Exploring Experiences of Hospitalised Angina Patients and their Partners: Insights from Participants in a Randomised Controlled Trial of the Angina Plan

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Research Article

ABSTRACT

Aim: The aim of this study was to explore the experiences of angina patients and their partners during their admission and recovery who had recently participated in a Randomised controlled trial of the Angina Plan.

Background: Angina patients are often admitted to hospital yet are often excluded from cardiac rehabilitation programmes. The Angina Plan, a facilitated self-help intervention based on cognitive behavioural therapy, was evaluated in a randomised controlled trial as a method of support post discharge. This study explored the experiences of those who did and did not receive the angina plan intervention.

Design and method: A qualitative descriptive study using semi-structured interviews (n=8) and three focus groups was completed on participants in both arms of the randomised controlled trial who had completed their 6 month follow up. Interview data was recorded, transcribed verbatim and analysed.

Results: Three main themes emerged: 'Satisfaction with care: information and support', 'Impact of angina' and 'The Angina Plan as a tool for change.' Participants reported inadequate provision of information about their condition in hospital, feeling they had to actively seek the information they needed. Partners felt particularly excluded from information provision. Angina impacted on people's recovery in different ways, ranging from restrictions and disability to a determination not to be beaten by this condition. Angina Plan patients liked the comprehensive, accessible information provided, contact with services and the reassurance this offered and reported increased understanding of their condition and lifestyle change. In contrast standard care participants reported no lifestyle change and were more likely to express the need for further information and support during recovery.

Conclusion: This study provided further insight into the recovery and rehabilitation needs of hospitalised angina patients and their partners.

Relevance to clinical practice: This intervention may offer one solution to address this gap in current care provision.

Keywords: Knowledge, Road traffic accidents, Structured teaching programme, Adolescents

INTRODUCTION

Angina pectoris is a common symptom of Coronary Heart Disease (CHD) and often results in hospital admission [1,2]. On-going chest pain, anxiety and depression and misconceptions of CHD may impair recovery, result in disability and increase hospital readmissions [3-14]. Risk factor change post-discharge is often limited [8,15]. The benefits of cardiac rehabilitation (CR) programmes on recovery following myocardial infarction (MI) are well documented [16-19], however angina patients however are often not included in traditional CR and recovery programmes [7,20].

The Angina Plan (AP), is a nurse-facilitated self-help intervention has been evaluated in Randomised controlled trials (RCT) in primary [21] and secondary care [22] and in clinical practice [23]. The AP intervention is based upon the principles

of cognitive behavioural therapy (CBT). The intervention included a 45 min in-hospital consultation during which cardiac misconceptions were identified and corrected. Individual cardiac risk was assessed and advice on risk factor modification provided. Patients received the AP which included a patient held workbook and an audio-taped information and relaxation programme. Over the next 12 weeks the AP nurse facilitators provided [8] telephone consultation using techniques of goal setting and pacing to support lifestyle change and recovery.

The AP has been shown to improve mood [6], reduce misconceptions and disability [6,22], reduce Body Mass Index, increase self-reported exercise, improve general health perceptions and social/leisure activities compared to those receiving Standard Care (SC) [22]. Whilst RCT's can generate evidence informing practice it's recognised that they also have limitations. The complementary use of qualitative methods to generate further understanding of the perspectives of trial participants has been recommended [24,25].

The aim of this study was therefore to complete a qualitative evaluation of a subset of the hospitalised RCT participants from the parent study [22] to compare the experiences of patients (and partners) who did and did not receive the Angina Plan.

AIMS AND OBJECTIVES

Research Design

The aim of this study was to attempt to explore, describe, interpret, compare and understand the experiences of angina patients and their partners who had recently participated in the RCT of the Angina Plan during their admission and recovery. A comparison of those who had received support through a nurse facilitated self-help intervention, the Angina Plan, and those who had received standard care was made using a qualitative, descriptive study design. Data was collected by semi-structured interviews and focus groups.

METHODOLOGY

Sample and Recruitment

The first sixty participants, 30 from each arm of the parent study) to complete the 6 month follow up were contacted by telephone and invited to participate in this qualitative study. This included 39 men and 21 women, with a mean age of 62 (SD 10.3) and 18 partners those interested were sent an information sheet and a convenient interview time and location was agreed. Prior to the interview written informed consent was obtained from all participants.

Data Collection and Analysis

Data was collected in two phases over 6 months. An interview guide was developed and validated by clinical experts to enhance face validity prior to the study. After piloting with one patient further revision enhanced content validity. A similar process was completed for partners.

Phase 1

Semi-structured individual interviews with 6 patients (4 AP and 2 SC) and 2 partners (one from each group) exploring their experiences before, during and 6 months after admission were completed.

Interviews lasting 45-60 min, were audiotaped, transcribed verbatim and analysed using a constant comparative method [26]. Common responses were grouped to form emergent categories which were compared by a second researcher to enhance inter-rater reliability and reproducibility. A randomly selected transcript was also analysed by an independent researcher for external verification and validation. Complimentary field notes highlighted non-verbal communication, intonation and any discussion surrounding the taped interview. Following this analysis a second interview schedule was developed and used to guide the focus group interviews in phase 2.

Phase 2

Three focus groups (with 4-6 persons in each) for AP patients, SC patients and SC partners respectively were conducted. These lasted 55-72 min. Purposive sampling was used to ensure that focus groups included men and women, and represented the age range and socio-economic backgrounds of the study participants. Due to the number of AP partners available and willing to participate, a focus group was not possible; therefore one additional individual partner interview was completed to gain further insight into their experiences. Data was transcribed, analysed and validated using the methods outlined above.

Ethical Issues

Local ethical approval was obtained. Participants were assured of their right to withdraw from the study at any time. Data was stored in locked filing cabinets and entered into password protected files. Tapes were destroyed following transcription and identifying details changed to maintain confidentiality and anonymity. The investigation conformed to the principles outlined in the declaration of Helsinki (last revision: Edinburgh, October 2000).

RESULTS

Three main themes emerged from the data analysis, namely 'Satisfaction with care: information and support', 'Impact of angina' and 'Angina Plan as a tool for change.'

'Satisfaction with Care: Information and Support'

Overall, patients from both arms of the study reported positive experiences of care throughout all stages of the patient journey, from the first contact of the ambulance team to the General Practitioners follow up;

"The ambulance crews were excellent" FG3/SC-part/M2[1]

"The attitude of the staff, their caring and professional attitude is excellent". I2/AP

This was also true of most partners:

"I was worried when my wife went into hospital, but she got extremely good care and after that I didn't worry too much". FG3/SC-part/M1

Information

Some patients however were less satisfied with the general level of information provided about their condition and future management.

"I find a lack of information on how you're progressing or regressing" FG1/AP/F1

"If you want to (know) anything you have got to ask" FG1/AP/F2

"I think you have got to fish for the answers, you have got to ask questions" FG2/SC/M1

Partners in particular felt excluded from this information provision:

"I never really saw any doctors, they only spoke to him" (husband). FG2/SC/F

After discharge from hospital, experiences in both groups of care and information provided by the wider community team were varied:

"Wife felt I didn't get support" "Not so caring" I1/AP

"They don't follow you up at all; you're fine so they forget about you" I4/SC

"My GP's very good; he actually asked to see the book" I2/AP

Support and follow-up

A key need for support emerged which respondents felt could be provided in the first instance by their doctor or primary care team, however the frequency of follow-up appointments was varied. Some described regular follow up:

"Well I've kept very close to my GP, he sees me once a month" I3/AP

"Practice nurse (measures) weight and BP every 3 months" I6/SC

Whereas others felt they did not get adequate support:

"They don't follow you up at all, it's a case of your in, you're out, and that's you, your fine so they forget about you". I4/SC

Or that this should be more structured

"I would like to see that standardised, rather than being the luck of which medical practice you are in" FG3/SC-Part M

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[1] Respondents are categorised as to whether they took part in a focus group (FG) or individual interview (I), whether they received the angina plan (AP) or Standard Care (SC), if they are male (M) of female (F) and if they are a partner (part).

Views of support

With regards to the AP follow up after discharge, perceptions again were positive:

"There was the information in this book that allowed my partner to predict what was going to happen, I was getting sent up anyway so I beat the gun, she got a lot of reassurance from that" FG1/AP/M

"The support was excellent, because it goes a long way to helping you understand" I2/AP

In contrast, partners of patients in the SC group asked for *"more information and support".*

"There was no direct information to me as a partner as to what was the best way, that Angina plan would have been useful, we are literate you know, we can read" FG2/SC/M2

"It's the reassurance side of it, as much for me as for my wife, I would like to see this as a regular for the first two years, getting a formalised situation" FG2/SC/M1

All participants in the study appeared to feel that their needs were met if they had some kind of follow-up, e.g. review appointments and tests. However, the information provided at these appointments was sometimes perceived as sparse, the main reason being cited as a 'lack of time'. Patients and partners would like these visits lengthened.

Impact of angina

The effects of angina on patients and partners both physically and psychologically were also reported in this study. Physically angina was seen to restrict or limit their activity:

"Slows me, I'm a lot slower than I used to be" FG1/AP/M

"To me it puts a wall around what I do…I don't want to go too far in case it comes back so it does constrain." FG1/AP/M

and psychologically, angina could be seen to vary from very disabling to feelings of no sense of being unwell

"I was scared, I was frightened" FG2/SC/F1

"I must admit I feel a bit of a fraud" FG1/AP/F2

Anxiety was also expressed by partners

"Well, because I'm always conscious of his breathing yet, so I don't sleep so well" I5/AP-Part

Some reported concern that their angina was affecting their families too, whereas others felt this was not the case

"Yep I feel it's affecting the family, they keep saying mum are you sure you're OK?" FG3/SC-Part/F1

"I feel that I'm holding them back because they are saying 'Are you OK? Do you want a seat?' and I feel that that's working me up more…" FG1/AP/F2

"I am not aware of it affecting them at all" I2/AP

Despite acknowledging the effects Angina could have on them and their partners there was also a strong will "not to be beaten":

"I'm not going to sit in a chair with a shawl around me" FG1/AP/F1

"I had a game of golf last week, I managed to get through it, I've just got to keep going" FG2/SC/M3

'Angina Plan – As a Tool for Change'

Generally, the AP intervention was viewed very positively by participants as it provided useful information, contact with services and reassurance:

"Information you took away and read at home" FG1/AP/M

"And the fact we had home contacts, oh lovely yes it was very good" FG1/AP/F2

"The ability to read it again, that's in the book when I need reassurance" FG1/AP/F3

Participants spoke very positively about the AP manual, some describing how they still use it and would refer to it frequently. Some reported this was also used by their partners. When asked if some form of support such as the AP would have been of benefit to them (SC group) the participants seemed to view this positively.

"I think it would be an asset to be given before discharge from hospital" I3 SC

Overall the information and relaxation tapes which complemented the manual, were considered useful, but two participants did not continue to use these

"I found the voice boring; I found it condescending"..."I never listened to them after the first time" I2/AP

"I'm afraid I couldn't stand them" FG1/AP/F3

On closer inspection it seemed that the voice in particular was found to be very irritating.

Role of Facilitators

In relation to the AP facilitators, who provided follow up for three months, the responses were very positive. In general patients were happy to be phoned; they felt it was "being remembered". Another recurrent theme was that they gained reassurance from having a contact number for someone in their direct care, rather than a complete stranger as with NHS 24.

"I never had any worries at all, they phoned me" I2/AP

"I didn't phone them, they phoned me" "It's made clear, you're not to hesitate" I1/AP

"It was reassuring having someone phoning up, considering the hospital didn't follow us up" I5/AP-Part.

Whilst both groups expressed varying levels of satisfaction regarding their post discharge care and information, the patients being contacted by the AP facilitator expressed increased reassurance

"It was reassuring to have someone phone up and ask how you were and you didn't need to care considering the hospital didn't follow us up or anything I think in that case it was of use yes." I7AP/Part.

Interestingly, some responses seemed to support the view that even minimal non-clinical input post discharge is perceived as a benefit.

"They are paying more attention to me than the doctors or hospital" I4/SC.

"They" refers to the researcher at the 6-month evaluation in the SC group. This seems to suggest that even a short interview with no intervention leaves a positive impression of care. Such contact with a research assistant has previously been reported as being viewed as an intervention in its own right [27].

Angina Plan as Tool

The AP was seen as an "extra" tool to aid recovery, both in hospital and at home. Again the benefit was seen in terms of the provision of information and reassurance.

"At least you had that information that you didn't get from any other body, you get more confident" FG1/AP/F1

"The plan gave reassurance, you could read it (the manual) and you would know in a generalised way that this had happened before" FG1/AP/M

"Especially in the initial days (after discharge), to find out you are not alone, there's lots of you out there, not as good as meeting in person but some reassurance" FG1/AP/M

The SC group differed by not expressing feelings of reassurance, nor feeling that they had control of their recovery as indicated by the AP group. However, as stated previously they appear happy with their care and the information received:

"It's been fine actually, she gave me a wee booklet (British Heart Foundation)...she was quite good" I4/SC.

"I wanted some reassurance on something so I phoned the number and got it...it saved me having an unnecessary trip to the hospital because if I'd phoned a got a certain doctor I would have been in." FG1/AP/M.

Participants expressed feelings of negative reassurance, in that people assumed that if no-one contacted you then it must be because there was no need – the notion of no news is good news. SC participants thought that by virtue of receiving SC and not receiving the AP information pack that they must be in good health:

"I thought that was great, I thought well there's not really serious that they want me back" FG2/SC/M3.

"You felt you weren't ill enough to be included" FG2/SC/F.

FACILITATING CHANGE

Goal setting and pacing techniques were used by the AP facilitators to promote lifestyle change and support recovery. Most participants of the AP arm could describe at least one lifestyle change:

"I now exercise more than I did" I2/AP

"I'm more conscious of my diet" I1/AP

"I've cut down on my alcohol intake" I3/AP

"I do more walking; my outlook on life has changed" I2/AP

"So that would probably be the best benefit I got from the plan was how to pace yourself" FG1/AP/M

These are mostly physical gains and perceived changes in lifestyle; other gains reported were again in relation to reassurance and support:

"It's let me know it's not life threatening, if it gets worse you have always got something to turn to" FG1/AP/F3

"Well basically it made me that I didn't want to give up" FG1/AP/M

Apart from the aforementioned benefit of people taking more notice of them as a participant in a research study, the SC group did not express any perceived benefits as a consequence of their SC.

DISCUSSION

This study aimed to better understand experiences of those who did and did not receive the AP to support their recovery after admission to hospital with angina. The themes which emerged from the current study were ''Satisfaction with care: information and support', 'Impact of angina' and 'AP as a tool for change.'

Whilst both groups were generally satisfied with their clinical care there were some gaps in care provision, notably in the quantity and quality of information provided to both patients and partners. The need for patients and partners to have information about their condition to enable their recovery has been reported in other cardiac studies [28-30]. Participants in both groups highlighted the challenge of obtaining relevant information, reporting that staffs were not proactive in this and patients often felt that they had to actively seek the information they required. Partners felt particularly excluded from this process, a problem previously reported after MI where partners actually demonstrated higher levels of anxiety and depression than patients [31].

Previous research has identified patients want to know about factors which affect survival, but have a limited understanding of their disease and cardiovascular risk factors [15,32-37]. Providing this information is important to facilitate understanding and lifestyle change in patients and their families [36]. Results from this study and the RCT supported the achievement of cardiovascular risk and lifestyle change in the AP group [22]. Evidenced-based self-management programs have previously been shown to promote knowledge and skills and improve outcomes such as pain, depression and disability [17,21,38-40]. Having increased control of their recovery, rehabilitation and health was also reported by patients using the heart manual as a self-help intervention [41].

The experiences of SC patients reflect previous studies which suggest patients and partners information needs are often not met [27,42,43] or are not known by patients and their carers until after discharge [40]. From this study it appears that information is available when staff is asked, but is often not readily available when not requested. The importance of having the opportunity to discuss their disease with heath care staff has been reported [36] yet information is sometimes given in a way which is not easily understood or at a time when patients are unable to absorb it [39]. Limited provision or recollection of information in relation to their condition or recovery has been reported after MI and surgery [27,38,40]. One SC participant expressed lack of information as their main problem in achieving adequate angina symptom management. Not meeting the information needs of this patient may have resulted in on-going angina and possible readmission as has been previously reported in angina patients [8].

Partners suggested that being present during the initial interview with participants on the AP arm of the main study would have been beneficial. One partner stated that there was no 'direct information' given to her as a partner suggesting that they felt isolated and 'out of the loop' in relation to their partner's care. The lack of information for partners is concerning particularly considering that partners often act to a lesser or greater degree as carers for the person with angina. The cause of the lack of staff and patient interactions in this study was perceived as staff workload, causing reluctance for the patient/partner to ask questions:

"A lot of it is down to a lack of staff, the nurses are run off their feet" FG1/AP/F3

This supports previous findings that patients worry about the appropriateness of their enquiry and about bothering a busy practitioner [40].

The timely provision of information through the AP which can be accessed repeatedly when the patient is ready to learn allows the message to be reinforced and may possibly avoid problems with inappropriate provision and timing of information. In addition this resource is available to family members who may also use this to support positive lifestyle

changes [41]. The positive responses reported by AP patients about the usefulness of this information resource for them and their families may potentially offer a solution. It would be helpful to consider alternative modalities to deliver the educational messages such as DVDs, video clips on mobile phones as not all patients can read.

Following discharge from hospital not all patients, particularly those in the SC group, felt adequately supported, indeed some expressed a sense of 'abandonment,' that they were 'on their own' and that they would have liked more support than they actually received. There was also a sense from some participants that support was a bit of a lottery. This period immediately following discharge is known to associated with shock, anxiety and a sense of vulnerability [40,42]. Participants expressed a need for reassurance more so than physical aspects of managing their condition. Even where patients and partners had contact with health services, these contacts were perceived as being as sparse, rushed and too short.

Many of the physical and psychological effects of living with angina as reported by the participants in this study are similar to those reported elsewhere [8,11,21,36]. Of interest was the sense of restraint and impaired physical activity that having angina imposed on patients. This participant also expressed fear that exertion may lead to further angina pain and harm as has previously been reported [14,36]. This reinforces previous research which identified that maladaptive beliefs and misconceptions about heart disease can have a negative impact on recovery [6,11,14,36]. Interventions effectively targeting misconceptions are thought to enable more effective self-management of CHD by giving patients the confidence to engage in recovery programmes and lifestyle change [6].

The RCT results of partner's mood, knowledge and misconceptions [22] did not capture many of the stressful issues raised in this qualitative study, e.g. the challenges of living with someone with cardiac disease. Partners reported the need to be constantly alert and vigilant for changes in their partner's condition; of not sleeping and being ever watchful [29,44,45]. This need to constantly know where their partner is has also been reported in other cardiac studies [29]. Some patients in both groups reported over protection by their partners and family members was restrictive, creating a source of tension between family members, an issue which has been previously reported [29].

However, despite the limitations and constraints resulting from angina symptoms, some participants saw their angina as a challenge to be faced. They were determined 'not to be beaten' and to live life to the full a concept previously been reported in cardiac patients who have responded to their event by carrying on as normal and refusing to let the event disrupt their lives [46].

The AP was clearly seen as a key influence in facilitating change for a number of participants. Patients and their partners valued the fact that it could be used over and over again. It offered a comprehensive source of information and was available to patients when they wanted it allowing messages to be reinforced when the patient was ready to learn, a finding also reported in a study of the heart manual post MI [41]. Even those who were not exposed to the AP during the RCT but who were shown the AP manual during the focus groups in this study could see the potential benefits of such a resource.

Whilst generally seen positively, the voice used on the audiotapes did seem to be a barrier to use for some participants. Audiotapes are an outdated medium and participants would have preferred a CD with the option to go directly to a chosen section.

Contact with and access to facilitators should concerns arise was seen very positively and particularly important to partners and has previously been reported [36,42]. A previous study highlighted patients were 'very satisfied' with information when professionals sat down with them and provided individualised information [47]. For AP participants the facilitator provided this valuable intervention through the structured interview and on-going follow up.

Participants valued having even minimal contact with someone in the health care team. One participant suggested that this contact may have prevented an unnecessary hospital admission, a key driver in the national policy documents to prevent unplanned admissions [48]. Such telephone contact has also been shown to prevent admission for other cardiac patients [49].

One other interesting observation was captured at the SC Focus Group where several participants interpreted being randomised to the Standard Care arm of the parent study to mean that they were not ill enough to require the intervention. This links to the issue of lack of contact being framed in a positive light - i.e., that no news is good news. This could perhaps be related to lack of understanding of the randomisation process in clinical trials. This highlights the need for clear information and explanations about randomisation and SC for research participants [25].

Some patients expressed the need for continued follow up by a dedicated 'angina team', and to have the opportunity to meet with like-minded patients, needs which have been previously reported [41,50]. Integrating angina patients into existing CR programmes, in line with current national aims may achieve this. Similarly cardiac support groups offer peer support, however the evidence base for their effectiveness is limited and variable [51]. There is a sense that participants in the AP arm of the study felt more in control of their condition and lives. In contrast, in SC, one participant expressed

lack of information as their main problem in achieving adequate angina symptom management. Not meeting the information needs of this patient may have resulted in on-going angina and possible readmission as has been previously reported in angina patients [8].

LIMITATIONS

As this study was completed soon after the 6 month reviews, the perceived benefits are short term and no assessment has been made on the long term effects of the AP as a recovery programme. The current changes in interventional cardiology mean patients have often undergone PCI during their admission The AP was not evaluated in this context therefore further evaluation should be considered. This study involved a subset of patients involved at the start of a RCT It is not known whether practice changed over the duration of the main study for usual care and therefore if the same issues would have come to light in later evaluation.

IMPLICATIONS/RECOMMENDATIONS

The findings of this study suggest angina patients who received the AP reported benefits from participating in this self-help programme after an acute admission to hospital. These benefits were mainly added reassurance, understanding of the disease, symptom control and adapting to living with angina which are all important areas in managing a long term condition such as heart disease.

The individual insights from patients and partners in this study complement the work of Zetta et al. [22] and have highlighted the potential benefits of this intervention. The results provide additional data which may help inform clinicians of the rehabilitation needs and wishes of angina patients and their partners. This increased understanding may further benefit the redesign and delivery of the cardiac rehabilitation services aiming to include angina patients in their services.

It supports the literature that suggests that CBT based interventions have a role to play in assisting patients to adapt to and more effectively self-manage their angina. It demonstrates how the AP may contribute to supporting patients following admission to hospital with angina and partners have suggested how this could be better utilised for their benefit too.

Further work specifically on how best partners' needs can be met should be undertaken. It was suggested that the AP plan may have prevented unnecessary hospital readmissions and further research in relation to this would be worthwhile.

Further consideration should also be given to the optimum medium for presenting the information and relaxation elements of the intervention to optimise participant engagement in the whole programme, thus maximising the potential benefits of the AP for angina patients and their partners.

CONTRIBUTORS

Study Design KS, PA, CH, SZ Data collection and analysis PA CH manuscript preparation KS, PA, CH, SZ.

CONFLICT OF INTEREST

The author(s) declare that they have no conflict of interests.

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