AIMS For a better birth...

Radical patient groups

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Charlotte Williamson explores the emancipation of patients

What are AIMS and other radical patient groups about? Radical patient groups constantly challenge or oppose the assumptions, policies and practices of health professionals, especially doctors. But they are not revolutionary: they do not seek to overthrow health professionals.

I believe that AIMS and other radical patient groups will come to be seen as leaders of a patient emancipation movement. Emancipation movements work to increase the opportunities of people to act in accordance with their own interests, values and responsibilities and to decrease the overt and covert coercion that prevent people from so acting. They work, that is, to support the autonomy of the people for whom they work. They aim to replace coercion and pervasive disadvantage with equality and with partnership. Their ultimate appeal is to humanity and justice.

Putting patient groups and emancipation together may seem strange because groups themselves have seldom, if ever, used the term or included it in their published objectives. Even radical patient groups ideally want to see the health professional-patient relationship as intrinsically benevolent. They value the good that health professionals do and honour their good intentions. But health professionals and the social structures that support their interests are dominant and patients' interests are repressed[1] Emancipation is the release from the control of more powerful others, from subjection to them, from their intellectual, moral or spiritual fetters.[2]

Looking back, one can see that emancipation has been implicit in radical patient groups' actions from their earliest days in the late 1950s and early '60s. Thus NAWCH (National Association for the Welfare of Children in Hospital) was founded in 1961 to oppose restrictions that prevented parents from visiting their children in hospital more than briefly, if at all. Restricted visiting coercively denied parents the means to act as they thought right towards their children. That is, restricted visiting denied parents their autonomy, for autonomy is self-determined action free from coercion by others.[3]

One of the early issues AIMS took up was the denial of choice of home or hospital birth to women, again coercion in place of self determination. Later radical patient groups often started for similar reasons. In the 1990s the Good Practice Campaign was founded to oppose GPs' right to remove patients from their list without warning or discussion, and the Insulin Dependent Diabetes Trust (IDDT) to oppose the compulsory replacement of all 'animal' insulin by the 'human' insulin promoted by pharmaceutical companies.

Emancipation has also been implicit in some of the words and phrases used by radical patient group activists. Examples from publication and speech include 'oppression' (AIMS); 'getting the patient's voice into research' (Breast UK, a breast cancer group); 'opposing control by doctors' (NAWCH); 'liberating' (AIMS); 'patients' views [should] carry equal weight [with clinicians' views] in decision-making' (IDDT); '[obstetricians] taking away our autonomy' (AIMS).

These actions and words suggest that emancipation or liberation can be thought of as a tacit but unarticulated goal of radical patient groups. (Liberation also means setting free but may lack the political over tones of emancipation.) This proposition can be supported by comparing radical patient groups with recognised emancipatory movements like the civil rights and the women's movements. I briefly note eight lines of evidence and argument here. None can stand on its own. Each could be a feature shared with many other social groups or be caused by other social factors acting on health care over the last 50 years. But together they seem to me significant.

Practice knowledge

Practice knowledge starts from activists' early decisions that something needs to be done. They begin to build up a knowledge base unique to their group, drawing on the knowledge, experiences, perceptions, intuitions and interpretations of themselves and of people like them (women, black people, patients, black women patients, etc.). They build on these experiences and on knowledge taken eclectically from various academic disciplines.[4] For AIMS, this includes observation, anecdote, and dialogue with staff as well as psychology, social science and medical science.[5] They use this socially-created new knowledge to inform their judgements of medical research and of clinical and psychosocial standards; to direct their actions; and to argue their cases for changes in health care.

Practice knowledge overlaps with health professionals' knowledge. That overlap can be used to identify consensus and to point out where deficiencies in practice contradict professionals' stated policies and standards. But some aspects of practice knowledge and professional knowledge are so different that each 'side' may feel that the other does not understand it.

The creation of this sort of new knowledge characterises radical groups as shown, for example, by US activist AIDS patients' challenges to conventional biomedical science.[6] Radiation Action Group Exposure (RAGE) is a UK group whose activists taught themselves to understand radiotherapy fractionation regimes in order to challenge the safety of specific regimes used or proposed in treatment and research[7]

AIMS has repeatedly criticised both obstetric research and the use made of its findings[8]

New knowledge helps release emancipatory movements from the intellectual fetters of dominant groups' ways of seeing and understanding things.

Sense of direction

Patient activists see respect, information, access, choice, shared decision-making, safety, representation, equity, support, representation and redress as essential supports to patient autonomy[9][10] Activists judge standards of care (rules for action) partly by the extent to which they incorporate these principles (general guides). So activists work to raise standards from low to high for information, support, choice, etc. Thus the lowest possible standard for support for children in hospital is no parental visiting and the highest is free access for parents throughout the 24 hours of the day and night.

Many changes to standards take place in progressive steps. As each new step is gained, the next one waits. The standard for partners' support for women in childbirth shows a sequence of these steps over 50 years. Each past step looks easy now. But each was attained through the persistent and painful efforts - the requests, the complaints, the arguments - of individual women, of patient groups and of those doctors and midwives who were willing to act to change the prevailing standard of the day.

In the 1950s, the woman's partner could stay with her in hospital only during the first stage of labour and only during visiting times. Restrictions were lifted for the first stage of labour in the late 1950s; for spontaneous deliveries in the 1960s; for instrumental deliveries in the 1980s; for elective Caesarean sections under epidural or spinal anaesthesia in the 1990s. The last step in this sequence will be to 'allow' (note the assumptions behind the word) the partner to be present for elective section under general anaesthetic. Patient activists have tried to secure this as a new national standard and a few anaesthetists offer it now. But most still do not.

These progressive sequences are common in the course of emancipation, though the final goal may seem so remote from the earliest steps as to have been unimagined then. Thus the first step in what became the black civil rights movement '[opened] the door to vistas which would have seemed too glaring before'.[11]

Unmasking new issues

Related to practice knowledge and their sense of direction is activists' ability to identify new issues. New issues arise when new technologies, procedures or other changes are introduced into health care. But activists also create new issues by discerning them in policies and practices long taken for granted by themselves as well as by health professionals, managers and the public. Sometimes a patient reports his or her distress to a patient group. Or an activist brings a new perspective to an old situation. Or patients or activists come across something that alerts them to some practice, hither to unknown to patients, that conflicts with their interests in safety or in information, or in shared decision-making, etc.

Hidden practices are coercive if they lead patients to accept situations or to make decisions that they might not have accepted or made had they known about the practice.12 Sometimes policies are deliberately kept from patients, like the post mortem retention of children's organs without their parents' knowledge.13 Sometimes they are practices that health professionals are so accustomed to that they hardly see them as controlling or harmful to patients' interests as patients would define them, if they were aware of them.

'Consciousness raising' or showing people the implications of what they had taken for granted, or been unaware of, is fundamental to every emancipation movement.14

This ability to discern or create new issues leads emancipatory groups to multiply the number of policies, practices and standards they are concerned about. Thus NAWCH, star ting from the single issue of restricted visiting, went on to oppose preventing parents from being with their children for the induction of anaesthesia, then from recovery from it, as well as parents' exclusion from treatment rooms and ward rounds. Even actions that are 'constructive', like pressing for better accommodation for parents or for play on children's wards, can have subversive aspects. As issues tend to remain unresolved for years, the scope and complexity of groups' work increases.

Appropriations

Emancipatory movements appropriate ideas from other sources and social movements: they both are influenced by and influence their socio-political environments. Patient autonomy as a pre-eminent value was probably adopted because autonomy is a key value in western society. Respect and shared decision-making probably came from the civil rights and patient movements in the US. Access, information, choice, safety, representation and redress probably came from commercial consumerism.

Movements can change the meanings or implications of the terms they appropriate. Thus some patient activists understand patient autonomy to include freedom from coercion and self determination, not only so that patients can act for themselves but so that they are able to act in the context of their responsibilities towards others and their relationships with them.15 Equity and access include the idea of helping disadvantaged patients to benefit from the opportunities that advantaged patients can take without support: it does not mean denying to all what some cannot easily secure unaided.10 Such shifts in meaning are, again, part of groups' creation of new knowledge and perception.

Alliances

Just as some white people worked for the emancipation of slaves in the 18th and 19th centuries and some men work for women's interests even when they conflict with men's, so some health professionals help radical patient activism. They provide support, ideas, technical and scientific advice. They demonstrate through their own practice that the changes and standards desired by activists are feasible and benefit patients. If they ally themselves conspicuously with radical patient groups, they gain their esteem. However, they may be regarded as deviants by conser vative members of their profession, as the

obstetrician Wendy Savage was.16

Alliances amongst individuals and groups and between them and those on the other 'side' are crucial for emancipatory movements. Groups and individuals sometimes oppose, sometimes support, dominant power holders, depending on their alignments and on the issue.

Schisms

Schisms, divisions that engender and reflect mutual hostility,2 between radical and conservative patient groups are common, as they are for emancipatory movements generally. There are at least nine different sets of thought and belief in the women's movement.17 Black civil rights movements have been torn by strife.18 Patient groups can easily see other groups or individuals as too radical ('too way out') or as too closely identified with health professionals ('too cosy'). Schisms can make working together difficult. They maintain the political weakness of the patient movement as a whole though they protect the integrity of individual groups. But similar groups can cooperate, as the radical Consumers for Ethics in Research (CERES) did with Breast UK, producing a charter (a set of desired standards) in 2000 for ethical clinical research. Drawing out positions held in common between radical and less radical groups, as AIMS and the National Childbirth Trust (NCT) did for their Charter for Ethical Research in Maternity Care, 1997, is important for spreading influence widely.

Gradual acceptance

Standards and expectations change: what was radical and controversial yesterday is commonplace and routine today. Information and autonomy are now considered impor tant by many conser vative patient groups.19 Terms like patient autonomy, shared decision-making, information and choice have also become common in professional and managerial discourse, though what they mean there is sometimes doubtful.20 Many once-radical tenets and standards come to be widely accepted by society, though how this happens is often puzzling, as some ideas are accepted immediately whilst others are rejected apparently indefinitely. Raised consciousnesses, politicians' perceptions of advantage and researchers' demonstrations of 'health gains' play parts. Patient surveys can influence managers. Activists' well argued cases can startle health professionals into enlightenment and conviction. Or years of repeated argument and evidence can have little effect.

In maternity care, some policies and practices appear to be as coercive as ever21 Others have improved so much that some women and staff may be unaware that things were ever different22 In health care overall, many patient activists probably would agree that progress has been made in the last 40 or so years towards supporting the autonomy, enlarging the freedoms and exposing the hidden coercion of patients. But sometimes one step forward, two steps back, feels more salient.

The gradual acceptance of ideas that were once too radical, too challenging to the status quo, to be widely accepted marks the success of emancipation movements. Without it, they would work without hope.

Commitment

People start or join radical patient groups from personal experiences or from moral or intellectual conviction. They enter a world of new meaning, of new purpose and of the companionship of others, known or unknown. Emancipation movements call on the strong emotions that can be the bases for protest, for political challenge and for strategic thought.23 Strong emotions are also needed to sustain activists through years of effort and of failure to achieve as much as they would like. Some activists have worked unpaid for more than 40 years. A sense of duty or 'principled commitment' characterises activists in emancipation movements.24

Conclusion

The patient movement is young and fragmented. Radical groups and individual activists have been part of it from the beginning. But they are in a minority, probably a small one. Activists probably acted intuitively at first. Intuition is an immediate insight about something without intervening reasoning2 It is not irrational, it springs from knowledge and experience. Activists' sense of purpose and of direction have usually been drawn from their work and practice knowledge, not from a detailed political theory or an explicit ideology. But social movements can only succeed if they have theoretical and intellectual underpinnings.25 Their members need to be able to develop and refine those underpinnings as society changes. Outsiders need to be able to understand what a movement is about.

For the patient movement, it is important that health professionals and managers understand that radical groups are seeking to bring policies and practices into line with wider social values and with the high ethical principles of the medical and other health care professions: they are not seeking to strip health professionals of their clinical autonomy, skills and judgement. Theoretical underpinnings and ideological explicitness are therefore desirable now that we can begin to articulate them. Indeed, they are especially necessary now that clinical autonomy, skill and judgement are under threat from managerialism in the NHS.

This brief outline of why I think that we are part of an emancipatory movement is my contribution towards putting into words what we are about. I would greatly welcome comments from other AIMS member.8

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