

Clinical nurse specialists in palliative care. Part 3. Issues for the Macmillan Nurse role

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Abstract: The remit and boundaries of the Macmillan Nursing role in the UK have been called into question recently by a number of policy-driven changes. The rapid appointment of tumour site-specific nurses and the development of posts for palliative medicine, stemming originally from the Calman–Hine recommendations for reorganizing cancer services, have created unparalleled challenges of adaptation to new working practices and procedures. The extent to which Macmillan Nurses are adapting to these new demands was addressed as part of a major evaluation study of UK Macmillan Nursing in 12 sites commissioned by the UK charity Macmillan Cancer Relief. This paper draws upon semi-structured interviews with Macmillan Nurses ($n=44$) and their key colleagues ($n=47$). We found that differences of expectation between Macmillan Nurses and their managers about the appropriate focus of their work lead to problems of role ambiguity and role conflict; that Macmillan Nurses lack resources with which to develop an educative and consultative role and yet substitute for inadequacies in skills and knowledge of other health care staff; and that problems are associated in co-working with newly appointed cancer site-specific nurses and palliative medicine colleagues. Macmillan Nursing has a crucial role to play in meeting the objectives in the NHS Cancer Plan. However, in order to ensure that their expertise is used efficiently and effectively, there is an urgent need to clarify the nature and scope of the Macmillan Nurse role, to attend to issues of team working and to improve the skills of nonspecialist staff in palliative care. *Palliative Medicine* 2002; **16**: 386–394

Key words: clinical nurse specialists; Macmillan Nurses; palliative care education; palliative care policy; palliative care practice; teamwork

Resumé: Les attributions et les limites des infirmières Macmillan au Royaume-Uni ont récemment été remis en question en raison de nombreux changements de politique de santé. L'habilitation rapide d'infirmières spécialisées en cancérologie et le développement de postes en soins palliatifs, initialement inspirés des recommandations Calman-Hine pour la réorganisation de la cancérologie, ont constitué un défi pour l'adaptation à des pratiques et des procédures nouvelles. Le degré d'adaptation des infirmières Macmillan à ces nouvelles demandes a été apprécié dans le cadre d'une étude de grande ampleur des infirmières Macmillan sur 12 sites commissionnés par la fondation Macmillan de lutte contre le cancer. Cet article rapporte les résultats d'entretiens semi-structurés avec des infirmières Macmillan ($n=44$) et leur collègues principaux ($n=47$). Nous avons découvert que le décalage entre les attentes des infirmières Macmillan et celles de leurs responsables à propos de leur rôle propre crée des problèmes à type de confusion de rôle et de conflit de fonction; que les infirmières Macmillan ne possédaient pas les compétences nécessaires au développement d'un rôle éducatif et consultatif et cependant tentaient de compenser le manque de compétence et de connaissances d'autres soignants; et que des problèmes étaient générés par le travail en commun avec des infirmières de centre

anti-cancéreux habilités et avec leurs collègues en soins palliatifs. Les infirmières Macmillan ont un rôle crucial à jouer pour atteindre les objectifs du plan de lutte contre le cancer du National Health Service. Cependant afin de s'assurer que leur compétence est utilisée efficacement et réellement, il y a un besoin de clarifier la nature et l'étendue des fonctions des infirmières Macmillan, de se pencher sur les problèmes du travail en équipe et d'améliorer les compétences des soignants non spécialisés en soins palliatifs. *Palliative Medicine* 2002; **16**: 386–394

Mots-clés: infirmières spécialisées; infirmières Macmillan; pratique des soins palliatifs; formation en soins palliatifs; politique en soins palliatifs; formation en soins palliatifs; travail en équipe

Introduction

In the UK, Macmillan Nurses have been pivotal in the development of specialist palliative care services in hospice, community and hospital settings. From being introduced in the 1970s as nurses with special responsibilities for caring directly for terminally ill people and their families, the role of the Macmillan Nurse has changed gradually to that of the clinical nurse specialist^{1–3} in which clinical, consultative, educational, research and supportive functions are combined. This evolution has occurred in response to the recognition that palliative care is a right for everyone with life-limiting illness.^{4–7} The parallel emergence of professional guidance on the development and definition of specialist nursing roles^{8–10} has been encouraged by wider policy initiatives emphasizing accountability and responsiveness to need. Throughout this paper, the term 'Macmillan Nurse' thus refers to nurses employed as clinical nurse specialists in palliative care.

The extent to which Macmillan Nurses can meet the ideals of specialist practice is, however, little understood, although problems of role clarity and role overload have been linked to clinical nurse specialist posts more generally.^{11–19} Bamford discusses the importance of supportive strategies for clinical nurse specialists, highlighting experiences of isolation and a lack of structured orientation to the role and to the organizational setting.¹⁹ Glen examines the concepts of 'role ambiguity', in which there is a lack of clarity about the expectations attached to the role or where postholders understand expectations but have no clear idea about how to carry them through; and 'role conflict', which occurs when people to whom the clinical nurse specialist relates in the course of the working day have different expectations of what the clinical nurse specialist should be doing.¹⁷ These concepts are likely to be highly relevant to Macmillan Nurses insofar as they occupy a 'boundary role' in which they liaise with multiple others outside of their immediate organization.

The remit and boundaries of the Macmillan Nursing role have been called into question recently by a number

of policy-driven changes. The rapid appointment of tumour site-specific nurses and the development of posts for palliative medicine, stemming from the Calman–Hine recommendations for reorganizing cancer services,²⁰ have created unparalleled challenges of adaptation to new working practices and procedures. Added to these significant changes are new opportunities to become involved in service planning and policy development as the reorganization of the NHS impacts on cancer and palliative care more broadly.^{21–23} This means that many aspects of the Macmillan Nurse role are now 'hidden' and not easily discernable to patients, carers and other health professionals with whom they have contact. Most recently, recommendations relating to the development and monitoring of national standards in cancer and palliative care²⁴ and the introduction of different levels of nursing practitioners^{25,26} have led to new pressures related to job performance, accountability and career advancement.

This paper examines the understandings and experiences of postholders in relation to the Macmillan Nurse role. Problems of ambiguity and role conflict facing Macmillan Nurses are highlighted through an examination of the mismatch of expectations between nurses and their managers about the appropriate focus of their work; key elements are then identified, which underpin these difficulties. Recommendations are made regarding the need to clarify the nature of the Macmillan Nurse role and the need to provide support and resources to postholders to best enable their adaptation to rapidly changing circumstances. The paper draws on the findings of a major evaluation study commissioned by Macmillan Cancer Relief and conducted using a comparative case study design in 12 settings in the UK.

Methods

The design and methods of the wider study are reported in an earlier paper.²⁷

In this paper, we draw specifically upon semi-structured interviews with the Macmillan Nurses ($n = 44$) and their

key colleagues ($n = 47$) across the 12 services (see Table 1). Four researchers (the lead author, PH, RM and JS) carried out the interviews in Trent region. Two researchers (NB and DH) carried out the interviews in Thames region. Semi-structured interview guides were developed for use across both regions, and interviews were tape-recorded with consent using high-quality recording equipment and transcribed verbatim. The researchers conducted initial analysis of the interviews during the process of compiling detailed case study reports on each site. At the end of the whole data collection period, one researcher (the lead author) cross-compared all 12 case study reports and all the individual interviews to identify core themes. The overall approach to data analysis was that of the constant comparative method employed in grounded theory.²⁸ The themes identified were as follows:

- managerial expectations versus day-to-day demands;
- 'learning the job';
- the changing nature of the patient care role;
- palliative medicine availability;
- site-specific nurse and palliative medicine consultants: issues of co-working and care pathway development;
- the role of education;
- research and audit.

These themes were subsequently presented to, and discussed by, the study participants at two one-day feedback conferences in January and July 2000. The January conference preceded the compilation of the final project report, while the conference in July was held to discuss the key findings of the report and six working papers submitted confidentially to Macmillan Cancer Relief during 2000. This paper draws on data presented in the latter documents and the issues highlighted by conference participants. It focuses primarily on 'managerial expectations versus day-to-day demands', 'learning the job', 'the role of education' and 'site-specific nurses and palliative medicine consultants: issues of co-working and care pathway development'.

Table 1 Interviews with Macmillan Nurses and their key stakeholders

Community Macmillan Nurses	22
Hospital Macmillan Nurses	19
Integrated (hospital and community) Macmillan Nurses	3
<i>Total Macmillan Nurses</i>	<i>44</i>
Senior Nurse Managers	16
Consultants	17
NHS Managers	8
Other	6 (1 psychologist, 1 GP, 3 tumour site-specific nurses, 1 clinical ethicist)
<i>Total key stakeholders</i>	<i>47</i>

Managerial expectations versus day-to-day demands

Macmillan Nurse managers emphasized the personal strengths of the individual postholders, their high clinical standards, their flexibility and their willingness and ability to work in a multidisciplinary way. However, one of the most critical issues reported by the nurses who participated in the study was that they perceive managerial expectations of their role to be at odds with the day-to-day demands made of them and their own interpretation of the job. The nursing managers of the Macmillan services saw their role as one of trying to support the nurses during their day-to-day work but also of acting as 'guides' in the ongoing process of development beyond a purely patient-centred role to that of service development and education. This was regarded as a crucial element in achieving the adaptation of services to structural and cultural changes associated with the wider provision of palliative care:

I think we are entering an era where I would expect the Macmillan Nurse to be functioning at a very advanced practice level, and having a bigger impact on practice across the board, rather than the more traditional nurse specialist post that does a lot of work with individuals. And so we should be leading research, should be leading clinical audit, should be evaluating evidence base across the profession, influencing colleagues, and that sort of high profile – I mean we still need the same kind of attributes, you know, that sort of caring and patient focus, but need to be perhaps a bit more strategic. (Senior Nurse, hospital service)

Macmillan Nurses in all 12 services were keenly aware of these expectations but felt often at a loss as to how to marry them to what they regard as central to the proper conduct of the job: direct contact with patients. All the nurses interviewed tended to identify closely with a traditionally patient-centred view of their role, and to derive maximum job satisfaction from face-to-face contact with patients. Indeed, face-to-face contact, particularly for hospital-based Macmillan Nurses who had the most opportunity to make this the focus of their work, was considered by some to take precedence over all other activities associated with the role:

This is why the notes don't get done, that's why there is always chaos, because we're not doing (other activities)... if we feel like we're not busy, we're not out there touching people and making face to face contact, we're not doing our job. (Hospital Macmillan Nurse)

For hospital-based Macmillan Nurses, maintaining clinical credibility among consultants and ward-based staff was especially important: without this, they could not hope to influence the culture and direction of 'acute' patient care towards a more palliative-focused model. A major way of maintaining credibility was to

be seen to be working closely, and very directly, with patients:

I also think in terms of credibility... it's important to have that patient contact. (Hospital Macmillan Nurse)

Identification with direct patient care was particularly important for postholders in comparatively newly established services where a 'clinical niche' had to be established; however, it was also marked among postholders who had been in the job since the early days of Macmillan Nursing. Some of these felt threatened by the rhetoric of clinical nurse specialism and continued to pursue a role that was almost exclusively concerned with direct patient care:

What I like most about this job, and I wouldn't work anywhere else in nursing, is the clinical work... I came into nursing to do clinical work, to work directly with people who were very ill. And I'm not interested in administration, management, teaching apart from as part of this [job] or anything else really. (Community Macmillan Nurse)

Overall, Macmillan Nurses perceived that pressures and expectations can pull in opposite directions:

I think there's a lot of pressure on us to do more and more of the indirect stuff such as the policy development, particularly with primary care groups evolving, [and] to do initiatives like developing pathways, I feel there's a big pressure on us to do a lot of that, but also from the primary health care team, you get a lot of pressure to have direct input to the patients because essentially they see you as having that role and being valuable in that way, so there's always a conflict between, you know, which bit is most important. (Community Macmillan Nurse)

Nurses not only recognized paradoxical pressures from clinical colleagues, they also worried that the public image of Macmillan Nursing, which they perceived as having been generated in part by the large-scale advertising campaigns of Macmillan Cancer Relief, was under threat because of the evolving emphasis on moving towards indirect care:

I think we're going to be put under an enormous amount of pressure to become less directly involved with patients but there again I think there's a conflict because Macmillan know that the way they generate monies is through generally our role the Macmillan Nurses and Macmillan Nurses being directly involved in families and in people's houses so on the one hand there is a big push to get us a bit more away from that but I think on the other hand they'll have, we'll always have to be there otherwise the generation of money won't, will probably start to dwindle. (Community Macmillan Nurse)

While recognizing the tensions around this issue of conflicting expectations, the majority of Macmillan Nurses in the services studied expressed high levels of commitment to developing the consultative and educational aspects of their role. In all cases, however, Macmillan Nurses reported that they felt that they rarely achieved the multifaceted demands of their work. For

many, a sense of overload resulted. As one experienced community Macmillan Nurse expressed it:

I think it's all the demands really, I mean you can sit in the office and purely do office work – you know around teaching and things, I could do that for a week, I'd never be finished. I could do academic work for a week, that would never be finished, and I could do solely clinical work and never finish, or never complete. So there's never a point where you think – or you know there is never a day where I don't have anything to do. (Community Macmillan Nurse)

Sources of conflict and ambiguity in the Macmillan Nurse role

We discuss here three key areas that contribute to the mismatch of expectations outlined above. One of these issues is new, while two are long-standing, but they conjoin to create a situation in which many Macmillan Nurses perceive almost insurmountable difficulties in reconciling their wish to continue to be closely clinically focused with the expectation that they reduce their clinical role and move towards a role that gives prominence to consultation and education. Resource concerns are a common element in each of the three areas.

Learning the job

Many nurses commented upon the importance of having some formalized support and supervision both in the early days of their career as a Macmillan Nurse and during ongoing professional development. Yet many had experienced little day-to-day mentorship, although most were appreciative of support they had received from particular senior individuals or from Macmillan Cancer Relief. For those nurses who had come out of 'pump-primed' funding, i.e., that provided for the first three years of their post by Macmillan Cancer Relief, opportunities for ongoing professional development were tightly linked to trust or directorate policy on study leave and the funding of programmes of study. Some nurses were better placed than others, and were given leave and some financial support to pursue undergraduate and postgraduate degrees, as well as other shorter courses. Others were less well supported, and found themselves trying to pursue educational opportunities whilst at the same time not being given either time or financial support to do so.

Education

The education of other health care staff, and to a lesser extent patients and carers, was regarded by all the Macmillan Nurses as critical in avoiding the 'crisis management' that many felt tended to characterize their role in regard to patient care. Education was seen to be the key to enhancing the assessment skills of other

staff and to ensuring that relevant patients are appropriately and quickly identified. Macmillan Nurses perceived a clear distinction between 'formal' education and 'informal education'.

Formal education was carried out by organizing study days and the development of educational materials for others. However, many nurses felt poorly prepared in terms of their educational background and information technology skills to carry out this type of activity and some actively avoided doing so:

You are just expected to suddenly go out and teach. So you have to teach yourself how to teach, and it's hugely, I think it's hugely difficult. (Community Macmillan Nurse)

Even for those nurses whose own education and prior experience better prepared them for delivering formal teaching, their abilities to expand and deliver such programmes were hindered by the underprovision of secretarial services, information technology and office facilities. Moreover, for the six hospital services where Macmillan Nurse numbers were very small, this aspect of their activities was constrained because of the constant demand posed by direct clinical care. The paradox here was that there was awareness that clinical demands would not lessen until a concerted period of time and significant resources had been spent in the very educational activities for which there was so little time. One hospital Macmillan service was notable insofar as the senior management had incorporated palliative care study days as part of the mandatory programme of education for all hospital staff. This was perceived to have led to a gradual shift in perceptions of the ward staff about the Macmillan Nurse role, and thus to more appropriate referrals and less 'fire-fighting' by the Macmillan team.

Informal educational activities were regarded as so integral to the Macmillan Nurse role that nurses found it difficult to consider them as separate from clinical care:

When you take into consideration that a lot of the education work is part of the clinical work as well in that there's education for patients and carers plus individual education, one-to-one, as in community nurses etc... so it's difficult I think to separate the two, to actually say what proportion, what percentage is clinical, what percentage is education and what percentage is consultative. (Community Macmillan Nurse)

All Macmillan Nurses recognized that in order to lessen dependency and repeated demands upon their time in the future, it is necessary to support and empower others rather than to 'take over'. Nurturing the skills of others in order to allow them to develop better understanding of how to react in particular situations was perceived as central to this process. This was described as close clinical contact, reminiscent of the type of clinical teaching remembered by many Macmillan Nurses as an integral part of their basic nurse training.

Moreover, Macmillan Nurses derived a significant amount of satisfaction from this type of close contact clinical teaching since it yielded the high level of patient contact many craved:

I was able to sit her down and work through the process; and rather than me rushing in and doing it for her, what I hope is that I was able to enable her to go and look at the issues and [that] she took it all on board. She said now you have explained it all to me, I can see what I need to do, I need to sit down with the patient first. So at least going through the steps with her gave her a better understanding of how to deal with the situation. (Hospital Macmillan Nurse)

I do sometimes think that's a good way of getting a handle on education. Like the old system when we did our training you have somebody there; a tutor with you that's going through things. (Hospital Macmillan Nurse)

An issue raised frequently, particularly by hospital Macmillan Nurses, was that pressures on ward staff often meant that they did not put into practice the skills that had been acquired. In such situations, ward staff might call on the Macmillan team almost as a 'knee-jerk' reaction:

Quite often at the moment because they, they're so busy... they're finding it difficult to think through situations – they don't seem to have that time. (Hospital Macmillan Nurse)

There was also a sense that Macmillan Nurses are put in the position of trying to act as role models, or even as substitutes, for inexperienced nurses and doctors who are overstretched and whose basic skills are lacking. Ward nurses, it seems, either frequently overlook, or simply do not know, how small interventions can make a big difference to patients' comfort and quality of life:

They can't move them, so they don't know how to deal with them, they don't know how to move [them], they don't know how to use their pain control, [or] to see the effectiveness of that pain control. (Hospital Macmillan Nurse)

Similarly, there was a sense in which junior doctors are left to deal with situations that are beyond them:

It was a good job I was there because it was left to a very junior doctor to break extremely bad news to her, so I was able to do it for him really, which I think was probably better in the long run. (Hospital Macmillan Nurse)

Several stakeholders highlighted the tensions that this type of role modelling could engender and how there was a risk that 'calling the Macmillan team' at times of difficulty could become part of routine practice for hard-pressed staff in hospitals.

Such problems were less frequently encountered in community services where District Nurses, who retain most responsibility for direct patient care, tend to be more experienced than their ward-based colleagues. However, lack of resources within community sites to pursue joint visiting with district nurses on a regular basis was perceived as thwarting the educational and 'partnership' potential of such activities.

Within both community and hospital services, the development of palliative care 'link nurse' positions is a commonly used way to try to address these problems. These individuals become responsible for 'cascading' information about palliative care to their colleagues. There were a number of pressures associated with the maintenance of this system. Firstly, a large number of 'link nurses' either leave or are promoted away from their original clinical area. Secondly, shortages of staff within some settings result in poor attendance at study days provided by the Macmillan Nurses for the link nurses. Lastly, the ability of Macmillan Nurses to spend the time needed to maintain regular contact with these postholders was limited. Again, the support of senior management in the provision of time and resources was critical in determining the degree of success of such innovations.

Site-specific nurse and palliative medicine consultants: issues of co-working and care pathway development

Following the recommendations of the Calman–Hine report in 1995,²⁰ tumour site-specific nurses are being introduced rapidly into cancer care services in the UK, particularly within hospitals. Macmillan Nurses saw the potential for tumour site-specific nurses to improve patient care, and noted the increased opportunities for developing shared education programmes, support networks for staff and improved strategic service planning for cancer and palliative care needs. However, more pessimistically, several issues of concern were raised. The constantly changing workload produced by the emergence of new posts that directly replicate the work of the generic Macmillan Nurses was perceived as stressful. Furthermore, anxieties were expressed frequently about the problems of overlap and potential confusion in the organization of clinical care between the two groups. In part, this results from the tendency to tie in new site-specific roles with particular consultants, with a sometimes inadequate regard for the 'goodness of fit' between the new postholder and the colleagues within the multidisciplinary palliative care field. This can mean that site-specific specialist nurses are isolated from their palliative care colleagues, with new postholders having to learn from scratch quite basic approaches to palliative care.

Issues of co-working were being addressed by the development of care pathways to guide the transfer of patient care between specialist nurses. However, the extent to which these were formalized varied, with some sites relying largely on informal contacts to arrange clinical care. Moreover, some managers did not perceive a particular need to supplement such informal contact with anything more formal. Where this was the case, and informal relationships and day-to-day contacts were weak, Macmillan Nurses expressed anxieties about the

possibility of patients not receiving an appropriate standard of care. Furthermore, where site-specific nurses did not have palliative care expertise, a risk was perceived of nonrecognition of palliative care needs.

Some trusts had decided to locate site-specific nurses and generic Macmillan Nurses within the same managerial structure, since it was recognized that site-specific nurses could suffer significant professional isolation. As well as improving support and supervision, the benefits that flowed from this arrangement included greater professional liaison and improved coordination of patient care. In these sites, worries about care standards were less frequently expressed.

A further issue concerned the Macmillan Nurses' relationship to palliative medicine. Some services had a history of established palliative medicine input; others were adjusting to the introduction of one or more posts in what was formerly a nursing-led service. Greater access to medical advice and support in coping with patients with complex needs were uniformly welcomed, as was the greater secretarial support that flowed from appointment of consultants to the service. Equally, it was appreciated that having a doctor on the team often made it easier to influence treatment, particularly where the patient's consultant tended to refer on a 'doctor-to doctor' basis or was reluctant to take advice from nursing colleagues. Policy and strategic planning is another area that was perceived to benefit, since senior doctors often have experience of this type of activity that is valuable to the rest of the team. Likewise, education of medical colleagues is often easier once a doctor is part of the team.

Notwithstanding these benefits, a number of anxieties were also voiced. These concerned the stress of adapting to different working patterns and referral procedures, a perceived risk of 'deskilling' among nurses and problems related to delineating role boundaries. Some doctors felt that they should be the natural team leaders, or they expected the Macmillan Nurses to fall in with changes that threatened the Macmillan Nurses' relationships with nursing colleagues *vis-à-vis* patient assessment. Most expressed a desire to nurture team working and collaboration with the Macmillan Nurses, but were at a loss to know how best to pursue this. In some cases, there seemed to be an ignorance on the part of doctors about what nurses did, or anxieties about goodness of fit between medical and nursing work:

I had a problem getting a sort of handle about what their workload was, as I say, what type of work they did in relation to palliative care, as opposed to other aspects of continuing or supportive care. It seemed that they were not always working purely from a clinical point of view; some of their work was almost sort of, benefits and social services, or working with that end of the spectrum... where I worked before, for instance, as part of an integrated hospice and home-care team... [it was] totally transparent what the nurses were doing, they knew what the policy was from

the doctors, and I think the medical policy should come from the doctors, you know, and go out from there, not necessarily – it's not a nursing decision about which drugs to use, whatever, that sort of thing. And I don't think they've necessarily fully appreciated that. (Palliative Medicine Consultant)

By contrast, in one multidisciplinary hospital service, relationships between doctors and nurses had been established particularly clearly, and enhanced collaboration and smooth relationships appeared to be the result. This team had evolved over a period of 12 years, and had been established from the start as a multidisciplinary service. It had not faced the challenges of sudden adaptation to team organization and had developed working practices (such as joint on call) that were highly conducive to shared medical and nursing care.

Discussion

Davies observes several issues concerning the impact of rapid change on nurses.²⁹ Most fundamentally, she notes that the influence on nursing work tends to be ignored, with health policy analysts and government pronouncements either assuming: 'that nursing is affected in similar ways to medicine but to a lesser degree, or [leaving] nursing altogether out of account'.²⁹ A critical aspect of this, argues Davies, is an overwhelming assumption that the work performed by nurses is enacted unproblematically *in spite* of any wider changes to the environments within which nurses practice. The service requirements to enable nurses to care for patients and their families are little discussed, and the nature of nursing work, even at the level of the clinical nurse specialist, is poorly articulated.

The provision of programmes of educational preparation and ongoing support and mentorship was an overarching problem for the Macmillan Nurses in this study as they struggled to adapt their roles to the demands of change. Although almost all appreciated that a broadly based educative approach was the best way of ensuring that the benefits of palliative care would be available for a larger numbers of patients, most lacked the resources, organizational infrastructure, managerial support and collegial mentorship with which to pursue such an approach successfully. Managers who were somewhat distant from the day-to-day lives of the Macmillan Nurses or who had little understanding of palliative care and its ideals, while allowing nurses to operate autonomously, were less helpful in situations where nurses needed guidance and support in developing a genuinely specialist palliative care service. Linked to this was the observation that most services had been expected to adapt smoothly to major changes in team structure, with little or no guidance in clarifying the

roles and responsibilities of colleagues in the multi-disciplinary palliative care team. Some services were addressing this issue effectively; for others, it remained an issue.

Some Macmillan Nurses, although by no means all, found the shift from very direct patient involvement extremely difficult. The reduction in direct feedback and immediate job satisfaction produced as this type of involvement lessened was experienced as painful, and in some cases was replaced by a sense of role overload, frustration and a lack of self-worth. In some sites, following on the recommendations of the Calman–Hine report,²⁰ clinical supervision had been introduced in an attempt to address these and other issues. Although mixed reactions were forthcoming, where the style of supervision was sensitive to individual postholders' needs, Macmillan Nurses found regular supervision invaluable in giving them a broader perspective on their work and in enabling them to address issues of working strategy and team building. This study suggests that there needs to be recognition that close and costly clinical contact, in the form of clinical 'tutoring' and informal education at the bed side, may continue to be necessary in situations where generic staff lack the time, resources and skills to care appropriately for people with palliative care needs. More fundamentally, it might be argued that an over-emphasis on specialism is misplaced in those contexts where 'basic care' cannot be given to an adequate standard. Recent reports show that this is of particular relevance to some areas of the acute hospital.^{30,31} Addressing this contradiction may require a hard examination of the relative status accorded to hands on 'caring' work with which the majority of nurses and nursing assistants engage, and from which it is so difficult for so many Macmillan Nurses to disengage. Davies makes the uncomfortable observation that those expressing ideas about professionalism in nursing, and by implication specialism in nursing, tend to remain silent about the caring work that nurses do, and with which the majority identify.²⁹

Conclusion and recommendations

The development of a supportive care strategy is a key aspect of proposals in the National Cancer Plan.²³ Improving access to care, enhancing the continuity of care and paying attention to patients' experiences of care are posited as key objectives. Macmillan Nursing has a crucial role to play in meeting these objectives and in influencing the speed with which they are achieved in the field of specialist palliative care. However, this study has pointed to a need to clarify the nature and scope of the Macmillan Nurse role in order to ensure that Macmillan Nurses' expertise is used efficiently and effectively (Webber J,

personal communication). This finding parallels evidence from a detailed review of the literature, which concluded that training and supervision, clarity over lines of responsibility and strategic planning with adequate resource allocation are all essential if change is to be accommodated effectively by nurses.¹⁸

We suggest that much greater attention be directed at the environments within which Macmillan Nurses operate. Specifically, we recommend that paying greater attention to issues of team working, increasing the staffing complement, improving the skill mix and enabling generic staff to put into practice the education they have received in palliative care have the potential to bring many benefits and ultimately will allow a climate to develop within which specialist practice in palliative care nursing can flourish. Ignoring these issues will mean that Macmillan Nurses face a period of rapid change in which the tension is likely to be heightened between the perceived imperative to provide direct patient care and the longer-term goals of developing a genuinely specialist service. Addressing these issues will enable Macmillan Nurses to contribute to a future in which 'support and care is more widely available and the expertise developed in palliative care is disseminated effectively'.³²

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