

An illness specific version of the Illness Perception Questionnaire Revised in patients with atrial fibrillation (AF IPQ-R): Unpacking beliefs about treatment and personal control and symptom triggers.

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Abstract

Objective: This study modified the Revised Illness Perception Questionnaire (IPQ-R) in patients with persistent Atrial Fibrillation (AF).

Design: Qualitative interviews and think-aloud techniques informed modification of the IPQ-R to be specific to AF patients. Confirmatory Factor Analysis (CFA) (n=198) examined the validity of the modified IPQ-R (AF-IPQ-R). Exploratory Factor Analysis (EFA) examined the new AF-triggers scale. Construct validity examined associations between the AF-IPQ-R, quality of life (QoL) and beliefs about medicines. Test-retest and internal reliability were examined.

Results: Interviews indicated that patients viewed triggers of AF rather than initial causes of illness as more applicable. Patients believed specific behaviours such as rest could control AF. Treatment control beliefs related to pharmacological and procedural treatments. These data were used to modify the IPQ-R subscales and to develop a triggers of AF scale. CFA indicated good model fit. EFA of the triggers scale indicated 3 factors: emotional; health behaviours; and over-exertion triggers. Expected correlations were found between the AF-IPQ-R, QoL and treatment beliefs, evidencing good construct validity.

Conclusion: The AF-IPQ-R showed sound psychometric properties. It provides more detailed specification than the IPQ-R of beliefs that may help to understand poor QoL in AF patients, and guidance for future interventions in this area.

Key words: *IPQR, persistent atrial fibrillation, illness perceptions, modification, factor analysis, AF-IPQ-R*

Introduction

Atrial fibrillation (AF) is an irregular heart rhythm affecting approximately 2% of the general population (Go et al., 2001). AF is deemed an ‘emerging epidemic’ and diagnosis of AF is steadily increasing over time on an age-adjusted and an absolute basis (Ball, Carrington, McMurray & Stewart, 2013). AF is associated with a five-fold increased risk of stroke (Camm et al., 2010). Patients with AF experience symptoms including palpitations, fatigue and dyspnoea, high levels of depression and anxiety and poor quality of life (QoL; Dorian et al., 2000; Thrall, Lip, Carroll & Lane, 2007). AF accounts for 3-6% of acute hospitalisations in the UK (Lip & Tse, 2007) and costs the National Health Service in England £459 million a year (Stewart et al., 2004). Patients with persistent AF experience continuous arrhythmia, have a higher risk of stroke, comorbidities and reduced quality of life (QoL) in comparison to patients with paroxysmal AF (episodic arrhythmia which terminates in < 7 days) (Chiang et al., 2012).

Examining potentially modifiable factors specific to persistent AF, such as cognitions or coping behaviours, and developing ways to sufficiently measure these factors, may allow researchers to obtain a better understanding of how to improve QoL in AF. The Common Sense Model (CSM) of illness (Leventhal, Meyer & Nerenz, 1980) has been widely used to examine clinical and QoL outcomes in chronic illnesses (Carnelli et al., 2017; Hagger & Orbell, 2003; Hallas, Wray, Andreou & Banner, 2011; Hermele, Olivo, Namerow & Oz, 2007; Molloy et al., 2009). According to the CSM, people construct cognitive representations of illness based on abstract (disease labels) and concrete (symptom-based) information sources. Cognitive representations then guide coping behaviours and outcomes. Cognitive illness representations consist of several components including identity (symptoms of the illness), cause (beliefs about precipitating factors of illness), timeline (acute, chronic, or cyclical nature of illness), consequences (illness effects on social, psychological and physical

functioning), control/cure (personal control over illness) and illness coherence (whether the illness makes sense) (Cameron & Leventhal, 2003; Moss-Morris et al., 2002). Emotional representations are processed in parallel with cognitive representations which reciprocally shape patients' cognitive representations (Cameron & Jago, 2008). An extended CSM incorporates patients' beliefs about treatment (treatment beliefs) which are processed alongside illness representations (Horne, 2003).

A few studies have investigated illness representations in AF. Steed, Newman & Hardman (1999) conducted a cross-sectional study examining adjustment in persistent and paroxysmal AF patients. Beliefs about the consequences of AF and illness identity explained a high proportion of variance in adjustment. A similar cross-sectional study in symptomatic AF patients found that greater consequences and poorer perceived understanding of AF (illness coherence) correlated with greater psychological distress (McCabe & Barnason, 2012). These studies suggest illness representations may predict outcomes such as adjustment and psychological distress, however further prospective studies are required to confirm this. Lane, Langman, Lip and Nouwen (2009) examined health-related QoL in lone AF patients (paroxysmal and persistent AF patients without structural heart damage) over 12 months and found illness identity predicted poorer physical health.

These studies used either the original Illness Perception Questionnaire (IPQ; Weinman, Petrie, Moss-Morris & Horne, 1996) or the Revised version (IPQ-R; Moss-Morris et al., 2002) which were developed to be used with all patient groups. Although they have shown good predictive validity across illness groups (Chilcot, Wellsted & Farrington, 2011; French, Cooper & Weinman, 2006; Frosthalm et al., 2007; Vedhara et al., 2016), they do not allow in-depth insight into idiosyncratic beliefs held by specific patient groups (French & Weinman, 2008). Similarly, the Brief Illness Perception Questionnaire (B-IPQ), a shorter nine-item measure of illness perceptions, has good psychometric properties including

predictive and discriminant validity (Broadbent, Petrie, Main & Weinman, 2006; Broadbent et al., 2015). The B-IPQ uses single item-scales which allow rapid assessment of illness perceptions, but may lack content validity and does not sufficiently assess patients' idiosyncratic beliefs (van Oort, Schröder & French, 2010). Idiosyncratic beliefs may be particularly important for designing clinical interventions for specific patient groups. In a recent qualitative study, AF patients spoke about gaining control over symptoms by avoiding activities which they believed triggered symptoms (Taylor, O'Neill, Hughes, Carroll, & Moss-Morris, 2017). The study indicates that unhelpful coping behaviours may contribute to poor QoL in AF patients and may be an area of focus for interventions. Although the generic IPQ, IPQ-R and B-IPQ measure perceptions of control over the illness, they do not capture what patients believe helps to control the illness. The latter may be more informative when trying to alter potentially unhelpful behaviours.

The treatment control subscale of the IPQ-R also has limitations as internal reliability of this subscale is often low (Moss-Morris et al., 2002; Chilcot, Norton, Wellsted, & Farrington, 2012). This may be because broad questions about whether treatment can control illness do not take into account the wide range of treatments patients may be receiving. AF patients are likely to be taking more than one type of medication (e.g. anticoagulants such as Warfarin and antiarrhythmics such as Amiodarone) and may have several different surgical procedures. Procedures which restore normal heart rhythm include direct current cardioversion, an electrical impulse delivered to the outside of the chest; and catheter ablation, a more invasive procedure involving radiofrequency scarring of areas of the heart generating arrhythmia (Camm et al., 2010). Cardioversion has a high acute efficacy of 90% (Boriani et al., 2007). However, recurrence at one year is high, with less than half of people remaining in normal sinus rhythm (Van Gelder et al., 1991). Catheter ablation has a one-year success rate of around 65%, which improves with multiple procedures to 86%. Patients on

average undergo two procedures (Ganesan et al., 2013). Atrioventricular node ablation (AVNA) is recommended for highly symptomatic patients when AF cannot be prevented by rhythm control strategies or pharmacological rate-control strategies (Kirchhof et al., 2016). AVNA involves insertion of a pacemaker to control heart rate but does not correct the arrhythmia (Camm et al., 2010). The ablation itself is successful in 97.4% of patients and AVNA is an effective therapeutic option for reducing symptoms in most patients (Vlachos et al., 2015). To account for the diverse nature and type of treatment, the IPQ-R may need to be adapted to represent AF-specific experiences. In addition, successful procedures which restore normal heart rhythm are not always related to improvements in symptom-reports and QoL (Erdogan et al., 2003). A more detailed exploration of illness representations in AF may help to understand factors contributing to QoL after treatment.

Most modified versions of the IPQ-R focus on minor changes such as substituting the disease label for 'my condition' or illness-specific additions to the causes and illness identity sub-scales (French & Weinman, 2008). While the IPQ-R takes more time for patients to complete than the B-IPQ, modifying the IPQ-R gives researchers a greater ability to describe more elaborated beliefs which may be amenable to change in future interventions. There are few validated modified versions of the IPQ-R but previous studies have been completed in breast cancer survivors, cervical screening and musculoskeletal pain (Hagger & Orbell 2005; Moon, Moss-Morris, Hunter & Hughes, 2017; Nicholls, Hill & Foster, 2013). These studies report the ability of the modified versions to access disease-specific beliefs as a foundation to developing interventions to support patients and provide further empirical support for the IPQ-R in different contexts.

The present study

This study aimed to develop a valid and reliable AF-specific version of the IPQ-R. In Part 1, the aim was to use qualitative methods to a) modify relevant items of the IPQ-R to be AF-

specific and b) explore the face validity of new and revised IPQ-R items using think-aloud methods. The aim of Part 2 was to use quantitative methods to examine the validity of the factor structure of the AF-specific IPQ-R (AF-IPQ-R), its internal and test-retest reliability and its construct validity in relation to AF QoL and a validated Beliefs about Medicines Questionnaire.

Part 1: Methods

Interviews were conducted as part of a broader qualitative study (inductive thematic data reported elsewhere; Taylor et al., 2017) and consisted of open-ended and semi-structured questions. The semi-structured questions related to components of the IPQ-R and patients' responses to these questions informed initial modifications to the questionnaire. Face validity of the AF-IPQ-R was examined using think-aloud methods. Ethical approval was obtained from NRES Committee North East: Newcastle and North Tyneside 1 (REC: 14/NE/0096).

Participants

Participants were purposively recruited from cardiology clinics and online via the AF Association (AFA), the largest UK AF charity, before data saturation was reached, i.e. sufficient data was collected to represent patients' experiences (Glaser & Strauss, 2009). Eligibility criteria required patients to have a clinical diagnosis of persistent AF and to have recently had (within 3 months), or scheduled to have their first AF procedural treatment (catheter ablation, cardioversion or AVNA). Patients with severe co-morbidities were excluded (active cancer, severe heart failure and diabetes related hospitalisation in the past year) as these more severe illnesses may make it difficult for patients to separate out beliefs pertinent to AF specifically.

[INSERT TABLE 1 ABOUT HERE]

Procedure

Clinic patients were screened for eligibility by healthcare practitioners (HCPs) and given further information if they were interested in participating. AFA participants were directed to further information about the study online and screened. Once participants gave informed consent a telephone interview was arranged. Interviews lasted between 15-43 minutes, were transcribed verbatim and patients' responses to the semi-structured questions were analysed using deductive thematic analysis with the CSM as a theoretical framework.

Results: Item development

Thirty participants were recruited for the initial interview phase of Part 1. Participant characteristics are summarised in Table 1. Mean age was 61.6 ($SD=11.98$), over 60% were male and the majority were white British. Themes reflected key components of the IPQ-R (see supplementary materials Table S1). A dominant theme was that patients felt their AF was unpredictable and could occur at any time. Patients reported specific activities or situations which they felt triggered symptoms and targeted behavioural-responses to avoid triggers. A second theme included patients' growing frustration and concerns about the risks and potential ineffectiveness of treatment. These concerns related to undergoing repeat procedures and medication side effects.

Interviews informed IPQ-R modification in three ways: 1) retention of original items; 2) minor revisions of existing items and; 3) development of new items. Minor revisions included wording changes in-line with recommendations for using the IPQ-R (Moss-Morris et al., 2002) including replacing 'my illness' with 'my AF'. Six AF-specific symptoms were added to the identity scale including swollen ankles, cold hands/feet, heart palpitations, other beating sensations, perspiration and changes in eyesight. Pain was modified to chest pain.

Additional minor changes were made to all other subscales, except chronic and cyclic-timeline components. An item on the consequences subscale relating to financial consequences of illness was removed and replaced with consequences to work life which was

more consistent with patients' reports that AF symptoms affected work life, including promotions and socialising with colleagues. The coherence subscale was modified to reflect treatment as well as illness coherence (*'I have a clear understanding of my AF and my treatment for it'*) as some patients reported poor understanding of treatment, particularly relating to procedures and warfarin. A new coherence item was developed reflecting patients' beliefs that it was unnecessary to understand AF or treatment (*'I don't feel the need to understand my AF or my treatment for it'*). For the emotional representation subscale, anger and feeling afraid were replaced with frustration and worries about heart-dysfunction.

More significant changes were made to the causes scale. Patients viewed AF as recurrent and believed certain events or behaviours could trigger AF symptoms. A symptomatic triggers scale appeared more relevant than examining patients' beliefs about the original cause of AF which was seldom mentioned. The stem to the casual scale was therefore altered to reflect which factors they believed triggered AF symptoms rather than caused AF. Based on the interviews, four new items were added to the AF triggers scale including exercise, caffeine, other cardiovascular illness and medication, to give a 16-item scale.

The unpredictability theme related to the personal control subscale and led to the development of new items. An item (*'the course of my illness depends on me'*) was removed and replaced with an item which captured patients' struggles to gain control over unpredictable symptoms (*'my AF symptoms are unpredictable and my control over them varies'*). Patients held beliefs that targeted-behaviours could control symptoms such as slowing down, resting and avoiding activities. This led to three additional personal control items: *'By doing less and slowing down I can control whether I have AF symptoms'*; *'Resting will prevent me from having symptoms'*; *'Avoiding certain activities will control my AF'*. Finally, treatment control items were re-worded to relate specifically to the pharmacological

and procedural treatments which patients were undergoing (including catheter ablation, AVNA, cardioversion, antiarrhythmics and anticoagulants).

Think-Aloud Modifications

A sub-set of six participants from the qualitative study (Table 1) were asked to review the first draft of the modified-IPQ-R using think-aloud methods. This allowed us to ascertain whether items were likely to be interpreted as we intended (i.e. face validity). Think-aloud analysis has been used to modify the IPQ-R in patients with Type 2 diabetes, breast cancer and in children of patients with multiple sclerosis (Bogosian, Moss-Morris, Bishop, & Hadwin, 2014; McCorry, Scullion, McMurray, Houghton, & Dempster, 2013; Moon et al., 2017). Participants were given the modified questionnaire and asked to read each item aloud during telephone interviews. Participants talked through how they would answer each question, whether the question was clear and understandable and gave their overall thoughts of the questionnaire. Interviews were audio-recorded and lasted between 16-40 minutes. Adopted changes to the questionnaire were based on the frequency of participants' comments relating to specific items and perceived relevance. Changes were discussed and agreed between two researchers.

Think-aloud interviews indicated that patients understood the questionnaire and that it had acceptable face validity. Changes were made to improve clarity on the illness coherence component. An item within the triggers scale was expanded upon to provide further context (*'my own behaviour e.g. pushing myself too hard'*). Some reverse items were outlined as problematic but participants could ascertain intended responses so no changes were made. Repetitive items were reworded or removed. The modified-IPQ-R (AF-IPQ-R) is available in Supplementary Materials (Figure S1).

Part 2: Quantitative Methods

Part 2 consisted of a cross-sectional questionnaire study which examined the factor structure and validity of the AF-IPQ-R. Ethical approval was obtained from NRES Committee London Bloomsbury (14/LO/2148).

Participants

Patients with a clinical diagnosis of persistent AF who were undertaking a procedural treatment (catheter ablation, cardioversion or AVNA) were eligible to participate. As described in Part 1 above, people with severe co-morbidities were excluded. A total of 198 participants were recruited from cardiology clinics (n=174) and online from the AFA (n=24). See Supplementary Materials Figure S2 for recruitment rates. The sample was in line with recommendation of at least 100 participants for factor analyses (Cattell, 1978). Mean age, gender, ethnicity and treatment type were very similar between clinic and AFA patients. A sub-set of this sample (see Table 1) participated in the test-retest reliability. These patients were opportunistically selected and agreed to be contacted two weeks after completing the baseline questionnaire and had not undertaken procedures.

Measures

Demographic and illness factors were examined including age, gender, ethnicity and treatment type (Table 1). Measures were included in a single questionnaire pack:

The AF-IPQ-R has a three-part structure. The first part measures illness identity. Participants rate whether they have experienced a list of 20 symptoms and if they believe each symptom is related to their AF. The latter is summed to provide an identity score. The second part consists of items measuring chronic-timeline (six items), cyclic-timeline (four items), consequences (six items), illness coherence (six items), personal control (nine items), treatment control (five items) and emotional representations (six items). The last 16-item

scale examines AF triggers. A five-point Likert-type scale ranging from ‘strongly disagree’ to ‘strongly agree’ is used to score components.

The *Atrial Fibrillation Effect on Quality of Life Questionnaire* (AFEQT; Spertus et al., 2011) is a 20-item AF-specific QoL measure routinely used in clinical practice. It assesses symptoms (four items), activities (eight items) treatment concern (six items) and treatment satisfaction (two items). The first three components are summed to provide an overall health score. A seven-point Likert-type scale ranging from ‘not at all’ to ‘extremely limited’ is used in all components. It has shown good reliability in AF patients undergoing different treatments, acceptable test-retest reliability and good construct validity in relation to other AF-specific QoL questionnaires (Dorian et al., 2013).

The Beliefs about Medicines Questionnaire (BMQ)-Specific (Horne, Weinman, & Hankins, 1999) measures beliefs using two factors: concerns (5 items) and necessity (5 items) of medication. In the current study beliefs were examined in relation to AF-specific procedures (cardioversion, catheter ablation and AVNA). Responses are made using a five-point Likert-type scale; ‘strongly disagree’ to ‘strongly agree’. The BMQ-general scales measure attitudes to medicines generally and was not used in the current study as the BMQ-Specific is a better predictor of outcomes in patients with long-term conditions (Horne et al., 2013). The BMQ-Specific has been validated in a range of chronic illnesses including cardiac patients and shows good reliability and discriminant validity.

Procedure

Patients were approached by HCPs at cardiology clinics. If they were interested in the study, they were given an information sheet and consent form to read and given the option to discuss the study further with a researcher. Patients who agreed to participate gave informed consent and were invited to complete the questionnaire in clinic or to return it later by pre-

paid post. AFA patients were directed from the AFA website to an electronic copy of the information sheet, consent form and questionnaire. Patients participating in the test-retest reliability study were invited to complete the questionnaire again after two weeks and were sent a copy of the questionnaire by post.

Statistical analysis

Confirmatory Factor Analysis (CFA)

Mean imputation was used to account for missing data as there was less than 5% missing. A CFA was conducted on the AF-IPQ-R using MPlus (V.7) and is the analytic tool of choice when refining measurements (Brown, 2014; Schreiber, Nora, Stage, Barlow, & King, 2006). The seven-factor hypothesised model was estimated to examine the components of chronic-timeline, cyclic-timeline-cyclic, consequences, personal control, treatment control, illness coherence and emotional representations. Individual items were specified to load on hypothesised components. As the authors of the original IPQ-R indicate a co-variation between illness-representation components, inter-correlations between variables were examined.

Weighted Least Squares with Mean and Variance adjustment estimation (WLSMV) were used to account for continuous and categorical data (Brown, 2014). To assess model fit, the Root Mean Square of Approximation (RMSEA), Comparative Fit Index (CFI), and Tucker-Lewis Index (TLI) were used (Jackson, Gillaspay, & Purc-Stephenson, 2009). These fit-indices are designed to overcome problems associated with small sample size in comparison to indices such as chi-squared (Schreiber et al., 2006). An RMSEA value of less than .08 and TLI and CFI values greater than .95 indicate reasonable fit (Hu & Bentler, 1999). Standardized factor loadings were used in case of model misspecifications and large residuals indicating lack of reliability were removed from the data (Brown, 2014). The CFA

was an iterative process although modifications were done sparingly and only when theoretically plausible (Jackson et al., 2009).

Exploratory Factor Analysis for Triggers Scale

An exploratory factor analysis (EFA) was conducted on the 16-item triggers scale to examine the underlying factor structure and latent variables. The EFA was conducted in SPSS (V.22) using maximum-likelihood extraction and oblique rotation (direct oblimin) as factors were expected to correlate.

Reliability and construct analyses

Reliability analyses were conducted in SPSS (V.22) on the AF-IPQ-R. Cronbach's coefficient alpha (α) tested internal consistency. Test-retest reliability was conducted using intra-class correlation coefficients (ICC) over a two-week period as recommended by Marx et al. (2003). An ICC can vary between 0-1.0 where 1.0 indicates perfect reliability. Bland-Altman plots examined the generalisability of test-retest reliability and potential outliers (Bland & Altman, 1986). Construct validity examined the interrelationships between AF-IPQ-R subscales with the BMQ (Horne, et al., 2002) and AFEQT (Spertus et al., 2011).

Results

Identity Scale

Symptoms most commonly associated with AF were breathlessness, fatigue, heart palpitations, dizziness and loss of strength. This is consistent with symptoms reported in the literature and supports the inclusion of AF-specific symptoms (See Supplementary Materials Table S2). The mean number of symptoms attributed to AF was 6.6 ($SD = 3.3$).

Confirmatory Factor Analysis

Initial CFAs were run individually for each scale of the AF-IPQR to eliminate items with low factor loadings. Removed items included three items on personal control: IPQR14 (*'My AF symptoms are unpredictable and my control over them varies'*); IPQR15 (*'Nothing I do will affect my AF'*); IPQR17 (*'My actions will have no effect on the outcome of my AF'*), one illness coherence item: IPQR27 (*'I don't understand my AF or treatment'*), and one chronic-timeline item: IPQR21 (*'My AF will improve in time'*). At this stage, poor model fit was indicated when conducting a single CFA for the treatment control sub-scale, however factor loadings of 0.35 (lower than the recommended 0.4) and above were retained as removal led to worse loadings.

A full factor analysis was conducted on the AF-IPQ-R which yielded an RMSEA of 0.063, CFI= 0.918 and TLI = 0.910. Data were visually inspected and showed that items correlated according to the subscales of the IPQ-R suggesting appropriate use of a CFA. IPQR16 (*'I have the power to influence my AF'*) (personal control) was removed due to factors loadings of less than 0.35. The final AF-IPQ-R showed good model fit: RMSEA = 0.063, CFI = 0.923 and TLI = 0.915. Factor loadings of the final CFA can be found in Table 2. Factor loadings ranged from 0.35 to 0.93. Beliefs about treatment control relating to procedures and to medication did not load onto the same scale and were therefore treated as separate scales. The highest factor loadings across the AF-IPQ-R came from two of the three newly developed personal control items which reflected specific rather than general control beliefs, as well as an item on poor illness coherence.

[INSERT TABLE 2 ABOUT HERE]

Exploratory Factor Analysis for Triggers Scale

Preliminary interpretation

To determine if any items may be redundant, ceiling effects were tested by examining item frequencies to ascertain whether 80% or more participants disagreed with any specified items

on the trigger scale. No items were removed on this basis. The most commonly attributed triggers of AF included stress/worry (54%), own behaviour (51%) and exercise (49%) (See Supplementary Materials Table S3). Inspection indicated a patterned relationship amongst variables except for IPQRT4 (chance) which was removed. Bartlett's Test of Sphericity $\chi^2(105) = 1106.44$, $p < 0.001$ further confirmed patterned relationships between items.

Haitovsky's test indicated that data did not have any issues of multicollinearity ($p < 0.001$).

Kaiser-Meyer-Olkin Measure (KMO) was .84 indicating the data was suitable for EFA.

Factor extraction and rotation

Using Kaiser's criterion, an eigenvalue of 1.0 cut-off and visual inspection of the scree plot, three meaningful factors were indicated. Factors were labelled as 1) Emotional Triggers, which contained items related to stress and emotional state, 2) Over-exertion triggers including exercise and over-work, and 3) Health Behaviour triggers including health-specific behaviours such as smoking and co-morbid conditions. See Table 3 for factor loadings. Good model fit was indicated with 27% of the non-redundant residuals with absolute values greater than .05. Factors moderately correlated: Emotional Triggers positively correlated with Health Behaviour triggers ($r = .52$) and Over-exertion triggers ($r = .53$). Health Behaviour triggers and Over-exertion triggers were less correlated ($r = .39$).

[INSERT TABLE 3 ABOUT HERE]

Test-retest and internal reliability (Cronbach's alpha)

The AF-IPQ-R subscales showed acceptable internal reliability. Cronbach's alphas ranged from .86 to .63 (Table 4). On average, patients took 20 days (range of 13-24 days) to return the two-week questionnaires for the test-retest analysis. ICC scores ranged from .82 to .58 and showed acceptable test-retest reliability and stability of constructs over time for all subscales (Table 4). Further analysis of test-retest reliability using Bland-Altman plots

showed that there were large variations in patients' responses for the chronic-timeline component, indicating lack of consistency in responses over time, which were not highlighted by ICC score. Bland-Altman plots also revealed systematic bias over time for the illness coherence component which indicated that in most patients, illness coherence increased over the two weeks.

[INSERT TABLE 4 ABOUT HERE]

Construct validity

Inter-correlations can be seen between AF-IPQ-R components in Supplementary Materials (Table S4). Correlations were in line with hypothesised relationships; emotional representations were strongly positively correlated with serious consequences. Cyclic-timeline positively correlated with illness identity, personal control, consequences and all triggers (emotional, health behaviours and over-exertion). Cyclic-timeline was negatively correlated with coherence. Treatment control and personal control were uncorrelated, indicating the relevance of separate control measures.

Expected correlations were also found between the AF-IPQ-R and AF-specific QoL (AFEQT) and procedural treatment beliefs (BMQ) (Table 5): QoL negatively correlated with identity, consequences, cyclic-timeline, emotional representations, emotional triggers and overexertion-triggers. Unexpectedly, personal control was also negatively correlated with QoL. A small positive correlation was found between illness coherence and QoL. Procedural necessity correlated positively with consequences, identity and procedural treatment control. Procedural concerns negatively correlated with illness coherence and treatment control and positively correlated with cyclic timeline, emotional representations and all triggers.

[INSERT TABLE 5 ABOUT HERE]

Discussion

Initial interviews completed as part of this study suggested the IPQ-R needed to be modified and extended to capture more specific features of AF patients' illness beliefs. Modifications included replacing the causes scale with a AF symptom triggers scale, relating the treatment control component to specific AF pharmacological and procedural treatments, and the addition of three personal control items related to beliefs about reducing activity to control AF symptoms. Factor analysis helped to reduce the scale to best fit items and confirmed the factor structure of this revised scale which was also shown to have good internal reliability and moderate test-retest reliability. Construct validity was confirmed.

Moderate test-retest ICC scores may be due to the unpredictable nature of AF influencing some beliefs such as personal and treatment control and chronic timeline. For instance, if the AF-IPQ-R is administered when patients feel symptom free they may rate the control and timeline of their illness more positively than at a time when they are experiencing symptoms. This was supported by Bland-Altman plots which indicated systematic change in treatment control beliefs which may have increased as an artefact of participating in the study, or because patients sought a better understanding of AF with upcoming procedures. A systematic review of the IPQ-R used in musculoskeletal disorders also found moderate test-retest reliability and suggested that in illnesses where symptoms fluctuate, illness representations may not remain stable (Leysen et al., 2015). Emotional representations was the most stable construct, as found in previous research examining internal reliability of the IPQ-R (Moon et al., 2017), and may indicate emotional representations about AF are more stable than cognitive representations.

The AF-IPQ-R showed good construct validity in relation to the interrelationships between the subscales, necessity and concern beliefs about procedures (measured by the BMQ) and QoL (measured by the AFEQT). Correlations were largely congruent with previous research (Moon et al., 2017; Moss-Morris et al., 2002; Snell, Siegert, Hay-Smith, &

Surgenor, 2010). Within the AF-IPQ-R subscales, the belief that AF is a cyclical condition was related to greater emotional representations. Contrary to previous research, believing AF to be cyclic was related to greater personal control. It may be that individuals who experience unpredictable symptoms believe they result from specific behaviours and are controllable by engaging in specific personal-control behaviours. This can be supported by the finding that behaviours such as overwork or exercise are perceived as AF triggers.

The study also confirmed the relationship between illness representations as measured by the AF-IPQ-R and QoL in AF. Attributing more symptoms to AF, holding beliefs that AF is recurrent and has greater consequences on everyday life, and having greater emotional representations about AF, were associated with poorer QoL. Interestingly, patients who held greater personal control beliefs also experienced poorer QoL. Rather than holding general personal control beliefs, AF patients may believe that specific, targeted behaviours can control symptoms, as evidenced by high factor loadings on the specific-personal control component. To gain control of symptoms, patients may feel it is necessary to continuously assess their own behaviours to find out which behaviours they perceive to be associated with worsened symptoms. In turn, constant control efforts may be associated with beliefs that AF has greater consequences on everyday life. In addition, personal control was measuring control through limiting activity and doing less. Although personal control is often viewed as a positive correlate of good outcome, believing illness should be controlled by doing less appears to be negatively associated with outcome. Specific personal-control behaviours may involve relinquishing activities (avoidance), contributing to poorer perceived QoL. Previous research indicates that engaging in avoidance behaviours is associated with illness-chronicity and mortality in patients with heart failure and irritable bowel syndrome (Murberg, Furze & Bru, 2004; Spence & Moss-Morris, 2007). Whilst the current study indicates that AF patients believe specific behaviours can control symptoms, further research is needed to examine

whether AF patients actually engage in these specific behaviours, and if so, should identify potential helpful behaviours which may improve QoL.

While the current study supports the CSM, interrelationships between the dimensions of cognition representations and emotional representations suggest these are interacting features of the model rather than parallel pathways as outlined in the original model (Leventhal et al., 1980). Negative emotional representations may result from perceived ineffectiveness of coping behaviours to reduce AF symptoms and perceptions that AF is uncontrollable. Stability of emotional representations evidenced in the current study indicate that negative emotional representations may be more resistant to change than cognitions, which should be considered when designing interventions. In addition, treatment beliefs may develop based on previous experiences of AF and established illness perceptions. For instance, even when treatment is successful in restoring normal sinus rhythm, patients' previous experiences and cognitive representation of AF as uncontrollable may lead to beliefs that treatment will be ineffective in controlling AF. This may result in continued coping behaviours such as avoidance and negative emotional representations. Longitudinal studies examining the direction of relationships are needed to investigate these potential pathways.

A strength of the current study is that a thorough process informed the initial modification of the AF-IPQ-R and robust statistical analyses were used for validation. In addition, different samples were used in the development (interviews) and validation (factor analyses) of the AF-IPQ-R. One limitation of the study is that the AF-IPQ-R is only validated in persistent AF patients so although it is likely the AF-IPQ-R would apply to patients with other types of AF, further validation across other types of AF is required to support the factor structure in the context of all AF patients. As users of an online support group, AFA patients may be more motivated to discuss their experiences than clinic patients, as reflected by higher recruitment rates in AFA patients. Overall, recruitment rates were low (47%). This

may be due to strict eligibility criteria as patients were required to return questionnaires prior to procedures. In addition, although severe co-morbidities were excluded, AF patients are likely to have other co-morbidities and invasive symptoms which may have inhibited the completion of questionnaires. Lastly, although the current study considers AF-specific treatments, further facets of treatment representations may exist. Future research should examine beliefs about the risk and side-effects of treatment and treatment coherence, which may influence coping and QoL outcomes (Horne, 2002; Karamanidou, Weinman & Horne, 2008).

In summary, the qualitative component of this study supported modifying the IPQ-R in AF patients. The original IPQ-R would not have assessed the idiosyncratic beliefs held by AF patients which the AF-IPQ-R captures, including beliefs related to the triggers of AF symptoms, specific ways to control recurrence of symptoms and procedural treatment beliefs. The AF-IPQ-R is a psychometrically sound tool which can be used to examine theoretical relationships in the context of the CSM. These data can be used to target modifiable CSM-related cognitions, emotions and behaviours to inform interventions to address AF-specific issues such as poor adherence to warfarin which increases stroke-risk (Kimmel et al., 2007). These studies could also inform the development of interventions to identify unhelpful illness perceptions which may be associated with distress and poor QoL and to reduce unhelpful behavioural responses to symptoms such as avoidance or unnecessary healthcare utilization.

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Table 1: Demographic characteristics of the samples included in the development of the IPQ-R

	Qualitative interviews	Think- aloud study	Validation Factor analysis	Validation test-retest reliability
Number of patients	30	6	198	26
<i>Age mean (SD)</i>	61 (12)	60 (12)	64 (9)	63 (12)
<i>Sex n (%)</i>				
Female	11 (37)	1 (17)	46 (23)	5 (19)
<i>Ethnicity n (%)</i>				
White British	29 (97)	6 (100)	192 (97)	35 (100)
Other	1 (3)	0 (0)	5 (3)	0 (0)
<i>Type of treatment n (%)</i>				
Cardioversion	11 (37)	2 (33)	116 (59)	17 (65)
Catheter ablation	10 (33)	2 (33)	71 (36)	9 (35)
AVNA	9 (30)	2 (33)	11 (5)	0 (0)

Note: SD, Standard Deviation. AVNA, AV node ablation.

Table 2. Confirmatory factor analysis of Atrial Fibrillation Illness Perception Questionnaire (AF-IPQ-R) items (excluding identity and trigger items) and factor loadings of final model.

IPQ-R item number and component	1	2	3	4	5	6	7
<i>Timeline (chronic/acute)</i>							
1 My AF will last for a short time	0.73						
2 My AF symptoms are likely to be permanent rather than temporary permanent	0.76						
3 My AF will last a long time	0.90						
4 This AF will pass quickly	0.80						
5 I expect to have AF for the rest of my life	0.71						
21 My AF will improve in time	R						
<i>Consequences</i>							
6 My AF is a serious condition		0.66					
7 My AF has major consequences on my life		0.83					
8 My AF does not have much effect on my life		0.70					
9 My AF strongly affects the way others see me		0.56					
10 My AF affects my working life ¹		0.61					
11 My AF causes difficulties for those who are close to me		0.72					
<i>Personal control</i>							
12 There is a lot which I can do to control my AF symptoms			0.38				
13 The things I do are likely to make my symptoms better or worse			0.41				
14 My AF symptoms are unpredictable and my control over them varies ²			R				
15 Nothing I do will affect my AF			R				
16 I have the power to influence my AF			R				
17 My actions will have no effect on the outcome of my AF			R				
18 By doing less and slowing down, I can control whether I have AF symptoms ²			0.74				
19 Resting will prevent me from having symptoms ²			0.90				
20 Avoiding certain activities will control my AF ²			0.89				
<i>Illness coherence</i>							

22	The symptoms of my AF are puzzling to me	0.81
23	My AF is a mystery to me	0.86
24	I don't understand my AF	0.93
25	My AF doesn't make any sense to me	0.85
26	I have a clear understanding of my AF and my treatment for it clear ¹	0.49
27	I don't feel the need to understand my AF or my treatment for it ²	R
<i>Cyclic timeline</i>		
28	My AF symptoms change a great deal from day to day	0.79
29	My AF symptoms come and go in cycles come/go	0.82
30	AF is very unpredictable	0.70
31	I go through cycles in which my AF gets better and worse	0.85
<i>Emotional representations</i>		
32	I get depressed when I think about my AF	0.86
33	When I think about my AF I get upset	0.89
34	My AF makes me feel frustrated ²	0.67
35	My AF does not worry me	0.55
36	Having AF makes me feel anxious	0.69
37	Having something wrong with my heart makes me feel worried ²	0.62
<i>Treatment control</i>		
38	There is very little that can be done to improve my AF/reduce my risk of stroke	0.43
39	My treatment* will be effective in curing my AF/reducing my risk of stroke ¹	0.78
40	My treatment* will stop my AF from coming back/me from having a stroke ²	0.59
41	My treatment* can control my AF symptoms/my stroke risk ¹	0.69
42	There is nothing which can help my AF symptoms/stop me from having a stroke	0.35

Note: ¹ modified item, ² new item. R removed item, *the treatment control component was phrased to relate specifically to relevant procedural (cardioversion, catheter ablation, atrioventricular node ablation) and pharmacological (antiarrhythmic drugs, anticoagulant drugs) treatments.

Table 3: Table showing results from exploratory factor analysis of the Atrial Fibrillation Illness Perception Questionnaire (AF-IPQ-R) triggers scale

Item Description	Factor 1 Emotional Triggers	Factor 2 Health behaviour triggers	Factor 3 Over-exertion triggers
Emotional state	.82	.00	.01
Mental attitude	.70	.04	.03
Family problems	.66	.01	.14
Personality	.56	.12	.07
Stress/worry	.45	.04	.30
Alcohol	.10	.80	.02
Smoking	.01	.72	.01
Caffeine	.08	.62	.10
Cardiovascular	.01	.62	.01
Immune system	.18	.54	.07
Medication	.27	.47	.05
Diet/eating habits	.10	.47	.01
Own behaviour	.01	.05	.92
Overwork	.23	.04	.52
Exercise	.01	.20	.43
<i>Eigenvalues</i>	<i>5.07</i>	<i>1.30</i>	<i>0.66</i>
<i>% of variance</i>	<i>33.80</i>	<i>8.70</i>	<i>4.40</i>

Note: Bold items indicate items loading on factors.

Table 4. Results for test-retest reliability for the Atrial Fibrillation Illness Perception Questionnaire (AF- IPQ-R)

AF-IPQ-R Component	Cronbach's alpha (α)	Test-retest ICC (95% CI)
Chronic timeline	0.84	0.58
Consequences	0.77	0.64
Personal control	0.76	0.60
Illness coherence	0.86	0.66
Cyclic timeline	0.83	0.60
Emotional representations	0.81	0.79
Treatment control	0.63	0.68
Identity	n/a	0.57
Emotional Triggers	0.84	0.82
Health Behaviours triggers	0.82	0.58
Over-exertion triggers	0.71	0.69

Note: ICC, intraclass correlation coefficient. CI, confidence interval. N/A, analysis not conducted on identity.

Table 5: Correlations between AF-IPQ-R, quality of life (AFEQT) and beliefs (concerns and necessity) about treatment (BMQ)

	AFEQT QoL	BMQ Concerns	BMQ Necessity
Identity	-0.39 **	0.07	0.30 **
Chronic Timeline	-0.06	0.08	-0.10
Cyclic timeline	-0.35 **	0.22 **	0.18 *
Consequences	-0.57 **	-.16 *	0.50 **
Illness coherence	0.17 *	-0.36 **	-0.04
Personal control	-0.15 *	0.16 *	0.27 **
Procedural treatment control	0.02	-0.17 *	0.40 **
Emotional representations	-0.39 **	0.30 **	0.32 **
Emotional triggers	-0.27 **	0.34 **	0.21 **
Health behaviour triggers	-0.13	0.28 **	0.11
Overexertion triggers	-0.30 **	0.23 **	0.23 **

Note: QoL quality of life; * p<0.05; **p<0.01.