Equity of access to community palliative care services

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Background
Equity of access to health care for people in equal need is an aim for many palliative care services: the English NHS plan promises that ‘all patients should have access to specialist palliative care advice and services that they need’. However there is evidence that the needs of patients may not be equitably met by palliative care services. Socio-economic and diagnosis related issues appear to affect utilisation and access with those who are older, who do not have a cancer diagnosis, who are not married, and who experience some degree of poverty being less likely to be users of palliative care services. Research has tended to concentrate on user characteristics rather than the possible impact of the health care system characteristics on equity of access.

Method
Aim
The aim of this research was to investigate the influences on referral decisions made within community palliative care services.

Methods
A qualitative case study strategy was adopted, as it provided a framework for facilitating the incorporation of multiple perspectives in a complex context, in a field where there has been little previous research, and where there is little theory to guide the investigation. Three cases (Primary Care Trusts A, B and C) in North West England were studied. Data collection used multiple methods (interviews, observation and documentary analysis, as well as mapping and profiling the palliative care services provided within the cases) from multiple perspectives (general and specialist palliative care professionals, managers, commissioners and patients). Data from analysis of 24 interviews with general and specialist nursing staff are presented here.

Analysis
Data were coded, charted, mapped and interpreted, developing a thematic framework and theoretical propositions. Detailed data analysis followed a framework approach, comparing and contrasting patterns within and across cases with these existing and developing theoretical propositions.

Results
Access to palliative care services was markedly affected by both the professionals’ perceptions of their own role, and also the way that they worked with their colleagues. However, nurses perceived equitable access in particular ways: that they treated everyone in the same way, but then individualised the care offered dependent on what patients wished.

‘I treat everyone the same’
Nurses were keen to stress that they approached the care of all their patients in an equitable way. This commenced with referral systems, which they felt gave everyone the same potential access to care:

‘We are an open referral system, I have an answer machine, that you can leave a message on. I give all the district nurses and GPs my mobile phone number. Over the years I have been here I have tried to build up links. I don’t want to be seen as this elite service that you have to have special tick boxes before you access us’ C/SN 2

‘I think that’s the thing with District Nurses, and some people think that’s a bad thing, and it can be because you could get anybody, anybody and everybody can be referred to District Nurses, and we’ve no referral criteria, but the positive side is that anybody and everybody can get you if there’s a problem.’ A/DN 4

Then once patients were referred and offered care, professionals emphasised that everyone was treated equitably:

‘I mean as district nurses we give the same standards of care to all of our patients.’ A/DN

Nurses were particularly keen to emphasise the equality of service they offered to those from black and minority ethnic communities.

‘It doesn’t matter to me, their ethnicity; they get the same service as everybody else.’ B/DN

This approach did not mean that everyone received exactly the same care, rather respondents suggested that their way of treating everyone the same was to offer everyone individualised care.

‘It depends what they want’
Nurses described individualised care, based on both the nurses’ assessment of care needs, and their interpretation of patient and carer choices. Hence while they felt they offered the same service to patients from black and minority ethnic communities, the offer of service was taken up in different ways:

‘It’s not saying that we don’t offer the services and the facilities, but they tend not to take them up, because they do really use their family members … If their needs are no different from a white person’s, say I had two referrals, they are treated no different or whatever.’ B/DN 4

Nurses in this study talked about patient choice, and saw it as very important, operationalising choice as asking patients about their preferences:

‘Yeah, I mean our role basically is we go and do the initial assessment and establish the needs during the assessment and agree that with the, you know, the patient and the family. And obviously the amount of times we visit would depend upon what is required ... if they’re happy with us coming weekly or fortnightly wherever there is somebody else who would like us every day, and we do fit in with that you know.’ C/DN 5

‘So we do the initial nursing assessment and take it from there basically and then we let the patient decide what they want…. sometimes they say oh well you decide, but we always put the ball back in their court and say “no it’s your decision, what do you want”.’ A/DN 5

So whilst potential care appeared to be offered on an equal basis, actual care received varied depending on the professionals assessment of need, and the patients desire to receive care.

Conclusion

• Nurses described offering different levels of care, conceptualised as responding to needs in an equitable, yet individual way.

• This concept of individualised care which accommodates different patients needs, yet allows nurses to argue that all patients are treated in the same way has been found in others’ work with district nurses *

• Such equality of care is seen as intrinsic to everyday work with patients, and allows them to perceive themselves as impartial, fair and just, despite the practical demands and resource constraints in their day to day work.

Such public accounts by nurses of their equitable approaches to care are at odds with evidence describing inequitable access to palliative care services. This may be for several reasons.

• Disparities in access may be related to disparities in clinical need, or to patient and carer preferences.

• Inequalities may be found in the referrals received, rather than how the nurses acted upon referrals.

• The public accounts of equitable treatment may be triggered by a wish to appear equitable to external scrutiny, and not reflect the realities of practice.

To explore this further, studies are required which examine the clinical needs of patients as well as their other characteristics, and which observe the work of professionals in addition to analysis of professionals’ descriptions of care.

Reference List


2. Ahmed N, Bestall JC, Ahmedzai SH, Payne SA, Clark D, Grande GE, Addington-Hall JM, Todd CJ. Place of death and diagnosis related issues appear to affect utilisation and access with those who are older, who do not have a cancer diagnosis, who are not married, and who experience some degree of poverty being less likely to be users of palliative care services. Socio-economic and diagnosis related issues appear to affect utilisation and access with those who are older, who do not have a cancer diagnosis, who are not married, and who experience some degree of poverty being less likely to be users of palliative care services. Research has tended to concentrate on user characteristics rather than the possible impact of the health care system characteristics on equity of access.

3. Grande GE, Addington-Hall JM, Todd CJ. Place of death and diagnosis related issues appear to affect utilisation and access with those who are older, who do not have a cancer diagnosis, who are not married, and who experience some degree of poverty being less likely to be users of palliative care services. Socio-economic and diagnosis related issues appear to affect utilisation and access with those who are older, who do not have a cancer diagnosis, who are not married, and who experience some degree of poverty being less likely to be users of palliative care services. Research has tended to concentrate on user characteristics rather than the possible impact of the health care system characteristics on equity of access.