AIMS For a better birth...

Lay perspectives

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Charlotte Williamson looks at the value of out-of-system knowledge

Lay means not trained or qualified in whatever profession is being considered – the law, medicine, the church. 1 Professionals learn valuable skills during training but they also lose some of lay society's everyday ethical values and behavioural norms, substituting professional ones.[2] Health professionals' perspectives, the stances from which they look at and interpret things, may come to deviate so far from lay people's perspectives that 'hospital scandals' result.[3]

In a multicultural society, lay people hold in common basic views of what is fitting or unfitting in patient care.[4] Tensions between professional and lay values and norms can impact negatively on patients' lives. We increasingly understand that lay perspectives are necessary for ensuring that professionals' treatment and care accord with lay society's values.

Exactly what those lay perspectives are has never been clarified but they are to do with the basic value of humaneness, in other words 'as befitting a human'.[1] In every day parlance, it means causing no avoidable harm or distress to any sentient being. Patient care is inhumane if it causes avoidable harm or distress to patients or is harsh or restrictive without therapeutic justification. By virtue of being lay, people are able to identify practices and policies they feel are oppressive or unkind when they read or hear about them or experience them as patients but they do not always use that ability. They may be diffident or feel deference towards professionals (or managers) or adopt their values and align themselves emotionally with them or accept constraints on what lay people should do.[5,6] Difficulties and confusions abound. Nevertheless, lay people can legitimately draw on whatever sources of knowledge they can find to inform their judgements and to give them the evidence and arguments they need to identify and oppose inhumane care. Here I put these sources of knowledge into three categories, starting with what all lay people know already, then moving on to the additional or specialised knowledge they need to identify inhumane care more widely. The sources overlap and reinforce each other; using them can give lay people confidence and authority.

General lay knowledge

Lay people can often see things that seem invisible to professionals and managers.[7] 'Wilful blindness' is a common way of not seeing other people's pain.[8] Examples from hospitals include windowless labour rooms in which women may spend many hours; frosted glass windows in a mother and baby unit in a psychiatric hospital, preventing mothers from soothing themselves and their babies by showing them the

view outside; extractor fans from nearby buildings droning non-stop into orthopaedic wards where patients are in pain (personal observations); the smell of urine and faeces from piles of dirty linen and clothes; call bells inaccessible or switched off and nurses abrupt with patients or absent altogether in geriatric wards.[9] To identify instances of obvious inhumane care like these, lay people only need a capacity to feel disturbed by deviations from ordinary norms and everyday standards and the courage to say so.

Semi-specialised lay knowledge

Lay people sometimes see or hear something that surprises or disquiets them but do not know whether valid reasons of safety or therapy justify it: maternity care is associated with unjustified practices, as AIMS members know. Taking flowers to patients in hospital has long been a custom in the UK, but many hospitals now ban them even in general and elderly care wards. That denies patients pleasure, deprives them of symbols of love and support from relatives and friends and removes from nurses a reminder that, in the outside world, patients are valued people. Flowers are banned because nurses believe that the water in flower vases contains harmful infectious bacteria: there is no microbiological evidence for this belief.[10] Similarly, staff tend to undervalue the support friends and relatives give to patients by visiting.

Specialised lay knowledge

Specialised lay knowledge starts from unease over clinical policies and practices that may be distressing or harming patients, examples include certain drugs' side effects, episiotomies and approaches to the third stage of labour. Setting lay values and norms against complex clinical matters apparently justified for clinical reasons requires thorough investigation. Drawing on and evaluating evidence from clinical research, as well as from accounts and surveys of patients' clinical experiences and professionals' discussions of controversial issues, is often necessary before making a judgement. Patient groups, real or virtual, are the repository for this specialised lay knowledge and knowledge from one patient group can sometimes be transferred to other categories of patients. With experience, lay people can build up expertise and an ability to judge the humaneness or inhumaneness of specific clinical policies and practices over a wide range of patient care.[11]

The medical profession now accepts that high standards come from marrying the perspectives of professionals and of patients.[12] In this context the word 'patient' applies to people in active clinical relationships at the time of the research or enquiry. Ideally, standards should be formulated by professionals and knowledgeable lay people (often former or recurrent patients in the speciality) working collaboratively as equals.[13] Collaborative standards are more likely to meet the interests, clinical values and ethical sensibilities of both professionals and patients than standards produced by either alone. (Like professionals, lay people and patient groups can have blind spots and biases.) Thus collaborative standards are likely to be humane. Making normal birth a reality, in which AIMS took part, shows what can be done.[14] Even one knowledgeable lay person can sometimes change the assumptions and practices of a group of professionals but the composition of collaborative groups should be checked

and tokenism challenged.

Conclusion

Lay people can draw on various kinds of knowledge to argue against policies and practices that inflict unjustifiable restrictions and hardships on patients. Most professionals want to give humane care. Sometimes they need lay help in discerning what that is. Lay people '*who do not doubt our good intentions, but are prepared to tell us things others will not*' sums up, in one doctor's words,[15] how to work effectively and humanely to make patient care befitting for those who give and those who receive it.

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