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Case conference

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Truth at the last—a case of obstructed death?

The following case breaks with tradition by having only one commentary upon it, and that is from the doctor who submitted the case. We invite readers to make their own analysis of his comments, and to respond as appropriate.

Case

Mrs Jasper smoked too much, and so did Mr Jasper. As each year went by, there seemed less breath to share between them, and by the age of fifty eight Mr Jasper had severe obstructive airways disease, was often wheezing, and had five serious episodes of infective bronchitis during the winter. Mrs Jasper just plodded on. Thus it was surprising to the family doctor to find himself called to their house to see someone with severe chest pain, and find that he was confronted by the wife. She looked unwell, and had all the appearances of having had a severe heart attack. As there was so little support at home for her with her husband being in the middle of an infective bout at the time, the doctor requested an admission from the hospital for Mrs Jasper, and sent her in. He was not in doubt about the diagnosis, and asked her husband to let him know how she got on, as he was not able to visit patients in that hospital easily.

There followed for the doctor a long silence from the family. When he rang the ward to enquire about Mrs Jasper's progress, he was told by the house physician that she had not had a heart attack, and indeed no one knew the reason for her chest pain, which had been persistent. There followed a further lapse of time, until Mr Jasper attended the surgery and said that Mrs Jasper was about to have an operation. The specialists thought that she had an unusual shadow on the lung, and that it should be explored and possibly removed. Meanwhile Mr Jasper had continued to go to work, and, although worried about the operation for his wife's sake, did not feel that anything out of the ordinary was occurring, and seemed to be in satisfactory communication with the hospital staff.

Three weeks later, Mr Jasper came again. He was a different man. He was hardly able to tell the family doctor that his wife was very ill, and that nothing could be done for her, and she was about to be sent home. It was some time before he could bring himself to say that he had been told she had cancer, and 'it was only a matter of time'. 'The only blessing is', he said, 'that she knows nothing about it. I don't think she could manage to cope with the news. But anyway, she didn't have to, as the surgeon who operated has told her that when he opened her up he found a fungus infection, and removed it. She's all hope now'.

Mr Jasper was completely unable to bring together the apparently irreconcilable ideas of his wife being seriously ill, but being full of hope. It appeared that he had asked the surgeon not to tell her about her illness when he had first been told about the diagnosis, and the surgeon had agreed that he would not. However, Mrs Jasper, having been so long in the ward under investigation, had been keen to know as much as possible when she was well enough to talk after the operation. She had made a good recovery, was looking forward to coming home and talked a great deal about her plans and about going back to work.

The family doctor, nonplussed, rang the hospital after Mr Jasper had gone and discovered that the version of the story that he had received was substantially true. Mrs Jasper had an inoperable and rare fibrosarcoma of the pleura, but had made a good post-operative recovery and was coming home. Her husband came on several occasions to see the doctor in the surgery, and each time discussed how the future would be. He had little support apart from a favourite unmarried daughter, who lived eight miles away but visited quite often and would be prepared to look after her mother if necessary. Both she and her father agreed that Mrs Jasper should not be allowed to gain any inkling of the real truth of her situation, as she was so happy at the time.

In due course, Mrs Jasper returned home, and, though in some pain, when this was adequately controlled seemed well enough to begin to get about. She was fairly cheerful, and her only reference to the hospital was to 'bless them all for their kindness', but to express relief that she was home at last. With everyone in attendance, her recovery proceeded: but she did not regain enough strength to get out of the house.

Both daughter and Mr Jasper were obviously under strain, but facing the future bravely. When the family doctor visited Mrs Jasper, her husband left the room, and only appeared later to let the doctor out. They had doorstep discussions, but

however the subject was approached, the husband was adamant that his wife should be told nothing, and appeared to be very alarmed when the doctor said that he would find it impossible to lie to Mrs Jasper if she asked him outright about the diagnosis.

This unhappy situation continued for nearly six months. The general practitioner visited regularly, as the hospital had left the follow-up to him, and each time he visited Mr Jasper left the room. Mrs Jasper's cheerfulness began to wear thin, and she was very disappointed with her progress. Breathlessness made her sit up all night, but the doctor was unable to find any collection of fluid that he could remove from the chest. Mrs Jasper did not bring out any questions at all, however much he put himself in the way of them. She became more and more fretful and depressed and began to be very irritable with her husband. He was drinking more than usual, smoking like a chimney, and sleeping alone in the bedroom. She stayed all day in the living room and sat up in the chair at night. Even the regular visits from the nurse, a very cheerful person, did not get her moving. It was a very miserable house.

At the end of six months, Mrs Jasper looked less well, and depressed, but had not lost weight. The pain was under control and she had been on antidepressants at full dose for a month, with little effect. The discussions were slightly stilted when the nurse or doctor visited, but Mrs Jasper said she had 'every faith that things would eventually improve,' However, they did not.

One day the doctor was summoned because she felt less well. When he arrived he found her much the same physically, but very agitated.

'I can't sleep doctor, and I can't get this thought out of my mind. I'm not getting better, in spite of what everyone says. I'm never going to go back to work, am I? What ever is the matter with me? What is wrong with me?'
'What's on your mind?'
'I've got something radically wrong with me haven't I doctor? Have I got cancer?'

The doctor's affirmation was part of a mixture of tears and hugs, as Mr Jasper appeared through the door to comfort his wife.

The atmosphere was strangely relaxed after that. More tears were shed by husband and wife, and they sat together holding hands. All three spoke, tentatively at first but then quite openly, about the horrors of the five months they had been through, and of the strange way in which things seemed at last to be clear. There was no mention of resentment that Mrs Jasper had been told something different by the surgeon, although she seemed to skirt around that subject as if it in itself were unpleasant. She kept on saying 'They were good, though. They were good to me'. She did not ask about the future, and eventually the family doctor left.

On his rounds two days later, he was diverted by a message to go urgently to the Jasper's house. He found Mrs Jasper in some distress with breathing. She had the previous day gathered all her relatives and close friends and they had had an evening together. They had talked quite openly, and drunk together: it seemed to have been a very happy occasion. Mrs Jasper had slept soundly in the chair afterwards and seemed well when Mr Jasper left early for work. When he got back at midday, however, his wife was not well, and he had called the doctor. While the doctor was preparing an injection of diamorphine, Mrs Jasper's breathing slackened and she died quietly.

After the funeral, Mr Jasper came to see the doctor on several occasions. Once he complained of chest pain. There was no physical cause to be found, and there was a discussion of his feelings about his bereavement. He was, however, not easily reassured.

The doctor writes

I have thought a great deal about this case since Mrs Jasper died. There are many important features, but two ideas stand out. Why did she die in this way? What are the rights and wrongs of the information she was given at first by the surgeon?

Although it may not stand out clearly from the account, Mrs Jasper's condition changed remarkably little after her discharge from hospital. She lost very little weight, although she did become increasingly breathless. In spite of being a brave and determined person, her physical weakness did not improve, and she remained housebound, speaking about going back to work, but making no physical progress that would indicate that this was ever a possibility. She was depressed in the last two months of her illness, but again this did not seem to change, or in itself be related to, her physical state. It was as if she were 'suspended' in one condition, until suddenly she wished to open the discussion realistically about her future. At this point, there seemed no reason for her to be more questioning than at any other, yet when she had a frank discussion the atmosphere in the house (and within myself!) changed very quickly. She was reunited with her husband emotionally, and they shared the last two days quite intensely, it seems. She was clear in her mind, arranged a very beautiful party, and suddenly died. No *post mortem* was done, and it was not clear at the time exactly what was her mode of death – she had no obvious pneumonia or pulmonary embolism. It appeared as if the relief of her anxieties were related to her dying. Within the framework of this one observation, we could say that either she suddenly became aware, through some physical or psychological sensation, that she was about to die, or that the unsatisfactory explanation she was given at the hospital in some sense impeded both her recovery and her demise.

When this was resolved, she was able to go. Her dying had been obstructed.

This may seem fanciful, but there remains often the problem of diagnosing a mode of death satisfactorily in the slowly dying patient. Very often, it is clear of what they are dying, but not why they die when they do. Equally, there is a feeling that some people just 'up and die', and there are reports of people in different cultural settings who die under the influence of witchcraft, sudden psychological shock or just because they apparently wish to do so. One can imagine many physical mechanisms for this, via cardiac arrhythmias or cerebral haemorrhage, for instance, but the fact remains that the death comes, at an apparently pre-determined or appropriate moment for the patient as far as the onlookers are concerned. It may well be that there are psychological mechanisms as yet undelineated which control our death, just as they control so many facets of our life. It does not seem to me unreasonable to suppose that hope, acceptance or perplexity might be components of those mechanisms.

There has been much written about the stages to acceptance of a bad prognosis, and about many aspects of communicating the prognosis to the patient. There are obviously times when honesty is appropriate, and times when it may be right to put a better complexion on the future than the physician in his heart feels is the case. However, it is always assumed that the physician, in withholding the full truth, may be acting with the patient's interests in mind. 'First do no harm' indicates, some feel, that the harm we should avoid is by telling the truth. But could withholding the truth, or worse, as with Mrs Jasper, telling a lie, be construed as harm, if there were a suggestion that under the influence of this information her life were changed for the worse?

The 'scientist' in everyone may rise up in revulsion at this suggestion, as it cannot in an individual case be proved or refuted. We cannot put the clock back and act differently, and so it would seem arrogant, on the basis of one case, to put forward the notion that a person could be harmed by false information in this sense. But wrong decisions may be made or wrong attitudes struck as a result of deception, whether intentional or unintended, and thus the patient's circumstances may be damaged or a mental trauma imposed. Direct harm seems far-fetched, but possible.

The reason for raising it as even a possibility is that in many places doctors do withhold information from seriously ill patients, and think that in so doing they are helping the patient. 'The truth, the whole truth and nothing but the truth' may be an unnecessary intrusion into a settled, satisfied or restricted mind, and set going a chain of anxiety and physical response that may be harmful, disable the patient with depression or render him or her a permanent invalid. The doctor, realising this, may evade the truth or even tell a lie, all in the patient's 'obvious best interest'. As in this case, a diagnosis of malignancy is reported first to the relatives, who are then asked, or who volunteer, instructions as to whether or not the patient should be told. Strangely enough an equally lethal but non-neoplastic diagnosis, like a major heart attack, is not withheld from the patient. There seems to be a different response from the medical profession to the diagnosis of malignant disease, and a very different response to the normal style of exchange between doctor and patient.

Under normal circumstances what a patient says to a doctor, and what the doctor finds or thinks he finds, is confidential to the participants of the consultation, or a known and agreed third party, like a life insurance firm. If a decision is to be made, one hopes that doctor and patient will consult and come to a mutually agreed plan of action.

In the diagnosis of advanced malignant disease this is often summarily reversed. The patient is told nothing, the plans for therapy are not discussed, and information is divulged to third parties without the patient's consent, and without the patient even knowing the information which normally requires his consent before it can be passed on to others. The normal ethical code is turned upside-down and nobody objects. This is done to prevent harm to the patient. I cannot believe that this is satisfactory. This case suggests it is sometimes the opposite.

If these manoeuvres of deception or evasion create false plans, obstruct dying, and by contamination reduce the power of medicine for other patients through their mistrust of doctors to reassure and make well, it appears that the apparent balance of benefit and harm that most doctors have in mind when confronted with terminal illness must be altered.