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Ethical dilemma: Should doctors reconstruct the vaginal introitus of adolescent girls to mimic the virginal state? (Who wants the procedure and why)

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Ethical dilemma

Should doctors reconstruct the vaginal introitus of adolescent girls to mimic the virginal state?

In some ethnic communities women must be virgins when they marry. These cultural traditions can raise difficult issues for doctors when they are faced with requests by young women from immigrant families to reconstruct their hymens. In this ethical debate Dutch doctors who carry out the procedure, a British gynaecologist, a senior lecturer in child health, two ethicists, and a psychiatrist give their views.

Who wants the procedure and why

A Logmans, A Verhoeff, R Bol Raap, F Creighton, M van Lent

During this century many immigrants from Mediterranean and African countries have moved to western Europe.¹ Second and third generations often face a conflict. They may follow the lifestyle of the new country and friends but have to remain mindful of the original traditions and attitudes of their families.

Many immigrant groups hold strongly with the tradition that girls must be virgins when they marry. If the bride cannot show her bloody sheet after the wedding night, her family are shamed. Her new husband's family may exact revenge in the form of violent reprisals and banishment of the bride. Because of these far reaching consequences, many gynaecologists in the Netherlands are willing to reconstruct the hymens of adolescent girls who are no longer virgins but wish to appear so.

Reconstructing the hymen

In our hospital, the operation is carried out as an outpatient procedure. We insist that an interpreter and social worker are present during the initial consultation and that the social worker attends the surgery. The epithelial layer that has grown over the ruptured hymen is removed and the hymenal remnants are adapted by a circular running suture or by left to right approximation. Where the hymenal remnants are insufficient, a narrow strip of posterior vaginal wall is dissected for reconstruction. Three weeks later, the patient is followed up and given an opportunity to discuss any emotional issues. As is legal in the Netherlands, the patient is offered the opportunity to remove or destroy any notes on this procedure from her medical record.

We followed up the first 20 patients seen in 1993. The mean age of the girls was 19 years (range 16 to 23 years). Eight were undertaking technical and vocational training, eight were attending secondary school,

and four were following courses of higher education. Ten girls claimed that they had lost their virginity as a result of forced intercourse, six were having regular intercourse, and four did not provide this information. All 20 were satisfied with the outcome of the procedure and none had any regrets. We evaluated only 10 young women long term. All 10 said the procedure provided a satisfactory outcome. All of the patients decided to have the details of the procedure removed from their medical records.¹

Ethics and culture

Immigration is often associated with a stepwise adaptation of the migrants to their new countries.² Some young women have sexual intercourse without foreseeing the consequences—that it will be impossible for them to marry in the traditional way. In the Netherlands the principal factors in ethical decisions are the patient's wishes—provided these are within the law—so medical decisions may conflict with cultural values.

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Many second and third generation immigrant girls remain mindful of their cultural traditions

We reject any suggestion that this operation is analogous to traditional clitoridectomy. There are strong arguments for rejecting a request for clitoridectomy, but equally strong ones exist for accepting hymen reconstruction. Most importantly, hymen reconstruction is not mutilating; the risk of physical, psychological, and sexual complications is far less than in clitoridectomy.³⁻⁷ Hymen reconstruction, like male circumcision, is an example of "ritualistic surgery." Our definition of ritualistic surgery, modified from that of Bolande,^{8,9} is "fulfilment of a person's need rather than a response to their medical condition." The ethics of hymen reconstruction could be compared to the ethics of cosmetic surgery, an accepted part of plastic and reconstructive surgery worldwide.

- 1 De Santis L, Ugarriza DN. Potential for intergenerational conflict in Cuban and Haitian immigrant families. *Arch Psychiatr Nurs* 1995;9:354-64.
- 2 Lipson JG, Hosseini T, Kabir S, Omidian PA, Edmonston F. Health issues among Afghan women in California. *Health Care Women Int* 1995;16:279-86.
- 3 Kluge EH. Female circumcision: when medical ethics confronts cultural values. *Can Med Assoc J* 1993;148:288-9.
- 4 Meniru GI. Female genital mutilation (female circumcision). *Br J Obstet Gynaecol* 1994;101:832.
- 5 Jordan JA. Female genital mutilation (female circumcision). *Br J Obstet Gynaecol* 1994;101:94-5.
- 6 Baker CA, Gilson CJ, Vill MD, Curet LB. Female circumcision: obstetric issues. *Am J Obstet Gynecol* 1993;169:1616-8.
- 7 De Silva S. Obstetric sequelae of female circumcision. *Eur J Obstet Gynecol Reprod Biol* 1989;32:233-40.
- 8 Bolande RP. Ritualistic surgery: circumcision and tonsillectomy. *N Engl J Med* 1969;280:591-6.
- 9 Wall LL. Ritual meaning in surgery. *Obstet Gynecol* 1996;88:633-7.

Commentary: The ethical issue is deceit

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The article of Logmans et al is presented as "an ethical dilemma." The chief point that strikes me is its apparent blindness to the real ethical issue involved. It considers and rightly rejects two objections to reconstructing the hymen—firstly, that it is analogous to clitoridectomy, which is agreed to be reprehensible, and, secondly, that it does not benefit the physical wellbeing of the patient. But these objections are trivial. The real ethical difficulty is that the operation involves collusion with deceit. Should a doctor participate in this?

Should the doctor advise the patient to be quite open with the bridegroom, and perhaps offer to join her in persuading him to accept the situation? If that seems feasible, well and good; but the patient may say that the bridegroom shares the traditional attitude of his family and cannot be persuaded. If the doctor still refuses to be involved in deceit, the consequence may be a breaking off of the marriage, or shame and rejection. Should the doctor be prepared to see that happen and to be partly responsible for it? I think not.

Or suppose the patient says that the bridegroom can perhaps be persuaded to accept the situation but his (and her) family cannot. Then the bridegroom will have to join in the collusion. The bride can ask the bridegroom to accept her past, but is it right for her to require him to join her in deceit? Can she predict whether he will be willing?

The difficulties are fewer if the bridegroom is involved anyway. Then deceit affects only the families of the couple. It is not obvious that a doctor should refuse to collude with deceit of that character. One can hardly say that the doctor's duty extends beyond the patient and her intended husband to the wishes of their families.

These are the questions that give rise to an ethical dilemma, not those discussed in the article.

Deceit needs justification

Who is being deceived? Is it just the families or the bridegroom too? It would not be proper for the doctor to say that he or she has a duty to the patient alone and has no responsibility for the morality of the patient's relationship with her husband. The proposed operation is intimately concerned with that relationship, and the doctor should not readily assist in deceit between spouses. Even if it is considered purely in terms of the patient's interest, the deceit can be harmful—it could be discovered one day and the fear of this might cause anxiety from the start.

Commentary: Promiscuity is acceptable only for men

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Culture, society, and family are important factors in the way an individual functions. The role of virginity, fertility, and the influence of the family are the main contributors to trends in sexual and marital relationships across cultures.¹ Although promiscuity may carry high prestige for men, promiscuous women are generally scorned. Men prefer chaste women in order to ensure their paternity.²

Ford and Beach, in their survey of 190 societies worldwide, divided these into three types: restrictive

ones, where sexuality outside marriage is discouraged; semirestrictive societies, in which formal prohibitions exist, but are not strictly enforced; and permissive societies.³ Broude and Greene reported that premarital sexuality in women was approved in 25% of the 141 societies they studied; virginity was valued and premarital sexuality was mildly disapproved of in 26% of societies and strongly disapproved of in 24%.⁴ In the last group, virginity had to be proved by tests, and reprisals were severe for those who failed.

Although long term psychological follow up of the 20 patients reported by Logmans et al is not available, the procedure highlights some of the problems of younger generations of migrants. When there is a split between two cultures, one prescribing virginity and the other allowing exploration of sexuality before marriage, the stresses on the individual are enormous. The double standards on the part of the groom's family, which may ask for a virginity certificate, further contribute to the stress. In addition, women who are exploring their sexuality may have no confidants and may feel isolated in their dilemmas. Bekker and Rademakers from the Netherlands point out that these women seek help from a number of sources and service providers may deal with them in different ways.⁵ The clinicians may view the surgical repair of the hymen as reflecting social injustices and yet more hypocrisy. The hymen, of course, is associated with myths, and men who are expected to succeed in defloration and show the evidence are also likely to feel stressed.

The dilemmas in providing this service are many. The loss of virginity may be related to incest and sexual abuse. After vaginoplasty the patient may experience post-traumatic stress disorder. The article of Logmans et al further emphasises the objection to medical intervention in these cases—namely, that it confirms sexual inequality and surgical intervention purely on social grounds.⁵ Without longer term follow up it is difficult to say whether surgery will “cure” all the psychological trauma of these young women.

- 1 Bancroft J. *Human sexuality and its problems*. Edinburgh: Churchill Livingstone, 1989.
- 2 Daly M, Wilson M. *Sex, evolution and behavior*. Belmont, CA: Wadsworth, 1978.
- 3 Ford C, Beach F. *Patterns of sexual behaviour*. London: Eyre and Spottiswoode, 1951.
- 4 Broude G, Greene S. Cross-cultural codes on 20 sexual attitudes and practices. In: Barry H, Schlegel A, eds. *Cross-cultural samples and codes*. Pittsburgh: University of Pittsburgh Press, 1980.
- 5 Bekker MHJ, Rademakers J. Study examines Islamic virginity issues. *Psychol Int* 1997;8:1.

Commentary: Education about the hymen is needed

Sara Paterson-Brown

The celebration of a bloody sheet, vividly portrayed in popular cinema, is based on strong religious and cultural beliefs. The Koran states that a bride has to be a virgin, and according to custom a woman found on her wedding night to have been “touched” brings shame to her family. Consequences include divorce through to death.¹

Young women, understandably, go to great lengths to get their hymens refashioned (hymenorrhaphy) before their wedding.¹ Hymenorrhaphy is illegal in most Arab countries, but it is performed unofficially; specialists undertake five or six procedures weekly (confidential communications). Egypt's trade in hymen repairs, reported last year, reduced “cleansing” murders by 80% over the previous 10 years.¹

The simplest technique of hymenorrhaphy, performed days before a wedding, uses catgut sutures to approximate hymen remnants (with or without incorporation of a gelatin capsule containing a blood-like substance which bursts on intercourse). The definitive procedure approximates undermined hymen remnants or vaginal flaps and often produces vascular bands across the introitus. These women may be told to instruct their husbands that their hymen is very vascular and that he should cut it with a “sharp instrument” before they attempt sexual intercourse.

Appearances are deceptive

In Western society hymenorrhaphy is legal and is comparable with plastic surgery in ethical terms. The concept of deception is not relevant; this operation is done for the woman; and the principle of confidentiality in medicine is as old as medicine itself. But factors such as sporting activities and use of tampons mean that bleeding with first sexual intercourse is not inevitable in the “Western” woman and is an unfair end point. I questioned 41 women

colleagues about this: 14 (34%) bled on first intercourse, 26 (63%) did not, and one could not remember. Previous reports on physical examination of hymens show that the virginal state was certain in only 16 of 28 (57%) virgins,² and appearances relate to tampon use.³

The report of Logmans et al on 20 cases of hymenorrhaphy in second generation Mediterranean and African immigrant women in the Netherlands exposes social issues that are of grave concern. Firstly, the youngest woman was 16 years old, and teenage sex in ethnic minorities is associated with a rising incidence of sexually transmitted diseases⁴⁻⁷ and teenage pregnancy.⁸ Secondly, 10 of 16 girls had been “forced” to have sexual intercourse. Are these girls receiving adequate sexual education, and are they more vulnerable to sexual harassment?

Hymenorrhaphy is justifiable in certain circumstances, when the woman would otherwise suffer disgrace or worse. More importantly, however, young immigrant women require appropriate sexual education and their families need to be educated about their adherence to the “bloody sheet” theory.⁸

I thank the numerous colleagues with whom I have discussed these issues.

- 1 Kandela P. Egypt's trade in hymen repair. *Lancet* 1996;347:1615.
- 2 Underhill RA, Dewhurst J. The doctor cannot always tell: medical examination of the “intact” hymen. *Lancet* 1978;i:375-6.
- 3 Emans SJ, Wood ER, Allred EN, Grace E. Hymenal findings in adolescent women: impact of tampon use and consensual sexual activity. *J Pediatr* 1994;125:153-60.
- 4 Fenton K, Johnson AM, Nicoll A. Race, ethnicity, and sexual health. *BMJ* 1997;314:1703-4.
- 5 Lacey CJN, Merrick DW, Bensley VC, Fairley I. Analysis of the socio-demography of gonorrhoea in Leeds, 1989-93. *BMJ* 1997;314:1715-8.
- 6 Low N, Daker-White G, Barlow D, Pozniak AL. Gonorrhoea in inner London: results of a cross sectional study. *BMJ* 1997;314:1719-23.
- 7 De Cock KM, Low N. HIV and AIDS, other sexually transmitted diseases, and tuberculosis in ethnic minorities in United Kingdom: is surveillance serving its purpose? *BMJ* 1997;314:1747-51.
- 8 Adler MW. Sexual health—a Health of the Nation failure. *BMJ* 1997;314:1743-7.

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Commentary: Cultural complexities should not be ignored

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There is no doubt that migrants experience cross cultural stress. Girls living in the West, but belonging to communities that are fiercely patrilineal and patriarchal, are perhaps particularly at risk. These girls do not live within one fixed culture with extrafamilial contact with another fixed culture. They live at the intersections of usually many cultures with widely different cultural norms, all of which change with time and place and influence one another. Members of the white ethnic majority can have little insight into the cultural complexities of their lives. What is clear is that premarital sex places these girls in a predicament which can threaten their chances of a secure future as adults in their own communities.

The suggestion that hymenal reconstruction is analogous to female genital mutilation is absurd. Whether approached from an absolutist or a culturally pluralist standpoint, female genital mutilation is a practice so dangerous, mutilating, and painful that there is no doubt of the appropriateness of its prohibition. Hymenal reconstruction, on the other hand, theoretically scores low on maleficence and high on beneficence, as it is a safe procedure which may preserve the personal and physical integrity of the woman requesting it. What is more debatable is whether it is needed at all, given that “defloration” and “the blood on the sheet” are largely the stuff of mythology.

This is an issue to be approached pragmatically and sensitively. This requires doctors who are trained in multicultural practice, an area largely ignored at undergraduate and postgraduate levels in British



Awareness of multicultural complexities is needed

medical schools. The multidisciplinary model described in Logmans et al's paper, given appropriate measures to maintain absolute confidentiality, would allow doctors to work with colleagues in other disciplines who do have these skills. In most cases education and counselling will be all that is needed.

It is alarming that at least half the young women in this study find themselves in this predicament as a result of sexual abuse. This has implications for protection of other children in the family and community. In Britain, all doctors have, under the Children Act, clear obligations to inform the appropriate authorities if they have information that suggests children are at continuing risk of harm.

Commentary: Surgery is not what it seems

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The decision by Dutch doctors to repair surgically the hymens of young women to mimic the virginal state is described as a case in which cultural values conflict with medical ethics. But this may not be an accurate description. Repair of the vaginal introitus is a low risk procedure that can be done as an outpatient procedure under local anaesthetic. It allows young women to bleed from intercourse on their wedding night. But it does not, as Logmans et al claim, show respect for cultural differences, nor is it proof that the immigrants cherish their traditional ideas. The surgery allows these women to appear as if they have conformed to these cultural expectations when their previous sexual experiences suggest otherwise.

Despite my rejection of their cultural argument, I agree with Logmans et al that there are reasons to support the doctors' decisions to perform the surgery. The surgery may protect these women from violent reprisal. This is particularly pertinent given that at least half of the women claimed that their previous sexual intercourse was forced. However, the data may be exaggerated if these women believe that claiming

forced intercourse will ensure that the doctors perform the surgery. Alternatively, the data may be an underestimation given the social taboos against the disclosure of sexual violence. In this context, the surgery may be crucial in averting further violence.

Although Logmans et al are correct to differentiate between vaginoplasty and clitoridectomy, a more appropriate comparison would be that between vaginoplasty and breast implants. Both allow women to fulfil physical ideals of their respective cultures—ideals that others argue are symbols of female denigration. Obviously, there are surgeons who feel that these surgical procedures are acceptable. In this case, if a woman believes that reconstructive surgery is in her best interest, the surgeons should respect her autonomy and proceed with the repair or refer her to doctors who will do it.

But it would be inadequate to stop the argument here. Respecting a patient's request for vaginoplasty must be understood in context. The surgery is only an interim solution because the true solutions are not medical but social; they are the promotion of greater gender equality in social norms and customs.

Lay perspectives: advantages for health research

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Although involvement of the consumer is increasingly being advocated in health related research, it is not welcome universally. Furthermore, the underlying rationale is rarely made explicit. Policy makers, health care professionals, and researchers need to be clear about the benefits and ways of including lay perspectives and the criteria for evaluating these. Examples of lay involvement in setting research agendas,¹⁻⁴ methodological debate,⁵ and specific projects^{4 6 7} are accumulating, but little clear evidence about the benefits and costs of different ways of incorporating lay input into health services research is available.

We outline two basic reasons for incorporating lay perspectives into research and discuss some common objections. A framework is offered to help clarify the dimensions of lay involvement in health research. We use the term "lay" to mean people who are neither health care professionals nor health services researchers, but who may have specialised knowledge related to health. This includes patients, the general public, and consumer advocates.

The origins of lay involvement

The current interest in incorporating lay perspectives into health services research reflects broad social and political trends and developments in health care that have involved some breaching of the boundaries between medical professionals and others. The assumptions that the "experts"—doctors and biomedical researchers—are the best judges of what research is needed and should be exempt from democratic accountability are questioned. In addition, theoretical and empirical work on the philosophy and sociology of science has shown that the culture and values of those involved can influence research and the knowledge derived from it.⁸ The relevance of much research that has been driven by narrow professional and academic interests is increasingly being questioned.^{9 10}

Given this context, there is naturally an increasing interest in incorporating lay perspectives in research. This is not confined to the identification and solution of local problems and empowerment of disadvantaged

Summary points

Including lay people in health services research has been mandated politically and could improve the quality and impact of research

Patients and other lay people often have insights and expertise that complement those of health care professionals and researchers

Input from lay people may influence the setting of research priorities; the identification of problems; the design and execution of projects; and the interpretation, dissemination, and implementation of research findings

There are many potential lay contributors and ways of identifying their views and incorporating these into decisions; the appropriateness of particular combinations will vary in different contexts

Incorporation of lay perspectives into research and the methods used to achieve this must be evaluated rigorously

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community groups, which cannot be done without lay involvement.^{11 12} Lay involvement is also advocated in more traditional empirical research that describes and analyses patterns of ill health, the causes and consequences of health problems, and the effectiveness of health care. We concentrate here on the last type of research, in which the potential benefits of lay involvement may be less obvious.

Why incorporate lay perspectives into research?

Including lay people in research may be seen, firstly, as politically mandated and, secondly, as a way of improving the quality of research. Although both these reasons include an element of moral imperative, each suggests a different approach and different criteria for evaluating input from lay people.

Politically mandated lay involvement

Research decisions are political as well as academic because different projects are likely to benefit different people. Prevailing notions of democracy suggest that the public, as the "owners" of publicly funded research, should have a say in what is done and how. They also suggest that research funds should be allocated by means that pay attention to the views of all those with legitimate interests. In the current climate, lay involvement may also be seen as politically expedient because it can serve to legitimise decisions.

When lay involvement is seen primarily as a political imperative, it becomes a goal in its own right. The processes of decision making become the focus of attention,



and concern for the quality of the resulting decisions (and hence research) may become secondary.

Improving the quality of research

The argument that greater attention to lay perspectives may improve the quality of research is based on the premise that lay views often differ from those of health professionals and researchers—that they have legitimacy and can sometimes add value. Students of the sociology of science are familiar with a case in which government scientists calculated safe limits for chemical exposure to agrochemicals on the basis of laboratory tests. The scientists were oblivious to what farm workers knew about the practicalities of spraying in the wind and rain, with flaws in their protective clothing and a cocktail of other chemicals in use; their calculations were therefore inadequate.¹³

Patients may also have important insights that researchers may overlook—insights into things that cause problems for patients, or the types of technology and outcomes that patients value or are concerned about. Diverse lay perspectives on the impact of health care interventions, for example, may enhance understandings in assessing health technology.¹⁴

Examples of the contributions lay people make to research include raising funds, identifying important questions and relevant outcomes, drawing up priorities for research topics, appraising protocols, recruiting and preparing information for participants, undertaking research, and interpreting research findings.^{4-7 15 16} Lay involvement in generating knowledge may increase the perceived relevance and acceptance of findings.^{4 17} It may also encourage consumer groups to disseminate research. The inclusion of lay perspectives may therefore lead to research findings being more fully implemented.

Objections to lay involvement

Objections to incorporating lay perspectives in research are often raised. These include claims that lay participants are rarely typical, that lay interests can be adequately represented by others, that lay perspectives will not improve decision making in research, and that lay people may be biased or partial.

Lay people who get involved are rarely typical

If lay people are to be involved as a way of legitimising politically a decision or project, individuals who are democratically elected or are recognised as being typical or representative may be required. However, if lay input is intended to improve the relevance and quality of research, people with specific expertise, insight gained from experience, or the ability to present a range of relevant lay views will be more appropriate. Statistical or electoral representativeness is not the only criterion by which the appropriateness of lay (or other) contributors should be judged.

Lay interests can be adequately represented by others

Health professionals often assume that they understand fully their patients' points of view and concerns, and that additional efforts to identify these are unnecessary. However, studies show this may not be the case,^{18 19} and many health professionals have a poor understanding of their patients' views.²⁰

Health professionals who are briefed explicitly to represent patients' interests may sometimes be able to do so. For example, a group who had prolonged contact with patients with end stage renal disease were able to identify the sort of information that people newly diagnosed with this condition require.²¹ However, the assumption that health professionals generally can identify patients' concerns and views across a range of issues is invalid. In addition, health professionals may have conflicts of interests that limit their ability to argue from lay perspectives.

Lay perspectives will not enhance research decision making

There is also a view that lay people who do not have much formal medical knowledge and are not familiar with scientific methods or current research evidence will not be able to add anything to research decisions. In research teams, however, everyone brings different skills and expertise, and lay people may provide valuable additional insights. Although lay participants, like others, may need adequate briefing and explanation of technical language, this does not render their contribution worthless.

Lay input will be biased or partial

Another objection is that the vested interests of patients may lead them to act in partial and non-scientific ways. For example, patients who believe that a new treatment is better than an existing one may be unwilling to support randomised controlled trials that compare the two. This objection can be countered on two fronts. Firstly, some patients might be more willing to contribute if they understood better the rationale underlying some types of research—for example, uncertainty about the effectiveness of unevaluated treatments. Secondly, patients are not the only people with vested interests—clinicians too are often reluctant to support trials because of their individual beliefs in the superiority of one treatment.^{22 23} Lay perspectives may provide an important counterbalance to other interests that have tended to dominate research.²⁴

An outline framework

The issues and practicalities of incorporating lay perspectives may vary according to the health topic being investigated, the stages of research being considered, and the types of lay input sought. We offer a basic framework to help clarify thinking about lay input from a researcher's perspective. The framework has three focuses that reflect important questions that are interlinked in practice, but separated here for clarity. Firstly, what is the aim of lay input, and at what stage(s) of research is it needed? The value of lay input and the appropriateness of different contributors may vary considerably according to the stage of research (box). Secondly, who can best contribute lay perspectives? Thirdly, which approaches will best identify, express, and use relevant lay views? Within each dimension, we suggest relevant variables (see box). Our lists are not, however, intended to be definitive.

Some strengths and weaknesses of individuals and groups

The potential contributors have different strengths and weaknesses. For example, people with experience of a specific disease as patients are likely to be more valuable than organisations with generic health interests to project teams considering which outcomes are important for studies of treatment effectiveness.

The variability of consumer organisations warrants particular mention. Not all are run by and for the people they represent, and some, such as professional groups, may have narrow views and vested interests. For some health conditions there are several consumer groups with conflicting views. This need not invalidate lay involvement, but it does suggest that contributors should be selected carefully and that several lay contributors may be needed.

Good practice

Identifying lay views and integrating these into decisions may be quite distinct processes. Lay people may thus be given a voice without necessarily being involved in decision making. The merits and practicalities of different approaches to incorporating lay views are beyond the scope of this paper, but suggestions about good practice have been made elsewhere.^{25 26}

Discussion

The incorporation of lay perspectives into health research may be politically desirable and in some circumstances may enhance the quality of the work done. Questions do need to be asked, however, about the advantages, disadvantages, and resource implications of lay involvement in different circumstances, and further debate is required about how it should be evaluated.

Groups who are planning to include lay perspectives in research should consider what they are trying to achieve. We have proposed a framework to encourage clearer thinking about the types of research decisions to which lay perspectives might contribute, the appropriateness of different lay contributors, and approaches to obtaining lay input. It is unlikely that there will prove to be one single "best" approach, but some combinations of types of lay people and ways of identifying and incorporating their views seem better than others in contributing to particular stages of research.

The willingness of lay groups and individuals to contribute on the terms set by policy makers, health professionals, or researchers needs to be considered. Although some groups explicitly seek representation on key research committees, others may see these requests for help from the establishment as a drain on their limited resources. It may be particularly important to provide potential contributors with explanations and evidence of how their efforts can benefit them or future recipients of health care and remunerate them for their input and expenses.

Lay participation may need to be facilitated, for example by technical briefing and skills training for lay people, and by training health professionals and researchers to enhance their ability to understand lay perspectives and to work effectively with lay people in different situations.

Outline framework for lay input into health research

Stages of the research process

- Broad setting of priorities (including decisions of funding agencies about the populations, health conditions, interventions, and problems to which research funds will be allocated).
- Specific research projects:
 - Identifying problems and formulating questions
 - Design of projects (including decisions about study design and outcome measures)
 - Project execution (including recruitment, data collection and analysis)
 - Interpretation of findings and development of recommendations
 - Dissemination of findings and implementation of any recommendations (including decisions by researchers, referees, and editors that influence how and where findings are communicated).

Possible contributors of lay perspectives

- Patients and former patients
- Carers (whose interests sometimes conflict with those of patients)
- Potential users of specific health services (for example, older people and pregnant women)
- General public as potential patients, citizens, or taxpayers
- Community leaders
- Individuals or organisations who serve or represent lay people (consumer advocates, self help groups, consumer health information services, community health councils, etc)
- Organisations with generic health interests:
 - Organisations with specific interests, for instance associations that focus on specific diseases
 - Health professionals, or social scientists who have studied lay views

Ways of identifying and using lay input

- By reading—both lay publications and studies of people's views
- Various forms of consultation (surveys, focus groups, Delphi studies, open meetings, etc)
- Citizen juries, lay consensus conferences
- Integration of lay people in the assessment of research proposals and reports
- Inclusion of lay people on committees and working groups

Although the primary aim of health care should be to benefit its recipients, and health services research should ultimately serve to improve health care, patients and other lay people are not the only ones with legitimate views and important insights to contribute. Many of the issues raised here also apply to those health professionals who have often been precluded from research activities, just as lay people have been.

Inevitably, attempts to reflect lay views in research will result in negative and positive experiences. Debate and practice should become better informed if people can evaluate previous attempts to incorporate lay perspectives. It is therefore important that experiences from diverse settings are documented and made available for others to learn from.

- 1 MacLwain C. AIDS activists say basic research is underfunded. *Nature* 1993;363:388.
- 2 Marshall E. The politics of breast cancer. *Science* 1993;259:616-7.
- 3 Tighe RJ, Biersdorff KK. Setting agendas for relevant research: a participatory approach. *Can J Rehab* 1993;7:127-32.
- 4 Oliver SR. How can health service users contribute to the NHS research and development programme? *BMJ* 1995;310:1318-20.
- 5 Nowak R. AIDS researchers, activists, fight crisis in clinical trials. *Science* 1995;269:1666-7.
- 6 Bell RW, Damrosch SP, Lenz ER. The polio survivor as expert: implications for nursing rehabilitation research. *Rehab Nurs* 1994;19:198-202.
- 7 Renfrew M, McCandlish R. With women: new steps in research in midwifery. In: Roberts H, ed. *Women's health matters*. London: Routledge, 1992:81-98.
- 8 Yearley S. Understanding science from the perspective of the sociology of scientific knowledge: an overview. *Public Understanding of Science* 1994;3:245-58.
- 9 Bastian H. *The power of sharing knowledge*. Oxford: UK Cochrane Centre, 1995.

- 10 Barnes B. *About science*. Oxford: Blackwell, 1985.
- 11 Cornwall A, Jewkes R. What is participatory research? *Soc Sci Med* 1995;41:1667-76.
- 12 Flynn BC, Wiles DW, Rider MS. Empowering communities: action research through healthy cities. *Health Ed Q* 1994;21:395-405.
- 13 Irwin A. *Citizen science: a study of people, expertise and sustainable development*. London: Routledge, 1995;111-5.
- 14 Ong BN. The lay perspective in health technology assessment. *Int J Technol Assess Health Care* 1996;12:511-7.
- 15 Chalmers I. What do I want from health research and researchers when I am a patient? *BMJ* 1995;310:1315-8.
- 16 Goodare H, ed. *Fighting spirit: the stories of the women in the Bristol breast cancer survey*. London: Scarlet Press, 1996.
- 17 Goodare H, Smith R. The rights of patients in research: patients must come first in research. *BMJ* 1995;310:1277-8.
- 18 Dolan JG, Bordley DR, Miller H. Diagnostic strategies in the management of acute upper gastrointestinal bleeding: patient and physician preferences. *J Gen Intern Med* 1993;8:525-9.
- 19 Hares T, Spencer J, Gallagher M, Bradshaw C, Webb I. Diabetes care: who are the experts? *Q Health Care* 1992;1:219-24.
- 20 Coulter A, Peto V, Doll H. Patients' preferences and general practitioners' decisions in the treatment of menstrual disorders. *Family Pract* 1994;11:67-74.
- 21 Groom PA, Hutchinson TA, Tousignant P. Content of a decision analysis for treatment choice in end stage renal disease: who should be consulted? *Br J Gen Pract* 1994;14:91-7.
- 22 Alderson P. Equipose as a means of managing uncertainty: personal, communal and proxy. *J Med Ethics* 1996;22:135-9.
- 23 Lumley J, Bastian H. Competing or complementary? Ethical considerations and the quality of randomized trials. *Int J Technol Assess Health Care* 1996;12:247-63.
- 24 Chalmers I. The perinatal research agenda: whose priorities? *Birth* 1991;18:137-45.
- 25 Hamilton-Gurney B. *Public participation in health care. Involving the public in health care decision making: a critical review of the issues and methods*. Cambridge: East Anglian Regional Health Authority, 1994.
- 26 Local Management Government Board. *Community participation in local agenda 21*. Luton: Local Government Management Board, 1994. (Local agenda 21 round table guidance.) (Accepted 21 July 1997)

Continuing medical education

Learning and change: implications for continuing medical education

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This is the third in a series of seven articles looking at international trends and forces in doctors' continuing professional development

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Medical education, particularly continuing medical education (CME), has been greatly influenced by studies of adult learning. The observation that it is not teaching but learning that leads doctors to change their practice has resulted in a shift in perspective: rather than education being regarded as instruction, it is regarded as facilitation of learning. This paradigm shift has been based on research into how and why doctors change their practice and into the role of learning in that process.

The direction of continuing medical education in North America and elsewhere has changed in response to the new perspective that has emerged from contemporary studies of learning and change. The nature of this new perspective is evident from a comparison of the common elements of CME in the 1980s with the approach that is now being used. Traditionally a CME programme was an educational event that applied appropriate resources and methods to fulfill set instructional objectives. Such programmes were often considered to be good if the information was valuable, the lecturer skilful, and the setting comfortable. Too often, however, there was little or no actual effect on medical practice, even though all three conditions were met.

The critical difference in the 1990s is that it has increasingly been accepted that CME programmes are based—or should be—on the principle of teaching and education as a means of facilitating learning. This new approach has been adopted in response to studies on how and why doctors change their performance in clinical practice and the role of learning in that process. This article describes some of these models and sets out the key principles that have emerged for continuing medical education in the past decade.

Understanding change in clinical performance

Understanding and managing change is an essential part of professional practice. Just as doctors wish to

Summary points

The purpose of continuing medical education is to facilitate change in clinical practice

CME should be based on the natural processes learners use to change

Three interconnected systems are used in making changes: self directed curriculums, small group interaction, and organisational learning

CME must construct systems to complement and support the learning of practice based learning

intervene in illness to change the health status of patients, the aim of CME is to intervene in those aspects of medical practice that can be improved. CME is a systematic attempt to facilitate change in doctors' practice.

Differences observed over time in patients' health and in doctors' performance and their knowledge and skills are the types of changes that have been the focus of research on CME. Change in one of these areas may or may not lead to changes in another. For example, a change in the ability to perform a clinical procedure does not always result in that procedure being incorporated into clinical practice. Furthermore, a change in clinical performance does not automatically lead to a change in patients' outcomes.

These distinctions have challenged planners of continuing medical education to identify their objectives more clearly. What has emerged is an emphasis on doctors' performance as the target of strategies to facilitate learning and change. This focus calls for needs and outcomes that are described in terms of the performance of doctors rather than their competence or the health status of their patients.

Understanding the context of change and learning

Clinical practice is influenced by many factors. Doctors who participated in a study of how and why doctors change described a collection of forces as the reason they changed their practices.¹ The forces emerged from their personal lives, their professional aspirations, and the social and cultural milieu of their practice settings. They included curiosity, sense of personal and financial wellbeing, stage of career, desire for new or enhanced competence, pressures from patients and colleagues, and pressures from the healthcare institutions in which they worked.

Different forces seemed to scatter doctors in different directions. Personal forces were associated with larger and more complex changes, professional and social forces with smaller and simpler changes. Regulations were associated with only small accommodations, which were usually made with resentment.

Once doctors note forces for change, they begin to imagine what it would be like to perform differently in the clinical setting and how the role of their staff may change. The image of change varies according to what forces are at work and what type of change is being pursued by the learner. Large or complicated changes are difficult to imagine; smaller simpler changes are easier. Rogers describes five features (box) which affect the process by which professionals encounter and use new processes and products in their professional practices.²

These ideas have been validated by a study on Canadian radiologists which found that these five features are characteristic clues as to why different types of changes are pursued and how this happens.³ It also suggested that how the change is imagined affects its adoption.

Understanding the role of needs and motivation

Once doctors develop an image of change, they use this image to estimate their personal need to make a change and to seek new levels of competence related to the image of change. This process of self assessment involves four stages:

- The doctor estimates where he or she ought to be in terms of knowledge, skill, and performance related to the change;

Features of an innovation that modify its adoption

- Complexity of the innovation
- Relative advantage over existing practices and procedures
- Opportunity to observe the innovation in use before adopting it into practice
- Compatibility with other similar products and procedures already in the professional's practice
- Opportunity to try the innovation before adopting it

- He or she also makes an estimate of what he or she presently knows or is able to do in terms of the image of change;

- The doctor estimates the discrepancy between what he or she ought to know or do and what he or she currently knows or does; and

- The doctor experiences a level of anxiety because what is known or done does not match what ought to be.

For example, a doctor considering prescribing a new drug for depression must imagine what he or she ought to know to manage the drug and its side effects. Then the doctor estimates what he or she currently knows about prescribing drugs for depression. This "gap" between what is and what ought to be is an estimate of his or her learning need. The drive to reduce anxiety associated with this need is the motivation to learn and change.

This model of need and motivation shows that altering doctors' perceptions of where they are, where they believe they ought to be, and the size of the discrepancy can alter their perception of need and the extent of their motivation to learn and change.

Understanding ways of learning

Research into the effects of continuing education on doctors' behaviour has fuelled further investigation into how learning explains changes in practice. Two different facets of practice based learning have emerged.

Self directed learning

The first model, referred to as the self directed curriculum, consists of three stages.⁴⁻⁶

- Stage 1—learning is directed toward understanding and estimating personal levels of need to learn in order to adopt a change in practice
- Stage 2—energies are applied to learning the new competencies needed to practise differently
- Stage 3—learning is organised around the problems of using new skills, altering the practice environment, or adapting the new way of practice to increase the goodness of fit.

In each of the three stages, the learner identifies and utilises resources drawn from three broad categories: human resources, especially colleagues and coworkers; material resources, especially journals and other sources of information; and formal continuing education programmes, such as national specialty society programmes. Because the selection and use of resources is under the control of the learner, the "curriculum" is self directed—it is developed and managed by the learner.



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Learners need to understand how they learn and how their learning strategies may improve in order to become more efficient and effective. Educators need to understand the natural patterns of doctors' learning so that they can design learning programmes and experiences that complement self directed curriculums in a profession where change and learning are routine and necessary.

Organisational learning

In self directed learning the focus is on the individual, but doctors also learn from their work with patients, on teams with other healthcare professionals, and in consultation with colleagues. Within the culture of health care, each setting from primary care to tertiary referral units represents a unique organisation with a personality shaped by beliefs, norms, and ways of thinking, learning, and adjusting behaviour to changes in the environment.

Explanations of organisational learning point to the potential power of adding together what each individual in an organisation knows in order to create some new way for the organisation to perform its functions.⁷ Understanding how knowledge grows in organisations, what fosters learning, and how organisations make changes in response is fundamental to the implementation of change. Senge asserts that organisations can learn and that learning can be enhanced by changes in organisational structure and climate.⁷ Structures can support evaluating experiences, transforming them into knowledge relevant to an organisation's core purpose and making them accessible to the whole organisation. Watkins and Marsick define a learning organisation as one that provides continuous learning opportunities, supports collaboration within the organisation, and fosters links between the organisation and other relevant organisations and individuals outside the organisation to promote its effectiveness and establish its place in society.⁸

Health care has used ideas from studies of organisational learning to develop systems to review and change organisational behaviours. Practice review procedures, patient care audits, and quality assurance reviews are examples of techniques that have become popular. Continuous quality improvement techniques, which are based on activities such as reviews of quality of care, surveillance of infection control, case reviews, and measures of patients' satisfaction, represent newer ways to shape organisational behaviours. All are intended to set standards that will ensure ongoing changes in clinical practice. Informal activities such as morning reports and rounds further support organisational learning by defining standards for behaviours appropriate to the culture. Healthcare organisations may also foster organisational learning by using outside resources. They may bring in a consultant to assess the protocol for coronary artery bypass surgery, incorporate standards set by an outside organisation for screening techniques, or collect population health statistics to improve immunisation rates in children.

Implications for the future of CME

In the future, comprehensive CME systems will incorporate what we know about learning and change into three interlocking components. The first, most basic,

Role of CME providers

- Facilitate self directed learning by providing for self assessment, the acquisition of knowledge and skills, and the opportunity to reflect on clinical performance
- Offer high quality individual and group education that provides authoritative information, knowledge, and skills based on expertise and evidence
- Assist healthcare delivery systems to develop and practise organisational learning

and essential component is the self directed curriculum designed by each doctor to incorporate new knowledge and make use of his or her own experience.

The second component is based on learning in groups. Ranging from journal clubs to formal, traditional courses of instruction, these activities may be sponsored by organisations such as medical schools and professional associations. Group learning serves as a source of interaction and helps to shape the image of change and the practice of medicine. Lectures and other formal teaching activities have a long history. They are both a creator of meaning and an artifact of the culture of medicine. Lectures will endure because they provide information on what ought to be and the opportunity to reflect on what is being done, as well as summarising evidence as to what can be done, to improve patient care.

The third component is learning within learning organisations. Hospitals, clinics, group practices, accreditation bodies, social service agencies, and governments reflect societal needs and demands in different ways. By gathering and processing information and feedback, learning organisations create some of the standards that govern practice and modify others to fit the local problems and needs.⁹ They also provide opportunities for doctors to learn how to adapt to these standards successfully.

These three systems must be integrated in order to be effective in facilitating change and learning in practice. Changes in health care, new research in CME, and future demands must be brought together in new ways that will be powerful and sensitive enough to respond to patients, practitioners, and healthcare systems.

- 1 Fox RD, Mazmanian PE, Putnam RW, eds. *Change and learning in the lives of physicians*. New York: Praeger, 1989.
- 2 Rogers EM. *Diffusion of innovations*. 4th ed. New York: Free Press, 1995.
- 3 Rankin R, Fox R. The process of innovation adoption by Canadian radiologists. *J Continuing Educ Health Professions* 1997;17:173-87.
- 4 Bennett NL, Casebeer LL. Evolution of planning in CME. *J Continuing Educ Health Professions* 1995;15:70-9.
- 5 Bennett NL, Fox RD. Challenges for continuing professional education. In: Curry L, Wergin JF, eds. *Educating professionals: responding to new expectations for competence and accountability*. San Francisco: Jossey Bass, 1993.
- 6 Fox RD, Davis DA, Wentz D. The case for research in continuing medical education. In: Davis DA, Fox RD, eds. *Physicians as learners*. Chicago: AMA Press, 1994.
- 7 Senge P. *The fifth discipline*. New York: Doubleday, 1990.
- 8 Watkins K, Marsick V. *Sculpting the learning organization: lessons in the art and science of systematic change*. San Francisco: Jossey Bass, 1993.
- 9 Confessore S. Building a learning organization: communities of practice, self directed learning and CME. *J Continuing Educ Health Professions* 1997;17:5-11.