

Exploring the patient's experiences of learning to live with an implantable cardioverter defibrillator (ICD) from one UK centre: a qualitative study

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Received 2 September 2002; received in revised form 6 May 2003; accepted 23 June 2003

Abstract

BACKGROUND: International expansion of indications for implantable cardioverter defibrillator (ICD) implant means increasing numbers of patients with devices worldwide. However, smaller numbers of patients with ICDs in the UK has meant that clinical expertise available to care for this specialized group is limited. Whilst North American patients' experiences of living with an ICD are well documented, European perspectives remain underrepresented. **AIM:** The aim of this study was to explore and describe patient's experiences around the time of their ICD device implant and after they returned home from one UK centre. **METHODS AND RESULTS:** Eligible patients were recruited from one regional cardiothoracic centre and interviewed in their own homes using semi-structured schedules. Analysis of data elicited three themes; non-individualised nature of information, adjustments to living with the device and future outlook. Unique findings identified were; (a) concealment of concerns and symptoms; (b) funding issues; and (c) unavailability of appropriate support and advice during and after time in hospital. **CONCLUSION:** Individualized care and support for these ICD patients appeared lacking according to respondents. Opportunities to discuss concerns appeared non-existent, which may indicate that UK patients are disadvantaged in the domain of psychological support compared with their European and North American counterparts. Findings remain tentative until explored with a larger, more representative and international sample.

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Keywords: Implantable cardioverter defibrillator; Patient adjusting experience

1. Introduction

Currently, over 4000 patients are registered in the United Kingdom with an implantable cardioverter defibrillator (ICD), the annual implant rate having increased from approximately 240 in 1996 to nearer 1500 in 2000 [1]. The United Kingdom (UK) is considerably behind the USA and comparable European countries in its use of the device.

However, recent national guidelines recommend an increased implant rate from 15 per million of population (pmp) to 50 pmp [3]. Indications for device implant

have expanded as clinical evidence is gathered so that not all patients having a device implanted will necessarily have experienced cardiac arrest but are deemed at 'high risk' of lethal arrhythmias due to existing clinical pathology—so-called 'primary prevention' (long QT syndrome, arrhythmogenic right ventricular dysplasia, fallots tetralogy) [3]. Evidence regarding the impact on individuals of having an ICD implanted has mostly been gathered from North America, with the Australasian and European patient perspective remaining under-represented. Key findings from available evidence suggest that fear and anxiety relating to the anticipation and unpredictable nature of ICD shocks are common whether patients have experienced a shock or not, although those experiencing shocks are most likely to present with

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continued morbidity [4–10]. Other areas of concern and adjustment identified in previous work include reduced physical activity (including sexual activity) [11–13], resentment of the driving ban [14–16], depression [15,17], anger [18], changes in relationships [11,15,18], changes in role function [15,19], sleep disturbance [18,20] and coming to terms with the fact that the device will not cure the underlying cardiac disease.

Whilst reduced hospital stay post-procedure has certainly decreased in-hospital costs [21,22], it creates less opportunity for patient and family education [23], which may impede adjustment to living with the device [18]. This may lead to ‘hidden’ costs from increased return visits from patients and/or their relatives seeking reassurance or advice from the implant centre, particularly as UK clinical expertise in this area remains limited due to small numbers. Therefore, gaining a better understanding of patients’ experiences requires investment in order to establish appropriate physical and psychosocial preparation and support mechanisms. In light of this and the presence of only one previous quantitative UK study [17], a qualitative study was designed to explore both patient’s and their partner’s experiences of life with an ICD from one UK centre. Earlier findings from this parent study have been reported, such as the specific issues relating to inadequacy of care provision for young women [13], the effects of the imposed driving ban on both patients and their partners [16] and a future paper will discuss general issues specific to the partners. This paper focuses on the unique experiences of eight patients.

2. Research design

As the purpose of the research was both to explore and describe patients’ lived experiences from one regional implant centre, a qualitative, descriptive design was employed [24]. Qualitative studies do not seek to quantify data but, by careful analysis and interpretation, use the data as a means of increasing understanding [25]. The aim of this study was to attempt to uncover, interpret and understand the reality and perceptions of ICD patients from one UK centre in respect of their experiences prior to and following ICD implant [24–26].

3. Methodology

3.1. Sample and recruitment

A purposive sample of potential participants were identified from a parent population of all ICD patients included on the implant register at one UK regional centre in November 1997 ($n=50$). Inclusion criteria were set as follows: (Table 1)

Table 1
Inclusion criteria

Over 18
Implant 3–18 months ago at commencement of study
Must have long term partner/spouse
Must not live more than 50 miles from regional centre

A total of 20 patients met the inclusion criteria and were invited to participate via an introductory letter from their Cardiologist explaining that participation in the study was entirely voluntary and that all responses would be treated confidentially. Included with the letter were details of the research team, a study outline and a consent form, which candidates were invited to sign after discussion with their families. Recruitment ceased after the first eight patients returned completed consent forms as large amounts of rich data were being generated through the interviews and resources for analysing such data were extremely limited. The eight patient’s characteristics are set out in Table 2.

3.2. Interview schedule

Open-ended questions were used to shape semi-structured, tape-recorded interviews with the aim of gaining in-depth information from the patient’s perspective [25,27,28]. General areas of enquiry were identified through previous research literature exploring the patient perspective. These included pre-implantation experiences, those immediately post-implant, transition from hospital to home and effects on lifestyle and future outlook. The interview schedule was distributed to other clinical experts in the field to enhance face validity prior to pilot [29]. The schedule was piloted to one couple. Length of time required, clarity and appropriateness of questions were reviewed to further enhance content validity [28] and minor modifications were made (Appendix A).

3.3. Data collection

This commenced in November 1997 and was completed by March 1998. Mutually agreeable dates and times for interviews were arranged on receipt of the consent forms. Interviews were conducted with the patient for approximately 45 min in their own home for their comfort and convenience so as to encourage openness of responses in a secure, familiar environment [30]. Participants were informed again of their right to withdraw from the study at any time and that they could refuse to answer any questions if they wished. The interviewer kept field notes in conjunction with the taped record to note non-verbal communication, intonation and any commentary before or after recording. To maintain consistency, one researcher interviewed all eight patients (JJ).

Table 2
Patient characteristics

Gender	Age	Indication for ICD	No. of shocks	Time since implant when interviewed
Female	38	Out of hospital Cardiac arrest –Hypertrophic cardiomyopathy	0	18 months
Male	58	Out of hospital VF arrest	1	18 months
Female	36	Recurrent VT due to Arrhythmogenic right ventricular dysplasia (ARVD)	0	7 months
Male	75	Recurrent VF arrests. LV impairment	0	5 months
Male	56	CAD (CABG). LV impairment	0	20 months
Male	61	Post myocardial infarction VF/VT No reversible ischaemia	2	20 months
Male	71	Severely impaired LV.	1	3 months
Male	51	CAD (angioplasty to LAD)	3	6 months

3.4. Ethical issues

Permission for the study was granted by the local ethics committee and consultant cardiologists whose patients were to be invited to participate. In anticipation of potential emotional responses, which could be evoked through encouraging patients to discuss their experiences, general practitioners (GPs) were informed of the interviews so that support could be offered if required. Tapes were destroyed following transcription and any names or other identifying details changed to maintain confidentiality and anonymity. The investigation conforms to the principles outlined in the declaration of Helsinki [31].

3.5. Content analysis

Qualitative content analysis, also known as ethnographic content analysis [32], facilitates contextual meaning in text through the development of emergent themes [33] derived from textual data. Repetition of coding produces the significance of particular themes [34]. Following this analytic principle, tapes were transcribed verbatim, then analysed independently by each of the three researchers alongside relevant field notes taken during the interviews. Phrases, words, poignant textual passages and meanings which captured common responses were grouped together and categorised to form a broad representation of the participant's experiences. These emergent categories were then compared using investigator triangulation to enhance inter-rater reliability and reproducibility. A high degree of reproducibility signifies a measure of shared, rather than individual, understanding of the data [35]. To add rigour to the study, a randomly selected, anonymous transcript was submitted to an independent research expert for external verification and validation [36].

4. Results

Three themes emerged around issues of the non-individualised nature of information presented; adjust-

ments to living with the device and future implications/outlook. Within each of these themes were sub-groups of common responses.

4.1. Theme one: non-individualized information

It emerged from the narratives that information received by patients prior to and following implant tended to focus on the technical aspects of living with an ICD. Information regarding the avoidance of hazards that might interfere with the device function such as arc welding, airport security scanners, mobile phones, un-serviced microwaves and driving was given verbally and in written form. This was either from specific device manufacturers or through a local hospital booklet. Information regarding preparation for life at home was scant and most patients seemed to have no real idea about what they might need to know as this informant suggests:

He told me what it would do and how it might affect me, but no other preparation. I didn't feel I needed any

Other information was described as inappropriate. For example, one patient lived 40 miles away from a support group and was unable to drive yet was sent information inviting them to attend:

I didn't actually send the information back because I thought it was a long way to go to ...(the regional centre)—especially when I can't drive.

Most patients were given correct information about avoiding driving for a period of one year (UK Driver Vehicle Licensing Authority regulations at time of study 1997–1998) but some received conflicting advice from their general practitioner or referring cardiologist regarding when they were permitted to resume driving. One man (two months post-implant) stated that his general

Table 3

DVLA Driving regulations for cardiovascular disorders at January 2003:

Implantable Cardioverter Defibrillator (ICD) criteria for reinstatement of driving licence

Group 1 entitlement – drivers of cars and motorbikes

Driving may resume when the following criteria can be met:

1. The first device has been implanted for at least 6 months
2. The device has not administered therapy (shock and/or symptomatic antitachycardia pacing) Within the last 6/12 (except during formal clinical testing)
3. Any previous therapy has not been accompanied by incapacity (whether caused by the device or arrhythmia) in the preceding 5 years
4. A period of 1 month off driving must occur following any revision of the device (generator And/or electrode) or alteration of any anti-arrhythmic drug treatment
5. The device is subject to regular review with interrogation
6. There is no other disqualifying condition

Group 2 entitlement – drivers of large lorries and public transport vehicles

Patients are permanently barred from driving

Prophylactic ICD Implantation

Asymptomatic individuals with high risk of significant arrhythmia

Group 1

If with non-disqualifying cardiac event as below:

- LVEF greater than 35%
- No fast VT induced on electrophysiology study (RR < 250 ms)
- Induced VT could be terminated by the ICD twice, without acceleration, during the post implantation study

Following implant, one month off driving. DVLA need not be notified

Group 2

Permanently bars

practitioner advised him as follows:

‘Dr said I could drive my car a little way if I wanted to, but I feel I don’t want to drive, I don’t know if I can trust myself. I did drive the car to town yesterday’

Driving, or not being permitted to drive, recurred throughout as major source of concern and inconvenience. Current regulations are set out later in the text (Table 3).

4.2. Theme two: adjusting to living with the device

Adjusting to living with an ICD included physical, psychological and social aspects and whilst some issues are obviously more discretely concerned with a specific aspect, others can be seen to cut across all three aspects such as over-protectiveness of family members leading to reduction in activity levels, which in turn led to increased dependence on others and loss of confidence, which in turn led to social isolation.

4.2.1. Physical adjustment to living with the device

Difficulties with physical adjustment seemed worse immediately post discharge when patients were ‘first at home’. For example, physical discomfort was experienced by all patients initially due to the incision site and most found this decreased over time. However, in contrast to male respondents, one woman described continued pain resulting from her sub-mammary site,

which, in turn, restricted the choice of bras she wore and her sleeping positions 6 months after implant:

I was getting a pain under my shoulder blade. I can’t lie with this arm underneath my breast anymore. I’d wake up, probably once the pain killers had worn off I suppose, approximately 3 o’clock in the morning.

The uniqueness of this and other aspects of the two women’s experiences led to the development of a separate paper [13].

Changes in physical activity levels were apparent in most participants, sometimes through their own instigation and sometimes through their partners. Finding acceptable levels of activity varied amongst respondents. Whilst they all expressed some degree of uncertainty about what they ‘should’ be doing, individually they coped with this uncertainty very differently in the absence of structured rehabilitation programmes. One young woman deliberately restricted her activity levels in order to avoid a shock.

I tend to be more wary of what I’m doing. I think oh, I think this is going to set it off... so I don’t do it

and qualified her restriction of activity by stating

I daren’t do too much because if it does shock me then I won’t be able to have the driving license back

In contrast, one male pushed himself to the limit to try to gain some control over his level of activity.

I deliberately triggered this thing because I wanted to know what it would feel like, what I could do and how far I could go and what the sensation was like. I wasn't going to let this thing beat me

In this particular instance he was alone, thereby placing himself at some risk and did not report the episode to the implant centre or his partner. Another man described how, after each shock he reverted to the exercise programme prescribed following his myocardial infarction. This involved not going upstairs on 'the day' of each shock, choosing to use a commode downstairs to accommodate this, which is a fairly drastic reduction in activity for an otherwise healthy 54-year-old man. Reduction in physical activity levels seemed to lead to negative feelings in some cases:

I got fed-up with doing nothing. I'd been in hospital for a month

.....I got a bit fed-up with it...I lost the inclination to do anything and at that point I said to myself I can't go on like this, I shall end up blowing my brains out.

For patients whose devices had been implanted a year or more earlier, some adjustment concerns seemed to be associated with on-going effects of medication (e.g. beta-blockers and lethargy/impotency), driving and body image. Concerns about altered appearance were evident in both male and female participants.

It's quite a big lump in your chest and I feel a bit self conscious when swimming or anything like that (Male 57 years)

I can't wear under-wired bras anymore. I think one (indicates left breast) is higher than the other now, but it doesn't bother me certainly (Female 35 years)

Another area of adjustment for these patients related to reduced levels of sexual activity. This reduction was mostly due to patient or partner anxieties:

I haven't managed things (sex) since. I mean I guess I could, but I'm a bit afraid to at the moment, I don't know if it (the device) will kick

my wife gets worried (about having sex), she thinks I'm going to overdo it

4.2.2. Adjustments to role and family dynamics

Adjustments to family dynamics and ascribed role functioning were described. In particular, responsibilities for driving, shopping and childcare were assumed by partners and other family members. Patients experienced

a lack of independence and loss of confidence. Over-protectiveness by family members at times increased the feelings of dependency and insecurity.

I always tell her (wife) where I'm going because she always wants to know. I want her to keep tabs on me all the time in case something happens

My wife would like to wrap me up in cotton wool, but I won't let her

my family say, oh, you can't do that, but I know I can do it

Socially, the prescribed driving constraints had a major influence on many aspects of daily living. The repercussions extended not only to patients but family and friends.

The biggest difference has been not being able to drive for six months. I've found myself really tied

If I do (get license back) no way will I drive with my grandchildren on my own

I lost my driving license. I had to surrender it and I was absolutely livid about this

With regards to resuming employment, the perceptions of others had an impact over patients' decisions about returning to work, as one woman explained:

They didn't think they could have me back 'cos all their equipment would interfere with the device

4.2.3. Specific adjustments relating to device function

Most patients described feelings of uncertainty and apprehension at the prospect of being alone and having a defibrillator shock in the early stages at home. This seemed to be closely related to uncertainty about what the first shock would do to them.

That's what used to bother me-not having the shock, but where I would be when it happened.....you do flake out!

I think I was just concerned about doing anything and wondering what was going to happen. Being on my own was another thing

Loss of confidence was described by male participants particularly in relation to unexpectedly receiving a shock or other therapy from the device.

The whole thing about this to me in blocked capitals is CONFIDENCE and every time I have a collapse, it's a knock back in your confidence

Despite anxieties about the device functioning, paradoxically patients described a sense of relief and gratitude that the ICD was keeping them alive:

I do rely on it you know. I'm quite content with it there

I trust the device. This thing is going to work for me

4.2.4. Concealment

Although emotions and experiences were expressed openly and candidly to the researchers, patients also described deliberately concealing their symptoms, ICD events and emotional concerns from their families and from staff at the cardiac centre.

'I think I've had a minor kick. They (the hospital) did say to get in touch if it was a big one, so I didn't tell them'

I didn't tell her (wife) anything, I told her after I had it (a shock) confirmed (at a clinic appointment several weeks after the event)

I didn't say anything to the wife, didn't want to panic her

4.3. Theme 3: future outlook

Concerns for the future included health relating to disease progression and device longevity, funding for generator replacements, employment and for the young women, pregnancy, childbirth and motherhood. One young woman with a four-year-old son understood that the device had not 'cured' her so much as bought her some more time. However, when asked how she felt about the future she looked at her son and said:

I wonder how long I'll live

supposing it gets to be like that all the time – I won't be able to take the dogs for a walk, I won't be able to go out and play with my son

Life expectancy was a concern shared by other participants too:

The only thing you don't know is how long it would last for, or how long you would last

Limited career prospects were identified as a result of having the ICD:

I'd like to apply for other jobs, but I'm limited in that if I lose it (driving license) again, I need to be somewhere where I can get to work easily

I'm not sure an employer would take me on to be honest with you

4.3.1. Funding issues

Prior to implantation, several participants described waiting for a decision from health authorities regarding

funding for their procedure and this arose as a concern for future generator replacements.

when I was in hospital having the first implant, there was a horrible delay of approximately 1–2 days whilst they were getting authority to fund it and my fear is that if I'm going to need this thing in 8 years time, whether the money is going to be available

I was surprised at my age to be going and getting something because..... I was told how much it cost. I wonder about funding for a replacement in 6 years.

5. Discussion

Whilst sample size restricts generalisability, this study illustrates that patients are likely to experience varying degrees of psychological, social and physical adjustment both leading up to and following ICD implant. Experiences of this group of UK patients corroborate many previous findings but also identify specific issues unique to them and not previously reported.

Unique to this study was the issue of funding, both for the initial device placement and for subsequent replacements. Average 'all-in' device costs of approximately £20 000 has meant that some UK national health service purchasing authorities would fund as few as six devices per annum [3,37]. Guidelines from the UK National Institute for Clinical Excellence in 2000 [3] clearly recommend an implant rate of 50 devices per million of population which should help to alleviate some of these patients fears. This issue may be specific to how UK healthcare is resourced as no other study has identified it as a concern. However, it does not make it any less concerning for this group of patients.

Issues specific to women with ICDs have only been documented by this research team and are discussed in-depth in a separate paper [13].

The issue of concealment has not previously been described and has important implications for both patients, their relatives and healthcare providers. Barriers to effective communication could easily be built up in an attempt by patients to 'protect' others from the trauma they are experiencing. Additional interpersonal difficulties arose from conflicting emotions driven by the patient's desire to retain independence contesting with the families well intentioned attempts to protect their loved one. This was evident through changing domestic roles and forbidding the patient to undertake certain physical activities, including sexual activities and being anywhere alone. Doolittle and Sauve [15] and Schuster et al. [8] similarly identified that patients experience a host of emotional problems, which are often contributed to by the over-protectiveness of the family.

Another important element in the overall findings of this study is the apparent lack of psychosocial prepara-

tion patients received either before implantation or prior to discharge home. Technical aspects of the device dominated any information given, with psychosocial implications of living with the device apparently receiving sparse attention. The interface between secondary and primary care appears poorly established according to this group of patients and there was very little evidence of holistic care. Nurses did not seem to feature in these patients' care experiences, which may partly explain the poor preparation for implant and discharge home. This is consistent with previous work by Dougherty [18] who reported that patients found providers of healthcare to be more concerned with device function than with the patient as a person. Sears et al. [43] conducted a survey to identify how 'comfortable' healthcare professionals were in discussing aspects of ICD patients care with them. They conclude that healthcare providers were generally most comfortable dealing with issues relating to lack of knowledge about the device and its functions and least comfortable managing emotional well-being issues. This may account for the technical focus of care cited in the current study. It may also explain why all the patients interviewed seemed to find the experience of being able to talk to someone about their experiences as cathartic, a phenomenon described by a minority of previous researchers [4,44,45].

Timing and format of information may be crucial with these patients, many of whom could have experienced neurological sequelae leading to cognitive impairments following a sudden cardiac death (SCD) event [5,15]. Fear, confusion and anxiety after a life-threatening event have also been identified by previous researchers as barriers to learning or retaining information [15,23]. Furthermore, patients and their families may not be able to anticipate their longer-term needs at such a juncture. Therefore, overloading them with information at the time prior to discharge could be inappropriate. Suggested strategies identified to compensate for poor retention of information with related patient groups include repeating key points often, both in and outside the hospital setting [23,39,40]. Dougherty [18] identified the period immediately after discharge from hospital as a vulnerable time both emotionally and physically for survivors of SCD and ICD implant. Results from her research emphasize the importance of and need for effective discharge planning and preparation of patients and their families for common feelings, experiences and emotions they may experience after discharge [18]. Increasingly, patients are discharged within 48 h after insertion of the device, leaving little opportunity to raise their concerns, yet only a minority of researchers have suggested that healthcare professionals require further education regarding what an ICD is and how patients live with it [18,38,43,46]. Therefore, lack of expertise and inappropriate information may contribute to poor preparation for life with an ICD. Interventions aimed at

improving care in this vulnerable time following discharge from hospital such as follow up visits at home [41] or follow up telephone calls [42] have been successfully introduced with other patient groups. Dougherty [18] has previously suggested that case managers working with this population greatly aid the process of recovery.

The imposed driving ban seemed to impact on all aspects of recovery and adjustment. Feelings of anger and resentment at having to stop driving were evident, as was a lack of knowledge or understanding about the possible consequences of driving illegally. More disturbingly, lack of knowledge on current regulations was also evident in some healthcare professionals, which resulted in inappropriate advice being given. This is congruent with previous research [14,47] and is likely to become increasingly significant since the advent of more recent guidelines from DVLA [48], Table 3, which are even more specific. Driving emerged as such an important issue within this patient group that it has become the focus of a separate paper [16].

As with previous research [4,6,7,9,11,44–46], anticipation of a shock and what it might be like gave rise to some anxiety and led to avoidance behaviours in this patient group. Indeed, similar characteristics are described in patients suffering from post-traumatic stress disorder. This condition may occur when an individual has been exposed to a life-threatening event and is characterized by a typical series of reactions: intrusive thoughts, avoidance behaviours and increased arousal, which must have been present for more than one month [49]. Such phenomena have also recently been linked to patients having suffered an acute myocardial infarction [50]. Within the current study, in some cases emotional sequelae appeared to be in response to disease progression as well as to the device and as with previous research, degrees of coping and amount of support needed varied, which may be linked to personality type [20] and number of shocks experienced [10].

Other than one woman who could not get to her nearest group, which was 40 miles away, nobody cited the role of support groups in their adjustment process. Although contrary to previous descriptions [44,51], this earlier work was conducted in the USA, where much larger numbers of ICDs are implanted and support groups are often led by highly skilled nurses with easy access to other healthcare professionals, e.g. psychologists, counsellors, psychiatrists [52]. Many implant centres in the UK have set up support groups for ICD recipients, but as yet there has been no formal evaluation of their effectiveness. Interestingly, clinicians from the USA have recently indicated that support groups alone are not sufficient to address all patient's psychosocial needs [53].

It has been suggested that follow up support of ICD patients in the UK could be incorporated within cardiac rehabilitation services [54] and the success of one such programme was recently published [55]. However, as these services are struggling to cope with increased demands made on them by targets within the national service framework for coronary heart disease [56], this is not routinely the case and therefore, accessing psychological support for most ICD patients remains arbitrary, particularly for those patients who are not comfortable in a group situation [57].

6. Conclusion

Results of this small study suggest that elements of the UK ICD patient experience may differ considerably from those previously documented in other countries. This can partly be accounted for by healthcare system and funding mechanisms and partly by the smaller patient population combined with shorter period of clinical experience. Clearly, ICD patients have heterogeneous needs and caring for these patients pre and post implant requires considerable skills and knowledge, both of the technical aspects of device function and of the bio-psychosocial effects on patients and their families. Information given to this group of patients was not tailored to individual requirements, was technically focussed and did not prepare patients for life at home post-discharge. It is apparent from the narratives that, without appropriate support and information from healthcare professionals, this group of patients resorted to 'do-it-yourself' rehabilitation and adjustment, some of which appeared to be inappropriate.

Raising awareness of the complex needs of these patients is an essential element in improving the care provided for them but further evaluation of service provision is required to identify ways to improve the existing fragmented care, both in and out of hospital. Future research should be extended to include a larger, national sample in order to further ascertain the significance of these findings.

ICD implants (all manufacturers)

Country	Total 1996	Total 1997	Implants per million population (1997)
USA	23 407	34 121	120
Germany	1975	3556	45
France	210	420	10
Italy	280	950	16
Spain	290	602	10
Netherlands	150	220	9
UK	240	410	7 (Source: Squirrel 1999 [2])

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