death rate by screening is only brought about through individuals attending and if necessary having treatment. This contrasts with other medical interventions where there is a biological aspect to the distributive ethic. For example, immunisation against an infectious disease provides protection for the individual that is immunised but also contributes to building the 'herd immunity': if sufficient people in a population are immunised, the infectious disease cannot easily spread through the population, so the non-immunised are also protected. With breast screening there is no biological effect beyond that of an individual's contribution to the population mortality statistics. There may be non-biological effects such as women considering attendance at breast screening to be a social obligation, and women wanting to be a good role model for their children by attending (Griffiths, Green, Bendelow et al., 2003).

The account of breast screening in the medical literature is reflected in the account given in the study, by an 'expert' among 'experts'. This interviewee advises at national level on issues related to breast screening, oversees the local screening service and assesses women in the follow up clinic.

I think about screening as an intervention.....to improve the population's well-being. And (pause) that, I think, is quite different to how other people perceive it...it's about dealing with whole populations, for population benefit. Within that population, a small number of women.....get a real major benefit. Doctor 02

This emphasises the distributive ethic improving population health. This doctor goes on to say:

The vast majority has no benefit from it at all, apart from perhaps false reassurance. And some people have real disadvantage from it. Doctor 02

The doctor thus acknowledges the individual ethic, concerned with the wellbeing of the individual including the disadvantages to individual women of attending screening which include anxiety about results (Green, Thompson, & Griffiths, 2002; Wadsworth & Green, 2003) and goes on to recognise that individual women attend screening

as they are looking for personal benefit out of it. Doctor 02

However, this 'expert' among 'experts' then re-asserts the intellectual understanding of the distributive ethic over the clinical individual benefit although acknowledges that his view of breast screening is perhaps different from how others see it.

it is nice to find someone whom you are offering a personal benefit to, but that's not the process from our—my point of view. Screening is about—screening, for me, is about reducing numbers of deaths in the whole population. Doctor 02

The next account comes from a doctor who assists in running the local screening service and sees women in the follow up clinic.

Mammography, of course, now it is that we strongly recommend it for everybody to have...I am totally convinced that it is helpful. And I see the people having benefit, both psychologically and otherwise....during my own practice I have seen the people diagnosed early, and they'll live. Doctor 18

This doctor seems convinced of the benefit of breast screening for the individual, thus giving more priority to the individual ethic. However, the doctor is clear that to achieve this, the population – 'everybody' - has to have breast screening, the distributive dimension. It is not completely clear whether the doctor uses the word 'people' to indicate a group or population of people or individual people. This slippage in the language between the distributive and individual effect of screening has a biological basis as mentioned above i.e. it is only through individuals having screening and treatment that the death rate comes down, unlike immunisation. However, it appears that the doctor is mostly drawing on clinical experience, seeing individual women live, rather than on population statistics. The doctor goes on to describe a further aspect of the impact of screening on the individual

They—you can always come up with some statistical evidence to say that it is not effective...but generally, it does good... they (women) don't feel guilty when they're diagnosed—that they're too late. Doctor 18

This comment may be interpreted as women considering attendance at breast screening as a social obligation: they must attend in order to contribute to the improvement in population health

(Griffiths, Green, Bendelow et al., 2003){Nettleton, 1997 #218}. Although there may be many explanations for the guilt women feel on being diagnosed with breast cancer, the emphasis on self-surveillance of risky bodies{Lupton, 1999 #168} encouraged by the promotion of breast screening may be a significant factor. Thus the guilt, and moral issue, that the expert above talks about, may be created at least in part, by the distributive ethic of screening. As Fox points out 'handling and mediating the individual and collective dimensions of medicine' (ibid page 245) creates tensions that are intellectual, clinical and moral. Each of these has been revealed in the accounts so far.

Women attending a follow up after screening may see the Breast Care Specialist Nurse, particularly if they have positive tests indicating cancer. This contact with individuals in distress perhaps accounts for the emphasis by the Specialist Nurse on the stress and fear for individual women as well as the benefit of screening:

I think screening... is always a big help for women....it gives them a reassurance, but it does stress them as well..... I think everyone dreads the results coming though....but I think you have to fight that fear really, you know, prevention's better than waiting for something to develop.. Nurse 10

Another Specialist Nurse also talks about the individual ethic,

for those that find it a worrying time, I think we need to accept and respect their views and concerns

but adds

hopefully they do come forward into the screening programme; and they're supported through that process.

reflecting her very positive stance towards breast screening

I would truly advocate screening to all other women We need to ensure that we profile screening in a very positive way Nurse 08

Both Specialist Nurses describe the tension between the distributive ethic, screening as a good thing for population health, and the individual ethic including the anxiety and fear it can create. This latter aspect is seen as something that individuals can overcome.

The final quote in this section is from a radiographer who only encounters individual women during the process of using the mammography technology and, apart from greetings and instructions, has very little dialogue with them. Their aim is a good technical result and the comfort of the women in the process. The radiographer said

the breast screening service .. (is).. a very good thing.....whether the interval is two years or three years, again, research will show whether we are using the right screening interval...all the changes that we've made we have made on ... scientific research.
Radiographer 01

The emphasis is on the distributive ethic, improving the health benefits for the population, and basing this on (population based) research.

There is variation in how the professionals or 'experts' understand, express and cope with the tension between the individual and distributive ethic of medicine. This seems to be partly influenced by the context and by how much contact each 'expert' has with individual women. Where their role is mostly orientated to the individual then the individual ethic of medicine dominates. Where their role is mostly orientated to the technology and screening process, the distributive ethic predominates. In most of the above accounts where the individual and distributive ethic were both mentioned, the account slid easily between the two, disguising the intrinsic tension. Only the 'expert' among 'experts' made the very clear distinction between the individual and distributive ethic and commented directly on the tensions this created, perhaps reflecting the difficulty for people of understanding and handling the tensions.

Epistemological uncertainty: the example of hormone replacement therapy

Fox suggests that the rise of the evidence based medicine movement in the 1990s 'brought to the surface fundamental epistemological uncertainty about the nature of good clinical research, good clinical practice, and the relationship between them.' (Fox, 2002). She suggests that the emphasis on 'evidence' based decisions has led to an oversimplification of the complexity of clinical decisions and a spurious claim to certainty. She refers to this issue as 'epistemological uncertainty' (Fox, 2002). Tanenbaum also identifies this issue and the importance given to the accuracy of risk prediction, which she refers to as 'certain probabilities' (Tanenbaum, 1994; Tannenbaum, Nasmith, & Mayo, 2003). Health professionals advise and treat individual patients, yet the evidence on which they base many decisions about health interventions is drawn from research with populations. For example, epidemiology and clinical trials may provide evidence for the need for the population to stop smoking in order to reduce the incidence of lung cancer, however it does not tell us which patient will get lung cancer (Willis, 1995). This tension between treating the individual patient and the nature of medical evidence has been an undercurrent in debate about the use of evidence in practice over the last decade or more. Tanenbaum (Tanenbaum, 1994), in discussing research such as clinical trials, identifies the politics of this type of research as the 'medical legitimisation of practice guidelines and the relative disempowerment of practising physicians' (more so with outcomes research than with bench science she contends) and 'additional interpretive work for practising physicians'. An indication of this additional interpretive work is given by (Glasziou & Irwig, 1995) in their guidance on how to interpret evidence for the individual patient based on data from clinical trials of intervention effectiveness, prediction of risk for the patient and the patients values. However, doctors find this difficult (Gigerenzer, 2002) and even where the evidence has been developed into guidelines, doctors find it difficult to apply the guidelines to many individual patients (Summerskill, William, & Pope, 2002).

HRT has been the focus of large epidemiological studies and clinical trials, the most recent of which reported in 2002/3. The results of a US clinical trials confirmed a higher incidence of breast cancer among women who have taken HRT long term (Writing Group for the Women's Health Initiative Investigators, 2002). These results were supported by a UK epidemiological study (Million Women Study Collaborators, 2003). Until this new research, HRT was recommended in medical literature for the relief of menopausal symptoms, the prevention of osteoporosis and as an intervention to be considered for the prevention of cardio-vascular disease such as heart attacks. Its use for prevention entailed the women taking HRT long term. Ballard demonstrated that although most women were using it primarily for symptom relief, their awareness of risk of osteoporosis was one explanation used by the women for remaining on HRT for longer (Ballard, 2002a; Ballard, 2002b). Until the publication of the 2002/3 research results, HRT was strongly advocated for the prevention of osteoporosis where a woman was considered to be at high risk. However, guidelines issued to health professionals about the length of use of

HRT and how often its use should be reviewed have now been changed (Boukes, Groeneveld, & Assendelft, 2003; Committee on Safety of Medicines and Medicines and Healthcare Products Regulatory Agency, 2003).

The accounts from 'experts' about HRT were collected prior to the publication of the new research results in 2002. The senior doctor at the clinic seems to be an advocate of HRT

...although there is obviously an awful lot we still don't understandI suspect that it would actually bring major benefits to several times as many people as are currently taking it...Doctor 11

He goes on to describe the approach he takes in the HRT clinic

..... we go through all their (women attending the clinic) risk factors for their bones and...their risk factors for all the other things that hormone replacement therapy could benefit and their risk factors for thrombosis and .. breast cancer. And we see what we've got on each side of the scales. And we weigh it up. So the decision to take HRT is based on an understanding of what the benefits are going to be and what the risks are going to be.
Doctor 11

The account seems to imply that the evidence on risk can apply directly to individual women to provide some form of prediction. This doctor goes on to describe how he perceives the understanding of risk of the women attending the clinic.

....with HRT they (women attending the clinic) usually know about the breast cancer risk.... they're sometimes surprised to know that although it's a very small increase, it's an increased risk which we believe starts on day one, because in the past people used to believe this risk comes along at five years or this risk comes along at ten years. And so a lot of women have developed a view that they would be completely safe up until the five years. And then suddenly they will be at risk. So, so sometimes they're, they're a little bit alarmed about that. They're not usually alarmed at the size of the risk, particularly, when we put in context with other breast cancer risk factors. That it's often a smaller level of risk than they thought it was. Doctor 11

The account does not mention the dilemma of applying risk based on population evidence to the individual but focuses entirely on misunderstanding and understanding the time-scale and size of the risk. Analysis of consultations from this clinic demonstrated that the emphasis given to weighing up risk and benefit led to the weaving of an account of HRT that implied certainty of outcome (Griffiths, Green, & Tsouroufli, 2005, In Press). A doctor, who is in training as a specialist at the clinic, also talks about weighing up risk and benefit

.. you have to have the balance between...quality of life and between the risk that you are taking with HRT...which is very small. And on balance...in outcomes between people who are not taking HRT and people who are taking HRT, the people who are taking HRT would come ...with a quality of life much, much better, plus protection for osteoporosis. Doctor 10

It is not clear from the interview whether the doctor is using 'people' to mean a population of individuals or the individuals he sees in the clinic, a slippage of language that was identified in accounts of breast screening above. The doctor goes on to say

And you have to put this balance to the patient. And they need to choose. Um, and they need to take the choice between...it's all about risks and benefits. Doctor 10

This doctor seems to be providing a similar account to that of the senior doctor in the clinic (Doctor 11). In their interviews these two doctors provide no indication of their understanding of epistemological uncertainty and the dilemma this creates. Other data from the study indicates that in other contexts this epistemological uncertainty may be explicitly recognised by health professionals (Griffiths, Green, & Tsouroufli, 2005, In Press). The 'experts' talking here are considered 'experts' by other doctors (or 'expert' in training). Their discourse is influential within their locality and reinforced through mechanisms such as clinical letters written to doctors about individual patients, and up-date lectures given for local health professionals. Their operationalisation of the medical discourse is likely to reinforce the pressure on other health professionals particularly those not 'expert' in this particular medical intervention, to take a similar approach.

A conceptual framework for uncertainty: the example of bone densitometry

In her analysis of medical uncertainty, Fox (2002) identifies the Human Genome Project to illustrate another form of uncertainty. She argues that the Human Genome Project provides knowledge, which is highly reductionist yet despite its many claims, 'there is as yet no conceptual framework within which this kind of micro-knowledge can be synthesised, consolidated and made pertinent to the organismic, pathophysiological level of medicine'. The writing of (Birke, 2003) suggest that the social and cultural levels, need also to be part of the missing conceptual framework. She argues that there is interaction of the biological, with social and cultural forces in a process of co-evolution that goes beyond the surface of the body to inside the body.

... We need to find ways of acknowledging that internal biology is a factor in our becoming, while at the same time recognising that there are many other factors too..... It is not biology that we need to reject wholesale; rather, it is simplistic assumptions that certain biological processes are primary, and that it's the biology of the isolated individual that matters' (page 44).

Biological systems can be conceived of as being nested within and interacting with social systems (Harvey & Reed, 1994) resulting in co-evolution (Byrne, 1998). Bone densitometry and accounts of this intervention from 'experts' will help us explore what Fox (2002) means by the missing conceptual framework and how medicine is perhaps groping towards filling this gap.

Bone densitometry, using a dual energy X-ray absorptiometry (DEXA scan), measures an individual's bone density and compares it with measurements from a 'normal population' (i.e. measurements of the bone densities of individuals sampled from the general population). If an individual's bone density is low relative to 'normal' the individual is considered at risk of osteoporosis in the future, as the density of bone decreases as people age. A very low measurement indicates osteoporosis is already present. The significance to the individual is that when bone has become thin (osteoporotic) it may fracture easily and the fracture causes pain and disability (Wilkin, Devendra, Dequeker, & Luyten, 2001).

The two doctors interviewed in the bone densitometry clinic were specialists in osteoporosis. The interviews focused on the use of DEXA scanning for people at risk of osteoporosis rather those considered to have a current diagnosis of osteoporosis.

In describing bone densitometry one of the doctors said

No test in medicine is perfect. What bone densitometry has been used as, is a definition. Like most things in life when you study it all disappears into the detail but people want simple answers. Doctor 28

There seems to be an acknowledgment of some uncertainty about the result produced by bone densitometry. This may in part be the 'epistemological uncertainty' as discussed above, as the notion of risk is applied to individuals.

The doctor goes on to say

it's a very good test for categorising people as to their future fracture risk Doctor 28

The use of the words 'categorising' and 'risk' in the same phrase gives a taste of the issues the doctor is struggling with. We will first follow up on 'risk'. Epidemiology has demonstrated that osteoporosis is more common in women as they get older, who have a family history of osteoporosis, a low body mass index (ratio weight:height), smoke, take little weight bearing exercise, take little calcium in their diet or have certain other health problems or treatments known to affect bone density (Royal College of Physicians and Bone and Teeth Society of Great Britain, 2001). These risk factors can be used to decide if a woman is 'at risk' and so considered a 'case' where bone densitometry should be used to clarify her classification as 'at risk' (ibid). The different risk factors do not combine in any straightforward way to predict risk of osteoporosis but are seen as 'important information in the overall decision making' (Wilkin, Devendra, Dequeker et al., 2001). It is also interesting to note that these risk factors relate to biological, psychological, social and cultural aspects of an individual's life.

Returning to the words of the doctor above, the use of the word 'categorising' may indicate the specialist is seeing the individual as a particular case rather than as a member of a population. In research terms 'cases' may be categorised into groups where the 'cases' are similar and characteristics of the whole 'case' is used for this categorisation. Populations are usually described in terms of variables, which are markers of only certain aspects of each individual (Byrne, 2002). What can be confusing with the example of bone densitometry is that the interpretation of a particular bone densitometry result is based on how it compares with bone density measurements (a variable) of the population. The result gives

a number to the degree of osteoporosis a person has. So it does enable people to see where they are in the spectrum of other patients results Doctor 27

So the interpretation of the bone density is in relation to a population. However, the result or 'number' as the above doctor calls it, is then viewed as applying to the particular women. The word 'categorise' is used to clarify this.

So bone mineral density is excellent. As a diagnostic tool or at least a categorising tool to say whether people are likely to benefit or not. Doctor 28

The individual 'case' is categorised into either a group likely to benefit from treatment or a group not likely to benefit. In 1992 DEXA scanning was recommended for use for case-finding (rather than population screening) in the UK (School of Public Health, 1992). A recent review of

clinical guidelines for the detection and prevention of osteoporosis says bone density measurement using a DEXA scan, can predict future fracture ‘with high specificity, but low sensitivity’ so recommends ‘the use of this test in the context of a case-finding strategy, rather than for population screening’ (Royal College of Physicians and Bone and Teeth Society of Great Britain, 2001).

The doctor goes on to expand on the case finding approach for osteoporosis. When deciding whether to undertake bone densitometry other characteristics of each individual ‘case’ are taken into account

If there’s err a couple of fractures, fairly non, a-traumatic, just the odd trip or whatever and ...if there’s a strong family history on the female side of osteoporosis then ‘yes’ (do bone densitometry). Doctor 28

There are clues here of the conceptual framework Fox (2002) sees as missing from medicine. The specialists are describing ‘cases’ using a constellation of factors. In the interviews the doctors also mention ‘lifestyle’ ‘medication’ (Doctor 27) and ‘age’ (Doctor 28) as well as heredity. Note again, as with the risk factors discussed above the specialists are talking about factors related to many aspects of life, not just the biological. However, the doctors give few indications of how these factors fit together.

There is some acknowledgement of the complexity of the interactions between factors, for example the changing importance of low bone density in relation to rate of fractures:

osteoporosis is a disease which increases (in) frequency with age and certainly fractures increase much, very much more rapidly because of the falling over contribution increases much greater later on. Doctor 28
(older people fall over more as they age which contributes to the increase in rate of fracture with age)

These accounts from bone clinic specialists seem to be groping towards an understanding of the missing conceptual framework (Fox 2002) for linking the genetic, the pathophysiological, the psychological, the social and the technological in medicine. The doctors indicate some ways in which factors from different levels of analysis interact with each other, but this is limited. Their accounts demonstrate the uncertainty of medicine as to how factors from different levels of analysis can be synthesised to develop an understanding pertinent to the individual ‘case’. Understanding the interaction of many factors for the individual woman is what McWinney refers to as the ‘science of particulars’ (McWhinney, 1989) and suggests medicine needs to develop research methods that give attention to the particular. This would require a conceptual framework that can synthesise knowledge from multiple levels of analysis (Fox 2002) and understand how factors interact and co-evolve. Interestingly, one of the specialists points out the use of bone densitometry as

a tool to guide and influence people to appropriate management decisions about them, lifestyle or medication changes they’re going to undertake. Doctor 27

thus acknowledging the bone densitometry result as more than a neutral number, but something that interacts with the individual women, influencing their decisions (Griffiths & Green, 2003b) and perhaps influencing their biology (Birke, 2003)

Before we leave the 'experts' in the bone clinic, we note that the account of bone densitometry from the specialist nurses were similar to that of the radiographer in the breast assessment clinic. They talked in terms of a good technological result and the comfort of the patients

I think it's a very good measurement, I particularly like the.. pixie scanner....for some people it's a long timeto lay...twenty minutes still, particularly if they've got other problems. Nurse 14

I was interested on going on the bone density scanner when they were first setting it up 'cos they needed volunteers to ... see if they could get a range...I can tell the patients I've had done myself and I know exactly what's it's about. Nurse 13.

Conclusion

This paper has explored three aspects of uncertainty in relation to three different medical interventions. At interview, uncertainty was not discussed explicitly by the health professionals or 'experts' however, their accounts reveal exactly the kinds of issues that Fox outlines:

because medicine is so integrally associated with the most profound questions about our individual and collective origins and identity, our sense of purpose and meaning, our shared human condition and our ultimate mortality, its relationship to uncertainty is also an indicator of how sure and unsure we are of where we have come from and where we are going, societally and culturally, as we enter the new millennium (Fox, 2002 page 250).

For breast screening we described the tension between the benefits for individuals and for the population as a whole. For HRT, we described the tension generated by using evidence from populations and applying it to the individual. With the exception of the national 'expert' on breast screening, for both breast screening and HRT, the benefit or risk of the intervention for the individual was the main thrust of the health professional's accounts. Through this focus on the individual, health professionals reinforce the idea that individuals are responsible for their own health. They advise individuals to act to reduce their own risk. However, these accounts from the 'experts' also suggest that there is an agenda beyond the individual's own health. There is an implication that individuals may be responsible not only for their own health but also for the health of the population. In other words, by reducing their own health risks, they contribute to a reduction in population risk and ultimately population measures of morbidity and mortality. Thus the accounts from the 'experts' working with breast screening and HRT illustrate a lack of clarity in the medical discourse about uncertainty related to what Fox describes as our 'individual and collective origins and identity' (ibid), and the tensions this creates. This lack of clarity seems to allow the medical discourse to ignore the multiple influences on health including legal, social, economic, cultural and household factors (Blaxter, 2003; Moss, 2002) and focus only on what individuals should do to reduce health risks for themselves and for the wider population.

The specialists in the bone densitometry clinic were struggling to express a different uncertainty in medicine. Through understanding each woman as an individual 'case' they were beginning to indicate that there were multiple influences on health, from heredity through to social factors. The uncertainty was because of their lack of conceptual framework for bringing all this together. Some areas of medicine such as general practice and disciplines related to medicine such as medical ethics, have started to develop such conceptual frameworks (Gorovitz & MacIntyre, 1976; Griffiths, 2002). Such frameworks acknowledge complexity, recognising that factors from many different levels of analysis may influence the individual and that these factors also interact

with each other and with the individual. Through this interaction there is co-evolution. For example, as Birke (2003) suggests, the biological and the social both change as a result of their interaction. Without an overarching conceptual framework medicine has been unable to make the most of this understanding. Fox cites how insights from the Human Genome Project may precipitate medicine into developing a conceptual framework so that 'this kind of micro-knowledge can be synthesised, consolidated and made pertinent' (Fox, 2002).

Discourses shape how we see the world and the biomedical discourse is a powerful one. Individualised, context free, concepts of health and health risk could continue to dominate how we perceive responsibilities for health well into the 21st century, if more sophisticated concepts are not developed. Whereas an individual undoubtedly may take some responsibility for their own health, this forms only one contribution to health improvement at both micro and macro-levels. Many disciplines including biological sciences, behavioural sciences and the social sciences have contributed to understanding the many different influences on health and how these have their effects (Blaxter, 2003; Moss, 2002). This work has demonstrated that health can only be improved through intervening at macro and micro-levels. These diverse disciplines are also developing conceptual frameworks that have a great deal in common with each other and that begin to make sense of how the many different influences on health fit together (see e.g. (Byrne, 1998; Holt, 2004; Sweeney & Griffiths, 2003). These may provide what Fox (2002) suggests is needed, a framework that allows us to understand how 'micro-knowledge', the detail about how biological or social processes fit together and how this micro level influences and is influenced by the more macro-levels. However, these conceptual frameworks are currently not well known within medicine. Ironically, it may not be until the Human Genome Project, a powerful influence within biomedicine, realises its need for this conceptual framework that it becomes adopted by medicine as its own.

References

- Armstrong, D. (1995). The Rise of Surveillance Medicine. *Sociology of Health and Illness*, 17, 393-404.
- Ballard, K. (2002a). Understanding risk: women's perceived risk of menopause-related disease and the value they place on preventive hormone replacement therapy. *Family Practice*, 19:6, 591-595.
- Ballard, K. (2002b). Women's use of hormone replacement therapy for disease prevention; results of a community survey. *British Journal of General Practice*, 52, 835-837.
- Birke, L. (2003). Feminism and the idea of 'the biological'. In S. Williams, L. Birke, & G. Bendelow (Eds.), *Debating Biology: Sociological reflections on health, medicine and society*. (pp. 39-52). London: Routledge.
- Blaxter, M. (2003). *Health* Buckingham: OUP
- Boukes, F.S., Groeneveld, F.P.M.J., & Assendelft, W.J.J. (2003). 'Dutch College of General Practitioners' Position on Hormone Replacement Therapy (HRT). <http://ntg.artsennet.nl/sitemap>, 2005(22 February).
- Byrne, D. (1998). *Complexity theory and the social sciences* London: Routledge
- Byrne, D. (2002). *Interpreting Quantitative Data* London: Sage
- Cancer Research UK (2004). *Breast Cancer and Breast Screening CancerStats Report*. London: Cancer Research UK.
- Committee on Safety of Medicines and Medicines and Healthcare Products Regulatory Agency (2003). *HRT: Update on the risk of breast cancer and long-term safety, Current problems in Pharmacovigilance* pp. 1-3). London: Committee on Safety of Medicines and Medicines and Healthcare products Regulatory Agency.

- Denny, E. (1996). New reproductive technologies: the views of women undergoing treatment. In S. Williams, & M. /calnan (Eds.), *Modern medicine: lay perspectives and experiences*. London: UCL Press.
- Edwards, A., Elwyn, G., & Mulley, A. (2002). Explaining risks; turning numerical data into meaningful pictures. *British Medical Journal*, 324, 827-830.
- Fairhurst, E. (1998). "Growing old gracefully" as opposed to "mutton dressed as lamb". In S. Nettleton, & J. Watson (Eds.), *The body in everyday life*. London: Routledge.
- Forrest, A.P.M. (1986). *Breast Cancer Screening: Report to the Health Minister of England, Wales, Scotland and Northern Island*. London: HMSO.
- Foucault, M. (1976). *The Birth of the Clinic* London: Tavistock
- Fox, R.C. (2002). Medical Uncertainty Revisited. In G. Bendelow, M. Carpenter, C. Vautier, & S. Williams (Eds.), *Gender, Health and Healing: The public / private divide* (pp. 236-253). London: Routledge.
- Gigerenzer, G. (2002). *Reckoning with risk* London
- Glasziou, P., & Irwig, L.M. (1995). An evidence based approach to individualising treatment. *BMJ*, 311, 1356-1359.
- Gorovitz, S., & MacIntyre, A. (1976). Toward a Theory of Medical Fallibility. *The Journal of Medicine and Philosophy*, 1, 51-71.
- Green, E., Thompson, D., & Griffiths, F.E. (2002). Narratives of Risk: women at midlife, medical 'experts' and health technologies. *Health Risk and Society*, 4, 243-286.
- Griffiths, F. (1999). Women's control and choice regarding HRT. *Social Science & Medicine*, 42, 469-481.
- Griffiths, F. (2002). Complexity in Health Care: An introduction. In K.G. Sweeney, F. (Ed.), *Complexity in Health Care*. Abingdon: Radcliffe Medical Press.
- Griffiths, F., & Green, E. (2003a). A normal biological process? Brittle bones, HRT and the patient-doctor encounter. In S. Williams, L. Birke, & G. Bendelow (Eds.), *Debating Biology : Sociological Reflections on Health, Medicine, and Society*. London: Routledge.
- Griffiths, F.E., & Green, E. (2003b). Managing health risks to women's midlife bodies: the patient-professional encounter. In S.J. Williams, G.A. Bendelow, & L. Birke (Eds.), *Debating Biology: Sociological Reflections on Health, Medicine and Society*. London: Routledge.
- Griffiths, F.E., Green, E.E., Bendelow, G., & Backett-Milburn, K. (2003). Innovative Health Technologies at Women's Midlife; Theory and Diversity among women and Experts (L218252038): ESRC.
- Griffiths, F.E., Green, E., & Tsouroufli, M. (2005). The nature of medical evidence and its inherent uncertainty for the clinical consultation: the example of midlife women. *BMJ*, 311, 511.
- Griffiths, F.E., Green, E., & Tsouroufli, M. (In Press). The nature of medical evidence and its inherent uncertainty for the clinical consultation: the example of midlife women. *BMJ*.
- Harvey, D., & Reed, M.H. (1994). The Evolution of Dissipative Social Systems. *Journal of Social and Evolutionary Systems*, 17, 371-411.
- Holt, T. (2004). *Complexity for Clinicians* London: Radcliffe Medical Press
- Klein, R., & Dumble, L. (1994). Disempowering midlife women: the science and politics of HRT. *Women's Studies International Forum*, 17(4), 327-343.
- Lupton, D. (1998). Going with the flow: some central discourses in conceptualising and articulating the embodiment of emotional states. In S. Nettleton, & J. Watson (Eds.), *The Body in Everyday Life*. London: Routledge.
- Mant, D. (1994). Prevention. *Lancet*, 344, 1343-1346.

- Martin, E. (1987). *The woman in the body* Milton Keynes: Oxford Univeristy Press
- McWhinney, I.R. (1989). An Acquaintance with Particulars... *Family Medicine*, 21(4), 296-298.
- Million Women Study Collaborators (2003). Breast Cancer and hormone-replacement therapy in the Million Women Study. *Lancet*, 362, 419-427.
- Moss, N. (2002). Gender equity and socioeconomic inequality: a framework for the patterning of women's health. *Social Science & Medicine*, 54(5), 649-661.
- Nettleton, S. (1996). Women and the new paradigm of health and medicine. *Critical Social Policy*, 16, 33-53.
- Nettleton, S. (1997). Governing the Risky Self: how to become healthy, wealthy and wise. In A. Peterson, & R. Bunton (Eds.), *Foucault, Health and Medicine*. London: Routledge.
- NIH (2004). Research Grants Database. <http://crisp.cit.nih.gov/crisp>.
- Oakley, A. (1984). *The Captured Womb: a history of the medical care of pregnant women* Oxford: Basil Blackwell
- Quinn, M. (2004). Trends and patterns in breast cancer incidence, survival and mortality in England and Wales, *West Midlands Breast Screening Programme Quality Assurance Conference*. Birmingham.
- Roberts, C. (2002). 'Successful Aging' with Hormone Replacement Therapy: It May Be Sexist, But What If It Works? *Science as Culture*, 11(1), 39-59.
- Rosenburg, C. (1998). Holism in Twentieth-Century Medicine, *Greater than the parts Holism in Biomedicine 1920-1950* (pp. 335-355). New York: Oxford University Press.
- Royal College of Physicians and Bone and Teeth Society of Great Britain (2001). *Osteoporosis: Clinical guidelines for prevention and treatment*. London: Royal College of Physicians.
- School of Public Health, U.o.L., Centre for Health Economics, University of York, Research Unit, Royal College of Physicians. In association with the Department of Health, (1992). *Effective Health Care: Screening for Osteoporosis to Prevent Fractures*. Leeds: University of Leeds.
- Sullivan, F., & MacNaughton, R.J. (1996). Evidence in consultations: interpreted and individualised. *Lancet*, 648, 941-943.
- Summerskill, William, S.M., & Pope, C. (2002). 'I saw the panic rise in her eyes and evidence-based medicine went out of the door.' An exploratory qualitative study of the barriers to secondary prevention in the management of coronary heart disease. *Family Practice*, 19:6, 605-608.
- Sweeney, K., & Griffiths, F. (2003). *Complexity and Health Care: An Introduction* Abingdon: Radcliffe Medical Press
- Tanenbaum, S.J. (1994). Knowing and Acting in Medical Practice: The Epistemological Politics of Outcomes Research. *Journal of Health Politics, Policy and Law*, 19, 27-44.
- Tannenbaum, C.B., Nasmith, L., & Mayo, N. (2003). Understanding older women's health care concerns: a qualitative study. *Journal of Women and Aging*, 15(1).
- Wadsworth, G., & Green, E. (2003). Changing women: an analysis of difference and diversity in women's accounts of their experiences of menopause. In S. Earle, & G. Letherby (Eds.), *gender, identity and reproduction, social perspectives* (pp. 205-221). London: Palgrave.
- Webster, A. (2004). Innovative Health Technologies ESRC Resaerch Programme.
- Wilkin, T., Devendra, D., Dequeker, J., & Luyten, F.P. (2001). Education and Debate: Bone densitometry is not a good predictor of hip fracture. *BMJ*, 323, 795-799.
- Williams, S., & Calnan, M. (1996). *Modern medicine: lay perspectives and experiences* London: UCL Press

Willis, J. (1995). *The Paradox of Progress* Oxford: Radcliffe Medical Press
Writing Group for the Women's Health Initiative Investigators (2002). Risks and Benefits of Estrogen Plus Progestin in Healthy Postmenopausal Women. *JAMA*, 288, 321-333.

Acknowledgement

Our thanks to the health professionals who participated in this project and to the other members of the project team Dr K Backett-Milburn co-applicant, Dr D Thompson researcher, and Dr M Tsouroufli researcher. The paper is based on data collected for the UK Economic and Social Research Council project number L218252038 and available in the UK Economic and Social Data Service Archive study number SN 5040.