Intimacy and terminal care

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SUMMARY. Four cases are summarized in which the general practitioner is involved in the terminal care of one partner of a stable marital relationship. The need to conceptualize the expectations of the patient, the family and the doctor in terminal care is stressed. An attempt is made to illustrate how the quality of the pre-existing sexual relationship, the dying person's own sexuality, and ultimately the capacity for physical expression of intimacy in the marriage profoundly influence choices in terminal care and the quality of dying.

Introduction

A SEARCH of the literature on terminal illness shows it to be singularly lacking in references to sexuality and its implications for terminal care. In this paper 'sexuality' is used in its broadest sense, that is, the capacity of the individual to link emotional needs with physical intimacy — the ability to give and receive physical intimacy at all levels, from the simplest to the most profound.

The doctor visiting a dying patient needs to be listening for the patient's expectations of that visit: Is the visit needed to show friends and relations that the situation is deteriorating and more help is needed? Is the doctor required for a limited 'clinical' function to alleviate symptoms, for example, to prescribe medication? Is this a 'crisis visit' for a new symptom or overwhelming 'panic' in the face of the unknown? Is the doctor called as a 'technician' to effect already formulated wishes (appropriately or inappropriately formulated), for example, 'We want you to get him into hospital'?

Or is this the opportunity for 'serious doctoring', for active joint exploration of a significant aspect of the management of the dying person? May this be the time to recognize the patient's spoken and covert wishes about intimacy and to translate these into relevant arrangements for terminal care? Not all of us wish to die at home with the potential for intimacy this may imply; the need of some people to die in the splendid isolation of a teaching hospital bed as a last event in a lifetime's avoidance of intimacy should be respected.

Case 1

This was a man in his early sixties, a retired jeweller, careful and fastidious. He and his wife did much charitable work. They were cautious, tidy people, and their home reflected this. There were two neatly folded, well-separated, single beds, which had been separate, one suspected, for a long time. They were childless. She described him as Mr B. to me. I felt there had long since ceased to be much warmth or physicality between them. He had been a smoker and a 'shadow' was discovered on a chest X-ray. There was no evidence of distant spread, no local symptoms, but Mr B. was overwhelmed by anxiety and despair. He became housebound overnight. I visited frequently. He wanted to sit for long periods, although he had no specific complaints of weakness or lethargy. There was discussion of the chair he wished to use. It was a reclining garden chair. It did not match the decor. Mrs B. was unhappy about its appearance and made this perfectly clear.

One morning the district nurse phoned in panic; Mr B. was suddenly in terrible pain. His screams could be heard in the background. I rushed from surgery, anxiously rehearsing the potential problems. Mr B. was in a state of acute fear. With talking, soothing and physical touch his screams diminished. There was no physical source of the pain. He started to talk in a precise, urgent tone. He knew he couldn't manage at home; he wanted to go into a hospice, where he wished to die quickly. I contemplated the potential difficulties of obtaining hospice care for a man without nursing needs.

At the door I talked to his wife. How many important conversations take place with one hand on the door knob; some pains seem to be unbearable in a closed room without the possibility of escape. Mrs B. implored 'You must do something, Doctor. We can pay'. A few tears, and then 'Doctor, you have no idea of the liberties that man is taking with me ... the things he wants me to do for him ...' There was a long silence in which I encouraged her to verbalize those 'liberties'. In those fraught moments, I was aware of what Casemont refers to as 'the creative tension of binocular vision',[1] that is, holding together knowing and not knowing; following with one eye those aspects of the patient about which one does not know and keeping the other eye on whatever one feels one does know. I suspected we were talking about physical intimacy, but did not know what these 'liberties' were for them. Finally, she spoke with a mixture of resignation and shame: 'Doctor, he asks me to brush his hair for him ...'

I was moved to tears for this fearful man, who was seeking some contact and knew the impossibility of achieving it. I realized there could be no comfort, no intimacy for him in dying at home. Perhaps he could find nurture in a hospice. He was admitted and died within weeks.

The cold, formal atmosphere of the house seemed to reflect the lack of intimacy in this marriage. Doctors trained in psychosexual medicine have commented on how women patients with sexual problems frequently use language about house and home as symbolic of their feelings about the vagina and their sexuality.[2] Perhaps Mrs B.'s resistance to her husband's wish for a chair which did not fit the decor, the reclining chair in which he could be at his ease, symbolized her fear of being manoeuvred into unaccustomed intimacy.

Mr B.'s screaming was potent 'communication by impact', stirring up feelings in the doctor which could not be communicated by words. His screams were for more than his dying, they were for dying without a wife able to brush his hair.

Case 2

Mr C. was 50 years old and had endured widespread carcinoma for two years, kept at bay but then suddenly recurring with a vengeance. He deteriorated rapidly. This was also a childless couple, but not by choice. Mr C. was installed in the living room, the centre of every comfort, with the television specially raised, flowers, cats on the bed, wife knitting by his bedside.

She was actively involved in his care. When I visited there was an immediate welcome, their dark approach road always carefully lit at night. Mr C. was able to accept her ministrations and she respected and cared for his fading body with the same robust love I suspect she had given it in health. Towards the end he needed a catheter. As she manoeuvred this tenderly on one oc-

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casion, there was a shared spark between them of old, happier touchings. 'Watch it, girl' he said, and they laughed together. She and I sat and talked when he was too weak to talk any longer. There was an intimacy and mutual respect in the relationship between this couple and those who were members of the 'caring team' which reflected their own intimacy.

The day he died I spent an hour sitting with her. It was a thundery day, the net curtains blew and it grew dark early. We sat largely in silence — I quote Elizabeth Kubler Ross 'At the end, those who have the strength and love to sit with a dying patient in the silence that goes beyond words will know this moment is neither frightening or painful'.[3] Sometimes it was difficult to feel if he was breathing. She washed his lips tenderly with glycerine — he died quietly. There remains an intimacy and respect between Mrs C. and myself to do with those last shared acts. If we extrapolate from the symbolism of this home we see its warmth adapted to his needs, moulded around him with love, as no doubt this women could mould herself in her lovemaking.

Case 3

Mr D. was a retired accountant, his wife a retired banker; both were 75 years old. Their home was tidy and utilitarian. A daughter lived abroad and visited infrequently. Many years previously Mrs D. had confided that she felt it a miracle that this daughter had been conceived because Mr D. was 'so disinterested in all that'. For years they had taken separate holidays, had separate living rooms, interests and bedrooms. I found Mrs D. difficult — she was dogmatic, with precise likes and dislikes about her doctors. She demanded 'special treatment' and it would take a brave soul to deny her special status. She would imperiously dismiss a partner who visited in my absence with a curt reprimand. However, she made it clear her wish to have me as doctor was not to do with any special perceived merit. A visit usually contained an element of confrontation. She had alienated many and had few friends.

Mrs D. developed an insidious malignancy, which was well spread before it was recognized. She returned home after major palliative surgery. It was unusual to be in the same room as them both. As we talked he wiped his eyes furtively. I was surprised at his tears and his protectiveness and wondered if he was able to show his feelings more, now that he was the 'strong' one — mobile and well. He learned to steam fish. She remained angry, demanding.

One day, he asked me into 'his' living room. With tears he said 'She can't cope'. He described her exhausted progress up the stairs the previous evening. He appeared overcome with embarrassment. 'It was so terrible ... she couldn't undress herself ... it was so humiliating for her ... I had to help her undress. Not completely of course' he hastily assured me. Years of humiliation and defeat seemed to hang in the air. 'Please get her into hospital'.

She wanted the teaching hospital and her eminent surgeon: 'He must be a great man because all the nurses are terrified of him'. She died slowly, in splendid isolation, resented and argued over by the surgeons as she occupied space for longer than anticipated.

Case 4

This was a couple in their seventies. Mr E. worked as a consultant engineer. Their son died in infancy. The flat had a faded glamour, with much gilt and pink lampshades. Even as Mrs E. became very ill with metastic carcinoma they struggled on entertaining friends, having bridge parties. As he nursed her, supported by the district nursing team, his arthritis worsened and numerous visits were required for their physical problems. She was very uncomplaining. Her eyes always turned to him for comfort. He gave it and wept later in the kitchen. There was an intimacy in the flat, the curtains were usually closed even by day, the warm lights on in the bedroom, the nursing dressings and paraphernalia kept hidden. The outside world seemed far away.

Help was accepted from doctors and nurses who were then dispatched kindly on their way, but the real business continued within those four walls. I was called in the early hours one cold night. She was near to dying and had been incontinent in their shared bed. Exhausted, he asked me to help change the sheets. As we sorted linen, I shared with him the likelihood that she would die during the night. He knew. 'We've slept together for 50 years. I want one last night with her'. Together we made up the bed with fresh sheets. It was impossible not to think of a bridal bed being prepared. I helped him clean and tidy her. She died in the night. He called me in the morning to certify the death, observed by friends and priest.

In the same way that a good sexual relationship is the private pleasure of a couple, so must the relationship in terminal care be respected as unique to that couple and part of their intimacy.

Discussion

Winnicott talks of a 'nursing triad' whereby a new mother is emotionally 'held' by a third person while she holds her baby.[4] One aspect of this emotional holding is to help the mother believe she is capable of being a good enough mother to her baby. Without such holding, there may be disruptions of subsequent mothering, which are made worse for the mother by others taking over and seeming to be better mothers to her baby.

Perhaps something similar happens in the dying situation — a dying triad. The 'carer' needs to be emotionally held during the nurturing of a dying partner. This emotional holding will be the totality of that individual's capacity for loving and intimacy, but can be reinforced during this critical time by external factors — the doctors, nurses, family and others who become involved. But professionals must have a great sensitivity to avoid taking over and being 'better' carers than the real carer.

In conclusion, patients may express their needs for intimacy covertly in the terminal care situation. The doctor needs to listen and learn from the patient. The confessions of the carers — 'This man is taking such liberties'; 'It was so humiliating for her'; 'I want one last night with her' — will be the cues for the organization of appropriate care. The opportunity for the unique individual solution is easily missed, especially if the doctor uses insight borrowed from other cases, however 'similar'.

> 'Death belongs to life as birth does. The walk is in the raising of the foot as in the laying of it down.' (From *Stray birds* by Rabindranath Tagore.)

References

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