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'She's an angel in disguise.' The evolving role of the specialist community heart nurse

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The 4H Project is a two year study (February 2001 – January 2003) designed to evaluate the impact of a nurse-led community cardiac rehabilitation service in an inner city area. The population has a high prevalence of coronary heart disease and low uptake of existing services for secondary prevention. Based on initial research exploring the needs of potential service users, the community heart nurse (CHN) delivers a holistic service to postmyocardial infarction patients in their own homes. The CHN has also initiated community-based interventions such as the setting up of support groups and a 'Walk your Way to Health' group. The CHN offers specialist advice to primary health care teams and works in close liaison with general practitioners (GPs) and practice nurses. This paper reports on service users' qualitative evaluation of the CHN role. Semi-structured interviews were carried out with 34 service users, from three weeks to 18 months postmyocardial infarction. The following aspects of the service were seen as important: the sharing of information and the accessible way it was presented; offering coping strategies; confidence building and reassurance; home-based care; easy access to CHN; regular checkups; and the opportunity to meet other patients. Additional services provided by the CHN such as advice on benefits or housing were not widely used, but were appreciated by those who did need this type of assistance. The emerging model of service delivery has both strengths and limitations but is entirely consistent with the increased emphasis on reducing health inequalities and promoting evidence-based care. However, with a relatively small caseload of patients, it is not surprising that a high level of patient satisfaction has been achieved. This paper will therefore include reflection on the difficulties besetting research attempting to evaluate complex, community-based interventions.

Key words: cardiac rehabilitation; primary health care; specialist roles in community nursing

Introduction

This paper sets out to describe the setting up and preliminary evaluation of a nurse-led, primary care based cardiac rehabilitation service. The paper will begin by briefly reviewing previous research relevant to this aim. It will then describe the background of the new service before moving on to consider service users' evaluations. The discussion will focus on the implications of previous research and service users' views for the developing role of the specialist community heart nurse. The paper will conclude with some observations on the difficulties inherent in evaluating complex, community-based services.

It will be noted that some of the literature reviewed relates to the secondary prevention of heart disease. Although it is conventional to distinguish between cardiac rehabilitation and secondary prevention, the authors contend that this is a false distinction. The key focus of the nurse-led service described in this paper is on phase 4 of cardiac rehabilitation, or the long-term mainte-

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nance of changed behaviour, and thus has much in common with structured disease management programmes addressing secondary prevention in a range of coronary heart diseases.

Background

Cardiac rehabilitation has been defined by the World Health Organisation (WHO) as:

> The sum of activities required to influence favourably the underlying cause of the disease, as well as the best possible physical, mental and social conditions, so that people may, by their own efforts preserve or resume when lost, as normal a place as possible in the community.
>
> World Health Organisation 1993 (cited in Stokes, 2000)

The WHO add that cardiac rehabilitation is not to be seen as an isolated form of therapy but must be integrated with the treatment process as a whole. This has been recognized in the UK Government's *National Service Framework for Coronary Heart Disease* (NSF for CHD) (Department of Health, 2000). A chapter of the NSF is devoted to cardiac rehabilitation, empasizing that 'it is important that cardiac rehabilitation is seen as an *integral component of both the acute stages of care and of secondary prevention'* (Department of Health, 2000: 3, italics in the original). The NSF summarizes the available evidence to conclude that cardiac rehabilitation 'works', and has been found to be effective in improving prognosis and/or function in a range of cardiac disorders. Cardiac rehabilitation can promote recovery, improve function and reduce the risk of death in people with heart disease (Effective Health Care, 1998).

However, although there is evidence that cardiac rehabilitation 'works', there is far less understanding of what forms of service provision work best, and for whom. Stokes (2000) noted that there are at least 300 cardiac rehabilitation programmes running across the UK. Most of these are hospital-based and 80% are co-ordinated by nurses. A bias in both service provision and research has been observed, with less attention focused on the needs and experiences of women, elderly people and those from ethnic minority groups (Thompson and De Bono, 1999).

A systematic review of 12 trials of secondary prevention in CHD found that structured disease management programmes have a positive impact on processes of care. Most trials report better quality of life or functional status among patients treated with disease management rather than usual care. However, the review concluded that 'the optimal mix of components and the cost effectiveness of these programmes is still uncertain' (McAlister *et al*., 2001: 961).

This paper will focus on rehabilitation following myocardial infarction, describing a primary care based intervention led by a specialist community nurse. Bowman *et al*. (1998) reviewed available evidence in relation to community-based cardiac rehabilitation. They argue that 'placing cardiac rehabilitation in the community should enable greater awareness of the individual needs of the person and their family' and that 'community-based cardiac rehabilitation can address the importance of the social and environmental context of the person's life in the rehabilitation process' (p. 250). They suggest that primary care staff understand the complexity of people's family and community circumstances, thus are best placed to influence health behaviour. This point is further developed by Stokes (2000), who questions whether nurses with a coronary care background – those who usually co-ordinate cardiac rehabilitation programmes – have the necessary attitudes and skills:

> For nurses used to working in a typically 'high-tech' treatment-orientated environment such as a coronary care unit, the shift to a different philosophical approach that is health-orientated rather than disease-orientated may be challenging.
>
> (Stokes, 2000: 413)

Clark *et al*. (2002) carried out focus group interviews with primary care and secondary care professionals delivering the cardiac rehabilitation services in one Scottish region. Their findings reflected previous evaluations of rehabilitation programmes: barriers to attendance included transport problems, and there were communication difficulties between secondary and primary care. Of particular interest here, however, is that Clark *et al*. found that hospital staff held a more individualistic view of patients' motivation to change their behaviours, emphasizing the individual's agency.

Primary care staff, on the other hand, placed more emphasis on the structural factors affecting patients' motivation:

> The primary care group appealed more frequently to a range of social and cultural factors in accounting for differences in individuals' capacity to change behaviours and thereby influence risk factors.
>
> (Clark *et al.*, 2002: 596)

In their review, Bowman *et al*. (1998) conclude that community-based cardiac rehabilitation can achieve health gains in the dimensions of adherence to treatment programmes: delivering education with a long-term impact, promoting exercise and providing psychological support. However, there are very few studies comparing hospital and community-based rehabilitation programmes and, again, little insight into what it is exactly that 'works'.

Interestingly, one of the few comprehensive trials of the follow-up of patients with ischaemic heart disease (IHD), the Southampton Heart Integrated Care Project (SHIP), offers an insight into what does *not* appear to work in the longer term. The SHIP trial covered all 67 general practices in Southampton and southwest Hampshire, recruiting 597 patients. Four hospital-based cardiac liaison nurses worked closely with practice nurses to facilitate the follow-up of patients discharged from hospital with angina or myocardial infarction (MI) at one month, four months and one year. The SHIP study found that, although the programme was effective in promoting follow-up in general practice, it did not improve health outcomes across a range of indicators (Jolly *et al*. 1999). A key problem was that the cardiac liaison nurses could not actually direct the treatment offered in primary care – they had a purely facilitative role so their effectiveness depended on the receptiveness of those they were working with. A second problem is that, after the conclusion of SHIP and the withdrawal of the cardiac liaison nurses, only two-fifths of the general practices continued to provide structured follow-up. The SHIP researchers found that the main reason given for discontinuing the service was lack of hospital discharge notification following the withdrawal of the cardiac liaison nurse service (Wright *et al*. 1999).

Moher *et al*. (2001) came to a similar conclusion regarding the lack of measurable outcomes following structured follow-up of patients with CHD in the community. A randomized-controlled trial compared three methods of promoting the secondary prevention of CHD in primary care. Patients of 21 general practices with CHD were assigned to three groups who received three different interventions. For the first group, the 'audit group', the intervention consisted of a survey of patients' notes and feedback to the primary care team. In the second group, patients were recalled for general practitioner (GP) review and, in the third group, recalled for review by the practice nurse. The study concluded that patient assessments were better in the nurse and GP recall groups (especially the nurse group), but that outcomes for patients in all three groups were similar at 18 months. In other words, 'follow-up by nurses is as effective as, and my be more effective than, follow-up by doctors' but 'improved assessment and follow-up does not necessarily improve clinical outcome' (Moher *et al*., 2001: 6).

Despite some evidence for the benefit of structured disease management programmes in CHD (McAlister *et al*., 2001), the jury is clearly still out on whether structured follow-up in primary care actually makes any difference to patient outcomes in the longer term. Also of interest are studies examining the value of a secondary-care based specialist nurse making home visits to CHD patients postdischarge. Frasure-Smith *et al*. (1997) found no benefit in relation to psychological well-being or prognosis following a nurse-led, home-based psychosocial intervention with post-MI patients. Blue *et al*. (2001), on the other hand, found that home visits from a specialist nurse decreased the hospital readmission rate among patients with heart failure. Again, the study by Blue *et al.* raises the question of 'what is it that works?' (home visiting *per se* or the specialist clinical interventions?). No attempt was made to evaluate the cost-effectiveness of such a service.

There appear to be no published studies evaluating the model of service to be described in this paper, i.e., a cardiac rehabilitation service led by a specialist community nurse. Anecdotal reports such as that of Ward (2002) suggest that a similar model is being implemented in Sheffield, and it is likely that community-based, nurse-led services are emerging elsewhere in response to the demands of the NSF. The recent publication of a strategy for primary care nursing (Department of Health, 2002)

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suggests that more nurses with advanced and specialist skills are needed to support generalists, perhaps providing a further boost to such models of service delivery. We can only agree with Masterson (2002) that:

> Comprehensive evaluation of new roles is desperately needed, using measurable clinical and patient-focused outcomes, to ensure that roles meet patient/client need and to secure continued funding and expansion if appropriate. There are both governmental and professional imperatives to develop a wider evaluative culture within service delivery.
>
> (Masterson, 2002: 337)

The 4H Project

This paper reports on the preliminary evaluation of a nurse-led community cardiac rehabilitation service serving the population of southeast Nottingham. The locality has a resident population of approximately 81000, many of whom live in impoverished inner city neighbourhoods. The Townsend score of the three most deprived wards within the area ranks them the third, fourth and seventh most deprived of the 104 wards comprising Nottingham Health Authority (Nottingham City Council, 1999). The entire locality forms part of Nottingham's Health Action Zone (HAZ), with a remit for health service providers to focus on the reduction of health inequalities. There is higher premature mortality for all chronic diseases compared to the Nottingham Health Authority average. Reflecting national and local priorities, the former Nottingham South East Primary Care Group Board decided in 1999 to make coronary heart disease (CHD) a priority for health improvement using HAZ money.

The resulting '4H' Project (where '4H' stands for 'happy, healthy, holistic, hearts') was set up as a two year study designed to evaluate the impact of a nurse-led community cardiac rehabilitation service in an inner city area. The research design is that of a prospective cohort study including all patients from the City South location of the Nottingham City Primary Care Trust (PCT) who have been diagnosed as suffering from acute MI. All patients are followed up for one year, at the end of which period progress is measured according to various physical, lifestyle and social outcomes. The population has a high prevalence of coronary heart disease and low uptake of existing services for secondary prevention. Based on exploratory research exploring the needs of potential service users, a community heart nurse (CHN) delivers a holistic service to postmyocardial infarction patients in their own homes (East *et al.*, 2004). The CHN has also initiated community-based interventions and offers specialist advice to primary health care teams. The aims of the 4H Project are described in Figure 1.

1. To use a combined social and medical model of care
2. To increase patients' perceived well-being
3. To increase the uptake of appropriate treatment
4. To support sustained lifestyle change

Figure 1 The aims of the 4H Project

The first aim, 'to use a combined social and medical model of care' draws on the theoretical framework provided by research exploring the links between health and social capital. The social capital thesis proposes that premature mortality is lower in regions where there are high levels of social capital, including trust, relationships of reciprocity and dense community associations (Lomas, 1998). The role of the CHN, therefore, included a community development element aiming to establish locality-based cardiac support groups and to promote user involvement in the development of the service. A further dimension of the CHN's work is to link service users with agencies providing welfare rights or housing advice where appropriate, suggested by Hoskins and Carter (2000) to be an important emergent role for community nurses.

The intervention to be evaluated in the 4H Project consists of the care pathway described in Figure 2. However, it should be noted that the CHN's role also includes research activity and liaising with and advising other professionals, as well as direct patient care. The element of community development is also significant and has had a number of outcomes: for example, the establishment of a 'Walk your Way to Health' group with

- Community heart nurse (CHN) notified of patient's discharge from hospital
- Home visit, plan of care negotiated
- Patient is encouraged to attend cardiac rehabilitation classes at the hospital
- Phone contact/home visits carried out as indicated in the plan of care
- Three month assessment, renegotiate care plan
- Phone contact/home visits as indicated
- Liaison with primary care team, e.g., over blood results or medication
- One year visit to collect end-point data

Figure 2 Care pathway offered by the community heart nurse

funding from the National Lottery. This dimension of the community nurse's work in the secondary prevention of CHD does not appear to have been part of the intervention in any of the trials discussed earlier.

Patients' evaluation of the CHN role

A year after the inception of the 4H Project, the research team evaluated service users' views of the service provided by the CHN. The CHN's caseload of 49 patients was selected, of whom it was possible to interview 34 people (14 women and 20 men, mean age 69 years). The interviews followed a semi-structured format, developed in partnership with the two patient representatives on the 4H Project steering group, and were carried out in the patients' own homes. All interviews were transcribed in full, then analysed in relation to the interview schedule.

Patients' views on the 'usual' services provided postdischarge were mixed. Some felt that they were quickly dropped by the hospital:

> You've had the plumbers in and they've done their job – just get on with it.

Others felt well supported through attending the cardiac rehabilitation classes at the hospital, and some felt very satisfied with the service they received from their GPs. These patients were the most likely to see little rationale for the CHN role, although they did find the CHN's visits congenial.

Other patients, however, felt the CHN was a 'lifeline' and would not have liked to miss the service. In particular, patients valued the accessibility of the CHN service and the individually tailored advice:

> There was someone there that you could turn to and if you were feeling down or if you'd got any questions, you know, if I had a certain pain I could always ask. It was stuff like that. I could ask her anything, anything at all, and if she didn't know she'd find out for me.

Other people found the physical checkups provided by the CHN reassuring:

> Whenever she's visited she's checked my blood pressure, weighed me and the first time she came she took samples and all that is, you know, very, very confidence building – it gives you confidence.

The fact that the CHN visited people in their homes has the advantage that transport was not a problem, something many people felt was a barrier to attending the hospital-based classes. It also led to increased contact with the patient's family, including the provision of health and lifestyle advice to other family members:

> It made one of my daughters go for a cholesterol test ... and my husband has stopped smoking.

The fact the CHN delivered care on a one-to-one basis was significant for a large number of service users, who were reluctant to mix with other people in a group – a common reason for electing not to attend the hospital-based cardiac rehabilitation programme. They come from relatively poor areas and many appear to lack confidence in social situations. For other users, the flexibility of the CHN service was important – for example, for one single parent the hospital-based classes clashed with the imperative to collect children from school. The flexibility of the service and the willingness of the CHN to advocate on their behalf surprised some patients:

> And any problem, she sorted it out, even to about – I was on about the shower. I'd like the bath taken out and she even delved into that for me. I'm sure that wasn't part of her blinkin' work but she even delved into that for me, even phoned the council up.

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Although 'counting' should be undertaken with caution in qualitative research, analysis of the interviews reveals the dimensions of the CHN role most often mentioned as particularly helpful (Table 1).

The valuing of the CHN's personality was apparent, hence the quote which forms the title of this study:

> She was an angel; she was an angel in disguise. She put my mind at rest.

Another patient pondered as to 'whether anyone else would have been the same. . .?'

Discussion

Service users' emphasis on the importance of a sympathetic personality immediately brings into focus a key problem in evaluation work of this kind. This finding confirms that of Attree's (2001) qualitative research, where the interactional and interpersonal aspects of caring were the most highly valued. Wiles (1997) conducted qualitative interviews with 22 patients participating in the SHIP study, and also found that interviewees often commented on aspects of the practice nurses' personal manner. However, such comments beg the question of whether patients are indeed observing the 'personality' of the nurse or the social and emotional *skills* of the nurse, as Wiles suggests. The 4H Project community heart nurse has many year's experience of district nursing in the inner-city, ensuring insight into patients' social environments and highly developed communication and assessment skills.

Table 1 Topics associated with satisfaction with CHN role

Topics associated with satisfaction	Number of patients mentioning topic
Useful information	18
Continuity of care/easy access to care	18
Checkups	9
CHN's personality	9
Psychological problems	5
Practical help	2
Tailored care	2
Maintaining links with other professionals	1

It is, of course, impossible to draw any firm conclusions from the current study as the intervention involved only one CHN and no comparisons can be made. In addition, this study suffers from the limitation common to research into patient satisfaction, in that the participating patients have not generally experienced alternative models of service provision and are thus unable to articulate a clear analysis of the relationship between their expectations and satisfaction. Interestingly, Wiles (1997) found that 'not all patients were convinced that practice nurses had the knowledge to offer the care and support that patients needed after their cardiac event' (p. 733). The current study found no evidence suggesting that service users doubted the competence of the CHN.

The second set of difficulties in relation to the current study centre on the question of the cost-effectiveness of the 4H service. It was noted earlier in this paper that none of the research on the structured management of secondary prevention in CHD suggests than an economic evaluation has been carried out. Published studies focus on the presence or absence of improved clinical outcomes of those receiving the interventions. However, where an intervention is shown to be effective in terms of clinical outcome, it becomes vitally important to attempt to cost out the benefits if new services are to enter the 'mainstream'. The evaluation of the 4H Project is clouded by the fact that it is a research project. The commitment of the CHN to research activity raises the question of how many more patients could be managed as part of a caseload if the research element was absent. The costs of training the CHN in his or her specialist role need to be taken into account, as do any costs incurred by additional investigations or treatments. A comprehensive evaluation of the CHN intervention described in this study is beset by the difficulty of assessing the more diffuse aspects of the role, such as educating other staff and community development activities.

Moher *et al*. (2001) observe that 'the difficulties of conducting pragmatic intervention trials in primary care are well recognized' (p. 6). This is certainly born out by the SHIP researchers, who have published a case study analysing the difficulties of conducting evaluations of complex services (Bradley *et al*., 1999). This case study high-

lights the value of qualitative research in articulating the perspectives of those delivering and receiving the intervention:

> Analysis of these phenomena can provide information about the process of implementing an intervention and can lead to suggestions about logistical changes needed to optimise the completion of tasks and processes within a local context.
>
> (Bradley et al., 1999: 714)

Iliffe (2000) observed that the local context is very important in studies of the roles of primary health care professionals. However, 'the division of labour, the rules and funding systems, the perceptions of local professional and lay communities, and the available resources all combine to produce or impede changes in practice, but trials only hint at the content of these black boxes' (p. 1021). If the final evaluation of the 4H Project demonstrates positive clinical outcomes among patients participating in the study (unlikely given the conclusions of similar studies and the lack of statistical power), then the contents of the 'black box' will still remain obscure. We will still not know whether the key variable is the CHN's professional skills or personality; whether patients achieved health gain as a result of participating in community initiatives designed to increase social capital or the degree to which home visiting is vital to the success of the model of service delivery. Nevertheless, the 4H evaluation is a step towards the development of a 'wider evaluative culture within service delivery' as recommended by Masterson (2002: 337).

Conclusion

The new strategy for primary care nursing (Department of Health, 2002) identifies a need for 'nurses with advanced and specialist skills to support generalists and provide more secondary care in community settings, first contact care and lead public health programmes'. The Department of Health's strategy endorses the role of the CHN described in this study, offering this role as a good example in the setting up of new services (p. 19). The Department of Health, also states explicitly that primary care nurses can 'improve access to cardiac rehabilitation by providing it in the community' (p. 33). Carr (2001) attempted to unpack what lies within the 'black box' of the processes of community nursing:

> The community context, and particularly the patient's home, appeared to offer patients greater opportunities to influence the practice agenda. The health care agenda in the community appears to be negotiated alongside the general 'life agenda' with which it competes or perhaps more accurately, in to which it fits.
>
> (Carr, 2001: 334)

The preliminary evaluation of the CHN's role within the 4H Project suggests that this is exactly what is happening, and is the dimension of care most valued by patients. 4H does not rest on the assumption that 'one size fits all' but offers a flexible, individualized programme of secondary prevention. The CHN works within the parameters of the service user's 'life agenda' to facilitate lasting change.

This paper has endeavoured to offer an account of a new, specialist role in primary care nursing that satisfies the needs and expectations of patients living in a disadvantaged urban locality. The emerging model of service delivery has both strengths and limitations but is entirely consistent with the increased emphasis on reducing health inequalities and promoting evidence-based care (Department of Health, 2000). With a relatively small caseload of patients, it is not surprising that a high level of patient satisfaction with the CHN role has been achieved. Further economic evaluation will be necessary at the conclusion of data collection for the 4H Project. We envisage that service users' views as captured in this study will aid the economic evaluation by identifying the elements of the service users find particularly helpful.

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