

Deep End Report 15

Palliative care in the deep end

The fifteenth meeting of "General Practitioners at the Deep End"

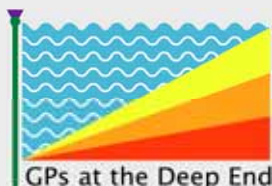
22 February 2011

15 practitioners, from general practice, community nursing and specialist palliative care met on Tuesday 22 February 2011 in the Academic Unit of General Practice and Primary Care at the University of Glasgow for a roundtable discussion and review of the challenges of delivering palliative care in severely deprived areas.

SUMMARY

- The essential key to delivering effective palliative care in the community is the trust established between district nurses and general practitioners, who know each other well, understand each other's roles and can contact each other quickly as the need arises.
- Neither the GP, nor the district nurse on her own, are "enough". GPs feel that district nurses are central to palliative care and fear the loss of attached district nurses more than any other staff.
- The work of palliative care in the community is increasing, but staff are not being replaced as they leave or retire, putting greater pressure on the remaining staff. No new district nurses have been trained in the last year.
- The group considered that all GPs should be active in palliative care, meeting patient and family expectations, and sharing the work of palliative care within the practice. A "GP who doesn't visit" was considered by district nurses to be a huge obstacle to providing high quality care ("Like having our hands tied behind our back").
- Effective joint working needs an "open door policy" whereby district nurses can always access the relevant GP when necessary.
- The over-riding problem for GPs is pressure of work and lack of time so that it may sometimes be impossible to visit a patient at home.
- It is reassuring for patients to know and see that the district nurse and GP are communicating with each other. The sooner the team is involved the better, establishing initial contact and relationships before urgent needs take over. "Reassurance" is less effective without a prior relationship.
- The trust and confidence of patients and their families in the palliative care team arises from successive positive experiences of teamwork in action.
- Palliative care for non-malignant conditions is much harder to arrange than palliative care for cancer, where the starting point and agenda are more easily understood and addressed.
- The group anticipate an increase in the need for palliative care for non-malignant conditions, especially as deaths increase from alcoholic liver disease.
- Hospices tend to have substantial expertise and resources, especially for palliative care of cancer, and a key issue is how these could be better deployed in supporting community care.
- Specialist nurses are valued, but can de-skill existing teams and interfere with their relationships with patients. Building up good relationships between general practice and outreach staff takes time.
- Families in very deprived areas are less demanding, often not knowing what is available (including financial help). They also have fewer skills in accessing professionals and may also have fewer resources, such as reliable telephones and cars.

- There is a culture of expecting the patient's "own GP" to visit.
- At the end of palliative care, the patient's home can be "like Piccadilly Circus" as a result of the number of professionals visiting to provide specific components of care. In general, the smaller the number of professionals involved in providing continuity of care the better.
- Social work was not represented at the meeting, despite invitations. It was noted that social work has no sub-speciality expertise in palliative care.
- It was said that community carers and their managers "don't understand what district nurses do" in assessing clinical aspects of care, and tend to withdraw as the end of life draws near. It was felt that community carers could be a very important part of the caring team, but that district nurses are best placed to lead the team.
- Current GP contractual arrangements supporting palliative care include "essential services", a Designated Enhanced Service (DES) and part of the Quality and Outcomes Framework.
- Minimum elements of care are inclusion on a register (so that care can be planned and reviewed), minuted regular multi-professional meetings and the availability and passage of relevant information for use out of hours.
- The DES is considered "too much a data collection exercise" and sometimes out of touch with the needs of the service at ground level, where flexibility and discretion are part of the art of tailoring care to individual needs.
- GPs described how it was sometimes "better not to put some patients on the palliative care list", because of the bureaucratic implications.
- The previous Gold Standard Framework had involved 80% of practices, without reward or incentives, but had been "torpedoed" by the DES.



"General Practitioners at the Deep End" work in 100 general practices, serving the most socio-economically deprived populations in Scotland. The activities of the group are supported by the Royal College of General Practitioners (Scotland), the Scottish Government Health Department, the Glasgow Centre for Population Health, and the Section of General Practice & Primary Care at the University of Glasgow.

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ATTENDING

Gillian McKinnon	District Nurse, Drumchapel
Eilidh Mackay	District Nurse, Possilpark
Ann Hunter	District Nurse, Parkhead
Wendy Morcos	District Nurse, Pollock
Shirley Byron	Macmillan Nurse Facilitator, Springburn
Euan Paterson	Macmillan GP Facilitator, Govan HC
Georgina Brown	GP, Springburn Health Centre
Linda Cherry	GP, Allander Surgery, Possilpark
Ian Aitken	GP, Crail Medical Practice, Tollcross
Alison Macbeth	GP, Gilbertfield Medical Centre
Maire O'Riordan	Medical Director, Marie Curie Cancer Centre Consultant in Palliative Medicine
Barbara Simpson	Community Clinical Nurse Specialist, Marie Curie Cancer Centre
Judith Marshall	GP, Drumchapel HC and Marie Curie Cancer Centre
Jackie Chaplin	Lead, Non-malignant Palliative Care, Greater Glasgow and Clyde HB
Graham Watt	Professor of General Practice, University of Glasgow

SUMMARY OF DISCUSSION

During a round of brief personal introductions, most looked forward to the opportunity to share experience and views. The meeting provided a rare opportunity to do this. While professional meetings within general practices are often multi-professional, meeting outside practices tend to be uni-professional.

It had helped to place district nurses in health centres as this facilitated contact and communication, but this did not necessarily work for practices outside health centres. Good professional contacts and joint working takes time and effort. Perversely, improvements in IT had improved some kinds of communication while worsening others.

It had proved impossible to arrange for a colleague from social work to attend the meeting. An individual had been identified but line management approval could not be obtained in the short time available to plan the meeting.

Patients and their families in very deprived areas make few demands and are readily satisfied, often not knowing what is available or what to expect (including financial help). A district nurse emphasised the importance of the GP ("so important"), who may need to take the initiative, and not necessarily wait to be asked or just respond to events. The GP's presence could be all that is required, conveying a positive message of caring and reassurance that everything that needs to be done is being done.

The over-riding problem for GPs is pressure of work and lack of time, so that it may sometimes be impossible to visit a patient dying at home, because of other demands.

The sooner the team is involved the better, establishing initial contact and relationships before urgent needs take over. It is reassuring for patients to know and see that the district nurse and GP are communicating with each other. The trust and confidence of patients and their families in the palliative care team arises from successive positive experiences of teamwork in action.

Problems were mentioned in joint working with Cordia staff. Hospital discharge packages could be communicated to community carers but not to nurses. GPs and nurses welcomed the prospect of Cordia staff being brought into the NHS.

Palliative care for non-malignant conditions is much harder to arrange than palliative care for cancer, where the starting point and agenda are more easily understood and addressed. It was said that the service is much more likely to fail patients dying from non-malignant conditions. This issue needed to be addressed before the predictable increase in the number of people dying of alcoholic liver disease.

Families in very deprived areas are not only less demanding, they also have fewer skills in accessing professionals and may also have fewer resources such as reliable telephones and cars. Domestic households may lack the space to provide adequate care at home. Family arrangements may also be complicated, with grandparents looking after children, if parents are ill, addicted to drugs or in jail. Dementia was said to be less common in deprived areas, especially at younger ages when premature death is relatively common ("Patients die either very young or very old").

One reason why cancer is considered easier to manage at home is the acceptance of patients, relatives and professionals about the likely course of events. With non-malignant conditions, there is greater concern that reversible aspects of the condition should not be missed and thus, greater recourse to hospital investigation and treatment.

The work of palliative care in the community is increasing, but staff are not being replaced as they leave or retire, which puts greater pressure on the remaining staff.

Relationships between staff who work together vary substantially. For GPs, experience on the out of hours service often gave penetrating insights on the variation between general practices in their approaches to palliative care. A “GP who doesn’t visit” was considered by district nurses to be a huge obstacle to providing high quality care (“like having our hands tied behind our back”).

Consultants in palliative care were considered expert on matters concerning cancer care, but less so in relation to the care of non-malignant conditions. Hospices tend to have substantial resources attached to them and a key question is how these could be better deployed, in terms of supporting community care. The involvement of Marie Curie nurses in the palliative care of non-malignant conditions was welcomed, “giving families a break”.

It was noted that palliative care had its origins in cancer care, and much charitable funding had been generated, supporting developments which statutory services had then picked up. It was noted that many developments in the care of previously relatively neglected conditions, such as stroke, end stage heart failure and COPD had been led by specialist units developing outreach activities in the community. There had been less promotion of the generic community features of continuity, coordination and flexibility. Specialist nurses are valued, but can de-skill existing teams and interfere with their relationships with patients and families.

It was recognised that the new breed of heart failure nurses has important expertise, which needs to be integrated in the palliative care of patients with advanced heart failure. Building up good relationships between general practice and outreach staff takes time.

At the end, the patient’s home can become “like Piccadilly Circus” as a result of the number of professionals visiting to provide specific components of care.

A GGC health needs assessment of non-malignant palliative care had shown substantially higher levels of need in deprived areas. It was difficult, however, to quantify the implications for the time of health professionals and to value the early intervention of spending time with the patient. When time is short, palliative care can reduce to end stage fire fighting.

A GP who does not visit a dying patient at home, “even when nothing can be done”, is likely to be criticised by relatives for not doing so. It was said that there is a culture of expecting the GP to be present when a patient is dying at home. A GP described being “haunted” by not having been able to visit, because of conflicting pressures, including GP partners being off ill and having to attend a child protection conference instead.

A district nurse might be visiting every day, but “is not the doctor” from the family’s point of view. Neither the GP nor the district nurse on their own are “enough”. Even though nothing can be done, their presence, and the implication that everything that needs to be done is being done can be very reassuring to the patient and for families. It was said that “reassurance” is less effective without a prior relationship.

GPs commented that good palliative care is often easier to organise out of hours, because there is more time and key support services are available.

There was ambivalence concerning the “intensive community case managers” who had been introduced in some areas to provide complex care for a “community ward” of such patients. It was said that such arrangements could by-pass the patient’s “real GPs and district nurses”, except during out of hours.

A major challenge is find ways of releasing the time of GPs and district nurses, for whom patient contact is becoming a smaller and smaller part of their working day.

A nine-fold variation was described between the numbers of elderly patients in different Glasgow practices identified at being at risk of subsequent emergency admission. It was said that two thirds of general practices in north Glasgow had opted out of the Local Enhanced Service for following up SPARRA data because of pressures on their time.

A similar Designated Enhanced Service (DES) for palliative care “had not been thought through”, becoming too much of a data collection exercise. The previous Gold Standard Framework was described as an effective way of improving the standard of palliative care, without incentives or penalties, but had been “torpedoed” by the DES. GPs described how it was “better not to put some patients on the palliative care list”, because of the bureaucratic implications. Politically driven national initiatives were considered suspect, and sometimes out of touch with the needs of the service at ground level, where flexibility and discretion are part of the art of tailoring care to the needs of individual patients.

It was noted that there is considerable interest at a high level within the NHS that the outcomes of palliative care should be measurable and subject to review. Simple outcome measures include place of death, whether the patient was listed as part of a DES, whether there was an “anticipatory care plan”, and whether boxes can be ticked on a care pathway. It was felt that such measures failed to capture the humaneness that is an essential component of palliative care.

There was concern that no new district nurses had been trained in the previous year. “Skill-mix” was often used as a euphemism for “down-skilling”. GPs felt that district nurses are central to palliative care and feared the loss of attached district nurses more than any other staff. Experience of district nurses being organised on a geographical model was described as “murder”. It was noted that secondary care had lost much of its teamwork ethos, as a result of how staff now work, and that this had to be avoided at all costs in the community.

Some types of patient, especially those with drug addiction, expected to be treated badly in hospitals. Some community staff also have negative attitudes and could achieve more by trying to understand such patients. Symptom control for patients with alcohol, liver and drug problems is especially difficult.

In considering how services could be improved for patients, the universal opinion comprised more staff and more time to spend with patients. Demands are not necessarily the same as needs. NHS resources should follow the latter, but this has to be seen as a Scottish problem and not just a Glasgow problem. In Lothian, where deprivation is a small problem, it was thought to have been easier for practitioners serving deprived areas to obtain extra resources, but in Glasgow, where “everyone is in the same boat”, special pleading does not work.

The attachment of district nurses to general practices was also considered essential. It was not clear that the new breed of University-educated nurses would provide the

same type of local commitment as older and retiring generations of staff. Experience and local knowledge are invaluable. GPs would fight strongly to retain this calibre of staff. Bands 6/7 are hugely more valuable than bands 2/3. Continuity counts as does the generalist nature of district nursing as a counterforce to fragmentation.

It was said that community carers (CORDIA) and their managers “don’t understand what district nurses do” and in particular the specific skills of nurses in identifying and addressing clinical aspects of care. CORDIA staff lack such skills and training and could very quickly (“within a few weeks of starting” find themselves out of their depth with clients who have entered the final stage of an illness.

Social work has no expertise (i.e. no sub-speciality) in palliative care. There needs to be a better way of involving social work colleagues in such care, based on mutual understanding and respect of each other’s roles. It was felt that if CORDIA staff could be attached to the district nurse teams, they would acquire extra skills very quickly. The loss of the role of nursing auxiliary was regretted. It was felt that when palliative care begins, the previous carers (who sometimes withdraw at this stage) should be included as part of the wider team, under district nurse direction.

Fragmentation of care is an ever present hazard at transitions in care, between services or as conditions progress, and is best avoided by investments in professional relationships. Continuity and flexibility are key. The smaller the number of professionals providing continuity of care the better. It was noted that a primary care team could have to deal with as many as a dozen different local pharmacies.

GP-district nurse joint working can suffer when they are based in different buildings. Effective joint working needs an “open door” policy, whereby district nurses can always access the relevant GP when necessary. The relationship described in one practice meant that district nurses had direct access to GPs, via receptionists, who understood the importance of such requests.

The group considered that palliative care is a core aspect of general practice, and that GPs with no interest in palliative care create a problem for patients and for other staff. It was felt preferable that all GPs are active in palliative care, sharing the load and their experience, rather than for some GPs to take a specialist interest and become overloaded. Patients usually want and value the specific GP whom they know.

Current contractual arrangements supporting palliative care include “essential services”, the DES and part of the Quality and Outcomes Framework. In contrast, the Gold Standard Framework had involved 80% of practices without rewards or incentives. Minimum elements of care are inclusion on a register (so that care can be planned and reviewed), minuted regular multi-professional meetings and the availability and passage of relevant information for use out of hours.