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**COMMUNITY NURSING ROLES AND THE GOLD
STANDARDS FRAMEWORK FOR COMMUNITY
PALLIATIVE CARE**

Final Report

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EXECUTIVE SUMMARY

INTRODUCTION

This report presents the findings and conclusions of a research study examining community nursing roles in palliative care, carried out by a research team from the Centre for Applied Psychological Research at the University of Huddersfield, and funded by Macmillan Cancer Support.

The Gold Standards Framework (GSF) is a systematic, evidence based framework to improve the provision of palliative care in the community for those approaching end of life. It is recommended in the NHS End of Life Care strategy (EoLC), and following a series of pilot stages is now utilised widely across the United Kingdom. The philosophy, principles and practices included in the GSF inform the analysis throughout the present study.

There have been major developments in community nursing and in EoLC in the community in recent years. Overall, policy has emphasised patient choice and the need to manage patients with complex conditions in their own homes. There has also been a growing recognition that palliative care provision must be extended to cover non-cancer patients, especially with conditions such as heart failure and chronic obstructive pulmonary disease (COPD). A recent development has been the introduction of the Community Matron role, with a brief to provide case management for patients with complex long-term conditions, in order to maintain them outside of hospital for as long as possible.

In this context of policy and organisational change, this study sought to examine community nurses' experiences of delivering palliative care, focusing especially on how they perceived their roles and identities and how they related to other agencies, patients and carers. The two main groups we included in the research were district nursing team members (District Nurses and Community Staff Nurses) and Community Matrons. The overall research question of the project was as follows:

What is the relationship between community nursing roles and the delivery of primary palliative care, from the perspective of best practice described in the GSF?

METHODOLOGY

The study took a qualitative, interpretivist approach, in line with its focus on participants' experiences in community palliative care, and its concern with the concepts of professional roles and identities.

Design

Semi-structured interviews were used to collect participants accounts. They were carried out in three geographical areas, selected to represent a diversity of conditions that might be expected to have an impact on community palliative care. The areas (anonymised with the use of pseudonyms) are described below:

Goldborough is in the south of England, and comprises a number of small to medium sized towns and smaller rural communities. It is mostly affluent, with a small ethnic minority population. At the start of the research its Primary Care Trust (PCT) was due to merge with others in the near future.

Woolbeck is in the north of England, centred on a large former industrial town, but also covering smaller towns and rural areas. In parts it has a very high ethnic minority (south asian) population, and high levels of deprivation. Woolbeck is covered by a single PCT with no history of, or plans for, merger with others.

Coaltown covers one medium-sized town and surrounding communities. Formerly dominated by a single heavy industry, it has high levels of deprivation and associated ill-health. The population is overwhelmingly white, has a high proportion of older people. Shortly before the project commenced, their PCT merged with a neighbouring PCT.

Participants

Our sample in each area consisted of three groups: district nursing team members (DNs), Community Matrons (CMs) and a small number of “key stakeholders” (KSs) from other professional/managerial groups. Totals were as follows:

Goldborough: eight DNs, six CMs, three KSs.

Woolbeck: ten DNs, three CMs, two KSs.

Coaltown: six DNs, six CMs, two KSs.

All but two of the participants were female.

Interview procedure

The interviews were in three parts. The first section asked about participants' involvement in palliative care and experience of the GSF. The final part asked for their thoughts on the future of community palliative care and nursing roles in it. In the middle section, we utilised a technique called 'Pictor' to elicit detailed accounts of particular cases. This involves the interviewee creating a graphical representation of how different parties were involved in the case. All interviews were audio-taped and transcribed in full.

Analysis

We used a version of the “matrix” approach. Key themes from each participant were summarised on tables, which were then condensed further in order to highlight patterns in perceptions and experiences, allowing comparisons between professional groups and across geographical areas.

Ethics

Approval for the study was granted by Liverpool MREC.

FINDINGS

Our findings are summarised under four headings: GSF utilisation and function, roles and relationships in community nursing, relationships between community nurses and other agencies, and relationships between community nurses and patients/carers.

GSF utilisation and function

The GSF was used widely (though not universally) in Goldborough and Woolbeck, but rather less so in Coaltown. The most important factor influencing uptake was level of support from GPs. Participants felt that the main reason for resistance to the GSF by GPs was their perception that it would involve them in too much additional work. Community nurses themselves were overwhelmingly positive about the GSF, although some of them – especially the Community Matrons – had not had much experience using it. Nurses felt that the GSF encouraged good communication and co-ordination, systematised care, and raised awareness of palliative care amongst health and social care professionals. District nursing teams who were not well-supported in using the GSF by GPs tried to work to implement its principles as much as possible, although there were limitations without proper GP engagement. Our participants generally were aware of the need to extend the use of the GSF to cover non-cancer patients, though the extent to which they were already doing so varied. There was a high level of enthusiasm for the Liverpool Care Pathway (LCP) which was being introduced in all three areas around the time of our study.

Roles and relationships in community nursing

In all three areas, relationships between district nursing teams and Community Matrons appeared to be problematic. Factors influencing this included: uncertainty about Community Matron roles in general, whether Community Matrons had prior local experience of working in the community, and whether other organisational changes had created tensions. These factors coincided to the greatest extent in Coaltown, where the relationship problems between the groups of nurses seemed most severe.

There was agreement amongst all our participants that district nursing teams played a central role in community palliative care. District Nurses saw themselves as in effect occupying a case management role for these patients. However, some of the Community Matrons and key stakeholders raised doubts as to how effectively District

Nurses were able to fully carry out case management. There were two main reasons for this: firstly, the pressure on District Nurses' time because of increasing workloads, and secondly, the reactive and task-focused nature of the district nursing role in general.

There was considerable variation in perceptions of how the Community Matron role related to palliative care. This was true within each participant group, but there was also a marked difference between them with district nursing team members overall seeing less of a role for them than the Community Matrons did themselves.

Relationships between community nurses and other agencies

Relationships with GPs differed markedly from practice to practice. At best, GPs worked closely with nurses, acting as a real team. At worst, nurses struggled to get any time from GPs to discuss palliative cases with them, and sometimes felt they (GPs) tried to “dump” too much responsibility on nurses. Some Community Matrons had also experienced hostility from GPs towards their role *per se*.

Our participants found Macmillan Nurses a useful source of specialist advice and support, especially regarding medication and symptom control at the very end of life. This was of greatest importance for staff inexperienced in palliative care, or where GPs were not supportive of nurses' work in EoLC. The level of contact between Macmillan Nurses and Community Matrons was strongly dependent on which area they came from. In Goldborough there were numerous examples of close collaboration while there was much less contact in Woolbeck and Coaltown.

Participants discussed relationships with many other professions in the course of their interviews, amongst which social services and the acute sector were mentioned frequently. Participants were generally understanding of the organisational and financial contexts in which social services staff worked, but were still sometimes frustrated at their relatively slow response times. Home care assistants were often praised for their work with patients and effective communication with nurses, although it was recognised that they varied in experience and ability. Regarding the acute sector, problems of communication and co-ordination were noted in some cases. Community Matrons tended to find it easier than district nursing teams to access professionals in the acute sector.

Relationships with patients and carers

All participants stressed the need to place patient and carer needs at the centre of service delivery, and there was consensus regarding the benefits of getting to know them over an extended period of time. Community Matrons often had an advantage, as their role meant they often picked up patients with long-term conditions before they reached the terminal stage. The nurses we interviewed all valued their involvement in palliative care highly, although some of them still felt uncomfortable discussing death and dying with patients and carers.

DISCUSSION

District nursing teams are enthusiastic about the GSF and play a key role in implementing the framework, although their ability to do so is partly dependent on GPs' level of engagement with it. Nurses see the main benefits as improved communication and co-ordination, greater awareness of palliative care, and systematisation such that patients are less likely to "slip through the net". In terms of providing a service in line with GSF recommendations, district nursing team members and Community Matrons both have strengths and weaknesses. The former are often well-informed about palliative care (at least for cancer), their role is understood and recognised by other agencies, and their skill mix teams ensure continuity does not depend on the presence of one individual. On the negative side, they have a heavy workload and their ability to case manage palliative patients may be limited by the task-oriented and reactive way in which they generally work. In contrast, Community Matrons have case management skills and the ability to use them optimally as they often build relationships with patients before the terminal stage. Their expertise is particularly in long-term conditions, and in managing such patients they link with wide networks of health and social care agencies. However, they do not work as part of a skill mix team, and their role is not well understood by other professionals – indeed at the time of our study many of them were none too sure about it themselves.

The difficult relationships that we found between district nursing teams and Community Matrons can be understood in terms of the main threats to professional identity they experienced. District Nurses and their teams had a well-established identity in community health services, but felt this was under threat from local and national

organisational changes. They therefore tended to have a defensive attitude towards their own role, and were cautious (or even hostile) towards collaboration with Community Matrons. In contrast, Community Matrons feared isolation and rejection in a new role, and therefore sought to be inclusive towards district nursing teams.

CONCLUSION AND RECOMMENDATIONS

Between them, district nursing teams and Community Matrons have a range of skills and expertise well-suited to the demands of community palliative care. For these to be utilised fruitfully, attention must be given to the development of community nursing teams. To minimize tensions and anxieties as roles change further, policy makers and managers need to keep issues of professional identity at the forefront of their thinking.

The Pictor technique we used in this study proved very successful in helping participants reflect on specific cases, and they found the task to be enjoyable and stimulating. We feel it has great potential both as a research tool and as an aid to education and development regarding joint working.

Recommendations for policy and practice

1. There needs to be much better integration between district nursing teams and Community Matrons in relation to palliative care. Including both groups within a single community nursing team seems to us the most promising option, but we recognise there may be other solutions.
2. Integration is likely to require at least some degree of service redesign, which should include outcomes measurements to determine efficiency of resource utilisation and effectiveness of any change to service provision.
3. The likely impact of revised work roles on professional identity must be seriously considered – both in terms of the nature of roles and the implementation process. This requires a review of the evidence from research literature, and proper consultation with those directly affected by changes.

4. To optimize their contribution to community palliative care, both groups of nurses are likely to need training and development. This includes: case management for both groups; community palliative care in general, and EoLC tools (GSF, LCP and PPC) for Community Matrons; palliative care for long term conditions for district nursing teams.

Recommendations for research and evaluation

1. Different models of community nursing team integration need to be evaluated in terms of relationships within the team, and outcomes.
2. Research needs to examine the links between community nursing teams and the acute sector, specialist palliative care and social services, to identify factors in these relationships that impact on the quality of care.
3. Our research highlighted the complexity and diversity of the networks of agencies involved in the community palliative care. Future research needs to examine how patients and carers experience their interactions with these networks.

1. INTRODUCTION

This report presents the findings of a research project funded by Macmillan Cancer Support to examine the roles of community nurses in palliative care, with a particular emphasis on the influence of their relationships with professional colleagues, patients and family carers in shaping role perceptions. In this section we will provide some brief background to the project in terms of the Gold Standards Framework for Community Palliative Care (henceforth 'GSF'), recent policy relevant to this area, and academic literature providing a theoretical conceptualisation of professional roles and identities. Subsequent sections will describe the methodology of the study, present the main findings, and consider implications for future policy, practice and research.

1.1 The Gold Standards Framework

The GSF is a systematic, evidence based framework to improve the provision of palliative care in the community for those approaching end of life and to provide encouragement and support for the primary health care team. Originally developed in West Yorkshire in 2001 by Keri Thomas, a GP specialising in palliative care, the GSF recommends a practice or locality based system which optimises the organisation of care for patients and carers leading to better co-ordination and communication between community teams. Advanced care planning is a core component of the GSF and suggests that teams need to move from reactive to proactive care to avoid crisis situations. The framework also seeks to maximise knowledge and skills within different community team roles (Thomas, 2003). The GSF ensures that primary health care teams can appropriately identify palliative care patients, assess and record their needs and initiate a plan of care that takes account of patients' choices with particular reference to place of care and place of death. The key standards in the GSF are summarised in the "seven Cs" (see Box 1, below). After several successful pilot programmes (King , Thomas, Martin, Bell and Farrell, 2005) Macmillan funded a spread programme and, by January 2006, the GSF had been introduced to nearly a third of GP practices in the UK.

Box 1: The seven 'Cs'

The seven 'C's' of the GSF focus on standards aimed at encouraging and enabling practices to improve care for patients:

Communication

with the recommendation for the compilation of a supportive care register to record, plan and monitor patient care

Co-ordination

by a named person, e.g. district nurse or GP, who takes responsibility for organising team meetings for discussion, case analysis and education

Control of symptoms* and *Continuity of care

where patient symptoms are assessed, discussed and treated and details of the plan of care are passed on to the out-of-hours services

Continued learning

through discussion of patients' problems and using significant event analysis to consider possible improvements for future work

Carer support* and *Care in the dying phase

where teams link together to make sure carers are listened to and supported in bereavement and the patient is enabled to die in the place of their choice.

1.2 Palliative care in the community: policy and practice

Currently, the National Health Service (NHS) in England is undergoing a period of profound change which is impacting on clinical roles and standardisation of care. Following the publication of the NHS Cancer Plan in 2000 that presented the government's strategy for investment and reform across the NHS, cancer services were given high priority. This remains the case as in 2007 the Health Secretary launched a comprehensive five-year plan to further improve NHS cancer services, the Cancer Reform Strategy. In 2001 The National Institute for Clinical Excellence (NICE) began working on guidelines for supportive and palliative care best practice to enable patients with cancer to be better cared for at the end of their lives and in 2003 the Department of Health (DH) strategy 'Building on the best: choice, responsiveness and equity in the NHS' was published. This strategy is based on evidence that patients and carers want choice over care at the end of their lives and, shortly afterwards, in 2004 the NHS End of Life Care (EoLC) programme began.

This programme aims to spread the principles of good practice that had been successfully developed to improve the lives of people with cancer, to those people with other long term conditions to make sure that all patients being looked after in the community receive equitable quality of palliative care. The EoLC programme advocates the use of three key educational tools (GSF, Preferred Place of Care (PPC) and the Liverpool Care Pathway (LCP)), to support practitioners to develop new service models in primary care and to provide an underpinning evidence base for best practice within palliative care. At the same time, in 2004, 'Improving Supportive and Palliative Care for Adults with Cancer,' guidance was published by the National Institute for Clinical Excellence which also recommended the three tools to support high quality care for end of life. The Liverpool Care Pathway (LCP) is promoted within the GSF for use at the terminal stage (the seventh 'C' as shown in Box 1, above). It consists of a multi professional document which provides an evidence based framework for caring for people at the end of their lives. Developed from the concept of transferring best practice in hospice care into other care settings, the LCP is now being used in the acute sector, care home and community setting where it was introduced in 2005. The LCP provides guidance for health professionals on how to manage symptom control in the terminal phase and provides advice on management of other aspects of terminal care. The PPC is a patient-held document which records and monitors patient and carer choice about the services and care they receive at the end of their lives. The document aids communication between the health professionals and agencies involved in a patient's care. The document provides an opportunity to record:

- A family profile and carers' needs
- The patient's thoughts about their care, their choices and preferences
- The services that are available in a locality and being accessed by the patient

Changes in care needs

This extensive work in the field of supportive and palliative care has now culminated in the imminent publication of the first definitive End of Life Care Strategy due in 2008 alongside Lord Darzi's NHS Next Stage Review Final Report. Practitioners now have clear evidence, tools and templates to enable them to provide optimum palliative care in the community to all patients, whatever their condition, at the end of their lives.

In February 2005 new DH guidance 'Supporting People with Long Term Conditions: Liberating the talents of nurses who care for people with Long Term Conditions' was issued to the NHS, nurses and health professionals. This introduced the new role of the Community Matron which would enable nurses to give one-to-one support to the most vulnerable patients with long-term conditions and complex needs, many of whom will have had repeat hospital admissions. The Community Matron acts as a case manager working closely with GPs, social care and other agencies. The Quality and Outcomes Framework (QOF) gives practices incentives to improve the way they care for patients with long term conditions and now includes clinical indicators for palliative care (Thomas and Free, 2006). The National Primary and Care Trust Development Programme (NatPaCT, 2005), however, claims that care is still reactive, episodic and geared around acute situations. National Service Frameworks (NSFs) have started to emerge offering guidance to nurses on how best to manage these complex conditions in the community. It is suggested that the Community Matron role provides a model for District Nurses to build on their success and work with colleagues in new and innovative roles to improve care in the community and reduce hospital admissions and it is anticipated that there will be 3,000 Community Matrons in post attached to GP practices by March 2008.

1.3 Theorising professional roles and identities

Effective joint working with other professions is crucial to the work of community nurses in palliative care (Williams and Sibbald, 1999; Poxton, 1999). Some of our own earlier research has, for example, shown the importance of positive working relationships between District Nurses and GPs for the implementation of the GSF (King et al, 2005) and the need for good communication and coordination between in-hours and out-of-hours services to support palliative care patients in the community (King, Thomas and Bell, 2003; King, Bell and Thomas, 2004). There are, however, many potential barriers to successful collaboration across professions in community palliative care. These include organisational issues (such as the lack of co-terminosity between service providers, or the different funding arrangements between professions) and issues of inter-group relations, reflecting both local circumstances and the wider historical and cultural contexts of different professions.

In our view, the concept of professional identity is fundamental to understanding many of these difficulties. People's sense of what it means to be a District Nurse, a GP, a Social

Worker or whatever shapes the way they understand their role and their perceptions of others' roles and identities. Thus a Social Worker may see "promoting independence" as a core to her professional identity, and react negatively to what she perceives as a District Nurse's attempts to "do too much for a client (King and Ross, 2004). Our understanding of professional identity draws on symbolic interactionist views of the professions (e.g. Macdonald, 1995) and constructivist psychological approaches to the person (e.g. Butt, 1996). These traditions emphasise that professional roles and identities are not fixed aspects of social structures, but are defined through the ways in which individual professionals interact with the social world they inhabit. This does not mean that community nurses (in the case of the present study) are free to construe roles and identities in whatever way they please; they are inevitably influenced by the views of professional bodies, their interactions with nursing and other professional colleagues, and of course the expectations of patients.

There are a number of implications for our research arising from this theoretical orientation. Firstly, it suggests that local differences in professional roles and identities are likely, and that we need to examine the social context of particular Practices and nursing teams to understand such differences. Secondly, it places relationships and interactions at work at the centre of the research agenda. Thirdly, it necessitates a methodological approach that is flexible and able to examine nurses' experiences in depth.

1.4 Development of the research proposal

The proposal for this project was developed through the iterative commissioning process used to support the work of the Macmillan Evaluation and Research Group. The original proposal was reviewed by the full group, including Macmillan managers, academics (most of whom are also clinicians) and two lay members. To facilitate input from the lay members, a separate lay version of the proposal was written. In the light of feedback from the group, a final version of the proposal was produced and funding for one year (later extended to 18 months) was approved. The project ran from May 2006 to November 2007.

The overall research question of the project was as follows:

What is the relationship between community nursing roles and the delivery of primary palliative care, from the perspective of best practice described in the GSF?

2. METHODOLOGY

2.1 Methodological approach

In line with the theoretical position described above, the methodological approach for this research will be qualitative and interpretivist. Such an approach facilitates a focus on the way participants make sense of the experiences under investigation – in this case, their involvement in community palliative care – and emphasises that these experiences must be understood in a range of contexts. The relevant contexts here include biographical, organisational (at the nursing team level) and health policy (as it relates to community palliative care). This kind of research does not seek to claim generalisability in the statistical sense, but rather to deepen our understanding through the detailed and thorough collection and analysis of data from particular cases. By careful selection of cases, and rigorous analysis clearly described, the research can provide lessons relevant to the practice of community palliative care more widely.

2.2 Method

2.2.1 Design

The study employed a semi-structured interview method to examine participants' experiences of working in community palliative care. Because we were interested in the ways in which contextual aspects (such as organisational arrangements and patient population characteristics) might shape community nursing roles and relationships, we carried out the study in three geographically distinct areas. In the light of the policy and practice issues outlined earlier, our data collection focused on two main groups of community nurses: district nursing team members (including qualified District Nurses and Community Staff Nurses) and Community Matrons. In each area we also interviewed a small number of "key stakeholders" from other professional groups to help broaden our understanding of the local situation regarding community palliative care.

2.2.2 The study areas

We selected areas which differed in population characteristics and organisational aspects of community palliative care.

*Goldborough*¹ is in the south of England, and comprises a number of small to medium sized towns and smaller rural communities. It is largely affluent, with some pockets of deprivation, and has a small ethnic minority population. At the start of the research this area was covered by a single Primary Care Trust (PCT); however, during the project this PCT merged with others to create a single larger Trust. Also at this time, Trust managers were pursuing radical changes to the way that community nursing services were commissioned.

Woolbeck is in the north of England, and corresponds to a single PCT that has not been involved in mergers. It centres on a large former industrial town, which has several areas of severe deprivation, many of which also have a very high ethnic minority (south asian) population. Elsewhere, the area covers smaller towns and villages, some of which are in quite remote rural settings. District nursing services are organised in three geographical areas. There is quite a high proportion of small and single-handed General Practices in some parts of the area.

Coaltown covers one medium-sized town and surrounding communities. Formerly dominated by a single heavy industry, it has high levels of deprivation and associated ill-health – notably in heart disease and Chronic Obstructive Pulmonary Disease (COPD). The population is overwhelmingly white, has a high proportion of older people and is notably insular. Shortly before the project commenced, this PCT merged with a neighbouring Trust within which different models of service delivery operated.

2.2.3 Participants

We sought to recruit the majority of our participants through Community Nursing managers in each of the three areas, who were asked to distribute information packs (including a reply slip indicating willingness to participate) to all district nursing teams

¹ Note all three areas are referred to by pseudonyms, to preserve participant anonymity

who had at least some experience of using the GSF. Similar packs were also distributed to all Community Matrons in the three areas. Our target was to recruit ten nurses from each area, of whom at least two should be Community Matrons. In the event, we found in all three areas that more Community Matrons were willing to be interviewed than anticipated; we therefore increased the sample size to a maximum of 14 nurses per area. It should be noted that in Coaltown, the final two District Nurses were interviewed together at their request, as a result of difficulties in finding interview times for them separately.

In addition to the Community Nurse participants, we interviewed up to three “key stakeholders” from each area. These were members of other professions involved in palliative care who were identified during the course of the study as people who could contribute to our understanding of how community palliative care operated in their locality.

Table 1 shows the participants from each professional group for each area. Only two of the participants were male – one Community Staff Nurse and one District Nurse.

Table 1: Participants

	<i>Participant type</i>		
	District Nursing team	Community Matrons	Key Stakeholders
Goldborough	5 District Nurses 3 Community Staff Nurse	6	3 (Clinical Managers for district nursing teams – all also had a clinical role)
Woolbeck	5 District Nurses 5 Community Staff Nurses	3	2 (End of Life Care Facilitator, Professional Lead for District Nursing)
Coaltown	5 District Nurses 1 Community Staff Nurse	6	2 (Consultant in Palliative Medicine, Palliative Care Social Worker)
Totals	15 District Nurses 9 Community Staff Nurses	15 Community Matrons	7 Key Stakeholders

2.2.4 Interview procedure

We developed an interview guide to help focus our semi-structured interviews, which we used flexibly to allow participants to bring up issues of importance to them that we might not have anticipated. (A copy of the interview guide is included in appendix **one**). All interviews were audio-recorded and transcribed in full. In one case (a key stakeholder in Woolbeck) the interview failed to record; this participant is therefore not included in the analysis nor in the table above.

The interviews were in three parts. The first part asked participants about their involvement in community palliative care, and their experience of using the GSF. The final part asked about their hopes, fears and expectations for the future of community palliative care and their profession's role in it. In between these two, we used a technique we refer to as "Pictor" to elicit an account of a specific palliative care case

from each participant and assist them in telling their story of their engagement in the case. (The technique is derived from a procedure initially used in family therapy by Hargreaves (1979) and first developed for use in research and education in community healthcare settings by Ross, King and Firth in 2005).

The first step in the 'Pictor' process is to ask the participant to bring to mind a palliative care case that they remember clearly. They are then provided with a large blank sheet of paper (A1 size) – and a stack of arrow-shaped 'Post-It' notes. The participant is asked to write on the arrows the initials, role title or a pseudonym for every person they can think of who had some involvement in the case. They must include themselves and the patient. There are no fixed rules as to how they should place the arrows, but we do suggest that they might use aspects such as the direction of the arrows and proximity to other arrows to indicate features of relationships in the case. Once the layout (or "chart") is completed, the interviewer uses it as the basis for a discussion of the case. Appendix two presents an example of one of the Pictor cases, including the chart produced for it.

2.3 Analysis

Interviews were analysed using a variant of the "matrix" approach (Nadin and Cassell, 2004). This is a style of analysis that is particularly well-suited to relatively large qualitative data sets, where the researcher wishes to abstract key issues for particular groups without losing sight of the context of the original accounts. We identified main thematic areas pertinent to the research question on the basis of our close reading and discussion of a sub-set of the data. For each respondent we summarised on a table ('stage one matrix') the key points from their transcript that related to each thematic area, indexing them by transcript line numbers to enable us to go back to respondents' original words as necessary. Next, we identified six emergent questions to guide our analysis of the data in the stage one matrices, such that it would enable us to address the overarching research question of the project. These questions served as thematic headings for second stage matrices, condensing and interpreting the material on the stage one matrices. (Appendices three and four present the thematic areas and emergent questions used in the stage one and two matrices respectively).

We produced separate stage two matrices for district nursing team members, Community Matrons and Key Stakeholders in each area, allowing us to see patterns of

similarity and difference between professional groups and areas. Throughout this process we referred back to the transcripts in order to clarify ambiguities and to guard against any tendency to “read in” to their accounts. We also critically examined each others’ analysis at each stage of the process.

2.4 Ethics

Approval for this study was obtained from the Liverpool MREC and from the appropriate NHS bodies responsible for research governance in the areas included. All names of participating individuals and organisations are replaced by pseudonyms, as are any other people or places they refer to that might identify them.

3. FINDINGS

On the basis of our examination of the sets of stage two matrices, we have organised our findings under four headings: GSF utilisation and function, roles and relationships in community nursing, relationships between community nurses and other agencies, and relationships between community nurses and patients/carers. Many of the major themes emerging from the analysis proved to be common across all three areas; we will indicate where this is not the case and local context had a substantial impact on participants’ views and experiences.

3.1 GSF utilisation and function

We have divided this section into two parts. In the first we look at participants’ perceptions of how the GSF is used in their area, and the factors they see as influencing this. In the second we look at their views and experiences in relation to three important issues for the future development of the framework: its use with non-Cancer patients, and the incorporation of other end of life care tools.

3.1.1 Perceptions of local GSF utilisation

In Goldborough and Woolbeck there appeared to be quite a high level of GSF utilisation, while this seemed lower in Coaltown. However, across all the areas participants noted significant variation in whether and how well the GSF was used in individual GP practices. The crucial factor here was the degree of support from GPs. Where GPs were interested in palliative care, the framework was well-embedded into the way practices

worked. In contrast, where GPs reportedly did not have a particular interest in palliative care, they were more likely to either make only limited use of the GSF or not to engage with it at all.

We're quite lucky here, we have a very pro-active GP group, but where I used to work the GP's were quite backwards really with things like this, and they weren't as willing to take it on and implement it properly. I think you have to have your GPs on side for it to work.

(Winifred Johns, District Nurse, Woolbeck)

Nurses felt that the main reasons for this were GPs' perceptions that fully adopting the GSF would mean extra work (especially extra paperwork) for them. In Coaltown there were additional historical factors that explained more widespread (but not universal) resistance from GPs – in particular, individual influential GPs were hostile to the framework, either because of aspects of the original implementation process or because of a dislike of the contents and philosophy of the programme itself. One Coaltown participant referred to the impact of the allocation of QOF points to GP practices for implementing certain processes and procedures in palliative care that are incorporated in the GSF. This was felt to be a mixed blessing; while it could encourage GPs to “sign up” to the framework, there was a danger that they could do so with a “tick-box” mentality where the goal was to do the least necessary to obtain the points, without any deep-seated changes to their delivery of palliative care.

While GPs were described as widely varying in their attitudes towards and involvement in the GSF, community nurses were overwhelmingly positive. (This included Community Matrons, although they varied considerably in how much knowledge and experience of the GSF they had, usually as a function of their career history before taking on the role). Nurses emphasised its value for encouraging good communication and co-ordination between agencies, systematising care so that all aspects were addressed with all patients, and raising awareness of palliative care amongst professionals.

Well it's good for the patient in the long run, you know what I mean...you don't forget anything, it's all there.

(Marie Dobson, District Nurse, Coaltown)

It gives you that framework and people who work in the palliative care area work within that and therefore they know who to communicate with, you know, it's not as fragmented as probably it used to be.

(Sylvia Budd, Community Staff Nurse, Goldborough)

District Nurses often took the lead role in implementing and running the GSF for the practice(s) they worked for. Where GPs were not strongly engaged with it, district nursing teams would try to use their relative autonomy to do as much as they could themselves. For instance, district nursing teams might hold their own palliative care list to supplement the more narrowly-focused cancer registers held by GPs. However, the impact of initiatives from community nurses could always be limited by GPs who did not share the nurses' prioritisation of palliative care, for example by refusing to hold regular meetings to discuss palliative care patients.

I cannot get a team meeting here with the GPs, the social worker - I mean this is the ideal: social worker, Macmillan nurse, district nurses, practice nurses, because they could be involved, and we (could) all sit down and all talk, and go through the patients and see what's gone on. That does not happen, that will not happen, they (GPs) will not entertain it.

(Jo Harper, District Nurse, Woolbeck)

While at the level of the individual practice GP support had a key influence on the utilisation of the GSF, at the area level the actions of influential champions was important. In Woolbeck, a very knowledgeable and experienced GSF Facilitator had played a substantial role in developing the framework, and two of the District Nurses we interviewed had had a close involvement with the very earliest stages of the development of the GSF. In Coaltown the arrival of a GP with Special Interest (GPSwl) in palliative care was seen as offering the possibility of countering the negative view of the GSF noted above. In Goldborough the community nursing clinical managers took an active role in driving forward the spread of the GSF.

3.1.2 The future development of the framework

From the start the GSF has been targeted at patients requiring palliative care for any conditions, but the reality is that the focus up to now has been heavily on cancer in most practices using the framework. In the light of policy initiatives that stress the importance of developing palliative care for patients with long-term conditions (see section 1.2 above), the use of the GSF for such patients is a high development priority. Amongst our participants there was quite a widespread recognition that the GSF philosophy and the mechanisms that operationalise it (e.g. registers, palliative care meetings in practices, out of hours handover forms) need to be applied beyond just cancer patients. The extent to which this had been actually implemented, though, varied considerably.

Looking at the degree of awareness and utilisation of the LCP and PCP tools alongside the GSF (see section 1.2 above), there were contrasting pictures. While only a handful of participants had even heard of the PCP, there was quite a high level of awareness of the LCP amongst our participants. In all three areas there were ongoing training events relating to it and some practices were already using it. The nurses were generally very enthusiastic about the pathway, praising its clearness and ease of use, and in a few cases contrasting it with the perceived complexity of GSF documentation.

When you've done the syringe driver and you've set every thing up and you're in the kitchen and you're writing - you seem to be writing for ever and a day, and you think: what are you doing here? Once you've done the job they (patients and carers) want you to go, you know, and you seem to be there a long time. But it's got to be documented, but the Liverpool Framework (sic) that we looked at last couple of days, it was probably a lot easier.

(Deborah Johnson, Community Staff Nurse, Woolbeck).

3.2 Roles and relationships in community nursing

In this section we will focus on the two groups of professionals at the centre of this research: district nursing team members and Community Matrons. Where it is relevant to our analysis, we will distinguish between District Nurses and Community Staff Nurses within the former group.

3.2.1 Relationships between district nursing team members and Community Matrons

Relationships between these two groups of nurses were often experienced as problematic by both sides, though there were individual exceptions to this rule in all areas. The situation was worst in Coaltown, where several participants (from both groups) became visibly upset when discussing how they related to each other and the wider impact of the introduction of the Community Matron role. A number of factors seemed to have contributed to the poor working relationships and mutual understanding in this area. Firstly, most of the Community Matrons came into their role from jobs in the acute sector and had little knowledge of the community setting, let alone district nursing. They therefore did not have strong existing relationships with nurses in the community upon which to build. Secondly, changes associated with the PCT merger created a good deal of uncertainty and job insecurity. Thirdly, there were resentments associated with banding issues affecting both community and acute sector nurses that fuelled resentment towards new senior roles such as the Community Matron.

I read a paper on supporting the nurse moving, well the acute trust into community matron role, it's a government paper just about that, and I initially laughed and thought 'Oh God, they must think we are stupid!' And how wrong I was, because that has been the most difficult part of the role. Not only moving from secondary care to primary care but not knowing the Trust, not knowing, having the networks and the support systems, that's been the most difficult thing.

(Jenna Villiers, Community Matron, Coaltown)

I am a Band 8A umh and, you know, I think because I have come from a completely different arena, I know people sometimes look at me and think, you know: 'what she's doing, she's only just come into community, she's got this band 8A, financial rewards that are linked with that?' But, you know, what they don't appreciate is that I've got 10 years of experience, I've got a masters degree and I worked as a Nurse Commissioner before I came in to do this so I feel as though we should be rewarded for that.

(Betty Allen, Community Matron, Coaltown)

Similar issues arose in Goldborough and Woolbeck, but in both these areas there were circumstances that to some extent mitigated the difficulties. All the Community Matrons we interviewed had previously worked in district nursing teams locally, most as District Nurses (although three of the Goldborough participants had spent a fairly short period of time in specialist public health roles immediately prior to taking on the Community Matron role). They thus understood the perspectives of their district nursing colleagues and could rely on existing personal relationships even where there was suspicion of the new role itself. Some of the Goldborough Community Matrons were based alongside district nursing teams, which helped them to feel less isolated than their Coaltown colleagues, and to work out their own solutions to problems of collaboration. Goldborough participants, like Coaltown, were affected by PCT merger and concerned about planned future changes to the organisation of services, but there did not seem to be the same degree of confusion regarding managerial responsibilities as was perceived to be the case in Coaltown. In contrast, participants in Woolbeck (especially the Community Matrons) *did* experience disruption and uncertainty in line management, but did not have to contend with a PCT merger.

A striking feature of the data as a whole was the apparent lack of guidance for nurses on when and how district nursing teams and Community Matrons should work together. While the broad aims of the Community Matron role were clear, in terms of case managing patients with long-term conditions, there appeared to be no strategy regarding how this new role was to be implemented within existing NHS organisations. As a Community Matron in Woolbeck said; “this is a brand new role, we’re knitting it ourselves, we’re making it up as we go along” (Winifred Jackson). The effects of this lack of strategy were very much apparent in relation to palliative care, as we will see in the next section.

3.2.2 Understanding of community nursing roles in palliative care

We will consider here how the two main groups of participants – district nursing team members and Community Matrons – understood their own and each other’s roles in community palliative care. Starting with the former, there was consensus that district nursing teams play a central role in caring for patients with palliative care needs in the community. They co-ordinated the input of other agencies, provided information and emotional support for patients and carers, as well as carrying out physical care tasks as

necessary. The District Nurses in effect saw themselves as case managers for community palliative care patients, supported by Community Staff Nurses and sometimes Health Care Assistants.

I always describe having cancer to patients as it's a bit like being dropped in a foreign land where you don't speak the language, you've got no map. You know that you're going to a nice comfy hotel with everything that you need but you've got to have somebody to tell you how to get there and I feel that's what we (District Nurses) do, we facilitate that.

(Lucy Nash, District Nurse, Goldborough)

I think sort of basically the district nurses are at the top of the tree, without her, you know, the whole world would collapse...it's the DN that talks to the family, discusses how they're coping, what they need and whatever...and you contact the appropriate agency, and pull them in. Now without actually the DN, you really would be struggling because there isn't anybody else that would pull it all together.

(Jo Harper, District Nurse, Woolbeck)

The Community Matrons and Key Stakeholders concurred with the view that District Nurses and their teams had a pivotal role to play in community palliative care. Several, however, did question whether District Nurses were able to fully carry out the requirements of a case management role for palliative care patients. Two main reasons were offered for such doubts. Firstly, some participants argued that the increasing volume and complexity of district nursing workloads meant they no longer had the time to properly case manage patients, even if they did have the requisite skills. (This was a view that many District Nurses themselves shared). Secondly, some Community Matrons pointed out that the district nursing service was by its very nature task-oriented and reactive. While District Nurses might spend much longer with a palliative care patient than they would in other circumstances, they still could not take a truly pro-active approach to managing the patient. One Woolbeck Community Matron compares how she looked at patients in her previous role as a District Nurse, with how she sees them in her new role:

So you think, 'right, well, this lady's got a wound on her arm so we'll sort that out' - but she's also got COPD or she's got diabetes ... so we (i.e. District Nurses) won't go there, it's like 'see that can, it's got worms in it, so we'll keep a lid on it', but whereas now I say, 'lets take that lid off, lets deal with these problems and all the other things that are involved in that patient's health and their future health, deal with it now.'

(Winnie Jackson, Community Matron, Woolbeck)

In contrast, district nursing team members did not see themselves as reactive when it came to palliative care patients. They did acknowledge, though, that quite often they were first called in to see a palliative patient at quite late in their illness, which limited the role they could play for that individual and their family. This reflected the widely-held view on all sides that district nursing teams had a special responsibility for patients at the final stage of their dying trajectory.

There was much less agreement regarding Community Matron roles in community palliative care than there was in relation to district nursing roles. The ways in which our interviewees understood the role tended to cluster around three positions, as outlined below.

1. The Community Matron has no real role in community palliative care. It might be conceded that should one of her patients “become palliative”, she could retain some input, but this would very much be peripheral to the role of the district nursing team.

We don't really need to involve them at all; I've been working at Goldborough for coming up for a year now and I've never needed to involve a community matron in any palliative care.

(Kathryn Just, District Nurse, Goldborough)

2. If and when their patients are identified as “palliative”, Community Matrons should hand over lead responsibility to District Nurses; however, they should retain a strong and active involvement to provide the benefit of their knowledge of the patient and family, and their expertise in long-term conditions.

It (Community Matron role) may stop perhaps crises happening, which is when we (DN team) get involved. She sees it coming and then we'll talk about it and maybe we'll go in before it happens, so it's probably a lot better for patients.

(Deb Reece, Community Staff Nurse, Woolbeck)

3. Community Matrons should maintain their case management role for all their patients, including those identified as “palliative”, with District Nurses increasingly involved as the physical care needs increase. (In a few cases even the assumption that Community Matrons should restrict their role to non-cancer patients is challenged).

I think the future for the community matron role in palliative care is to proactively identify patients that are mainly a year or just before that of potentially dying so that we can get in there and effectively plan the care that's needed... if we can have more of a skill mix within our team so that we (CMs) can do the first assessments ...and if we can have some of them (registered nurses or HCAs) within our team I think we can really ensure that patients are gonna die where they want to be.

(Sam Morgan, Community Matron, Goldborough)

The majority of district nursing team members took the first view. A significant minority voiced the second position that Community Matrons should retain a significant but secondary role. None argued for Community Matrons having the lead responsibility in palliative care, even for long-term conditions alone. In contrast, none of the Community Matrons felt they had no role in palliative care, with most taking the second position described above. Several expressed the third view - that they were in the best position to take on case management in community palliative care, at least for conditions such as heart failure and COPD.

3.3 Relationships between community nurses and other agencies

We will consider here the nurses' relationships with other agencies involved in the provision of community palliative care. The two groups discussed most frequently were GPs and Macmillan Nurse. Others mentioned in many interviews included social services, hospices, the acute sector and pharmacists.

3.3.1 Relationships between community nurses and GPs

As we noted earlier with regard to the GSF, community nurses found that GPs' willingness to engage positively with them in providing palliative care varied considerably. At one extreme were cases where GPs worked very closely with the community nurses, sometimes visiting jointly with them and remaining in close and regular contact. At the other extreme were cases where the nurse struggled to get even the minimal level of input from the GP. The quotes below illustrate both poles of this dimension.

We work very closely with the GP's and we've a very good working relationship with our GP's ... each patient that has a diagnosis of cancer - particularly the active ones - have a lead GP and lead district nurse identified on the patient records, so if anybody has a concern about a patient they know who to go to, to talk to.

(Lily Shaw, Community Staff Nurse, Woolbeck)

They're all different the GPs, that's across the board - but there's one in particular, it's a difficult GP surgery ...we have a lot of problems trying to get home visits and things like that.

(Community Staff Nurse, Coaltown)

Community Matrons experienced the same variation in quality of relationships with GPs as did their district nursing colleagues. The one difference was that in some cases, they also had to contend with a general suspicion or hostility towards their role from GPs, something that district nursing teams never had to face. More common than outright hostility was simply confusion and uncertainty from GPs regarding the nature and scope of the Community Matron role.

GPs generally allowed District Nurses to take the lead role in managing community palliative care patients, and were willing to follow their direction regarding many aspects of patient care and support. District Nurses appreciated this recognition of their expertise, but on occasion some felt that certain GPs took it too far and expected nurses to make decisions that should have been their responsibility. Most commonly such instances occurred in relation to prescribing, where nurses felt uncomfortable that GPs were expecting them to make decisions where quite a high level of specialist knowledge was required.

*I think he was very reluctant to be involved he very much wanted to keep on the outside, almost made that my role, you know, 'well tell me what to (prescribe) and I'll do it and you carry on and do it all'.
(Kelly Mann, Community Matron, Woolbeck)*

3.3.2 Relationships between community nurses and Macmillan Nurses

Macmillan Nurses were used as a source of advice and support by most of the district nursing team members we interviewed, especially regarding medication and symptom control near the end of the patient's life. Some also called on them as a source of emotional support for themselves after the more difficult and upsetting cases. Across all three study locations, participants said that most of their contact with Macmillan Nurses was by 'phone, although occasionally they carried out joint visits to patients. Some interviewees (especially in Coaltown) regretted what they saw as a decline in opportunities for direct joint working with Macmillan Nurses, blaming this on reduced staffing levels.

The extent to which district nursing teams involved Macmillan Nurses depended on three main factors: the quality of personal relationships, organisational issues such as staffing levels and the effectiveness of communication channels, and the levels of expertise in palliative care of team members and the GPs they worked with. Thus, team members who were less experienced in this area, and teams who did not feel well-supported by their GPs with regard to palliative care, were more likely to rely on input from Macmillan Nurses.

I started reducing the syringe driver...now my other staff wouldn't try that, cos they haven't got the expertise - so they'd speak to the Macmillan nurse. But I would do things because I've got the expertise to do it.

(Jo Harper, District Nurse, Woolbeck)

We had problems with the GP so therefore our first line of contact was usually Macmillan for advice.

(Harriet Lee, Community Staff Nurse, Coaltown)

It seems to me that if the GP's are doing their bit properly the Macmillan nurses don't have as much to do.

(Becky Janus, District Nurse, Woolbeck)

Although our participants were generally very positive about the input of Macmillan Nurses, a few raised concerns about their role. Several reported that patients and carers sometimes expected Macmillan Nurses to be more “hands-on” than they were. A Coaltown District Nurse (Maud Allen) described this as an “old fashioned view” whereby families saw the Macmillan Nurse as doing something “magical” for the patient, and perceived the district nursing team as “secondary... inferior... like we're the auxiliaries for the Macmillans”. Interestingly, one Goldborough District Nurse (Kathryn Just) raises a very different patient/carer perception: that there is a “stigma” about bringing in Macmillan Nurses, because of their association with death and dying. Another Goldborough District Nurse (Wilma Short) complained about Macmillan Nurses sometimes “taking over” patients, expressing a very strong sense of ownership towards “her” patients:

Sometimes it's (i.e. relationship with Macmillan Nurses) fantastic and it's helpful and it's really good and you can work together, and at other times they will try and take over, and they'll also take over the interesting cases, if there's something a little bit more interesting...suddenly you lose your patient and you think 'oh my gosh, what's happened?' - but very often it's a very peculiar relationship that we have really, its not good, I wouldn't say its good.

(Wilma Short, District Nurse, Goldborough)

The amount of contact Community Matrons had with Macmillan Nurses varied quite noticeably between geographical areas. In Goldborough, the majority of the Community Matrons described working quite closely with Macmillan Nurses, helped in several cases by the fact that both groups attended GSF palliative care meetings. There was less contact in the other two areas, especially Coaltown. In part this appeared to relate to staffing levels and other organisational issues, and with regard to Coaltown it should be borne in mind that all but one of the Matrons had not come from a community nursing background.

3.3.3 Other relationships

In the course of the interviews – and in particular in their discussion of their Pictor cases – participants mentioned a wide variety of other agencies that they had worked with in community palliative care. We do not have the space to examine all of these in any detail, so will concentrate here on relationships with social services and acute sector staff.

Relationships with individual social services staff were generally described as positive – especially with the care assistants who were frequently included in the course of Pictor case descriptions. Some participants did note, though, that the skills and experience of care assistants could vary enormously and it was rather “pot luck” who was employed to work with a particular patient. Problems relating to social services were seen as stemming from their organisational structure, culture and funding, which differed markedly from those of community nursing. Participants were aware of (and largely sympathetic to) the budgetary limitations within which social services departments operated. Nevertheless, several noted with a mixture of frustration and wry amusement the difference in how “urgent” was understood by community nurses and social workers:

With social services they, even if it's urgent, they've got something like five days, so we have had situations where we've referred people to social services and they've deteriorated...only the other week, someone phoned from social services and said 'this patient has now been allocated to me, I just wanted a bit of background information on her', 'oh yeah, well you're a bit late, she died yesterday.'

(Jo Harper, District Nurse, Woolbeck).

I think the social workers, you know, that they're easily accessible. They do take a lunch break - they don't answer the phone at lunchtime (both laugh), yeah really! (Susan Smith, District Nurse, Woolbeck).

Coaltown had the unusual resource of a specialist palliative care social worker, based in the hospital. She was able to facilitate good communication with community nurses about discharged patients, ensuring that social care packages were in place very promptly for them.

Regarding relationships with the acute sector, participants often found it hard to gain access to hospital-based specialists – especially Consultants - when they needed to discuss patients who had been discharged. This was all the more frustrating when community nurses received insufficient or inaccurate information about patients coming out of hospital. Interestingly, some of the Community Matrons felt that they were better able to communicate with Consultants and other hospital staff than District Nurses. They explained this in terms of the perception that they were themselves “specialists” and as one Community Matron noted, the fact that they did not wear a uniform was helpful here. Nevertheless, Community Matrons also observed that building good relationships with hospital staff required persistence on their part.

Other agencies frequently appearing in Pictor case descriptions included hospices, pharmacists, rehabilitation teams, and specialist equipment suppliers. Accessibility, promptness of response and willingness to share information were characteristics our interviewees valued in such services.

3.4 Relationships with patients and carers

All our participants placed their relationships with patients and carers at the centre of how they viewed their role in palliative care. They provided emotional support, advocacy where necessary, as well as physical care and co-ordination of services. Quite often they offered support for families post-bereavement, or organized access to bereavement counseling services. Participants commonly stressed the importance of negotiating with families and patients about the level of care that they wanted to receive.

Participant: We've got a palliative care patient who might need their leg dressing or something like that so there is input and we do support people. We do monthly, weekly, hourly, whatever the patient wants us to visit.

Interviewer: So you would negotiate that with the patient then about how much they need?

Participant: yes absolutely, yeah.

(Susan Smith, Community Staff Nurse, Woolbeck)

Many participants emphasized the dedication to patients of the district nursing team, pointing to their willingness to carry on working with patients and families where relationships were difficult and other agencies sought to withdraw (and sometimes actually did so). Gemma Mason (District Nurse, Goldborough) described in her Pictor exercise the case of a woman living with her husband in a remote and very unhygienic setting. In the last stages of her illness, the woman's personality changed drastically and she became aggressive and abusive to those around her, including health and social care professionals. The combination of the location and the patient's behaviour led to many agencies pulling away from involvement:

We were all at the end of our tether, and we (district nursing team) were the last people still to go in throughout it all. So they (other agencies) were threatening to withdraw because they couldn't handle it, everybody, all the carers...but who would blame them? So it was left to us.

(Gemma Mason, District Nurse, Goldborough)

Gemma describes this as the case where the district nursing team had come closest to admitting defeat, but in the end they were able to support the patient and her husband so that they could achieve their wish for her to die at home.

There was consensus amongst participants that their role in supporting patients and carers was enhanced when they were able to build a relationship with them over time. In these circumstances they not only got a fuller knowledge of the patient's medical needs, they also got a better understanding of how care could best be tailored to their social circumstances, and it became easier for the nurses to discuss difficult and sensitive issues with them. In terms of building relationships, the Community Matron role had

advantages over that of the District Nurse, as they were more likely to have got to know the patient and carers before they reached the stage where palliative care was needed. While this could sometimes happen for District Nurses, quite often they were brought in late in the patient's illness because up until then there had not been any nursing tasks requiring their involvement. For example, one of the Community Matrons in Coaltown (Rebecca Johnson) describes how she built a good relationship with a patient who had often had difficult interactions with health professionals in the past. She was able to persuade him to give the local day hospice a try, despite his initial reluctance; he was now "loving" his time there.

The nature of their relationships with patients and carers at such a critical time in people's lives is key to explaining why so many community nurses value their involvement in palliative care so highly.

You are helping that person to go through a journey and you are part of that journey, and it's a privilege really to be involved at that stage of somebody's life, you know. It's an honour.

(Wilma Short, District Nurse, Goldborough)

Nevertheless, not all our participants appeared to be comfortable in discussing issues of death and dying with patients and carers. This was most notable amongst district nursing team members in Coaltown, perhaps reflecting the weaker penetration of the GSF into this area compared to the other two.

4. DISCUSSION

Although this study is not an evaluation of the GSF per se, it is useful to consider briefly our participants' experiences of how the GSF functions in comparison to the findings of earlier research looking at the implementation and utilisation of the framework. Both King et al (2005) and Munday et al (2007) used qualitative interviews to examine primary care staff's perceptions of using the GSF. The picture provided by our current research is in many respects not substantially different from that given by the previous studies. District Nurses and their teams remain central to the successful operation of the GSF, are mostly enthusiastic about the framework and about palliative care more widely. The

extent to which community nurses can use the framework effectively is dependent to a large extent on whether GPs are committed to it. It is worth noting that there was more evidence in the present study than the earlier ones of district nursing teams seeking to use aspects of the GSF even without support from GPs, although even in these cases the nurses felt that lack of GP involvement inhibited what could be achieved. There were two aspects of the GSF where we did see changes from the earlier situation – especially from the Stage Two implementation examined by King et al (2005). There was a wider acknowledgement that the GSF applied to non-cancer as well as cancer patients, and expectation that services needed to be prepared for a growth in community palliative care provision in conditions such as heart failure and COPD. There was also much greater awareness of the LCP, with many participants having just started to use it around the time we conducted our interviews.

Turning to our central concern – community nursing roles and relationships in palliative care – our findings reveal some important and consistent trends, alongside local differences. There was a consensus that District Nurses and their teams play a key role in community palliative care, especially in the terminal stage of a patient’s illness, and that their involvement went beyond carrying out nursing tasks to co-ordinating services and supporting patients and carers up to the end of the patient’s life (and sometimes providing bereavement support afterwards). Many of our participants explicitly described this as “case management”, often pointing out that palliative care was the one area of their work where they could and did perform such a role. However, our findings suggest there are limitations in the extent to which district nursing teams can fully carry out a case management role for palliative care patients. For many, their workloads are such that they struggle to find the time with patients that case management requires. More fundamentally, because their role in general is task-oriented and reactive they are quite often only called in late in a patient’s illness, when specific “nursing needs” are identified. This is especially true for patients with long-term conditions, though it can also apply to cancer patients who are asymptomatic. Also, if district nursing teams are only using case management skills with palliative patients, those who do not have a very high caseload of such patients will have limited opportunities to develop skills and experience.

Regarding Community Matron roles we saw considerable variation in participants’ views; with district nursing team members generally seeing less of a role for them than the

Matrons did themselves. In our view – especially on the evidence of their Pictor cases – the nature of the Community Matron role has some distinct advantages for their involvement in palliative care, but also certain disadvantages. On the positive side, they often get to know patients and their families well before they reach the terminal stage, and they are able to consider the patient's illness in the context of their social world and lifestyle. Additionally, they are familiar with accessing wide networks of other agencies and professions in the course of managing patients, and may have more success than district nursing teams in building relationships with senior staff in the acute sector. Finally, Community Matrons' expertise in long-term conditions is valuable, given their increasing profile in end of life care policy, and the fact that district nursing teams often lack experience in palliative care for this group of patients.

On the negative side, Community Matrons lack the skill mix which district nursing teams rely heavily upon in managing palliative care patients. Those who did not come from a district nursing background are likely to have had little training and experience in palliative care, and they may miss out on end of life care training in the community where it is targeted specifically at district nursing teams. Alongside these limitations, the suspicion – sometimes hostility – of other community health professionals towards the new role of Community Matron can inhibit their effectiveness as case managers for patients with palliative care needs.

As this last point indicates, the difficulties in relationships between district nursing teams and Community Matrons are unhelpful for the development of community palliative care. From our constructivist theoretical position, outlined in the introduction, these problems can to a large extent be understood in terms of the different types of threat to professional identity experienced by the two groups of nurses. For District Nurses and their teams, organisational changes in the NHS threaten key aspects of their view of themselves as professionals, including their lead role in both caring for and (as they see it) case managing palliative care patients. They are therefore likely to seek to erect barriers against those perceived as threatening their role, such as Community Matrons. In contrast, what Community Matrons face is not a threat to a well-established identity, but rather the challenge of carving out a new identity in the face of uncertainty and potential isolation. It therefore makes sense for them to seek to be inclusive in how they work with district nursing teams (and others), and to be conciliatory regarding boundary

issues. The fact that many of the Community Matrons were previously District Nurses only strengthens these tendencies.

5. CONCLUSIONS AND RECOMMENDATIONS

Between them, district nursing teams and Community Matrons have a range of skills and expertise well-suited to the task of delivering high quality community palliative care in line with the expectations of the GSF. But for this to happen, serious attention needs to be given to the development of role definitions, competency frameworks, and standard operational procedures to encourage joint working. In making such changes, it is probably inevitable that further tensions and anxieties will emerge; to minimize these, policy makers and managers need to keep issues of professional identity at the forefront of their thinking.

The present study examined how community nursing roles and relationships related to community palliative care in three geographical areas. Such exploratory, qualitative research seeks to identify and make sense of the key issues relating to the topic at hand, from the perspectives of those directly involved in them. We do not and cannot offer evidence regarding the relative merits of different solutions to the problems identified; for that, further larger scale work is required, as highlighted in our “recommendations for research” section. What we can offer is insight and guidance for those developing and evaluating new initiatives in this area, based on themes that have emerged strongly from our close examination of our participants’ experiences in their diverse settings. Our own experience beyond the three study areas – both academic and in practice – does not lead us to suspect that the main issues we have highlighted are unique to Goldborough, Woolbeck and Coaltown.

In terms of methodology, the use of the Pictor technique to elicit accounts of specific cases was a distinctive feature of this project. Almost universally, participants appeared to find it engaging and revealing, and several commented on how helpful it was in assisting their reflection on the way they worked with a wide range of agencies and individuals. Without a doubt, many important issues relevant to our research emerged from the discussions stimulated by the technique, and we feel it has great potential both as a research tool and as an aid to education and development regarding joint working.

5.1 Recommendations for policy and practice

5. There needs to be much better integration between district nursing teams and Community Matrons to capitalize on their respective strengths in relation to palliative care, and minimize their weaknesses. Including both groups within a single community nursing team seems to us the most promising option, but we recognise there may be other solutions which could be tried.
6. However integration is to be achieved, there is likely to be at least some degree of service redesign required which should include outcomes measurements to determine efficiency of resource utilisation and effectiveness of any change to service provision.
7. If this redesign is not to create as many problems as it solves, the likely impact of revised work roles on professional identity must be seriously considered – both in terms of the nature of roles and the implementation process. This requires a review of the evidence from research literature, and proper consultation with those directly affected by changes.
8. To optimize their contribution to community palliative care, both groups of nurses are likely to need training and development. On the evidence of the areas we looked at, Community Matrons require training in community palliative care in general, and end of life care tools in particular (GSF, LCP and PPC). For district nursing team members, training in palliative care for long term conditions is likely to be a priority. Also, both groups of nurses must be provided with an understanding of case management philosophy, principles and application.

5.2 Recommendations for research and evaluation

4. Different models of community nursing team integration need to be evaluated in terms of relationships within the team, and outcomes for palliative care patients and carers.

5. Research needs to examine the links between community nursing teams and the acute sector, specialist palliative care and social services, to identify factors in these relationships that impact on the quality of care and support provided for patients at the end of life and their families.

6. Our research, especially through the use of the Pictor technique, highlighted the complexity and diversity of the networks of agencies that can be involved in the provision of community palliative care. Future research needs to examine how patients and carers experience their interactions with these networks.

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Appendix 1

COMMUNITY NURSING ROLES AND THE GSF

INTERVIEW TOPIC GUIDE

As is standard practice with semi-structured interviews, the list below represents the main areas that the interviewer will explore with each interviewee. The exact phrasing of questions, and the use of additional probe questions, will be responsive to the context of each individual interview.

1. Personal and Practice history of involvement in GSF

How you yourself first came into contact with GSF

Initial and subsequent training re. GSF

Support from GSF Facilitator for area

How Practice(s) you work with became involved in GSF

Any changes in involvement over time

2. Nature of own nursing role and those of colleagues

Grade and job title

Organisation of Community Nursing services locally

Own main duties and responsibilities

Extent and nature of own involvement with palliative care

How own role compares to those of colleagues

3. Ways in which definition of nursing roles shapes implementation of GSF

Are there aspects of GSF that participant finds hard to implement because of nature of role? What? Why?

Are there aspects of GSF whose implementation is particularly facilitated because of nature of participants' role? What? Why?

4. Impact on own role of involvement in GSF (including any changes over time)

Has the participant's own role changed in any way through involvement in GSF? Why/why not? In what ways (obtain examples)

5. Relationships with colleagues, other professions, patients and carers, in the context of the GSF

Have the participant's relationships with colleagues changed as a result of involvement in the GSF? Why/why not? In what ways (obtain examples)

Have the participant's relationships with other professions changed as a result of involvement in the GSF? Why/why not? In what ways (obtain examples)

Have the participant's relationships with patients and carers changed as a result of involvement in the GSF? Why/why not? In what ways (obtain examples)

6. The future of community palliative care and the GSF

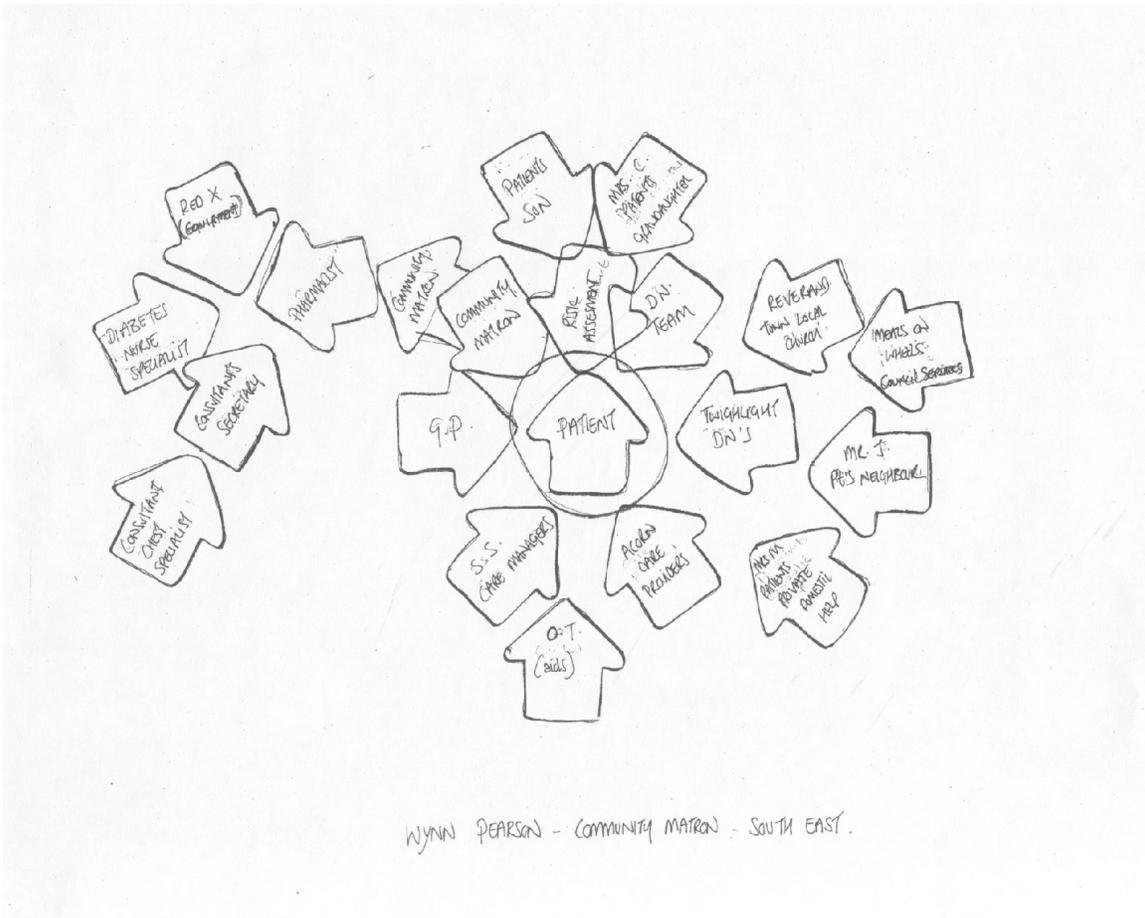
How would you like to see community palliative care develop in future?

Role of GSF in this?

Role of Community Nurses in this?

Appendix 2

Pictor case: Wynn Pearson, Community Matron, Goldborough



Wynn Pearson, Community Matron, Goldborough

Margaret was a woman in her late seventies with COPD and diabetes who had been on Wynn's caseload for several months. When she took Margaret on, she was already receiving a care package from social services, including Home Carers from a private agency, and Occupational Therapy input. Soon her condition began deteriorating and it became necessary for Wynn to involve other agencies – especially as the patient lived on her own and was adamant that she did not want to go into hospital or a hospice. Wynn made numerous joint visits with the GP, and brought in the district nursing team along with the “twilight” team who provide nursing support for the early evening period. She also liaised with a range of other agencies, including the acute sector, pharmacists, and social services. As Margaret's health worsened, Wynn was required to carry out a risk assessment, to enable the involvement of social care staff to continue.

Wynn's work with this patient also involved interaction with her family and friends. Her son and his daughter were in regular contact with her by telephone. They lived a long way away, and Wynn describes them as “extremely caring” but also commented that “they didn't drop everything and come down, so it's a bit of a strange relationship”. Wynn realised that Margaret was concealing the severity of her illness from her family, and persuaded her to be more open with them so that proper arrangements could be set up for communication between all parties in case of an emergency. In supporting the patient, Wynn was able to rely on the help of Brian, a neighbour who - although over eighty himself - proved very reliable in checking up on Margaret every day. Another old friend, Jenny (who had previously been employed for many years by Margaret as a cleaner) also called in regularly. The local vicar from the church where Margaret attended a luncheon club visited once; Wynn describes him as “a very nice chap”.

In the end, after several falls Margaret was admitted to hospital with heart failure. She died within 48 hours. Although Wynn and the other agencies had not been able to keep her at home until the very end, she was pleased that they had managed to prevent admission for as long as they did. Wynn attended the funeral and the family expressed gratitude for meeting Margaret's wishes as well as possible.

On her Pictor chart, Wynn placed what she referred to as an “inner” and an “outer circle” of those directly involved in helping and supporting the patient – the distinction indicating the regularity and closeness of involvement. She used two overlapping arrows to show herself both closely supporting the patient, and reaching out to a separate cluster of agencies whose input she needed to co-ordinate but who did not directly contact the patient: the pharmacist, equipment hire service, diabetic specialist nurse, and Consultant chest specialist (accessed via his secretary). The circle she chose to draw around the ‘patient’ arrow emphasises Margaret as the centre of all this activity.

Appendix 3: Blank stage one matrix

AREA

	GSF				
Participant	Barriers/problems	Positive influences	Impact of	Personal level of involvement	Practice/team level of involvement

AREA

	DESCRIBING WORK CONTEXTS 1		
Participant	Personal career history	Organisation of Comm Nurse service	Own work organisation

AREA

	DESCRIBING WORK CONTEXTS 2		
Participant	Own/team role in pall care	Population	Case load & referrals

AREA

	ORGANISATIONAL CHANGE		
Participant	Impact on roles	Impact on pall care	Feelings about change

AREA

Participant	RELATIONSHIPS WITH PATIENTS/CARERS

AREA

	PROFESSIONAL ROLES AND RELATIONSHIPS 1			
	District Nurses and Community Matrons			
Participant	Role perception	Communication	Boundaries	Personal relationships

AREA

	PROFESSIONAL ROLES AND RELATIONSHIPS 2			
	Community Nurses and GPs			
Participant	Role perception	Communication	Boundaries	Personal relationships

AREA

PROFESSIONAL ROLES AND RELATIONSHIPS 3				
Community Nurses and Macmillan Nurses				
Participant	Role perception	Communication	Boundaries	Personal relationships

AREA

PROFESSIONAL ROLES AND RELATIONSHIPS 4				
Other Relationships				
Participant	Role perception	Communication	Boundaries	Personal relationships

Appendix 4: Stage 2 analysis matrix

AREA

Participant	Job title	How GSF functions	How involvement in pall care relates to work context	How organisational change affects pall care

AREA

Participant	Job title	How relationships with patients/carers contribute to pall care	How relationships with other professionals contribute to pall care

AREA:

Participant	Job title	How own professional role relates to pall care	How others' professional roles relate to pall care