Case conference

Obstructed death revisited

Roger Higgs Editor

A number of comments have been received on the Case conference in the March 1982 issue 'Truth at the last - a case of obstructed death?'. As this was commented on by only one person, some of the comments that have been received since are reproduced here. One is a thoughtful reinterpretation of the case, some report further instances of apparently delayed or 'obstructed' death, and we comment further upon the issue of honesty and openness.

1: A case of misplaced loyalty

Throughout the period extending from the time of Mrs Jasper's admission to the hospital to rule out a heart attack to the time just after her surgery, Mr Jasper takes his wife's misfortune in his stride, suspecting nothing out of the ordinary. Upon learning that she has cancer and is dying, Mr Jasper is a changed man. He strenuously denies the shocking news and apparently implores the surgeon not to inform Mrs Jasper of her condition on the grounds that she would surely be unable to cope. The surgeon complies, telling her that his exploration revealed a harmless infection which he removed. At this report, she is according to Mr Jasper, 'all hope'.

Is it not rather Mr Jasper who was all hope, against reason and the odds? The clean bill of health from the surgeon, combined with her rally following the operation, led her to expect a full recovery. But as the days became weeks and the weeks months, Mrs Jasper was unable to regain sufficient strength to return to work and became depressed. It is an all too familiar chain of events. One thinks of Simone de Beauvoir's mother in *A Very Easy Death*, her confidence in her doctors and her future waning, exclaiming, 'These doctors are beginning to irritate me. They are always telling me that I am getting better. And I feel myself getting worse'.

One can sympathise with Mr Jasper's sincere but ill-fated desire to spare his wife the suffering of knowing that she is dying. One must, at the same time, wonder whether the surgeon was not overly compliant with the request not to disclose Mrs Jasper's diagnosis to her, knowing that in time the cancer would reveal the deception. Granted, Mr Jasper introduced the deception, but the surgeon need not have acquiesced in it.

What is more, it is arguable that the surgeon ought to have reviewed with Mr Jasper the propriety, or at least the likely consequences, of attempting to conceal the truth of Mrs Jasper's condition from her. In any event, the doctor's first responsibility is to the patient. Some patients want the facts, neat and unembellished; others want the news imparted gently. As John Hinton has wisely put it, the doctor's task is to keep pace with the patient's growing realisation that recovery will not come. Whether Mrs Jasper was the former sort of patient or the latter I am unable to discern from the case report. It is clear, however, that during the immediate post-operative period, Mrs Jasper wanted to know what ailed her.

The family doctor refused to lie to Mrs Jasper 'if she asked him outright about the diagnosis'. But no matter how hard he tried he could not prompt a straightforward request for the truth from Mrs Jasper. My guess is that as her condition worsened she saw through the charade, suspected the worst but took part in the deception for her husband's sake until, that is, near death, she felt so miserable and demanded the truth.

This comment was received anonymously from the Institute for the Medical Humanities, Medical Branch of the University of Texas. If the kind author would like to come forward, we should be grateful! (Case conference editor)

2: Obstructed death

Several cases have been received where someone's death from a longstanding natural illness seemed to have been delayed to an unexpected degree by external events, or to have occurred rapidly after an unsatisfactory situation had been resolved. Some of these cases concern patients who had been clearly bolstered up or driven along by a real hope; only when that hope had been realised could they relax and die. In one case a young grandmother of fifty 'waited' until the birth of her first grandchild and in another, a father lived until his son returned from a long expedition abroad where the son could not be contacted. In a further case, a patient died after his doctor, also a personal friend, had returned from holiday and had received a gift that the patient wished to pass on to him.

'Unfinished business' is a phrase often used by those describing feelings amongst the bereaved that they did not have time or opportunity to conclude discussions, set right feelings or resolve differences with the person they are mourning. To resolve these feelings may become very important, if normal grief becomes prolonged. It is less often observed that such a need – to set his or her affairs in order in the emotional as well as the physical sphere – exists also for the dying person. A strong emotional need for the patient may be to know and understand the disease process itself, and it is likely that this will become more important as the tendency increases for doctors to be more truthful, and for patients to expect them to be so.

Another need for the patient may be to give a relative or friend time to come to terms with the diagnosis, as in the first writer's interpretation of misplaced loyalty in the Jasper case. Initially, this seems to go against preconceived ideas of a close, sharing relationship, and therefore it is a problem which may be missed unless it is sought. But close families do not necessarily talk easily to each other. Professionals should understand from their own experience that what is communicated from one person to another may depend not only on the quality of the relationship but also on the distance being right. A warm empathic relationship may bring two people close enough for one sort of communication, but may bring them too close for another. 'I know you too well' said a woman to her male general practitioner when requesting a gynaecological examination from his partner: she had discussed the intimate and distressing details of her sexual and family life with him, but to be physically examined she needed someone more distant and uninvolved. This is borne out in terminal illness also by Hinton's recent study in which it appears that spouses communicate their knowledge of their terminal illness *less* if the relationship is a close one. Love may be blind, but can also render mute (1).

3: Commitment to honesty

If there is business to finish between husband and wife in order to establish the truth, what about between patient and doctor? Could more have been expected of the surgeon than the direct but reassuring deception?

In behavioural terms, the answer is undoubtedly yes: there is a gradual but definite shift amongst professionals in the health services towards more openness with patients, a trend confirmed by research in several places. It is surprising to note that none of the formal Declarations which have previously attempted to codify medical behaviour have suggested that doctors should tell the truth. Honesty may be presumed to underline such concepts as 'trust' and 'informed consent', but it had not been clearly stated as such until the American Medical Association's recently adopted Principles urged members to 'deal honestly with patients and colleagues' (2).

It is possible that Mrs Jasper's surgeon thought he was 'dealing honestly' with her, though a direct lie

might be thought difficult to justify in this way. He might have seen the issue more clearly if Mrs Jasper had tried to deceive him about some important factor in her own illness. This reversal of roles may also help to clarify another, perhaps more general issue: that medical ethics do not stand apart from morality in general. The principles of medical ethics are the same as the principles of ordinary day-to-day morality. Medical professionals are also citizens and in legal and moral terms they have to consider their actions as ordinary citizens as well as doctors. Society expects its citizens, especially those in public positions, to tell the truth, and in certain situations the law will punish those who lie. Even if there are double standards at many levels, these will never stand up to public scrutiny, and most people would agree that honesty is a basic principle in society to which public and professional persons should be seen to adhere. If ordinary morality expects truthfulness, so should medical ethics: a ruse is a ruse is a ruse, whether at home, in the office or on a ward round.

Thus, if doctors and nurses are to be permitted to tell lies or conceal the truth, there has to be some special justification. They have to be exempted from normally expected standards of moral behaviour for some particular and pressing reason, just as a policeman might be allowed to deprive someone of his liberty against that person's will only while making an arrest. The circumstances are clearly defined as to when that can happen in civilised society, and a police officer would always have to justify his or her action. We do not expect to be at risk of arrest while we go quietly about our lawful activities, and a patient would not normally expect to be deceived by a doctor or nurse in the course of an illness. The assumption must be the reverse, or society could not tolerate medical activities.

There is a growing enthusiasm for a more equal model of interactions between professionals and patients in health care: a patient is seen as an autonomous individual, free to make decisions about his own future based on information freely available from the professional. The question is not, then, the paternalistic 'Should I tell?', but 'What possible justification could I have for withholding information from the patient?' Some have called the relationship contractual, and a 'contract' depends on honesty, unless it specifically excludes it by allowing the professional to provide less than the truth. The professional should be expected to justify the exemption from honesty. It is hard to see how terminal illness in itself could justify such an exemption. The above thoughts on finishing business before death implies exactly the reverse.

One reasonable justification would be that the patient herself desired the truth to be withheld. Only the patient could make this request. Establishing that the patient really wished this exclusion would not be easy unless the doctor made it clear from the outset that all information would be given honestly. Then a patient not desiring information could be assumed to be asking for a suspension of the normal 'rules'.

Equally, nothing should be imposed against the patient's will: individuals must be free to decline information, whether trivial or important. The fine balance which this implies, where honestly conveyed information is freely available but not imposed, requires skill to maintain. And skill is the hallmark of a true professional.

References

- (1) Hinton J. Whom do dying patients tell? *British medical journal* 1980; 281: 1328.
- (2) Text of the American Medical Association's new principles of medical ethics. *American medical news* 1980; Aug 1-8.

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