Health Literacy, Rationality and Pregnancy: Decisions in the Making

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This article analyses a particular strategy of Australian main stream health promotion policy, that is, the encouragement of individuals to actively seek out and use health literature in order to become health literate. It analyses the definition of health literacy as understood by main stream health promoters. The paper considers the way in which main stream health promotion is constituted and limited by rational scientific, economic, middle class and managerial approaches to health. Through interviews, it explores how women consider themselves knowledgeable about health in ways that both use and disrupt the boundaries of narrow understandings of health literacy. Examples and suggestions will be made about how main stream health promotion might acknowledge the uncertainty and "every day reality" of women's lives.

INTRODUCTION

Whether pregnancy is planned, desired or unwanted, it seems that women attract more attention at that time from health professionals, family members and others concerned with their health, than at any other time. It is also a time recognised by health professionals as when women are particularly amenable to health advice (Howse 1993).

This article is based on interviews undertaken as part of my Ph.D. research. My main interest is how women negotiate and make decisions about health behaviour in relation to pregnancy in the light of the enormous amount of information made available. Although many issues were raised by the women interviewed, this article explores a particular contention of main stream health promotion that in order to make the "right" decisions, women must read health information and demonstrate their health literacy by complying with main stream health promotion information. The different ways women interact with main stream health information and promotion are discussed, as well as their approaches to decision making in relation to health information.

I will discuss how the rationalist bases of health promotion research confine responses to health promotion campaigns and other main stream health information in particular ways. Some of the interactions of the women interviewed with main stream health promotion information will be examined and suggestions for different ways of thinking about health promotion raised.

THE INTERVIEWS

Twenty women were interviewed for the research study using in-depth, semi-structured interviewing techniques. The women were asked to describe what they thought were

good things to do while pregnant both for themselves and their baby. They were also asked specific questions about pre-natal testing, planned pregnancy and two main stream health promotion campaigns. At the time of interview women were experiencing or had experienced in the previous six months, their first, second or third pregnancy to come to term. Ten of the women had or were intending hospital birth, while the other ten had or were intending home birth. It should be noted that the home birth women were overrepresented in this study. Nationally the rate of home birth is less than two percent of all births. Home birth women were included to see if their responses to health promotion were different to hospital birth women.

HEALTH PROMOTION: COMMON CRITIQUES

The tendency for main stream health strategy to emphasise individual health concerns, "healthism," and to advocate changes in lifestyle rather than addressing the social and economic contexts of health are issues raised in a number of critiques of main stream health promotion (Becker 1993; Bunton et al. 1995; Hunt 1991, S3). Feminist critiques of health promotion in particular raise concerns about main stream health promotion's inability to recognise individual constructions of health (Hunt 1991, 54). An anthropological analysis points out that "members of society are not empty vessels waiting to be filled with whatever health knowledge is being advocated," (Good 1994, 26). Women's health centres recognise the importance of women's own experiences in relation to their health and emphasise the importance of recognising health within economic, emotional and social contexts (Whitford Women's Health Centre 1995). These contrast with the Health Promotion Journal of Australia which describes the health outcomes emphasised by main stream health promotion campaigns in Australia, as demonstrating reduction, or prevention, of mortality, morbidity and disability. Social outcomes, quality of life and equity are less often considered a priority (Lowe 1996, 1). Individual responsibility for a healthy lifestyle has been encouraged by health promoters and health policy in Britain and Australia (Nutbeam 1996).

A number of articles and editorials published in the Health Promotion Journal of Australia from 1991 to the present discuss the research basis that informs health promotion campaigns in Australia. Many articles emphasise that health promotion campaign outcomes should be evaluated in terms of reduction and prevention of mortality, morbidity and disability and also economic viability (Hawe and Shiell 1995; King et al. 1995; King D, 1996; Viney 1996). There is a demand for health promotion campaigns to be informed by "evidence-based" research. Evidence-based research is that which is informed by scientific research and population based epidemiology. For example, the editorial of the Health Promotion Journal of Australia, (Lowe 1997,7,3,152) states that "Reports of programs submitted to the Health Promotion Journal of Australia are based more and more on scientific literature," and "We must continue to strive to improve and reduce the number of programs started by well meaning individuals who do not have health promotion background or understanding of the literature." The latter comment seems to be asserting that individuals who may be well intentioned, but without an understanding of the literature should not attempt health promotion. A specific kind of

health literacy then is required by main stream health promotion practitioners as well as the target population. Health literacy is defined in the Health Promotion Journal of Australia as "the ability of individuals to, gain access to, understand and use information in ways which promote and maintain good health" (Lowe 1996,1). Information as it is described here seems to refer only to information provided by main stream health promotion. It excludes the varied sources or interpretations of health information as understood by the women interviewed.

There is an emphasis on the economic value of particular health promotion campaigns (Viney 1996). Similar developments have been noted in Britain where it is claimed "More and more the organisation and delivery of health care is being framed and articulated in terms of 'value for money' rather than any alternative moral discourses" (Burrows et al. 1995,10,2,242). I am not suggesting that other kinds of research should replace scientific or economic research, however I do suggest that the privileging of these does limit the scope of health promotion campaigns and consequently the responses to these.

RATIONALITY AND HEALTH PROMOTION

The health promotion campaign based on "evidence" that simply and clearly demonstrates a cause and effect, for example, spina bifida in babies is caused by lack of folate, makes non-compliance difficult. As Harris observes in her analysis of expert health discourses, most people would not deliberately choose to be ill (Harris 1994,115). Or in the case of pregnant women, would not calculate in such a way as to deliberately harm an unborn child. Women are not "victims" of health promotion campaigns, nor could the women interviewed be described as cultural dopes, nonetheless there is considerable pressure to comply with health promotion campaign instruction especially in relation to pregnancy. Women are not only responding to health promotion campaigns in a context of "healthism," but also as pregnant women, whose behaviour is more likely to be publicly scrutinised. It could be argued that they are doubly more interesting as health subjects.

Health promotion campaigns as expert information reflect both instrumental and value rationalities (Harris 1994,113). This means that apart from being discourses that value efficiency and productivity, they also share common values or beliefs with the people they target (Burrows et al. 1995, 242). Health promotion campaigns targeting women during and pre pregnancy are instrumentally rational in the sense that they require the efficient production of a perfect product. They are value rational discourses in the sense that they value good health for the foetus, something women themselves desire.

The notion that a health literate person has the ability to "gain access to and use information..." is based on western ideas about sovereign individuals and their right to act autonomously. Literacy is understood to be an individual's ability to read and understand written text as well the ability to communicate by writing. The Health Promotion Journal of Australia defines health literacy in terms of an individual's ability to seek out, read and understand health promotion and use it by responding positively to its instruction as a learning, rational subject. What I find interesting about "health literacy" is that if it is indeed a quality attained by rational, learning subjects, how are pregnant

women positioned in relation to this?

The privileging of the bounded, autonomous, rational individual has been criticised by a whole body of literature, including theories informed by feminist, post-modem and cultural perspectives (Hekman 1995; Stainton-Rogers 1991). White western women, unlike white, western men have been less visible as literary, learned and rational subjects. These exclusions whether privileging ideas about mind over body, or what constitutes a citizen who can act in the public world, have relegated women to the less than rational and literate in many areas of their lives (Hekman 1995; Lloyd 1984; Tuana 1992). The consideration of this legacy led me to consider how might women demonstrate theirhealth literacy in relation to pregnancy and birth information? Here the dichotomies intersect, the pregnant and birthing body with the reasoning mind. These ideas have been explored by Thiele (1994) and Young (1990) and the possibility of "thinking" through the body raised.

There is a blurring of distinctions of a different kind in relation to women and health promotion campaigns. There is an expectation, albeit limited, that reproductive women do have the ability to act as rational subjects. Health literacy as defined by health promoters relies on the ability of an individual to reason in a logically cognitive fashion, to make the right decision by reading and complying in entirety with main stream health promotion information.

There is an increased expectation by health experts and women themselves that they will not wait to be told information about pregnancy and birth by their doctor. Health promoters, medical and health professionals encourage women to read up and find out for themselves. Many of the women I interviewed would assure me that by reading widely they were informing and empowering themselves. They saw this as a positive process, stating that "they were not just letting things happen." Many maintained that if they did not "read up," they would not know the correct questions to ask their doctor or midwife.

This planning, preparing, managing approach to pregnancy is similar to how people are advised by experts to conduct their lives in health, child rearing, relationships, planning for retirement and many other areas (Harris 1994,115). It is expected that good citizens and pregnant women are actively seeking information and managing their lives in a responsible and rational fashion.

Most of the women interviewed read about pregnancy and birth from a wide variety of sources. Popular pregnancy books and magazines topped the list, whilst people such as midwives, doctors, relatives and friends were also important sources of information. Health promotion literature and campaigns were mentioned less frequently as important sources of information. Women's use of individuals and support groups as sources of information will be addressed later.

Although many women read widely, some of them claimed this could be confusing and gave examples of conflicting advice. The use of various technologies has also affected the way women in Western countries experience pregnancy and read and use information.

TECHNOLOGY AND RATIONALITY

It is only in the last 20 years or so that we have been privy to images of the insides of

women in photographic and other visual forms. Ultrasound scanning of the foetus is now routine, and many women have more than one during pregnancy. Recently there have been developments in the ultrasound technology that make it possible for "3D" images of the foetus to be clearly seen. No longer is the ultrasound image a blur requiring careful scrutiny. It has been argued that this visibility of the foetus has contributed to the production of women as little more than "environments" or "incubators" for the foetus (Duden 1993, 6; Rothman 1994,34). Ultramicroscopes make visible the very moment of conception and documentary evidence and imagery is collected and stored about individual foetal cells and genetic codes (Weir 1996).

Ultra sound images, morbidity and mortality tables, genetic bar-codes, pre-natal testing and other records render visible, and pose, both the abstract and real possibilities of birth defects, developmental deformity, variance and disease. At the same time they chart and measure very precisely and in a static fashion the range that is normal development. These processes potentially make visible statistics or images considered abnormal or undesireable; objects that may require ongoing management, surveillance, advice and assessment. Birth defects, deformity, disease and variance represent the uncertainty that can only be properly managed and prevented by reasoned and logical responses.

The existence of these technologies, and the uses they may be put to, contributes to the amount of reading up a pregnant woman may be expected to do. Western, middle class women are expected to be informed about the availability of reproductive technologies, what they do, what might be the possible consequences of this or that, action.

One example of this can be demonstrated by describing the responses of the women interviewed to questions about pre-natal testing. I asked women whether they had been offered pre-natal tests and how were they informed about them? The test most often mentioned by women, although not one they were necessarily all offered, was amniocentesis. Most of the women interviewed mentioned this test as one they would be most reluctant to have. Many women felt that the procedure was too invasive, others had weighed up risk factors such as their age, comparing these with the statistical probability of miscarriage associated with the procedure, deciding the risk of miscarriage no matter how slight, was one not worth taking.

Their responses are interesting to consider when asking questions about how women make decisions about pregnancy and birth. Whatever a woman's response is to amniocentesis, she is encouraged to justify that response by demonstrating her health literacy on that particular subject. For example, to say, as did one woman that, "they stick a needle in your abdomen, and I find that disgusting," would not be considered a valid reason for declining to have the test done in terms of health literacy. To say as another, that she had read about the chances of having a Down's Syndrome baby in relation to her age. That she had then weighed up this knowledge with what she had read about the incidence of miscarriage using the procedure, might be considered a more reasoned approach. A decision to decline the test made by this process would be more difficult to argue with. The woman would have demonstrated that she had read.

cited reports and statistics, considered the probability of two sets of risks. She would have demonstrated her ability to reason, to use the logical cognition required to be defined as health literate by main stream health professionals.

WOMEN AND HEALTH PROMOTION

It is no easy task to unravel the intersections of health promotion information and the different ways women have of knowing about pregnancy and birth. It would be misleading to suggest that women's ways of knowing are all the same, or that women do not find health promotion information useful in some instances. However during interviews it was clear that women made use of a wide range of information to inform their health decisions. They demonstrated a capacity to make decisions about pregnancy and birth in the face of all kinds of complexities and difficulties.

The women interviewed never entirely ignored all health promotion campaigns and only rarely did an individual woman comply strictly with all the advice. The next section of the paper will focus on the interviews in relation to the folate campaign. Similar findings were obtained in relation to questions asked about the Listeria campaign, however space does not permit these to be detailed here.

FOLATE AND CONSTIPATION

The folate campaign advocates that women start to take folic acid or eat folate rich food at least one month before pregnancy and three months after. The campaign is based on scientific research from North America, Britain and Australia. This research maintains that increased folic acid intake before pregnancy may reduce significantly the risk of babies born with spina bifida and other neural tube defects. Recent evaluations of the campaign claim that it has been very effective and that most pregnant women and those planning pregnancy have heard of it (Bower et al. 1996, 11, 3, 177-187). The folate campaign is one that is concerned with a health outcome defined as the prevention of disability. Ideally the campaign advocates that women plan their pregnancies and prefers women to take folic acid as a daily measurable supplement. Many popular breakfast foods and milk are now fortified with folic acid as well. -,

There is a number of concerns within the scientific and medical literature about the fortification of food and also for the long-term effects of increased folate intake by the entire population, not just reproductive women. None of these uncertainties is referred to in the folate pamphlet, poster or campaign (NH and MRC 1994; Ride 1994).

Some of the women interviewed did mention that taking folic acid was a good thing to do while pregnant, however would usually mention other things first. They most often mentioned that it was more important to "look after yourself, rest, relax, be stressfree, eat right and exercise," before they mentioned folic acid. Other women did not mention it at all until prompted. Home birth women were less likely to mention folic acid as a "good thing to do" while pregnant and would be more likely to respond to the prompt. All the women interviewed mentioned other things as "good" before folate. Just under half of the women in both hospital and home birth groups had planned their pregnancies. Most women mentioned that they wanted to feel surprised by pregnancy and actually found it quite distasteful to rationally plan a pregnancy.

The evaluative study referred to earlier found that most women had heard of folate (Bower et al. 1996), was the case for the women interviewed as well. All of the women interviewed did know about folate, although not all of them were exactly sure why they should take it. Some women adhered strictly to the health promotion campaign recommendations, which are, to take a folic acid supplement one month before and three months after pregnancy. However, as mentioned previously, as many women did not plan their pregnancies, strict compliance with the instruction was not possible and something that the women were willing to "chance." Those who did comply more strictly by taking supplements rather than "chancing" their diet, were more likely to be hospital birth women who had been given the folate pamphlet by their doctor or had read about it in a popular pregnancy book or magazine. Home birth women were conscious of the need to take folate, however they were far less reliant on supplements and would mention that they ate plenty of vegetables that were folate rich, some also mentioned having their folate levels tested by homeopaths. Many of the women interviewed from both groups were concerned about the quality of the food they ate. Of all the women mentioned only two purposely did not follow the instruction of the folic campaign and one was a hospital birth woman, this was because.

When I was trying to fall pregnant, before that is, when I knew about folic acid, and because it constipated me so bad I stopped taking it. I tried so many years to fall pregnant and it didn't work so bugger the folic acid.

If an individual's health literacy is understood to be the response they have to a particular main stream health promotion campaign then perhaps the woman interviewed would be considered to fall short of this ideal. However, women and people generally do not live their lives according to the dictates of one health promotion campaign.

A more complex story emerges when the specific background of the woman being interviewed is included. The woman whose response to the folate campaign is quoted had tried for over ten years to become pregnant. She had tried for so long she had given up using any form of contraception. Her pregnancy was unexpected and unplanned, consequently she had not taken the folate supplement one month before, neither was she particularly conscious of eating a folate rich diet. She did start to take a folate supplement after she knew she was pregnant by which time two months had elapsed. They made her feel unwell and not willing to chance any possibility of jeopardising her pregnancy she stopped taking them. She stated that her doctor was always busy and became impatient with her questions, she did not, in other words want to bother him with her constipation. Where does a situation like this leave our understanding about what constitutes health literacy?

A woman's own understanding of her health needs disrupts the confining boundaries of health promotion's understanding of what is good pregnancy behaviour. Although the woman quoted above did not comply with the advice of the folate campaign, her knowledge about other health issues was extensive. For example, she demonstrated her knowledge about infertility and the health services that were available to assist in this. She raised concerns about the quality of food available for people generally and pregnant women in particular. Can health literacy only be recognised if there is demonstrated compliance with one particular health promotion campaign, or in the case of pregnancy three or four?

Many of the health promotion campaigns seem to be written in isolation from each other and offer contradictory and conflicting advice. Women mentioned the Listeria and Iron health promotion pamphlets in particular, noting conflicting advice about eating liver (for iron); and not eating liver pate, which may be dangerous because of possible listeriosis contamination. The fact that this issue amongst others, was confusing for many of the women interviewed despite their extensive reading, does indicate that narrow definitions of health literacy are not very helpful.

By describing how the women interviewed responded to main stream promotion campaigns I have attempted to illustrate the partiality of main stream health promotion approaches to health issues of interest to pregnant women. The next section of the paper analyses the way in which the discourses of women intersect with main stream health promotion discourse; how the decision-making processes of women are negotiated and mediated in ways that both use and disrupt the term "health literacy."

INTERSECTIONS

The women interviewed all claimed they were interested in the health and well being of themselves and their baby. However, women perceived that being concerned about this encompassed more than being knowledgeable about health promotion campaigns. Many of the women mentioned friends and relatives who had babies as good sources of information. Many used groups such as yoga as well as antenatal classes run by midwives and hospitals. The types of health information from these sources varied, for example antenatal classes run by midwives focussed less on the biological aspects of pregnancy and more on emotional issues. However, what was most frequently mentioned by the women interviewed as useful about attending these groups was their interaction with other women. Much of the information women use comes from other women. Pregnant women may read up about pregnancy and birth but then use other women to "sound out" and discuss issues as part of their decision making process. The home-birth women seemed to have more opportunity to do this, many mentioned midwives as people they could talk issues through with. Others used different kinds of support groups, relatives and friends, and a few mentioned doctors as people they could discuss issues with. All of the women did talk through issues with other people, and this was considered an integral part of the way they made decisions. Some of the women interviewed also talked about being guided by what was good pregnancy behaviour by "listening to their bodies" or "listening to their babies." For example, one woman claimed that if she was doing something and the baby was moving around a lot she would stop, or modify what she was doing because she felt the baby was telling her something, or that the baby was under stress. Women who had previously experienced pregnancies and births used these as important sources of information and many of their decisions were guided by their personal knowledge of pregnancy and childbirth. It would not be appropriate to idealise

informal, anecdotal or experiential ways of gaining access to, understanding and using health information. However, neither should they should be dismissed as low-level, irrational or illiterate.

Most of the women interviewed envisaged a place for main stream health promotion information, however, they did point out that it was not always realistic in its expectations. This was not only in terms of expected outcomes but also in how women were instructed to achieve these. It was surprising to encounter high levels of scepticism about health promotion campaigns and main stream health information generally. This may be partly due to the paradox where people expect science and medicine to deliver in terms of health, but are at the same time sceptical of the claims made about what is good or bad health behaviour. This scepticism is apparent too in the increased number of people in Western countries seeking alternate, homeopathic and herbal information about health and other issues. The women interviewed who had previous pregnancies and births were more sceptical of the information than were women who were experiencing pregnancy for the first time. This has been recognised in a Malay study, which was, conversely concerned with the women's use of traditional, rather than western medical practices in pregnancy. In this study women who were pregnant for the first time tended to play it safe by using traditional as well as western practices (Huang 1996).

The women in my study who had previous pregnancies and births had more confidence in sources other than textual to inform the decisions they made about pregnancy and birth behaviours. The Health Promotion Journal Australia discusses the need as do other health promotion theorists, for individuals to become health literate (Burrows et al. 1995,10,2,242; King L, 1996,6,2,50; King D, 1996,7,3,161). Health promotion campaigns were one of the least important sources of information for women. Popular pregnancy books, magazines, friends, relatives, midwives and doctors were all mentioned as more important than health promotion pamphlets or posters. Some of these sources do of course reflect the same sorts of ideas as main stream health promotion; for example popular pregnancy books also talk about the importance of folate and listeria (Stoppard 1993). Unlike health promotion campaigns they acknowledge in some way, and some more than others that women's lives can be complex and contradicting.

The women interviewed did then seek out, understand and use information about pregnancy and birth from a variety of sources. Women recognised their own limitations and that of the information they accessed. They tended to use what was useful for them in their particular circumstances, would often "make do" while at the same time acknowledging there may be an ideal behaviour or pregnancy practice, that just was not possible for them in their particular circumstance. For example, a woman who smoked during pregnancy, claimed that she knew that it was "bad" but was more concerned about how stressed she would be if she stopped, and what the ramifications of this would be on the rest of her family. Many women described themselves as researchers, demonstrating they had read up all the literature and "researched" this or that issue. Are these women as researchers akin to those described by the Health Promotion Journal of Australia as "well-meaning" but wrong (Lowe 1997,7,3,152)? Are they unqualified as health promoters in their own and their baby's interests?

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The problem is not, as the women mentioned, that health information is available in textual form. Most women would relate how they loved reading up about pregnancy, looking at diagrams about the developing foetus, reading about other women's experiences. For them, being knowledgeable about health was taking the next step and placing these ideas into the context of their own lives and experiences. This mediation, discussion and interpretation, this flexibility in their use of the information is not recognised as health literate. Much of women's decision making in relation to health information does involve the kind of logical cognition so valued by expert information providers, however it is also importantly influenced by feelings, and women's own bodily experiences. This does not necessarily denote a descent into the realms of irrationality or health illiteracy. Pregnant woman live, work, nurture, love and play within a multiplicity of contexts and roles. They will be guided by other than health promotion campaigns as to how to live in the optimum way for themselves and their families. Women demonstrated time after time their extensive health knowledge but would then remind me of the every day experiences of their lives that made it difficult for them to always comply exactly with advice.

A chance conversation of my own with a health practitioner who worked for a women's health centre alerted me to the different ways that health promotion information can be delivered and evaluated by the people it is created for. She described the "Food Sense" health promotion campaign targeting Aboriginal women. The health workers and Aboriginal women created recipes from the recommended food list, purchased, prepared, cooked and ate meals together. Several weeks later some of the women were contacted to find how useful this approach had been, to ascertain if they were still cooking and eating their creations and interpretations of the recommended food list. This is just one example of how creative and imaginative approaches may be possible in terms of health promotion. This suggests that health literacy as a necessary and privileged condition for the demonstration of health knowledge leaves much to be desired.

Rather than a static definition of health literacy that puts the onus on individual, pregnant women to learn the ropes and obey the rules, health promoters could perhaps, reflect on their own ways of knowing, and team to incorporate some of the uncertainty and complexity that women accept as part of pregnancy, health and life. An expanded sense of what is considered health knowledge could more modestly contribute in the ways that pregnant women are constituted as learned and rational subjects. Non-compliance with health promotion instruction could then be viewed as other than lack or deficiency in rationality and literacy on the part of an individual woman.

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