Recovering from a heart attack: a qualitative study into lay experiences and the struggle to make lifestyle changes

Susan Gregory\textsuperscript{a}, Yvonne Bostock\textsuperscript{b} and Kathryn Backett-Milburn\textsuperscript{a}


\textbf{Background.} The adoption of healthy living advice by people with heart disease is known to be poor even in targeted interventions. Reasons for this can range from confusion about the seriousness of the condition to ineffectiveness in the form of advice and how it is conveyed. However, the social setting can be an important influence on lifestyle change.

\textbf{Objectives.} To identify views and experiences of people recovering from myocardial infarction, specifically barriers to, and facilitators of, following advice about lifestyle change and maintenance.

\textbf{Methods.} Focus groups and interviews were undertaken with men and women discharged from hospital two/three years previously. A total of 53 people (35 men and 18 women) took part, recruited via a coronary care unit and patients’ GPs.

\textbf{Results.} A major finding was participants’ desires for long-term monitoring and support. While reported sources, form and content of coronary heart disease advice varied, most participants agreed that long-term follow up or back-up would be helpful, although what this should include and how it should be undertaken was not the same for all participants. This would fulfil needs such as: help in following lifestyle advice; sharing with people with similar experiences; regular contact with medical/health professionals (for confirmation of good health and to ask questions); providing reassurance to other members of the patients’ families.

\textbf{Conclusions.} A long-term programme is needed incorporating mutual support and sharing with regular (not necessarily frequent) input from practitioners of information, advice and reassurance, as a support strategy for lifestyle change.

\textbf{Keywords.} Heart disease, lay experiences, lifestyle change, long-term support, quantitative research.

\textbf{Introduction}

This paper offers an insight into how people who have recovered from heart disease view their own long-term needs and progress. Although deaths from coronary heart disease (CHD) are gradually reducing, considerable numbers of men and women, particularly in Scotland, are surviving myocardial infarction (MI) and so require strategies for preventing further heart disease problems.\textsuperscript{1} Interventions to promote changes in exercise, diet and smoking have been introduced for patients recovering from heart disease in both primary and secondary care, but adherence in the long term is known to be poor.\textsuperscript{2–4} The Scottish Intercollegiate Guideline Network (SIGN) guideline number 57,\textsuperscript{5} on cardiac rehabilitation (CR), notes the effect of a healthy lifestyle in substantially reducing further coronary risk, but acknowledges the difficulties patients have in achieving and maintaining this. The guideline also draws attention to exercise-based cardiac rehabilitation trials that have found considerable benefits associated with exercising for 12 weeks or longer. It goes on to say that for these benefits to be sustained, moderate physical activity should continue on a long-term basis, but that this is often unsuccessful once supervision has been withdrawn. It continues to be the case that long-term support and follow up tend to fall to the immediate family and/or primary care, but there is

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\textsuperscript{a}Research Unit in Health Behaviour and Change, School of Clinical Sciences and Community Health, University of Edinburgh Medical School, Teviot Place, Edinburgh EH8 9AG and \textsuperscript{b}Bostock Consulting, Edinburgh, UK. Correspondence to Susan Gregory; Email: s.gregory@ed.ac.uk
contradictory evidence of how effective this can be.\textsuperscript{6–9} The views and perspectives of people with heart disease on the value of long-term support and the form it might take are not reflected in this literature.

This qualitative, exploratory study aimed to elicit the views and experiences of men and women about their recovery from a heart attack (MI), with a view to identifying barriers to and facilitators for lifestyle change and maintenance within the family setting. This paper addresses one specific theme that emerged during the analysis of the transcripts. This theme identifies the uncertainty felt by patients with this type of chronic illness, indicating a blurred boundary between being ‘ill’ and being ‘well’ after discharge from hospital.\textsuperscript{10–12} The paper describes this theme and discusses its implications for future interventions and the roles of medical and health professionals.

\section*{Methods}

\textbf{Participants and setting}

The research design aimed at conducting five male-only and five female-only focus groups and two mixed groups. In the event, data were collected through nine focus groups and three interviews, as follows: five male-only groups (FG1, FG2, FG3, FG4, FG5) two mixed groups, that is, both male and female (FG6, FG7) and two female-only groups (FG8, FG9). Each focus group had 6 participants, apart from one male and one female group that had 4 participants each.

As can be seen, the recruitment of female participants for the focus groups was less successful compared to that of male participants. So, to compensate for this, the researcher undertook three one-to-one interviews with women to improve their representation in the study. These were conducted after the completion of the focus group discussions which allowed the pursuit of areas of interest that had emerged from the focus groups. It is speculated that the difficulty in accessing women to take part in the study may have been associated with the older age at which women tend to develop heart disease combined with a possible reluctance to travel to take part in the study.

The groups comprised people who had been discharged from the coronary care unit two to three years prior to the study in 2003. A qualitative approach, utilising focus groups, was chosen as the most effective way of bringing participants together to discuss their experiences in an informal and loosely structured manner. This approach allowed participants to raise those issues that were of particular relevance to their own everyday lives, but that might not have been anticipated by the research team. As an exploratory study, the themes identified were able to emerge in ways not possible in a pre-determined structured quantitative format.\textsuperscript{13,14} Participants were initially identified through the coronary care unit in a large teaching hospital in the central belt of Scotland, and then invited to take part via their own GPs. Information sheets and opt-in forms (forms indicating willingness to take part) were sent to participants with letters of invitation to take part from their GPs, and which they were asked to read carefully before volunteering. In order to ensure that participants did not feel any form of coercion to take part in the study, someone external to the research team was employed to identify participants’ addresses and their GPs from the cardiac liaison nurse’s files, and to send the invitations to take part via, and with the agreement of, their GPs. The information sheets gave the potential participants the opportunity to read about the study and then to complete and send the opt-in forms (in a pre-paid envelope) to the research team if they decided to volunteer to take part.

The catchment area for the hospital was very wide and, from those people who volunteered, we approached those located in geographically grouped clusters and, where possible, deprived areas to take part. However, because of the small-scale size of the study and the nature of this recruitment process it was not possible to create a systematic balance of deprived and privileged areas to allow comparisons in terms of inequalities. The participants were allocated to either male only, female only or mixed groups (5 male-only groups, 2 female-only groups and 2 mixed groups).

The participants were of employment age (i.e. under the age of 65 years). For the purposes of this small, exploratory study it was felt important to limit the level of potential variability between the participants in some respect. It was considered likely that people of employment age (whether they were in employment or not) would have different views and experiences compared to people of formal retirement age, but that it would be difficult to tease these differences out in a study of this size. So, in this study, the focus was directed at people of employment age, with a view to undertaking comparative work in future studies in which such comparisons would be more realistic.

Most of the participants (31 men and 14 women) were living within a family setting. A total of 35 men and 18 women took part in the study. Two thirds of the women (12) and more than a third of the men (13) had attended cardiac rehabilitation programmes at the hospital (6 weeks in length, involving exercise, dietary and other advice, often using the Heart Manual\textsuperscript{15}). Participants completed consent forms prior to taking part in the focus group meetings.

\section*{Data collected}

A topic guide was developed based on background literature and previous studies by the researchers, but in a form that would also allow participants to raise issues of importance to them. A trained focus group facilitator/interviewer (YB) opened the discussions by
inviting participants to speak briefly about their diagnosis experience and whether and how they had been offered CHD advice. They were then asked to talk about how they managed their recovery and the recommended advice (e.g. exercise and diet) within the home and family in the long term, including what they had found helpful or problematic. In the spirit of focus group methodology, participants were encouraged to share and compare their experiences, as well as to respond to the issues that the facilitator asked them to discuss. The group discussions were audio-taped and fully transcribed.

Data analysis
The transcripts were examined by the focus group facilitator and the principal investigator separately, during the course of conducting the data collection to identify potential emerging themes, to make comparisons (drawing upon a grounded theory approach16) between completed focus groups and to inform the next focus group. The transcripts were examined again together after data collection was completed. The research team held regular discussions during the course of the data collection and the process of analysis to identify significant themes that represented differences and similarities in experiences and views, including the unexpected as well as the anticipated, and any ‘outliers’ (i.e. one-off unusual cases). This formed the basis of the final report.17 A further, more focussed, analysis was undertaken to explore a theme identified from comments and discussions that represented participants’ views about long term follow-up and support and general reassurance. This topic had not been anticipated in the project design, but emerged clearly as an area of importance to the participants and so forms the basis of this paper.

Results and discussion
The main thrust of this analysis has been to identify a desire expressed by participants, in different ways, for a form of ongoing long-term monitoring and support that goes beyond any cardiac rehabilitation, if, indeed, this had been undertaken. As the study was aimed at eliciting information about the long-term management of CHD, a systematic examination of views about CR was not undertaken. However, in enquiring into lifestyle management, the sources and forms of advice generally were important to ascertain. Thus these results begin by reporting on the participants’ memories and views of the advice they had received on discharge from hospital (or during CR if attended) two to three years previously, moving onto how this advice was accommodated into their lives and what they felt was helpful.

Lifestyle advice
When asked to talk briefly about any heart disease advice and information they might have been given, participants’ comments revealed considerable variation in how this had been offered, in terms of: how much (if at all), where (in hospital or at home) by whom (consultant, nurse, dietician, GP) or who with (with a family member or alone). Many participants said they could not remember things, or could not ‘take it all in’, or that there was too much information or that the information seemed contradictory.

A1: “… You do get contradictory advice. On the one hand you are told that you shouldn’t be putting too much strain. Then, … I wanted to go and do some work, like manual work in a timber yard, not a problem, he [GP] said. Just carry on as normal. That was a bit confusing. Mixed messages.” (FG2)

However, when the CR programme was mentioned, all who had attended said they had enjoyed the classes and found them useful. Those who had chosen not to attend or had not been invited to attend, on hearing other participants’ descriptions of the classes, expressed interest in attending.

Adhering to lifestyle advice
All participants showed awareness of the importance of adhering to particular healthy lifestyle recommendations, whether new to them since the heart disease had been diagnosed, or whether they felt that they had always done so. This included regular exercise activities, as well as healthy eating habits and quitting smoking. However, the difficulty in maintaining aspects of the advice over the long term was a topic that emerged in all discussions. Many spoke of the shock of having had a heart attack and said this was a prime motivator for paying attention to the advice they had been given, but went on to say that this diminished over time. Some mentioned lack of time, especially if returning to work, others mentioned lack of motivation, boredom, stress events (especially related to returning to smoking).

G1: “… It is easy if you are just out of hospital, you are full of good intentions. But you are living on your own, and there is no inclination. It is not like I am working … It is not easy.” (FG2)

A2: “But you can control the house, I leave at 7am and don’t return until 5.30pm. I have customers and deal with the public, the service industry. … and there is nothing worse than dealing with the public … It is stress related.” (FG6)

When talking about help in changing and maintaining healthy lifestyles, whilst most of the men commented on how essential was the help given by family members (usually spouses), many complained about their
families being over protective. In contrast, none of the women seemed to see concern from family members in a negative way. However, many of the women reported being uncomfortable with having to rely upon family members to do household tasks that they felt they themselves should be doing.

*Lifestyle advice and ‘leading a normal life’*

In all of the focus group discussions, comments were made by participants indicating their (and their families’) uncertainty about the future. This suggests that for most of these participants (and members of their families) there was a tension between trying to understand and follow the advice which, they had been told, was essential to prevent recurrence of a heart disease event, on the one hand, and trying to ‘lead a normal life’ (which seems to mean ‘putting the illness behind you’), on the other hand. The participants gave a variety of responses when asked how they felt about their level of fitness and likelihood of developing further heart disease problems. A few said they were convinced that they were fully recovered and would never have another heart attack, whilst at the other extreme some people spoke of constant concern about attempting anything that might trigger another event.

**Help with adhering to lifestyle advice**

In the discussions of what would help with adhering to a healthy lifestyle, most participants mentioned the need for some form of ongoing support or monitoring. These comments fall into three categories, as the following quotes illustrate. Firstly, there were participants who said they wanted someone in authority (outwith the family) to make sure that they followed the medical advice they had been given.

G2: “It is not easy. I think it would be easier if there was somebody else, the right person there. Saying you should do this and that. When I do slip.” (FG2)

K1: “you feel as though you are left on your own as soon as it finishes [cardiac rehabilitation class].”

[all agree]

K1: “if it were still going, then at least you know somebody is looking after you, trying to get you back to normal.”

M1: “you are still under supervision.” (FG8)

Second, there were participants who expressed a need to talk to people who had had similar experiences to themselves.

“I can understand what you felt. I got tremendous comfort from going to the [cardiac rehabilitation class] and talking with kindred spirits and going through the sessions we had, and it was more emotional.” (FG7)

P1: “It would have been nice to have spoken to someone like you (YB) after the fact. . . To say how I felt then—I didn’t want to bore [husband] with it. If I could have just spoke whatever I was feeling to someone else, I think it would have helped.” (FG9)

Finally, there were participants who felt they wanted some kind of informal access to someone medically or health qualified to reassure themselves and/or their families that all was well.

C1: “It might have been nice after a year, if this nurse from the heart clinic care had maybe turned up after a year. Just to make sure everything was hunkydory, go over your manual with you again. The GP has not really got time to do that.” (FG4)

B1: “My wife’s reaction has been one of total fright. She got a hell of a fright. Where she could have benefited more in terms of information was to be told if I had stopped smoking that I would be fine. I keep telling her that I am fine, but she is not always convinced. It might help for her to sit down with the doctor and be told that, to be given the information as well.” (FG4)

This access also included, perhaps not surprisingly, being able to ask questions about symptoms or medication, or for reminding, refreshing or clarification.

S1: “I think perhaps, not so much as help but confirmation that everything . . . or having not instant, but sort of easy access to say, a doctor . . . . in the same way that they have these well women clinics . . . . Or perhaps something that you could just go along without actually saying to the doctor there’s something wrong. In the early stages, I know that there were a couple of occasions where I was a bit concerned.” (FG3)

JEM: “I think you could invite, groups like that, invite a dietitian along for half an hour to an hour for a talk. Just to go and remind you, freshen up things. Then you could have, I know it may be difficult, a doctor come along, a coronary doctor of some kind. Doesn’t need to be a consultant, as long as he is expert, where you could open the discussion.” (FG5)

These preferences were often articulated tentatively, and were issues that the participants seemed to feel did not warrant a formal consultation with their GP. However, viewed collectively, these data indicate the expression of a need to feel less isolated and more connected to an informal infrastructure that could provide support and monitoring and yet would emphasise reassurance rather than diagnosis.
Conclusions

The perspectives of people with heart disease about their preferences on the nature and form long term support might take have not been directly investigated to date, despite acknowledgement of the need for comprehensive long term support. This paper offers a valuable contribution to ongoing debates about how people might be encouraged to adhere to medical and healthy lifestyle advice post MI. These findings, from an exploratory study, suggest that on-going monitoring and support that goes beyond what the participants felt able or willing to expect from family and friends would be appreciated by people with heart disease, although this varied in form and content. Although some preferred the idea of regular, if informal, contact with medical and/or health professionals, others saw the emotional support of people with similar experiences as primary. In fact, both sets of lay perspectives on this process suggest that the long term and routine nature of continued supportive contact would provide, in itself, a reassurance that would facilitate moving on from the acute stage of the event. At the same time, this might provide a means by which lifestyle changes might be sustained. Such an approach would be in the spirit of cardiac rehabilitation guidelines. SIGN Guideline 57 also suggests that “the main responsibility for long term follow up in coronary disease lies with the individual and is facilitated by primary care” but that “[t]here is plenty of opportunity for aspects of care to get lost during transfer [from hospital to primary care], and plenty of evidence that this happens in practice”. Long-term strategies to help people manage their heart disease are needed that go beyond six week CR programmes located in hospitals, and for those who, for a range of reasons do not attend these programmes. The debate about whether and how people with heart disease should be managed within primary care has been going on for some time. Whilst the new GP contract requires annual review for CHD patients (more frequently if hypertensive), there are recent changes in the structure of health care, including Community Health Partnerships in Scotland and Primary Care Trusts in England, Local Health Care Co-operatives and CHD Managed Clinical Networks, that offer settings within which a less formal structure, incorporating more informal monitoring or feedback and mutual patient support, could be developed. A flexible, community-based form of routine monitoring and support, providing both patient-centred mutual support and sharing and medical/health professional input, from both primary and secondary care sectors, would be a useful way of addressing the needs and concerns of patients and their families and also practitioners’ work pressures. Further specific research is now needed into long-term advice strategies and support systems to determine how such a structure might be organised, such as research currently being undertaken by the first author of this paper, with colleagues, into the use and value of CHD support groups. This group of studies will, together, inform the evaluation that might be made of future CHD support structures by highlighting potential outcomes that indicate effectiveness and satisfaction, for both users and practitioners.

Declaration

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References


