Palliative care: community nurses’ perceptions of quality

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Abstract
Objectives—To identify community nurses’ perceptions of quality care provision for patients requiring palliative care. Design—Semi-structured interviews were conducted with community nurses working within the district nursing service. An adaptation of Flanagan’s critical incident technique was employed to elicit factors associated with high or poor quality palliative care. Interviews were tape recorded and transcribed. Data were analysed using thematic content analysis, recurrent themes being agreed by the research team.
Setting—One community healthcare trust.
Subjects—62 members of the district nursing team (grades B–H).
Results—Respondents recounted the context in which high quality palliative care could be provided, the actions required, and the indicators that suggested the desired level of care had been achieved. Key factors identified were: the early referral of patients to the district nursing service, family circumstances, the availability of time, the accessibility of services and equipment, and the relationship with other healthcare professionals and informal carers. There was a general view that a positive outcome had been achieved when patients retained control over their circumstances and died a peaceful death, in the place of their choice, supported by their family.
Conclusions—Community nurses were able to articulate clearly the essential components of high quality care. Whilst these factors do not represent a comprehensive list, they are put forward as a useful starting point for standard setting and subsequent audit.

While some recent studies have been undertaken with regard to the work of community nurses and patients requiring palliative care, these are generally on a small scale and are dependent on quantitative methods or are limited in perspective. For example, while the views of community nurses are represented, those of community nurses of other grades working within the district nursing service have not been explored. Much of the published literature predates the major changes that have impacted on the work of community nurses, although useful summaries of the “state of play” in palliative care prior to these changes have been published. Perhaps the most radical changes that have taken place can be attributed to the Community Care Act enacted in 1993 which resulted in the transfer of some nursing work to social services. Notwithstanding the debate surrounding this division, the nature of the work of community nurses has changed. An outline of palliative care services in the UK is shown in box 2.

In addition to the division between healthcare workers and social services, other recent changes have affected the context in which community nurses provide care. The emphasis on providing care in a patient’s home and the early discharge of patients from hospital who are more sick has placed increasing pressures on the district nursing service. The introduction of the market economy into the NHS, with a purchaser/provider split, has altered the way in which community nurses work. Although

Key messages
• Community nurses were able to identify many factors that contribute to the provision of high quality palliative care for patients. Important components included: (a) the early referral of patients to the district nursing service; (b) family circumstances that support the care of patients in their own home; (c) sufficient time to meet more than the physical aspects of patient care; (d) availability of equipment and support services.
• Community nurses invested a considerable amount of time in the formation of positive relationships with patients, families, healthcare professionals, and informal carers to facilitate the provision of good care.
• The general view was that a positive outcome had been achieved if patients retained control over their circumstances and had a peaceful death in the place of their choice.
A community trust is the employing authority for district nursing services within a given location.

The district nursing service provides care for patients in a home setting and includes the following personnel:
- District nurse: a registered nurse with an additional qualification in district nursing
- Community nurse: a registered nurse working within the district nursing service who does not possess a district nursing qualification
- Nursing auxiliary: a care worker who does not possess a nursing qualification but works in a supportive role to the nursing staff under the supervision of a registered nurse.

Clinical nursing related posts range from grade B (nursing auxiliary) to grade I (the most senior level for registered nurses working in a clinical setting).

The term “community nurse” is used in this paper to include all of the above members of the district nursing team.

Box 1 District nursing services.

Changes in government policy have produced a shift towards more collaborative methods of working, it remains imperative for healthcare workers to demonstrate their value and the uniqueness of their role. This is set to continue, given the establishment of primary care groups who will ultimately be responsible for defining and organising service delivery in a community setting.

The last decade has seen an expansion in the services involved in the provision of palliative care, not least the Macmillan nursing service (box 2). This, coupled with developments in the hospice movement where care provision is now more flexible, has increased the number of available services on which the community nurse is able to draw.

There are no recent studies that seek explicitly the views of community nurses regarding the factors that facilitate the provision of high quality palliative care. The need for the district nursing service to provide clear indicators of the quality of service they provide has been given increasing impetus in the current climate.6 The recent Audit Commission report7 on district nursing services identified a need for “robust methods of measuring standards of clinical quality (in terms of processes and health outcomes). Clinical audit is a key quality improvement process which enables practitioners to examine their practices against standards based on evidence of good practice from research or consensus.”

The lack of audit activity may be related in part to the absence of good practice standards. A re-examination of the nursing role in the provision of high quality care is therefore timely as this goes some way towards obtaining consensus regarding the required evidence of good practice.

The findings presented here form part of a wider study with a remit to identify community nurses’ perceptions and definitions of quality care provision for three patient groups—those newly discharged from hospital, those with chronic wounds, and those requiring palliative care. This paper presents respondents’ views regarding the provision of palliative care.

Box 2 Palliative care services in the UK.

Methods

Population and sample

The study was conducted in three localities that make up one community health care trust. Interviews were conducted with 62 staff (grades B–H) between March and June 1998. A senior nurse manager randomly selected community nurses for interview from the staff database as access to these data is restricted to personnel employed by the community trust. Randomisation was effected by the use of computer generated random numbers. Respondents were informed of the study by a letter from the research team and were invited to participate in interviews. All participants were assured of anonymity. The wishes of community nurses who did not want to take part in the study or have the interview tape recorded were respected.

Study design

A critical incident approach8 was employed to elicit factors associated with the provision of high quality or poor care. The particular strength of this technique is that it seeks information on both the positive and negative aspects of care provision from those most closely involved—in this instance, community nurses. The specific questions were:

“Can you tell me about a recent occasion on which you had contact with a patient requiring palliative care which you think went particularly well?”

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Palliative care: community nurses’ perceptions of quality

153

College of Nursing.

standard setting system developed by the Royal
employed by the nursing profession in defini-
are analogous with the Donabedian structure,
desired level of care had been achieved. These
care, and the indicators that suggested that the
actions required to provide good quality
which care of a high quality could be provided,
Respondents spoke in terms of the context in
Results

DATA COLLECTION AND ANALYSIS
Interviews lasted between half an hour and one
and were conducted by a team of four
researchers. Respondents recounted situations
in which they had been able to provide a good
service for patients requiring palliative care and
situations in which this had not been possible.
Whilst it is acknowledged that the terms “pal-
liative care” and “terminal care” have specific
definitions, respondents tended to use both
terms interchangeably and this is reflected in
the text. Most of the interviews were tape
recorded but in four cases notes were taken as
the interviewee did not wish to be recorded.
Interviews were transcribed prior to data
analysis. In total, the respondents described
approximately 120 incidents relating to palla-
tive care.
Copies of the full transcripts were circulated
to each member of the research team. The
transcripts were divided into case types (wound
care, hospital discharges, palliative care); the
data presented here relate only to palliative
care. The transcripts were analysed inductively
with each researcher undertaking preliminary
analysis and identification of key themes for
their own interview data. Subsequent meetings
of the research team were used to agree coding
categories for factors that contributed to or
prohibited the provision of high quality care.
These coding categories were then applied to
the full data set. Given the impetus for the
study was the identification of factors that
contribute to the provision of high quality care
that could be used as quality indicators in subse-
quent audit, data analysis and presentation
focused on areas in which there was broad
consensus amongst respondents.

Results
Respondents spoke in terms of the context in
which care of a high quality could be provided,
the actions required to provide good quality
care, and the indicators that suggested that the
desired level of care had been achieved. These
are analogous with the Donabedian structure,
process, and outcome categories commonly
employed by the nursing profession in defini-
tions of quality—for example, the dynamic
standard setting system developed by the Royal
College of Nursing. The findings are summa-
rised in a “structure/process/outcome” format
in table 1 and are detailed below.

STRUCTURES
Early referral of patients
The early referral of patients to the district
nursing service was viewed as essential as it
facilitated contact with the family at a critical
stage and ensured that the community nurse
could make an assessment of the patient’s and
family’s needs and make suggestions as to the
kind of support they might wish to receive:
“I like to get to know them while they are
reasonably well really and build up a relationship
then with them. And when they do become
terminal ill they tend to accept more and trust you
and see that they do know you and you do know
what you’re doing.”
Situations in which the district nursing serv-
ice had not had early contact with the patient
could present difficulties as this created a “cri-
sis” situation in which the provision of ideal
care was not always achievable:
“I much prefer to be involved very early on, right
from diagnosis. Now (some GPs) tend to wait until
they’ve got a problem, either it’s pain control or the
patient is vomiting, and they’re not getting on top of
the vomiting or the pain control or whatever aids
and adaptations to the house, so you are brought in
a lot later, which I think is a problem.”

Family circumstances
Family circumstances played a central role.
Respondents used terms such as a “good
home” to work in. Generally, this was a home
in which the family was actively involved in
care, receptive to the community nurse and
other services, and willing to adapt the home to
meet the patient’s needs:
“It was lucky with this particular family that
they had expressed a wish to be involved where pos-
sible. I mean you could tell really as soon as you
went into the home that they would, whether it was
little bits of meals that they were making for—or
they had even attempted to wash and change a
night dress, just personal things and attending to her
hair.”
Relationships within the family also played a
notable role. Patients who lived with or had
support from family members were deemed
more likely to receive better care. This related
in part to practical matters such as someone
being there who could help the patient with
their physical needs or provide services such as
cooking meals. It also contributed to patients’
general well being by providing emotional sup-
port which enabled patients to stay at home in
familiar surroundings if this was their wish.
Conversely, difficulties were encountered if
there appeared to be some friction within the
family or if the family was hostile to the district
nursing and other services. Care provision was
also problematic in situations in which the
patient or family appeared to be unaware of the
diagnosis or prognosis, not least because of the
implications with regard to drawing in other
support services.
Caring for patients was also more difficult if
relatives were willing but unable to provide
care, or felt unable to cope. Respondents made
reference to family members who lived some
distance from the patient or had other com-
mittments. In “crisis” situations patients were
<table>
<thead>
<tr>
<th>Structures</th>
<th>Processes</th>
<th>Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beds/mattresses/hoists/syringe drivers</td>
<td>Relationship with the patient and family</td>
<td>Patients/family and the district nursing team</td>
</tr>
<tr>
<td>Access to support services e.g.</td>
<td>• establishes early contact with the patient/family to assess their needs/expectations</td>
<td>• receives care in the place of their choice</td>
</tr>
<tr>
<td>Access to equipment e.g.</td>
<td>• provides continuity of care for the patient by limiting the number of district nursing staff caring for the patient</td>
<td>• retains some control over their circumstances</td>
</tr>
<tr>
<td>Hospice</td>
<td>• plans and coordinates care for patient/family</td>
<td>• maintains some quality of life</td>
</tr>
<tr>
<td>Macmillan nurses</td>
<td>• ensures the patient/family are aware of services available to them</td>
<td>• has their symptoms controlled to a level which is acceptable to them</td>
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<tr>
<td>Marie Curie services</td>
<td>• provides support for both the family and the patient</td>
<td>• dies in the place of their choice</td>
</tr>
<tr>
<td>Supportive and accessible GP</td>
<td>• provides care in a way which is consistent with the patient’s/family’s wishes</td>
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</tbody>
</table>
Palliative care: community nurses’ perceptions of quality

155

that they had positive working relationships with the personnel involved.

main this was welcomed although some caregivers considered themselves to have expertise in palliative care, the Macmillan nurses were used as a resource for advice and support for myself and for family members. In many instances, the Macmillan service was viewed as the psychological support mainstay, complemented by the community nurse. While many support networks were in place, their availability was, nonetheless, dictated by the demands being placed on them at any one time:

“Sometimes people need, maybe need a bit more help at home and you’ve not been able to necessarily offer it...I mean if somebody is really poorly then the last few days of their life, sometimes we’ve had a sitter in every night, and that has been OK. But you know there are occasions when maybe there’s a lot of demand on the service and you can’t always offer that, so that’s a bit sad.”

Overall, community nurses valued the Macmillan service in terms of the support they could provide for patients and as a resource for staff. The focus of the work of Macmillan nurses was viewed as the psychological support of patients, an aspect of care interviewees did not always feel able to provide because of the demands placed on their time:

“I feel that, you know, I can counsel people but sometimes you’ve not always got the time when you’ve opened up...so I do feel that like the Macmillan service, I use them an awful lot, I find them invaluable because I have had experience, myself personally with them, so that, you know, I would use them for advice and support for myself and for the families.”

Whilst many of the nurses interviewed considered themselves to have expertise in palliative care, the Macmillan nurses were used as a source of specialist advice or support. In the main this was welcomed although some respondents alluded to the fact that this could lead to some duplication of effort or lack of continuity of care because of the number of personnel involved.

GP services: The role of the GP was critical in determining how successfully the patient could be cared for. Many respondents noted that they had positive working relationships with the GPs although, as already noted, difficulties could be encountered if patients were not referred at an early stage. In general, GPs did not appear to be routinely involved in the day to day care of patients and were only likely to be contacted by the district nursing service when the patient required some form of symptom control, most commonly analgesia. Problems emerged when the GP’s view of the need for symptom control differed from that of either the nurse or the patient. A number of respondents recalled incidents in which this had led to patients appearing to be distressed or in pain:

“We felt this man should have a syringe driver to control his pain...we wanted the syringe driver mainly for some sort of sedation that would settle this man, allow him to die peacefully, and she (his wife) would be—have a last couple of days with him and remember something peaceful rather than the constant tussle she was having trying to keep this man in bed. The GP didn’t want to put the syringe driver up, for whatever reason, she kept saying he didn’t need it...So we ended up—on the day the man died—he finally said alright, you can put a syringe driver in...we finally got the syringe driver set up at something like 7 o’clock in the evening and he died in the early hours of the following morning and to me that wasn’t acceptable.”

PROCESSES

In addition to structural considerations, the processes of care provision that contributed to high quality care were apparent from the interviews with community nurses. These processes hinged on the development of a positive relationship with the patient, the family, other healthcare professionals, and formal carers.

Relationship with the patient and family

It was considered to be good practice to ensure continuity of care for the patient by keeping the number of community nurses involved to a minimum. This enabled staff to establish a good rapport with the family and aided the establishment of trust between the nurse and the family. This relationship aided the planning and provision of care and helped to ensure that care provided was consistent with the wishes of the patient and family. Indeed, a great deal of emphasis was placed on caring for the family as much as the patient by all grades of staff:

“I think just generally getting on with the whole family rather than just seeing to the patient then I’d go and have a chat with the carers and see how they’re coping because obviously it affects them as much. You know, not just going into the patient—it’s the family as a whole. I mean that was it, a good relationship.”

Anything which could be done to alleviate the distress of carers was valued. In some cases this necessitated staff “managing the environment” by contriving situations in which they could speak to a family member when the patient was not present. Care of the family was often extended beyond the time of the death in the form of attendance at the patient’s funeral and bereavement visits. 
Relationship with other healthcare professionals and formal carers

The relationship in place with other healthcare providers and formal carers influenced the provision of care. If a good relationship between the district nursing service and other agencies could be maintained, this made it easier to introduce support from these services when it was deemed appropriate. In this respect, the district nursing service appeared to act as the “lynch pin” or “gatekeeper” to services provided by other professionals. This was explicitly stated by a number of respondents who viewed part of their remit to be a coordinating role, assessing the need for other services and introducing these when considered necessary. The importance of good communication leading to a successful multidisciplinary approach was stressed:

“It was nice how all the services pulled together. And within a day we had all the equipment that we needed. The rise and fall bed, hoist, everything in the house. We had hospice at home team in offering sits. We had Marie Curie involved. We also had rapid response involved. This all took over a period of maybe a fortnight before he died but everybody worked really very closely together and it worked very well...good coordination, good communication. Everybody let each other know what they could do, what input they could provide, and it was all coordinated really from the district nursing service.”

OUTCOMES

The primary function of palliative care was to maintain the patient’s quality of life up to the time of their death. Patients who retained control over their circumstances were cited as positive examples and death was seen as more acceptable if patients were pain free, comfortable, and had their dignity retained. Ultimately, the desired outcome was a patient who died a peaceful death, in the place of their choice, supported by their family. Alongside this, families who felt supported and able to cope when caring for a dying relative were also given as examples of cases where good care had been achieved. Other indicators related to the feelings of staff. It was not uncommon for respondents to cite cases where they felt they had “done a good job” or cared for someone as they would wish themselves to be cared for. These sentiments are expressed in the following quotation, which encapsulates many of the factors indicative of high quality care:

“We were able to provide a very high standard of care I feel—and his family do—and enabled this man to stay at home doing exactly what, you know, he died where he wanted to be. He was pain free and dignified and we achieved that by working with the hospice. Any voluntary agencies I could muster round any support, we used everybody. We had a truly multidisciplinary approach to this man’s care. And it worked very very well. His wife was very supportive and of course the patient was, you know. It was nice; it was a privilege to look after that man because everything was set up really well. It was a nice home to work in. Nice in the sense that his wife was willing to accept people in her home. Because it’s difficult isn’t it when you know it’s your home and you’ve got all these people and I think it was—I’m blowing my own trumpet really—good planning. It was I felt as if I did a good job in planning and anticipating well what they might need, and it paid off.”

Discussion

Community nurses were able to articulate clearly the essential components of high quality palliative care and the circumstances that militate against this ideal. Whilst a number of key factors were identified, forming a good rapport with the family was central to the provision of effective care. The importance of the bond between the patient and nurse has been acknowledged elsewhere.14 19 Williams19 found that therapeutically effective care was more likely to occur in positive relationships characterised by the establishment of rapport and trust. In this respect the care needs of patients were more easily met if the nurse knew the patient. The findings of this study extend this concept to the community setting where a collaborative working relationship with the family as a whole acted as a precursor to high quality care.

Given the pivotal role played by establishing a strong relationship, the early referral of patients to the district nursing service was of primary importance. Occasions on which this did not occur could prove problematic as the nurse was intervening in a crisis situation in the absence of prior knowledge of the patient or family. Despite the fundamental nature of this requirement, respondents commonly described unsatisfactory care in the context of the late referral of patients. In this respect the study mirrors the findings of others where late referrals were highlighted as a source of dissatisfaction.4 6 10 20–21 Goodman et al10 surmised that late referrals to the service and the emphasis on the practical role of community nurses in patient care indicate that the contribution of the district nursing service is not always recognised by those who are involved in referral, notably GPs. The recent Audit Commission report14 highlights the importance of clarifying the referral criteria to the district nursing service, since currently one in 10 referrals are inappropriate and other patients are not referred at all.

This study has shown that the early involvement of the district nursing service facilitates patient care by enabling the community nurse to act as key worker in orchestrating the introduction of other services. Providing care in a supportive environment, preferably one in which there is open awareness of the patient’s diagnosis, reduced the dependence on support services and enabled patients to remain at home if this was their wish. There was a widely held perception that most patients would prefer to die at home and care was seen to have failed if this was not achieved. A good working relationship with the GP was deemed as essential if inappropriate admission to hospital was to be averted.

The relationship with the GP was critical in three key respects: (1) in the early referral of patients to the district nursing service; (2) in...
maintaining contact with the community nurses to avoid the unnecessary admission of patients to an institutionalised setting; and (3) in symptom control. The role of Macmillan nurses was also valued in terms of the expertise and support they could provide.

Spending time with patients requiring palliative care was highly valued by community nurses, sometimes at the expense of other aspects of their work. Palliative care was clearly an area in which community nurses derived a great deal of job satisfaction. Nurses often described aspects of care that could be viewed as being “over and above” that required to meet the patient’s immediate nursing needs. Others have identified this phenomenon—for example, Williams noted that additional nursing care which went “over and beyond” usual care epitomised high quality care and that these “extras” are the first things to go when time is limited.

Whilst palliative care is an area of work which community nurses have always valued, it has achieved greater significance since the transfer of some nursing duties to social care services. Palliative care is one area in which all aspects of care may be provided by the district nursing service and where the care provided is truly holistic. It is seen to legitimise aspects of care which would, in other circumstances, be defined as social care. Griffiths also describes the phenomenon in which terminal illness sanctions activities that might otherwise be described as illegitimate and permits nurses to “take on their more traditional pre reforms role of the total care of a person and their family in their own home”. In her study she suggests that this is an area of care which has not yet been passed on to others. In this respect the findings reported by Griffiths differ from the comments made by some of the respondents in this study who indicated that the notion of holistic care provision was sometimes problematic, even for patients who were terminally ill. The firmer establishment of the division between health care and social care may explain this.

It is worthy of note that, despite the changes over the last decade, the factors associated with attaining high quality palliative care reveal a remarkable similarity to those described in earlier studies. Seale, in a major study of the role of community nurses and the care of the dying, drew on accounts by relatives and nurses to describe the adequacy of care. This study replicated a previous investigation in 1969. Seale’s study highlighted tensions between the community nurses and GPs in areas such as pain management, with half the nurses stating that patients were not referred to them early enough. This prohibited nurses from getting to know the patient early on and establishing a relationship with them. Difficulties were encountered if nurses were brought in to manage a crisis situation or if the patient was unaware of their diagnosis. It was noted that patients were less likely to be cared for at home if relatives were unable, or did not wish, to do so. One of the major problems was lack of time for care provision with nurses expressing a strong desire to spend time with patients, build up a relationship, and provide emotional support rather than simply providing physical care. These concerns were also reflected in Bergen’s review of the literature.

Clearly, community nurses have been placed in a position in which they need to make their contribution to patient care more apparent. It has been argued that, if purchasers do not have a clear understanding of how a service operates, then it may not be adequately funded. Our findings suggest that many of the activities viewed by community nurses as leading to high quality care are relatively “invisible”—for example, emotional support, forming good relationships, coordination of service input. The need for clear articulation of the core components of the contribution of community nurses to high quality palliative care is therefore readily apparent.

Conclusion

Respondents related situations in which they had been able to provide palliative care in a compassionate and holistic way. It was clear that this was a situation in which staff felt a desire to provide care at a level which might be viewed as “over and above” that required to meet the patient’s immediate nursing needs. The district nursing service was viewed as central in terms of planning and coordinating care and ensuring that the services of other agencies complemented rather than duplicated care. In general, care went well if there was an open relationship which facilitated a partnership between the district nursing service, the patient, the family, and other services.

It was clear that establishing a close relationship with the family was highly prized by respondents, and situations in which this was possible proved the most satisfying in terms of achieving desirable outcomes for patients. Many of the working practices of those interviewed therefore centred on achieving this particular goal. What is also clear is that what community nurses view to be at the heart of their work—the provision of holistic care—is not always fully understood by others.

Finally, despite the changes in the district nursing service and the provision of palliative care, there are certain tenets that hold true over time with regard to what constitutes good care. Perhaps what is more surprising is that the difficulties encountered in meeting these ideals have not been resolved. This study offers a useful contribution to the body of knowledge on the provision of high quality palliative care in a community setting by community nurses. The “structures/processes/outcomes” identified in table 1 could be viewed as the first stage in the development of benchmarks for a quality review of palliative care provided by community nurses. While this standard might be viewed as a useful building block, as opposed to a comprehensive list, it is of particular value given the “bottom up” approach adopted in the identification of key factors. Further studies examining the perspective of others—for example, patients, carers, and specialist nurses—could be used to augment this standard. This is particularly pertinent since the perceptions of
patients may not be congruent with those of service providers. While not all of the factors are under the direct control of the community nurses (most notably, the family circumstances and the actions of other health care professionals), many are—for example, the manner in which care is organised. Furthermore, other influential factors are eminently suitable for audit—for example, the manner in which care is organised. Furthermore, other influential factors are eminently suitable for audit—for example, the number of patients who are referred to the service at an early stage and the number of patients who are cared for and die in the place of their choice. Findings from such an audit may indicate why desirable levels of service are difficult to achieve and could lend weight to discussions with other services if a change in their practice is considered desirable.


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