Two views of generic care work in 'end of life' care

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Abstract

This small explorative qualitative study examines the experiences of a small group of home carers (9) trained to work as generic care workers (GCWs) with 'end of life' patients and their carers. The views of informal carers (7) were also sought to see how the service was received. Through a combination of focus group discussion and the completion of a structured questionnaire the GCWs reported increased job satisfaction and motivation, less stress, felt an improvement in professional status and demonstrated a willingness and ability to undertake training. Informal carers were interviewed by independent interviewers asking a series of closed and open ended questions regarding the quality of the service they had received. They reported receiving help with administering personal care and low grade medical tasks, along with domestic assistance and social support with short periods of daily respite; all factors identified in the research literature as crucial to maintaining 'end of life' patients at home. This partnership project was delivered at very little extra cost. Given that an ageing population brings with it increasing demands on health and social care agencies for palliative care services the scheme has the potential, on the evidence provided within the limitations of this study, to provide an effective support to the NHS End of Life Care Programmes.

Keywords: Generic care workers, home care, end of life care, terminal illness, partnership work, focus group, structured interview.

Introduction

As a result of Government policy (HMSO, 1990; Department of Health, 2006) to maintain people in their own homes, home care services have gained considerable momentum over the period 1993-2004. The number of home care contact hours has grown consistently from 1.78 million hours in 1993 to 3.38 million hours in 2004 (Health and Social Care Information Centre, 2005). However, the role of home carer has been variously depicted over this period as one characterised by low pay (Mathew, 2004), low social status, (Mathew, 2004; McClimont & Grove, 2004) with a high turnover of staff and with difficulties in recruitment (UKHCA, 2004).

The growing demand for domiciliary care and home carers has been well documented and yet the aforementioned discrepancy exists. How can staff be attracted to the role of domiciliary care? The NHS Plan (Department of Health, 2002) focused on the development of health and social care workforces to cope with increased demand by working differently through 'role redesign'. The NHS Modernisation Agency's 'Changing Workforce Programme' has been at the forefront of developing support worker roles in rehabilitation and intermediate care services in both health and social care organisations (NHS Modernisation Agency, 2003).

Partnership working (Department of Health, 1997) and the integration of services (Care Services Improvement Partnership, 2007) are now at the heart of developing health and social care services. The terms used to describe health and social care working together to improve efficiency and patient/client outcomes are plentiful. The literature is awash with terms such as cooperation, joint working, interagency working, collaboration, coordination, and networking (Huxham, 1996; Powell & Exworthy, 2002). In order to succeed health and social services departments need to work together to provide both a comprehensive service to clients/patients and make the role an attractive proposition to encourage recruitment and retention.

The Generic Care Worker Pilot Project

As in many other local authorities, Blackpool Social Services Department has experienced extreme difficulties in the recruitment of home care staff. The recommendations from an internal review of home care services, in conjunction with those contained in the ADSS/Local Government Association (2003) report calling for the modernisation of the workforce with the development of, for example, generic care worker posts led to the development of a partnership between Blackpool Council and Blackpool PCT. The partnership's brief was to create a group of trained staff to deliver health and social care to people in their own homes.

External funding was obtained for a time limited Workforce Development Officer post to launch and monitor the project. In order to determine which type of work the project should focus on, an audit of the current demands on the home care service was carried out. The team were receiving many referrals for support from those service users with a terminal illness.

The White Paper *'Our Health, Our Care, Our Say'* (Department of Health, 2006) provides a series of actions that local partnerships can develop to improve service delivery. The creation of End of Life networks is one of five local actions for partnerships and fits in with local health initiatives concerned with terminal illness. The NHS Cancer Plan (Department of Health, 2000) noted that support for people coping with terminal illness at home could be poorly coordinated and not always available 24 hours a day. A number of health initiated schemes are now available to enable those with a terminal illness to be cared for at home. The Liverpool Care Pathway (Liverpool Care Pathway Central Team UK, 2006), the Gold Standards Framework (Thomas, 2003) and the Preferred Place of Care scheme (Storey *et al*., 2003) all aim to provide an opportunity for those facing a terminal illness to end their lives in a familiar setting, surrounded by loved ones. Research shows that over 50% of people facing this predicament wish to die at home (Lancashire & South Cumbria Cancer Network, 2006). However over the period 1994 to 2003 the proportion of home deaths in the U.K. resulting from cancer fell from 27% to 22%. This finding is echoed worldwide where the majority of cancer deaths occur in hospitals (Davies & Higginson, 2004). A King's College review of research (Gomes & Higginson, 2006a) into the factors influencing death at home in terminally ill cancer patients argued that:

> *Evidence shows … many terminally ill patients, particularly those suffering from cancer, want to die naturally, with dignity, in familiar surroundings and with their families*

close by. Clearly this indicates a preference for ending their days at home rather than in hospital and we need to adopt a new approach to ensure these wishes are carried out (www.kcl.ac.uk/phpnews/wmview.php ?ArtID=1155).

This review identified a number of factors influencing decisions about home deaths, one of which concerned the availability and level of home care. Recommended actions from the review included palliative care training for nurses and home helps and efforts to improve care at home facilities. In view of the number of referrals to the home care team for end of life care and the developing health initiatives in this sphere, the Blackpool partnership focused the pilot project on 'end of life' care.

With the exception of a one year external grant, to fund a full time post for the launch and monitoring of the project, this project was maintained within existing resources. GCW staff were recruited from existing home care teams and their training was carried out by the Primary Care Trust's District Nursing staff as part of their ongoing duties. The partnership agreement enabled the service to provide a number of intensive care packages using staff experienced in home care and trained to carry out a variety of low level medical tasks. The partnership agreement enabled this service to be delivered at very little additional expense to the PCT and Social Services Department.

Two clinical nurse managers from the PCT determined the clinical tasks in which the Generic Care Workers (GCWs) would receive training and how this training would be delivered. Staff were then recruited to the project from the Blackpool Council Home Care Team following awareness presentations on the GCW role and project. The majority of home carers felt it was a good development of the service and saw the role positively. The subsequent recruitment of staff to the GCW roles did put pressure on other areas of home care work and did break up regular teams of carers. However, home care team leaders noted a lot of interest in the GCW role from staff and reported many home carers would have liked the opportunity to undergo the training. At the time of writing, following the completion of the pilot project the PCT and Social Services are discussing the further development of the GCW scheme.

Those appointed to the role of GCW were very capable carers who could demonstrate extensive experience of both dealing with people at a difficult time and with working closely alongside family carers. They were also keen to develop good working relationships with district nurses and willing to undergo further training to develop clinical skills. Over the course of the pilot project 9 home care staff underwent a six week training programme supervised by district nurses which covered:

- skin assessment and basic wound care
- infection control
- continence care
- moving and handling
- basic life support
- baseline observations.

In addition, the clinical skills lab provided training in the fundamentals of care and some specialised palliative care training was provided by the local hospice. Much has recently been documented about workforce development and achieving improved outcomes and efficiencies. However, how has this new way of working been received by the staff actually doing the

job and those receiving the care? The aim of this paper is to seek the responses and reactions:

- of GCWs to the new way of working and to highlight the benefits as they experienced them; gauge the appeal of such change to influence staff retention in light of the possibility of advancement along a career structure; and identify any lessons learned about the extent to which this group of home carers can be trained to undertake limited health care tasks alongside home care tasks to terminally ill clients;
- of informal carers (families) to see how the generic care worker type of service facilitates the caring process during the last few weeks of life.

The Generic Care Worker pilot project was a scheme involving 9 GCWs who provided packages of care over a 9 month period to a total of 33 service users. The findings presented here must be viewed, therefore, as resulting from a small exploratory study and any conclusions reached must be viewed tentatively given the small numbers involved.

Method

All GCWs were invited to attend a focus group towards the end of the pilot project and to complete a short questionnaire on their work experience. In order to compare their current with their previous job satisfaction levels as home carers a retrospective pre-test method was deployed (Campbell and Stanley, 1963). Respondents were asked to rate their current levels of job satisfaction (post-test) as GCWs and then were asked to think back and rate their satisfaction levels prior to the GCW project when they were employed

as home carers (retrospective pre-test). The two levels were then compared to gain an impression of how this group perceive their satisfaction levels at two points in time.

The traditional method of completing a pre-test prior to the start of the intervention (i.e. the Generic Care Worker Project) was not possible as a detailed project evaluation had not been developed at the outset of the scheme hence the retrospective pre-test was used to gain an insight into satisfaction levels. This method has a number of documented weaknesses such as:

- desire for respondents to demonstrate increased satisfaction to please the researcher/project leader;
- validity of the results may be questioned due to memory recall and using midpoint responses when unsure;
- pre-test and post-test data collected post intervention at the same time is not standard research practice advocated in text books and may be seen as lacking methodological rigour.

Despite the highlighted drawbacks of using this method, several studies (Rockwell & Kohn, 1989) have looked at the differences between the retrospective pre-test and the standard method of administering a pre-test prior to an intervention followed by a post-test. The two differing methods produced very similar results. It was concluded the retrospective pre-test method was a suitable method if the traditional pre-test/post-test method was not possible and, as far as possible, findings should be corroborated by supplementary methods to illustrate the pre and post levels. In this case, the GCWs corroborated the retrospective pre-test result during the focus group

discussion which looked at their responses and reactions to the new way of working. Their responses echoed the retrospective pre-test result demonstrating satisfaction with the new GCW post and much less satisfaction with their previous home care role. The retrospective pre-test design was also used to investigate confidence levels in carrying out generic care work at two points in time. The level of confidence was ascertained for the point immediately following completion of the training course and again at the time of the focus group. A short questionnaire gathering demographic data and investigating general attitudes was also completed by the GCWs prior to the focus group.

The informal carers took part in a structured interview conducted by independent interviewers. A series of open ended and closed questions sought to determine the informal carer's satisfaction with, and the overall quality of, the GCW service, as well as identify any areas for improvement. A series of closed questions as reported in the PSSRU Discussion Paper on user

experiences of home care services (see Netten *et al.*, 2004) were used to introduce a series of topics around GCW service quality such as service reliability, flexibility, continuity, communication, staff attitudes, staff knowledge and skills. As each closed question was asked the interviewers then probed respondents to investigate the reasons for their opinions. Given the small number of respondents involved in this exploratory study it is not appropriate to report the figures in each closed question response category, however, a number of recurring themes did result from the interviewer probing and these themes are reported below.

Findings

Of the 9 GCWs involved in the project, 7 were able to attend the focus group (78%). The group was composed of 5 women and 2 men with an average age of 51 years (range 44 years to 59 years) and their average length of service as home carers was just over 9 years (range 6 months to 19 years).

Figure 1: Level of job satisfaction at two points in time
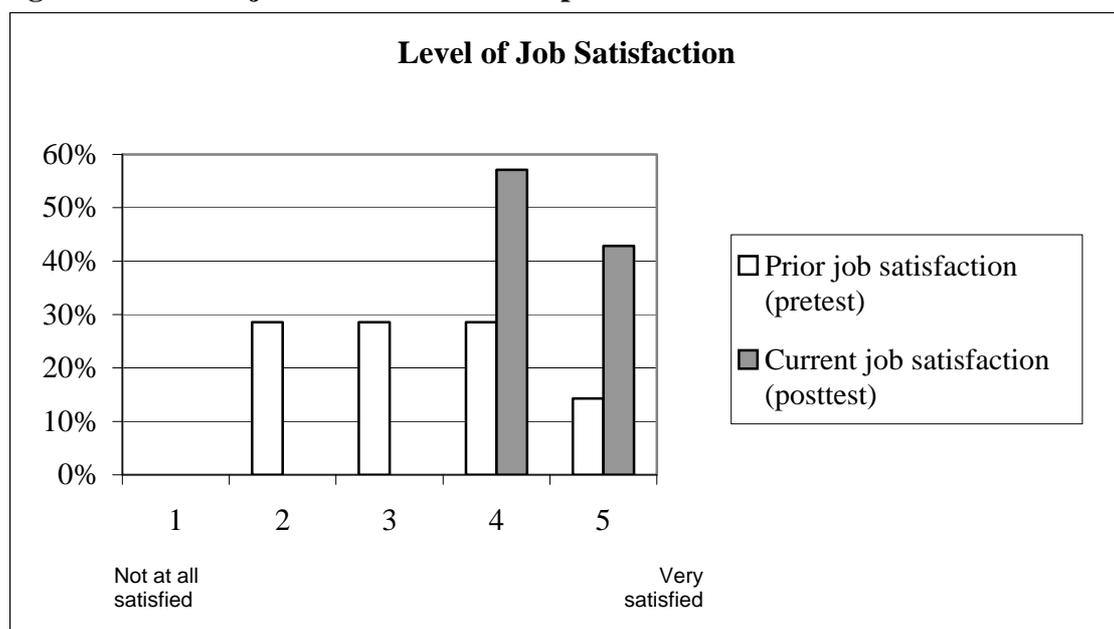
The Generic Care Workers completed a post-test and retrospective pre-test questionnaire item regarding their level of job satisfaction. They were asked to indicate on a scale of 1 to 5 (where 1 = not at all satisfied and 5 = very satisfied) their current level of job satisfaction as a Generic Care Worker (post-test) and then similarly indicate their level of job satisfaction as a home carer prior to their involvement in the generic care project (pre-test).

Just under 43% placed themselves at the top end of the job satisfaction scale (level 4 or 5) as home carers prior to the start of the generic care worker project. However, this figure rises to 100% at the top end of the job satisfaction scale following training and employment as a generic care worker.

The focus group was part of the project evaluation and took place after the project had been running 8 months so all GCWs who took part had experience of both home care work and GCW. The post-test then pre-test satisfaction findings were corroborated by the focus group discussion which highlighted a number of positives regarding this way of working:

- the new way of working was felt to be more interesting and varied. As a result the workers felt more motivated. One generic care worker stated they found work "a bit boring before but now I can use my brains more".

- the additional responsibility of the low level medical tasks was not found to be more stressful but rather less stressful than home care visits. Generic care workers were providing an intensive service to a small number of clients. They reported the most stressful elements of home care work emanated from encounters with sometimes 'abusive' clients who felt they were receiving a disjointed service from many home carers. The service provided by generic care workers did not engender this type of response.
- the generic care workers felt families had more confidence in their abilities as carers and felt "treated with more respect".

The GCWs had mixed feelings about having to undergo training and admitted to being apprehensive at the outset. However once on the training course all GCWs felt it was a good experience. The training course was considered to be a success "… the actual training was excellent".

Regarding their level of confidence in carrying out the generic care worker role, they were asked to indicate on a scale of 1 to 5 (where 1 = not at all confident and 5 = extremely confident) their current level of confidence in carrying out the generic care worker role (post-test) and then similarly indicate their level of confidence immediately following completion of their training as a generic care worker (pre-test).

Figure 2: Confidence levels
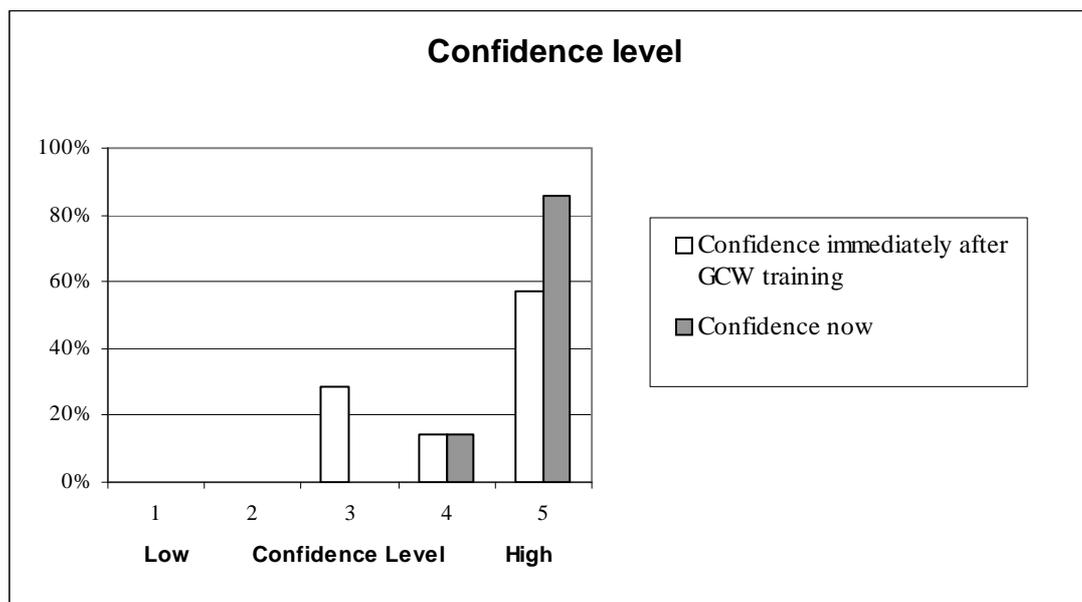
The training and experience of working as a generic care worker increased their levels of confidence in carrying out generic work. Using the retrospective pre-test post-test questionnaire method the generic care workers' levels of confidence increased from a group average of 4.3 after completion of training to 4.9 at the time of the focus group. The increase in confidence felt by the GCWs over the course of the project was attributed to the following positive outcomes identified during the focus group discussion:

- their selection for the project;
- the development of a new set of clinical skills;
- good working relationships developed with the community nursing teams;
- increased confidence when contacting district nurses and health centres on behalf of their clients to report deteriorating medical conditions; and
- they felt participation in the GCW project had improved their professional status as care workers.

Following their experience as GCWs, staff felt positive towards and were willing to undertake further training and recognised the importance of continued professional development. The move towards NVQ qualifications and the opportunity for generic care work training were felt to be positive inducements to encourage staff into care work. Respondents felt these inducements "will attract staff" and were felt to be "a good idea" for those wishing to develop their career.

In addition to the above comments made by GCWs on career progression, qualifications and training, they also completed a number of short questionnaire items related to these attitudes. They were asked to rate on a scale from 1 to 5 (where 1 = 'very important' and 5 = 'not at all important') the importance of a series of statements relating to their training, career progression, qualifications and a career path (see McClimont and Grove, 2004). All GCWs scored the following statements at 1 or 2 thereby indicating

they attached high importance to the ability to:

- undertake training
- undertake NVQ qualifications
- have a clearly defined career path.

The ability to progress to senior care worker was not viewed as important as the above, however all GCWs did rate its importance between 1 and 3 thereby indicating importance was attached to this item albeit with reduced intensity. In addition to the above benefits, the generic care workers identified a number of advantages for the clients resulting from the employment of this type of staff. The GCWs now felt they provided a comprehensive service to their clients.

> *"When we worked as home carers there was overlapping with auxiliary nurses … now we're trained we can do it all … shower someone and redress the wound …"*.

There was also felt to be a strong rapport built up with their clients and families. The intensive and comprehensive nature of the service meant they spent quite a lot of time on each visit. They felt a bond was built up with the clients and their family which came from the continuity of care and personal nature of the work undertaken. GCWs reported that the "… families seem able to talk to us better than the district nurses" and "they treat us more as friends … we're more hands on, approachable". They were able to deal with low grade nursing tasks and provide psychological support at a very stressful time for families.

In total 33 informal carers had been involved in the project at the time the exploratory study was carried out. The informal carers who underwent the in-depth interview were either actively involved in end of life care or were

recently bereaved. Given the range of individual circumstances it was not felt appropriate to invite all informal carers to take part in the interviews regarding their experience of receiving a service from the GCWs as this was considered to be, for some people, an unwanted and insensitive intrusion into their already busy caring schedule or private grief. Hence those informal carers who the project leader considered able to cope with the interview process (17) were invited to take part and 7 eventually put themselves forward for the in-depth interview which was carried out by interviewers independent of the social services department.

The structured interviews with the informal carers produced a number of themes which demonstrated both the benefits and needs of the service.

Experienced staff
End of life care can be a very stressful period for informal carers and their close family. One theme mentioned frequently was the individual characteristics of the GCWs (Henwood *et al*., 1998; Woodruff & Applebaum, 1996; Edebalk *et al.,* 1995). Respondents talked of the need for the 'right calibre of person for terminal patients'. A recurrent theme was the need to have confidence in the ability of the GCWs "they were very understanding and just seemed to know what to do". Similarly, the need for well developed personal skills with the ability to gain the client's confidence and treat them with respect and dignity was repeatedly mentioned. One informal carer noted that she "felt respected myself. My husband's dignity was always catered for" and another commented "always treated with respect, sometimes above and beyond the call of duty to both Mum and me". The group of staff chosen to be GCWs were very experienced in the field of home care and this appeared to be

appreciated by the informal carers, "they are older with life skills".

All informal carers 'strongly agreed' or 'agreed' with the statement 'The generic care workers are well trained for their job' and were happy to corroborate with anecdotal evidence "all knew what they were doing". The GCWs were able to identify problems and liaise with district nurses and GPs at an early stage "pointing out for example a rash … they contacted the GP … and the GP attended that day and gave medication" and "noticed pressure sores … telephoned our GP for advice". Thereby alleviating anxiety and keeping on top of problems at an early stage.

Despite working in extremely stressful situations where families and informal carers were facing the loss of a loved one, the GCWs were able to bring appropriate humour to the situation. Respondents commented the GCWs would "chat with us, have a joke, smile" and "also have a good laugh with them". The appropriate use of humour has the ability to reduce stress and tension, and facilitate communication in extremely difficult situations (Astedt *et al.*, 2001). Given the potential for highly charged emotional situations, the GCWs need to be aware of the emotional state of the informal carers they were assisting as humour may not always be accepted as an appropriate response. This perhaps demonstrates one of the key benefits of employing mature, skilled staff as GCWs in that they have experience of care-giving in potentially difficult interpersonal situations which in this instance allowed them to successfully use appropriate humour to facilitate the caring process.

Social support
Research has highlighted the importance of robust social support networks for carers and the negative impact the

absence of social networks can have on the carer's ability to maintain their caring role (Payne *et al.*, 1999; Gomes and Higginson, 2006b; Given *et al.*, 2001). One of the themes emanating from the open ended questions concerned the social support that the informal carers derived from their regular contact with the GCWs. As one carer explained, it was "… someone to talk to about Mum's care … I felt I could take a breath and felt less pressure, less isolation". Another informal carer experienced "less (of) a feeling of being on my own".

Domestic help
Caring for loved ones at the end of life phase can be a time of high anxiety when thoughts are focussed on the loved one and not necessarily on everyday mundane domestic tasks. Tasks which, nevertheless, need carrying out. The informal carers noted of the GCWs that "… they always did extra bits like putting the used sheets into the washer" and "they were helpful and flexible". One respondent added that they "could not have managed without them or the nurses. Mum wanted to be at home, totally trusted me but I needed the help". The research literature has similarly identified assistance with domestic help as being a priority for carers at this time (Hileman & Lackey, 1990; Neale, 1991; Harding & Higginson, 2003). A comprehensive package of assistance incorporating not only basic nursing tasks but also the traditional assistance provided by the home care service plays an important role in assisting informal carers to provide end of life care to their loved ones.

Continuity of care
Informal carers mentioned that any staff changes "are really too many". To have to regularly explain routines and tasks to new staff is not the hallmark of an excellent service. As the informal carers

commented, "need some faces regularly … you get used to them and them to you … feel confident, secure, provides continuity of care … feel invaded if there are too many". Due to achieving continuity of care with the same group of GCWs attending regularly, respondents commented the GCWs were "almost an extension of the family", "they have become like family" and "fitted in with our routines". Continuity of care has been described as one of the factors important to providing not only high quality palliative care (Luker *et al.*, 2000) but also high quality home care (Francis & Netten, 2004).

The pilot project provided packages of care to 33 service users in their final days/weeks of life. In 14 cases (42.4%), service users were entirely supported at home by primary care staff and the GCWs thereby avoiding a final hospital/ hospice/care home admission. The remaining service users in the pilot project were able to leave hospital care and spend some additional time at home due to being able to receive care from the primary care team and the intensive home care service from the GCWs prior to their eventual readmission and death in hospital. As mentioned earlier, information available on place of death shows the majority of cancer deaths occurring in hospital (World Health Organisation, 2004). This contrasts strongly with research evidence which shows 50% of people facing a terminal illness wish to die at home (Lancashire & South Cumbria Cancer Network, 2006). The results from this small exploratory study suggest the intensive and comprehensive service as described above and offered by GCWs to terminally ill patients has the potential to create an end-of-life 'care environment' which would assist in facilitating this wish.

Discussion

A criticism inherent in the reporting of findings from a solitary focus group concerns the extent to which the findings can be generalised to the target population. The aim of this exercise has been to gather detailed information from a small group of GCWs on their experiences of their role as a generic care worker. For this study, the advantages of using focus groups are they are a good method for: ascertaining the view of the GCW; enabling the researcher to find out what it's like in the GCW's shoes; and identifying the elements of generic care work seen as important to the GCW. However, the findings must be viewed in the context of a limited ability to generalise to the wider population of GCWs due to the small numbers taking part in the focus group and the non-representative nature of this group.

The responses and reactions of the GCWs to this new role can be characterised by increased levels of job satisfaction compared to their satisfaction with their home care role, alongside increased motivation and less workplace stress. They had more confidence when communicating with primary care staff and felt a closer working relationship had developed with the community nursing teams. As they developed experience of generic care work their levels of confidence increased and they felt their professional status as care workers had improved. They recognised the importance of, and demonstrated a willingness to undertake and successfully apply, training. The GCWs felt the move towards attaining professional qualifications alongside career development opportunities such as the generic care project were positive enhancements to promote social care as a career. However, this group were composed of very experienced home

care workers and their views could not be taken to accurately represent all experience levels within this occupation group. A stratified sampling technique taking into account all levels of experience, age groups and gender would be required to produce a definitive answer to these questions on incentives.

This group were overwhelmingly in favour of the change in focus from home care to generic care work. They considered this a positive occupational move forward, however, they did caution that generic care work may not be suitable for all home carers. The main reason surrounded the practical nature of carrying out low level medical tasks such as dealing with wounds/changing dressings, tasks which they felt would not suit all home carers.

The results from the retrospective pre-test and post-test questions do not, in themselves, provide evidence that the GCW service is an improvement on those services previously received. Rather the GCWs show, as a group, they are gaining more job satisfaction and feel more confident in their role. As a result this suggests, along with the findings from the focus group, a group of staff with increased motivation, improved morale and professional status. Coupled alongside the positive response from the in-depth interviews with the informal carers this would allow us to infer the actual service provided is better as a consequence of the GCW initiative.

The small number of informal carers who agreed to be interviewed following this project precludes the results from being generalised to all carers supported by the service. However, the findings are suggestive that this type of intervention has the potential to work alongside primary care workers and make a contribution to enhancing health schemes aimed at enabling those with a terminal illness to be cared for at home.

Caring for anyone with a terminal illness is a task requiring a great deal of both formal and informal support as the informal carers' needs at this time are substantial. Depending on their individual circumstances carers can face some or all of the following: psychological distress (Payne *et al.*, 1999; Schulz & Beach, 1999), reduction in social support (Northouse *et al.*, 2000), need for information (Hileman *et al.*, 1992), fatigue (Jensen & Given, 1993; Kristjanson & Aoun, 2004), domestic help (Hileman & Lackey, 1990; Harding & Higginson, 2003; Wingate & Lackey, 1989), anxiety (Higginson & Priest, 1996) and financial difficulties (Covinsky *et al.*, 2001). To compound these troubles carers are not aware of the length of time they will be expected to deal with these demands. Thereby creating an open ended situation where informal carers are unable to pace and conserve their energies over the course of the illness (see Kristjanson & Davis, 2004). In addition, if carers are themselves elderly, they may be performing their caring role whilst managing their own health problems. Having to cope with their own ill health along with the additional strain of caring for a terminally ill relative can make caregiving extremely difficult. In view of the considerable range of strains and pressures faced by carers it would appear crucial to the provision of an 'end of life' service to be able to provide adequate support for carers. Failure to achieve an adequate level of carer support can undermine the whole process of providing a comprehensive 'end of life' service for those wishing to die at home.

The research literature shows that amongst the most common reasons for admission to a hospital or hospice during 'end of life' care is the need for carer respite. Regular assessments of patients and their carers showed carer fatigue, anxiety and the need for relief as major factors in carers' conditions particularly in the final stages of their loved one's illness (Hinton, 1994). The range of comments obtained from the family carers demonstrated the GCW service assisted with a number of the informal carer's needs identified in the research literature. They reported confidence in the GCWs, felt they were well trained and provided a continuous comprehensive service. This regular contact inherent in the continuous service not only provided domestic assistance, personal care and low grade medical tasks but also social support with short periods of daily respite.

Conclusion

An ageing population brings with it increasing mortality and morbidity associated with a range of chronic illness such as heart disease, cancer and respiratory disease. The erosion of the influence and support of the extended family as a result of industrialisation and urbanisation coupled with increasing divorce and migration means that the traditional informal care givers are reducing in numbers. Their replacement in the face of an increasing demand for palliative care is a major problem facing both health and social care agencies. The needs of informal carers are considerable and to achieve a successful palliative care service which allows people to die with dignity at home depends to a large extent on providing adequate care to sustain informal carers through this caring process. The provision of palliative care at home focuses on two groups of people, those at the end of their life and those caring

for them. To maintain quality of life, dignity and care for all those concerned, multi-professional support across primary care and social care teams is a necessity to support the NHS End of Life Care Programmes.

References

Association of Directors of Social Services (2003) *All Our Tomorrows: Inverting the Triangle of Care,* www.adss.org.uk/publications/other/allo urtomorrows.pdf (accessed 14/11/2006)

Astedt-Kurki, P., Isola, A., Tammentie, T. & Kervinen, U. (2001) 'Importance of humour to client-nurse relationships and clients' well-being', *International Journal of Nursing Practice,* **7**(2), pp. 119-125.

Campbell, D.T. & Stanley, J.C. (1963) *Experimental and Quasi-Experimental Designs for Research,* Chicago: Rand McNally.

Care Services Improvement Partnership (2007) *www.integratedcarenetwork.gov.uk/inde x.cfm?pid=25* (accessed 13/2/2007).

Covinsky, K.E., Eng, C., Lui, L.Y., Sands, L.P., Sehgal, A.R., Walter, L.C., Wieland, D., Eleazer, G.P. & Yaffe, K. (2001) 'Reduced employment in caregivers of frail elders: Impact of ethnicity, patient clinical characteristics, and caregiver characteristics', *Journals of Gerontology Series A: Biological Sciences and Medical Sciences,* **56A**(11), pp. 707-713.

Davies, E. & Higginson, I.J. (eds) (2004). *The Solid Facts: Palliative Care,* Europe: WHO.

Department of Health (1997) *The New NHS: Modern – Dependable,* London: Stationery Office. www.archive.official-documents.co.uk/document/doh/newnhs/wpaper10.htm (accessed 15/11/2006).

Department of Health (2000) *NHS Cancer Plan,* London: Stationery Office.

Department of Health (2002) *HR in the NHS Plan: More Staff Working Differently,* London, Stationery Office.

Department of Health (2006). *Our Health, Our Care, Our Say: A New Direction for Community Services,* London: Stationery Office.

Edelbalk, P. G., Samuelsson, G. & Ingvad, B. (1995) 'How elderly people rank order the quality characteristics of home services', *Ageing and Society* **15**(1), pp. 83–103.

Francis, J. & Netten, A. (2004) 'Raising the quality of home care: A study of service users' views', *Social Policy & Administration*, **38**(3), pp. 290-305.

Given, B.A., Given, C.W. & Kozachik, S. (2001) 'Family support in advanced cancer', *CA:A Cancer Journal for Clinicians,* **51**(4), pp. 213-231.

Gomes, B. & Higginson, I.J. (2006a) www.kcl.ac.uk/phpnews/wmview.php?ArtID=1155 (accessed 15/11/2006).

Gomes, B. & Higginson, I.J. (2006b). 'Factors influencing death at home in terminally ill patients with cancer: systematic review', *BMJ*, **332**(7540), pp. 515-521.

Harding, R. & Higginson, I.J. (2003) 'What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness', *Palliative Medicine,* **17**(1), pp. 63-74.

Health and Social Care Information Centre (2005) *Community Care Statistics 2004: Home care services for adults England,* NHS Health and Social Care Information Centre, Adult Social Services Statistics 26 May.

Henwood, M., Lewis, H. & Waddington, E. (1998) *Listening to Users of Domiciliary Care Services: Developing and Monitoring Quality Standards,* Leeds Nuffield Institute for Health, Community Care Division.

Higginson, I. & Priest, P. (1996) 'Predictors of family anxiety in the weeks before bereavement', *Social Science and Medicine,* **43**(11), pp. 1621-1625.

Hileman, J.W., & Lackey, N.R. (1990) 'Self identified needs of patients with cancer at home and their home caregivers: a descriptive study', *Oncology Nursing Forum*, **17**(6), pp. 907-913.

Hileman, J.W., Lackey, N.R. & Hassanein, R.S. (1992) 'Identifying the needs of home caregivers of patients with cancer', *Oncology Nursing Forum*, Jun **19**(5), pp. 771-777.

Hinton, J. (1994) 'Which patients with terminal cancer are admitted from home care?', *Palliative Medicine,* **8**(3), pp. 197-210.

HMSO (1990) *The NHS and Community Care Act 1990.*

Huxham, C. (1996) *Creating Collaborative Advantage,* London: Sage.

Jensen, S. & Given, B. (1993) 'Fatigue affecting family caregivers of cancer patients', *Supportive Care in Cancer,* **1**(6), pp. 321-325.

Kristjanson, L.J. & Aoun, S. (2004) 'Palliative care for families: Remembering the hidden patients', *Canadian Journal of Psychiatry,* **49**(6), pp. 359-365.

Kristjanson, L.J. & Davis, S. (2004) 'The impact of cancer on the family', in Porock, D. & Palmer, D. (eds), *Cancer of the Gastrointestinal Tract,* London: Whurr Publishers, pp. 51-68.

Lancashire & South Cumbria Cancer Network (2006) www.cancerlancashire.org.uk/ppc.html (accessed on 15/11/2006).

Liverpool Care Pathway Central Team UK (2006) *Liverpool Care Pathway for the Dying Patient (LCP): Goal Definitions/Data Dictionary.* Liverpool: The Marie Curie Palliative Care Institute. www.mcpcil.org.uk/files/GoalDefinition datadic_NEW_-Dec.pdf (accessed 30/04/2007).

Luker, K.A., Austin, L., Caress, A. & Hallett, C.E. (2000) 'The importance of 'knowing the patient': community nurses' constructions of quality in providing palliative care', *Journal of Advanced Nursing*, **31**(4), p. 775.

Mathew, D (2004) *Commissioning Home Care. Changing Practice: Delivering Quality,* UKHCA Ltd April.

McClimont, W. & Grove, K. (2004) *Who Cares Now?: An Updated Profile of the Independent Sector Home Care Workforce in England,* UKHCA Ltd.

Neale, B. (1991) 'Informal Palliative Care: a review of research on needs, standards and service evaluation', *Occasional Paper No. 3,* Trent Palliative Care Centre.

Netten, A., Francis, J., Jones, K. & Bebbington, A. (2004) 'Performance and quality: user experiences of home care services. Final Report'. PSSRU Discussion Paper 2104/3 April 2004 www.pssru.ac.uk/pdf/dp2104_3.pdf

NHS Modernisation Agency (2003) *Changing Workforce Programme: Developing Support Worker Roles in Rehabilitation and Intermediate Care Services,* London, Department of Health.

Northouse, L.L., Mood, D., Templin, T., Mellon, S., & George, T. (2000) 'Couples' patterns of adjustment to colon cancer', *Social Science and Medicine,* **50**(2), pp. 271-284.

Payne, S., Smith, P. & Dean, S. (1999) 'Identifying the concerns of informal carers in palliative care', *Palliative Medicine* **13**(1), pp. 37-44.

Powell, M. & Exworthy, M. (2002) 'Partnerships, quasi-networks and social policy', in Glendinning, C., Powell, M. & Rummery, K. (eds), *Partnerships, New Labour and the Governance of Welfare,* Bristol: Policy Press, pp.15-32.

Rockwell, S.K. & Kohn, H. (1989) 'Post-then-pre evaluation', *Journal of Extension,* **27**(2) www.joe.org/joe/1989summer/a5.html (accessed 15/11/2006)

Schulz, R. & Beach, S.R. (1999) 'Caregiving as a risk factor for mortality: the caregiver health effects study', *Journal of American Medical Association*, **282**(23), pp. 2215-2219**.**

Storey, L., Pemberton, C., Howard, A., & O'Donnell, L. (2003) 'Place of death: Hobson's choice or patient choice?' *Cancer Nursing Practice* **2**(4), pp.33-38. (also www.cancerlancashire.org.uk/ppc.html accessed 30/04/2007))

Thomas, K. (2003) 'The gold standards framework in community palliative care', *European Journal of Palliative Care,* **10**(3), pp. 113-115 (also www.goldstandardsframework.nhs.uk accessed 30/04/2007).

UKHCA (2004) *Who Cares Now? An Updated Profile of Independent Sector Home Care Providers and their Workforce in England,* UKHCA Ltd October 2004.

Wingate, A.L. & Lackey, N.R. (1989) 'A description of the needs of noninstitutionalised cancer patients and their primary care givers', *Cancer Nursing*, Aug; **12**(4), pp. 216-225.

Woodruff, L. & Applebaum, R. (1996) 'Assuring the quality of in-home supportive services: a consumer perspective', *Journal of Ageing Studies*, **10**(2), pp. 137-169.

World Health Organisation (2004) *Palliative Care: the Solid Facts.* www.euro.who.int/document/E82931.pdf (accessed 15/11/2006).

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