

Evaluation of post-MI patient diaries show concerns

The British Heart Foundation has piloted a patient-held diary for post-myocardial infarction patients with the aim of supporting and empowering patients. This article discusses the evaluation of the pilot scheme.

Introduction

The British Heart Foundation (BHF) diary has been designed to be a personal record for patients post-myocardial infarction (MI) to record their progress, keep a record of their condition, provide guidance on services and basic information on medication and risk factors, and to provide pages that the patient can use to manage their condition.

The diary was first introduced at Addenbrooke's Hospital in Cambridge as one of many initiatives at a local level to address National Service Framework targets to support and empower patients. This work was brought to the attention of the BHF who decided to pilot the diary in association with three Cambridgeshire hospitals to produce a cardiac resource that could be made available nationally. A steering group representing a range of health professionals and patient groups was formed and the diary was developed further for a pilot.

The pilot diary was evaluated to assess how patients, family and health professionals valued it and also to find out whether the diary realised certain BHF objectives including:

- whether it helped increase patients' knowledge about their condition, improved self management, and increased involvement in their care and treatment
- whether it was a means of increasing patient awareness of local and national support services.

Methods

The Tavistock Institute carried out the qualitative evaluation of the pilot diary in two stages. During the first stage the

diary was offered to all patients with MI admitted to the three hospitals over a six-month period in 2004; 60 volunteer patients were recruited.

In the second stage, an improved and revised diary was piloted with similar methods. Some 88 patients agreed to take the diary, 42 patients and carers took part in interviews and focus groups to consider the use and value of the revised diary, 40 patients responded to a survey after they had been in possession of the diary for between one and five months, and five phase IV cardiac rehabilitation instructors and one general practitioner (GP) responded to requests for opinions on the diary.

Results

The evaluation showed 40% of patients admitted into the three hospitals declined the diary. Reasons for this included being too preoccupied with their diagnosis, feeling 'too poorly', or having too much on their mind at the time. The research therefore explored patients' views on receiving the diary at a GP surgery or at a phase 2 rehabilitation session. Over half the patients, however, said that the hospital was the best place to receive the diary. Patients acknowledged that these early days in hospital were when they were most motivated to make changes and had easy access to the expertise of rehabilitation nurses.

Generally patients felt that the diary should not be first given out at their GP's surgery as they needed to engage with it at an earlier stage. Only three indicated that they felt this was a better place to receive the diary. More patients (34% of those interviewed) felt that GPs generally did not have enough



Eighty-five per cent of patients in the survey felt they would make more use of the diary if supported by health professionals

time to talk to them about their anxieties or lifestyle adjustments but would provide blood pressure and cholesterol readings if asked. The diary acts as a prompt to patients to request these measurements by having a section where patients 'fill in' these readings. In return, the nurse or GP can see that the patient has somewhere to keep a record.

Some patients (six of the 38 interviewed [16%]) felt that their GP did not have the expertise to answer their questions; four did not even show their diary to their GP. Comments were focused around patients not being confident that the GP knew a lot about "heart problems" or was not a specialist. These six patients were all over 55 years old; none thought that their MI had been misdiagnosed but four felt the GP

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had got some aspect of recovery wrong, or in one case, had referred their questions to the cardiac rehabilitation unit and had dismissed the patient's requests about alternative treatments.

The majority of patients felt confident that the rehabilitation nurses had the necessary expertise and time; 56% of the survey respondents said they had used the diary to discuss something with a health professional, predominately a rehabilitation nurse.

The survey showed only five patients had brought the diary to their doctor's attention. Although most patients understood that the diary was for their own use, disappointment was often expressed when GPs and consultants did not talk to patients about the diary. Most patients said they would use the diary more if health professionals took more interest. The phase IV instructors, practice nurses and one GP who responded to requests for views on the diary during the evaluation were generally enthusiastic about its benefits and felt they would be able to support patients in their use of the diary.

Overall, of the 88 patients that took the diary, the majority (85%) made use of the diary and, of these, 90% rated it as useful.

Previous research

Previous research on the use of diaries and patient records has suggested that such tools do not appear to have any impact on the quality of life of patients or improvement in the provision of information or satisfaction with information.² Research on patient records in the 1990s^{3,4} and more recently in 2001 and 2002^{5,6} reported health professionals' anxieties in relation to patient records in other fields around duplication of information and time constraints, as well as the need to market the record to health professionals. However, many of the same studies found that some patients find their own record useful^{2,3,5,6} and report similar patient attitudes as in this BHF evaluation.



Key messages

- Over half the patients using the diary felt the hospital was the best place to receive the diary
- Many patients (34%) felt the local GP would not have enough time to talk to them about their anxieties or lifestyle adjustments but said they were confident about asking the GP for health readings such as blood pressure and cholesterol
- 15% of those interviewed expressed the view that their local GP did not have the expertise to deal with their questions on MI
- There was an expectation from patients that health professionals should proactively support them and 85% of survey respondents felt that they would make more use of their diary if a health professional took an interest

Conclusion

Patient perceptions that the GP does not have the time or expertise to answer their questions coupled with any perceived lack of interest from their health professional may result in the patient not presenting the diary at appointments or discussing fears and problems. This may leave some patients unsupported, particularly those not attending rehabilitation classes or those without access to practice nurses.

- The BHF diary is freely available to health professionals and hospitals who wish to give this to their patients. Contact the BHF on 0870 600 6566 for further information.

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Conflict of interest

The British Heart Foundation commissioned the Tavistock Institute to evaluate its patient-held diary for cardiac patients.

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