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[W]e have accorded doctors the right to inflict pain. Our concern therefore has to be to see that health workers do not inflict pain unnecessarily.... We believe our skills as social scientists make it possible for us to point out the unintended suffering inflicted, suffering which is unrecognised and which may perhaps be unnecessary or avoidable. ... Our gaze has been trained to look at the working of the mind and of society.... to look below the surface of the commonsensical and to see the deeper implications (Stacey 1979: 186-7)

Preventing avoidable suffering

The above words concluded a book about the welfare of children in hospital. In *Beyond Separation* (Hall and Stacey, 1979) sociological researchers showed how children in hospital were not suffering simply from the maternal deprivation which the Robertsons (1989) reported. Children also suffered from being lifted from their daily everyday social contexts into hospital wards where they languished, bored, lonely, frightened, and the 'work objects' of health professionals. The book reported years of team research which was indirectly initiated by the government's expert report *The Welfare of Children in Hospital* (DHSS, 1959). Most hospitals took no notice of the new government policies that mothers should be encouraged to care for their children in hospital, and continued to ban parents from children's wards. Struck by the contrast between official policy and her own experience of local hospitals, Meg Stacey started the Welsh Association for the Welfare of Children in Hospital (AWCH) to campaign for change, she also organised related research. An English version began, eventually being named the National Association for the Welfare of Children in Hospital (NAWCH).

By the mid 1970s, hospitals varied. Some welcomed and supported parents in children's wards, others continued to limit access, as I found when my children became patients, and I joined NAWCH and to help to change hospitals. Practical and policy experience developed into theoretical interest and ten years later I began work on a PhD about parents' consent to children's heart surgery.(1) The paediatric cardiac centres were sites of intense suffering as well as joy and relief. One in ten of the children who had surgery died. The units still had ambiguous policies about welcoming or excluding parents, which exacerbated the unintended suffering of families who were often far from their homes and support networks. Later, I researched children's consent, mainly to orthopaedic surgery.(2)

This chapter reviews research about informed and voluntary consent, and how suffering and moral feelings can expand the awareness which informs consent. Legal and ethical meanings of consent are contrasted. The opportunities for consent to prevent and reduce suffering are reviewed, and contributions from social science, which look below the surface of the commonsensical, towards understanding these links and opportunities are discussed, mainly in relation to parents' and children's consent.

Informed and voluntary consent

The law treats consent in terms of precise verifiable facts, requiring that patients be told the purpose and nature of proposed treatment, the risks and hoped-for benefits, short and longer term effects, and any alternative treatments (Montgomery, 1997:227-248). People should know that they can ask questions, discuss and possibly negotiate proposals, have time to reflect, and that

they are free to make an unpressured decision which may be to withhold consent.(3) Most research about consent consists of psychological surveys of how patients can recall and recount medical information (though often without detailing what they were told) and tends to find that patients' understanding is inadequate (for example, Kaufman, 1983). Psychometric research assesses patients' anxiety levels on being informed, implicitly assuming that anxiety is a negative reaction to be reduced and avoided (Fallowfield, 1990). Analyses of decision making in medicine (Thornton, 1983) and bioethics (Beauchamp and Childress, 1989) examine how patients use expert clinical information to make rational cost-benefit and risk calculations. Much of this literature seems to regard the patient as a philosopher in pyjamas, giving consent to his (*sic*) own treatment as the calm, intellectual equal of the doctor (Gillon, 1994).

Medicolegal consent combines partial contradictions between Kantian autonomy which makes correct personal decisions without interference or constraint (Kant, 1796), and Mill's respect for liberty which is so precious that people must be free to make personal choices, including foolish ones and best guesses (Mill, 1858). The correct choice and the best guess meet in cases of high risk surgery, when people strive to make the wisest possible decision while accepting danger and uncertainty. Until recently, minors were excluded as too immature to make either correct decisions or best guesses, lacking courage to stand by their mistakes, and needing their 'best interests' to be protected until they develop adult autonomy.

In the mid-1980s, Mrs Gillick sought to ensure that the courts would close the legal gap left by the Family Law Reform Act 1969, which allowed minors aged over 16 to give valid consent to treatment but said nothing about people aged under 16 years. Eventually the Law Lords ruled that a competent child is one who 'achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed' and 'has sufficient discretion to enable him or her to make a wise choice in his or her own best interests'.(Gillick v Wisbech and W Norfolk AHA [1985] 3 All Er 423). Doctors who decide that in their clinical judgement a child is competent can legally accept that child's consent (Age of Legal Capacity (Scotland) Act 1991, 4,2). Later court cases, however, complicated the law, as reviewed later.

All the aspects of consent considered so far are very important, but they concentrate on the reasoning 'informed' side of consent, to the exclusion of the equally important 'voluntary' side. Medical research is regulated by the Declaration of Helsinki (WMA, 1964/1989) which emphasises the value of research to 'help suffering humanity'. Not until clause 9 is 'the subject's freely-given informed consent' mentioned. The Declaration, written by doctors, differs from the first international guidance on consent (Nuremberg Code, 1947). The Code was written by lawyers mindful of human rights and the crucial respect for physical and mental integrity which was violated during the 1940s as illustrated during the Nuremberg trials. The Code begins: '1. The voluntary consent of the human subject is absolutely essential.' It sets voluntariness, an emotional experience, act and state of mind, first: 'the exercise of free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion'. These phrases come well before 'having the knowledge....to make an understanding and enlightened decision' which the Code assumes that ordinary adults can do, whereas Helsinki contrasts scientists' expertise and ultimate responsibility versus lay people's much less informed views.

Voluntariness has also become rather lost in positivistic research and bioethics. For example, the leading bioethics text on consent (Faden and Beauchamp, 1986:257) concludes :

These many confusing terms surrounding the term 'voluntariness' are too much, we believe, to combat successfully through a conceptual analysis that attempts to tidy up its meaning, and hence we avoid the word entirely. We substitute a conception of noncontrol

that does not have the history and connotation that burdens [*sic*] the terms 'freedom', 'voluntariness' and 'independence'.

This 'tidy' solution of 'noncontrol' paradoxically denies the essence of voluntariness which concerns patients' agency, power and control to give or withhold consent. The quotation reveals the underlying notions in much functionalist bioethics of eschewing emotion, and of the expert, correct and active doctor and the relatively ignorant, fallible and passive patient, so that 'noncontrol' is seen as avoidable coercions which health staff refrain from exerting. This approach reflects the current trend away from remembering Nuremberg, and consent as an essential defence against the violation of human integrity, towards preoccupation with 'informed choice' which implies that life and death decisions are as mundane as shopping. Consent then dwindles into a polite formality which tolerates patients' idiosyncratic preferences abstracted from those issues in their daily lives which make their hopes and fears significant.

Consent thus tends to be seen mainly as the medicolegal device which transfers responsibility for risk and injury from the doctor to the patient. Consent can also protect patients from unnecessary suffering, make doctors be accountable, and help patients to become informed and prepared for interventions. Although the law prevents bad practice rather than promoting best practice. In contrast, an ethical approach sees consent as the formal means of promoting mutually respectful partnership between doctors and patients throughout the treatment. Yet how can bewildered and extremely distressed parents and children who consider major treatment possibly achieve Kantian wisdom and Millian courage? And even if people are accepted as having some voluntary power, despite being unavoidably constrained by illness, fear and pain, as they struggle to resolve dilemmas and arrive at a firm decision, how can such elusive invisible issues as voluntariness, wisdom, respect and trust be researched?

My PhD research involved learning about sociology, cardiology, bioethics and law which, with evidence about parents' experiences, seemed to stretch the topic of parents' consent into conflicting directions and a mass of irreconcilable contradictions. Gradually they merged into some coherence with help from theories about: moral emotions which inform, rather than undermine, moral reasoning (Gilligan, 1982); respect which includes care (Seidler, 1986); contradictions which are also complementary and can be held in tension together (Ramazanoglu, 1989); and philosophy which sees everyday experiences and settings as constituting moral problems instead of cluttering up and obscuring abstract moral principles (Grimsahw, 1986).

The social context and knowledge

The work of AUCH and NAWCH set a practical background to my research on consent in emphasising the importance of the social context. How can parents give valid, informed consent if they are not allowed into the wards and intensive care units, or if there is no chair for them beside the cot, or if they have little idea about what is going on? Ethnographic research showed how parents' consent to complex treatment plans is a process not an event, grounded in hours spent sitting with their child, watching and talking with the staff, gradually learning and emotionally coming to terms with new knowledge. In turn, these opportunities are influenced by hospital funding and policies, staff training and support whether there are quiet times and spaces for practitioners and families to exchange knowledge, and whether parents have sufficient help with high transport costs, care of their other children, and their other severe anxieties. Such support respects their priorities and responsibilities.

Clinicians who respect parents and children accept their knowledge as valid when, for example, a mother considers that regular injections are less distressing to her baby than numerous attempts to insert a line into her veins. Orthopaedic surgery aims to relieve pain or to improve mobility or

appearance. In all three areas, the patients are the experts in knowing how much pain, difficulty or difference in appearance they can accept before they are willing to undergo surgery which might not work and might make matters worse. Some surgeons respect children's knowledge and wishes, correcting a 'minor' spinal curve if a child is very unhappy, but leaving some more serious curves untreated, or waiting until a child is ready to consent. Decisions about timing extremely risky heart surgery, as children become progressively weaker, involve clinical tests and also social evaluations: Is it better to wait another year or two, or to try earlier surgery when the child has more strength to survive it, and might lead a much fuller life afterwards? Consent as a process of exchanging personal and medical knowledge and discussing options can prevent the suffering of feeling coerced or deceived, and the fear and possibly increased pain of unwanted treatment.

Consent works in cycles. Continuing discussion informs staff about the processes and outcomes of their care, they can monitor and raise standards, and also give more accurate information to future patients. One example is how the staff gradually gave in to pressure from parents who wanted to accompany their children into the anaesthetic room and stay until they were asleep, instead of having to watch a crying child being taken from the ward, especially when the operation might be fatal.

The working of the mind

Besides the external, observable processes there are inner psychological ones. Knowledge as factual information differs from knowledge as deeply absorbed and experienced awareness of the personal implications. People need time to acquire the latter, if their consent is to be informed and committed. Parents and children described their emotional and intellectual journey, initial fear and horror on hearing the diagnosis and treatment proposals, gradually growing trust in the hospital staff and confidence in their skills, slow acceptance that the untreated illness would be worse than the high risk heart surgery and its hoped for benefits, and increasing faith and courage. Their moral feelings of trust and hope and parents' pity and concern for their child gained strength and meaning through their experiences and relationships. Anxiety was not wholly negative and could bring insight and courage.

Families described how doctors who seriously informed and consulted with them relieved their anxiety and misunderstandings, and increased their courage and mutual respect. This also encouraged their informed cooperation on which the success of treatment might depend, such as with exercises, diet or medications. Alison, aged 14, fainted on first learning that her curved spine would be straightened during two risky operations but added that she would much rather be told. Kerry, aged 12, agreed to the proposed surgery but was extremely distressed when plans were changed at the last minute to another procedure and later she wanted to refuse all further treatment, giving one of many instances of the advantages of respecting patients' voluntary consent if possible, and the suffering that can ensue when it is bypassed (Alderson, 1993:123-9).

During emergencies, this emotional journey cannot be experienced, yet 'emergency' is an elastic term, stretching sometimes into days when there may be time for to consider consent, albeit less thoroughly. Shock and grief do not necessarily inhibit thought; people are shocked because they understand and if parents were not shocked when considering their baby's heart surgery they would be insufficiently aware. Years later, parents recalled neonatal emergencies in intense detail, indicating that they were highly aware at the time. 'After the Caesarean, the nurse put her head round the door and asked my religion, and I thought my baby was dying.' Children also remembered times, when they might have seemed scarcely aware. An anaesthetist came to see

Brenda and remembering surgery three years earlier when she was aged 6, Brenda said: 'Please can I have gas? I don't like the injection and please can I have the mint flavoured gas like I had last time?'

People especially remember any hints of good or bad news. Observations in the wards showed how they sifted information into these categories, and showed the difficulties for the staff in managing the import of any news they gave to parents, trying to sustain reasonable but not undue optimism, trying to help parents to lose hope if their child was dying. The large busy medical, surgical and nursing teams also had to attempt to sustain some uniformity in their accounts to families and inevitably there were discrepancies in tone and language when even simple phrases could be confusing. Heart valves were referred to by one doctor as thicker, and by another as narrow, both meaning that the thicker valve walls narrowed the space between them.

Perhaps most importantly, the consent process helps people to make sense of painful and alarming experiences, to see the context and the 'story' of how they might recover, to help them to cope during stressful times and come to terms with the outcomes, successful or not. This means making a decision they can live with in future. During my research in the 1980s, many parents said they attached exceptional importance to being informed, respected and consulted about the child for whose life they were responsible, 'we have to sign the consent form', while making what they said was the hardest decision in their life. During 1999-2000, major enquiries are being conducted in England into parents' consent: to heart surgery, to the removal of deceased babies' organs, to surveillance of suspected Munchausen-by-proxy, and research about ventilation. Some parents express gratitude after their child has died, when they feel that everything reasonable has been attempted with care and respect. Other still express grief and anger, twelve or twenty years later, about being misinformed or excluded from decision making about their child (Power, 1998).

Beyond the commonsensical

The ethnographic research revealed intense emotions which the families and staff discussed during interviews, but how can valid social research interpret such data? The following reservations about interviews will be reviewed.

Humanistic interviewing methods which try to elicit intimate data are 'superficially seductive....Just as we are suspicious of the media's claim to access personal experience through interviews with celebrities, we should be wary of the claim that research interviews have uncovered authentic human experience....we may have done nothing more than elicit familiar and socially acceptable ways of accounting for success or failure' (Silverman, 1993:95).

Yes, we may have, although assuring confidentiality and concealing people's identity in reports, besides addressing issues other than self-promotion, may make research interviews very different from media celebrity interviews.

Interviews are like a dance of expectations, opportunities for impression management (Goffman, 1959). I produce my actions in the expectation that you will understand them in a particular way. Your understanding reflects your expectations of what would be a proper action for me in these particular circumstances which, in turn, becomes the basis of your response which, itself, reflects your expectations of how I will respond, and so on (Dingwall, 1997:56)

Reflexive research can also analyse how people step out of the dance of expectation, such as when young children show profound understanding and competence, or challenge how researchers infantilise them, leading to reexamination of how childhood is socially constructed (Alderson, 1993; Mayall, 1994).

It may be dressed up like a conversation between friends. But an interview is not [that]. It is a deliberately created opportunity to talk about something which the interviewer is interested in and which may or may not interest the respondent (Dingwall, 1997).

Conversation between friends are not always mutually interesting. When the interview is about topics of central importance to interviewees, if they are not interested this may be a failure of the interviewer rather than of the interview medium.

A meeting between strangers, unfamiliar with each others' 'socially organized contexts' does not provide the necessary contextual basis for adequate interpretations' (Mischler, 1979).

Many meetings between strangers depend on rapidly established 'bases for adequate interpretations' - in health care, business or parties. Society could not exist without strangers' abilities to establish these at some adequate level, and neither could informed consent. Rather than assuming that an ideal level should, but cannot, be reached, sociological interpretations can take account of the limitations of brief encounters, and of all other research methods.

Rather than evaluating interview data as more or less accurate reports of external reality, we are obliged to view them as occasions when individuals feel called upon to give accounts of their actions, feelings, opinions etc., in such a way as to present themselves as competent, and indeed moral, members of particular communities (Murphy et al, 1998: 120).

This method, of treating interviews not as topics (sources of overt information) but as a resource (through examining underlying structures, such as the moral account, generating findings, and constructing meaning) is, however, suspended when researchers select which data to treat as topics, and when they assume that readers will treat their reports as topic not as resource. When researchers examine how, for example, parents of children with a heart condition structure their accounts to present themselves as moral people (Baruch, 1981), rather than taking accounts 'as more or less accurate reports of external reality' this can be covert and deceptive research. Interviewees may sense this and be more defensive. Gaining their informed consent would involve saying something such as: 'My main interest is not your experiences of your child's illness, but how you structure your account to rationalise your reactions morally. It is irrelevant whether your account is "true" except for what you unconsciously reveal in structuring your replies.' Few people would, perhaps, then agree to be interviewed, and if they knew the research was about moral accounts, this could affect their responses and jeopardise the research. Interviews with parents and children about consent and their competence to understand the plans, partly repeat their observed 'real' conversations with hospital staff.

In contrast to these commentaries, Oakley (1981), Cornwell (1984), West (1990), Pill (1995), and many other researchers describe breaking through formalities into 'private', frank and

mutually absorbing discussions, and into unanticipated areas (Britten, 1996), such as discussions about 'non-compliance' with prescribed health care (Morgan and Watkins, 1988), sometimes so successfully that some researchers are concerned that this shared intimacy risks over-exposing and exploiting people (Finch 1984).

If we cannot know whether we can elicit private accounts about 'deep' feelings and experiences, we cannot be certain that we are not doing so. Gender differences between the sceptics, mainly men, and those generally convinced by interviews, mainly women, suggest psychological bases for their differing views, such as that women tend to welcome intimacy and men tend to fear it (Gilligan, 1982), women tend to use communication to make connections and men tend to use it to take control, one to become engaged the other to remain detached (Tannen, 1991). The 'radical critique' of interviews (Murphy et al 1998:120) may be influenced by the sceptics' own research interests in such 'public' topics as professionalism, organisation, management, and the professional presentation of self (Atkinson, 1981; Dingwall 1977; Silverman, 1984, 1989), in preference to more intimate topics. Trust is unlikely to develop when people describe their most intense, painful experiences to a researcher who 'brackets off' the 'truth' of their account. This reservation is not simply neutral. By bracketing off,

'and trying to ignore questions about the content of a [religious] belief, [sociology] fails to take seriously the fact that to the person holding it, the most important aspect is that *it is true*....Any sociological interpretation which undercuts this, falsifies what it is interpreting.....By side-stepping issues of truth and falsity, sociology has often forgotten the importance of claims to truth. Ignoring that can appear tantamount to assuming their falsity' (Trigg 1985:36).

There appears to be an implicit model of people as empty vessels through which shared public discourses swish. 'Familiar and socially acceptable ways of accounting for success or failure' (Silverman, 1993) are voiced like empty cliches with no way of telling how true or relevant each comment is. Yet as, for example, Hochschild (1976:281-3) asked about Goffman's theory of the person's presentation of many selves like costumes hung on a peg (Goffman, 1959), where is the core self that they are all hung on to? If parents and cardiologists cannot be regarded as telling what they see as the truth, or if there are no such truths, how can any statement have any validity, including statements which deny truth in interviewees' accounts, and so on in endless regress? Then, why should anyone care to say anything, without some way of ordering priorities of meaning, relevance and importance? How can sociologists claim that their own reports are valid and more than moral presentations? It is also unclear why parents' and doctors' concern with self-presentation should predominate over concern for the sick child.

Morality seems to be reduced to manners, to an etiquette of being seen to do the correct thing, rather than of wanting and trying to do so. Presenting oneself as a moral person is an important part of much of our discourse, but it is not the whole or always the main part. Murphy et al (1998) make many valuable points about conducting qualitative research. But they dismiss patients' views about health technology assessments (though not professionals' views) although patients' unique and essential knowledge of the processes and effects of health technologies is among the richest resources for social research. The practical value of research about moral accounts is usually illustrated with the sole example of a new support clinic being organised for parents in a heart surgery centre (Baruch, 1981; Silverman 1985:171; Murphy et al, 1998:122). Yet the clinic was soon discontinued as impractical. Many more useful policy and practice changes have been effected through taking users' directly expressed concerns seriously, while

also taking account of the sociological reservations listed above, and treating interviews as topic and resource.

The working of society

Our research about children's consent (2) began in the year of the Children Act 1989 and the UN Convention on the Rights of the Child which both enshrine Gillick-like precepts about listening to children. The research ended in 1991 when Lord Donaldson in the Court of Appeal began the 'backlash against Gillick'. He ruled that R, aged almost 16 and refusing mental health treatment, could be forced to have medication (re R [1991] 3 WLR 592), and that W, aged 16, who had anorexia could be force-fed (re W [1992] WLR 33:758-82). This overturned the 1969 Act mentioned earlier which respected 16 year olds as having adults' rights of consent. The 1989 Children Act increased the potential number of people with 'parental responsibility', and Lord Donaldson further ruled that if any one of these adults gave consent, this could override the refusal of everyone else concerned, including the 'Gillick competent child' aged up to 18 (reviewed in Alderson and Montgomery, 1996).

Lawyers criticised both rulings on several grounds, including the point that the cases concerned mental illness rather than children's (in)competence, and so should not be generalised to all minors, although this has happened. Doctors often mention that 'the law does not allow children to refuse'. Of course children can refuse, no law can stop them. The question is whether doctors should or must override refusal. They can respect the informed decision of a child they deem to be competent as mentioned earlier, and they may feel ethically obliged to do so. There are probably many unreported cases of doctors and parents accepting the informed refusal of terminally ill young children (Alderson, 1993), such as Samantha aged six who refused a third liver transplant (Irwin, 1996). Yet debate is dominated by the reported court cases which all authorise doctors to treat or not treat as they originally intended and rule against children's and parents' wishes. The sole exception, was the young boy whose parents refused a proposed liver transplant. They were intensive care nurses and may have been seen as experts counterbalancing the expert medical views which the courts usually favour against the families' lay views.

Medical authority was taken still further when doctors were authorised to transplant a new heart into M, aged almost 16, despite her refusal. Previously healthy, she had developed heart disease a few weeks earlier and a transplant was proposed two days before the court hearing (Dyer 1999a). M was quoted as saying that she did not want to die but that she did not want a new heart either, and the judge concluded that she was too over-whelmed to make a competent decision. Yet M's reactions are typical of the initial stages of parents' consent to heart surgery as they begin to address dilemmas between mutually incompatible ends, such as gaining health and avoiding surgery, and gradually think and feel their way towards a resolution. .

The desperate urgency felt by M's parents and doctors and the judge is understandable, but it is unfortunate when such extreme cases encourage beliefs that almost any procedure can be enforced on minors. Adults' own refusal has to be respected in English law, to the extent of respecting women's refusal of Caesarean section even if the baby might die. Newspapers compared M's case with cases of force-feeding girls with anorexia (London Metro, Daily Mail, 17.7.99), ignoring the great differences between administering food and implanting a heart. Most seriously, these rulings undermine the respect for informed, willing consent which, to many practitioners, is an integral part of therapy. Shortly after, M was reported to have agreed to have surgery.

The judge said he considered M's views, but these had little influence in the inevitable precedents-based legal outcome of supporting medical opinion, demonstrated in two further cases

that month. David Glass's mother failed to obtain a court ruling that treatment should not be withheld from her severely disabled son, aged 13 (Dyer 1999b). The courts also upheld consultants' refusal to refer Katie Atkinson aged 9, who has Down's syndrome, to be assessed for a possible heart transplantation. The cases should be understood as enforcing the 'medieval power of the courts' and not as rulings on children's rights or competence (Bynoe, 1993), despite their powerful influence over society's views on these issues.

Sociological study of consent can bring together seemingly conflicting views into some coherence: medicolegal concepts of consent as precise knowledge, and the key which gives doctors the right to inflict pain but can prevent avoidable suffering; ethical concepts of respect for the wise choice or the best guess; evidence of complex experiences which challenge popular dichotomies such as reason/emotion, medical/lay knowledge, competent adult/incompetent child, inner feelings/public policies, showing how they overlap. A minority want to decide for themselves or else to leave others to decide for them, but most adults and children want to have more or less share in deciding about their consent, partly depending on the information, respect and support they receive over time. Like the nurse who described gently 'nudging' girls into talking about their fears and misunderstandings before their operations, clinical staff who used open questions, conversational exchanges and narratives appear to encourage consent that is more informed and voluntary.

Notes

1. Parents' consent to paediatric cardiac surgery, 1984-1987, funded by the ESRC, ethnographic research in two London hospitals in all related hospitals departments, interviews with parents and staff, surveys of parents' and nurses' experiences (Alderson, 1990).
2. Children's consent to surgery, conducted with Jill Siddle in three London hospitals and one in Liverpool, 1989-1991, funded by the Leverhulme Trust, observations and interviews with 120 patients aged 8 to 16, their parents and 70 staff, see (Alderson, 1993).
3. In the absence of statute law in Britain, standards of consent to medical treatment and research have evolved through case law, and guidance from the Department of Health (1990), the Royal Colleges (such as RCPCH, 2000), the European Union and the World Medical Association (1964).

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WMA- World Medical Association 1964/1989 *Declaration of Helsinki*, Fernay-Voltaire: WMA.