

'To call it work somehow demeans it': the social construction of talk in the care of terminally ill patients

Carl May BScEcon PhD

Senior Research Fellow, Department of General Practice, University of Manchester, Rusholme Health Centre, Walmer Street, Manchester M14 5NP, England

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The nurse has an important role in helping the terminally ill patient come to terms with the imminence of death. Such work is highly demanding and often stressful, but is work which is accorded a high moral priority by respondents in the study reported in this paper. The paper explores the ways in which nurses work to respond to patients' expressed psychosocial problems and the emphasis that they placed on providing opportunities for patients to speak about their impending death.

INTRODUCTION

The past decade or so has seen the emergence of a sociological literature informed by the work of Michel Foucault (e.g. Foucault 1986), which explores in depth the constitution of the health care professions and their interactions with patients and clients. The impetus of this work has been to point to the ways in which the patient is increasingly understood to be more than a problematic body (that is, an *object* of clinical attention), but also a locus for a new array of psychosocial problems (possessing a problematic subjective experience of illness and care).

This period has also seen a profound shift in ideas about how clinical practice should be organized around the terminally ill patient, and a move from a general absence of openness about impending death to a more active set of ideas about the importance of its disclosure to the patient (Field 1989). At the same time, the question of sensitive interpersonal relationships between nurses and patients in terminal care has received an increasing degree of attention (May 1993).

Disclosure of terminal diagnoses

The disclosure of a terminal prognosis by medical staff is the formal evocation of the patient's organic crisis. It signals a substantive shift in his or her status as a social actor

and as an object of clinical attention. For the patient, this disclosure actualizes a traumatic crisis, that, as Elias (1985) has observed, emphasizes and confirms separation and isolation from others, and forces a confrontation with the imminence of disengagement from the world. Clearly, disclosure involves other actors — both intimate and remote — in contact and confrontation with this crisis, and this paper explores the ways in which openness about the patient's final trajectory is managed by nurses.

As interpersonal relationships have become a more central focus of professional discourse in nursing the patient's subjective status has been given ever greater priority. In relation to this, Silverman (1987) has documented the emergence of a 'discourse of the social', which underpins the ways in which the patient is now apprehended by health professionals. This paper focuses on the way in which such a discourse is accommodated in nurses' accounts of their practice with terminally ill patients. The ways in which the subject is the focus for *work* is explored, and problems of the definition and legitimation of this subjectifying work are considered.

The paper thus examines the ways in which a group of nurses working in a general hospital responded to some of the problems which they confronted in dealing with terminal illness, dying and death. It has long been noted that this is difficult and stressful work for the nurse (Folta 1963, McIntosh 1974). The focus of what follows, however,

is not on death itself, but on the ways in which knowledge about its imminence is disclosed and handled, and on the ways in which this involves nurses in very particular kinds of 'talking and listening' with the patients in their care

Study group and method

Nurses with 2 or more years post-qualification experience were interviewed as part of a wider study on the nursing care of terminally ill patients. Twenty-two respondents were drawn from the acute medical and surgical wards of a general hospital in a Scottish city. Interviews were semi-structured, tape-recorded and transcribed by the researcher, and followed the methodological theory and practice set out by Strauss (1986). Although the constant comparative technique of data analysis was initially used, subsequently a *post-hoc* analysis of these transcripts was undertaken in which respondents' accounts were related to Foucault's concepts of pastoral power and surveillance. In this paper, respondents' accounts are identified by a code number, the researcher by initials.

DEALING WITH BAD NEWS. CONDITIONS FOR SURVEILLANCE

In the period after disclosure 'talking and listening' with patients becomes a central focus of nurses' accounts of their work. It is important to emphasize that these terms refer to activities which respondents perceived as important elements of nursing work, which involve the collection and collation of knowledge about the patient. The forms that this knowledge takes, and the purposes to which it is put are at the centre of the discussion which follows. For obvious reasons, the patient who has recently been told that his or her condition is lethal may be anxious, depressed or agitated, and respondents stressed the potential for interventions which helped patients to respond to their new circumstances.

I think that one of the first things that we have to get over to them is that we can make sure that they're pain free, because that's one of the things that they get worried about. Another thing is getting over the fear that's involved, because dying is a very fearful thing. Dying alone and dying in fear are the two things that people fear the most. So I think you have to be open with the patient, and you *cannot* be seen to be avoiding them just because it's a difficult thing to tackle. It's our responsibility to make sure that the patient gets all the comfort that they need. They have to know that if there's something that they want, we will organize it for them and that all the stops will be pulled out. (N206)

Whether such prescriptive demands can be met in practice is problematic, but at the root of work which is intended to meet them are notions of 'knowing' the patient (May 1992). Clearly, work which is directed at the collection of information about the body is a relatively constant

feature of interactions between nurses and patients, and its legitimacy is very rarely questioned by the patient, whose presence on the ward is defined by the necessity for observation and treatment of the body. In this context, nurses' enquiries about how the patient 'feels' are relatively unproblematic. They refer specifically to the body and are undertaken against the background of a mass of 'scientific' medical knowledge about 'normal' and 'abnormal' pathology.

While for most patients the experience of this work is directly connected to their restoration to health, the terminal patient has no such potential and surveillance of his or her responses to this state are undertaken through 'talk'. Bloor & McIntosh (1990) and Lawler (1992) are among a number of researchers who have drawn on the work of Michel Foucault to suggest a 'therapeutic gaze' through which such surveillance can be mobilized. They assert that surveillance, or monitoring, of the intimate disposition of the subject is a key mode of exercising power in such settings, and such a gaze can only be fully exercised through conversational practices. Respondents' accounts are organized around such talk — through which the patient is revealed in depth — being seen to be an entirely legitimate activity that most patients will wish to do and will find helpful. While talk is stressed in nurses' accounts, it is important to note that surveillance of the patient's social and emotional condition involves visual indicators of behaviour as well as verbal exchanges. Nurses 'know' the patient by how they 'look' as well as by what they say.

These observations are constituted through enquiries about the patient's social and emotional — rather than organic — state, and have a different basis to those made about the state of the body. In this context, knowledge about the body is organized around apparently objective benchmarks — the difference, for example, between a 'normal' and 'abnormal' body temperature — but such benchmarks are more difficult to come by in the observation of the patients as a 'normal' human subject. Ambiguity about what particular behaviours may mean is compounded by the problem of establishing what normal behaviour is for an actor dislocated from a 'normal' environment. Moreover, while enquiries about the body may be viewed as entirely appropriate by the patient, enquiries directed at how the patient 'feels' about his or her disorder and what it means, may not be considered legitimate.

I think once the patient has been told about their prognosis the atmosphere thereafter can be very difficult, because they're not sure whether you know what's going on or whether you want to talk about it. You can put out all sorts of cues to them if you want to, but if they don't respond then that can be difficult. You feel that the patient doesn't want to talk about it, or that they don't want to talk to you about it. That can be hard. (N107)

In this account the respondent is concerned to emphasize the uncertainty which underlies the relations with patients at this stage in their career. While the legitimacy of talk between the nurse and patient about how the patient feels has to be negotiated and established by mutual agreement, this may be difficult if the nurse (or a nurse) has not been present at the disclosure interview.

Some people just don't want to talk about it afterwards, some people just talk to you for hours. You just don't know. But if you were there, then at least they know you know. Sometimes I think that when medical staff go to speak to them about it some patients are under the impression that we don't know what's wrong with them. And perhaps they don't speak to us because they don't want to, they'd rather discuss it with family, or else they're under the impression that we really don't know what's wrong with them or what was said by medical staff, so they just don't say anything (N206).

Uncertainty about whether the patient wishes to talk, and understands that it is legitimate to do so may be oriented around patients' assumptions about what nurses 'do' and what they 'know' about the patient's condition. If the nurse is present at disclosure such assumptions about the extent of nurses' knowledge are undermined.

I think this business of the nurse sitting in [at disclosure] it's not so much that it gives us an opening, because I would never talk about it if they didn't mention it to me first. You can give them openings to speak if they want to, but if they don't it's fine — but if you were present at the interview, and they know you were present, then there's a much higher chance that they will speak to you — unless they've got an absolutely brilliant relationship with someone else so the chances are reasonably high, just probably because you were there. It means that sometimes you don't even have to hint, they'll speak to you anyway if they want to and they don't always (N219).

While observation of the body is a feature of the experience of nursing work over which patients have little control, observations directed at establishing their need or desire to talk are dependent on their volunteering this information to the nurse. How nurses approach the patient in these circumstances is crucial.

When somebody has been informed of their diagnosis is somebody able to spend time with them? (CM)

We usually try and ascertain first if they actually want to speak, because some people don't want to talk about it at all. You go to them and introduce it casually and say 'has the doctor been to see you?' and 'what did he say?' Take it from there and see how they react to it rather than push it, you know, force them to say how they feel. Often they don't want to talk for maybe a couple of days, 'till it sinks in (N103).

These accounts emphasize the extent to which the configuration of the nurse-patient relationship after disclosure

is dependent on its legitimation by the patient, and that the patient has a moral right to refuse to enter into 'talk'. Of course, the patient who does want to talk is unproblematic in this respect but there may be a number of reasons why talking does not take place.

For example, a patient then denies that they've been told anything, and they just carry on as if nothing has happened. I think it's more difficult to deal with — because you don't know if you should be the one to bring up the subject to see if they want to actually talk about it or not. Usually they'll come round (in time) (N107).

The non-legitimation of 'talk' extends the period of uncertainty about what it is appropriate for nurses to do and say. It also has the effect of greatly reducing the potential for action on the part of the nurse. While palliative care can still be administered in respect of the organic disorder, no such care can be offered to the patient as an experiencing subject. This is asserted emphatically in the following account.

Because people react in very different ways don't they — are there particular patients' responses that are difficult? (CM)

I think the patient who, colloquially speaking, turns their face to the wall is very difficult — because it doesn't give the opportunity to do something and nursing as a profession has to be seen to do something. So that can be a problem, because at the same time you instinctively know that you might be able to offer the patient some kind of help — although not a cure — to ease the pain a little bit. But they are detaching themselves from the situation and they won't let you become involved in that, and that can be difficult too — because you can't actually perceive how they feel (N110).

Underpinning nurses' accounts of the ways in which patients resist talking is an acceptance that this behaviour can be understood as a natural response to the situation. Accounts which emphasize the voluntary nature of talk — but which stress nurses' concern with establishing the conditions in which patients may undertake it — clearly involve questions of legitimation. This in turn raises questions about the kinds of 'talk' that are being legitimized, and the purposes and interests which they serve.

TALKING AND LISTENING: PRACTICES OF SURVEILLANCE

In the period leading up to, and including, disclosure the relationship between nurse and patient is organized around work directed at the body. This involves interactions in which the nurse establishes the patient's knowledge about her or his disorder and its effects, and mediates between doctor and patient. After disclosure, however, the patient comes to occupy a more problematic position. At this stage in the patient's trajectory nursing work is

directed at the maintenance of the body rather than its restoration, and at social closure rather than the rehabilitation of the patient as a conscious and interactive subject. Because nurse-patient relationships are constituted through nursing work and through the modes of behaviour consequent on it, this shift in attention has the effect of reconfiguring interactions between nurse and patient.

Nurses' accounts of the ways in which their attention is directed beyond the body in work with terminal patients are characterized by references to availability rather than action. Patients are understandably anxious about the implications of their illness, and also its impact on their social relations with others. In the following account a nurse describes an encounter with a young woman who had been offered surgery to alleviate the immediate effects of terminal cancer, and the issue of 'others' is brought clearly into the foreground.

You were talking earlier about people being afraid — what kinds of things do you think you can do to mitigate that? (CM)

I think you've got to sit and listen to them and let them vocalize it, and let *them* talk it out — what they're frightened about — everything. I've spent time with a lady yesterday who's been given a choice of surgery. And she's very frightened because she's got two young children and this operation could affect her memory and if it does, then she'll never be able to be alone with them again. You know, she's really frightened. You know, I have no children, I can't relate to that woman. We're put in a totally unrealistic situation — what would I do? I don't know. But if she doesn't have the operation she could just stop breathing. (N108)

Sitting and listening requires the suspension of the elaborate set of moral pressures on the nurse to adopt a proactive role in exposing features of the subject. However, this is still work directly intended to assist the patient to take stock of, or to come to terms with, radically changing circumstances. As work it is constituted not through material tasks and technical expertise, but by sympathetic presence, and involves the construction of 'spaces' within other work undertaken with the patient in which this presence or availability can be mobilized.

'Taking time' with patients demands that the nurse contends with other, competing, demands of work on the ward. Time in which talking can be undertaken may require the re-arrangement of other work and the re-allocation of staff. The arrangement of time and space is clearly important, but it also raises the question of who is talking, and what is being spoken about. As the following account suggests, this kind of talk may not require the nurse to take an active part in the conversation.

Sometimes if they've got a very poor prognosis then it's a case of them wondering how they're going to tell their families and what's going to happen to them, how their spouse is going to cope, if they've got children — things like that. It depends on who they

are, if they've got a big family, whether they live on their own, and so on. Usually they find it a bit of a muddle at first and then everything starts to come with a rush. You've really got to sit down and work through a few points with them and then if they've had enough, come back later. (N304)

While the importance of being available to listen to patients when they wish to talk is emphasized in these accounts, it may also need to be stressed to patients. In the above account, a nurse describes the importance of encouraging patients to see the nurse as a figure who is both available and sympathetic to their concerns.

Accounts of sitting and listening emphasize the ways in which nurses are concerned not just with palliative care of the body, but with features of the patient as an interactive subject. The accounts discussed thus far set these concerns out in a prescriptive form, but also locate them in the context of the pragmatic negotiation of other work on the ward. Here, the need for patients to be reassured that they will not suffer, and that their last days will be dignified, is set against the possibility that staff might avoid them because of their condition. Similarly, conveying to patients that work directed at them is seen as important and is not the 'poor relation' of more 'successful' treatments is stressed, but is contrasted with the possibility that other competing demands on the nurse might not be successfully negotiated. Sitting and listening is clearly set out in these accounts as work, not as an informal or ephemeral activity connected with other tasks, but as a specific field of labour which is highly problematic.

THE CONFIGURATION OF NURSE-PATIENT RELATIONSHIPS

At the beginning of this paper it was noted that the Foucauldian impetus in recent medical sociology has emphasized the ways in which health care professionals are increasingly interested, not only in the career of organic disorders, but also with the ways in which the patient experiences these. Here, the announcement of a terminal prognosis presents all those who take part in it with major difficulties. Even so, nurses' accounts reveal an order and predictability to the forms of work which they mobilize in the period in which the patient is coming to terms with this bad news. Turner (1987) has observed that because of the emotional and social tensions surrounding dying and death, the aim of the hospital or hospice setting is to establish a regular and routine pattern of death for large numbers of patients and thus to avoid contingency.

In this context, the construction of the 'psychosocial' has taken the form of creating a new set of idiosyncratic symptoms which parallel the trajectory of organic disorders, and which can be treated by modifying the form of encounters between health professionals and patients.

The aetiology, symptoms and objectives of care that are generated by this focus on the patient are problematic. In this paper, for example, respondents' accounts draw on the work of Kubler-Ross (1970) to describe discrete 'stages' — anger, denial and withdrawal — through which terminal patients pass. Kubler-Ross has been highly influential in setting out a theory and practice of terminal care and, as Arney & Bergen (1984) have asserted, in emphasizing the importance of the dying patient *speaking*. The lengths to which respondents indicated that they were prepared to go to secure circumstances in which this was possible suggest that they were attempting to secure more than order and predictability in their work. *Contra* Turner, they were prepared to risk contingent and difficult circumstances to attend to the patient's perceived need to give an account of his or her interior state.

Here, while sitting and listening or talking to patients was clearly seen as part of work and as purposive, it was underwritten not only by ideas about therapeutic intervention, but also by much more ambiguous notions about the moral nature of nurse-patient relationships. This is emphasized in the extract below.

To call it work somehow demeans it — I don't know whether its because I've fallen for the hype that it's a vocation or what — but you meet people at this intense period in their lives and because of that the normal social barriers and etiquette is gone. It's like you're sort of down to a deeper layer, a deeper contact which isn't just work, it's about caring for people and wanting to make a difference — I don't know, to help or heal or support — I've lost track (N200)

It is clear that nurse-patient relationships have their constitutive basis in the performance of nursing work, in the description above this is imbued with a moral value and investment which undercuts its status as paid labour. The nurse asserts that the period after disclosure is in some sense special and demands a particular form of attention. This attention or concern can be characterized as 'sympathetic presence'. Even so, the encounters in which this is mobilized, and the configuration of the nurse-patient relationship within them, raise further problems of categorization and explanation.

First, it is important to consider the moral character of 'sitting and listening' and 'talking' to patients. This extends beyond the patient being the object of clinical attention or a subject manifesting psychosocial problems. Here the patient not only wishes to speak, but also to be known to nurses in an intimate and private way. But while clinical attention — whether it is directed at the body or at the psychosocial — involves the nurse in actively intruding into the private space occupied by the patient, attention which responds to the patient's profound sense of social loss and isolation and to the exposition of what the experience of being a dying patient means, involves the patient in voluntarily revealing this. Similarly, it

requires the nurse to arrange her work in a way that makes it possible for the patient to speak, and to be willing to participate in the encounter. Because of this mutual negotiation of the legitimacy of talking and because of the ways in which patients express what particular figures and events mean to them, it is suggested that these encounters take on the character of the confessional (May 1992).

This leads in turn to the question of the form which the relationship between nurse and patient takes within the confessional encounter. This involves the nurse in an uneasy conjuncture of roles: the underlying structural inequality of relations between professional and patient remains in place, the nurse expresses sympathetic concern while at the same time the patient reveals the most private aspects of his character, and the mobilization and expression of sympathetic presence corresponds closely to a formal act of counselling and comfort. It retains this formality precisely because of the way in which it is underwritten by the nurse seeing particular kinds of encounter as part of work, and by the ways in which these encounters seem not to involve exchange. While the patient reveals a great deal, the interaction is not reciprocal. In this respect the most effective way to characterize the nurse's role — and the basis of her or his relationship with the patient — in these encounters, is to see it as being in some way pastoral.

The significance of talking and listening as an arena in which this moral work — sentimental work according to Glaser & Strauss (1965) — takes place is rooted in the way in which it forms the final sequence of encounters in which the patient comes to be 'known'. Equally, it is underpinned by an implicit ideal for the terminal trajectory. The announcement of an organic trajectory opens up the possibility of it being experienced for what it is, and of the potential for the subject to be integrated into it. It thus demands a more potent mode of surveillance and management, and it is precisely this which emerges in the accounts presented in this paper. It is no accident that those patients typified as problematic in some way are those who cannot be integrated into the new career that disclosure announces, that is, those who are not disclosed to, or those who will not be integrated, i.e. withdrawn and angry patients. It is these patients whose subjective experience is impenetrable to the therapeutic gaze of the nurse.

CONCLUSION

The aim of this paper has been to bring into the foreground some of the practices of individualization and subjectification that are involved in the organization of interactions between nurses and dying patients. As the patient comes to be constituted as more than just an object or 'thing' to be treated, a new set of problems which involve the production of knowledge about individuals are encountered. In this paper, specific nodal points in the patient's

terminal trajectory have been used to illustrate the different forms of knowledge that are produced, and the different modes of surveillance that are activated to produce them

The key point is, however, that a very particular subject is being specified in these encounters. This subject is identified and organized around the experience of problems associated with illness. (This is not to deny the obvious fact that this subject does experience illness.) First, the patient is specified as the site of work. The objective of this work is to gently guide the patient through the various crises that are built into the experience of the hospital. That is, its purpose is to make bearable institutional constraints, rather than the experience of illness. Similarly, the patient is anticipated to need to talk to be self-monitoring and to be expressive. The patient has needs and problems which may only be exposed in this way, and so establishing a 'good' relationship with the patient is now demanded in the same way that caring for the patient requires an effective regime of physical care. A subject who affirms life (either positively by accepting impending death, or negatively by denying or 'withdrawing' from it) is one for whom the application of this work is problematic. Such a subject resists being 'known' through deflecting the therapeutic gaze.

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