Provision of rehabilitation services to patients with implanted cardioverter defibrillators: a survey of UK implantation centres

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Abstract

This study investigated the current level of provision of cardiac rehabilitation (CR) for automatic implanted cardioverter defibrillator (ICD) patients in the UK, the clinical and technical staff views on the need for such a service, and the current level of provision and the most commonly reported barriers to meeting these needs. The study was carried out via a postal questionnaire survey of all NHS implantation centres for ICD patients.

The majority of respondents (99%) believed they should provide rehabilitation for their patients, but only 14 (36%) centres had a programme for rehabilitation that ICD patients could access and only four (10%) of these were specifically designed for ICD patients. The majority of respondents (74%) believed they were not meeting their patients' needs for rehabilitation. The most commonly endorsed barriers to providing and developing CR services were limited multidisciplinary staff, a wide geographical catchment area, and administrative and organisation difficulties. There was wide support for the potential of using a home based, remotely monitored, rehabilitation package. This shows that the vast majority of staff in implantation centres agree with the recent NICE recommendations that there is an unmet need to provide CR for ICD patients.

Key words: defibrillator patients, cardiac rehabilitation, survey, self-help.

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Introduction

The most recent Cochrane review and meta-analysis of cardiac rehabilitation (CR) included 8,440 patients and revealed a 28% reduction in all-cause mortality.[1] Other systematic reviews have established that CR also brings about an improvement in exercise tolerance, an improvement in symptoms, an improvement in blood lipid levels, a reduction in cigarette smoking, an improvement in psychosocial well-being and a reduction of stress.[2-4]

Given the wide range of benefits from CR, numerous authoritative bodies from the World Health Organisation to the UK government's *National Service Framework for coronary heart disease*[5] have advised that all patients with coronary artery disease should be assessed for CR and those who might benefit should receive such a service. There is no universally agreed protocol for CR, however, and it is delivered in a variety of formats and settings. Most national clinical guidelines therefore now stress that it must be multidisciplinary in nature and contain components similar to those recommended in this statement from the US Department of Health and Human Services, Public Health Service Agency for Health Care Policy and Research and the National Heart, Lung, and Blood Institute guidelines:[6] "The process begins with assessments regarding all relevant aspects of the patient's status: medical, nutritional, psychosocial, educational, and vocational. The implementation of cardiac rehabilitation, based on these initial assessments, is designed to address the individual patient's needs as he or she works toward achieving optimal outcomes".

The guideline quotes the US Public Health Service definition of cardiac rehabilitation: "Cardiac rehabilitation services are comprehensive, long-term programs involving medical evaluation, prescribed exercise, cardiac risk factor modification, education, and counselling. These programs are designed to limit the physiological and psychological effects of cardiac illness, reduce the risk of sudden death or reinfarction, control cardiac symptoms, stabilise or reverse the atherosclerotic process, and enhance the psychosocial and vocational status of selected patients".

Thus, although there is currently no agreed protocol for CR in the UK, there is general agreement about the constituent parts of cardiac rehabilitation.

Relevance to ICD patients

But how are these recommendations on CR relevant to ICD patients? Firstly, most ICD patients have coronary artery disease and it has been suggested that they might benefit from the medical and secondary prevention aspects of CR in a number of ways

including, possibly, a reduction in firings.[7] ICD patients and their families are also at risk of a number of specific psychological and quality of life deficits. For example, reviews have shown that 15–50% of patients may have problems with anxiety and depression.[8] Living with an ICD brings unique worries such as the device firing, with consequent pain and possible social embarrassment, or the device malfunctioning.[9-12] A common reaction to this worry is for ICD patients to severely reduce activity levels,[13,14] thus further impoverishing their lives and potentially damaging their health. This led the UK's National Institute for Clinical Excellence (NICE), in its guidelines for the use of ICDs in the National Health Service to recommend that ICD patients should receive "a rehabilitative approach to aftercare which includes psychological preparation for living with an ICD".[15]

To date, there have been several small, mostly non-randomised studies aimed at improving quality of life or psychological status of ICD patients. These have included treatments such as attendance at a support group and counselling. All reported subjective improvements in psychological well-being and quality of life.[16-19] One prospective, randomised, controlled trial of individual cognitive-behavioural intervention with ICD patients reported decreased depression and anxiety and increased adjustment to living with the device, particularly among those patients who had experienced a firing.[20] More recently, a comprehensive 12-week CR programme showed that not only is CR safe for patients with ICDs, it can also improve exercising ability and lower levels of psychological distress.[21] Support for the effectiveness of such programmes has been further strengthened by evidence from a 12-week comprehensive CR programme devised for ICD patients, where significant benefits in terms of psychological and functional adaptation to living with the device were again seen.[22] Both these programmes included:

- a simple, low impact, self-paced, exercise programme
- educational and discussion sessions about common ICD and cardiac misconceptions and concerns, and discussion on common but unhelpful coping responses
- weekly goal setting and pacing, to help patients resume enjoyable activities that had been abandoned or severely reduced following implantation
- educational sessions on the cognitive model of anxiety and panic, and on identifying and challenging negative automatic thoughts, especially those related to heart disease and the ICD
- use of a group-based format allowing opportunity to share feelings, experiences and coping strategies, and provision of emotional support with others in similar circumstances.

In the climate of emerging evidence for the value of comprehensive CR for ICD patients, we wished to ascertain the following: the degree to which ICD patients in the UK are currently receiving CR; the opinions of staff working most closely with these patients as to the need for providing a rehabilitation service to ICD patients; and, if they agreed that it was necessary but were not providing it, the most common barriers that they perceived to doing so.

Finally, both the randomised controlled trials of CR for ICD patients described were hospital-based. In the latter programme, it was noted that only a proportion of eligible ICD patients actually participated – a large number declined the option to participate due to problems with regularly attending hospital for the duration of an out-patients' programme. The use of a home-based, self-help rehabilitation package similar to those developed and evaluated for other groups of cardiac patients could help solve this problem.[12,23-26] For example, the Heart Manual has been shown to be an effective form of rehabilitation post myocardial infarction.[25] Interestingly, a recent article published in the *BMJ* reported on the safety and efficacy of CR in community centres and patients' homes.[27] Therefore, we were also interested in ascertaining staff views on the acceptability of using this method of CR delivery for ICD patients.

Subjects and methods

The survey included the 39 NHS centres providing ICD implantation in the UK as taken from the National Pacemaker Database. A postal questionnaire was used, modelled on one used previously in a survey of rehabilitation provision in paediatric cardiology.[28] Three copies of the questionnaire were sent to each centre, one each for: the cardiologist identified in a telephone call to the centre as the 'lead' for ICD implantations in that centre, a cardiac rehabilitation nurse and an ECG physiologist. If a response was not received within four weeks, a written reminder was sent. Answers were scored and entered into SPSS database (version 10.0) for analysis.

Results

Between March and May 2002, questionnaires were returned by nurses from 20 (53%) of the centres; 19 (47%) were returned not completed as the centre had no rehabilitation nursing provision for ICD patients. This therefore represents a return rate of 100% of those nurses eligible to reply. Completed questionnaires were received from 37 (93%) of the ECG physiologists (two returned the questionnaires without completing them, as they had recently stopped doing ICD work in that centre). Of the cardiologists surveyed, 22 (51%) returned completed questionnaires, two (5%) declined to participate and 19 (44%) did not respond. As there were no significant differences between the answers given by the nurses and the ECG physiologists, except for the percentage of patients deemed suitable for CR and whether or not they believed they were meeting NICE guidelines, their other responses were pooled.

The mean number of ICD implantation procedures performed per month in centres in the UK was 5.0 (SD 3.1, range, 1–16). The number of ICD patients alive and actively being followed up ranged between 11 and 400 (mean 125, SD 89). On average, each patient spends 3.5 (SD 2.7, range 2–14) days in hospital at the time of initial implantation.

The mean percentage of patients deemed suitable for rehabilitation by nurses was 93% (SD 13, range 50–100); the mean percentage of patients deemed suitable by cardiologists was 93% (SD 9, range 70–100), while ECG physiologists only

Table 1. Barriers to provision and development of cardiac rehabilitation (CR) services for internal cardioverter defibrillator (ICD) patients

Barrier to provision/development of CR services for ICD patients	Nurses endorsing n (%)	Cardiologists endorsing n (%)	ECG physiologists endorsing n (%)	Total All groups n (%)
Distance patients have to travel to hospital to attend	14 (70)	10 (46)	24 (65)	61 (48)
Nowhere/no venue for patients to meet for rehabilitation	9 (45)	4 (18)	14 (38)	34 (27)
No and/or limited staff available to provide rehabilitation	14 (70)	19 (86)	29 (78)	79 (62)
No perceived need on the ICD patients' part	4 (20)	2 (9)	6 (16)	15 (12)
No perceived need on staff's part	4 (20)	1 (5)	7 (19)	15 (12)
Administrative/organisational limitations	13 (65)	14 (64)	28 (76)	70 (55)

Table 2. Number of rehabilitation nurses, cardiologists and ECG staff who endorsed barriers to provision and development of rehabilitation services for ICD patients

Other perceived barriers to providing/developing rehabilitation services at your hospital	• Funding of rehabilitation services (4) • Limited multidisciplinary staff with expertise (4) • Lack of professionals' time (3)

Table 3. Categorised verbatim responses (number) of nurses, cardiologists and ECG physiologists to open ended question about the need for improvement of rehabilitation services

Question

Can you identify which aspects of ICD patient care you would like to see improved and/or changed?

Summarised responses

- More psychological support and education/information for both patients and families at time of implantation and at follow-up (17)
- Provision of a dedicated ICD patient support nurse (8)
- Dedicated ICD patient and family rehabilitation service/programme (7)
- No/limited evidence-base for provision of rehabilitation (3)
- Development of ICD patient and family support groups (2)

Footnote: Proposed improvements to provision and/or development of rehabilitation services for ICD patients, 37 (32%) of staff responded

deemed 82% (SD 22, range 25–100%) as suitable. All of the nurses and cardiologists, and 99% of the ECG physiologists, believed that there was a need for these patients to receive rehabilitation – 14 centres (36%) reported having a CR programme that ICD patients could access. Of these, the majority were programmes run for acute myocardial infarction (MI) patients. Only four (10%) of implantation centres provided rehabilitation specifically for ICD patients. Three centres (8%) from this latter group had a multidisciplinary programme that included educational, psychological and exercise expertise as recommended in clinical guidelines for CR. A local cardiac support group was available in 12 (31%) centres.

When asked "Do you think you are currently meeting NICE rehabilitation criteria for ICD patients?", six (30%) nurses, five (23%) cardiologists and six (16%) ECG physiologists answered 'yes'. Asked if they believed if current rehabilitation services at their centre met the needs of ICD patients, three (15%) nurses, two (9%) cardiologists and eight (22%) ECG physiologists answered 'yes'. Asked if spouses or partners of ICD patients should also be involved in rehabilitation, 100% of nurses and cardiologists and 99% of ECG physiologists answered 'yes'. In response to the question: "If a self-help rehabilitation manual specifically for ICD patients were available, would you consider using it with your patients?", 100% of respondents answered 'yes'.

Staff were asked which of a common set were the main barriers to providing or developing a CR service for ICD patients in their centre and to report any other barriers not listed. Their responses are shown in tables 1 and 2. Additionally, staff were given the opportunity to suggest the ways in which they would like to improve the provision of rehabilitation in their centre. These are shown in table 3.

Discussion

It is clear that almost all of the nurses and ECG physiologists working with ICD patients in the 39 UK centres believe that these patients may benefit from cardiac rehabilitation. Caution is required in interpreting the views of cardiologists who implant ICDs due to the fact that only half replied – information obtained about cardiologists' opinions may therefore be skewed. However, the half that did were all in favour. Interestingly, the response rate from these cardiologists was many times greater than that from an almost identical survey conducted last year in all of the UK's paediatric cardiology centres. On that occasion, only two of 17 (12%) replied.[28]

Despite this enthusiasm and the NICE recommendation, only four UK centres provide a dedicated ICD rehabilitation service. The main perceived barriers were: a lack of skilled staff, the distance patients would have to travel to attend a hospital-based programme, and organisational and administrative difficulties. A potential solution suggested in the survey to overcome some of

Key messages

- Despite enthusiasm for and acknowledgement of the need for cardiac rehabilitation for ICD patients, few centres provide this
- Main barriers to providing cardiac rehabilitation for ICD patients are reported as lack of appropriately skilled staff, the distance some ICD patients live from centres, and administrative and managerial difficulties

these difficulties of a home-based self-help rehabilitation programme supervised by brief telephone calls appeared to be well supported.

In conclusion, despite NICE recommendations and an almost universal endorsement of the need for rehabilitation from multidisciplinary staff involved in ICD patient care, the great majority of centres are aware that they are not meeting patients' rehabilitation needs or national guidelines.

The main barriers appear to be a shortage of skilled staff, the distance patients live from the centre, and unspecified administrative and organisational difficulties.

Conflict of interest

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