Palliative care nursing can be a rewarding but emotionally stressful specialty in which to work, and therefore stress and burnout may contribute to issues of staff sickness and retention. Studies have shown that although staff perceive themselves as coping, many nurses do experience compassion fatigue and burnout (Abendroth and Flannery, 2006; Edmunds, 2010). The purpose of this study was to undertake an assessment of hospice at home nurses’ experiences and wellbeing while caring for palliative and dying patients. Anecdotal evidence identified a lack of education and training regarding self-help strategies in the local nursing team. Clinical supervision is available for the team but uptake had been poor. The literature includes studies undertaken with palliative care nurses working in a hospice environment, but few published studies have looked specifically at hospice nurses working out in the community.

Background
Nursing has been described in many studies as a demanding and stressful profession, particularly for those working in direct clinical care (Hawkins et al, 2007; Edmunds, 2010). Compassion fatigue may be triggered by becoming overly empathetic with patients, having unreal expectations of outcomes, and experiencing personal crises (Abendroth and Flannery, 2006). It may affect an individual caring for someone who is experiencing a traumatic event such as dying. A nurse may experience helplessness and react by turning off his or her emotions. Compassion fatigue is also often linked to burnout, which can be defined as: emotional exhaustion, sometimes accompanied by a cynical approach, that can be experienced by individuals in a caring role (Maslach and Jackson, 1991). Burnout may affect the mental and physical health of the nurse, which could ultimately affect the quality of their nursing care (Maslach and Jackson, 1991). Some have also suggested that burnout is contagious and can be communicated from one nurse to another (Bakker et al, 2005).

Palliative care nursing is often viewed as a psychologically distressing and stressful specialty (Gambles et al, 2003). Palliative care nurses are fully aware that all the patients in their care have an incurable illness with a life-limiting prognosis and are expected to die. Furthermore, national strategies such as the UK’s End of Life Care Strategy (Department of Health, 2008) promote high-quality care for all adults at the end of life, which includes conditions with complex needs. This may pose further challenges and stresses for palliative care staff. However, it is now recognised that the benefits of early intervention and symptom control in the palliative patient help to maintain quality of life (World Health Organization, 2002). Also, studies suggest that palliative care staff report lower levels of burnout than other specialties, including oncology and intensive care nursing (Vachon, 1995).

Lower levels of distress have also been reported for hospice nurses than for staff

Abstract
The literature has evaluated studies of hospice nurses and stress but very few studies have focused on community hospice nurses. This study explored hospice at home nurses’ experiences of caring for palliative and dying patients. Hospice at home nurses working in the community across North West Wales were interviewed and a grounded theory approach was used to categorise the data into the following themes: job satisfaction, stressors, coping strategies, and support. Recommendations arising from the study include encouraging the use of clinical supervision, attendance at multidisciplinary meetings, and the provision of stress-awareness training, and raising awareness of the role of hospice at home nurses in primary care. Implementation of these recommendations might be beneficial for staff wellbeing. Further work would identify whether such recommendations can help to prevent sickness and promote staff retention.

Key words: Hospice at home nurses; Stress and coping; Dying patients; Qualitative methods
"Studies have shown that although staff perceive themselves as coping, many nurses do experience compassion fatigue and burnout...\" working in other areas, which implies that hospices are positive environments in which to work (Payne, 2001). The same study examined stressors, coping, and demographics in relation to burnout and hospice nurses. It found that stressors such as conflict with staff made the greatest contribution to burnout. The importance of not labelling an individual as coping 'well' or 'badly' in relation to burnout has also been highlighted, as this can oversimplify the coping/burnout relationship (Payne, 2001).

The participants in the study reported here were hospice at home nurses working in the community setting, which is not compatible with the nurses in Payne (2001). The role of the hospice at home nurse embraces the biopsychosocial approach to human functioning, particularly in relation to illness or disease (Engel, 1977). The importance of psychosocial factors in nursing is recognised, and the development of a close, holistic relationship with patients is encouraged (Aldridge, 1994; Luker, 1997). This can take a considerable amount of time (Skilbeck and Payne, 2003). Hospice at home nurses can spend between 1 and 2 hours with the patient and their family on a first visit. Subsequent visits may be shorter or longer depending on the needs of the patient and the disease progression. Toward the end of life the hospice at home nurse may need to make multiple extended visits on one day.

The emotional element of 'getting to know' patients and their families is difficult to define, not least because of the lack of clarity surrounding the terminology. The phrase 'emotional care and support' is used interchangeably with 'psychological care and support' or 'psychosocial care' (Skilbeck and Payne, 2003). However, different meanings can be attributed to each term depending on the contexts and theoretical backgrounds. The term 'emotional labour' draws on a sociological background and is used to represent hard work, and indeed the difficulty of caring for patients at the end of life has been acknowledged (Froggatt, 1998; Jones, 2001a). Emotional labour places demands on the individual as they are constantly creating and sustaining relationships with patients who subsequently die. The nurse then has the continuous task of assimilating the loss of the patient and of the relationship. Dealing with the demands of this emotional 'yo-yo' may gradually erode one's resilience and result in stress-related issues for the nurse. However, the emotional labour involved in palliative care is often underestimated and undervalued (Henderson, 2001).

Mechanisms for coping with this aspect of nursing dying patients are varied and well documented (James, 1993; McNamara et al, 1995; Froggatt, 1998; Jones, 2001b). The benefit of staff training in self-care through counselling sessions and stress inoculation training is recognised (Ablett and Jones, 2007; Desbiens and Fillion, 2007). It has been suggested that the opportunity for reflective practice in end-of-life care may help staff come to terms with the emotional impact of the work (Jones, 2001b).

Some researchers suggest that a stress-resistant personality type and personal factors such as hardness and a sense of stability and structure may enable hospice nurses to be buffered from the stressful effects of palliative care nursing (Ablett and Jones, 2007). Factors that promote resilience and wellbeing in nurses could be developed through training and supervision (Ablett and Jones, 2007). Clinical supervision and reflection are recognised as viable mechanisms for supporting palliative care nurses (Jones, 2001b). However, there is a lack of agreement concerning definitions, models, and use of clinical supervision. Known variously as 'mentorship', 'supervision by manager', and 'reflective practice', clinical supervision was very popular in the late 1990s; however, little is known about how or whether it is used by clinical nurse specialists (Yegdich and Cushing, 1998; Skilbeck and Payne, 2003; Jones, 2006).

**Aim**

The aim of the study was to explore the feelings and experiences of hospice at home nurses when providing palliative nursing care for patients in the community. The study sought to identify key issues that contribute toward stress in hospice at home nurses working in primary care.

**Method**

Qualitative methodology was used as this is more suited to exploratory studies of people in their natural settings. The potential participants were a team of hospice at home nurses working in the community across a large rural area in North West Wales.

**Ethics**

The study was presented to the North Wales Research Ethics Committee-West and a favourable opinion was awarded subject to management permission being granted. The study was given full management permission in accordance with NHS research governance arrangements.

**Research team**

The research team comprised the nursing team leader (with management, clinical, and research
experience), the project manager (with management and research experience), and a hospice at home nurse (with clinical experience).

**Participants**
The hospice at home nursing team in North West Wales comprises ten qualified nurses and one health-care assistant. All had worked in the palliative care setting for a minimum of 12 months. The nurses deliver ‘hands on’ nursing care in collaboration with various community nursing teams, providing symptom control and advice for patients and their carers in the community. Their work sometimes necessitates travelling distances between 10 and 110 miles per day.

The nurses were informed of the study and invited to participate at the regular nurses’ meeting by their colleague, the first listed author. It was made clear that they were under no obligation to take part and that they could withdraw at any time during or after the study without having to provide a reason and without fear of compromising their working relationships. Confidentiality was assured both verbally and in writing, with the usual exception of disclosure of any unsafe, unethical, or illegal practice.

**Data collection**
Each nurse was asked to participate in a tape-recorded semi-structured interview lasting a maximum of 45 minutes. The interviews were conducted by the palliative care project manager. This position has no professional responsibility for the nursing team (managerial or otherwise) and is external to the hospice at home nursing service. The interviews all took place in the palliative care department in a quiet designated room at times convenient for the nurses and fitting in with their clinical duties. As the interviews could prove to be emotional or distressing, the nurses were offered the opportunity of counselling. There is currently an arrangement between an independent counselling service and the Health Board to provide free counselling sessions for Health Board employees.

The interview schedule is provided in Box 1. The interviews comprised a list of open-ended questions, guided by the interviewer. Interviewer prompts were included to avoid long silences during the interview process. Leading questions were avoided. The questions were managed in a conversational style to maximise flexibility and versatility.

**Data analysis**
The transcripts of each interview were analysed using the grounded theory approach initially developed by Glaser and Strauss (1967). This approach is favoured in nursing and the social sciences owing to the systematic and structured way that the data are collected and analysed. The term ‘grounded theory’ refers to the idea that the data are not obtained from the researchers’ preconceived hypothesis but are discovered or derived. Themes that are repeatedly present or notably absent in the data are deemed significant enough to be categorised and each piece of data

**Box 1 (part 1). Interview guide**

<table>
<thead>
<tr>
<th>Items in italics were used as prompts for the interviewer in the event that the interviewee had difficulty responding to this question.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age:</strong></td>
</tr>
<tr>
<td><strong>Gender:</strong></td>
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<tr>
<td><strong>General nursing experience:</strong></td>
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<tr>
<td><strong>Hospice nursing experience:</strong></td>
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<td><strong>Qualifications:</strong></td>
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<td><strong>Area of work:</strong></td>
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<tr>
<td>1a) Can you tell me about a good working day as a hospice nurse?</td>
</tr>
<tr>
<td>i) What would you say contributed towards making it a good day?</td>
</tr>
<tr>
<td>1b) Can you tell me about your worst working day as a hospice nurse?</td>
</tr>
<tr>
<td>i) What would you say contributed towards making it your worst day?</td>
</tr>
<tr>
<td>2) How do you feel your work affects you emotionally?</td>
</tr>
<tr>
<td>i) Would you say it affects you physically?</td>
</tr>
<tr>
<td>In what way?</td>
</tr>
<tr>
<td>ii) Would you say it affects you mentally?</td>
</tr>
<tr>
<td>In what way?</td>
</tr>
<tr>
<td>3) How do you cope with an emotionally demanding day?</td>
</tr>
<tr>
<td>i) Would you say you talk to work colleagues?</td>
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<tr>
<td>ii) Would you say you talk to family?</td>
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<tr>
<td>iii) Would you say you talk to your manager?</td>
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<tr>
<td>iv) Would you say you talk to friends?</td>
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<tr>
<td>4) How would you say you cope with the physical demands of your working day?</td>
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<tr>
<td>i) Would you say you exercise, walk, cycle or go to the gym?</td>
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<tr>
<td>ii) Would you say you relax in a warm bath?</td>
</tr>
<tr>
<td>iii) Would you say you switch off in front of the TV?</td>
</tr>
<tr>
<td>iv) Would you say you catch up with outstanding household ‘jobs’ such as cleaning or gardening?</td>
</tr>
<tr>
<td>5) How would you say you cope with the psychological demands of your working day?</td>
</tr>
<tr>
<td>i) Would you say you browse the Internet?</td>
</tr>
<tr>
<td>ii) Would you say you discuss your day with others?</td>
</tr>
<tr>
<td>iii) Would you say you meditate or use any other form of mental exercise?</td>
</tr>
<tr>
<td>iv) Would you say you have an early night?</td>
</tr>
</tbody>
</table>
is constantly compared with another until no further new data are discovered.

Data analysis was carried out following transcription of all of the interviews. The transcripts were typed verbatim with the exception of participant names, which were omitted. The transcripts were independently read and re-read for familiarity by individual members of the research team, who were blind to each others' critique of the data until they met to discuss the content of the transcripts.

The data were analysed by an open coding procedure in which the first step of the analysis is conceptualisation of the data. Concepts are identified through analytical procedures such as asking questions about the data and looking for differences and similarities between phenomena, events, and incidents through constant comparison. The common themes that emerged from the data were then grouped together for identification and labelled with an abstract name to produce categories.

Meticulous records of the research process were maintained with the aim that other researchers would be able to analyse the data and reach the same conclusions. Analysis triangulation by the different members of the team was intended to ensure reliability and reduce bias and error.

Results and discussion
Of the ten registered nurses in the hospice at home nursing team, seven participated in the study. One nurse was excluded because she had a role in the research team, one nurse was absent on maternity leave, and one nurse declined to participate. The reason given for non-participation was that the nurse preferred the interview to be conducted in Welsh. This option was not available to the study without introducing extra financial costs and increasing potential bias. All of the nurses were female, and they had an average age of 54 years (range 41–62 years). All were registered nurses at a minimum, with a mean of 24 years of nursing experience (range 10–39 years).

There was unanimous consensus among the research team that four super-ordinate themes emerged from the data:

- Job satisfaction
- Stressors
- Coping strategies
- Support.

Job satisfaction
Job satisfaction was identified as an important determinant of the nurses' stress levels. Several of the nurses discussed the merits of 'making a difference':

> 'When you've walked in and there's a crisis, the patient is in pain, family in distress, they are not coping, they are frightened. By the time you have left the home, having sorted out the pain, the symptom control issues and you've calmed the waters ... the families are happy.'
> Nurse 2

> 'I mean we can make things better. We can't change what's happening but we can make a difference.' Nurse 7

> 'If you can nurse someone at home and make them as comfortable as possible in their last days of life, it's a privilege to do it ... it's well worth everything you do.' Nurse 1

Similar views from nurses regarding the rewards of nursing dying patients were reported in a study from Taiwan (Wu and Volker, 2009). These Thai nurses acknowledged the job satisfaction and sense of self-worth obtained from helping their patients achieve a good death. However, it should be noted that there are significant differences between the cultures and approaches to end-of-life care between a hospice in Taiwan and the setting of the present study.

Another study that investigated stress in palliative care nurses also identified a theme called 'making a difference' (Ablett and Jones, 2007). In the study reported here the nurses' commitment to their work and the sense of being in control of...
the work situation were indicated as being a source of job satisfaction. Contact with dying patients was also indicated to be a key source of job satisfaction by Grunfeld et al (2005).

Prioritising the workload was important for the nurses in the present study to be able to manage their day effectively:

'The distances that you are travelling between patients and the requests for input can be demanding. You've got to be assertive and say 'No, I can't physically do that.' You need to prioritise patient care and then go with that priority.' Nurse 1

The large distances involved in the nurses' daily work and the collaboration with a number of community nursing teams, all with different demands, can result in increased activity and stress for the hospice at home nurses. A study of district nurses found that they had similar experiences when caring for dying patients (Burt et al, 2008).

Stressors
The nurses identified conflict with colleagues from outside the team and difficulty communicating with the GPs and district nurses as a source of stress:

'The GPs can be difficult to get hold of and they are not always proactive, and without that, then your job is almost impossible to do.' Nurse 2

Nurse 7 identified that district nurses are now also so busy that palliative patients are missing out on visits:

'That's quite stressful, when you tell a colleague that a patient is going down or whatever, they don't hear, because they don't want to hear what you are saying.'

In a recent study, 'fellow workers not doing their job' was among the top identified stressors, along with feelings of isolation (Martens, 2009). Nurse 1 described occasionally feeling lonely and isolated:

'It depends on the patient, on their family, it depends whether your local colleagues are working as well or whether you are on your own.'

Many of the nurses commented that the job was 'mentally draining'—more so than working in a different clinical scenario.

'Maybe you don't want to talk so much when you finish your shift. I think it does affect you.' Nurse 7

Conversely, another nurse denied feeling mentally affected by the job:

'I think that it is down to experience, age and maturity. If the work started to worry me ... that's when I stop.' Nurse 4

Sources of emotional labour and occupational stress in female hospice nurses were also identified by Payne (2001). The most frequent stressor was 'death and dying', then 'inadequate preparation', followed by conflict with doctors and nurses. The least problematic stressors were 'lack of support' and 'uncertainty of treatment'. However, organisational factors such as a high workload and lack of resources and support have been identified as a significant source of stress for hospice nurses by other studies (Hawkins et al, 2007). Occupational stress is recognised as a major reason for ill health; however, it must also be noted that the stresses experienced are context-dependent (Desbiens and Fillion, 2007; Martens, 2009). Consequently, it is important that the introduction of any coping strategies decreases stress and promotes positivity, encouraging a beneficial response.

Coping strategies
The nurses identified the need to 'switch off' after work:

'It's very sad really, you know when it comes to the end of their life it can hit you emotionally, but I don't take it home and think about it for hours.' Nurse 1

'I can switch off at the end of the day, I've always been able to do it because I don't think you do your patients any good if you're fretting too much and can't do your job properly the following day.' Nurse 3

Many of the nurses said that walking and exercise were means to help them unwind after a difficult day:

'I find exercise helps. I go to the gym twice a week in the morning and I find that really helps.' Nurse 7

Other after-work relaxation methods included watching television, listening to music, and attending craft lessons.
“Increased use of clinical supervision and reflection is indicated, along with the provision of stress-awareness training.”

It has long been established that there is a medium-to-high risk of hospice nurses experiencing compassion fatigue, but also that healthy professional ‘distancing’ learned from years of nursing experience and ‘self-care’ can balance out stressors (Abendroth and Flannery, 2006). However, it has also been reported that the job of dealing with multiple deaths and accompanying the dying does not seem to have a major affect on palliative care nurses (Desbiens and Fillion, 2007). Furthermore, stress levels are similar to or lower than in nurses working in other fields.

Support
The nurses identified support from colleagues as being important for their coping:

‘I chat with my colleague and the district nurses … make sure we have lunch together in the office so that we can chat and you know say how we feel, so that helps.’ Nurse 5

Nurse 3 worked in a particularly isolated rural area and found that:

‘Coming and mixing with the other people that you work with in the department weekly, is actually more beneficial probably than anything else.’

Other nurses also found support among family and friends:

‘My husband and I we do discuss things if I have got something on my mind. I would tell him … without naming names, that’s how I unload properly.’ Nurse 6

The majority of the nurses in Wu and Volker’s (2009) study identified the importance of seeking peer support, especially if there is a difficult case, and support from colleagues was also recognised in Payne’s (2001) study. Social support has been found to be an important coping strategy, and supervision and support groups should be encouraged as an approach to coping with stress (Hawkins et al., 2007). The use of reflection in and on practice for the nurses in the present study takes place both informally among the team and formally at the weekly multidisciplinary team meeting. The team meeting is recognised as being a safe and supportive place to discuss a variety of problems related to practice and complex symptom management (Arber, 2007).

Recommendations
The study highlighted a number of factors that contribute to the wellbeing of hospice at home nurses. From these, various recommendations can be made. Care providers should promote regular attendance at weekly multidisciplinary team meetings and, where relevant, local monthly team meetings including the palliative care consultant and Macmillan nurses as well as hospice at home nurses. Meetings can be held in the local place of work, supplementary to the weekly multidisciplinary team meeting. Increased use of clinical supervision and reflection is indicated, along with the provision of stress-awareness training. Raising awareness of the role of the hospice at home nurse in the primary care setting is also relevant, as conflict outside the palliative care team and communication difficulties between the hospice at home nurses and primary care teams were identified as a source of stress for the hospice at home nurses.

Limitations
This study was undertaken in a relatively small team of hospice at home nurses working closely with one another to provide a community palliative nursing service across a wide geographical area of North West Wales. For pragmatic reasons the project manager conducted the study interviews. Although known to the team members, the project manager does not have a clinical relationship with the nursing team members. Using an existing member of the team to undertake the role of interviewer may have had positive and negative effects. Being interviewed by a familiar person may be less threatening, leading to a more relaxed discussion. Alternatively the nurses may have felt inhibited because they knew the interviewer, although during the interview process the interviewer had no sense that the nurses felt awkward in any way.

Despite the interview transcripts being anonymised and the order of the transcripts randomised for each researcher, in one or two cases it was still possible for the researchers to identify the interview participant. This familiarity was present to some degree for all three of the researchers; however, each researcher was blinded to their colleagues’ critiques of the transcripts.

Interestingly, consensus was quickly apparent when the researchers met to discuss the outcomes of the study. During discussion of the transcripts and identification of common themes there was agreement that saturation had been reached and no loss of data was apparent in the conclusions drawn from the transcripts.

Conclusion
End-of-life care is everyone’s business, from generalist to specialist, regardless of care setting.
With increasing emphasis being placed on achieving preferred place of care at time of death, the hospice at home nurse represents a critical resource that is valuable not only to patients but also their families and health professionals. Further studies are needed to ascertain the potential of the recommended interventions to improve the wellbeing of hospice at home nurses.

Acknowledgments
The authors wish to acknowledge the participation of the hospice at home nursing team, without whose contribution this study would not have been possible. Acknowledgement is also due to the NHS organisation R&D department for sponsoring the study.

Department of Health (2008) End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life. DH, London

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