

Survey of Demand for Specialist Palliative Care Face-to-face Assessments at Weekends and Bank Holidays in the Yorkshire Cancer Network

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ABSTRACT

NICE guidance states that specialist palliative care teams in hospitals and in the community should be staffed to a level sufficient to undertake face-to-face assessments between 09.00 and 17.00 seven days a week. This survey examines the demand for such a service in the Yorkshire Cancer Network, and considers the results in light of existing evidence about the need for such services. In doing so it highlights the lack of awareness and use of existing out of hours specialist palliative care support services within the network, and reveals misconceptions amongst some colleagues in other disciplines about the role of specialist palliative care. While it is difficult to define and quantify true need for a service, this study does not demonstrate an unmet demand for out of hours specialist palliative care face-to-face assessments as recommended by NICE.

INTRODUCTION

NICE guidance states that services for adults with advanced cancer should, as a minimum, include specialist palliative care in-patient facilities as well as hospital and community teams “staffed to a level sufficient to undertake face-to-face assessments of all people with cancer at home or in hospital, 09.00-17.00, seven days a week. In addition, there should be access to telephone advice at all times (24 hours, seven days a week).”

(1)

The Yorkshire Cancer Network (YCN) has a population of 2.5 million in an area comprising two large city conurbations, several localities of 150,000 - 500,000 each and considerable tracts of countryside. Specialist palliative care (SPC) advice for adults is available by telephone at all times in five out of the six YCN localities. There are 10 hospices and 19 specialist palliative care teams (SPCT) with common eligibility criteria for specialist palliative care. These teams routinely provide face-to-face assessments between 09.00 and 17.00 on weekdays but not at weekends. Since publication of the NICE guidance, none of the primary care trusts (PCT) in the YCN has agreed to provide a weekend service, nor has a case been made for its funding. A weekend service which had been set up in one YCN locality was underused and consequently withdrawn. (Personal communication, 2007. Dr M Kiely. Consultant in Palliative Medicine, Huddersfield Royal Infirmary, Acre Street, Lindley, Huddersfield, HD3 3EA.) A palliative care needs assessment in Wakefield and Pontefract in 2001 demonstrated a need for a 24 hour district nursing service and for out of hours (OOH) specialist palliative care telephone advice, but not for face-to-face consultations. (Personal communication, 2007. Dr A Seymour, Consultant in Palliative Medicine, Wakefield Hospice, Aberford Road, Wakefield, West Yorkshire, WF1 4TS). Since no new funding accompanied the NICE recommendation for a weekend face-to-face service, its provision might compromise

existing services. This project was designed to assess the demand for a weekend face-to-face assessment service provided by palliative care clinical nurse specialists (CNS) in the YCN. Demand, rather than need, was chosen as an end point because it is more easily defined and measured.

METHOD

The YCN Palliative Care audit subgroup designed questionnaires to assess weekend workload (09.00-17.00) specific to palliative care patients. Customised questionnaires (examples shown in appendix 1) were distributed to the following: Specialist Palliative Care Teams (SPCTs) supporting patients in hospital and at home; on-call palliative medicine consultants; hospice advice lines; non-specialist teams including hospital nurses and doctors, general practitioners (GPs) and district nursing teams. Specialist teams were asked to identify patients “at risk” prior to study weekends, patients who had crises (identified by calls over the weekend or on the next working day), patients admitted to hospital or hospice over the weekend, and whether any of them would have benefited from specialist palliative care (SPC) face-to-face assessment. Non-specialist teams recorded the number of their patients with palliative care needs, the nature of the palliative care problems, whether or not SPC telephone advice was sought, and whether or not face-to-face SPC assessment would have been beneficial. All questionnaire responses were analysed using Microsoft Excel spreadsheets. All days surveyed were weekend days or bank holidays. A further questionnaire was devised and distributed to patients and carers known to SPC services within day hospice and community settings, and will be analysed elsewhere (Personal communication, 2007. H Ankrett, Head of Care Services, Sue Ryder Care Wheatfields Hospice, Grove Road, Headingley, Leeds, LS6 2AE and C Rock, Clinical Nurse Specialist - Palliative Care, Bradford Royal Infirmary, Duckworth Lane, Bradford, BD9 6RH). The local medical research ethics committee advised that formal ethics approval was not needed as the surveys constituted a needs assessment.

RESULTS

Total data for each professional group are presented. These results have then been extrapolated to give an idea of demand across a typical locality in a given period of time.

NON-SPECIALIST PROFESSIONALS

Nurses in Charge of Wards and Junior Doctors

Nurses in charge of hospital wards, and junior hospital doctors were surveyed in three hospitals over a total of 2557 bed-days. The response rate was 46% (207/446), nurses being better responders than doctors (53% vs. 29% of surveys completed). 109 staff identified patients with palliative care needs. Thirty-two professionals thought face-to-face SPC assessment was warranted, but only one had rung for specialist advice. Only two did not know that they could ring for specialist palliative care advice.. Seventy-nine problems were identified in these patients. These related to symptom control (32%), communication issues (17%), opioid use or titration (5%), syringe drivers (9%), decision making about medical interventions at the end of life (11%), place of care at the end of life (14%), hydration and nutrition at the end of life (11%) and one unspecified problem (1%). One professional suggested that any patient known to a palliative care CNS should have that CNS available on call at weekends. Other comments included “distressed families feel the need to speak to palliative care team at the weekend” and “extra support/advice on symptom control would be helpful when required”.

District Nursing Teams

District nursing teams were surveyed across the whole network with a mean of 9.2 days surveyed in each of six localities. There were 253 patients with palliative care needs. Community nurses identified 38 patients who might have benefited from face-to-face palliative care assessments, but telephoned for specialist palliative care advice in only 16 of these cases. Only three nurses did not know that they could ring for specialist palliative

care advice. In cases where face-to-face assessment might have helped, nurses were asked to report how the assessment would change the management plan. There were 23 responses to this and the perceived benefits were as follows: patient and family support (13%); staff support (9%); prevention of hospital/hospice admission (9%); improvement in continuity of care at weekends (9%); medical assessment needed (9%); help in organising equipment or increased care at weekends (13%); would be useful or 'nice' to have specialist resource (38%). Other comments included "main problem is getting day/night sitters", "continuation of communication & support for DN (district nurse) who felt isolated and needed advice/support" and "useful to have access to SPC nurse or Macmillan nurse at weekend as many patients visited at weekend not known to us".

Figure 1 - Demand for specialist palliative care at weekends as perceived by professionals outside specialist palliative care

	Hospital Nurses and Doctors	District Nursing Teams	General Practitioners
TIMESCALE	Over 2557 bed days	Over a mean of 9.2 weekend days	Over 10 weekend days
No. of professionals with patients with palliative care needs	109	253	11
No. of professionals who rang for SPC advice	1	22	1
No. of patients for whom face-to-face assessment would be considered helpful	32	38	4
No. of professionals wanting face-to-face assessment who rang for SPC advice	1	16	1
No. who did not know they could ring for advice	2	3	1
Reasons for requesting face-to-face assessment: (NB respondents could give ≥1 reason for each patient)			
symptom control	23	32	4
communication issues	13	14	1
opioid dose/conversion	4	5	2
syringe drivers	7	5	2
end-of-Life decisions:			
- medical interventions	9	5	3
- place of care	11	7	3
- artificial	9	4	2
nutrition/hydration			
Other	1	6	0

General Practitioners

GPs working out-of-hours were surveyed for 10 days in two localities. An average shift covered 6-9 hours, with some doctors in primary care centres and some undertaking house calls. Of 108 questionnaires distributed 17 were returned (16% response rate).

Eleven GPs identified patients with palliative care needs. A face-to-face SPC assessment

was considered appropriate in four cases. Perceived benefits of a face-to-face assessment included “advice/support” and “may speed up setting up of syringe driver”. In one case the GP was unaware he could ring for advice. In two cases the GPs stated that they did not need advice – but for one of these, difficult symptom control, syringe driver problems and issues relating to artificial hydration were reasons for wanting a face-to-face assessment.

SPECIALIST PROFESSIONALS

Hospital and Community Specialist Palliative Care Teams

All 19 SPCTs in the Network (eight community, eight hospital and three combined) were surveyed. For analysis, results for combined teams were separated into community and hospital, depending on the location of the patients, giving a total of 22 teams. Eleven community teams surveyed a total of 107 days (a mean of 9.7 per locality) and 106 days were surveyed by the eleven hospital teams (a mean of 9.6 days per locality).

Community Teams

Fourteen patients left messages on the community teams’ telephone answering machines. The teams considered that telephone contact with SPCTs would have resolved the concerns for nine (64%) and that six (42%) would have benefited from face-to-face contact (three for patient/family support and three for symptom/treatment review). Respondents did not view these two categories as mutually exclusive, indicating that some patients whose problems might be resolved with a telephone call might have added benefit from a face-to-face assessment. Teams identified 28 patients who had palliative care crises over the weekends. The teams considered that for 18 patients (65%) telephone contact with SPCTs would have been sufficient to address their problems and that 10 (35%) would have benefited from face-to-face SPC assessments. Nine patients were admitted to either a hospice or hospital. The teams considered that face-to-face SPC assessments were

indicated in three (33%) cases – in two cases admission could have been prevented, and symptom and treatment review could have been improved before admission in one case.

Figure 2 - Demand for specialist palliative care at weekends as perceived by specialist palliative care teams

	Community Teams	Hospital Teams
No. of patients at risk over the weekend, whom team predicted might benefit from:	82	39
-telephone call from SPCT over weekend	47	27
-face-to-face assessment by SPCT over weekend	17	11
Number of patients identified as having had a crisis over weekend, for whom:	28	22
-SPCT telephone advice might have been adequate	24	14
-face-to-face assessment might have helped	13	5
Number of patients admitted to hospice or hospital over the weekend	9	2
-for whom SPCT face-to-face assessment would have helped	3	0

Hospital Teams

Six crisis calls were left on the hospital teams' telephone answering machines. In one case it was thought that face-to-face review of the patient by a palliative care CNS would have given added benefit because of the need for review of symptoms and medication. The teams considered that telephone contact with SPCTs would have been sufficient to address the concerns for four (66%) cases, and that one patient (17%) would not have benefited from face-to-face contact or telephone advice. Teams reported 16 patients who had palliative care problems (a "crisis") over the weekends. In 10 cases (63%) it was thought that SPC telephone advice would have been adequate, but no help was sought for seven of the ten. It was felt that four of the 16 (25%) would have benefited from face-to-face SPC assessments (one for symptom/treatment review, two for patient/family support, and one for detection of a drug error). In none of these cases had help been sought from on-call SPC services. Two patients were admitted to either a hospice or hospital. The

teams considered that face-to-face SPC assessments would not have helped in either case.

Calls to Palliative Medicine Consultants

In five of the six localities in the YCN, out-of-hours' SPC advice is available from Consultants in Palliative Medicine. Palliative care CNSs in the locality without this service both predicted and reported no weekend crises and no admissions. In total, 81 days were surveyed. Excluding calls from hospice inpatient units, consultants received 32 calls between 09.00 and 17.00. There were three cases (9%) where a telephone call was not considered adequate of which two (6%) may have benefited additionally from face-to-face assessment. The cases where telephone advice was considered insufficient involved an agitated patient who had previously tried to commit suicide and a case where there was a language barrier between the consultant and the nurse who called her. The cases where there might have been added benefit from face-to-face assessment involved a patient who was transferred from an accident & emergency department to a hospice and a case where the patient needed assessment for the cause of agitation and the family and staff involved needed support and reassurance.

Calls to Hospice Advice Lines

Such calls are answered by the most senior nurse on duty at all of the hospices. While most of the hospices advise that community patients and relatives contact primary care services first at weekends, some ask patients to contact the hospice directly in the first instance. In total, 87 days were surveyed across nine hospices (mean of 10 days each). During that period, 82 calls were received between 09.00 and 17.00 from patients, their relatives and professionals in the community. The staff answering calls to the help lines thought SPC face-to-face assessment was indicated in 30 (37%) cases. One hospice in one of the larger cities generated 14 (47%) of all cases in the network where SPC face-to-face assessment was deemed appropriate. In that hospice it was considered that 14 of 18 calls (78%) warranted face-to-face assessment. Of the 14 in need of face-to-face

assessment, nine calls came from patients and their relatives/carers, and five from other professionals.

‘DEMAND’ AND ‘NEED’ FOR FACE TO FACE ASSESSMENTS CALCULATED FOR AN AVERAGE LOCALITY

It is not easy from the above results to determine the demand or need for face to face assessments over the whole Network or for a typical locality of 500,000 people. We have attempted to calculate these (calculations and assumptions shown in detail in appendix 2), In summary, results from generalists – hospital doctors and nurses, district nurses and GPs –give a demand within a ‘typical locality’ of one face-to-face assessment/day in the community and at least 6.3 assessments/day in a district general hospital. However, many of the staff wanted a face to face assessment but did not seem to want telephone advice – ,even though most of the problems described seemed to be appropriate for telephone advice. If we remove the patients for whom specialist palliative care telephone advice was not sought (see appendix 2 for further justification of this), the numbers reduce to just over 0.5 face-to-face assessments/day/locality in the community and none in hospital.

The numbers of patients where such assessments were said to be useful in the opinion of specialist teams and those giving specialist telephone advice came to 1 /day/typical locality using data from all specialist groups surveyed.

DISCUSSION

AIMS OF STUDY

This project aimed to assess demand (as a proxy for need) for face-to-face specialist palliative care assessment 9-5 over weekends and bank holidays across the Yorkshire Cancer Network. It was carried out in response to NICE guidelines recommending such a service; these were supported by Cancer Peer Review Standard 1E-120 in 2004 (2). In West Yorkshire, 24 hour district nursing is well established in all localities and 24hr consultant specialist palliative care telephone advice with occasional face-to-face review is available in all but the smallest locality. Across the network the specialist palliative care providers were not sure there was a need to expand the weekend service; PCTs were not offering to pay for any such expansion.

PUBLISHED EVIDENCE FOR NEED FOR OUT OF HOURS FACE-TO-FACE

SPECIALIST ASSESSMENT

There is a lack of definitive evidence to support the NICE guidelines, and few published studies looking at the demand for specialist palliative care assessment OOH. Published papers, in both hospital (3) and community (4) settings, whilst describing service developments which have been positively received, are inconclusive as to the need for face-to-face OOH assessment. Advice lines for professionals appear to be beneficial, with most calls related to the use of opioids, syringe drivers and other issues around symptom control (5,6). However, consideration needs to be given regarding competence and confidence of staff triaging calls (7).

Hospital or hospice at home services may result in fewer GP OOH visits and improved symptom control and psychological support, but no increase in the likelihood of remaining at home (8). In addition knowledge of current specialist palliative care services is generally

poor among GPs (9,10), and a minority would rather have no involvement in community palliative care (10).

LIMITATIONS OF STUDY

The survey was carried out by an audit subgroup of the YCN Palliative Care Group. There was no funding for this group – surveys were designed, collected and analysed by members of the sub-group during working hours and in their free-time.

This study has several limitations.

- 1) Due to limited resources and the large scale of the audit, different professional groups in various localities completed their questionnaires over different calendar months. It was therefore impossible to cross-reference reported need from the community or hospital with calls to hospices or consultants or with patients identified by SPCTs as having had problems.
- 2) Response rates from doctors in hospitals and GP OOH services were low. There was no way of assessing demand from non-responders. Only three hospitals in the network were surveyed.
- 3) Demand is not an exact proxy for need – indeed in this survey the authors found some respondents' wish for a face-to-face assessment surprising given the type of problem described (see below). To try to clarify the difference in opinion about need in this study, we have documented the level of demand for face-to-face assessments exactly as respondents described it, and then documented 'filtered' demand once those who did not ask for telephone advice were excluded. This 'filtered' demand is based on judgements made by the authors who all work in specialist palliative care and have a particular bias – that if telephone advice is not sought then face-to-face assessment cannot definitely be said to be needed. The combined results do at least show how opinion can affect the assessment of need.

4) In general, we assumed that respondents understood what is meant by palliative care, although the introductory letter with the survey did offer some guidance on this. The results, however, suggest that there is a variation in understanding of what constitutes specialist palliative care. Some community nurses' comments suggest that they thought an OOH face-to-face SPC assessment would result in easier access to equipment and night sitters. Perceptions amongst hospital nurses seemed to differ with the expertise and seniority of clinical staff. Questionnaires completed by junior nurses contained less information, especially free text, and much lower numbers of patients identified with general palliative needs. The same differences in interpretation were evident in returns by community OOH doctors, some of whom stated they did not need SPC telephone advice, but then went on to describe problems relating to syringe driver medication or end-of-life management.

DISCUSSION OF RESULTS – WHAT DO THEY MEAN?

Results from generalist staff

Community nurses did seem to know what palliative care meant, did know how to get specialist palliative care advice, and did use this service for the majority of patients where they felt they had problems they could not deal with. Overall, their wish for face-to-face assessments was at a frequency of about one request per day per locality, which reduced to one every two days if those who did not seek telephone advice were excluded.

However, comments on how face-to-face assessment might have altered management showed that support for patients, families and staff would be an important additional effect (although not the reason for the original request). We suspect that community staff feel unable to give the support they are capable of because of pressure of work. One nurse also pointed out the loneliness of giving palliative care at weekends, without readily available advice and support. Telephone advice from a consultant cannot reduce the

workload (and in fact may increase it) and is unlikely to give the same support as a nursing colleague.

Hospital staff, especially more junior ones, seemed less able to define palliative care problems, and their expressed need for face-to-face assessments, though high, is confusing. Again, almost all knew they could ring for advice but did not think telephone advice would be useful, although three quarters of the problems they described related to symptom control which should be amenable to telephone advice. We wonder if they felt they had neither the skills nor the time to make the basic assessment necessary for discussion of the problems on the telephone. We also wondered whether a consultant advice line was too intimidating for hospital nurses and junior doctors to use – although we know they do use it at times. As with the community nurses, comments suggested that, in nearly half of cases, patient/family support and staff support/education would be part of the benefit from a face-to-face assessment. In nearly half of cases where a face-to-face assessment was wanted, the respondent did not think it would alter the patient's management. As in the community, we suspect, from comments written and from discussions with staff after the survey, that hospital nursing staff feel they do not have the time to give adequate attention to palliative patients at weekends. Overall, if ward staff assessment of need is used then any palliative care CNS in a DGH would be busy with face-to-face assessments all day at weekends. If ward staff had to use an advice line first, then there would be very little for the specialist nurse to do.

Out of hours on call doctors:

The small numbers of doctors who sent back the survey do not indicate a significant demand for face-to-face assessments. However, even among these few respondents there was a lack of understanding of palliative care, and a lack of understanding of what telephone advice could offer.

Results from specialist staff

Specialist Hospital and Community Teams – In their analysis of incidents after a weekend, the teams did identify a few patients where a visit would have made a difference – these were mainly for symptom control and support. There was some difference between the community teams – eight of the 16 patients who would have benefited from face-to-face assessment were identified by two of the 11 teams. Again this demonstrates the variation in assessment of ‘need’.

Consultants had some – but not many - calls for advice. They felt that these calls were usually amenable to telephone advice. They identified only a few patients where a face-to-face assessment would have been useful, and these were complex patients where it is doubtful that a palliative care CNS who did not know the patient well would have been able to assess with confidence – e.g. a patient threatening suicide.

Hospices – The demand identified from five of the hospices was calculated as about one face-to-face assessment every 5 days per locality, which is low. But our results did uncover again considerable variation in opinion, with the other two hospices considering that three quarters of all calls could usefully have resulted in a face-to-face assessment – this would result in a demand in this city for two face-to-face assessments per day. This is an important finding – it demonstrates a real difference in the way the hospices are used in different localities. In the larger city, it seemed that their two hospices were rung for advice more frequently by patients. We think this does reflect a real difference in emphasis – in the five other localities, hospice staff were clear that they rerouted patients’ OOH calls to primary care services as a matter of policy.

Overall Results

Looking at all results, after telephone advice was sought, and where primary care dealt with calls from patients, then the demand for face-to-face assessments in a locality of 500,000 would be approximately one per day. This would make it uneconomical to have one specialist nurse per locality on call over the weekends and bank holidays. If we use

the raw figures for demand from the community and hospital staff, and the demand identified from a minority of hospices, then a specialist nurse in each locality would be asked to do about nine face-to-face assessments per day at weekends (which is much more than on a usual weekday). It would seem that the 'need' for such a service is very dependent on the philosophy of the overall system of care.

THE COST OF FACE-TO-FACE SERVICE

If extra staff are employed to cover weekends and bank holidays the main cost is financial. Due to the distances between localities in our network six nurses would be needed for each day of cover. If current teams are used to cover a seven day week, there will be an impact on the weekday services:

- specialist staff would be spread more thinly during the week
- there would be a reduction in continuity of care during the week due to days off - this would affect patients, but also discussion with GPs, DNs, pharmacy staff and others
- there would be reduced attendance by specialist nurses at primary care meetings including Gold Standards Framework (GSF) meetings, and hospital ward round and multi-disciplinary team meetings (MDTs) during the week. National cancer quality measures state that SPCTs should be represented at certain core MDTs in acute trusts. This attendance has become an important part of education offered to primary and secondary care, and a prime factor in the specialist nurses becoming part of the community multi-disciplinary team (MDT) looking after each patient
- Hospital specialist nurses and community specialist nurses would have to cover community and hospital at weekends. As their skills and experience are currently different, there would be implications for training.

At weekends, patients are unlikely to see a palliative care CNS whom they know.

Continuity of care would continue to depend on good OOH handover forms and easy

access to patients' records. A few generalist professionals reported a need for face-to-face assessment in order to improve continuity of care, but this assumes that the same CNS assessing the patient during the week would be working at the weekend.

HOW SHOULD PEOPLE WITH PALLIATIVE NEEDS BE SUPPORTED IN HOSPITAL AND THE COMMUNITY? – WIDER IMPLICATIONS

Our survey has uncovered some differences in the way that OOH specialist palliative care works in different localities across the network, and highlights two possible models of care for patients with terminal illnesses.

- 1) A specialist based service. In this model, a patient's care is managed by specialist teams who may act as the first point of contact when patients have palliative care problems. This model assumes that generalist services are not able to deal adequately with the majority of patients' palliative care problems.
- 2) A service where initial assessment and treatment is provided by non-specialist services in hospital and the community. They ask for help from specialist teams when they are not competent or confident in dealing with palliative problems that arise. This model assumes that non-specialist doctors and nurses have skills in assessment of problems, their treatment and the support of patients.

The NICE guidelines could be interpreted as tending towards the first model in saying that the usual specialist palliative care face-to-face assessments must be available seven days a week. The Cancer Peer Review Standards modify this by asking for clear criteria for referral to specialist palliative care services at weekends. Our current service in the majority of the YCN assumes the second model is operating. Much effort is deployed by

specialist community and hospital teams in education, and care taken that specialist intervention does not de-skill non-specialists. Community CNSs attend GSF meetings to ensure a team approach with primary care. It is considered essential that the primary care teams know their palliative patients well, and that all palliative patients have an OOH palliative care form completed with basic information about the illness, its stage and existing advance care plans.

CONCLUSION

Unfortunately, we are not able to give clear evidence-based conclusions from this study about the 'real' need for weekend specialist nursing cover. However, after triaging and giving telephone advice, this study does not demonstrate a clear need for a palliative care CNS working 9-5 at weekends. We recognise that our service is not entirely adequate at weekends. The consultant advice lines are underused, particularly by hospitals, and there is probably a lack of time and support for community and hospital nurses looking after palliative care patients at weekends. It seems likely that before setting up a new weekend service we should:

- publicise the consultant and hospice advice services and ensure that junior staff feel able to use them
- consider how to give more support to those ringing for advice
- review non-specialist staffing at weekends in each locality for palliative care patients
- ask PCTs to find out whether inadequate staffing or ill-defined competencies are making it difficult for generalist staff to deliver good palliative care
- look at differing practices within the network and see which models have which advantages
- reassess the need once the above have been achieved

If the PCTs do decide to provide routine SPCT face-to-face assessments at weekends, then they would need to make clear decisions about what generalists should deal with and give clear criteria for referral to specialist services.

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The appropriateness of a patient's place of care

The use of artificial hydration or feeding

- Any other, please explain

Did you seek Specialist Palliative Care advice, for example, hospice or on-call Consultant?

- Did not require any specialist advice
- Did not know I could ring
- Did not consider ringing
- Did ring for advice

Who did you receive advice from?

- Nursing staff at the hospice
- On-call doctor at the hospice
- Palliative Medicine Consultant on-call

Was the advice you received helpful?

Yes/No (please explain)

In addition to the Palliative Care telephone advisory service, would a face-to-face assessment of any of these patients by a Specialist Palliative Care or Macmillan Nurse this weekend have been helpful?

Yes/No

If yes, for how many patients approximately?

What areas would the assessment have helped with? Please tick any that apply

- Difficult symptom control, for example, pain or nausea and vomiting
- Managing difficult communication issues with a patient and/or their carers
- Prescribing opioids and/or opioid titration
- Converting a patient to syringe driver medication
- Managing end-of-life decisions:

The appropriateness of medical interventions

- Prescribing opioids and/or opioid titration
- Converting a patient to syringe driver medication
- Managing end-of-life decisions:
- The appropriateness of medical interventions
- The appropriateness of a patient's place of care
- The use of artificial hydration or feeding
- Any other, please explain

Did you ask an out-of-hours GP to assess? Yes/No

If yes, did this help?
Yes/No

Did you seek Specialist Palliative Care advice, for example, hospice or on-call Consultant?

- Did not require any specialist advice
- Did not know I could ring
- Did not consider ringing
- Did ring for advice

Who did you receive advice from?

- Nursing staff at the hospice
- On-call doctor at the hospice
- Palliative Medicine Consultant on-call

Was the advice you received helpful?

Yes/No (please explain)

Appendix 2 Needs of a typical locality

RESULTS EXTRAPOLATED FOR AVERAGE LOCALITY AND ENTIRE NETWORK

It is not easy from the results in the paper above to determine the quantity of demand for specialist palliative face-to-face assessment across the Network. For ease of analysis, we have calculated for each group of respondents the following figures:

1. *The total demand described by the professional group across the whole network.* The network has a population of 2.5 million people. It is divided into six localities, one larger city of approx 800,000, one small locality of 150,000, and four localities of about 450,000.
2. *The calculated demand per day for a population of 500,000 with one District General Hospital (DGH) with 500 beds for potential palliative care patients (excluding paediatrics, obstetrics and gynaecology).* We have chosen this as a typical locality within the network. It seems to us that this 'typical locality' would be the largest area across which on-call cover for face-to-face assessments could be provided by one staff member per day. Distance between localities and the large rural areas in some localities mean that combining cover across more than one locality would be impractical.
3. *Demand as translated into apparent need when other factors are considered.* We have primarily looked to see whether non-specialist respondents who wanted a face-to-face assessment actually sought specialist palliative care advice from the existing on-call SPC telephone service. If this had not been accessed, nor found to be inadequate, it is difficult to argue that there is an unmet need.

NON-SPECIALIST PROFESSIONALS

Nurses in Charge of Wards and Junior Doctors

2557 bed days were surveyed in three hospitals. Thirty-two professionals felt a face-to-face assessment for at least one patient would have been helpful, i.e. for at least 32 patients or one per 80 bed days. For a 500-bed hospital this gives a demand of at least 6.3 requests for a face-to-face assessment per day. However, in only one of these cases was specialist palliative care advice sought. This gives, by our method of filtering demand, no identified need for face-to-face assessment.

Community / District Nursing Teams

Community nurses recorded demand over an average of 9.2 days. Across the network, there were 38 patients for whom community nurses felt a face-to-face assessment would have been helpful, i.e. 4.1 patients per day. This equates to 0.8 patients per day in a typical locality. For 16 of these 38 patients no specialist palliative care advice was sought.

This gives a calculated need for face-to-face assessment of 22 patients over 9.2 days across the locality i.e. 2.4/day across the Network and just under 0.5 patients/day across a typical locality.

General Practitioners

GP numbers in the study were disappointingly low, but 17 GP shifts (average shift 6-9 hours, maximum 12 hours) revealed four cases where a face-to-face assessment would have helped, or 0.24/ shift. Specialist palliative care advice was sought in only one of these cases giving a 'need' figure of 0.06 per shift.

SPECIALIST PROFESSIONALS

Specialist Palliative Care Community Teams

Eleven teams were surveyed over an average of 9.7 days per team. For 16 patients, it was thought that a face-to-face assessment would have been helpful, i.e. 1.6/day across the whole Network, and 0.32/day in a typical locality.

Specialist Palliative Care Hospital Teams

Eleven teams were surveyed over an average of 9.6 days per team. For five patients it was thought that a face-to-face assessment would have been useful, i.e. 0.5/day over the network and 0.1/day in a typical locality.

Consultants in Palliative Medicine

81 days were surveyed across five localities (the sixth has no consultant advisory service). This equates to 16.2 days across the Network. There were seven patients for whom a face-to-face assessment might have been useful, i.e. 0.4/day across the Network, and just under 0.1/day in a typical locality.

Hospice advice lines

Nine hospices were surveyed for an average of 10 days each. It was considered that 30 patients would benefit from face to face assessment, i.e. 3/day across the whole Network and 0.6 /day for a typical locality. However, 22 of these 30 came from two hospices in one of the larger cities. In this city, patients known to

SPC teams are sometimes advised to ring the hospices directly if they have problems, rather than seek a GP review first. If we exclude this city's results, and those of the hospice from the very small locality (which had no calls for advice in eight days), we can calculate the demand from the six hospices in the four localities (of 450,000 – 500,000 people) which have had a policy of advising patients to ring their DN service or OOH doctor for help. These four localities had eight patients over a mean of 10 days for whom a face-to-face assessment was thought likely to be of benefit, i.e. 0.8/day over the four localities or 0.2 patients /day in each locality.

SUMMARY

In summary, results from generalists – hospital doctors and nurses, district nurses and GPs – within a 'typical locality' give a demand of a total of one face-to-face assessment/day in community and at least 6.3 assessments/day in hospital. However, removing the patients for whom specialist palliative care telephone advice was not sought, the numbers reduce to just over 0.5 face-to-face assessments in community and none in hospital. The numbers of patients where such assessments would be useful in the opinion of specialists are less than 1/day/typical locality from all groups surveyed.