Shared decision-making: Personal, professional and political

Good communication is key to satisfactory and satisfying medical consultations and encounters of all kinds, be they in the GP surgery; in a hospital setting; in public health promotions; and in public health programmes such as screening or vaccination.

Jane Smith's editorial in the BMJ of 6th November 2010 was entitled 'Decisions, decisions...'. It was subtitled “If choice can be disabling as well as enabling, it’s important that “choice” in the serious matter of healthcare is well managed and supported.” Her editorial gave tasters for various papers in that issue on topics around choice and decision-making, set against the background of the UK government’s desire to increase patient choice. Angela Coulter's view is that use of evidence-based decision aids improves patients’ knowledge, understanding of options, and perception of risks and can reduce demand for surgical procedures. But clinicians' unwillingness to offer such support was identified as a barrier to utilising such support. Glyn Elwyn and colleagues worried that much more research has gone into creating decisions aids themselves than into creating a culture where professionals espouse shared decision-making as a skill and routinely used the tools. What is the use of developing expertise in decision aids; communication of ‘numbers’; of risk; etc., if clinicians don’t fully realise how important these ancillary skills are when in consultation with their patients?

‘Informed uptake’ or ‘informed decision-making’?

A further paper was a report of an Australian randomised study by Sian Smith and colleagues who had compared the effects of using one of two variants of a decision support aid in a group of people with a low level of education and literacy with a similar group of people who had received only standard information about screening for bowel cancer (by faecal occult blood testing). They found that the authors report that they showed greater knowledge, understanding of options, and perception of risks and can reduce demand for surgical procedures. But clinicians' unwillingness to offer such support was identified as a barrier to utilising such support. Glyn Elwyn and colleagues worried that much more research has gone into creating decisions aids themselves than into creating a culture where professionals espouse shared decision-making as a skill and routinely used the tools. What is the use of developing expertise in decision aids; communication of ‘numbers’; of risk; etc., if clinicians don’t fully realise how important these ancillary skills are when in consultation with their patients?

A historical case study: informed consent for breast screening by mammography

Should anyone be in doubt about whether a policy of informed uptake rather than informed decision-making should be adopted, it is hoped that the following history of numerous attempts to see that women invited for breast screening by mammography are properly informed may provide food for thought and help your decision-making.

The methods used for inviting women in the UK for two decades to attend for population breast screening by mammography by the NHS Breast Screening Programme (NHS BSP) have been openly, repeatedly and increasingly challenged. It and resultant trials seeking evidence for management of screen-detected abnormalities have been challenged on both ethical and practical grounds for many years. The last couple of years in particular have seen compelling evidence of many kinds, and include several systematic reviews with covering editorials in leading journals. Professor Klim McPherson’s recent review, called for by the BMJ, drew similar conclusions to other reviews that “there is no doubt that screening for breast cancer has limited benefit and some possibility of harm for an individual woman and marginal cost effectiveness for a community.”

Yet women are still being invited today by the NHS BSP to be screened without benefit of proper information in spite of repeated challenges over 2 decades about the inadequacy of their consent process and available models of better quality information. Respect for a woman's autonomy and her decision-making ability – if given true evidence-based facts about the potential for breast screening by mammography to be of benefit to her, as well as its potential to cause her harm – has been behind the motivation for these challenges. As respect for autonomy is one of the four ethical
principles (beneficence, non-maleficence, autonomy and justice) of proper medical professional behaviour, the effect on the uptake to the programme should not be a consideration, particularly since there are no herd immunity factors to consider within the range of disease that is labelled as ‘breast cancer’. Conversely, the consequences of being diagnosed through the programme with a pseudo-, non-invasive ‘carcinoma’ can result in repercussions on the next generation as my daughter and I have personally experienced.14

Fiona Godlee in her covering editorial15 described the “sense of measured outrage” that such an important national programme could exist for so long with so many unanswered questions”, and drew attention to McPherson’s call for a “full and dispassionate examination of individual patient data from all recent studies and, in the meantime, much more honesty from the NHS screening programme about the scientific uncertainties.”

An alternative proposal: risk assessment/risk management (RARM)

Proposals were put before the House of Commons Science and Technology Committee some while ago by Michael Baum for a ‘risk assessment/risk management’ (RARM) scheme, offered as a transitional replacement for the current breast screening programme.16 It would, by triage, sort women who came forward into low, medium and high-risk of getting breast cancer. Software is available to do this, already in use in clinics in the United States. Women identified as at low risk would not require to be screened, but could be given lifestyle advice (re: smoking; consumption of alcohol, obesity; diet; exercise) which would also lower their risk of a much more likely threat, that of cardiovascular disease. The high-risk women would receive genetic and other counselling. The medium risk women (who might just benefit from being screened) who wanted to consider whether to go forward for screening, would be properly informed about the known harms, limitations and consequences of going forward to be screened by mammogram, as well as the small chance of benefit, based on the most up-to-date evidence. Her decision would be made with the help of equally well-informed health professionals who had been trained to communicate the ‘numbers’ (statistics) properly and well.17,18 The pros and cons - the risk of potential harm when set against the potential for possibility of benefit - tailored to her own individual risk profile (age; family history; lifestyle factors (as listed above) etc.) - would be discussed with her with the help of decision tools. This method would at least begin to reduce the number of women going unnecessarily (unknowingly) to be incorrectly labelled with ‘cancer’, and may also begin to lower the level of fear in women whipped up by current approaches.

A call for individual patient data for analysis and appraisal by NICE

As called for by McPherson and Godlee, the National Institute for Health and Clinical Excellence (NICE) should call for individual patient data from screening trials to be made available for independent analysis. An independent organisation such as the Clinical Trials Service Unit (CTSU) could be commissioned by NICE to do this.

Ethical considerations

The ethical considerations, sometimes brushed aside as being of secondary importance, must be emphasised. As citizens paying the costs for this activity, and targets for numerous screening invitations and programmes, should we not all be more concerned and ask ourselves whether the ethical imperatives to put a stop to duping women with ‘The Facts’19, whether harming more women than are being helped; whether failing to respect individual women’s dignity and autonomy are more than sufficient reasons to insist on proper informed consent, and, in the case of breast cancer, warrant an instant move towards a RARM initiative? This method would utilise expertise and resources to better effect and, moreover, would satisfy the current need to cut unnecessary waste in health expenditure. Risk management for prostate cancer is the preferred and well-accepted approach – why not for breast cancer, and other diseases as appropriate?

When considering the ‘rightness’ of this approach against the prevarications; iniquitous delays; failure to tell the truth; failure to justify ‘estimates’ of 1400 lives saved by screening per annum of the NHS BSP; etc., should we not also ask ourselves where our energies, time and money should best be used, to put a stop to the current process of ‘trawling a healthy population group’ which is continuing to damage millions of women psychologically, physically, socially? Is it not well past time to put a stop to the current paternalistic system of coercing women to come forward, since many hold that it is morally unacceptable and a disrespectful way to treat competent adults capable of making their own decisions if given evidence-based information; decision tools; ‘numbers’ presented graphically as well as in tables and words to aid an individual’s risk assessment; and ‘neutral’ advice from competent health professionals?

Furthermore, (leaving aside the different parameters that obtain for making policy decisions about offering population screening in different disease areas,) a morally correct motivation for providing ‘The Facts’ when offering breast screening should surely also be the motivation for offering ‘the facts’ in other population screening programmes, including that for bowel cancer?

Action taken: further recommendations for action

The Cancer Director and the NHS BSP were specifically challenged 21 months ago,20 because there had been no action in response to numerous other previous calls to reform the breast-screening programme. Since that February 2009 challenge, well over 3 million women in the UK will have gone through the current inadequate screening system. Good quality evidence has been accumulating in that time to reduce the uncertainty about the harm/benefit ratio. McPherson and Godlee and numerous others have called for an independent analysis using individual patient data. Concrete proposals have been put before the Science and Technology Committee for an alternative RARM approach. Women continue to be unknowingly over-diagnosed and over-treated. Citizens are waiting for an explanation and a constructive response from those NHS officials responsible for profligate use of public money. How much longer do we have to wait? What other action can be taken? Perhaps citizens in our democracy who are now all targets for being persuaded to attend for screening of one kind or another, should ask their own spokesperson – their member of parliament – to see that equity, respect for autonomy, justice, beneficence, and non-maleficence govern how healthy people are approached and treated in such public health programmes?

Setting this account against an academic’s suggestion for a policy of informed uptake rather than informed decision-making, it is clear that much needs to be done to see that citizens are enabled to make well-informed decisions, and that doctors, surgeons, clinicians of all kinds, need to be aware, not just of the evidence, the practicalities and technicalities of offering screening programmes, but also of the ethics that should underpin personal, professional and political decision-making. We all have a responsibility, whether health professional or layperson, to be vigilant with
respect to suggestions for mischievous manipulations of ‘the facts’ prompted by unsuitable motivations.

Conflict of interest
None declared.

References


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