

Valued aspects of primary palliative care: content analysis of bereaved carers' descriptions

Gunn E Grande, Morag C Farquhar, Stephen IG Barclay and Chris J Todd

SUMMARY

Background: Informal carers provide the bulk of palliative home care. They largely rely on general practitioners (GPs) and district nurses to support them in this role, yet little is known about what carers themselves consider important in this support.

Aim: To identify what informal carers valued in the palliative support provided by GPs and district nurses by using carers' own descriptions of such support.

Design of study: Retrospective interviews.

Setting: Primary care in Cambridgeshire.

Method: Semi-structured interviews with bereaved carers of 48 patients with cancer and 12 patients with non-cancer diagnoses. Content analysis of carers' evaluative descriptions of GP and district nurse support.

Results: The accessibility of the GP and district nurse emerged as the most important aspect of support. Enlistment of help from other agencies was also extensively mentioned, together with provision of equipment. Attitude or approach during interactions, and relationship with the professional were important, particularly regarding GP support, whereas support for the carer, information, and symptom control were mentioned less often. Data suggested that support was not as good for older patients (≥ 75 years), but this finding requires further investigation.

Conclusion: Results largely confirmed findings of previous, quantitative research and the importance of a patient-centred approach. What emerged most strongly, however, was the central importance of accessibility of support services for lay carers responsible for end-of-life home care. This mainly concerned GP and district nurse support, but accessibility of additional care and equipment were also important. In short, carers' main focus was the basic support that enabled them to sustain care in the home.

Keywords: palliative care; caregivers; primary health care; home nursing.

Introduction

MOST of the last year of life is spent at home.¹ This is the preferred place of care for the majority of patients and their informal carers, and also often the preferred place of death.²⁻⁴ The bulk of caregiving rests with informal carers⁵ and the likelihood of home death is closely associated with the availability of informal care support.⁶ In performing their caregiving role, carers first and foremost rely on support from the general practitioner (GP), who has the prime responsibility for the patient's medical care in the community.⁷ Additionally, a substantial part of home nursing towards the end of life rests with the district nursing team.^{5,8,9} GPs and district nurses are the gatekeepers of specialist and additional nursing care, and the services most likely to follow patients throughout their disease trajectory. Successful home care, therefore, depends considerably on carers receiving adequate support from their primary healthcare team.

Two studies have investigated variables associated with carer satisfaction in this context.^{10,11} Satisfaction with GP support was associated with visiting,^{10,11} ease of getting an appointment,¹¹ informing carers of the diagnosis,¹⁰ having time to listen and discuss matters, and efforts regarding symptom control.¹¹ Satisfaction with district nursing was associated with frequency of visits,^{10,11} contacting other agencies, giving help at night,¹⁰ and sufficient knowledge of the patient's condition and the care required.¹¹ However, these studies used structured questions, and the dimensions rated did not emerge from carers' own evaluations.

There has otherwise been little systematic investigation of determinants of carers' satisfaction with palliative support overall,¹⁰ and even less with GP and district nurse care. Some studies have suggested that GPs' willingness to visit,^{5,12} provide explanations, and arrange for other types of care¹² were valued. Reasons for dissatisfaction with nursing care included poor continuity of care and nurses being rushed;³ reasons for dissatisfaction with GPs and community services overall included professionals' attitudes, and a lack of unsolicited support and help with physical problems.¹³ Several studies reported carer dissatisfaction with information,^{3,5,14} and lack of symptom relief.^{3,5,13,14} Again, these studies predominantly used structured questions of satisfaction. Where open-ended responses were collected, the focus of the GP and district nurse analysis was on quantitative data.

What has been missing in these studies is the carers' own voice. In contrast, this study focused on what carers themselves chose to talk about when describing good and bad GP and district nursing support, to assess what was important in

GE Grande, lecturer in palliative care, School of Nursing, Midwifery & Health Visiting, University of Manchester; MC Farquhar, research associate, General Practice & Primary Care Research Unit; SIG Barclay, general practitioner and Macmillan clinical fellow, General Practice & Primary Care Research Unit, University of Cambridge; CJ Todd, professor of primary care and community health, School of Nursing, Midwifery & Health Visiting, University of Manchester, Manchester.

Address for correspondence

GE Grande, School of Nursing, Midwifery & Health Visiting, University of Manchester, Coupland III, Oxford Road, Manchester M13 9PL. E-mail: Gunn.Grande@man.ac.uk

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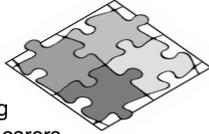
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HOW THIS FITS IN*What do we know?*

Thus far only quantitative research, using predefined scales, has considered what carers want from the primary healthcare team to support them in provision of end-of-life home care.

What does this paper add?

In contrast to past research this is a content analysis of lay carers' own evaluative descriptions of support and therefore represents carers' own voices. The accessibility of help emerged more clearly as a key concern to lay carers responsible for end-of-life home care compared with findings from previous quantitative studies. Nevertheless, the emerging themes also confirmed findings of past research.



such support from carers' viewpoints. As older age and non-cancer diagnoses often are associated with poorer access to palliative care,^{6,15} this study also assessed whether descriptions of generic care varied with patient age and diagnosis. Carer age was also considered as age is related to reported satisfaction with care.¹⁶

Method*Sample*

Participants were bereaved carers of patients referred to a Cambridge hospice-at-home service over 15 months.¹⁷ A key informal carer was identified for 214/249 (86%) of patients. Of these key informal carers, 123 (57%) agreed to participate in a semi-structured interview 6 months post-bereavement. To capture the potential range of participant views within the available material,¹⁸ a purposive, stratified sample of 60 interviews was selected to be representative of interview participants regarding patient and carer age, cancer versus non-cancer diagnoses, and use of oncology and palliative care services.

Interviews

Carers were contacted by letter and interviewed at home. Following a collection of brief demographic data, interviewees were asked to 'tell the story' from the first signs of the patient's illness until death. This formed the core of the interview. This was followed by structured questions regarding the adequacy of support from specific services provided by the National Health Service (NHS), and the overall adequacy of support in relation to personal care, night care, psychological and practical support, information and symptom control, details of any end-stage discharge or admissions, and views on place of death. The contents of the interview protocol were based on topic areas from the Regional Study of Care for the Dying⁵ and previous work by the authors.¹⁹ The structured questions formed part of an evaluation of local palliative care services.²⁰ The present analysis is based on the carers' story of the patient's illness and any further spontaneous comments. It does not include material from the structured questions.

Interviews were conducted by an academic researcher (29 interviews), GP (26 interviews), and a qualified nurse (5 interviews). All had previous palliative care research experience and an interest in home care. Although interviewer background may have influenced the data that emerged, the mixture of professional backgrounds should ensure that the overall data set did not have a systematic professional bias.²⁰ Interviews were tape-recorded and transcribed. Procedures for contact, consent, confidentiality, and study protocols were approved by Cambridge Local Research Ethics Committee.

Analysis

Content analysis was performed on all spontaneous descriptive, evaluative statements about GP and district nurse support. This represented 49% of the evaluative text on home support, the remaining 51% representing all other NHS services, social services, and private nursing care combined. The focus was on GP and district nursing care because of their central role in home support, as noted in the introduction. These were, furthermore, the services most prevalent in care provision and carers' evaluations (all patients had GP support, and all but three district nursing support).

Transcripts were analysed using QSR NUD*IST 4.²¹ Two researchers identified all spontaneous evaluative comments about GPs and district nurses, coding them as 'positive', 'negative', 'possibly positive', or 'possibly negative'. The researchers initially coded the same six transcripts separately, compared the coding and resolved any discrepancies. Next, four new transcripts were coded separately, yielding a Cohen's Kappa value of 0.853, which suggests almost perfect agreement,²² in identifying evaluative comments. Thereafter, the researchers each coded half of the remaining interview transcripts.

Content analysis using Ritchie and Spencer's framework approach²³ was used to analyse the data. This approach has been developed for applied qualitative research. Its data collection is often quite structured for qualitative research and analysis more informed by *a priori* reasoning and objectives.²⁴ As our aim was to achieve a simple, consistent and relatively neutral description of a data set that was quite large for text analysis, this method was considered more appropriate than more in-depth qualitative approaches. The full data set is covered in the analysis and results presented here.

Analysis involved initial familiarisation through review of all evaluative comments. Next, a thematic framework was designed through an iterative process. Statements describing something about health professionals' actions, attitude, characteristics, and manner were retained for further analysis. Those merely containing positive adjectives without further content (for example 'nice', 'wonderful', 'sweet') were considered uninformative for the present analysis and excluded.

Evaluative transcript segments were indexed according to the thematic framework,²³ and all text relating to each theme subsequently extracted. This allowed final category revision, assessment of the number of respondents raising each theme, and classification of each respondent's evaluation for each theme as positive or negative overall.²³

One researcher performed the content analysis; another assessed all text material for the resulting themes or categories, and reviewed the classification of evaluations into positive or negative. Differences in interpretation were discussed and resolved.

Results

Sample characteristics

Table 1 shows the demographic, clinical and service input variables for the interview sample. Of the 60 interviewees, 41 were spouses, 15 children, and the remaining four relatives or friends of the deceased. Nine patients had input from all palliative care services (Macmillan, Marie Curie and hospice); 17 patients had none.

Themes emerging from content analysis of carer evaluations

The themes emerging from the comments covered the following:

- accessibility of health professional,
- enlisting help from other agencies,
- provision of equipment and supplies,
- attitude or behaviour of health professional during interactions,
- relationship with health professional,
- support for carer,
- information regarding patient's illness, and
- symptom control.

Although the vast majority of comments underlying each theme were positive, approximately a fifth of carers made negative evaluations or provided a balance of praise and criticism. As such, each theme is derived both from positive and negative comments.

Accessibility. By far, the largest evaluative category reflected the accessibility of health professionals. Of the 60 carers, 46 mentioned the accessibility of the GP and 38 the accessibility of the district nurse. The majority of these were comments about health professionals' willingness to visit (43 carers regarding GPs; 31 regarding district nurses):

Carer: 'His doctor would pop in whenever she could' (Case 194.)

Carer: '[The GP] used to call, he used to make a point of calling'.

Interviewer: 'So he'd just come without you having to ask?'

Carer: 'Oh, yes' (Case 232.)

'Well, I think maybe if they [GPs] had come out a little more often they might have ... with a doctor's visit, they don't always see the actual, well, in [patient's] case, the agitation, I mean sometimes he was so restless he was scratching about in the bed and struggling to get out

Table 1. Demographic, clinical and service input variables for interview sample (n = 60).

Variable	Patient	Carer
Median age in years (quartiles)	74.8 (64.0–82.0)	60.6 (53.0–69.9)
Male sex (n [%])	31 (52)	22 (37)
Diagnosis (n [%])		
Cancer	48 (80)	
Non-cancer	12 (20)	
Oncology treatment (n [%])		
Yes	25 (42)	
No	35 (58)	
Macmillan nurse (n [%])		
Yes	25 (42)	
No	35 (58)	
Marie Curie nurse (n [%])		
Yes	26 (43)	
No	34 (57)	
Inpatient hospice (n [%])		
Yes	23 (38)	
No	37 (62)	
Any palliative input (n [%])		
Yes	43 (72)	
No	17 (28)	

and that sort of thing. The doctors didn't see that because perhaps they could come at a time when he was resting more ... I think they didn't perhaps see just what the problems were in some ways, but they were very good. I'm not making complaints.' (Case 353.)

'When I needed [the district nurses], they came every day. Towards, you know, the last 3 or 4 days they came every day, sometimes twice.' (Case 269.)

Some carers also noted the ease or difficulty with which the doctor or nurse could be contacted (15 regarding GPs; six regarding district nurses):

'To me what was very helpful was her GP because I knew I could pick the phone up and ring him anytime. He did say 'don't hesitate to ring' which was very, very helpful — knowing I could do that.' (Case 360.)

'[It was] difficult to get in touch with [the district nurses]. We had to either ring the surgery up or ring the place at [x] where their offices are and some days they were not sure where they were, they couldn't get in touch with them either, or they had 'just gone' and they did not know where they would be within the next hour or so.' (Case 298.)

Included under this theme were also a few instances of delayed arrival (four instances) or unpredictable arrival (two) once a home visit had been promised; difficulties in getting hold of one's own doctor versus a locum (four); and the willingness of the GP or district nurse to stay beyond the designated time when problems developed (three). Each carer may have commented on more than one aspect.

Several comments within this theme showed professionals going beyond their remit to make themselves accessible, that is, providing their home telephone number, showing willingness to be contacted or to visit when not on duty, and staying beyond the hours of duty (14 regarding GPs; five regarding district nurses):

'[The GP] was just really good, and the last weekend ... he wasn't on duty, but he came out, he gave me his home phone number and that I thought was brilliant.' (Case 218.)

'... I rang the doctor at home because I'd got his unlisted number and his wife answered the phone, and I said that [the patient] wasn't very well and he wanted to see the doctor, and he was at the camp at [x], so she said 'Well, don't worry ... I'll get him to ring you'. And he didn't ring me, he turned up.' (Case 233.)

Enlisting help from other agencies. Another important category concerned professionals' efforts to enlist or ensure appropriate support or action from other agencies. Twenty-two carers mentioned the GP in this respect, and 21 the district nurse. This mainly related to recruitment of other community support (14 GPs; 17 district nurses):

'When Mum was becoming ill [the GP] put us onto all the appropriate people that she needed' (Case 199.)

'[The district nurse] was absolutely terrific, and she enrolled anybody and everything that she felt that I needed.' (Case 236.)

'[The district nurse] was really on the ball, you know. Once she thought that mum needed help in any way, she organised it. She was fantastic.' (Case 284.)

Eight carers also commented on hospice involvement being ensured for admission and/or specialist support, and five on the GP putting in effort to obtain hospital appointments or tests:

'... my doctor rang [the hospice] and said, "You have got to find a bed, she must have a rest", which they did.' (Case 201.)

'... it had got worse and worse and worse ... and the GP said he'd phoned [the hospital consultant] three times in one day and said "You must see [the patient], she's really deteriorating" and after much humming and aahing and "Do you really think this is necessary?" and so on, and my conversations with a rather snooty secretary, I managed to get an appointment ...' (Case 354.)

Provision of equipment and supplies. Twenty-five carers mentioned district nursing efforts to ensure availability of equipment and supplies, including the supply of medicines (three instances). Three carers mentioned the GP regarding supply

of medicines and two regarding ensuring financial help:

'We got great support from the district nurse ... when we were running out of supplies she would steal supplies from somewhere. We got through a lot of pads and waterproof sheets, those papery things that you put on the bed and we got through loads of supplies and they always kept turning up ... if we were getting low on something it turned up from somewhere. How it turned up I've no idea. I think they were breaking into warehouses and things [laughter]. That was great.' (Case 400.)

'... if the doctor wanted to give [the patient] some other form of pill or something like that, I didn't have to bother to go and get the damn thing. Either the district nurse brought it or the next time the doctor came, she brought it ...' (Case 225.)

Attitude or behaviour during interactions. Twenty carers commented on GP behaviour or attitude during interactions, and four regarding district nurses. Attitude (for example, being kind, caring, sensitive, sympathetic) was mentioned by 12 carers regarding the GP and by one carer regarding the nurse:

'I just couldn't believe a doctor could be sort of so caring.' (Case 312.)

GPs' attitudes towards unconscious patients in particular appeared to make carers pleased or upset (five instances):

'[The GP] was very, very good and he absolutely refused to sort of say anything in front of [unconscious patient]. Every time ... he came downstairs and talked to us about it which I thought was very sensitive, very, very good ... I'm sure [the patient] could understand.' (Case 370.)

'He was in and out of consciousness all the time, you see? ... and that was when we could have willingly strangled that doctor ... and she came in. So she said "What's the trouble?" So we told her. She came round here. She stood in front of him. She said "We know he's got cancer and know he's not going to get any better and there's nothing we can do for him." She didn't know he couldn't hear what was being said, 'cause he could.' (Case 394.)

Behaviour (for example spending time with the patient, talking, listening, engaging in joint problem solving) was noted by 10 carers in relation to the GP, and by three carers in relation to the district nurse:

'The GP was always prepared to listen ...' (Case 207.)

'Whatever doctor came, whatever time during the day or night the doctors came, they had time. It was like they didn't have to go to anyone else.' (Case 294.)

Relationship with health professional. Fourteen carers mentioned the relationship with the GP, six with the district nurse. Six carers noted the patient's personal liking for, or trust in, the GP, and two the nurse:

'... she liked [the GP] and respected him very much and there was a very good, trusting relationship.' (Case 387.)

Common ground between the patient and professional beyond the clinical interchange was described for GPs in three cases, and the district nurse in one. This included interests and same gender rapport:

'Being a lady doctor they had a lot in common, roughly the same age, you know, women and women. You know what I mean ... perhaps it was woman to woman and women understand women better than anybody else.' (Case 250.)

Seven carers mentioned the importance of familiarity with the GP, and three with the district nurse — particularly when a problem occurred:

'... but Mum, she just had too much of different people [coming in]. She knew the district nurse from the practice, so that was fine.' (Case 256.)

'... you felt you didn't really want a doctor who you didn't know coming in at that point.' (Case 455.)

Support for carer. Nine carers noted support provided for themselves from the GP, four from the district nurse. These statements indicated that the professional specifically talked to the carer and checked how he/she was doing:

'[The GPs] were very, very good and they were good to me as well after they'd been talking to my husband, you know, they used to come and sit here and talk to me as well.' (Case 376.)

'And naturally the doctor kept on coming, but he couldn't do anything, just came to see if I was alright, that's all I reckon [laughter]' (Case 409.)

Information about the patient's illness. Seven carers commented spontaneously on the information given by the GP about the patient's illness. Four felt they had not had enough information, two in particular because of their caregiver status; three praised the GP. Two carers also praised the information given to them by the district nurse:

'I said to [the GP] "well can you tell me about [the patient]?"... and he said "he's my patient, no I can't talk to you about him"... and so it was like hitting your head against a brick wall ...' (Case 215.)

'[The district nurse said] "Is there anything you're worried about?" and I said to her, "Yes I am. I want to know what I've got to look out for." I said "I know we can't stop

it but if suddenly something happens and you're not expecting it, it's much more frightening than if I know what might happen" and so she told me the things that might happen ... I said "Well thank you ... now I know how to cope".' (Case 455.)

Symptom control. Eight carers made spontaneous evaluative comments about symptom control by the GP. These mentioned failure to control nausea, pain, or constipation; three commented on instances of inducing unwanted coma or hallucinations through drugs, and two mentioned instances of the desire for more sedation to control anxiety or restlessness. One carer felt nurses were very slow to respond to the patient's inability to pass urine:

'... the frustration there was because constipation seems such a straightforward thing ... she couldn't understand, we couldn't understand why it couldn't be sorted out.' (Case 387.)

'A doctor came ... not her normal doctor, and prescribed ... extra morphine tablets or upped the morphine and after she took those she was sort of zonked out; she was nowhere, absolutely zonked. We thought, not knowing, I think ... "Is this the time, sort of thing?" ... she was completely gone.' (Case 237.)

Miscellaneous statements. Of the remaining statements, four carers praised the district nurses' competence. Competence was, however, questioned in three instances (one GP and two district nurses). Six carers commented on GPs' speed of specialist referral in response to early symptoms: one positively, five negatively. Two carers praised arrangements for follow-up by a named GP while the patient's regular GP was away and two commented on coordination of services: one positively, one negatively.

Introduction of specialist equipment into primary care had been delayed according to two carers. In contrast, one carer praised the GP's proactive approach to the introduction of specialist equipment. One district nurse team was praised for grasping an early opportunity to become familiar with the patient, one criticised for failing to do so. Aside from these, no other aspect of care was mentioned by more than one carer.

Relationship between themes and background variables. The above themes were considered in relation to diagnosis, patient age, and carer age. There were some differences in theme content relating to patient age. When evaluating accessibility, only one in 10 carers of patients under 75 years of age reported poor GP accessibility and a third described exceptional accessibility (for example, giving home phone number or visiting off duty). In contrast, a third of carers of patients aged 75 years and above reported poor GP accessibility and only one in 10 reported exceptional accessibility. When evaluating the provision of equipment or supplies, none of the carers of 13 patients under the age of 75 years criticised district nurse efforts, compared with a third of the carers of patients aged 75 and above. There was no evidence that this pattern could be attributed

to cancer diagnosis, and no other patterns emerged for the background variables considered.

Discussion

Summary of main findings

Accessibility was by far the most commonly mentioned aspect in carers' evaluations of GPs and district nurses. Enlistment of support from other agencies was also important, and mentioned by a substantial proportion of carers in relation to both professions. Many carers commented on the ability to ensure equipment and supplies, mainly in relation to district nurse support; behaviour or attitude during interactions was often mentioned in relation to GPs, but less often commented on regarding district nurses.

The relationship with the health professional was also mentioned by several participants, regarding both GPs and district nurses. Fewer, but still a noteworthy number of, carers mentioned support for themselves, information about the patient's illness and symptom control. There was some indication that elderly patients may experience poorer accessibility and provision of equipment. Thus, this explorative analysis may suggest that primary care support was perceived to be less good for elderly patients. Given the present methodology, this should mainly be considered a hypothesis warranting further research. It should be noted, however, that existing studies may suggest there is age bias in support.^{5,9,25}

Correspondence with existing literature

Although considerable dissatisfaction with information^{3,5,10,12,14} and symptom control^{3,5,13,14,26} have been identified in previous palliative quantitative research, these topics featured less in carers' spontaneous comments than many other aspects of care. Although symptom control remains core to palliative care, carers' concerns in this context appeared to be expressed through other themes, such as accessibility when there was a problem, recruitment of specialist help, provision of equipment (for example, to prevent bedsores), or having a familiar doctor attend at a time of crisis. Information about diagnosis and prognosis may be sought in hospital and specialist contexts, rather than from the primary healthcare team. Furthermore, there may be some ambivalence about information regarding the illness trajectory; carers may need sufficient information to be prepared, but not so much as to be overwhelmed.

Findings confirm the importance of a patient-centred approach,²⁷⁻²⁸ that is, one that focuses on empathy and sensitivity, listening, giving time, communicating, engaging in joint problem solving, building rapport, and ensuring continuity. Past research has shown that carers value these aspects;^{11,13} patients themselves tend to derive more satisfaction from patient-centred consultations,²⁹ and value continuity, particularly under serious illness.³⁰ Although continuity has been found to be difficult to achieve in out-of-hours palliative primary care,³¹⁻³² it appears that dedicated health professionals in the present study attempted to address this.

The most important component of care to emerge, however, was accessibility — mainly that of primary care

professionals, but also of supplementary services and equipment. The value of accessibility to carers is confirmed by previous quantitative research,^{5,10-12} but its prime importance becomes more clear within the context of carers' spontaneous comments. This contrasts with patients' views of valued aspects of GP and district nurse support in an earlier qualitative study.³³ Patients predominantly focused on psychosocial components of support, inherent to a patient-centred approach,²⁷⁻²⁸ but less so on accessibility of professionals or mustering help from other sources.

Strengths and limitations

Participants were carers of patients referred to a hospice-at-home service in a semi-rural area, with a relatively stable population and good service provision. Hospice-at-home patients may be unrepresentative of the local palliative population³⁴ and, as such, the data presented here may not be representative of carer experiences as a whole. However, emergent themes appear to reflect fundamental carer concerns in the home setting, and correspond with issues highlighted in past research. Results are based on carers' own spontaneous accounts, which increases their validity.

Researchers with different backgrounds participated both in data collection and analysis, thus ensuring that results were not biased towards a single professional viewpoint.²⁰ All were, however, interested in palliative home care, which may have made interpretations more similar to previous research. However, this also aided an understanding of respondents' concerns and their context.

Given the study aims and the size of the data set, simple, descriptive analysis was employed, taking accounts at face value. Such a 'problem-oriented' approach is common in health services research, where problems are usually predefined and an assessment of service delivery is sought.³⁵ However, future research would benefit from in-depth qualitative analysis to understand how interview context, perceptions of appropriate carer role, and self-presentation influence accounts.³⁵ Perceptions of appropriate carer role and self-presentation may explain why, for example, accounts were mainly positive, and reference to carers' own support needs few.

Progress beyond simple description would also be aided by drawing on sociological and psychological theory to understand the social and cultural context of death,³⁶ and the factors underlying stress and coping.³⁷ Integration of research findings into a common theoretical framework is necessary to progress our understanding of why, and under which circumstances, certain components of support are effective.

Clinical implications

When carers described what is good or bad about the support from GPs and district nurses, they mainly focused on the basic support that enabled them to cope with caring for the patient at home. The key issue appeared to be accessibility — mainly the accessibility of primary care professionals, but also of supplementary services and of equipment. Such accessibility becomes more acute in the

community compared with inpatient care, where help and equipment are more readily to hand. At home lay carers will often be on their own, looking after a very ill person for most of the day and night, with all the uncertainty and anxiety that this entails.

A reliably quick response in times of crisis, regular visits for monitoring, appropriate and effective recruitment of home care with resort to respite and specialist involvement when necessary, and the ability to obtain the tools to manage the problems of everyday life, are essential in making sustained home care feasible for carers. Although important for all home care, these concerns are more acute under the anxiety and strain surrounding impending death. Likewise, a patient-centred approach may be particularly valued in this context.

Good accessibility raises concerns about workload, and GPs and district nurses already feel they lack resources to support carers.³⁸ However, if it can empower carers, allay their anxieties, and prevent budding problems from escalating into major crises, accessibility may imply a redistribution of work rather than an overall increase.

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