### **RUHBC research findings 7**





# Women and health technologies:

views and experiences of women at midlife

As women approach midlife, hormonal changes and related health issues result in their becoming potential candidates for a range of health technologies. These are promoted as beneficial for maintaining, enhancing and managing their current and future health and quality of life. A recent study focused on three linked health technologies: the use of hormone replacement therapy (HRT) for the prevention of osteoporosis and cardiovascular disease; screening for osteoporosis using bone densitometry; and screening for breast cancer using mammography screening and 'breast awareness'. These technologies, particularly HRT, are much discussed in the media. The study examined areas in which there has been little previous research: women's own assessments of the risks and benefits involved; the medical and informal knowledge women draw upon; and how social and cultural contexts and women's own agency affect these health-relevant decisions.

### Key findings

- The health concerns of women at midlife vary and must not be treated as the same. The social, economic and cultural contexts of women's lives and the range of their experiences all need to
- The medicalisation of the menopause, the shift towards personal responsibility for health, and women's own feelings of agency are all central to understanding women's relationships to health technologies.
- Women's views and experiences of mammography, bone densitometry and hormone replacement therapy were often quite different; each technology should be treated as discrete and having diverse meanings.
- This sample of midlife women said they knew less about bone densitometry and used it much less often than they did HRT and mammography.
- Women drew on a variety of knowledge, lay and expert, as well as their own experiences, to make sense of the health technologies and health-relevant options facing them at midlife.
- Women's decisions about these technologies are rarely based simply on medical or scientific grounds, but involve complex assessments of the wider landscape of social and health risks and benefits.



### The Study

This report focuses on one part of a larger qualitative study, conducted in two socio-economically contrasting areas in England. It examined the approaches to, and understandings of, health technologies by midlife women and a range of health professionals in order to understand the social processes and contexts involved in their use. Midlife was defined as the years between the ages of 45 and 64. A total of 98 women was interviewed, sampled for diversity of background on the following dimensions: use of the health technologies, ethnicity, sexual orientation, disability and socio-economic characteristics. Interviews were also conducted with 58 health professionals, working in a variety of health care settings, and 109 relevant consultations from primary and secondary health care were recorded. Here we report some key findings from the analysis of the midlife women's interviews.

## Background: women, medicalisation and health technologies.

The study built on a growing body of work, particularly by feminist researchers, on women's health at midlife. Such research developed partly as a counter to dominant biomedical ideas, which tended to portray midlife women's bodies in universal and undifferentiated terms. It is argued that, particularly at the time of menopause, women's bodies begin to be depicted as ageing, leaking hormones. and 'failing'. As such, they become the primary target of 'medicalisation', which renders women as passive recipients of treatment. It is claimed that the increasing objectification of the menopause as a 'disease' treats women's bodies as problematic and imbued with negative metaphors of decay and degeneration. Other sociological critiques of the biomedical model show that women's experiences of the menopause are quite different in other cultural contexts and that their health care and health care practices need to be seen in the context of issues of gender and other social divisions, such as class, ethnicity and age.

At the same time, other analysts argue that there has been a partial demise of the biomedical model and that, increasingly, we are being subjected to a form of social control founded on self-regulation, self-monitoring and the avoidance of 'risk' through developing healthy lifestyles and keeping well. This is seen as placing particular additional responsibilities on women who, in line with the rise of an emphasis on individual responsibility and the role of 'experts', are encouraged to monitor their own health lifestyles (and those of their families) and to participate in a range of screening programmes.

More recently, however, there has been a renewed focus on women's own decision making in these processes. This is based on an acknowledgment that health maintaining practices are not 'stand alone' but are made sense of, and taken up by, women in terms of their own lives and experiences. This may also involve challenges to experts'

judgements about risk. Moreover, some researchers have argued that, far from being victims, women themselves seek out health technologies to improve their lives, treating these as 'lifestyle choices' to counter the effects of ageing and as opportunities to 'reinvent' themselves.<sup>1</sup>

### **Findings**

### Views and experiences about the health technologies

From the interviews it was evident that women's decisions about these health technologies were rarely based upon purely medical or scientific grounds. Rather, such decisions reflected women's present concerns, embodied\* experiences, experiences of health and health care, and a complicated mixture of expert, lay and experience-based knowledge. Perhaps unsurprisingly, there was considerable diversity within our sample in their attitudes towards these technologies. However, just as it is important not to treat midlife women and their experiences as the same, so the research showed that each of the three technologies elicited a range of views and experiences.

### Mammography: health screening as social obligation

Most of the sample expressed positive views about breast screening; it seemed that women trust this technology and the 'experts' behind it. From all of our data sources it was also apparent that mammography was rarely discussed with health professionals and its safety seldom questioned by these midlife women. Of the women interviewed, 85% of those eligible had taken up mammography screening; those who declined came from diverse backgrounds. Interviewees spoke about mammography in ways suggesting that it was seen as a routinised, often unquestioned, social obligation. Because this technology is available as part of a national, publicly funded screening programme for women over 50 in the UK, it seemed that, as 'responsible citizens', most interviewees felt obliged to participate in order to reduce the incidence of breast cancer. Even those women in our sample who felt ambivalent about the experience itself, often speaking of the pain and discomfort involved, still expressed the feeling of obligation. For example, one woman whose first mammography had been 'absolutely horrendous', still spoke of mammography as 'the norm' explaining that:

'I was really quite frightened to go the second time, but even though I was, I know it was important for me to go' (woman no. 60)

### Bone Densitometry: the importance of being within the 'normal' range.

In comparison, lay knowledge about and use of bone densitometry was much lower than the other two technologies studied. Consequently, fewer interviewees expressed specific opinions about this technology; those

<sup>\*&#</sup>x27;Embodiment' is a social science term which emphasises the interconnectedness of the emotional and physical self and how this is experienced in everyday social life.

who did were either neutral or positive in their views. From the interviews with the subsample who had experience or knowledge of bone densitometry (and from relevant recorded consultations), it seemed that women focused on how the results of the test should be interpreted and how 'bone management' could keep them within the perceived range of 'normal'. Technology was central to decision making in the bone/HRT clinics. Results are in the form of a numerical measurement, which is then interpreted as above or below 'normal'. The data from health professionals indicated that they knew, and often indicated to patients, that the bone densitometry result is only one indicator of potential risk of osteoporosis. Nevertheless, it appeared that most of those interviewed perceived these results as enabling 'objective' and precise calculation of future health risk and, as the next quotation suggests, many of these interviewees seemed to be seeking certainties of diagnosis:

'and then she (Doctor) suggested I went and had, umm, the bone density checked (following a fracture of the foot), which I did and it wasn't very good at that point, it was just teetering off the bottom end of normal and from that point of view I was aware that the HRT should help and prevent or reduce the risk of sort of osteoporosis. It was really only from that point of view that I decided to take it' (woman no. 61)

### Hormone Replacement Therapy: an embodied experience

Over half the midlife women interviewed had used HRT. These women were from a range of income groups, had differing levels of educational attainment, and were representative of the range of community and health care groups in the sampling frame. Although usage and attitudes towards HRT varied within these diverse groupings, lesbian women and those from ethnic minorities were less likely to have taken it. Concerns about its production and safety were the main reasons given for not using HRT by the sample as a whole, as the following quotation illustrates:

'Well HRT has been offered when I've been, there's a nurse there, but I don't really want to go on it. Em, not through choice, I wouldn't go on but if I had to and I felt it was advantageous to me then... I think there are certain risks to it and certainly my elder son's mother-in-law developed breast cancer which she was then told at the hospital was directly attributable to the HRT she had been on' (woman no. 18)

Women's decision making about taking HRT was multifaceted and complex. Interestingly, although most health professionals interviewed said that discussing risks of HRT was important, only a minority of the midlife women in our sample recalled such discussions taking place. A minority of women reported that one overwhelming factor had dominated their decision making. These included bodily experiences, such as multiple sclerosis or depression; social factors, such as a new job or concern about intimate relations; a medical intervention, for example a hysterectomy. Most interviewees, however, described a more incremental process, gradually changing their decision threshold, with 29 women describing precipitating

factors, often connected with embodied experiences such as insomnia or hot flushes, which 'tipped the balance'.

### Social and cultural influences on women's decision making

### Whose knowledge is it anyway?

From the interviews it was evident that women's embodied health experiences, concepts of social and health risks, and their perception of access to sympathetic health care all influenced their decision making about these health technologies. The process of making sense of their options involved drawing on a variety of knowledge from popular media sources, local lay sources, direct experiences of friends and family as well as from health professionals. Each woman assessed the relevance of these varied kinds of knowledge for her own particular circumstances in the light of her personal embodied experience and outlook, as is illustrated by the following quotation from one woman, who had not yet had a mammogram:

'I have no personal knowledge of it (breast screening), 'cos I've never actually been but I have quite strong feelings on the treatment I would ask for if I did have it (cancer). So I suppose really I'm putting off going in case there is anything wrong... But I think I'm being a little bit like, em, sticking my head in the sand. It's quite a difficult thing to discuss with people because very few people feel like that, and really it just goes back to a programme I saw a long time ago on television... As I say my friends, none of my friends feel the same as I do, so it's easier not to discuss it' (woman no. 50)

#### Weighing up the risks and benefits

The assessment of health and social risks at midlife and the part played by health technologies was another dominant theme. Seeking reassurance or greater understanding about the risks and benefits of health technologies could be seen as part of the development of 'information landscapes'. These landscapes signify the spaces and places where people actively or passively acquire information about health and then take 'patient pathways' through them in an attempt to understand and manage health issues. In the present study, however, when asked if they felt they had sufficient information for decision making about the technologies, only a minority of midlife women said they did. This was particularly noteworthy with regard to HRT, which was the technology most interviewees chose to talk about when discussing their health needs. The following quotation, where the interviewee cannot remember if risks and benefits of HRT were discussed, was typical:

Int: You said before that health professionals haven't given you enough information sometimes. But, um, do you think they have raised the question of safety and risks in relation to health care? Like HRT, did they ever mention, you know, the risks that might be involved?

R: 'Mmm, they might have done... I don't think... perhaps I didn't want to hear about the risks'

Int: (laughs) OK.

R: 'So I possibly didn't want to hear about them' (woman no. 23)

When asked about the nature of the decision making process with health professionals about taking HRT, and whether this was shared, one third said that it was a shared decision, half that it was the health professional's decision and one sixth that it was their own decision. In contrast, the majority of health professionals said they aim for shared decision making with women in relation to HRT. Some women pointed to constraints on health professionals, including time and the types of health care they are able to discuss, which, according to our interviewees, rarely includes alternative therapies.

Given these findings, it is important to consider the wider landscape of risk, most notably social risks and benefits, which our interviews showed to be important in women's decision making. Perceived social risks related to, for example: appearance, including weight gain; becoming dependent on others; personal relationships; and the workplace. Interviewees commonly expressed concern about gaining weight, and its subsequent effects on self esteem and self identity, as one of the perceived negative side effects of taking HRT. However, for many, this was weighed against the social risks attached to experiencing severe menopausal symptoms, and feeling out of control of their bodies in different situations and places, such as the home and workplace. The following woman recounted, particularly vividly, her embodied experiences leading to the decision to take HRT. At home she was affected by being too hot at nights, leading to sleeplessness and fatigue. At work, she found hot flushes particularly hard to cope with in meetings, describing the experience as follows:

I think usually I just kind of tried to keep quiet and let the meeting go on without me, em, perhaps be not quite as involved in the meeting as I would have been normally, you know. Kind of not wanting to draw attention to myself. Um, and feeling quite uncomfortable and just wanting to run basically. It's actually quite hard to maintain the thread, you know, and your concentration. The more I think about my group of friends or work colleagues, I can't think of anybody who is not on some form of HRT in the kind of medium to long term' (woman no. 52)

#### **Implications**

At present there is concern about the nature of the interaction between technology and society. The findings from this study lead us towards increased understanding of the social and cultural contexts of midlife women's decision making about health technologies, in particular:

- There is a need for greater appreciation of the knowledge on which women base their health relevant decisions, particularly the ways in which everyday knowledge, media messages and experience mix with expert knowledge.
- The design of the health care system for women at midlife needs to take account of the social and cultural contexts and how these influence women's decision making processes.
- The style of communication in technology-related health care consultations and health education could be improved by taking account of these findings.

#### References

<sup>1</sup>Griffiths, F. (1999) Women's control and choice regarding HRT. Social Science and Medicine 49, 469-481.

#### The Study

This study was part of a larger project - Griffiths, F., Green, E., Bendelow, G., Backett-Milburn, K. (2003) Innovative Health Technologies at Women's Midlife: Theory and Diversity among Women and 'Experts'. End of Award Report (L218252038) Economic and Social Research Council, Swindon, UK. ESRC website www.esrc.ac.uk.

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