

Disclosure of terminal prognoses in a general hospital: the nurse's view

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Some of the issues which nurses confront when they deal with the disclosure of terminal diagnoses and prognoses to patients are explored. In such circumstances, the nurse must respond to the competing demands of patients, relatives and medical staff. The paper examines the way in which a group of experienced staff nurses in a general hospital accounted for their activities during and after the disclosure of a lethal diagnosis. In particular, it explores the ways in which nurses are included or excluded from decision making about disclosure by medical staff.

INTRODUCTION

The promotion of an enlightened and humane regime of care for the dying patient has been a topic of key interest for nursing and medical professionals in the past 2 decades. Much of the debate about how this may be best achieved has revolved around psychosocial and interpersonal aspects of dying and death, and has focused on problems encountered in professional relationships with the dying patient.

This debate has drawn on key contributions from the social sciences — notably work by Glaser & Strauss (1965) and Sudnow (1968) — which emphasized the importance of interpersonal communication between health professionals and patient. Here, the period since the end of the 1960s has seen a profound shift in ideas about how nurses' communicative practices should be organized around the patient (Armstrong 1983, Silverman 1987). In the case of the terminally ill, this has involved a shift from a general absence of openness about impending death, to a more active set of ideas about open disclosure, in which the patient may be given opportunities to come to terms with — and come to accept — his or her dying and death (Armstrong 1987).

In this context, the work of Elizabeth Kubler-Ross (1970) has been of seminal importance, and the developing body of ideas about how to manage terminal illness has stressed the need for health professionals to permit the

patient to speak and to be heard (Arney & Bergen 1984). Nevertheless, the social management of the terminally ill patient in hospital remains highly problematic.

STUDY GROUP AND METHOD

This paper reports results from a study which explored a range of aspects of the nurse–patient relationship, and which used the issues raised by terminal care as a mediating question. The study used qualitative research techniques. 22 staff nurses with more than 2 years post-qualification experience were interviewed. All respondents worked on two medical and three surgical wards of a large teaching hospital in a Scottish city. Interviews were informal and semi-structured, and the research design and practice was informed by the methodological theory and practice set out by Strauss (1986). All interviews were transcribed and this material formed qualitative data which were subjected to constant comparative analysis. In this paper, individual nurses' accounts are identified by a code number.

PRACTICAL DILEMMAS: SHOULD THE PATIENT BE TOLD?

At the moment at which a diagnosis is confirmed and a lethal disorder identified, the patient becomes the focus of a

potentially dramatic set of events. This is a rite of passage of considerable magnitude for the patient. However, because the act of diagnosis tends to take place away from the patient in hospital, it may be a rite of which he or she may be only minimally aware, since the practices through which it is performed may be hidden from view. Similarly, the nature and extent of the disease may be concealed by kin and friends.

The effect of this confirmation of the trajectory of a disorder is to clinically define the patient more closely. Nurses come to know in detail the dimensions and effect of the illness, and to match the material practice of nursing work to it. Beyond this, it raises questions about the ways in which this definitive description of the disease and its trajectory can be explained to patients, and about which patients are the appropriate subjects for disclosure.

In this study, nurses' accounts of their management of information about diagnostics and prognostic work on the body were predicated on the assumption that the patient *would*, at some stage, be told about the implications of his or her disorder. The confirmation of a diagnosis of a lethal condition presents medical staff (whose prerogative disclosure is) and nursing staff (whose position in the decision making process may not be central) with a set of practical dilemmas about its provision to patients (Field 1984).

Respondents characterized themselves as marginal actors in decision making about this, but expressed a general preference for open and honest disclosure to the patient.

N104 I am very much of the opinion, and I think the charge nurse is too, that as long as there are no untoward factors, I would sooner people knew

Even so, respondents' accounts were organized around the assumption that there were some patients for whom there were good reasons not to disclose prognoses directly. Their accounts contain an informal set of criteria that underpin this assumption and which revolve around the patient's capacity to 'cope' with disclosure. The first of these is related to the capacity of patients to retain information about their condition if it was given to them.

N101 You know, if they've short term memory loss you've had it because every day you're giving them this new bombshell that they're terminally ill. These are the sort of patients that I don't think I would tell

The repetition of disclosure demanded by this type of condition was seen as highly stressful not simply for the patient but for all participants. However, such conditions are not common. The perceived needs of relatives were given great weight by nurses, especially with regard to the second 'type' of patient for which there was a bias

against open disclosure, very elderly people. Confused or demented elderly patients were seen as problematic because of doubts about their capacity to comprehend information provided to them about their condition. As a consequence, it was most unlikely that such patients would be advised of their prognosis.

CRM Some patients actually might not be told, for various reasons. How do you deal with that?

N109 I'm trying to remember. I think I've got to go back to geriatrics to a time when I worked with patients who didn't know. And yet in that sort of situation they didn't know, but they weren't being told because they couldn't have dealt with the information anyway because they weren't mentally up to it anyway, so it wasn't really a problem. I honestly don't think I've had to deal with keeping it a secret from someone who was going to ask awkward questions and put you in an awkward situation of what do you say and what do you don't. It's a case of them being demented or something. They weren't going to ask you, they were in a happy little land of their own.

Although the decision to tell the patient lies in the hands of medical staff, nurses are actively involved in the collection of information on which that decision might be based. In the case of very elderly people, this involves incorporating relatives into the decision-making process.

N104 I tend to see what the social circumstances are, how old he or she is, if there's a spouse. Quite often we tend to speak to sons and daughters about people who are over 70 and then decide. Obviously you do get very fit 80-year-olds who are completely with you and want to know.

Relatives

The role of relatives in decision making about disclosure may be highly problematic in itself, since they may have their own reasons for resisting disclosure.

N206 It upsets me when relatives say, 'Oh, don't tell my father he's not going to come out of hospital — he couldn't cope with it'. And what are they *really* saying, that *they* can't cope with the knowledge that he's not going to come out of hospital? I think it's often a fallacy that patients can't cope with the knowledge that they're going to die — I think it's a protective mechanism for the medical staff or the relatives.

While the capacity to retain or comprehend information can be demonstrated or tested in different ways, judgements about whether the patient can 'cope' or not have a quite

different basis, as the nurse recognizes in the following account

CRM Is there a general policy on the ward about what patients are told?

N217 I would say no I'm not aware that there is It's slightly different from places like Oncology where there are more ethical issues involved My personal feeling is that every patient has the right to know what's happening to his body, and if the prognosis is poor then they need to be given the opportunity to do what they feel is the next step

I've often heard it said that a patient wouldn't be able to cope with that kind of information Again, I think that is wrong Unless you can back that argument up with some psychological assessment of the patient's ability to cope — and that's not something that either medically or psychologically we can pinpoint

The lack of concrete clinical criteria over which patients should be told, and the practical ethical dilemmas that disclosure involves, add to the stresses that Bennet (1987) has reported in decision making about disclosure This is highly stressful for nursing staff for a variety of reasons, and there is no doubt that in practice some nurses try to avoid it, as Field has noted (1989) The existing literature about decision making by medical staff about disclosure is contradictory, and historically there is a good deal of evidence that medical professionals have resisted open disclosure (Williams 1989) However, the practices which are involved in disclosure are not only dependent on the decisions of a small number of senior medical staff, but there is also a good deal of variation in individual consultants' and registrars' conduct

N107 Every 6 months medical policy undergoes a reversal because the senior registrar changes, and really, in many ways, as I say, medical staff-wise policy comes from the senior registrar more than from the consultants because really we only see the consultants each once a week, and the registrars are there daily So, I'd say a lot of that sort of policy decision comes from them So it changes every 6 months But generally as nursing staff we feel patients should be told, and talked about, and actually they are, on the whole, and someone talks to them

Irrespective of the actual practices employed by specific consultants and registrars, some respondents questioned the right of doctors to make such an important decision without consulting nursing staff

N103 Well, first of all there's the controversy about telling

the patient his diagnosis, which I have very mixed feelings on Ethically I suppose they are entitled to know what's happening to them But quite often, one of the consultants particularly, he makes the decision whether the patient knows or not, which upsets me because I feel they're only the consultant, they're not God

And they *cannot* make the decision Different individuals will react very differently to being given the diagnosis Obviously, if relatives are very close to a patient and advise not telling, I think that needs to be seen to be very carefully considered However, medical staff *never* approach nursing staff and ask what we would like them to be told or, you know, should they be told There's no discussion at all

Decision not to disclose

The decision not to disclose renders interactions between nurses and patients highly stressful and parallels the uncertainty that exists prior to the confirmation of diagnoses In cases of 'closed' awareness, the appropriate response to patients who articulate suspicions or alarm about their condition is always uncertain, and since disclosure is not within the nurse's remit responses must be negotiated with medical staff (Field 1984)

CRM Some patients don't get told, do they?

N209 No Some very elderly people it wouldn't be, I don't think, very beneficial to tell them But usually, relatives are told

CRM What kinds of problems does that give you?

N209 You're just very fearful, in case they ask something You don't want to say, 'I'll go and ask the doctor' as if you're shrugging it off You do have to answer as honestly as you can It's very hard at times Obviously, you don't want to say too much because then you're going above the medical staff You tend to consult them first and find out what you can say

As the extract above shows, non-disclosure also has the effect of diminishing the nurse's field of discretion to manage the patient The limits of that discretion are dependent on the advice of medical staff Even so, accounts of decision making about disclosure stressed the absence of explicit policies about how it should be conducted, even in specialities in which relatively high levels of mortality were experienced

All respondents were asked if there was general policy about disclosure on the ward on which they worked, and while all answered in the negative discussion about disclosure policies frequently involved an appeal by respondents to the individual characteristics of each case However, as in James' (1986) study of the nursing care of

terminally ill patients in a hospice, it was difficult to locate specific *individual* characteristics against a general set of 'types' oriented around age, intellectual competence, neurological disease or deficit, and relatives' attitudes. Those patients who were elderly and whose next of kin resisted the prospect of disclosure were least likely to be told, while relatively young patients were disclosed to more often.

One group of patients was almost certain to be told doctors, pharmacists and nurses. It would be very difficult to conceal the nature of their disorders from this group given their familiarity with symptoms and procedures. In only one area from which respondents were drawn was there a suggestion that all those who could be disclosed to were, and this was explained on the basis of the danger to the patient of some of the surgical interventions undertaken there.

N300 They are told the pros and cons every step of the way — that's one thing I can say for them. The consultants take so much time with each individual, they go through it from beginning to end.

The nursing work involved in decision making about disclosure was characterized by respondents, where they were involved, in terms of the collection and collation of knowledge about the patient which might be useful to medical staff as a basis for decision making. Even so, for respondents, the preference in favour of disclosure was related closely to the magnitude of problems associated with non-disclosure. As one nurse pointed out, 'once folk know what's wrong they are much easier to deal with'.

Precisely how, and to whom, diagnoses and prognoses are communicated by medical staff remains problematic. Clearly, the question of disclosure is underwritten by important ethical considerations as respondents make clear, there is the question of whether the patient has a right to know and the influence of other actors on medical staff in the events in which these decisions are made. It is important to note here that although medical staff are at the centre of decision-making about disclosure, nurses' emphatic demands to be included in such discussions can be seen to be founded on their knowledge about the extent to which (a) the patient is already aware of his or her situation and (b) the extent to which the patient has expressed — implicitly or explicitly — desire to know about an unwelcome prognosis.

Nurses advocated a number of connected issues in relation to this: the patient has the right to open and honest disclosure, relatives should have no right to prevent disclosure, but also, medical staff should not make disclosure without first consulting those nurses or relatives who know

the patient. As might be expected, these considerations were organized around the practical question of what patients and their relatives were felt to *want*, rather than in terms of an appeal to a more elevated set of ethical categories. Beyond this, however, they were underpinned by a set of ideas about the importance of *negotiating* a jointly constructed approach to the patient.

'Awkward' questions

For the nurse who has been faced with 'awkward' questions from a patient during the period in which a diagnosis and prognosis have been established, and who is then confronted, perhaps, by relatives who wish to delay or prevent disclosure, and who may also be uncertain about the way in which the registrar or consultant intends to deal with this, the situation raises a number of dilemmas. There is no doubt that such situations can be highly stressful for nurses (May 1990). On the threshold of disclosure the nurse is coming to know the patient not just as an individual whose life has been dislocated by the routines and administrative practices of the hospital — or by the trajectory of a lethal disease — but also as a person at the centre of a set of potentially conflicting set of decisions about disclosure.

As has already been emphasized, these may not coincide with the nurse's own values. Where such decision making ignores the work that nurses invest in 'knowing' the patients in their care, it also undermines attempts to implement individualized nursing care. It is important to note that the 'knowledge' about patients on which individualized care depends is always provisional and never complete: the discontinuity of nurse-patient relationships, the clinical trajectory of the patient, and a number of other factors — notably the extent to which the patient is willing to talk about her or himself — will inhibit its collection and collation.

TELLING THE PATIENT

The period in which a diagnosis is established is rendered problematic for the patient, nurses and medical staff by uncertainty about the possible trajectory of the disease. Once a diagnosis and prognosis are confidently established, however, it is possible to pass this news on to the patient. Respondents' accounts of their work in these circumstances revolve around their relations with medical staff. Although the presence of a nurse may be seen as desirable to ensure that the patient is accompanied by a familiar and sympathetic figure (Charles-Edwards 1983), this did not feature in respondents' descriptions of their work. It was, however, seen as vital that a nurse should be present at disclosure.

The emphasis here was on nursing staff being adequately informed

CRM Then, presuming the patient is well enough to be told, because I know some won't, what would happen?

N203 The next of kin and the doctor and nurse would go and speak to them That would take place in a quiet room Quite often the person may already be in a single room, we'd make sure of that And the patient would be told, obviously to their level of understanding And we would know what was said, so we wouldn't be contradicting the doctor, and we also document quite strictly on the notes who was there and what was said

The nurse's demand for inclusion in the disclosure interview focuses on the power of medical staff to set out an authoritative account of the patient's trajectory Here, the patient must be provided with a single account of the nature of her disease The onus for this is placed on the nurses who must avoid contradicting the doctor's account, since this not only subverts working relationships between medical and nursing staff, but may also confuse or upset the patient The location of the disclosure 'interview' underlines its special nature typically, this will take place in private

N219 They're always told in private, but if they're in a four-bedded male room we've no option but to tell them there Then they'll be taken through to the relatives' room [a small bedroom off the ward, normally reserved for patients' relatives who have to stay overnight] which'll give the doctor and nurse a chance to speak to the patient and gives the patient a chance to ask questions

Co-operation and consequences

Co-operation between medical nursing staff means that the consequences of disclosure may be jointly dealt with Even so, nurses are the practical managers of the events which follow disclosure and need to have a full account of what has been said Patients and relatives are unreliable witnesses and, having just experienced the full shock of such an encounter, may have 'lost' or misunderstood and doctor's words In the period directly after disclosure, much of the nurse's work may revolve around interpreting medical information to the patient and relatives, rather than comforting or counselling them Because so much of this work is predicated on what patients have been told and how they have reacted, the exclusion of nurses from the interview itself may be highly disruptive

N102 We like a member of nursing staff to be present and that doesn't always happen I've been left in an

extremely awkward situation, when the medical person actually went in and told the man No, tell a lie, he told the wife first, in the relatives' room, without letting me know they were in there While I was in comforting the wife — because obviously this was drastic news, he only had a couple of days left to live — he went in and told the patient without me there either

This vivid description of a failure in the joint formulation of disclosure points to the catastrophic consequences that such events have for the patient and relatives, as well as for good feeling between professional groups The respondent adds

N102 And I spent the next half hour running between the two, because neither could speak to each other, because they were scared of what the other would think And eventually you get them together and everything's alright I was still in a position where I was fishing for information about what the doctor actually said, because he left without telling me

This incident emphasizes the importance of an orderly organization of disclosure, in which nurses and doctors cooperate to bring bad news to the patient in a way that is manageable Like nurses in other studies, Field's (1984) being a case in point, respondents expressed a strong commitment to a more open and honest provision of information to the patient about his or her condition Of course, this needs to be qualified since judgements about whether or not the patient would be able to comprehend this information, and more ambiguous notions of whether disclosure would be 'beneficial' were consistently brought into play

While an element of idealization may underwrite respondents' accounts of disclosure, there is good evidence that informed patients are less problematic in terms of their clinical management (Raiman 1988) and there seemed to be no doubt among nurses in this study that patients in possession of information about their condition were 'easier' to manage and asked fewer 'awkward' questions

Power

More importantly, and this somewhat undercuts the possibility of idealization or evasion, is the emphatic political demand for inclusion in the decision-making process about disclosure which runs through nurses' accounts of their work at this stage This lack of inclusion clearly separates the respondents in this study from those described by Field (1984) Not only are patients and relatives uncertain about the nature of the disorder, as nurses may be initially, but

nurses are themselves uncertain about the extent to which they will be involved in — or know about — medical decision making about disclosure

At issue here, as Porter (1991) points out, are policy decisions made by a small number of powerful actors within the medical staff

CONTEST OVER DISCLOSURE

The practical dilemmas which nurses meet in their interactions with the newly diagnosed terminally ill patient have their sources elsewhere, in the ordering of power relations between nurse and doctor. It is apparent from their emphatic demand to be included in the encounter at which disclosure is undertaken that nurses are negotiating in these circumstances not simply difficult interactions with patient but problematic *doctors*

The question of inclusion operates at three distinctive but inter-related levels in respondents' accounts. First, it represents contest over the general arrangement of power relations between medical and nursing staff, and the negotiation of structural inequalities between them, (May 1992). Nurses asserted that they were non-marginal actors and demanded that their role as the managers of patient care be accepted and legitimated by medical staff at this contested stage in the patient's career. The variability of medical practice, and the differing degrees to which nurses are routinely incorporated into disclosure, points to the ways in which these encounters are negotiated, rather than structurally determined.

Second, contest over the inclusion of nurses in disclosure may be seen to represent the negotiation of the order and routine of nursing work. The construction of such an order minimizes contingency and disruption. In this context, the demand for inclusion emphasizes the need for a predictable order to events that are highly stressful (Turner 1987). Third, the demand to be included relates to the ways in which nurses are involved in negotiating the patient's passage to an open awareness of his or her condition and its implication (Glaser & Strauss 1965). In this context, the nurse works to make institutional constraints bearable, securing a location for the interview in which, for example, privacy is assured.

The question of inclusion is important not only because it reveals substantive problems in the organizational relationship between medical and nursing staff in the hospital, but also because of its impact on the nurse-patient relationship. Such relationships are complex, and highly dependent on their social context (May 1990). But these relationships also mediate or channel concerns about the

patient's psychosocial health and welfare and these concerns are intimately related to the question of opening up awareness about terminal illness. Where nurses are excluded from decision-making processes about disclosure, their intimate knowledge of the patient is rendered useless.

In the context of the study reported here, this is revealed in the ways in which respondents' accounts focus not on the ethical problems which are associated with disclosure, but on the practical difficulties which are associated with the everyday exigencies of relationships between professional groups.

Ethical issues

There is now a wide range of studies which report, in different contexts, conflict over decision making between doctors, nurses and other health care professionals (May 1992). Clearly, there are issues of professional power and control which are at issue in such decisions but there was no evidence in this study that respondents wished to enter into the provision of disclosure of terminal prognoses themselves. Instead, contest over nurses being present at disclosure was directed at the *orderliness* of the patient's clinical career.

In this context, these nurses felt that in not having access to the disclosure interview they were denied key information about what the patient knew, how this knowledge was imparted and how the patient reacted. This is of key importance in any subsequent counselling that the nurse may offer.

The ethical issues which nurses confront in these circumstances are also encountered by other health professionals, and indeed by patients' relatives and friends (who may feel them much more deeply and more severely). However, while doctor's contacts with the patient are episodic and formal, the nurse is in much closer proximity to the patient, and hence much more aware of his or her emotions and anxieties. In order to judge properly how to respond to the patient who is expressing psychosocial problems, or asking for more information, knowledge about the patient is crucial.

This is not solely a technical matter of providing the most effective mode of nursing care. There are more existential considerations at stake. Here, as Elias (1990) has observed, the experience of knowing that death is imminent is characterized by a profound sense of loneliness. In the longer term, this involves feelings of disconnection and separation not only for the patient but also for others. This may be characterized as the onset of *social death*, and in turn may follow a somewhat different trajectory from the pathological processes which the patient experiences and

the nurse observes. The organization of the general hospital is profoundly hostile to the expression of patients' deepest emotions (if this is in fact what patients wish to do). This demands time and attention on a scale rarely available to nurses working on a busy medical or surgical ward.

CONCLUSION: INDIVIDUALIZED NURSING CARE

In the context of individualized patient care, in which nurses are expected to develop helping relationships, there can be no doubt that such work is problematic. Moreover, models of individual nursing care — which tend to emphasize the nurse's role as being one which encourages patient self-care — may render this work more difficult.

The implications of the terminal patient's psychosocial dependence for individualized nursing care have been inadequately explored. It may well be that, as these organizational systems become more common as a basis for ward practice, new and intractable problems will emerge.

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