International Journal of Palliative Nursing

The quarterly journal promoting excellence in palliative nursing

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What terminally ill patients value in the support provided by GPs, district and Macmillan nurses

Gunn E Grande, Chris J Todd, Stephen IG Barclay, Janet H Doyle

Abstract

The aim of this project was to investigate how patients view the care and support provided by their doctors and nurses. Forty-three patients with a life expectancy of 1 year or less who were being looked after in their own homes were asked to give their views of the support given by general practitioners, district nurses and Macmillan nurses. Patients had predominantly positive views of the support received. The content of their positive statements suggested that psychosocial aspects of support, including communication and kindness and consideration shown, were valued most. Actions in the form of helpfulness, organization of support and being accessible were also important, while clinical aspects received less emphasis. Clinical aspects of care were emphasized more when patients expressed negative views of support. Patients' statements suggested that emotional support and information were provided predominantly by Macmillan nurses.

these were the health professionals found to be most involved in the patient's care. Full details are given in Grande (1994).

Method

A random sample of 150 Cambridgeshire GPs were contacted by letter and asked if they would identify all patients on their lists who had a life expectancy of 1 year or less and who were being looked after in their own homes. Eighty (53%) of the GPs agreed to do so. In all, 105 patients were identified, including patients of GPs' partners. Subsequent consultation with the GPs suggested that 75 of the identified patients would be physically able to participate in an interview, and these were approached by letter. Of these patients, 43 (57%) were interviewed, 18 (24%) refused to take part and 14 (19%) became too ill to take part.

As part of the interview patients were asked to identify the community services from which they received help and to rate the quality of support offered by each of them. The rating categories were: excellent, very good, good, fair and poor. After each rating the patients were asked to explain their reasoning, e.g. 'What is it about the district nurse support which makes you rate it as very good?'. Throughout the interview patients were also encouraged to talk freely about the support received and their views of it.

The three main providers of community support were GPs, district nurses and Macmillan nurses, and therefore statements relating to these health professionals formed the basis for the present analysis. All interviews were transcribed and subjected to content analysis (Holsti, 1969). Included in the analysis were all the answers provided when patients were asked to explain why they had given a particular rating, and any additional evaluative statements about support which

While useful guidelines exist for the provision of palliative care, these were often developed by health professionals for health professionals, and mainly gave advice on organization and coordination of care (Southwest Thames Regional Health Authority, 1991; Standing Medical Advisory Committee/ Standing Nursing and Midwifery Advisory Committee, 1992). In order to ensure that care provision is responsive to patients' needs we also need to know what constitutes good quality support from the patient's point of view in one-to-one interaction with health professionals, and what aspects of support are seen to be provided by whom.

One way to improve our understanding of this is to ask patients to talk about the support provided by their doctors and nurses. As part of a project looking into domiciliary palliative care the authors investigated what patients valued about their doctors and nurses by noting which aspects they chose to emphasize when asked to explain what they felt was positive or negative about their support. Using qualitative analysis, the study focused on support from general practitioners (GPs), district nurses and Macmillan nurses as

Gunn E Grande is Research Associate, Chris J Todd is Senior Research Associate and Director of Health Services Research Group, Stephen IG Barclay is GP and Macmillan General Practice Facilitator, Health Services Research Group, Institute of Public Health, Department of Community Medicine, University of Cambridge, University Forvie Site, Cambridge, and Janet H Doyle, is Freelance Health Service Consultant, The Cottage, The Street, Great Wratting, Haverhill, Suffolk

'A considerable number of comments in praise of doctors and nurses centred around psychosocial aspects of their support...A large proportion of statements concerned the interpersonal relationship between patient and professional, i.e. how they related to each other.'

emerged spontaneously during the interview. Interview transcript segments were coded using the Ethnograph software package. Segments were grouped and regrouped to form what appeared to be the most meaningful categories on the basis of the material.

Results

Patient characteristics

The interview sample comprised 39 patients with cancer, two with cirrhosis and two with respiratory disease and/or ischaemic heart disease. There were 18 men and 25 women, and the mean age was 65 years. Median survival following identification was 215 days. Although 87% of the patients were able to move about indoors independently, only 58% were

able to climb stairs. While 62% were able to get about outdoors, only 31% could use public transport independently and 33% could drive a car.

Support

All patients had some contact with a GP. In addition, 24 (56%) had contact with a district nurse and 16 (37%) with a Macmillan nurse at the time of the interview. The percentage of patients reporting contact at least once a month was 70% for the GP, 42% for the district nurse and 26% for the Macmillan nurse.

Ratings

Thirty-four patients (79%) rated GP support as excellent or very good, seven (16%) as good, one (2%) as fair and one as

Table 1. Content of positive statements about GPs, district nurses and Macmillan nurses showing the number of patients mentioning each category and the number of statements (in brackets)

Content	GP	DN	MN
Psychosocial	22 (33)	16 (25)	14(24)
Interpersonal relationship	17 (24)	7 (12)	10 (11)
Communication	11 (12)	4 (5)	7 (7)
Cheering up	5 (5)	3 (5)	3 (4)
Familiarity	4 (4)	0 (0)	0 (0)
Other	3 (3)	2 (2)	0 (0)
Kindness and consideration shown	7 (9)	12 (13)	3 (3)
Emotional support for patient and family	0 (0)	0 (0)	6 (10)
Actions	23 (38)	10 (11)	6 (11)
General helpfulness and expenditure of effort	12 (15)	2 (2)	2 (4)
Facilitating role	9 (10)	3 (3)	3 (3)
Accessibility	13 (13)	6 (6)	4 (4)
Clinical	4 (10)	5 (5)	5 (6)
Medical expertise	2 (2)	0 (0)	0 (0)
Thoroughness	2 (8)	0 (0)	0 (0)
General helpfulness in provision of nursing support	0 (0)	5 (5)	0 (0)
Source of advice and information	0 (0)	0 (0)	5 (6)
General	13 (17)	5 (6)	7 (10)
Generally positive	9 (12)	5 (6)	4 (6)
Waxing lyrical	4 (5)	0 (0)	3 (4)
Other	5 (7)	0 (0)	0 (0)

GP=general practitioner; DN=district nurse; MN=Macmillan nurse

'Comments relating to the lightheartedness of the interaction and its ability to cheer them up were also made. A few statements about the GP stressed how familiarity eased the interaction.'

poor. Of the patients who currently had contact with a district nurse, 21 (88%) rated this support as excellent or very good, 2 (8%) as good and 1 (4%) as fair. Fifteen (94%) of the patients who had a Macmillan nurse rated the support as excellent or very good and one patient rated it as good. There were no significant differences between health professionals in the distribution of ratings.

Content of positive statements

The interviews yielded a total of 203 positive statements about GP, district nurse and Macmillan nurse support. The content of positive statements appeared to fall into four broad categories:

1. Psychosocial aspects
2. Actions
3. Clinical aspects
4. General praise.

Table 1 shows the number of patients mentioning a category of support and the number of positive statements relating to each category. It also shows possible sub-groups of each category. In praising a health professional, one patient may at one point have made a statement about psychosocial support and at another a statement about actions. Likewise, one patient may, for instance, have made several comments about psychosocial aspects of the GPs' support during an interview. Hence, the number of patients mentioning an aspect of support differs from the number of statements dwelling on this aspect of support.

Psychosocial aspects: A considerable number of comments in praise of doctors and nurses centred around psychosocial aspects of their support. This category could be seen as having several facets. A large proportion of statements concerned the interpersonal relationship between patient and professional, i.e. how they related to each other. Such statements to a large extent focused on some aspect of communication, including listening, being easy to talk to or taking time with the patient. Comments relating to the lightheartedness of the interaction and its ability to cheer them up were also made. A few statements about the GP stressed how familiarity eased the interaction. Statements made about communication included:

'Well, I can talk to her [the GP] about anything, you know, there's no sort of boundaries at all. She's very good, and she's always willing to listen.'

'The district nurse she comes in and she sits and she talks...Whatever I ask her about she'll talk to me and tell me.'

Statements about lightheartedness and cheering up included:

'Well, I like him [the GP] cause I have a joke with him...we laugh about it, you know what I mean.'

'I think it's her [the Macmillan nurse's] cheerfulness...you can feel right down in the dumps, she'll come, she's bright, breezy, she'll come in and she'll sit and chat. We don't talk about me at all, we talk about all sorts of things...she always has a joke...it seems to brighten me up no end.'

The importance of familiarity is apparent in the following statement:

'I think the fact that it's the same doctor...and he knows what the problem is...you don't have the trauma of explaining what's wrong. I mean the only time you ever ask them is when you're feeling ill anyway, and to be honest, you don't want to go through all that.'

Another group of psychosocial statements appeared to emphasize the kindness and consideration shown in the attitude of the doctor or nurse. Here the professional may be described as caring, nice, kind or supportive:

'I think the caring, you know, caring herself [the district nurse] she cares about me.'

'I've never bothered [to ring the GP]. I always ring the Macmillan nurse because I know she cares.'

Some psychosocial statements stressed the emotional support provided for them or their family. Such statements were made only in connection with Macmillan nurse support:

'Yes, she's spoke to [my husband] once or twice. It was very hard for him to accept, but I think the Macmillan nurse has helped. And she still sees him now when she comes...they help the patient as well as the family and they really have here.'

Actions: Action statements emphasize the actions carried out by the health professional rather than psychosocial aspects such as communication or what the doctor or nurse is like. In some cases the distinc-

'Clinical statements about Macmillan nurses mentioned them as a source of advice and information about the illness and treatment.'

tion may be small, e.g. 'she is very kind' may carry the same meaning as 'she is very helpful'. Nevertheless, in one case the patient attributes a trait, kindness, to the doctor or nurse while in the other the patient dwells on what the health professional does.

Action statements could also be seen as having different facets. Some related to general helpfulness and expenditure of effort, i.e. the doctor or nurse's general willingness to help and put in an effort for the patient:

'...[the GP] is wonderful. Whatever I want if he possibly can get me he gets it, he gets it done there and then, not in a week or two. It's there and then with him.'

'Well they're [district nurses are] so helpful, aren't they? They're ever so good, they couldn't be better really.'

Other statements appeared to stress the health professional's role as a facilitator, i.e. their ability to secure access to hospital or to organize things:

'He's [the GP is] in control and can sort out the other people that are dealing with me as well.'

'...and [my wife] really said "I could just do with getting [my daughter] another morning in playgroup" sort of just talking in general to her [the Macmillan nurse]...the next day she rang up and said "I spoke to the Macmillan fund and I have arranged for her to go for an extra morning"...and you come off the phone and think "somebody does care".'

Some statements focused on accessibility, i.e. the doctor or nurse's willingness to be contacted or to visit:

'Because I can phone him [the GP] up any time I want to and he'll come over if I need him.'

'She's [the district nurse is] there when I need her. If I did need her I know she'd come. I think basically that's it, you know, and in herself she's a good nurse.'

Clinical: Clinical aspects of the doctor's or nurse's role were also mentioned in patients' positive evaluations. However, as the clinical roles of GPs, district nurses and Macmillan nurses are different, clinical statements appeared to have a different content depending on the profession. Statements about the GP could be seen to relate to medical expertise and the thoroughness of the GPs' approach:

'His medical expertise to start with...'

'...he's so good in his ways and regular and asks me too many questions, how I am you know, where I am and that, if I've got pains anywhere. Oh he's very good.'

Statements about the district nurse were related to how good the nursing care was:

Patient: 'Well, she got those bedsores better than I had.' Carer: 'Ah, they were terrible when you got home, weren't they? [The district nurse] was very good.' Patient: 'And she got those better and that's all really. And they brought me that cushion and the sheepskin.' Carer: 'And the bed...'

Clinical statements about Macmillan nurses mentioned them as a source of advice and information about the illness and treatment:

'Well, I liked her the first time, and the second time I understood her a little bit more, because she seems to know everything there is to know about cancer and explains it all to me. It was lovely to hear her and listen...It was marvellous.'

General: Some statements were positive without mentioning any particular aspect of the support provided. In the main these were just generally positive:

'Yes, they're [district nurses are] very [good] in everything really. I mean, we can't find no fault.'

In a few instances, patients bordered on waxing lyrical:

'He's [the GP is] just perfect. He's just, I can't explain it. He's just so good. What else can I say about him. He's excellent, he's perfect.'

Content of negative statements

There were 18 negative statements made about GP support. This small number of statements made any grouping into categories difficult. Three patients mentioned lack of attention, which may be seen as lack of willingness to put in an effort for the patient or lack of accessibility. For example, one patient complained:

'...going actually down to see the doctor, [my daughter] said my father's not getting the attention he should be getting, and things really moved from then onwards.'

Three patients mentioned clinical aspects, e.g. one criticized his GP for