Living with an implantable cardioverter defibrillator: the partners' experience

Nina K HUMPHREYS, PhD, Assistant Psychologist, Counselling Psychology Service, Morriston Hospital, Swansea

Rob LOWE, PhD, Senior Lecturer, Psychology Department, College of Human and Health Sciences, Swansea University, Singleton Park, Swansea

Professor Jaynie RANCE, PhD, Director of Post Graduate Research, Department of Public Health, Policy and Social Sciences, College of Human and Health Sciences, Swansea University, Singleton Park, Swansea

Professor Paul D BENNETT, RN, PhD, Professor of Clinical Psychology, Psychology Department, College of Human and Health Sciences, Swansea University, Singleton Park, Swansea

Corresponding author:

Prof. Paul D. Bennett, Psychology Department, College of Human and Health Sciences, Swansea University, Singleton Park, Swansea SA2 8PP, UK

Email: P.D. Bennett@swansea.ac.uk

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Abstract

Aim. To explore the experiences of partners living with an implantable cardioverter defibrillator (ICD) recipient, with a focus on ICD shock(s) and primary / secondary indication status.

Background. Research suggests caregivers of implantable cardioverter defibrillator (ICD) recipients experience significant psychological distress. ~~Patient's~~ This has been shown to be linked to the recipient's psychological adjustment and adherence to ~~modifyiab;e~~modifiable risk factors ~~have been linked to partner anxiety and marital function. Research suggests caregivers of ICD recipients experience significant psychological distress~~. However, t~~T~~here is a dearth of qualitative research ~~as~~ in relation to how ~~the~~ ICD shock(s) or the primary / secondary prevention ~~indication~~ status of the recipient ~~influences~~ influence partners' ~~lived~~ experiences.

Design. Qualitative study with semi-structured interviews analysed using a thematic approach.

Methods. Interviews were carried out with a purposive sample of 18 partners of ~~implantable cardioverter defibrillator~~ICD recipients during 2012-2014~~.~~, at a mean period of one-year post-implantation.

Results. Partners described the ~~lived~~ experience of living with an ~~implantable cardioverter defibrillator~~ICD recipient. Two broad themes were identified: (i) emotional consequences (including feeling traumatised by cardiac event, anxiety and fear, frustration and anger) and (ii) coping with the ICD including problem-solving and emotional regulation. ~~The lived experiences of the ICD device by partners of secondary prevention recipients did not differ to those of primary prevention recipients. However, p~~Partners who ~~had~~ witnessed a sudden

cardiac arrest prior to implant ~~had been~~were traumatised by the event. By contrast, many primary prevention recipients reported anger at not being made aware of the seriousness of the recipients' cardiac condition. Those who witnessed a shock were also likely to experience more anxiety than those who had not.~~.~~

Conclusions. Differences ~~did exist~~exist in the experiences of partners of recipients who ~~had an~~experienced an acute cardiac event and/or ICD-shock ~~from~~ and those who had not. The former may have to deal with the outcomes of trauma and significant fear of future shocks. ~~The lived experiences of the ICD device by partners of secondary prevention recipients did not differ to those of primary prevention recipients. However, partners who had witnessed a sudden cardiac arrest prior to implant had been traumatised by the event.~~ Partners of ICD recipients would benefit from an intervention to help them cope with the emotional sequelae of living with the device and managing adjustment especially as ~~they~~ many appeared to conceal fears from the recipient.

Impact Statement

Why is this research needed?

- Research suggests that partners of ICD recipients who experience a shock or who have a secondary prevention indication experienced higher levels of depression during the first year post implant compared to those partners of primary prevention and non-shock patients. No qualitative research has explored this.

What are the three key findings?

- Partners of primary prevention recipients and those who experienced an ICD shock were more traumatised and anxious than those without these experiences.
- ~~were angry that they had not been warned of the seriousness of the recipient's condition whilst waiting results.~~
- Partners expressed considerable anger when the ICD was for a heritable condition and reported the combined burden of caring for the recipient and their children.
- Anger was vented towards the health care system for the late diagnosis and inflexibility in its response.

How should the findings be used to influence policy/practice/research?

- The experiences found in this study should help ~~facilitate~~ nurses to understand and respond to partners' concerns and anger especially during the first year post implant.
- Partners ~~to~~ of ~~–~~ICD recipients should receive psychological support prior to and following the implantation.
- Partners ~~to~~ of ICD recipients who have had the implant due to familial cardiac disease should receive specialist psychological support for genetic and predictive genetic testing of their children.

Keywords

Qualitative, thematic analysis, implantable cardioverter defibrillator, partners, emotional consequences, coping, nursing

Introduction

Many patients at risk of sudden cardiac arrest are fitted with an implantable cardioverter defibrillator (ICD) for primary[1] or secondary[2] prevention of a life-threatening arrhythmia. The ICD is a medical device implanted in the body and terminates a rogue cardiac rhythm within five to fifteen seconds of its onset and ensures the survival of almost hundred per cent ~~survival~~ of ~~patients~~ recipients (Hussein, & Thomas, 2008). ~~While~~ Unfortunately, while ICD implantation significantly improves survival rates, it also appears to carry an emotional burden; both recipients and their partners frequently report high levels of psychological distress (Fluur, Bolse, Stromberg, & Thylen, 2014, Pedersen, van den Berg, Erdman, Van Son, et al., 2009; Van den Broek, Habibović & Pedersen, 2009; Sears & Conti, 2002; Sears, Matchett & Conti, 2009, Fluur, Bolse, Strömberg & Thylén, 2014).

Background

Patient's psychological adjustment and adherence to changing ~~modifying~~ modifyiable risk factors have previously been linked to partner anxiety and marital function (Dougherty & Thompson, 2009). Pedersen, van den Berg, Erdman, von Son et al. (2009) posited that although partners of all cardiac patients were confronted with having to cope with a partner's potentially life-threatening disease, ~~they suggested that~~ the experience was worse for partners of ICD patients. In the immediate post-discharge period ~~this distress may be~~ they may experience distress as a consequence ~~due to~~of their partner's survival being reliant on a medical device that delivers painful shocks (Pedersen et al., 2009). Albarran, Tagney and

[1] Primary prevention refers to preventing the first cardiac arrest
[2] Secondary prevention refers to preventing further cardiac arrests

James (2004) found that partners were afraid to leave the recipient on their own when they arrived home from hospital and felt ill-prepared to look after them. Over time, partners gained confidence in the ICD, but often remained anxious about the defibrillated shock and coping if the recipient lost consciousness. These fears caused them to become hyper-vigilant to any reported symptoms and be overprotective.

Albarran et al. (2004) found partners tried to prevent stressing the recipient, believing this reduced the likelihood of a shock. They avoided arguing; but in doing so, increased their own feelings of annoyance, guilt and distress (Albarran et al. 2004; Williams, Young, Nikoletti & McRae, 2007). Behavioural avoidance often extended to intimate sexual relationships; sexual activity is avoided or reduced due to fear that recipients' increased heart rate might trigger a shock (Steinke, Gill-Hopple, Valdez, & Wooster, 2005).

Partners play an important role in providing the recipient with physical and emotional support, supporting dependent children, and being responsible for the day-to-day running of the home. Considering this, it is surprising that, to the authors' knowledge, there are only five qualitative studies (Albarran et al. 2004; Williams et al. 2007; Steinke et al. 2005; Tagney, 2003, Fluur, Bolse, Stromberg & Thylen, 2014), that have focused on their experiences. Moreover, these studies did not delineate between recipients' shock and clinical status. ~~This~~ The latter may differ according to whether ~~the ICD implant was because~~ the recipient had already experienced a cardiac arrest (secondary prevention) or was at risk of such an event (primary prevention). This study ~~aims~~ aimed to address these deficits. ~~The analysis includes the proportion of participants from four categories: 'shock' versus 'non-shock partners' (shock status); 'primary prevention' versus 'secondary prevention partners' (clinical indication status).~~ It used a qualitative approach to explore the experiences of four differing groups of ICD partners of ICD recipients (within a total sample size of 18 participants) over the year following implantation: shock versus non-shock, and primary versus secondary

implantation. The findings complement our report of the patients' experiences following ICD implantation (Humphreys, Rance, Lowe & Bennett, 2015).

Method

Design:

A thematic analysis qualitative study design based on guidelines of Braun and Clarke (2006) was used.

Sample:

Participants were partners of ICD recipients from two UK hospitals who were part of a larger study (see Humphreys, Lowe, Rance & Bennett, 2016). Partners could only take part if the recipient also consented to join the study and vice versa.

Data Collection:

Participants were identified from a hospital database by Arrhythmia Specialist Nurses who were responsible for the recipients' continuum of care. Inclusion criteria: being 18 or over, being fluent in English, and the ICD recipient had to have been implanted with their first device three to 24 months previously. Specialist Arrhythmia nurses sent partners a letter on behalf of the researchers inviting them to join the study. Partners consented to being contacted by the researchers if they wanted to take part. Participants were interviewed in their homes by a researcher (NH). All participants were assured of confidentiality, anonymity and their right to withdraw from the study. The interviews were semi-structured and lasted about one hour. The cardiac event, perceived benefits and disadvantages of the ICD and coping with the ICD were explored (see Appendix 1 for interview guide).

Ethical Considerations:

Ethical approval for the study was obtained from the relevant National Health Service (NHS) Ethics Committee. All procedures were carried out in accordance with the ethical standards of the NHS research committee and with the Helsinki Declaration of 1975, revised in 1983.

Data Analysis:

Interview transcripts were analysed using the phases outlined by Braun and Clarke (2006). The first phase involved transcribing the data. Audio recordings of the interviews were listened to several times, checking against transcriptions to ensure their accuracy. Transcribed interviews were read and re-read to facilitate data immersion. At the same time, initial thoughts and ideas were noted down in the margins. In the second phase the data was coded. Coding was completed by building on the notes and ideas generated through transcribing and immersion in the data.

The third phase involved identifying themes by combining text labelled with similar codes. Disparate themes or those that were not supported by more than one participant were discarded. Phase four involved ensuring the coded data represented themes and that these themes accurately reflected what was evident in the data set. Themes and sub-themes were discussed at review meetings with the other authors until a consensus was agreed. Phase five involved defining and naming the themes. In doing so, note was taken not only of the story told within individual themes but how they related to the overall narrative evident in the data.

Rigour

Credibility was established through the richness of data from including participants of recently implanted ICD recipients who were willing to share their experiences. Data analysis

was overseen by two experts in qualitative analysis. Themes were critically examined to ensure dependability. To facilitate transferability, a clear description of the participants and the process of data analysis have been presented.

Findings

The final sample of partners comprised seven males and 11 females (see Table 1). The mean number of months they had been living with their partner's ICD was 11.55 (standard deviation 4.12). Partners ranged in age from 28 to 68 years (mean age 55.7 years, standard deviation 11.75) (see Table 1) and represented a wide range of jobs/occupations and family backgrounds. Each participant represented a primary or secondary clinical *and* a shock or non-shock category. All but one participant, who was at the end of their second year, were approaching the first year anniversary of their recipients' ICD.

Two broad themes were identified: (i) emotional consequences (including feeling traumatised by cardiac event, anxiety and fear, frustration and anger, and (iii) coping with the ICD, including: (i) problem solving: becoming informed, monitoring and engaging in protective behaviours and (ii) emotional regulation: concealing worries and acceptance.

(Insert Table 1)

Theme: emotional consequences

This theme identified the emotional sequelae following the recipients' implant. Sub-themes included feeling traumatised by the cardiac event, anxiety and fear, and frustration and anger.

Feeling Traumatised

Secondary prevention partners, who had experienced of an out-of-hospital sudden cardiac arrest had experienced trauma. ~~(see Table 2).~~ Three secondary prevention partners had witnessed the cardiac arrest and two of these continued to feel traumatised. One had distressing images of her husband lying 'dead' whilst medics resuscitated him.

"He don't remember nothing but I remember it all ... he was just on the bed ... (they were) pumping and pumping ... shocking him, pumping him ...." *[E]*

One male partner was at home when his wife arrested and he had performed cardiopulmonary resuscitation until paramedics arrived. Subsequently he had frequent distressing thoughts of his wife dying, leaving him to raise his young daughter by himself. Interestingly, both partners expressed resentment towards the recipients who were oblivious to their distresses.

"... I've actually said to her 'you don't know anything about it' ... When she woke up she was in hospital and she doesn't know about anything's that's happened. I find that really strange, although it happened to her, the trauma's left with me... " [Q]

Anxiety and Fear

In general, all partners worried about the recipient's cardiac health. However, shock and secondary prevention partners appeared more anxious and fearful of another cardiac event.

Partners generally felt unprepared as the recipient's sole carer: *"I mean initially, I wasn't quite sure what was expected of us ... I didn't know whether I was supposed to be with him 24-7" [A]*. Worries for two shock partners were exacerbated when the recipient was 'brusquely' discharged from hospital: "*... the consultant said 'right, you can live a normal life now, you're fine, off you go' kind of thing." [D]*. Perhaps in response to feeling unqualified, many partners became hypervigilant and catastrophised and ruminated over recipients'

physical symptoms. Irrespective of shock or clinical indication status, many partners worried about physical symptoms and their meaning. One male partner, who felt totally responsible for his wife's health, agonised over what to do when his wife felt unwell:

"... any illness ... any symptom, you attribute to something going wrong .... before the device had been fitted ... if you were ill, you were ill. But now if you're ill, is there an underlying reason why you're ill? And should I be doing something about it" [O]

~~In this study, the unease over how to respond might have related to gender as it was two male non-shock partners who admitted taking responsibility for their wife's health. However in doing so, their anxieties increased and merely appeared to add to their burden of keeping the recipient safe.~~

All partners believed the ICD would fire at some point. Non-shock partners lived in fearful expectation of the first shock, wondering how and when it would occur and if the device would fail to resuscitate.

"...the first six months I was like, I was so scared, every time he felt dizzy, I thought he was going to collapse on me or die. I'd be like a cat, you know, if he said he felt unwell, I could feel my whole nervous system kicking in, adrenalin, and I'd be so anxious" [D]

Counter intuitively, perhaps, this fear appeared heightened in shock partners and in the secondary prevention categories. Since secondary prevention recipients are more likely to receive a shock than primary prevention recipients (John & Stevenson, 2012), it might be the shock status rather than the indication status that accounted for the increased fear felt by secondary indication partners. The shock experience appeared to reinforce awareness that life was fragile and for some, it was a reminder of the initial cardiac event.

Frustration and Anger

A slightly higher proportion of non-shock and primary prevention partners vented frustration and anger towards the health care system. Primary prevention partners were angry at not being warned of the seriousness of the heart condition whilst waiting for test results:

"... he was running along the Taff Trail ... on his own ... nobody around and I .... you talk to people afterwards who live along the Taff Trail or walk along it quite regularly, and they say they do find people just drop dead ... on the trail, and I'm thinking that could have been Tom and I'm thinking you knew of it, so why haven't you contacted us before now', you know. So, I was frustrated and annoyed more than anything" [C]

Irrespective of shock or clinical indication status, partners with children~~,~~ who might have inherited ~~the~~ a genetic condition, such as Long Q-T Syndrome, expressed considerable anger; mainly because they could not protect their children.

"We've also got a lot of worries about [daughter], to think there's a 50 per cent chance that [daughter] could have what [wife] has got. ... well they said the only way to tell is a DNA test, which there is no funding for and I said well I'll pay for a DNA test, and they said you're not able to pay for it. And I thought what type of crazy place are we living in" [Q]

Two non-shock partners, (one primary and one secondary), were annoyed and frustrated with their recipients who were unwilling to accept the ICD and the impact this was having on their marital roles. One partner, for whom the recipient used to care due to spinal problems ~~for as he had a bad back,~~ resented having to look after his wife, ~~–~~whilst another believed her husband was merely '*feeling sorry for himself'[H]*. ~~However~~Incidentally, these two partners

also reported being routinely woken up during the night by the recipient when they were distressed. Their apparent acceptance of interrupted sleep might highlight an unseen burden that some partners have to cope with.

Theme: coping with the ICD

Partners engaged in both problem-solving and emotional regulatory strategies to help them adjust to living with the recipient's ICD.

Problem-Solving

Regardless of clinical indication or shock status, partners reported that they closely monitored the recipient especially in the first few days after hospital discharge. Monitoring appeared to reduce over time, but not for all. One partner ~~even~~ continued to monitor his wife at two-year post implant:

"Yes [I ring her] to see if she's alright [every] five minutes, 10 minutes … 'cos it's a worry. Even when she goes to the toilet … and I'll go and say 'are you alright love?'" [R].

Linked to this monitoring was the use of protective behaviours, many of which were helpful and adaptive for the recipient; one partner, for example, bought her husband an identity tag should he collapse:

"For Christmas I bought him a dog-tag (laughs). A heart-shaped dog tag, he'll kill me for it I know ... his name, ICD, and a telephone number" [C]

A second form of protective behaviour involved attempts at reducing or avoiding situations likely to increase the recipient's stress or acute physical exertion: including ~~sex~~ intercourse. The use of protective behaviours might have been, at least in part, a consequence of feeling increased emotional closeness to the recipient, which was often also reported.

Many partners tried to find ~~our~~ out as much as they could about ICDs, which they found reassuring. A higher proportion of non-shock to shock partners read up about the ICD; the clinical indication of the recipient appeared less important. A higher proportion of shock and secondary indication partners demonstrated protective behaviours but they also reported feeling increased emotional closeness to the recipient, which might have contributed to these.

Emotion-Regulation

~~In this study, shock~~Shock-partners kept their fears that the recipient might die during a shock hidden to protect the recipient's feelings: *"... I don't really tell 'husband' about those [fears of him dying]. You know he's got enough to worry about, I don't think telling him I fear he's going to die will be helpful" [D]*. Being a primary or secondary prevention partner did not appear to influence concealing fears.

Although the majority of non-shock partners and all the shock partners appeared to have 'accepted' the ICD by one-year, the nature of this 'acceptance' varied. A few experienced a *resigned* acceptance (accepting the ICD because it was the option available), whilst the majority of others showed a more positive, *grateful*, acceptance (gratitude for the device). The nature of this acceptance was achieved in various ways, ~~which included~~including feeling reassured by presence of the ICD. Shock partners alone had the knowledge that the device had prevented a sudden cardiac death: *"He's still here, otherwise he wouldn't be!" [C]*

Discussion

The study was the first qualitative analysis of the emotional and coping responses of partners to an ICD implantation, considering the experience of pre-implantation cardiac health and

whether the ICD had 'fired'. The experience of secondary prevention partners of recipients who had experienced cardiac arrest prior to surgery did not differ from primary ones, except for feeling traumatised by the cardiac arrest itself. MNot surprisingly, many partners who experienced an ICD-shock expressed significant concern over the risk of future cardiac problems; many also hid these anxieties from the recipient. All the shock partners accepted the device but more than half were still engaging in avoidant behaviours at the time of interview. A higher proportion of non-shock to shock partners read up about the device, and found this reassuring.

After the ICD implant, the primary goal for many partners appeared to be to return to 'normal living'. Non-shock partners, particularly, expressed anger and frustration when this goal was apparently not shared by recipients. The shift in the balance of their relationships from a partnership of equals to having to take on a caring role evoked the feelings of burden and frustration often found in other contexts and conditions (Poulin, Brown, Ubel, Smith, Jankovic, & Langa, 2010).

There appeared a fine line between being protective (e.g. being sensitive and offering support) and being *over*-protective (assuming responsibility for the recipient's health). The latter appeared to negatively affect partner's wellbeing, as they endeavoured to safe-guard the recipient from any stressor and thereby limited their life experiences. All partners engaged in monitoring/checking behaviours in the early weeks post hospital discharge and many continued to do so in the longer term. Paradoxically perhaps, this monitoring did not reduce the degree to which they experienced intrusive worries - a state not significantly different to that found in obsessive-compulsive behaviour and long-term health anxieties (Wells, 2000).

In general, this study found that irrespective of shock or clinical indication status, most participants reported similar emotional experiences and coping responses. However, there

~~were a few differences noted between the categories found: secondary indication partners who had witnessed an out-of-hospital sudden cardiac arrest prior to implantation still appeared traumatised by this. Not surprisingly, perhaps, as they had more traumatic memories than those for whom the ICD was used for primary prevention. In addition, in this study, only shock partners concealed fears from the recipient and only non-shock partners felt anger and frustration towards the recipient.~~

The majority of the findings in this study ~~supported~~ support ~~the findings~~those of previous research (e.g., Albarran et al., 2004, Fluur et al., 2014, Steinke et al., 2005). However, to the authors' knowledge, some findings have not been reported before. Secondary indication partners who had witnessed an out-of-hospital sudden cardiac arrest prior to implantation still appeared traumatised by this. In addition, only shock partners concealed fears from the recipient and only non-shock partners felt anger and frustration towards the recipient. Primary prevention partners were angry that they had not been warned of the seriousness of the recipient's condition whilst awaiting test results. This might have reflected poor communication of the practitioners in this study and warrants further research into communication practices in cardiac services. Partners also expressed anger and frustration when the ICD was for a heritable condition and reported the combined burden of dealing with their feelings towards both the recipient and also their children. Anger was vented towards the health care system for the late diagnosis and its inflexibility in response to it; f~~.~~ ~~F~~or example, not facilitating what they would consider to be appropriate diagnostic assessments such as DNA analysis.

Conclusion

Given the important role partners play in the rehabilitation of the ICD recipient and concurrent negative effects on their well being, it is clear ~~from the findings in this study~~ that partners of ICD recipients would benefit from psychological support. An intervention that normalises negative, antagonistic feelings, and helps reduce monitoring/checking behaviours might be helpful. The recipient and partner might also benefit from a discussion around adapting existing marital roles ~~w~~as a source of frustration for some. Pragmatically, this may as a minimum involve co-attending rehabilitation meetings~~,s with recipients~~ so that both recipients and partners can access the same information. Such meetings could also facilitate joint goal setting between recipient and partner, including reducing health monitoring over time. This process may be facilitated by the presence of expert health professionals who could give meaningful guidance on how this could be developed. Few partners would require more than this, and those who do may have significant issues that require specialist support including worry management (Wells, 2000) and post-traumatic counselling particularly where partners have witnessed a cardiac arrest.

Limitations

This study was limited in that nurses may have excluded partners who they believed were too distressed to take part. Partners who were using avoidant behaviours may not have elected into the study. This study did not differentiate between those ICD devices that were remotely monitored, although this did not appear to be an issue. Also, medical stability of the recipients was not taken into account. Lastly, due to a limited time period in which to collect data, only five shock partners were recruited.

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Appendix 1: Interview guide

Before the interview began, rapport with the participant was established. The interview covered the cardiac event, feelings about the ICD and coping, using the questions below:

Participants were asked to describe their experience of the cardiac event, which had precipitated the recipient's need for an ICD and their experience of being told about the ICD.

Participants were asked how they felt about the ICD;

Participants were asked what were (if any) the perceived benefits of the ICD and

Participants were asked to consider if they perceived any disadvantages living an ICD.

Participants were asked how they coped living with the ICD on a daily basis and what were their concerns (if any)

Table 1. Characteristics of Participants

ID	Shock status	Gender of Partner	Age of partner	Cardiac Condition of Recipient	Time with ICD	Primary/ Secondary
A	S	Female	66	Undiagnosed Cardiomyopathy	≤ 1 year	Primary
B	N	Female	65	Heart Failure	≤ 1 year	Primary
C	N	Female	47	Arrhythmogenic Right Ventricular Dysplasia	≤ 1 year	Primary
D	S	Female	40	Idiopathic Dilated Cardiomyopathy	≤ 1 year	Secondary
E	N	Female	50	Out of Hospital SCA	≤ 1 year	Secondary
F	N	Male	65	Undiagnosed cardiomyopathy	≤ 1 year	Primary
G	N	Male	65	Out of Hospital SCA	≤ 1 year	Secondary
H	N	Female	44	Hypertrophic Cardiomyopathy	≤ 1 year	Primary
I	N	Female	67	Sustained tachycardia	≤ 1 year	Primary
J	N	Female	60	Out of Hospital SCA	≤ 1 year	Secondary
K	S	Female	60	Undiagnosed cardiomyopathy	≤ 1 year	Primary
L	N	Female	56	Brugada Syndrome	≤ 1 year	Primary
M	S	Female	64	Heart failure	≤ 1 year	Secondary
N	N	Male	54	Multiple SCA during operation	≤ 1 year	Secondary
O	N	Male	57	Bundle Branch Block Syndrome	≤ 1 year	Primary
P	N	Male	30	Post partum cardiomyopathy	≤ 1 year	Primary
Q	N	Male	28	Long Q-T Syndrome	≤ 1 year	Secondary
R	S	Male	55	Long Q-T Syndrome	≤ 2 years	Primary