



Innovative Health Technologies at Women's Midlife: Theory and Diversity Among Women and 'Experts'

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RESEARCH FINDINGS

KEY FINDINGS

The focus of the project was health technologies aimed at midlife women (hormone replacement therapy (HRT), breast screening and bone densitometry).

How do women and health professionals from diverse backgrounds and experience perceive the health technologies?

How is risk and benefit discussed and understood by women and health professionals in their assessment of the health technologies and during health care consultations related to the health technologies?

How do the micro-level processes explored in the project influence the perception of health technology in society more generally?

- Women's decision making is multi-faceted and complex. Individual experiences are woven from experiences of their body, their concept of health, access to health care (particularly trust in health professionals), family history and social risk. These woven strands of gendered commonality result in diversity within and between groups of women.
- Risks of HRT were considered by most women including, 'how does the evidence apply to me?' Health professionals expressed commitment to explaining risks of HRT but only a minority of women reported hearing this. In some health care consultations health professionals conveyed certainty about future benefit and risk; others negotiated provisional decisions, a strategy for taking account of uncertainty, which avoids reinforcing the myth of technological giving certainty for the future.
- Mammography screening has become a routinised social obligation, with risks rarely considered.
- Bone densitometry gains an elevated status in clinical settings which impacts upon decision making about HRT. Most women perceived bone densitometry as enabling 'objective' and precise calculation of future osteoporosis risk. Above or below 'normal' results are only one pointer towards an as yet unformed eventuality, but clothed in the language of precise, technology related measurement, they are interpreted as predicting a certainty that requires intervention and treatment.
- The misleading but widely held perception of technology as providing precise, definite results encouraged both health professionals and patients to 'over interpret' related test results.

RESEARCH TEAM

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Women's Perceptions of the Health Technologies

Most women were positive about breast screening, of the women interviewed, 85% of eligible women had taken up mammography screening. The women who declined came from diverse backgrounds. Lay knowledge about bone densitometry was low. Within each of the sampling groups there was a range of views and usage of this technology. Over half the women interviewed had used HRT; there was no relationship between use of HRT and household income or with educational attainment. Women using HRT were found in all community and health care sampling groups (except those sampled for their non-use). There was considerable diversity of perceptions and use of HRT and bone densitometry among the women, but this diversity did not map on to the dimensions of diversity used from sampling. Diversity of health perceptions, embodied experience, experiences of health and health care, and of social context, all influence attitude and decisions about use of the technologies.

Health Professionals' Perceptions of the Health Technologies

Most health professionals were positive about mammography. Some expressed concern about risk from radiation, false reassurance for women and anxiety caused by screening. Bone densitometry was considered positively for women considered 'at risk', for example, women who had an early menopause or a family history of osteoporosis. There was little discussion of the nature of test in interviews or in health care consultations. Health professionals focused on the interpretation of the results for women, with the aim of maintaining the woman's bone density within the perceived range of 'normal'.

Most health professionals were positive about HRT for the relief of menopausal symptoms and for prevention of osteoporosis but there was some diversity of view on their role in encouraging its use, particularly in primary care. In both interviews and in health care consultations, health professionals discussed HRT in relation to the woman's embodied experience and social context and in terms of risks and

benefits. When discussing HRT in relation to a bone densitometry result, discussion focused mostly on the role of HRT in alleviating future risks for health. Once on HRT, discussion between women and health professionals was often brief with an apparent underlying assumption of continuing the HRT. All health professionals were concerned about the possible effect of HRT on breast cancer risk.

Risk taking and Decision Making

Women's decision making about HRT and to a lesser extent bone densitometry, was multi-faceted and complex. Women's embodied experience and concept of health, together with their perception of access to sympathetic health care and of social risks, influenced their decision making. Women had diverse embodied experiences, which were recounted as menopausal symptoms and other illness narratives. Many of them described symptoms as 'acting on the body', not as 'part of their body'. Where women had few distressing embodied experiences, they tended to see health in terms of keeping active. Others, with more distressing embodied experiences expressed health in terms of acceptance of limitations and stoicism. Perceived social risks related to, for example: their appearance including weight gain; becoming dependent on others through disability; sexual function and personal relationships; presentation and functioning in the work place.

For most women, decision-making seemed to be an incremental process with interaction between many factors although many women identified a precipitating factor in their decisions about the technologies. For a minority of women there was one overwhelming factor that 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 such as hysterectomy. No pattern in the decision making and its influences was found in relation to the sampling groups in this project. Individual experiences are woven through a mosaic of gendered commonalities, highlighting differences between and within groups of women, and shared histories and experience.

Decisions about mammography appeared more straightforward. Women seemed to accept it as a routine social obligation, and discussed it only briefly at interview. Risks of screening mammography were not discussed: most health professionals pointed to it being provided outside of their health care context: women did not question its safety. At the time of breast screening there is no discussion with women about the test.

Although most health professionals agreed that discussing risks of HRT was important, only a minority of women recalled discussion of risks. When asked if they felt they had sufficient information for decision making about the technologies, only a minority of women said they did. When asked about the nature of the decision making with health professionals in relation to HRT, and whether it was shared, one third said it was a shared decision, half said it was the health professional's decision and one sixth said it was their own decision. In contrast, the majority of health professionals said they aim for shared decision making with the women in relation to HRT. Some women spontaneously pointed to constraints on health professionals for sharing decisions. These included the limited time available for consultation and the limited training of most health professionals in alternative therapies.

Bone densitometry gains an elevated status in clinical settings and this impacts upon decision making. Most women perceived bone densitometry as giving a measurement that enables 'objective' and precise calculation of future risk of osteoporosis. They listened intently to the test results, which were in the form of a numerical measurement interpreted as above or below 'normal'. Although this is only one pointer to a yet unformed eventuality, clothed in the language of precise technology related measurement, it is interpreted as certainty that requires intervention and treatment. This is enhanced by health professionals' attempts to weave a coherent account of the results and their meaning, which although it may include detail of risks and benefits, the

overall tenor of the account becomes one of certainty.

Mammography when used for screening gained an elevated status with women. Negative mammography was perceived as a definite result that the woman did not have breast cancer, and many women interpreted this as meaning they were alright for the next three years, until the next screening test. However, mammography is a diagnostic test that does not give any evidence about future breast cancer. When women had a positive mammography result they were followed up in the breast assessment clinic. Here the health professionals discussed the results of tests in terms of certainty in time and place, for example, this breast tissue at this time is not cancer. Certainty was emphasised within this limited frame of reference: many women were reassured by this but others were left with doubt.

In consultations about HRT, many health professionals wove coherent accounts of HRT which included detail of risks and benefits but which kept this detail out of focus so the impression was one of certainty about the effect of taking it. However, in contrast, some health professionals negotiated provisional decisions with women about its use that tackled the issue of uncertainty and risk head on, and avoided reinforcing the myth of technological certainty.

Implications

In our current society there is concern about the nature of the interaction between technology and society. This project illuminates some of the processes by which society is shaped by and shapes technology from which the following implications are drawn for health service design and health practitioner training:

- Diversity clearly has an important impact, however, the diversity of perceptions about the technologies and the diverse routes by which women come to make decisions, highlight the complexity of developing policy or planning for health care interventions that 'target' certain groups or communities and the dangers of stereotyping these groups.

- Provision of interventions through systems outside of traditional health care provision may result in loss of interaction and so loss of engagement of users with the technology and its risks and benefits.
- The widely held perception of technology as providing precise definite results, affects how individuals engage in interpretation of the results of medical technology, for themselves/their patients and their context.
- Health care organisation, including accessibility to follow up, may be a factor leading health professionals to emphasise the coherent 'certain' account rather than negotiating a provisional decision.
- The use of the apparent 'certainty' from technology for reassurance or support for individuals (an understandable response to feeling vulnerable) reinforces the 'myth' of certainty from technology. Health professionals and patients both use and seek the myth of certainty. This individual coping strategy has wider social implications.
- The provision of information about health technologies and the discussion of how information/evidence relates to an individual may be best separated, especially where the issue is prevention to avoid misleading impressions of certainty of outcome.
- Responsibility for gathering information may be placed more with the individual and outside of consultations with health professionals with increased resources for health education/information services.
- In consultations with individuals, health professionals could focus on interpretation of evidence for the individual patient and their context (rather than provision of generalised information).
- Health professionals are constrained by time and in the types of health intervention they are able to discuss (e.g. lack of training in alternative therapies).

About the Project

This study is part of the ESRC/MRC programme of research on Innovative Health Technologies, studying interactions between health technology and society. It examined the approaches used by individuals, both lay and professional, to health technologies focused on women at midlife (hormone replacement therapy (HRT), bone densitometry and breast screening) in order to understand the broader impact of health technologies, and the specific social processes and mechanisms involved. Risk, diversity, embodiment and the patterning of women's health were central concerns of this project.

The project interviewed 98 lay women, midlife to retirement age (45-64 years) sampled for diversity of background along the following dimensions of diversity: use of the health technologies, ethnicity, sexual orientation, able-bodiedness and socio-economic context. The interviews allowed exploration of women's own perceptions of the health technologies including risks and benefits associated with adopting or refusing them and the ways in which risk narratives are interwoven with life histories and personal circumstances.

The project interviewed 58 health professionals involved in the provision of the technologies. They included nurses, doctors and professions allied to medicine and were drawn from primary, secondary and community health care sites. With health professionals the interviews explored the perspectives and models they used in connection with the health technologies, including what factors influence their approach and how this may vary in different contexts and with different patients.

The project recorded actual consultations from primary and secondary health care including general practice, bone clinic, breast assessment clinic and HRT clinic. Consultations included nurses, doctors and professionals allied to medicine. 109 consultations were relevant for the project as they included mention of one of the health technologies.

Diversity was important to the project both in its sampling, as described above and in the conduct of the research. Diversity was enhanced by collecting data in two geographically separate sites. The research generated the three distinct types of data which were not directly comparable namely, health professional interviews, lay women interviews and consultations. Of particular importance were the differences between firstly, women's personal stories and professional's abstract accounts of their practice, and secondly experiences recounted in interview and recording of actual consultations. Analysis both used and took account of the diversity of data. The process of analysis was undertaken by the interdisciplinary team, again creatively using the diversity of their disciplines including sociology, clinical medicine, education and social policy. Analysis involved discussion of data by the team to identify key themes and issues, then checking the data set for data supporting and challenging these. Study results were discussed with stakeholders including health professionals and lay, towards the end of the project.

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