

**EXPLORING THE LIVED EXPERIENCE OF INDIVIDUALS WITH VOCAL CORD
DYSFUNCTION USING INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS**

By

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CONTENTS

Introduction	1
Chapter 1: Development Of A Research Proposal To Enable The Creation Of Questionnaire Measuring Health Related Quality Of Life In Those Living With Vocal Cord Dysfunction	
Reflection	6
Introduction	10
Design & Methodology	13
Description of analysis	17
Summary of Ethical Issues	20
Chapter 2: An Exploration Of The Process Of Recruitment For Research On Psychosis: The Challenges Of Recruiting Within An Actively Researched Population	
Introduction	28
Method	36
Challenges & Questions	46
Reflections	49
Chapter 3: Exploring The Lived Experience Of Individuals With Vocal Cord Dysfunction Via Interpretative Phenomenological Analysis	
Abstract	52
Introduction	54
Method	58
Results	68

Appendices to chapter 3

3A: NRes approval letter	99
3B: Birmingham research approval letter	103
3C: R&D approval (Heart of England NHSFT)	106
3D: Participant Information Sheet	108
3E: Invitation to participate	110
3F: First Interview Schedule	111
3G: Second Interview Schedule	113
3H: Participant Screening Questionnaire	115
3I: Summary of cross case thematic structure & descriptions	117
3J: Summary of cross case thematic structure & quotes	120
3K: Example of participant theme development table	145

References

Chapter 1	150
Chapter 2	153
Chapter 3	155

INTRODUCTION

Prior to this MRes I completed a conversion diploma in psychology over the course of a year, which provided a broad overview of the subject. I also spent some time volunteering as an assistant psychologist and worked part time as a support worker. On the course I therefore was looking to further develop my clinical and research knowledge and skills, and as I did not feel tied to a particular area of interest I also wanted the opportunity to work with different client groups.

During my first placement at Heartlands Hospital I helped develop a research proposal, which would support the creation of condition-specific questionnaire measure. The aim of this measure was to capture health-related quality of life information for a health condition called Vocal Cord Dysfunction (VCD), which could be used as a standardised outcome measure to assess change. The main challenges of the first placement therefore were threefold: 1. Learning about VCD; 2. Learning about questionnaire development; 3. Completing an ethics application.

This placement allowed a fascinating insight into the multifaceted ways that psychology is applied and its role in physical health care. Furthermore, I felt that it provided me with some excellent experience of Multidisciplinary team (MDT) working as my research colleagues included a speech and language therapist, a doctor and clinical psychologist. By the end of the placement I had created and submitted an ethics application, which was granted approval.

Supervision enabled me to refine the research proposal and gain some in-depth information about the condition. I also co-facilitated a focus group with individuals with VCD, which gave me a really fascinating initial insight into how people lived with the condition and the impact that it had on their lives.

During my second placement I recruited clients at an Early Intervention (EI) service for psychosis. The aim of the research was to explore the relationship between shame, trauma and psychosis and my task involved presenting the research to care teams, identifying potential participants, contacting them to see if they would like to take part and visiting them with questionnaires for completion.

One of the main challenges of this placement was recruitment in an over-researched population and undertaking home visits with a client group with which I was not familiar. I utilised supervision to explore different ways of approaching these challenges and also to further my understanding of EI. Organisation, planning and minimisation of burden on busy colleagues were crucial for working with care teams. Clear and simple explanations of the research were helpful when recruiting participants and it was also essential to be sensitive to participant needs and flexible with regards to recruitment plans. This provided me with an excellent insight into the work of EI, a burgeoning knowledge of compassion-focused therapies and also some really valuable experience of client work.

My third placement was a return to the research on VCD, where I completed part of the first stage of the questionnaire project. My main tasks were recruitment of six individuals with VCD for semi-structured interviews about their experience of living with the condition, and transcription and analysis of these data using Interpretative Phenomenological Analysis (IPA).

Developing an interview schedule with open questions that would elicit reflective responses required some refinement as the interviews progressed. However, I also learned that some interviews would be richer than others simply because some individuals were more reflective.

I utilised supervision to help develop my skills for coping with emotive information and for discussing emergent themes and refining ideas. I felt in many ways this was personally the most challenging project I have undertaken. Transcription, analysis and organisation of such a large amount of rich information often felt overwhelming. I also had to find ways to manage my own anxieties, which reading about the condition provoked. Supervision was invaluable here in helping me structure the findings and normalise how I was feeling. I will be continuing to work with the VCD research team in order to disseminate the findings.

I have thoroughly enjoyed all my placements and I feel like I have learned so much about psychology (both in terms of theory and process) as well as about research methods and my own ways of working. If there were a psychological thread through this work I would argue that it is potentially to do with trauma,

stress and shame, and the implications of psychology for physical health. Consequently I have become very interested in approaches such as compassion-focused therapy, which offers ways of working with these issues. I feel I have therefore achieved my aims of gaining research and clinical experience with different populations and expanding my knowledge of NHS working practices and the various applications of psychology.

CHAPTER 1:
DEVELOPMENT OF A RESEARCH PROPOSAL TO ENABLE THE
CREATION OF QUESTIONNAIRE MEASURING HEALTH RELATED
QUALITY OF LIFE IN THOSE LIVING WITH VOCAL CORD DYSFUNCTION

Reflection:

The main aim of this placement was to learn about Vocal Cord Dysfunction (VCD) and questionnaire development in order to put together a research proposal for the development of a questionnaire measure which will capture information about Quality of Life (QoL) in those with VCD. The deliverable components of the placement contract were researching the existing literature around VCD and completion of an ethics application. A secondary, deliverable component was the co-facilitation of a focus group exploring the symptoms of VCD and analysis of data arising from the group.

As I had never previously heard of VCD, my first task was to familiarize myself with the current understanding of the condition. Nicola Pargeter, the speech and language therapist within the research team, was a source of enthusiasm and information, both clearly explaining the condition and providing some key references. This was a good opportunity for putting into practice the literature searching skills I had recently learned on the MRes course.

At this early stage in the placement I was invited to co-facilitate a focus group exploring individuals experiences of VCD symptoms. I enjoyed the session and learned a lot from it both in terms of the practicalities of running a focus group (such as the importance of assigning responsibilities to colleagues prior to the group in order that the session can run smoothly) to the value of service user involvement. Witnessing first hand the overwhelmingly positive response from individuals given the opportunity to share their experiences with each

other was galvanizing, whilst the wealth of information gained from participants helped to solidify my understanding of the condition and its very real impact.

Subsequent analysis of the focus group transcript and development of themes with the rest of the research team gave me an opportunity to use some of the qualitative analysis skills I learnt earlier in the year. Information from the focus groups also provided a good steer regarding what kinds of things the new questionnaire might contain, which in turn fed into the search for potential questionnaire measures against which to compare the VCD Questionnaire being developed.

Having gained an understanding of VCD I was able to turn my attention to the task of questionnaire development. I read method papers summarizing current questionnaire validation guidelines as well as papers that described the development of health-related quality of life measures for specific conditions. By combining these different perspectives on the topic I was able to begin to understand the practicalities of implementing this proposal alongside the criteria for good questionnaire validation. Furthermore, the usefulness of having detailed guidelines for developing good questionnaires, coupled with an absence of literature detailing how IPA is used for questionnaire development, has highlighted a potential gap for an IPA methods paper that could emerge out of this research.

Although laborious, the ethics application was essential for working out the finer details of our proposal. Each question prompted further questions ensuring that any process had to be thought through from various angles, down to the last small detail. Therefore, whilst learning about ethical considerations, such as informed consent and data storage, I also found this process very useful in prompting us to flesh out the structure of the overall proposal. Furthermore, completing the ethics application allowed me the opportunity to learn about and develop supporting materials such as participant information leaflets, which clearly and concisely describe the participant's role in the research.

In terms of refining the research proposal I feel that I was able to build upon my existing experience working as part of multi-disciplinary teams in both clinical and non-clinical settings. Regular team meetings and email communications to those with specific skills or knowledge were essential to moving the proposal forward. I also learned to use the track changes feature in Word in order to clearly communicate changes to the rest of the team and reciprocally to track other people's suggestions for improvements. Having had the opportunity to develop a group research proposal as part of the MRes also improved my confidence in my ability to gather and synthesize information effectively.

Looking back to the start of this placement I am surprised by how much I've learned. This is in no small part due to the research team, staff at the university of Birmingham and my supervisors Dr. Jodie Fellows and Dr. Ruth

Howard, who all patiently provided constructive and knowledgeable suggestions and support throughout. I am grateful to everyone who took the time to read a draft, offer feedback, to sit with me to explain something or simply to offer reassurance that I was on the right track. I look forward to taking the ethics application through committee and interviewing individuals with VCD as part of my project next year.

Introduction:

What is the principal research question/objective?

The development of a Vocal Cord Dysfunction Questionnaire that reliably and accurately captures information about symptom severity and quality of life (QoL) in individuals with the condition.

What is the scientific justification for the research?

Vocal Cord Dysfunction (VCD) is an unpredictable condition whereby the vocal cords go into spasm. This can affect an individual's ability to breathe, which causes distress both during, and in anticipation of, an attack (Mansur, 2013). The condition appears and resolves suddenly but in some cases may result in the individual passing out through lack of oxygen.

As the key symptoms revolve around breathing difficulties and can be accompanied by a wheeze, the condition is often misdiagnosed as asthma (Mansur, 2013). Abnormal vocal cord movement was observed as early as 1869, however it was over a century later before Christopher et al. (1983) published a thorough description of Vocal Cord Dysfunction presenting as asthma, which noted the characteristic "vocal cord adduction" (inward movement of the vocal cords) (Morris & Christopher, 2010). VCD is also found in those with asthma, therefore making it even more difficult to disentangle the two conditions.

The prevalence of VCD is unknown, although it appears to be more common in females (with a 2:1 or 3:1 predominance) and it has been inconsistently reported to be comorbid in individuals with a previous psychiatric diagnosis (Gimenez & Zafra, 2011). VCD appears to have many potential triggers (exercise, allergen, stress, Gastroesophageal Reflux Disease) and symptoms (difficulty breathing, voice change, cough,). Additionally, it has gone by a variety of names (including “paradoxical vocal cord motion”, “irritable laryngeal wheeze”, “Munchausen’s stridor”, to name but a few), which all hint at the variously hypothesized causes of the onset of the condition (Mansur, 2013). Gimenez and Zafra (2011) suggest that appropriate treatment is dependent on correct diagnosis, e.g. Psychological counseling for those with VCD of a psychological origin.

This study aims to take a phased approach, initially seeking to understand the experiences of adults, who have been diagnosed with VCD, through participant led interviews. By collaboratively exploring people’s experiences of the condition we will be able to draw out information on symptom severity and quality of life (QoL). QoL has been defined as the participant’s subjective assessment of his physical, mental and social wellbeing and functioning (Hauser et al., 2007). Information on individual experiences of VCD will be used to develop a theoretical framework of the condition and also as the basis for the questionnaire items.

This study is necessary because VCD is not a well-understood or well-researched condition (Rameau et al., 2012). Morris and Christopher (2010) argue that the causes, symptoms and management of the condition remain poorly understood and the literature is dominated by retrospective studies. Consequently, new tools, such as this questionnaire measure, would contribute to the ability of services to plan prospective studies by enabling them to capture essential information on QoL and severity of VCD-specific symptoms, both before and after treatment.

Furthermore, misdiagnosed individuals are likely to receive treatments that are excessive, inappropriate and ineffective, consequently resulting in more time spent in medical care (Ibrahim et al., 2007). There is some initial evidence that Speech and Language Therapy for VCD can significantly reduce symptoms (Pargeter & Mansur 2006; Sullivan et al., 2001) and hospital admissions (Pargeter, Manney & Mansur, 2013). Therefore, understanding more about both the condition and treatment outcomes has significant potential benefits for the individuals being treated, as well as in terms of cost savings to the NHS.

Summary of design and methodology:

Design

In phase one, qualitative methodologies will be used in order to gain rich information about individual experience of VCD. Information gathered in this first stage will be used to generate a questionnaire and a conceptual framework of the condition. Quantitative methodologies will then be used in phase two, to analyze completed questionnaire data and to further refine the questionnaire.

Participants

As we want to understand the experience of living with VCD we are seeking to recruit adults diagnosed with VCD according to the criteria set out in the European Respiratory Society Handbook: Respiratory medicine (Mansur, 2013).

Flow Volume Loops	A graph that shows amount of air breathed in/out over time. The shape of the graph enables us to see the restriction of air flow breathing in, which suggests VCD.
Nasendoscopy examination of the larynx/voice box	Fibre optic scope placed through the nose, allowing a view from above of the larynx/voice box. Allows the team to see partial or total closure of the vocal cords when breathing in with associated breathlessness/wheezy noise. Sometimes symptoms need to be provoked with a known trigger (e.g. inhalation of aerosol spray).

Clear Patient Description	<p>Sudden onset. Difficulty breathing focused at throat level (“like breathing through a straw”). Strangled sensation/throat tightening often with associated coughing/wheezy breathing. Change in voice also indicative of VCD.</p> <p>“Attacks” usually provoked in response to known triggers (e.g. strong smells, change in temperature).</p>
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Table 1.1. VCD Diagnostic Criteria (Mansur, 2013)

Procedure

In phase one, interviews exploring the experience of living with VCD, lasting approximately 1 hour, will take place between one participant and one researcher and will be guided by the principles of Interpretative Phenomenological Analysis (IPA). IPA has a broad agenda and seeks to explore individual experience, encouraging the interviewee to steer the agenda of the interview toward what is important to them (Smith, Flowers & Larkin, 2012). Therefore, by utilizing this method we hope to gain some really in-depth information about each individual’s experiences of VCD. We will generate initial questionnaire items from the information gathered during this process. Subsequently, a 5-point likert scale will be added alongside the items, so that participants can rate the importance of each item, and this will form the initial version of the Vocal Cord Dysfunction Questionnaire.

This will be followed by cognitive debriefing with approximately 10 individuals, which will consist of participant completion of the questionnaire followed by the interviewer asking the participant a series of questions relating to the

meaning and comprehension of each item (Teschendorf, 2011). This allows the participant to think aloud about how they reached their answer and highlights items that are potentially problematic, for re-wording.

At this stage we will also have a wealth of information regarding VCD, which will enable the research team to draw up a conceptual framework of the condition. This will provisionally, be guided by the World Health Organization's *International Classification of Functioning*, which is an internationally agreed framework for assessing the impact of a condition on an individual's life (World Health Organization, 2002).

Phases 2 and 3 will consist of the refinement of the questionnaire, its statistical validation and initial piloting. Articles by Sushil and Verma (2010) and Terwee et al. (2007), regarding how new questionnaire measures should be validated, have provided invaluable guidance for these phases.

We are targeting distribution of version 1 of the VCD questionnaire (VCD-Q) to approximately 600 adults who have been diagnosed with VCD, based on the number registered at Birmingham Heartlands and The Royal Preston Hospital Airways Clinic, Preston.

Participants will also be asked to complete the following:

1. Basic demographic information and screening questionnaire (2 sides)

2. A distress thermometer (Roth et al., 1998)
3. Selected dimensions of up to four existing validated questionnaires

The distress thermometer will be used to capture how distressed participants are feeling at present. Scores from the newly developed VCD questionnaire will be compared with scores from existing instruments measuring similar constructs as part of the validation. The standard of existing questionnaires will be assessed according to the COSMIN checklist, which is a guide for reviewing the quality of questionnaire measures (Terwee et al., 2012).

A second copy of the VCD-Q will be sent out to a random selection of respondents for completion 2 weeks after the initial questionnaire in order to assess test-retest reliability. Participants will also be asked to complete the distress thermometer. We would expect that where distress has not changed between questionnaire completions, the test-retest should show consistent scores. Testing these pre-agreed hypotheses will help determine whether the questionnaire is reliable.

Please describe the methods of analysis by which the data will be evaluated to meet the study objectives.

IPA interviews will be audio-recorded and later transcribed and analysed by the researcher according to IPA principles and guidance offered by Smith, Flowers and Larkin (2012); Some of the key aspects are as follows:

Bracketing and reflection: This is to do with the researcher coming to each case aware of their own preconceptions and continually acknowledging and reflecting on this during transcript analysis in order to understand what they are bringing to the interpretation and offer transparency with regards to the interpretative process.

Supervision: An important part of the analytic process is to produce an account that is feasible, given the evidence available and a key part of this is to check emerging interpretations with others to see if they make sense.

Grounding the analysis: An essential component of sense making requires the researcher to stay close to the text, and ground the analysis and interpretations in direct quotes, whilst looking for instances that confirm and contradict emerging interpretations.

This will be followed by cognitive debriefing interviews, where participants will complete the questionnaire and then explain to an interviewer what they understood about each of the questions and why they gave a particular answer. This is undertaken to ensure that understanding of items is the same for different participants and highlights instances where wording of items may need amending (Teschendorf, 2011).

In phases two and three the method of analysis will be quantitative.

Confirmatory Factor Analysis (CFA) will be used to ascertain whether the questionnaire structure fits together in the ways hypothesized via the

conceptual framework. With CFA we will explore whether the items that we predicted would group together do actually group together. CFA will be undertaken using an appropriate program such as AMOS for SPSS. The model fit will be evaluated using various statistical fit indices (Iyer & Loxton, 2008).

The Chi Square statistic is a measure of fit between the estimated and actual co-variance matrices and should be non-significant, to indicate that any difference between the models is due to sampling fluctuation (SAS Paper 200-31; Hinkin, 1998). As the Chi-Square statistic is a strict test and is influenced by sample size, other indices will also be used to assess model fit (Browne & Cudeck, 1993). If an unacceptable model fit is found, an Exploratory Factor Analysis will need to be performed using SPSS (SAS Paper 200-31).

Internal consistency of the questionnaire will be assessed by looking at the Cronbach's alpha scores, which will tell us how well the questionnaire items fit together. The Cronbach's alpha statistic will be generated using data entered into SPSS. The score should be at least 0.7, although too high (>0.9) may indicate that items are too highly correlated and items may be redundant, and therefore a decision will be made to remove one of the items from the questionnaire (Rattray & Jones, 2007; Terwee et al. 2007). This will therefore help us to validate the structure of the questionnaire, by letting us see that similar items are related but contribute unique information, and also to reduce the number of items.

In phase three, we will compare scores from this questionnaire with scores on similar dimensions of pre-existing measures. Precisely which dimensions of existing questionnaires will be used will be confirmed once the initial feedback from participant interviews has been analysed, because interview data will determine which existing measures are relevant. Scores will be compared using the Pearson's R correlation statistic, which will be calculated using SPSS.

Additionally, test-retest reliability will be assessed using test scores from the VCD questionnaire completed by the same individuals at a 2-week interval. The scores will be compared via SPSS, using the Intraclass Correlation Coefficient, as this is unbiased for any sample size (Hopkins, 2000). The ICC can range from 0 to 1 and a score of 0.70 or above is considered acceptable (Elkin, 2012).

Summary of the main Ethical Issues

PHASE 1

Summary

Initially, informed consent will be needed in order to recruit approximately 6-10 individuals with VCD, for in-depth interviews. The Interpretative Phenomenological Analysis method (IPA) will be utilised in order to understand their personal experience of living with VCD. Following these interviews, a list of questionnaire items will be drawn up, then completed and reviewed by a second group of individuals for comprehensibility. This will require the recruitment of 10 additional individuals with VCD who did not take part in the IPA phase, for Cognitive Debriefing.

Informed consent

It will be essential that individuals taking part in IPA and Cognitive Debrief interviews have the capacity to consent. The Mental Capacity Act (2005) provides guidance for assessing capacity in four stages:

- *Comprehension of information relevant to making a decision.

- *Retention of information for enough time to make a decision.

*Ability to utilize and weigh up the information in order to arrive at a decision.

*Ability to communicate their decision.

These stages have been considered during the design of the information for the recruitment of participants. Furthermore, the research team includes a clinical psychologist, Dr. Fellows, who has experience working with psychologically vulnerable adults and will be available for guidance and support with regards to these issues.

In order to effectively facilitate informed consent it will be essential to provide potential participants with a written information sheet, detailing in plain English:

1. The purpose of the research and researcher contact details.
2. Expectations regarding the role of the participant.
3. What will be done with the data.
4. Right to withdraw consent.

The participant information sheet will contain the contact details of one of the researchers, so that potential participants can call to ask questions about the research and what their involvement would entail. Once the participant has indicated an interest in being involved they will be contacted to arrange a convenient time to attend for interview. At the beginning of the interview

participants will be reminded of the details of the study and asked to sign a consent form.

Risks to Participants

The Interpretative Phenomenological Analysis (IPA) interview method is participant-led and endeavours to gain rich data regarding individual experience; consequently interviews may move into emotional territory (King & Horrocks, 2010). VCD symptoms, such as the feeling of not being able to breathe, can be traumatic and therefore participants may feel distressed when talking about the symptoms and also the impact that it has made on their life.

It is therefore essential that throughout the interview the consent process is an ongoing conversation between the participant and the interviewer, with the latter being aware and responsive to how the participant is feeling and responding to the situation appropriately and sensitively (Brinkmann & Kvale, 2008). It is recommended that emotional responses to interviews should be addressed and breaks should be offered so that the participant can reflect, regroup and decide whether to continue with the interview (King & Horrocks, 2010). The interviewer will be a psychology researcher at masters level or above and will be supervised by an experienced clinical psychologist; therefore they will be sensitive to the issues that may arise and competent to respond.

At the end of the interview the participant will be given the opportunity to debrief and contact details of the Samaritans. Participants will be reminded that they can withdraw consent to participate any time up to the point that data analysis begins. After transcription of data participants will be sent a copy of the transcript in order to agree it for accuracy.

Data Storage/Use

Audio recordings of interviews will be stored in a locked cabinet within the office of the Principal Researcher (Nicola Pargeter), at Heartlands Hospital until transcription (which will take place within 1 week following the interviews).

At transcription the interviews will be anonymised and given an identifier number. The key to the identifier numbers for each transcript will be kept in a locked cabinet on NHS property, separate from the other documents to which they relate. After transcription and anonymisation the audio files will be destroyed and transcripts will be stored for 10 years (in accordance with university policy) on the hard drive of a password-protected computer on NHS property, which can only be accessed by a member of the research team.

A single copy of the transcript will be sent via post to each individual for accuracy checking. Participants will have 2 weeks from the postal date to discuss any questions or concerns with the Research Assistant. A member of

the research team will analyse the transcript and anonymised summary data, in the form of questionnaire items, will be presented back to participants for the opportunity to feedback.

Cognitive debriefing interviews will be audio recorded and notes will be made. The audio recordings will be reviewed by a member of the research team in order to assess whether any further changes need to be made to the wording of the questionnaire items. Audio files will be stored in a locked cabinet within the office of the Principal Researcher (Nicola Pargeter), at Heartlands Hospital for 10 years (in accordance with university policy).

PHASES 2 & 3

Summary

These two phases will entail recruitment of participants, diagnosed with VCD, to complete the VCD-Q developed in phase one and the subsequent analysis of this data.

Informed Consent

A questionnaire pack will be posted to the home address of all individuals registered with Birmingham and Preston NHS, diagnosed with VCD. The questionnaire pack will include:

1. A participant information sheet (PIS).
2. Researcher contact details.
3. A consent form.
4. The newly developed VCD questionnaire.
5. Up to four comparative questionnaires.
6. A two-page screening/demographic document.
7. The Distress Thermometer.
8. A prepaid envelope in which to return the questionnaires.

The consent form will need to be signed and returned along with the completed questionnaires in a pre-paid return envelope. Participants will be able to withdraw at any point up to data analysis.

Additionally, a second mailing will be sent to a random sample of half the respondents, to be completed at 2 weeks after the initial questionnaire (Sushil & Verma, 2010). This will be used for the purposes of assessing the questionnaire's reliability over time and will include the following:

1. A participant information sheet.
2. A copy of the VCD-Q.
3. The Distress Thermometer.
4. A prepaid envelope in which to return the questionnaires.

For individuals who have not responded after 30 days following the initial post date, one further attempt to contact them will be made via phone by an administrator, and if this is not successful one further questionnaire pack will be sent to them. If they do not respond within one month following this, it will be assumed that they do not wish to take part in the study and they will not be contacted again.

Data Storage/Usage

Nicola Pargeter will be responsible for storing received forms in a locked cabinet within NHS property. Documents will be identifiable by a unique reference number and the key to this information will be kept separately from the data itself in locked cabinet on NHS property. Once data have been entered into the SPSS database for analysis, they will be anonymous and the SPSS files will be stored on a password-protected drive on an NHS computer on NHS property for 10 years (in accordance with university policy).

CHAPTER 2:
AN EXPLORATION OF THE PROCESS OF RECRUITMENT FOR
RESEARCH ON PSYCHOSIS: THE CHALLENGES OF RECRUITING
WITHIN AN ACTIVELY RESEARCHED POPULATION



An Exploration of The Process of Recruitment...

The challenges of recruiting within
an actively researched population.

by Catherine Maskell

This presentation explored my experience of recruiting participants for a piece of research on psychosis with reflection on the challenges of recruiting within an actively researched population.

Aims of Presentation...

An exploration of the process of recruitment for a study seeking to understand the impact of past experiences of shame and trauma on individuals with psychosis.

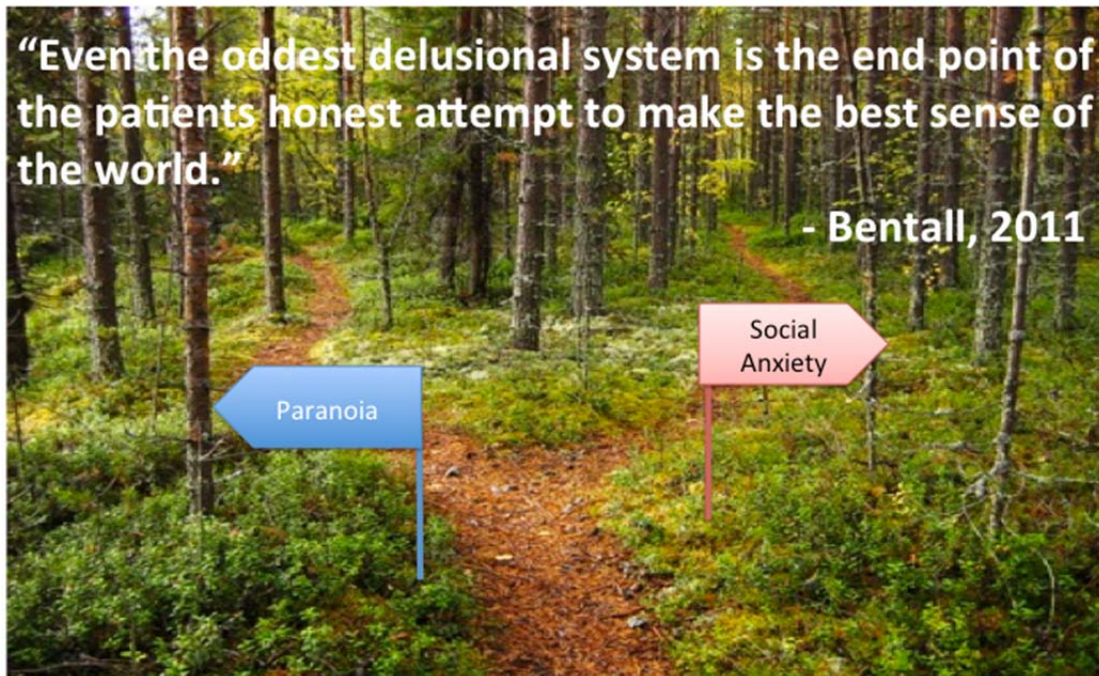
- Introduction to the research topic.
- Method: Approaching the task of recruitment.
- Challenges and questions.
- Reflections.

This presentation explored recruitment of individuals with psychosis for a piece of research seeking to understand the impact of shame and trauma experiences.

I will give an introduction to the area and then examine how the task of recruitment was approached. I will then briefly touch upon some of the challenges and questions that arose from this process of recruitment and finally I will reflect on what I have learned.

Introduction

Psychosis - a meaningful reaction to life events.



In his book 'The Divided Self', R.D.Laing proposed that 'schizophrenia' should be reconceptualised as something that could be understood within its unique 'existential context' (Laing, 2010).

More recently Richard Bentall has stressed the need to explore the individual experiences behind 'schizophrenia', stating, "Even the oddest delusional system is the end point of the patient's honest attempt to make the best sense of the world." (Bentall, 2011)

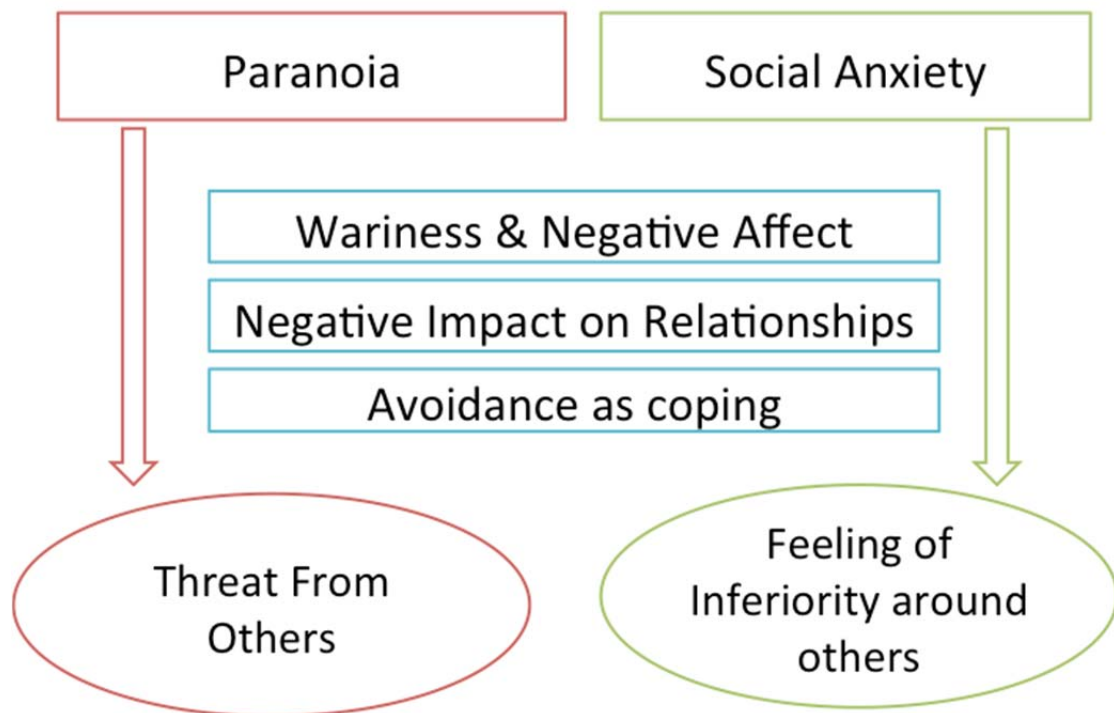
So there is a renewed focus on pathways to psychosis and there is evidence that:

1. Traumatic events feature strongly in the histories of those who have developed psychosis (Read & Gumley, 2008).
2. Shame experiences can have the characteristics of a traumatic event and that these experiences may be linked to paranoia and social anxiety (Matos et al., 2012).
3. Paranoia and social anxiety are common presentations within psychosis.

Therefore, this piece of research was seeking to explore the evidence for shame and trauma in the histories of individuals with paranoia and social anxiety.

We will briefly explore these concepts in further detail.

Introduction



Paranoia and social anxiety are common presentations for young people with psychosis.

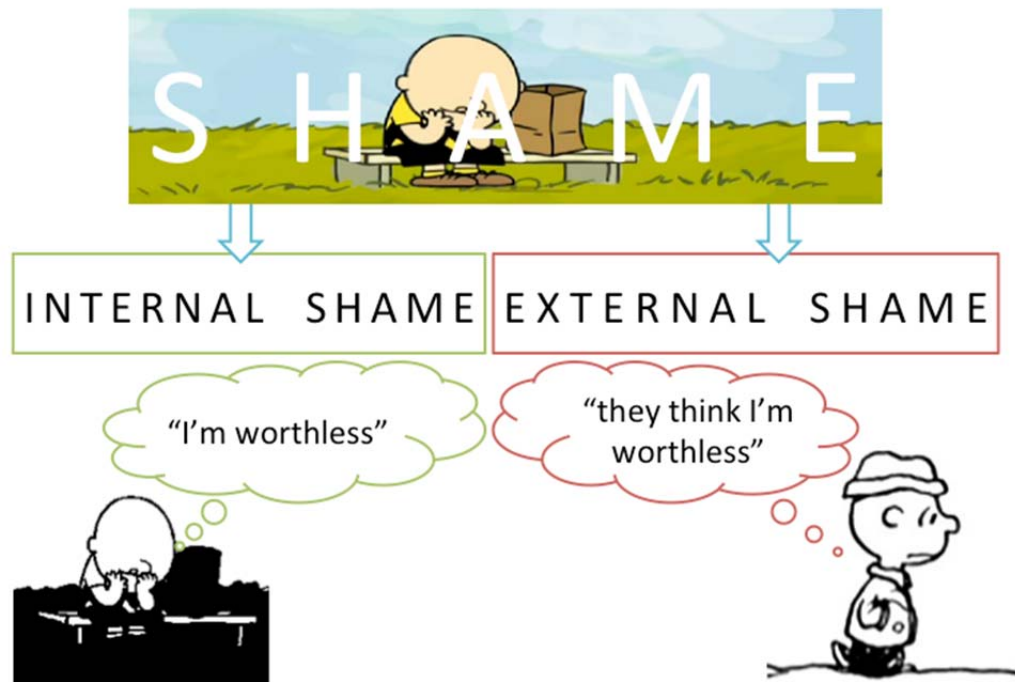
Paranoia is estimated to feature in about 50% of cases (Sartorius et al., 1986) and social anxiety in around 23%-36% (Michail & Birchwood, 2009).

Superficially they may appear similar as both are concerned with wariness of others, utilise avoidance as coping and have a detrimental impact on relationships.

However, paranoia is focused towards a threat from others whilst social anxiety is focused on feeling inferior around others.

Having clarified this distinction we can now explore the concept of 'Shame'.

Introduction



Gilbert (2003) proposes that shame is part of a social threat detection system warning us we exist negatively in the minds of others and that we are at risk of social exclusion or harm (Turner et al., 2012).

Research into shame found it could be both internally and externally focused (Matos & Pinto-Gouveia, 2009). Internal shame is to do with negative thoughts individuals might have about themselves; whereas external shame is about other people thinking negative thoughts about you.

A 2012 study by Matos et al., with a non-clinical population found a link between:

1. Higher social anxiety and higher internal shame.
2. Higher paranoia and higher external shame.

Shame experiences can have the characteristics of a traumatic event (Matos et al., 2012).

Introduction

HYPOTHESIS 1:



HYPOTHESIS 2:



Hypotheses:

1. Individuals diagnosed with psychosis with higher paranoia will have higher external shame and more traumatic backgrounds.
2. Individuals diagnosed with psychosis with higher social anxiety will have higher internal shame and comparatively less traumatic backgrounds.

My role within the research team was to organise recruitment, visit participants and facilitate the completion of questionnaires.

Recruitment Target: 50 individuals from the Birmingham and Solihull Early Intervention (EI) service.

Method

Getting Started...

- Familiarisation with research area.
- Supervision.
- Learning about the EI service/NHS.
- RIO training.
- Getting organised...

Questionnaire packs

Database creation



My initial task was familiarization with the research area. Reading around the topics enabled me to understand where the research fitted into current thinking about psychosis and helped my confidence about explaining it.

I had regular pre-placement meetings with my supervisors, which enabled me to find out more information about EI. I found the idea of recruitment quite daunting as it required visiting individuals in their homes but there was another student who was able to undertake these visits with me. Discussing these concerns was absolutely essential to feeling confident about the placement.

Prior to recruitment I was trained in RIO (the system for documenting client information), which was crucial for efficient recruitment because it enabled me to check patient notes, retrieve contact information and minimize burden on colleagues, which kept the recruitment process moving.

As myself and Keith Aherne (the lead researcher) were both recruiting it was essential to be organised regarding which clients had already been approached. Therefore, we set up a spreadsheet on a secure drive that we could both access. This enabled us to minimise the burden on others because we weren't both approaching the same people and we could tell at a glance where we were with recruitment.

Method

MDT Working...

- Presentation & recruitment from teams – a staged process.



- Making sure it is easy for care teams to be involved.
- Collaborative approach & sensitivity to workloads/ appointments.

We began recruitment by presenting the research proposal and participant inclusion criteria to the care teams.

We did a first round of recruitment from each of the 5 EI teams and then a second round to see if any other clients had, in the interim, become potential participants.

Advantages of approach:

1. Focusing on one team at a time we presented, then immediately recruited whilst everything was still fresh in the minds of our colleagues.

2. Some clients who may not have been suitable at one point in time at a later date were (because of improvements in their condition).

Disadvantages of approach:

1. Dips in recruitment momentum resulting from a high demand for participants in other studies.
2. A limited list of potential clients amplified negative feelings about failures to recruit. Whereas, with a longer list of clients, it was easier to move on following declines to participate.

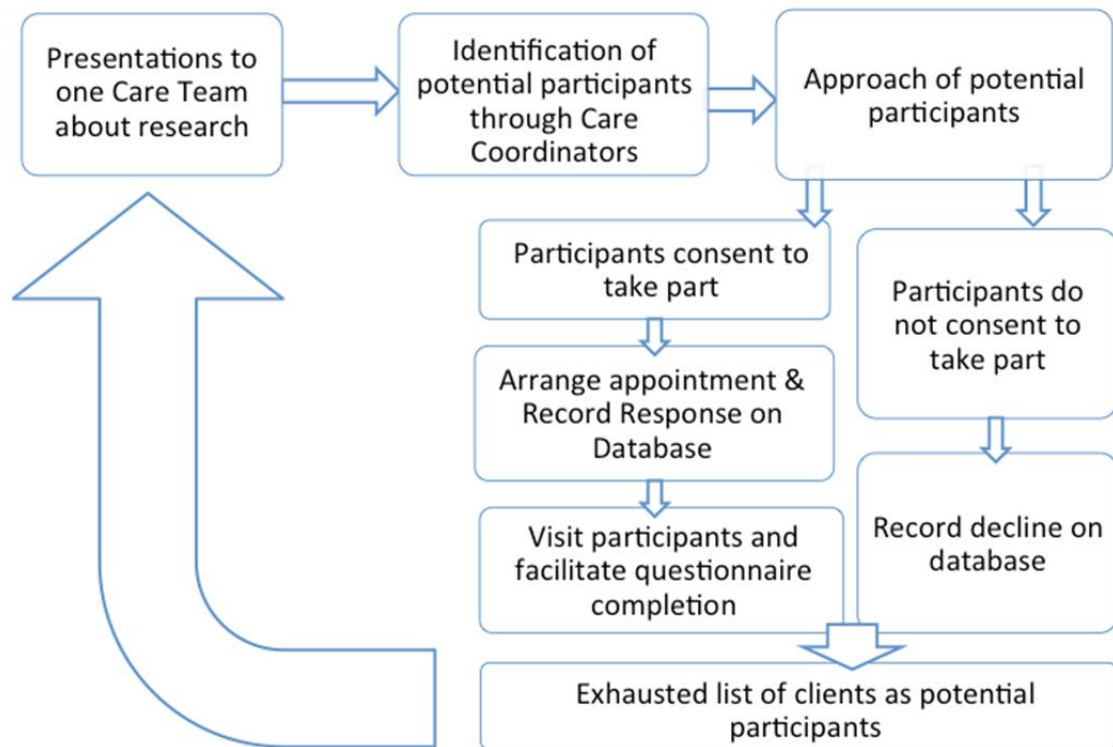
Having witnessed how busy colleagues were with their own clients and with other researchers approaching the same individuals, it was vital to make involvement as simple as possible.

Another researcher mentioned a list of clients and care coordinators, which I was able to utilise, thus improving efficiency and minimising the burden on colleagues.

The other aspect of recruiting within a busy MDT that worked well was consulting with the care teams on recruitment process. This included pre-agreeing the best time of day to approach care coordinators as well as being sensitive and flexible about existing workloads.

Method

Target Recruitment: N.50



A flow-chart showing the recruitment process.

Method

Recruitment: Initial contact



Where care coordinators were happy for their clients to be approached, it was necessary to work on strategies for engaging clients in a short space of time.

This took some refinement.

One of the first tasks in this phase was thinking about how to explain the research in plain language. In this I sought advice from my supervisors and went from talking about 'shame' and 'trauma', which were potentially quite difficult and emotive terms, to talking about past experiences.

Initially, I wrote quite an extensive telephone script encompassing much of the participant information sheet, however clients were declining to participate. I sought advice from one of the researchers and simplified the script. My aim

was to arrange to visit the individual so that I could tell them about the research in person, which was a much more successful approach.

As is fairly common within EI there were times when an appointment was booked but the client was not there on visiting. Therefore, I would often phone ahead to re-confirm appointments.

Method

Recruitment: Home visits & Questionnaire completion



Visit Preparation:

Preparation for each visit was essential. It was important to be able to explain the research and putting the participant information into my own words helped with this.

Ensuring questionnaire packs were ready ahead of a full day of appointments, I could be confident that everything I needed was ready for use.

Sensitivity to individual situation & needs:

It was also important to understand a bit about who I was going to see: What is their current presentation? What is their history? Are there risks or sensitive topics to bear in mind?

Getting any information prior to a client visit was useful for feeling prepared and to help to build a rapport.

Engaging Individuals:

Face to face explanations of the research were useful for checking in with the client.

I also attended some visits with the lead researcher and learned from watching how he would give people time to take the information in and space to ask questions. I therefore focused on developing two aspects:

1. Finding a good reason for the individual to do the research: I began to stress how much hearing from everyone's unique experiences would ultimately help us to provide better services. At times this could be quite a powerful motivator.

2. Checking in throughout the explanation: By asking, “how does that sound?” I was able to see if there were any questions as well as getting a view on how they were feeling about participating.

Flexibility:

Questionnaires could take between 30 minutes up to over an hour to complete so I tried to be mindful of fatigue or distress. Flexibility for rearranging appointments was essential.

Feedback to Care Teams:

Finally, it was crucial to feedback any concerns to care coordinators as well as typing up a record of the visit on RIO.

Challenges & Questions



Comprehension – a shared understanding?



Cultural Variation (Gender?)



Diagnosis



An over researched area



Self-Selection Bias

Comprehension:

Some of the questions were difficult to follow (e.g. “I try hard not to do things that will make other people avoid or reject me” in the ‘UCLA Loneliness Scale’). Additionally, I wondered was I explaining the questions in the way that the authors had intended and what impact might this have on the results? Furthermore, when participant answers seemed inconsistent, it was difficult to explore this as I did not want to undermine participation.

Cultural Variation & Gender:

Some of the questions seemed particularly British, e.g. “Would you walk out of a shop knowing you had been short changed?” Should the answer from a male refugee from Eritrea be judged against the same criteria as a middle class British female? Additionally, should male and female participants be judged by the same standards when exploring a concept such as submissiveness?

Diagnoses:

Are we overly optimistic to expect homogeneity within this diagnostic group and do we need to explore more specific clusters in order to find meaningful patterns? Again, there is a question of something as simple as gender here, as John Read has noted that males and females might be differentially impacted by developmental factors, implicated in the emergence of psychosis (Read & Gumley, 2008).

An over-researched area:

Members of the EI team expressed research fatigue for themselves and their clients but EI is a burgeoning area that needs research. The question here is how to achieve balance. It was mentioned that previously there was a

'research administrator' who sequentially scheduled research projects with the teams, which seemed like a sensible way to manage research burden.

Self-selection bias:

There was certainly a self-selection bias with individuals declining to take part because they did not want to talk or think about their past. This raises the question of how will this affect results. What are we missing in the people with experiences they don't want to talk about?

Reflections

- Real world research is messy!
- Ethics in practice
- Questionnaire development
- Recruitment:

Optimism Vs. Fatigue

Importance of support & curiosity



THANK YOU QUESTIONS?

Real world research is messy, but the experiences on this placement have left me with more questions to ask of papers, which will undoubtedly influence my critical thinking.

My first placement was an ethics application and undertaking recruitment has given me a good insight into ethics in practice and how informed consent is an ongoing conversation between the researcher and the participant (Brinkmann & Kvale, 2008).

Using the questionnaires on a regular basis has also made me sensitive to issues in questionnaire generation, such as difficult wording. This perspective

will influence the way I approach my final project, which is to do with the creation of a new questionnaire measure.

My placement goal was to recruit individuals to the study and although I achieved this (just a few short of my target number of 25 participants) at times, particularly when I got a number of declines in quick succession, it could feel like quite a lonely and thankless task.

Support from my supervisors and advice and help from the assistant psychologist in the team where I was based were invaluable in helping me stay motivated. I have learned much about the process of recruitment, which seemed quite daunting at the start of the task.

CHAPTER 3:
EXPLORING THE LIVED EXPERIENCE OF INDIVIDUALS WITH VOCAL
CORD DYSFUNCTION VIA INTERPRETATIVE PHENOMENOLOGICAL
ANALYSIS

Abstract:**Background:**

Vocal cord dysfunction (VCD) is a medical condition which impacts on breathing ability and can be misdiagnosed as asthma and therefore treated inappropriately (Mansur, 2013). There is some evidence that psychological factors can contribute to the onset and maintenance of the condition (Morris et al., 2013). Little has been written about the patient experience of VCD and therefore this study was seeking to understand what it is like to live with the condition.

Aim:

To explore how individuals live with VCD and the impact it has on their lives.

Methods:

Six adults diagnosed with VCD were interviewed and transcripts were analysed via Interpretive Phenomenological Analysis (Willig, 2009).

Analysis:

Seven themes are reported to illustrate the experience of living with VCD.

Conclusions:

Analysis illuminated three broad areas: 1. Living with VCD requires ongoing reassertion that it exists, which can be difficult. 2. VCD can be a chaotic and

traumatic condition to experience. 3. The mind has a key role to play in management.

Introduction:

Vocal Cord Dysfunction (VCD) is a medical condition where the vocal cords adduct (move inwards to close), thereby affecting the ability of a person to speak and breathe (Mansur, 2013). As it is often accompanied by a wheeze and can be co-morbid with asthma, it is a condition that suffers from misdiagnosis and therefore inappropriate, ineffective and sometimes excessive treatment (Mansur, 2013; Ibrahim et al., 2007).

It is not a well-understood condition and symptoms can appear and resolve sporadically, further making diagnosis difficult (Morris & Christopher, 2010). Patients are diagnosed via laryngoscopy, which allows observation of vocal cord movement when symptomatic (Mansur, 2013). Existing data suggests that average age of onset is 14.5 years in children and 33 years in adults (Mansur, 2013).

Symptoms of VCD include intense coughing, wheeze on inhalation and feeling like intake of breath is significantly restricted as though breathing through a straw (Mansur, 2013). VCD episodes can be triggered by a variety of antecedents including: inhaled irritants, exercise and gastro-esophageal reflux disease (GERD) (Richards-Mauze & Banez, 2014).

Psychological factors and emotional stressors have also been hypothesised as contributing to the onset and maintenance of VCD (Morris et al., 2013).

Mansur states that “The larynx is innervated by a complex neurological

network”, and that there is evidence for an association between stress, psychological diagnoses and VCD attacks (Mansur, 2013, p.1). Furthermore, the condition has been reported to a limited extent in individuals suffering from combat stress and survivors of Childhood Sexual Abuse (CSA) (Craig et al., 1992; Guglani et al., 2014; Morris et al., 2006; Morris et al., 2013; Freedman et al., 1991) and it has been estimated that as many as 70% of cases of VCD are psychological in origin (Forrest et al., 2012).

A multidisciplinary approach is therefore taken to VCD management, with treatment depending on particular case history and suspected causative factors (Guglani et al., 2014; Mansur, 2013). Throat exercises, taught by a Speech and Language Therapist (SALT), can be used when the patient experiences VCD symptoms. Good preliminary evidence exists demonstrating symptom reduction and decreased admissions to hospital from use of these exercises (Pargeter & Mansur 2006; Sullivan et al., 2001; Pargeter, Manney & Mansur, 2013). Additionally, the patient may also be prescribed Heliox (a mixture of Helium and Oxygen used to improve airflow through the larynx) or offered psychological therapies (Mansur, 2013).

Psychological interventions for VCD can address potential precipitating issues, such as anxiety and stress (Morris et al., 2013). However, the experience of a VCD attack itself (described as feeling like “choking” or “strangulation”) can also be very distressing and therefore, psychological interventions can be used to help the patient to develop relaxation and coping strategies to manage attendant stress and anxiety (Mansur, 2013).

In a systematic review of psychological interventions for VCD, Guglani et al. (2014) found some evidence for the efficacy of psychological interventions for the treatment of VCD. The interventions utilised included biofeedback (providing information about what is happening to the vocal cords in order to improve control), hypnosis, psychotherapy, Cognitive Behavioural Therapy (CBT), personal construct therapy, behavioural therapy and patient education (Guglani et al., 2014).

The difficulty with drawing conclusions from these existing studies is that many were small case series, making it problematic to generalise, and almost all involved a combination of interventions meaning that isolating the mechanism behind improvements is difficult. Furthermore, different outcome measures were used to document improvement and therefore there is inconsistency in assessment criteria (Guglani et al., 2014).

The current piece of research is the first stage in a project designed to create a condition-specific measurement tool that can capture and document changes in health-related quality of life (HRQoL) for individuals living with VCD. This is needed because VCD is a relatively unknown condition and there is very limited information available on the patient experience of it. This particular piece of research is designed to understand what it is like for individuals to live with their VCD.

Interpretative Phenomenological Analysis (IPA: Willig, 2009; Smith, Flowers & Larkin, 2009) was chosen as the most appropriate method to explore the lived experience of VCD. IPA is a qualitative methodology that aims to gain an in-depth understanding of another person's 'life world' via close examination of what is said (Smith, Flowers & Larkin, 2009). It is utilised in many areas of psychological and health research, including studies on living with chronic long-term health conditions (e.g. Dickson et al., 2007).

An important element of IPA is that it takes an idiographic approach and is therefore concerned with the detail of the particular (as opposed to the statistical reduction of groups of people favoured by quantitative methodologies). IPA also recognises the inherently interpretative nature of any act of analysis and encourages reflection on the potential impact of researcher bias (Smith, Flowers & Larkin, 2009). To enable a detailed understanding of the particular, IPA utilises an iterative process for data analysis known as the hermeneutic circle, which examines parts of an account in order to understand the whole, and then in light of this new understanding of the whole, re-examines the parts (Smith, Flowers & Larkin, 2009). By utilising this method it will be possible to gain a more in-depth understanding of what it is like for those living with VCD.

Method:

Ethical Approval:

Prior to participant recruitment, ethical approval was obtained from the NRES Committee West Midlands: The Black Country (Appendix 3A) and from the University of Birmingham (Appendix 3B). Additionally, a research passport was secured with the Research and Development Directorate at Heart of England Foundation Trust (Appendix 3C), who were hosting the research project.

In the process of designing the research project three potential ethical issues were identified and addressed:

1. Ensuring that informed written consent is obtained from participants who have capacity to consent.
2. Confidentiality regarding data collection, storage and analysis.
3. Distress from talking about VCD symptoms and their impact.

In order to ensure that consent to participate was fully informed, participants had the opportunity to speak to the researcher over the phone and ask any questions, prior to agreeing to participate. Furthermore, a clear, concise and detailed information sheet was sent to participants with the invitation to participate, and this was also reviewed with participants prior to interviews

(Appendix 3D). Participants were fully debriefed following the interview and they were also reminded of their right to withdraw.

All data were collected by the researcher and stored securely in keeping with the protocol detailed in the ethical application. Transcripts were anonymised and identifying information within the transcripts was removed.

As recommended by Brinkmann and Kvale (2008) the process of consent was thought of as an ongoing conversation between the researcher and the participant. Researcher awareness of how participants were feeling throughout the process and sensitive responses to distressing aspects of their experiences was important.

Sampling:

Six individuals diagnosed with VCD were recruited using purposive methods, via the Severe and Brittle Asthma Unit at Birmingham Heartlands Hospital. For the first round of recruitment the SALT identified 10 potential participants. A letter and a participant information sheet (Appendices 3D & 3E) were sent to each of these individuals via the team secretary, so that the researcher was unaware of the identification of potential participants.

Potential participants were asked to contact the researcher if they were interested in participating and were offered £10 reimbursement for travel expenses. Five participants responded and were contacted by the researcher

to discuss participation and arrange an appointment for interview. In order to develop a meaningful analysis, without being overwhelmed by the data (Smith, Flowers & Larkin, 2009) the target sample size was six participants, therefore a further two research invitations were sent out and both participants responded favourably. The researcher contacted both individuals; however, due to time constraints only one was interviewed.

Participant Descriptions ¹:

Name	Comorbid Health conditions	Age Group	Time lived with VCD post-diagnosis	Time lived with VCD pre-diagnosis	Comments
Sadie	Several, including severe asthma	45-64	Over five years	Over 20 years	Her VCD is exacerbated by certain smells (e.g. bleach) and laughter and she prefers to use Heliox to manage the condition.
Isobel	Several, including severe asthma & acid reflux	45-64	Over five years	Over five years	Her VCD is exacerbated by smells and she has also linked it to a series of abusive relationships. She has been hospitalised over 60 times for VCD symptoms and manages the condition using a combination of breathing exercises and Heliox.
Alice	None declared	65+	Over one year	Approx. one year	She reported that her VCD could be pinpointed to a tablet that she took following a knee operation. She does not know what exacerbates her VCD and she uses breathing exercises to manage the

¹ Participants have been given pseudonyms in order to maintain patient confidentiality.

					condition; following diagnosis she had a tracheotomy but this has since been reversed.
Jonah	Several, including severe asthma & paraplegia	45-64	Over two years	Most of his life	His VCD is exacerbated by colds and particular foods, and smells (e.g. perfumes). He uses breathing exercises to manage the condition, and has had hospital admissions previously for VCD symptoms.
Ben	Mild asthma	45-64	Over two years	Three months	He feels that his VCD is exacerbated by foods and experiences symptoms of varying severity at most mealtimes. He uses breathing exercises to manage the condition.
Lauren	Several, including severe asthma, allergies & GERD	45-64	Over five years	Over ten years	She reported that her VCD can be exacerbated by anything, including the damp. She uses breathing exercises to manage the condition.

Table 3.1. A summary of participant information

Procedure (including interview schedule):

An interview schedule (Appendix 3F) was designed to enable the exploration of the lived experience of VCD with each of the participants, focusing broadly on the following areas:

- Symptoms
- Diagnosis
- Impact
- Management

In keeping with IPA guidance, this was flexibly applied, allowing participants the opportunity to talk about what was meaningful to them and to steer the interview (Smith, Flowers & Larkin, 2009). Following the first interview the schedule was revised to include more prompts and different ways of approaching the topics in order to encourage reflective responses (Appendix 3G).

Prior to interview, participants were asked to complete a 9-item screening questionnaire and basic demographic information (Appendix 3H). The screening questionnaire was designed by the research team (including the principal SALT) and based on recognition of features that are distinctive to VCD e.g. response to asthma inhalers with VCD is poor and so we asked participants whether response to asthma inhalers for VCD was

poor/inconsistent or good (Mansur, 2013). This was to ensure that participants could distinguish their VCD symptoms from other co-morbid conditions (such as asthma). All participants scored above the cut-off predetermined with the research team and were therefore able to participate in the interviews.

Interviews lasted between 50 and 90 minutes and were audio recorded and then transcribed verbatim by the researcher. All identifying information was removed for analysis. Transcripts were posted to participants so they could check for accuracy however no feedback was received.

Analysis:

Data analysis followed the recommendations of Smith, Flowers and Larkin (2009). In total six analysis readings (summarised in Fig 3.1) were completed for each transcript and each transcript was analysed in its entirety before beginning the next, with a view to allowing each participant their own unique story.

The first stage of the analysis consisted of initial noting of anything of interest within the transcript. Descriptive noting followed this, which consisted of describing each part of the transcript. Narrative points were noted during the third reading, seeking to understand what stories were being told. This was followed by a fourth reading, with a view to understanding what was important in the participants' life world. The fifth reading was focused on noticing how language was used. Finally, myself and two other members of the research

team met to discuss impressions from the analysis and audit emerging themes to ensure conclusions were plausible given the data.

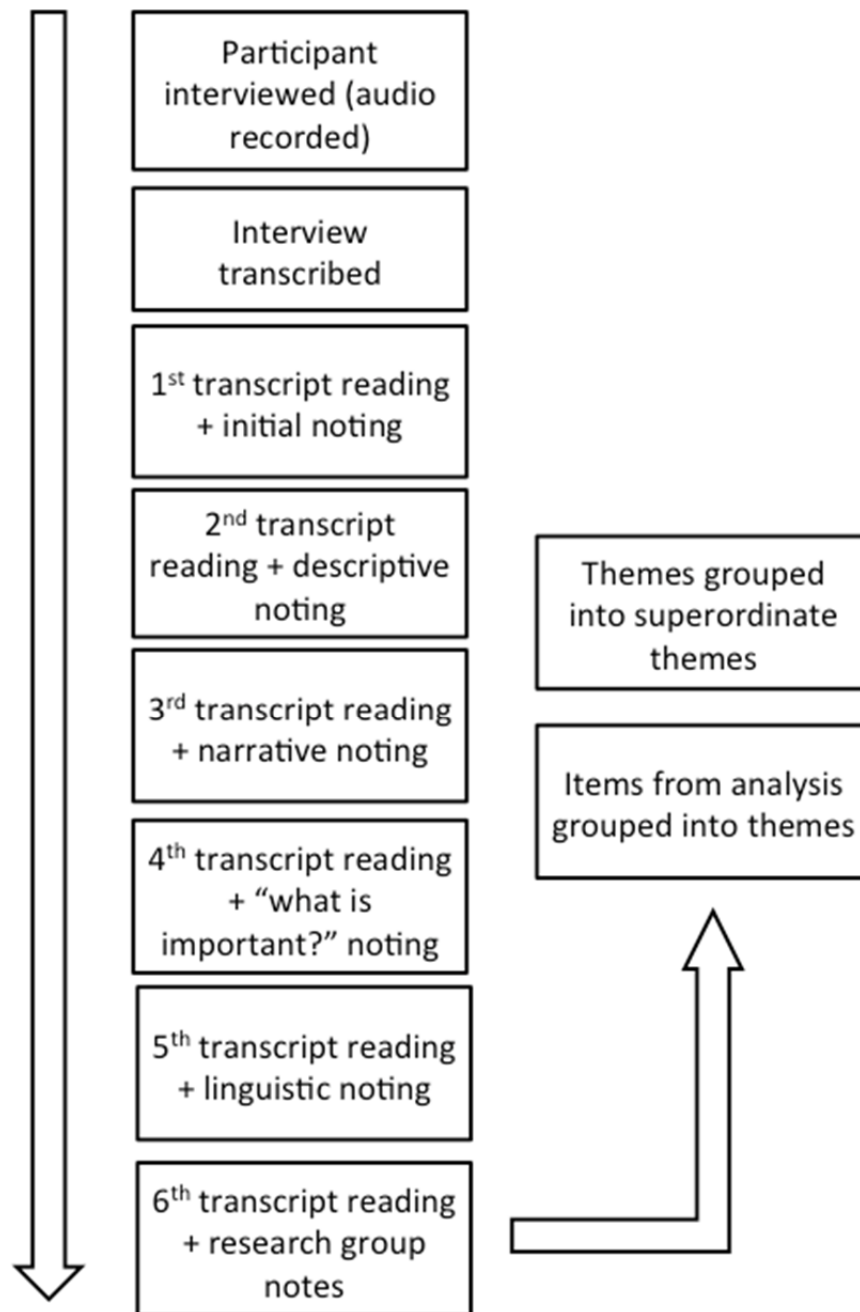


Figure 3.1: Flowchart of Stage One analysis (undertaken for each participant)

Following this analysis all items identified during the previous six stages were written onto post-it notes, then grouped into themes. These were then typed up into tables, which summarised groups of themes, items and supportive quotes for each item (Appendix 3K). At the end of this part of the analysis, grouping similar themes together created provisional superordinate themes.

This process was repeated for all six participants and following this, 36 superordinate themes, using data from all participants, were analysed and grouped, to find commonality and divergence across the cases. This final task was initially undertaken by the researcher and academic supervisor and once finalised was presented to the two research team members for comment and audit.

The latter part of the process was challenging and required revising, regrouping and returning back to individual cases to see whether there were themes that might further help illustrate a cross-case superordinate theme that was being developed.

Researcher Reflections:

Throughout my research on VCD I have been very curious about the question of causation. In part I think this was a reflection of the concerns of those I had met who were living with the condition and in part I felt anxious that I too could develop VCD.

If there was no reason to it, then it could happen indiscriminately to anyone, but also if there was seemingly no external cause, then did that not potentially suggest that something psychological could be involved? I would say that these two strands have influenced my interactions with the topic and subsequent analysis.

I have been both physically and psychologically haunted by VCD during this process, feeling sensations such as the tightening in my own throat as I analysed the experiences of others and becoming intently focused on that. I think that this has undoubtedly deepened my appreciation of my participants' experiences and influenced my analysis.

Furthermore, I was working with a researcher who knew the participants so transcript discussions were influenced by this knowledge. This sometimes introduced an external interpretation, but overall I felt that these discussions enhanced my exploration of the participants' life world, although it was necessary to take care to ensure that all interpretation was grounded in the data.

Results:

Due to space for reporting themes it has been necessary to focus on a limited number of themes, which each illuminate something about the five cross-case superordinate themes. The seven themes reported here were selected for revealing VCD-specific concerns in order to give a view of what could be considered unique to the VCD experience, as opposed to reporting more generic themes such as *Identity Changes*, found across health research. The complete table detailing all themes and superordinate themes can be seen in appendices 3I and 3J.

Superordinate Theme	Theme
Diagnosis	<i>The Struggle</i>
Living With Uncertainty	<i>Chaos Vs. Control</i>
The Invisible Illness	<i>The Invisible Illness</i>
The Trauma Of VCD	<i>Violence Against Self</i>
The Trauma Of VCD	<i>On The Mind</i>
Helpful Relationships	<i>Power Of Professional Reassurance</i>
Management: The Balancing Act	<i>Breaking The Panic Cycle</i>

Table 3.2. A summary of selected themes for discussion & the superordinate themes to which they relate.

Diagnosis

The struggle:

Five of the six participants had been living with their VCD for months or years before they were diagnosed and five out of six had experienced taking their complaint to the doctors and being told either that there was nothing wrong or that the staff member did not know what was wrong.

Lauren: ...'cause every six months I go to the ward... every time I was going, "but I'm still wheezing!" You know, and I don't know what it is, why do I keep wheezing? "Well your chest sounds clear", on the odd occasion, tell em, "yeah you've got a bit of a rattle". But, you know, I kept saying "but I'm wheezing all the time"... probably before I was actually diagnosed was probably about, well saying that, yeah was probably about three years. (742-57)

As is illustrated by Lauren's quote, in many cases the participants felt that the doctors were checking for the wrong things (such as asthma) but also not hearing the patients, which Jonah describes as "like talking to a brick wall". Although two of the participants did have their throats examined, they were told that there was "nothing wrong". The following extract highlights how brief and dismissive these interactions could feel.

Sadie: I was having the choking fits. I was referred to ENT... And er, he had a feel of me throat and he asked me a few questions and he had a look down me throat. And he stuck a little camera down, up my nose and he says there was nothing wrong with me. (444-9)

These experiences of VCD symptoms being unheard, dismissed or not understood by the medical professionals treating them, were both disconcerting and frustrating. For Ben, the continued absence of a diagnosis causes turmoil, so that alongside the chaotic symptoms of the VCD, he also has to contend with the revelation that his route to help is unclear and uncertain.

Ben: I was frightened. I couldn't understand why nobody would help me. You know you go to the doctors to help you, and I, and I, like I don't make a fuss, so when I am not well, I think well, you should fix me because I don't turn up here very often <laughs> ... See, I was frightened I was frustrated, uhm, worried, desperately tired, can't tell you how tired I was, uhm... even the animals were upset. (957-64)

During the period prior to diagnosis, patients often felt like they were passive recipients of information and ineffectual treatment, with their passivity conveying a real sense of helplessness. Isobel felt like she had been "written off" by everyone.

Isobel: Y'know, you've all written me off, you've all put me on these, all these tablets, and, you've made me feel as if I'm an absolute fruit cake [I.Yep] and I'm not. (164-166)

The invisible illness

The invisible illness

This theme is about living with an unknown condition that has limited outwardly visible indicators of its existence, therefore it is invisible both through being an unknown condition and also because it is unseen. There is some overlap here with the previous theme, as the issue of medical professionals not knowing about it is again a significant concern. For Isobel she feels this invisibility leaves her open to possible judgment from others.

Isobel: If I'd 've had a rash, you'd 've seen it... but people perceive disabled people. They see them parking in a disabled spot and think "Well you don't look disabled"... because you haven't got a false leg or... but you don't know what's going on inside (410-413)

Jonah has been treated by military doctors, who he believes have an understanding of VCD and can spot it, whereas it seems invisible to all other medical professionals and this puts him in danger of being incorrectly treated.

Jonah: I want the military people there, because they can like see it str- just by looking at you ... You know, that you've got

VCD to them, but anybody else sees it as either asthma or like your respiratory. (243-8)

Individuals with VCD are not continually or consistently symptomatic adding another dimension to its “invisibility”. This variability contributes to feelings of confusion and guilt as the size of the gap between ability and action is unclear and changeable. In the following extract, Alice highlights the difficulty of knowing whether she is able to make plans to socialise and echoes the sentiment of one of her close friends that maybe it is all in her head. This difficulty in knowing about the VCD compounds the guilt she feels about her social responsibilities, as she is not clear on what her capabilities are.

Alice: It has affected every- my life. It has. I mean I used to think nothing of just going out, but not now... But then later on, when I'm sitting there and I'm thinking I wish I'da gone now, I feel alright, why didn't I go?

Interviewer: I guess it's just that not knowing that you're going to feel alright.

Alice: Exactly. That's what it's all about. It's all up here <head> I'm convinced. (764-73)

VCD does not have a clear cause and effect relationship, meaning it is not experienced like other illnesses or injuries, which further contributes to feelings of invisibility. This absence of a clear reason for its emergence and repeated onset fuels the feeling that it is a difficult and strange condition,

largely because it does not adhere to any logical pattern. The following quote from Ben also conveys the difficulty he felt trying to talk about this “ridiculous” condition.

Ben: ...it doesn't sound right... uhm... because if you say “I can't breathe”, it's ridiculous because you're sat there breathing. <laughs> How can you get to the doctors, to tell them that you can't breathe, when you can fully function and sit there and breathe. [I.yeah] And there's no pain... I've got a bad knee and I've got a bad hand because I've played years and years of football and I have pain, and I know why I've got pain, and it's because I've hurt them. There is no pain. It doesn't hurt. It- you just can't breathe. (984-93)

Over half the participants felt that the “invisibility” of the condition could be used to their advantage, as it could be hidden from others. This allowed individuals some control, which was viewed as useful for managing recovery, avoiding social embarrassment and, for Lauren, it was useful for minimising other people's feelings of panic about VCD symptoms.

Lauren: ...to them, it's just something that, probably I'm a bit, can't get my breath, you know. But they just think that's part of my asthma and not part of my vocal cord dysfunction. And that's how I like it to be. (287-93)

Living with uncertainty

Chaos Vs. Control

One of the overwhelming impressions from participants' descriptions of VCD was of the randomness and the suddenness of the condition. This theme is about the struggle for control emerging from the chaos of the VCD. All participants commented on how the VCD can happen for no apparent reason and it can strike suddenly, at any time, with little to no warning.

Jonah: ...when I can be at home just doing anything, and I can,
<clicks fingers> and it just goes like that. (72-3)

The random suddenness of VCD creates an unstable world for the patient to inhabit.

Isobel: Both physically, mentally, uhm... and you just, the
bottom drops out your world. (113-114)

This imminent and unpredictable potential for chaos caused participants to feel weakened and vulnerable. Sadie felt that this had the potential to place her in real danger if a VCD attack happened when she was in the wrong place.

Sadie: ...when I'm walking round I have to keep stopping... If I'm going anywhere I can't keep doing that... Especially, if I'm coming home from my, my daughter in-law's house and it's getting dusk, y'know, living in **place**, it's not a safe area to be walking out on your own [l.mm], showing weakness of sorts, cause you'd have no chance. <chuckles> (598-603)

For many participants, a key focus for living with it was around management of the VCD symptoms, which offered an element of regulation for an otherwise chaotic condition. The following quote from Ben illustrates how being in total control of something that is so apparently random seems unrealistic and therefore knowing how to manage it, when it does happen, is felt to be the next best thing.

Ben: I know what to do when it happens, I can't stop it, I haven't to been able to control it. I can just manage it better, is what I do. (35-7)

Another aspect of the chaos of VCD is that the throat seems to have assumed control over the individual. The majority of the participants described episodes of VCD as though control was elsewhere or as though the throat was autonomous. Isobel illustrates this idea of the autonomous throat, in terms of the extent to which the throat could be thought of as though it was a separate thing with its own opinions and demands, requiring a mediator for disputes.

Isobel: ...sometimes it shows it's boss. But, er, but then part of me will say, yeah well you might think you're the boss, but this is my body. And, I know you're kicking off cause you don't like something, but, I'll give in to you this once but, y'know what I mean? Almost like a, sort of a child, throwing it's teddy out of a pram. I, I'll reason with you, but I'm not letting you beat me. (883-889)

As can be seen, some participants viewed symptom flare up as the VCD temporarily taking control, yet they maintained a long-view that ultimately they were still in control of their lives. However, Lauren seemed fearful that allowing the symptoms to dictate what she was doing, even temporarily, would result in her being overwhelmed by the condition. For this participant there was no option but to remain in control.

Lauren: I want to live my life, as best I can. I don't want to let it rule me and dictate to me, and tell me what I can and I can't do. If it starts doing that, I ain't gonna have a life, I ain't gonna do nothing. So, I've got to be in control of that, and not let that control me. So that's what I look at it as. (379-84)

The Trauma of VCD

Violence against the self

Participants all described variants on the “trauma”, the “turmoil” and the “torture” of experiencing a sudden and extreme episode of VCD and feeling like they might die. There is a strange horror that the body is doing this to itself and an ultimate fear that it will eventually kill them.

Alice: If you never had it you don't know. It's a horrible feeling.

You think you're going to die. Mmm. (372-4)

Before diagnosis especially, participants related how being able to feel the bodily changes associated with the VCD as they happened, but not having any means to stop the progression compounded the feelings of terror. As is highlighted by the following quote from Lauren there is a claustrophobia to the sensation of the throat “closing in” and the muscles tightening. It is as if life is quickly, perceptibly slipping away as the ability to breathe gets less and less.

Lauren : ...obviously once your throat starts to close up, your airways start to close, so it's almost like you know, your airways are gonna start closing in, so your muscles close in so you get a small hole <hand in loose fist with hole in centre/points to hole> whereas you can breathe normally, but then when it starts you can feel that, it actually closing, it's like the muscles

are actually closing in, and you can feel the hole getting smaller and smaller. (32-8)

Three participants described their experiences of the VCD episodes with violent imagery, as being hit “like a rock”, “being smothered” and “like a bullet firing out of a gun”. Isobel even felt like she was reliving the physical abuse suffered in a past relationship, hinting at the very real, violent and traumatic potential of the VCD experience.

Isobel: Uhm, but I was very conscious, and I kept, again, thinking back to the abusive relationship. Am I re-living, [I.right] that moment? [I. Yep] And so I, I just didn't know what was going on. But I was... frightened, because I just knew I couldn't breathe and I needed help. (67-71)

Finally, there is the feeling of being under continual threat of attack from the body, although this was much more prominent prior to diagnosis. Ben felt the VCD was on a targeted, purposeful and vindictive mission in pursuit of a harassed individual and he clarifies the dramatic impact of that experience on his life before diagnosis.

Ben: You just think you've had it. And if it's not gonna kill you this time, it'll kill you next time ... that's why you can't sleep and that's why you don't want to eat. That's why you- I, I just locked meself away for 3 months, I didn't go anywhere. (562-8)

Even after diagnosis there is still the lingering fear for many of the participants that they are unsafe and that there is an element of luck to their survival of this condition.

Isobel: Uhr, it's like you're clapping your hands, and as you're clapping <clap> your hands, your throat <clap> has just closed. And your brain has forgotten, gone into turmoil, and you're thinking. You don't know what to do. I don't know what to do. And you're thinking, Am I gonna die? [I.Yeah] And, yeah, I thought I was gonna die [I.Yep] And I still think, I'm lucky to be here. (805-811)

On the mind

Participants all spoke about feeling conscious that the VCD was ever-present. This caused some participants to worry about it. Some simply felt very aware of the possibility of it happening and one participant felt that she had no option but to block it out and just get on with her life.

Feeling conscious of VCD led to increased vigilance by participants in the majority of instances, especially around times or activities when it had previously happened or immediately after a recovery. In the following extract Isobel describes using her exercises prophylactically.

Isobel: [No, I do them every day] when I wake up in the morning, I always start off the day, before I've even left my bedroom, I do my breathing exercises. Then I have my medication, because I know then... just in case it's slipped into a sleepy state <hand around throat>... I think I do them again at lunch time and tea time, uhm, and I'm sure I do them when I'm, just before I go to sleep, in case... uhr, just in case it has a little moment in the night. (452-63)

Isobel illuminates something of the extent to which it can be on her mind, as it is the first thing she thinks of when she wakes up and the last thing she thinks of before she goes to sleep. She is continually performing the breathing exercises throughout the day, to try to help the throat.

Ben: It's... kind of with you all the time. I'm conscious of it all the time. It doesn't, I'm not frightened of it, and it doesn't, not like I used to be, but uhm, different parts of the day I'm more aware of it. In the morning, I'm more aware, it seems to be... if it's gonna happen, it'll happen in the morning, that tends to be the worst time for me, uuuhm... but any meal, anything I eat I have to have drink. (18-22)

This extract from Ben further highlights how the VCD is perceived to be always there and how measures need to be taken at times when it is more likely to happen. This extra vigilance at times when it has previously caused a

problem is seen in the other accounts too, suggesting that in addition to a physical attack, it can mentally intrude at anytime also. This type of intrusion into thoughts can cause worry or fear as Alice states.

Alice: And I'm frightened. I go in the shower and I'm frightened, I'm frightened. I am. All the time. Am I gonna have another one? (369-71)

Participants describe being especially vigilant for the recurrence of VCD in the period after an attack. Jonah explains having to live within this uncomfortable uncertainty, for months, which necessitates a focus on the feelings of the throat as the VCD "sort of lingers".

Jonah: ...it sort of lingers for about 2 months after I've had a VCD attack. [I.goodness] but not half as bad or anything, but you've still got that feeling, [I.yeah] will I go through that door and be- and it comes back. (705-8)

Living with the vivid memory of a particularly upsetting attack prevents Alice from getting involved in activities that she had previously enjoyed for months after the event and even afterwards it is still on her mind. Even recalling the "big one" causes Alice to wheeze suggesting that it is a traumatic event to recall and the horror of it can still be clearly remembered.

Alice: The big one I had. I had a big one in September, yeah. That was the worst I've ever had, and er, I never, I didn't go to the clubs til after Christmas, started going back <wheeze> erm... yeah, I'm alright but, I'm always... conscious. (36-9)

An exception to it being on the mind seems to be Lauren, who has resolved to not worry about it.

Lauren: ...it it can be just with anything... Because it can happen at anytime, anywhere, you know, uhm, so I don't tend to worry about it. (586-90)

It is important to note that Lauren had not experienced any hospital admissions due to asthma or VCD suggesting either her symptoms were milder or that she was better able to cope. She also had multiple other co-morbidities and experienced her VCD regularly (many times a day), suggesting that coping with these health conditions may be a significant part of her daily life.

Helpful Relationships

Power of professional reassurance

The analysis showed that participants found speaking to a professional who would listen and validate their experiences, extremely powerful. Furthermore, having a safe place, which they felt they could return to with their problems and questions, was invaluable to those struggling to live with VCD.

Sadie: ...the whole team has been absolutely fantastic because they don't poo poo you. They listen to what you've got to say ... if it's um, if they can help you with advice of something you're not sure of they will do it every time. They've always been there. I mean, it's like I got my new cylinder but I hadn't got a mask, they sent me a mask in the post, which was really nice... Y'know, little tiny things like that, mean a lot to somebody in my condition and position. [I.Yeah] Just some, y'know, if I've got a problem I can pick the phone up anytime and talk to somebody from the team. (932-47)

When contextualised within a narrative of not being diagnosed for years or having her symptoms dismissed, the power of being heard and being taken seriously assumes even greater significance. Similarly, Isobel reflects enthusiastically on how well she was treated, when receiving her SALT therapy to cope with a VCD attack.

Isobel: But I can come out of it very quickly ... But that's thanks to the training from [SALT] erm who has taught me well. She's taught me very very well. And, if I could issue, a damehood she would get it (612-616)... because she's one hell of a lady, erm, she is just remarkable. Very calm [I.yep], er sincere. I just think she's, she's way up there in my- If I won the lottery I would give it all to her. (620-622)

This extract illuminates her gratitude for and trust in the SALT and touches upon the potential importance of the therapeutic alliance in delivering treatment against a backdrop of potentially traumatic VCD experiences. Isobel feels she has received so much from her treatment that she wants to richly reward the clinician responsible.

Further illustrating the power of professional reassurance, the importance of being told, "you'll come out of it", resonated loudly throughout the accounts, with all participants reflecting on how this powerful and positive message is recalled at difficult times in order to boost confidence.

Jonah: *[talking about his treatment for VCD]* But it's given me a lot more confidence now. You know. It's something that I can live with. You know. And when it does come I thought right,

you're not gonna get the better of me, I'm gonna get over this.

(152-5)

The SALT team provides invaluable reassurance that the participant “won’t die” and that they will make it through an attack, which is in stark contrast to how frightening the experience can feel. It is a combination of this powerful positive message and providing participants with the tools and knowledge, which gives them the confidence to handle the VCD but also, importantly, to soothe their own fears.

Alice: And they showed me that, and they’ve given me confidence as well.

Interviewer: Yeah, confidence in what sense?

Alice: That I can handle it. Because she said to me, you won’t die. I said, well I nearly died. She said you won’t die, you’ll come out of it. (169-173)

The impact of this positive message of survival and recovery on mental wellbeing cannot be underestimated, especially when it has followed a struggle to be diagnosed, as is the case for Ben.

Ben: I get quite emotional about it actually, but it, it, it is that big a deal to be told you’re alright, you’re not gonna die <small laugh> (1017-8)

Belief in future recovery and in the effectiveness of the exercises, which has been imparted by SALT, is therefore a vital element to the recovery process, providing a positive counterpoint to moments of panic.

Lauren: You're thinking "god, it's still closing up" uhm, eventually you think to yourself, it's gonna open up eventually.
[l. yeah] If I keep doing what I'm doing, so... (537-41)

Management: the balancing act

Breaking the panic cycle

All participants commented upon the feelings of panic associated with a lack of control that were an automatic reaction to the symptoms of their VCD. All reflected upon strategies for regaining control of thoughts, in order to prevent symptoms from worsening.

Lauren: ...you can't panic because the more you panic the worse it gets, you know and then, you you telling yourself you're lacking oxygen then you collapse and then you, you know, so I said you just don't think about it, you just do your exercises get on with it and not worry. (499-502)

All participants also felt that it was difficult not to panic because of the distressing physical sensations (such as feeling strangled) associated with the VCD.

Sadie: ...it's not nice to have because you panic because you can't breathe, you're not supposed to panic [I.Yep]. Supposed to keep calm, and it's easier if you keep calm but. Panic and it get's worse. (871-4)

Strategies employed to help stop the VCD symptoms centred on physical exercises, medication and challenging negative thoughts. To regain control over their breathing, participants used Heliox and exercises. However, they also made use of mental strategies for recovery, such as intently focusing on their internal world and using reassuring self-talk that recovery was imminent and that they would be OK.

Isobel: So you need to, almost a Tai Chi moment, uhm, it's just me thinking, OK. And I do close my eyes, and I do just switch off completely, to allow my body to recover. (569-572)

As is illustrated by this extract from Isobel, a key part of recovery for over half the participants was focused around an almost meditative practice, with participants retreating within themselves to focus intently on what they need to do to recover. Participants described how they would “shut out” the world and bring their focus intently to themselves. This is an active engagement with their physical sensations that keeps them “busy” as it occupies all of their energy at the time.

Alice: I don't- nobody talked, I can't talk <slight wheeze> cause I'm busy doing all this <fingers to thumbs in meditation type pose> mmm. (190-1)

Throughout these accounts of using the mind to break the panic cycle there was a sense of power regained from knowing which strategies to employ, how they should work and symptom progression.

Jonah: ...now I know where to go with it and what to do with it.

[I.yeah] So I do it on my own now, when I'm in hospital I can just sit in a chair, look out the window, take my mind off everything [I.mm hmm] literally close off from everything around me and do my breathing [I.yep] and it brings me round, and I thought, I'm getting there, I'm getting there <whispered> keep going, keep going [I.yeah] you know. (367-73)

In contrast to the pre-diagnosis stage where Jonah did not know “where to go with it”, he now has direction, purpose and control. He feels in control and can use self-management strategies when experiencing an exacerbation of symptoms. The reassuring messages that he tells himself to soothe the panic are that he *can* do this if he keeps going. This felt almost reminiscent of the story of *The Little Engine That Could*, with the participant encouraging himself onwards with the belief that he will succeed (Piper, 1930). That classic children's story, which is all about optimism and the power of hard work, touches upon a key theme in Western culture, that an individual can achieve anything he puts his mind to.

Discussion:

It is evident that VCD has impacted on various aspects of the lives of those living with it. These findings highlight three broad areas for discussion: 1. Living with VCD requires ongoing reassertion that it exists, which can be difficult. 2. VCD can be a chaotic and traumatic condition to experience. 3. The mind has a key role to play in management.

Living with VCD requires ongoing reassertion that it exists

A lack of knowledge about VCD in the medical profession creates an environment where patients have reported feeling unsupported and unsafe. Touched upon in both *the struggle* and *the invisible illness* themes, this is a significant element of the VCD experience that has the potential to undermine patient expertise and negatively impact on the self. This is consistent with a broader issue of delegitimation (where someones experience or perception of their condition is said to be untrue), which exists in the literature for other difficult to diagnose health conditions such as Chronic Fatigue Syndrome and Chronic Pain (Dickson et al., 2007; Kouyanou et al., 1998).

There is some evidence for the implication of psychological issues in the onset and maintenance of VCD, and two participants in this study disclosed a history of Childhood Sexual Abuse (Guglani et al., 2014). However, the idea of contributory psychological factors was not palatable to the majority of the participants in this study, perhaps because it further threatened the legitimacy

of their condition. Also, describing VCD-type symptoms using the term 'Munchausen's Stridor' could potentially serve to perpetuate the idea that it is a factitious illness (Morris et al., 2006). It is therefore important that medics find a way to sensitively explore potential psychological factors, in order to ensure referral for appropriate treatment pathways and support.

VCD can be a chaotic and traumatic condition to experience

VCD can feel extreme and appears suddenly and with no warning, making it a chaotic and frightening condition to live with. This is illustrated in the themes *Chaos vs. Control*, *Violence Against the Self* and *On The Mind*. There is evidence for PTSD following a severe asthma attack and also that PTSD severity was related to perceived asthma severity (Chung et al., 2012). The aforementioned study also recommended that individuals who do not meet full diagnostic criteria for PTSD might still require treatment for PTSD symptoms (Chung et al., 2012). Many of the participants perceived their VCD to be life threatening, suggesting that those who have experienced a traumatic episode of VCD should be offered appropriate psychological support.

Participant experiences of the condition were not homogenous, highlighting that different types and severities of VCD experience are possible both within a single individual and between individuals. This raises the question of why some people experience less extreme attacks than others. It has been suggested that two different phenotypes of VCD exist, Exercise Induced VCD and Spontaneously Occurring VCD (Doshi & Weinberger, 2006). The

categorisation of the latter is unsatisfactory in that it has simply grouped everything that cannot be explained by exercise, therefore further exploration of differences would be beneficial for illuminating possible reasons for differing severities.

The mind has a key role to play in management

Many strategies were adopted for coping with VCD, but a key thread throughout all the accounts was the role of the mind in facilitating recovery. In the themes *The Power of Professional Reassurance* and *Breaking the Panic Cycle*, regaining control over the panic and fear, which could overwhelm the mind during a VCD episode, was crucial to recovery.

There is some initial evidence for the efficacy of CBT in this population (Richards-Mauzé & Banez, 2014). CBT would be helpful for improving participant understanding of the link between thoughts, feelings, actions and bodily sensations as well as to address potentially detrimental coping strategies, such as avoidance of activities. It is also possible to interpret some participant descriptions of internal focus during an attack as a variation on mindfulness, suggesting that this could be usefully adapted for use with a VCD population, especially as there have been some successes with this approach in an asthma population (Pbert et al., 2012).

The analysis showed that reassuring messages from the SALT were recalled at difficult times. One explanation of this is that interaction with an empathic

and trusted health care professional facilitated a kind of self-soothing (Gilbert, 2009). The SALT researcher within this project also relayed that after patients had been discharged, some still contact her to update her when they experience an attack, suggesting a potential role for SALT as a safe base for patients to return to. Further investigation of specifically what comprises the helpful qualities in this patient-practitioner relationship could inform future service provision.

Clinical Implications

There is much work to be done in disseminating existing knowledge about VCD to all medical practitioners, many of whom may still lack an awareness of the condition. Furthermore, providing individuals with VCD alert cards on diagnosis could offer validation as well as a way to clearly communicate important condition-specific information to others.

There is considerable potential for psychological interventions to positively impact on patient wellbeing, and CBT and mindfulness may have a role to play in alleviating feelings of stress and worry associated with VCD. Further research is also needed on VCD phenotypes in order to offer the most appropriate interventions.

Finally, support groups that facilitate the meeting of individuals with this little known condition would provide support, a means of normalising the condition and a place to share potentially valuable patient expertise, as well as serving

the function of encouraging individuals to socially re-engage, if this has been affected by the condition.

Limitations of study

Generalisability from qualitative studies is inherently limited as each case is particular, however these cases illuminate human experiences, which are available to many (Smith et al., 2009). Furthermore, as VCD is not well known and this is the first paper exploring the lived experience of the condition, it can inform clinical knowledge of patient experience. The next stage in this project will be to synthesise this information along with what is currently available in the literature, into a model of the condition.

Additionally, it is worth noting that many participants had experienced an extreme episode of VCD and wanting to help others was a primary motivator in their involvement, suggesting the potential for self-selection bias. As there may be varying severities of VCD experience, it is probable that these accounts represent only part of a spectrum.

Conclusions

VCD has the potential to significantly affect those living with it. Using IPA to explore how individuals live with VCD, we identified that the lack of knowledge about it, combined with the dramatic nature of the attacks, can make it a difficult condition to cope with and this can significantly impact on mental

wellbeing. Utilisation of psychology to offer ways of understanding the feelings elicited by the condition and develop coping strategies could be helpful for participants and future research should continue to explore this.

APPENDICES TO CHAPTER 3

APPENDIX 3A: NRES Approval Letter

APPENDIX 3B:
Birmingham Approval Letter

APPENDIX 3C:
R&D Heart of England (NHSFT) approval letter

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APPENDIX 3D:

Participant Information Sheet

VOCAL CORD DYSFUNCTION & YOU

INVITATION TO TAKE PART IN AN INTERVIEW

INTRODUCTION...

We would like to invite you to come in for a one to one interview about your experience of Vocal Cord Dysfunction. We are seeking to understand the impact that the condition and its symptoms have on your life. Please get in contact if anything is unclear or if you would like further information.

What is the purpose of the interview?

Within the Severe & Brittle Asthma Unit at Heartlands Hospital we are planning to undertake a study on Vocal Cord Dysfunction (VCD). What we learn about your experience with VCD will be shared with other professionals working with VCD, and will be used to inform psychosocial interventions for VCD. In order to do this we are looking for volunteers who have experienced VCD to come to Heartlands hospital for a one to one interview with a researcher.

What will this involve?

Taking part in will involve attending a one to one interview at Heartlands hospital where you will have opportunity to talk about your experience of living with VCD. In particular we are looking to understand about your symptoms of VCD and the impact the condition has had on your life. The interview should last no longer than two hours and initially you will be required to complete a short questionnaire, with some basic information about yourself and your VCD, before being asked to talk about your experience of VCD.

Refreshments will be provided and you will receive £10 reimbursement for travel. Audio recordings and notes will be taken at these meetings, transcribed and looked at. All responses will be kept anonymous and this data will be stored securely and accessed only by members of the team involved in this study.

After the interviews you will be posted a copy of the transcript (the typed up document from the interview) and given the opportunity to check this for accuracy. You will have two weeks to check this and come back with any questions or if you wish to query something in the transcript. If we do not hear from you within two weeks we will assume you have no comments or questions and will progress with studying the transcript to identify key themes. Once these have been identified in all of the interviews, you will receive a summary of these key themes as well.

Why have I been invited to take part?

We need the input of people who have experience living with VCD and are inviting patients who have or had VCD to discuss their experiences of the condition.

Do I have to take part?

No. Taking part is optional and you are free to stop your involvement at any time, without providing a reason up until the point that we begin to look at your transcript (2 weeks after you receive a copy of it in the post). This will not impact on any treatment you receive from the hospital. If you have any questions about the interviews or to help you decide if you want to take part, please ask (contact details are provided at the end of this sheet). You will be asked to give your written consent before the interview.

\$

Confidentiality

The information we collect will be anonymised so that identifiable information is removed. We intend to share the findings of the interviews with all participants and the research team. The findings will also be published in a research journal and short quotations will be used. We will not report the names or any other identifying details of those who participated in the study. The audio recording and transcription of the interview will be securely stored and accessed only by those undertaking the research. The recording will be kept for up to three weeks after the transcript has been posted to you and will then be deleted.

\$

What happens at the end of the study?

After the interview you will receive a summary via post of the transcript and should respond within 2 weeks if you have any comments on this. When all the interviews have been looked at you will receive, via post, a summary of the findings and you will have opportunity to provide further comment on these documents. This information will be incorporated into research papers about VCD. It is hoped that this data will help inform further research, training and clinical practice in VCD.

Interviews are planned to take place during April and May 2014 and if you are interested in taking part we will contact you to arrange a convenient time for you to attend for interview.

If you are interested in taking part in or would like further information, please do not hesitate to contact us:

Nicola Pargeter
Principal Speech and Language Therapist
Severe & Brittle Asthma Unit
Birmingham Heartlands Hospital

Jodie Fellows
Principal Clinical Psychologist
Severe & Brittle Asthma Unit
Birmingham Heartlands Hospital

Or complete an online form and a member of the research team will get in contact with you:
<http://www.surveymonkey.com/s/CNYJCVD>

Many Thanks

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by The West Midlands, Black Country Research Ethics Committee [DATE]

APPENDIX 3E:
Participant Invitation Letter

SEVERE AND BRITTLE ASTHMA UNIT

8th May 2014

Dear Sir/Madam,

We would like to invite you to attend an interview about your experience with Vocal Cord Dysfunction. We are seeking to understand a lot more about the condition and its impact on the lives of people living with VCD.

We would be grateful if you could read the attached information sheet and if you are interested in being involved or to find out more information please phone Julie Marsh or Ann Danks and a member of the research team will get back to you.

If we do not hear back from you within 3 weeks from the date of this letter we will assume that you do not wish to participate in the study.

Yours sincerely

Catherine Maskell
Research Assistant

Jodie Fellows
CLINICAL PSYCHOLOGIST

Nicola Pargeter
**PRINCIPAL SPEECH AND LANGUAGE
THERAPIST**

APPENDIX 3F:
Version one of interview schedule

- HOW WOULD YOU DESCRIBE VCD TO SOMEONE WHO HAD NEVER HEARD OF IT?
PROMPTS: what is it? What does it do? How does it make you feel?
- HOW CAN YOU TELL THAT IT IS VCD (and not asthma or panic)?
- CAN YOU TELL ME A BIT ABOUT THE FIRST TIME YOU EXPERIENCED VCD?
- WHAT SETS OFF/EFFECTS YOUR VCD ?
PROMPTS: cold weather?, smells?, exercise? Psychological – stress, worry etc.?
- WHAT HAPPENS BEFORE, DURING & AFTER VCD?
PROMPTS: how does it feel? Can you talk me through the order of events? Key symptoms?
- WHAT DO YOU DO WHEN YOUR VCD HAPPENS?
PROMPT: how do you cope with it?
- DO YOU DO ANYTHING ONGOING TO MANAGE YOUR VCD?
PROMPT: What changes have you made to your lifestyle/ways of doing things?
- HOW WAS YOUR VCD DIAGNOSED? & WHAT WAS THE IMPACT OF THE DIAGNOSIS?
PROMPTS: What was your life before diagnosis? How did you find out you'd got VCD? What has happened after the diagnosis?
- HOW HAS YOUR VCD AFFECTED YOUR LIFE? (socially, personally, physically, mentally?)
- CAN YOU TELL ME A BIT ABOUT THE TREATMENT YOU'VE RECEIVED FOR YOUR VCD? PROMPT: What treatment have you received, what has been helpful/unhelpful & why?
- HOW HAS TREATMENT FOR VCD IMPACTED ON YOUR SYMPTOMS?
PROMPT: What has been helpful/unhelpful for symptom control?
- HOW HAS TREATMENT FOR VCD IMPACTED ON HOW YOU ARE FEELING?

- HOW HAS TREATMENT FOR VCD IMPACTED ON WHAT YOU CAN DO?
- HOW HAS YOUR TREATMENT IMPACTED ON THOSE AROUND YOU?

APPENDIX 3G:
Version two of interview schedule

SYMPTOMS:

- HOW WOULD YOU DESCRIBE VCD TO SOMEONE WHO HAD NEVER HEARD OF IT?
PROMPTS: what is it? What does it do?
- DOES THE VCD AFFECT HOW YOU THINK & FEEL?
PROMPTS: can you tell me a bit more about that?
- HOW CAN YOU TELL THAT IT IS VCD?
- WHAT SETS OFF/EFFECTS YOUR VCD ?
PROMPTS: Cold weather? Smells? Exercise? Stress/Worry etc.?
- WHAT HAPPENS BEFORE, DURING & AFTER VCD?
PROMPTS: how does it feel? Can you talk me through the order of events?
How do you feel in yourself after the VCD?

DIAGNOSIS:

- CAN YOU TELL ME A BIT ABOUT THE FIRST TIME YOU EXPERIENCED VCD?
- HOW WAS YOUR VCD DIAGNOSED?
- WHAT WAS THE IMPACT OF THE DIAGNOSIS ON YOUR CONDITION?
- WHAT WAS THE IMPACT OF THE DIAGNOSIS ON HOW YOU WERE FEELING?
PROMPTS: how did you feel differently after your diagnosis?
- WHAT WOULD YOU SAY HAS CHANGED IF YOU COMPARE YOUR LIFE BEFORE THE DIAGNOSIS TO YOUR LIFE AFTER THE DIAGNOSIS?

IMPACT:

- HOW HAS YOUR VCD AFFECTED YOUR LIFE?
 - Socially?
 - Personally?
 - Physically?

- In your thoughts?
 - In your feelings?
- COMPARING YOUR LIFE BEFORE VCD TO YOUR LIFE AFTER THE VCD, WHAT WOULD YOU SAY THE MAIN DIFFERENCES ARE?
 - HOW DO YOUR FAMILY & FRIENDS PERCEIVE THE VCD HAS AFFECTED YOU?

MANAGEMENT:

- WHAT DO YOU DO WHEN YOUR VCD HAPPENS?
PROMPT: What is going through your mind? How do you feel?
- WHAT CHANGES HAVE YOU MADE TO YOUR LIFE IN ORDER TO MANAGE YOUR VCD?
PROMPT: How do you feel about those changes?
- CAN YOU TELL ME A BIT ABOUT THE TREATMENT YOU'VE RECEIVED FOR YOUR VCD AND WHAT HAS BEEN HELPFUL OR UNHELPFUL? – WHY?
- HOW HAS TREATMENT FOR VCD IMPACTED ON YOUR THOUGHTS OR MOOD?
- YOU DO ANYTHING ONGOING TO MANAGE YOUR VCD?
PROMPT: What changes have you made to your lifestyle/ways of doing things?
- HOW HAS TREATMENT FOR VCD IMPACTED ON WHAT YOU CAN DO?
PROMPT: hobbies? Work? Social/family life?
- HOW DO YOUR FAMILY AND FRIENDS PERCEIVE THE IMPACT THAT YOUR TREATMENT HAS HAD ON YOU?

APPENDIX 3H:

Participant Screening Questionnaire

1. Below is a list of 9 statements with two optional endings in **BOLD CAPITAL LETTERS**. Please circle the ending which best describes your VCD.
Please only respond about your VCD.

OR...

1. The onset of my VCD symptoms is...	GRADUAL	SUDDEN
2. My recovery from a VCD attack is...	GRADUAL	SUDDEN
3. My response to inhalers is...	POOR/INCONSISTENT	GOOD
4. My response to VCD therapy/exercises is...	POOR/INCONSISTENT	GOOD
5. My VCD makes it difficult to...	BREATHE IN	BREATHE OUT
6. My VCD symptoms are mainly in my...	CHEST	THROAT
7. I experience VCD wheeziness in my...	CHEST	THROAT
8. My voice...	CHANGES/IS LOST	DOESN'T CHANGE
9. I experience VCD tightness in my...	CHEST	THROAT

2. Are you a smoker? (PLEASE CIRCLE)

YES NO

3. What is your gender? _____

4. How often do you take any regular exercise? (PLEASE CIRCLE)

Once a day	More than once a week	Once a week	Once or twice a month	Rarely	Never
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5. In addition to your VCD, have you been given any additional medical or psychiatric diagnoses? (PLEASE STATE)

Continued overleaf...

6. What is your ethnic group?

Choose one option that best describes your ethnic group or background

White	please tick
1. English / Welsh / Scottish / Northern Irish / British	
2. Irish	
3. Gypsy or Irish Traveller	
4. Any other White background, <i>please describe</i>	
Mixed / Multiple ethnic groups	
5. White and Black Caribbean	
6. White and Black African	
7. White and Asian	
8. Any other Mixed / Multiple ethnic background, <i>please describe</i>	
Asian / Asian British	
9. Indian	
10. Pakistani	
11. Bangladeshi	
12. Chinese	
13. Any other Asian background, <i>please describe</i>	
Black / African / Caribbean / Black British	
14. African	
15. Caribbean	
16. Any other Black / African / Caribbean background, <i>please describe</i>	
Other ethnic group	
17. Arab	
18. Any other ethnic group, <i>please describe</i>	

7. What is the highest educational or school qualification you have obtained?
(PLEASE TICK)

GCSE/O-LEVEL/NVQ level 1 or 2	
A-LEVEL/NVQ level 3	
UNIVERSITY DEGREE / NVQ level 4 and above	

Other – please specify: _____

8. Please indicate which age group you are in (PLEASE TICK):

18-24	
25-44	
45-64	
65 and over	

APPENDIX 3I:
Summary of cross case thematic structure & descriptions

Thematic structure and descriptions of subthemes		
Theme	Subtheme	Description
Diagnosis	The Struggle	This was to do with patient experience of their VCD symptoms being dismissed or ignored by medical professionals. Participants struggled both personally and with medics to validate their experience of the VCD. For some the VCD totally stopped their lives and/or threw them into turmoil for a prolonged period of time.
	The victory of diagnosis	This is to do with the patient experience being validated (and made real) by professionals. It is also to do with how being given a diagnosis & a way to manage the condition was life changing.
The Invisible illness	Lack of Knowledge	Frustration comes from having to explain what it is to every level of medical professional. At worst this was thought of as a willful ignorance, which could ultimately endanger lives and at best it was seen as embarrassing to doctors. Lack of trust in medical professionals increased potential feelings of <i>isolation</i> experienced by participants. There is so much not known
	The Invisible Illness	VCD is an unknown condition with limited outwardly visible symptoms. This has implications for how participants feel towards it – makes it seem like a strange thing. Can cause guilt over having this condition, which randomly appears and disappears.
Living with uncertainty	Identity changes	There were a variety of feelings represented towards changes to identity with the VCD, Most had to deal with it changing a central element of who they were. Others had assimilated it into their identity more easily (even choosing to <i>mask it</i> as part of asthma).
	Chaos Vs. Control	VCD has introduced uncertainty and chaos into the lives of participants, increasing feelings of vulnerability and decreasing perceived control as the throat adopts an almost autonomous role separate from the rest of the body and the wishes of the individual. This is also to do with the suddenness & randomness of it and links to the theme about there being so much that's still unknown.
	Social Intruder	Interferes with the social lives of individuals, whether that is work colleagues, family members or friends who treat them differently or it interrupting social occasions (parties, dinners, weddings). It intrudes upon & disrupts their social activity – both the voice change and the not being able to breathe are to blame. Not for P006 – control.

The Trauma of VCD	Violence against the self	This is to do with the extreme violence of the VCD (being hit, being shot, being strangled, being suffocated) and the horror of the body is doing this to itself. The trauma that ensues from this experience, almost like being tortured by it (P005).
	Fears about possible futures	To do with negative thoughts about future progression – that it is or it will get worse. (individuals imagine the illness (“total closure” “stuck”) as this impossible thing that prevents breath (and by extension life)).
	Distressing to others	This is to do with the significant impact the VCD can have on close others, being a very distressing condition to witness. This is somewhat alleviated when close others are given a role to play in recovery.
	On the mind	Feeling conscious that it is there all the time and feeling frightened of it. Heightened vigilance in situations where it’s previously happened or immediately after recovery. It can stop participants doing something they want to do or impact on enjoyment.
Helpful relationships	Importance of support from trusted other(s)	This is about the importance of a close trusted other who can share in, understand and support the process of recovery, In some cases there was the unspoken question of what would happen if these support structures were no longer available.
	Power of professional reassurance	This is about the power of speaking to a professional who will listen and validate your experience and provide a place to go for problems and questions. Furthermore, it is about being told you <i>will</i> be ok, and how that powerful, positive message is recalled at difficult times.
Management: the balancing act	Breaking the panic cycle (the role of mind in recovery)	This is about the spiral of panic that can occur and how that will make the VCD worse. The importance of using calm, focused thoughts and breathing in order to stop the panic and regain control.
	Avoiding & adapting	About going around things or avoiding known or even possible triggers just in case. Making small changes in order to not have to deal with a big one. Evaluation of this avoidance as prevention means participants play down the losses? Keeping the throat happy.

APPENDIX 3J:
Summary of cross case thematic structure & quotes

Thematic structure and descriptions of subthemes: SUPPORTING QUOTES		
Theme	Subtheme	Description
Diagnosis (initially this theme was centred around the victory of diagnosis, but when I examined the subthemes that made that up they seemed to be divided into two groups – one was around the victory felt after diagnosis but in order to get to that it was necessary to illuminate the struggle to get to that point, facing the frustrations of trying to get the diagnosis.	The Struggle	<p>P001: I was having the choking fits. I was referred to ENT and I thought, I can't remember what his name was now... stocky man... ... big man. And er, he had a feel of me throat and he asked me a few questions and he had a look down me throat. And he stuck a little camera down, up my nose and he says there was nothing wrong with me. (444-9)</p> <p>P002: Y'know, you've all written me off, you've all put me on these, all these tablets, and, you've made me feel as if I'm an absolute fruit cake [I.Yep] and I'm not. (164-166)</p> <p>P004: It was frustration, because I knew there was something there but, I knew there was something there, that wasn't related to my asthma, but it was just trying to get through to people what is was [I.yeah] you know and that was the frustrating part" (284-7)</p> <p>P005: I was frightened. I couldn't understand why nobody would help me. You know you go to the doctors to help you, and I, and I, like I don't make a fuss, so when I am not well, I think well, you should fix me because I don't turn up here very often <laughs> I'm not one of these that pesters you all the time, you just tell me what to do and I'll do it and I'll be fine. See, I was frightened I was frustrated, uhm, worried, <i>desperately</i> tired, can't tell you how tired I was, uhm, and even the odd time... even the animals were upset. (957-64)</p> <p>P006: Yeah and then everytime I was going to the- cause every 6 months I</p>

go to the ward anyway, for for like, you know to see them [I.mm] and it was a case of everytime I was going, but I'm still wheezing! You know, and I don't know what it is, why do I keep wheezing? Well your chest sounds clear, on the odd occasion tell em, yeah you've got a bit of a rattle. But, you know, I kept saying but I'm wheezing all the time... probably before I was actually diagnosed was probably about, well saying that, yeah was probably about 3 years. (742-57)

The victory of
diagnosis

P001: P. [At least] I knew I weren't imagining it

I. Yep

P. And I wasn't just being a silly woman <chuckles> (484-6)

P002: I was thinking there's other people like me, I'm not the only one. [I.Yep] I'm, I'm not alone in this [I.Yep] Uhr, and this is not my fault [I.Yep] Uhm, and I just wanted to sort of like, stand on a chair if you like, and shout "wooooooh" <waves arms with fingers pointing outwards> (158-162)

P004: ...when I was diagnosed with the VCD I thought, I don't need that now. It was so weird, it was as if a- it was as if like the curtains had been opened and I could go through them and start a new life [I.yeah], and that's what I've done. (302-6)

P005: it was just a life-changing day. Cause up to that point... er, you're just going nowhere... (1115-7)

CONTRADICTORY EVIDENCE: P006: I mean I just put it down to being asthma, cause I'm an asthmatic anyway, I just presumed it was part of my asthma. But erm, obviously it wasn't, it was something that was called, erm, vocal cord dysfunction, and so I don't suppose I really knew what it was

		because I'd never experienced it, or been told what it was before then. (53-58)
The Invisible illness	Lack of Knowledge	<p>P001: The Pharmacist there had no idea what – about vocal cord dysfunction and I was explaining to him about it. (36-7)</p> <p>AND</p> <p>Y'know, you're a pharmacist, you've got access to these search engines [I. Yep], if you do a search on there or get your local librarian to do it for you." (42-4)</p> <p>P002: Ur, and I just felt as if, yes, I'm the patient but I'm teaching you what you should know. [I. Yep] and I still probably feel a little bit like that now... and I think the more health professionals, they should be forced to do courses, [I. Yeah] they should be forced to, maybe, listen to our stories, [I. Yep] to see how we feel, because then they might treat us differently. (171-178)</p> <p>P003: Mmm [I.yeah] They reckon I'd lost 68% of oxygen. [I. goodness] According to the ambulance lady, she said to my friend, cause she came with me there, she said, we nearly lost her we didn't know what to do. Cause they hadn't heard of it <clapping sound> (133-7)</p> <p>P004: they keep coming at me saying, <u>well your chest is clear!</u> <high> and I thought I know my chest is clear <through gritted teeth> and it's not, and you just <u>cannot</u>, you're back to square one then (683-6)</p> <p>AND</p> <p>Next generation of doctors don't know</p> <p>we've got all the medical students, and whatnot, and er 10 of them are like next door neighbours and not one of them know, [I.yeah] what it is" (565-7)</p> <p>Access to an abundance of medical knowledge but none of them</p>

know (water water everywhere but not a drop to drink)

P005: So yeah, hopefully you'll, if you just get the word to GP's you'll make [I. yeah absolutely], I think that's the key cause, certainly my GP was typing it all in about what it all was and [I.yeah] what treatment I've got and what I had to do, so it's all in my notes. [I.mm, but that's one GP] That's one GP yeah. So she knows, I mean does the rest of the practice know? I don't know, I imagine they have best practice type discussions about things but I don't know (1239-46)

P006: When there's other people out there that've never heard of it, even, you know even the paramedics haven't heard of it, you know. And if paramedics ain't heard of it then you understand well, obviously it's not well know. And, look, you know, it does need to be thought about, it does need to give you more idea of what it is, how people deal with it, how you can cope with it and how it affects your life. (676-82)

The Invisible Illness

P001 [I just wake, I just wake] up and I'm ok so that's what I think's happened, I'm only assume- that because I can't see what's happening when I'm out [I.yep] (344-6)

P002: If I'd 've had a rash, you'd 've seen it [I.mm] but people perceive disabled people. They see them parking in a disabled spot and think "Well you don't look disabled" [I.yep] because you haven't got a false leg or... but you don't know what's going on inside (410-413)

P003: P. It has affected every- my life. It has. I mean I used to think nothing of just going out, but not now.

I. Yeah

P. But then later on, when I'm sitting there and I'm thinking I wish I'da gone

		<p>now, I feel alright, why didn't I go?</p> <p>I. Yeah</p> <p>P. mmm</p> <p>I. I guess it's just that not knowing that you're going to feel alright.</p> <p>P. Exactly. That's what it's all about. It's all up here <head> I'm convinced. (764-73)</p> <p>P005: it doesn't sound right... uhm... because if you say "I can't breathe", it's ridiculous because you're sat there breathing. <laughs> How can you get to the doctors to tell them that you can't breathe, when you can fully function and sit there and breathe. [I.yeah] And there's no pain. You know, I've had injuries, you know you play football, you get kicked and you have a big lump missing, it hurts. I've got a bad knee and I've got a bad hand because I've played years and years of football and I have pain, and I know why I've got pain, and it's because I've hurt them. There is no pain. It doesn't hurt. It-you just can't breathe. (984-93)</p> <p>P006: they're none the wiser, they don't understand what it is, uhm so really they just think of it as part of me, it's they don't know me any different to what I am, because they've never seen me where I can't control it. So to them, it's just something that, probably I'm a bit, can't get my breath, you know. But they just think that's part of my asthma and not part of my vocal cord dysfunction. And that's how I like it to be (287-93)</p>
Living with uncertainty	Identity changes	<p>P001: [I, I, I have to] warn people that erm, that y'know, please don't be offended, if you think I'm shouting tell me. I'm not shouting, I'm not the type of person that shouts, y'know? [I. yep] uhm, and my voice, the tone of my voice will change, don't be offended cause if I'm annoyed with you I will tell you straight that I'm annoyed with you, [I.yep] not the tone of my voice cause I can't control it [I.mm hmm]. Y'know I can't control how loud it is,</p>

the tone of it." (683-9)

P002: But, I never talk, now people, y'know, you'll put a mouthful in and you'll chat. [I.Yeah] I don't do that anymore, [I.OK] Uhm, because I know what the consequences are. (236-8)

P003: P. I don't like that. I mean I'll be sitting with friends and y'know you've got a big conversation going on and I want to say it, but I won't because <demonstrates struggling to inhale> I ca- , you know I cant get there, so I don't, I don't say it. I just keep quiet. So it has changed. (697-701)

AND

And I had a comment once and I said to somebody, I tell you what I'll swap you my life for yours anyday... <laughs> [I.Yep] And that's- And they just don't know. And I do. I am outspoken. [I.yeah] Uhr, I never used to be. I used to be quite the, a timid person [I.yep] But it's brought me out of myself and I think I've learnt things about me that I didn't think were capable [I.Yep] So, in a way, it has had negative effects, but it's also had a positive effect. (413-20)

P004: I'm not soo... within myself now, I'm more active. I'm, I, I do, I do, I, I do a, I do a lot more now. I've just taken up swimming again. (335-6)
POSTIVE CHANGE AFTER DIAGNOSIS (cf. P002, who is more outspoken because of this)

P005: I'm not very good at being- I'm never sick and when I'm ill, I'm not sick, you know, even when I had, drank loads and loads of beer I was never sick, I'm not a sick person. (249-51)

Chaos Vs. Control

P006: I think that's probably because I've just learned to live with it, uhm, and so now it's part of my everyday life, it's part of how I live now, and I think, I have to live like that now, there's nothing for it, so, that's my way of dealing with it, and keeping with it I suppose. (43-7)

P001: when I'm walking round I have to keep stopping [I. mm hmm]. If I'm going anywhere I can't keep doing that, y'know what I mean? [I. yeah] Especially, if I'm coming home from my, my daughter in-law's house and it's getting dusk, y'know, living in ****place****, it's not a safe area to be walking out on your own [I.mm], showing weakness of sorts, cause you'd have no chance. <chuckles> (598-603)

P002: Both physically, mentally, uhm... and you just, the bottom drops out your world, [I. Yeah] all of a sudden. (113-114)

AND

P002...sometimes it shows it's boss. But, er, but then part of me will say, yeah well you might think you're the boss, but this is my body. And, I know you're kicking off cause you don't like something, but, I'll give in to you this once but, y'know what I mean? Almost like a, sort of a child, throwing it's teddy out of a pram. I, I'll reason with you, but I'm not letting you beat me." (883-889)

P003: Erm, *Slight* control. I wouldn't say 100% no. I have got a bit of control, because I do know- like the other night, I do know that I can control that breathing. I mean, if I had a great big one I don't know what I'd do, I think I'd be pressing the button <wheeze> [I.yeah] But yeah, slight one I can control it now – with all this sitting here doing this <clear breaths> sitting quietly and just doing my breathing." (819-24)

	<p>P004: ...when I can be at home just doing anything, and I can, <clicks fingers> and it just goes like that” (72-3)</p> <p>P005: I know what to do when it happens, I can’t stop it, I haven’t to been able to control it. I can just manage it better, is what I do. (35-7)</p> <p>P006: It’s something I’ve got, that ain’t gonna go. It can make a hinder on my life and make me not do what I want to do, or I can still try doing things and living life as best I can. And that’s what I want to do. And it’s the same with everything else I’ve got. I want to live my life, as best I can. I don’t want to let it rule me and dictate to me, and tell me what I can and I can’t do. If it starts doing that, I ain’t gonna have a life, I ain’t gonna do nothing. So, I’ve got to be in control of that, and not let that control me. So that’s what I look at it as. (376-84)</p>
Social Intruder	<p>P001: [That I said, yeah, yeah, made me] far more wary of it. Actually, I feel very uncomfortable about the fact that I’ve got to explain myself every 5 minutes, every time I speak to somebody that don’t know me and never spoken to me before. (714-7)</p> <p>AND</p> <p>P001: she used it as an excuse that I couldn’t do this and I couldn’t do that. But I can do this and I can do that. No, I can’t bend down and pick books from the bottom shelf because I would be kissing the floor, because of my blood pressure and stuff like that [I. mm] And my balance isn’t good enough, uhm... ... it-it’s just the way she, she treated me differently (640-5)</p> <p>P002: if it’s a party or something, smoke machines. If you go to a party, I think, oh god no, please don’t let them get out the smoke machine. Because</p>

I'm out the door, and I have, I have now, I ask: Are you having a smoke machine? [I.Yep] If they say yes, then I say well I'm really sorry I'm not coming, because, er, and it's not just my VCD, it's my asthma as well. [I.mm hmm] it's just, my body doesn't like it. Uhm, so yeah it it, but now, all my friends, if they're offered it say, no no no no, you can't put that on, cause ***participant***'s <chuckles> you can't have that [I.Yep], she'll collapse on the floor <high pitched single laugh> it hasn't been that dramatic but [I.Yep]... it did happen at a wedding [I.right] because they didn't know he was going to put it on, uhm, and once I came round, I just go off, do my exercises, an hour later, reappear (250-63)

AND

P002: Uhm, cause obviously people still smoke, and that's their choice, that's fine. Uhm, and if it's their house I can't dictate what they do and don't do [I. Yep] Uhm, so now I find that I'm not invited [I.that must be...] but erm, that did upset me a lot at first <voice breaks/disappears and P has tears in eyes> [I.yep]

<Silence for 12 seconds>

But it's something I've gotta get over" (278-286)

P003: Oh, it's me that's more embarrassed than them cause, I met a lady the one day, just coming out of the supermarket. And she said "hello, how are you?" and I said "not too good" And she said "Oh, I'm sorry to hear that, what's wrong?" and I said, what it was. And she said oh I've never heard of that, the usual, and I just said, it's the vocal cords, I always do this and show them <moving first and second fingers and then pressing them together> And then, I said, I'm ever so sorry but do you mind, I can't talk anymore <wheeze> I was getting a bit, y'know. And she said, OK that's fine. And then

	<p>a few days later I rang her up and apologised. And she said, oh nothing to apologise for, she said I understand. So I get a little bit like that.. (427-38)</p> <p>P004: we went out for lunch the other day with somebody and they put that much pepper on my dinner and it went up me nose and straight away me throat went funny, and I went OH! <laughs> you know and, and I, I literally had to come out for a bit, take my inhaler, [I.yeah] and it's things like that, you know you think I can't be any- I can't be round anybody that takes a lot of pepper, [I.yeah] you know, cause it goes up, so I have to have the one that you grind in the pepper mill, [I.yeah] so we don't have the other pepper now. (851-9)</p> <p>P005: [No, I,] I don't like fuss, getting these things, back to <inaudible> uhm, but it is quite, it's never happened, or it, it did happen at work, because I remember now, we were at a conference. Uhm... and I just left the table and they had no idea what was going on. Uhm... and I disappeared for an hour, because that's how long it takes to get, that was rice, uhm, to get it out. Er, and I did go, there was, a big grounds, and I went off into the grounds, and I was sick behind a tree <laughs> which is horrible. But then I just want to be away, I just want to go away I don't want to be there, I don't want a fuss, I don't want a scene. (897-906)</p>
Violence against the self	<p>P001: P. Uhm, then it just gets... worse. And I will then start coughing. Little cough. And that little cough will go into two coughs and it'll keep going and multiplying and until I'm going to a full blown choke. And usually, if I'm getting several coughs I'll go and get a drink. Sometimes, if I'm doing something I'll go in a minute and then I'll realise I've left it too long. And if I haven't done trying to do, uhm, my exercises, uhm then it'll go into a full blown attack. I'll either use my heliox, which'll clear it off, um, fine. I recover quite quickly. Uhm, otherwise, uhm, I will black out... and then I</p>

will wake up. Either slumped in the chair, if I'm sat down, or on the floor
<laughs> (208-17)

P002: Uhm, but I was very conscious, and I kept, again, thinking back to the abusive relationship. Am I re-living, [I.right] that moment? [I. Yep] And so I, I just didn't know what was going on. But I was... frightened, because I just knew I couldn't breathe and I needed help. (67-71)

P003: If you never had it you don't know. It's a horrible feeling. You think you're going to die. Mmm. (372-4)

P004: Uhm, but, the – the worst of it is, is when it just hits me <clicks fingers> like a rock. (167-8) AND it's a horrible feeling. But you feel like you're being smothered [I.yeah] when you lie down and you just can't lie down. (809-11)

P005: you think you're gonna die. You just think you've had it. And if it's not gonna kill you this time, it'll kill you next time [I.mm hmm] And that's why you can't sleep and that's why you don't want to eat. That's why you- I, I just locked meself away for 3 months, I didn't go anywhere, uhm, I didn't want to go anywhere. I was kind of frightened that something was just going to happen. It was just awful. (562-8)

P006: obviously once your throat starts to close up, your airways start to close, so it's almost like you know, your airways are gonna start closing in, so your muscles close in so you get a small hole <hand in loose fist with hole in centre/points to hole> whereas you can breathe normally, but then when it starts you can feel that, it actually closing, it's like the muscles are actually closing in, and you can feel the hole getting smaller and smaller

		and that's when you have to learn, what to do with it, not to panic (32-9)
The Trauma of VCD	Fears about possible futures	<p>P001: P. Wake up, and I'm breathing and I'm breathing ok, they've relaxed, believe it or not <?> they have relaxed. But the, there's always the chance that you're not gonna wake up, they're not gonna relax.</p> <p>I. Right</p> <p>P. Y'know, it's, y'know... I... it's gonna happen one day to somebody</p> <p>I. Yeah</p> <p>P. Touch wood I hope it's not me. But you, you don't know when it's gonna happen [I.ok]. I just hope y'know, it's quick for whoever it is, who it happens to y'know, they don't feel any pain. But... cause obviously if you, if they've close up, there's nothing to open it up for them [I.mm], eventually, they are, y'know, somebody is going to die. (331-41)</p> <p>P002: If people don't get referred to those centres, they might end up in a box. (753-754)</p> <p>P004: It's a bit annoying, but more so it's frightening. Because, I'm just, I can't say, well I can say I'm dreading the day I go in again, if I go in again, cause you never know when it's gonna happen. But you- I'm dreading the day I go in and there isn't a military person there... anybody else sees it as either asthma or like your respiratory but not VCD [I.yeah]. You know and I think, there's gonna be a day when I come in here and there's not gonna be one of those <almost laughing>, you know? (239-51)</p> <p>P005: that's the one that still, that's the one that worries me in terms of looking down the line. Is that the thing that's gonna get worse for me is eating and swallowing? Is, does it, does it get worse, or will my symptoms always be the same or will they get- because things rarely get better in life <I.laugh> and once you get something it generally gets worse over time,</p>

	<p>uhm, and I- you kind of think is it gonna be worse or is it just, this is just how it is, and it'll always gonna kind of be like this. (326-33)</p> <p>P006: Uhm, I don't know, I don't even know if if that's uhm expected from it. Over the years, it'll get, it increases and it gets worse. I mean it's probably like everything else isn't it, you know it it can get worse over years of having it. You know, some things don't some things stay as they are but other things can get worse, I mean, I've never been told whether it can get worse. (430-6)</p>
Distressing to others	<p>P001: Well, I could say to people, what was wrong, you know because people notice, more than I did, that I'm choking and stuff y'know? [I. Yeah]. Not saying more than I did because obviously <chuckles> I noticed I was choking, [I. Yep] but they were upset more by it. (548-551)</p> <p>P002: Uhm, ***husband*** was frightened to death to leave me at home, on my own. Because he didn't know what was going to happen. (122-124) AND ...he panics and I don't. [I.OK] I feel that's the difference. [I.Yep] Uhm, and maybe it's good sometimes he panics cause I maybe leave it too long. (534-537)</p> <p>P003: "I think he worries a lot about it, because every day, he's ringing me or he's coming round. At the very beginning when I had the first bad one, I came out of here, he came and stayed with me. Looked after me, shopped, oh, did everything. It was marvellous." (527-30)</p> <p>P004: she was getting frustrated because I was suffering and she was seeing me suffer [I.yeah] with it. And she said, if I could take it, I'd take it off you. And I said I don't know what it is, but you wouldn't have it anyway, I</p>

wouldn't let you (557-60) suffering

P005: And **daughter** that time in the restaurant, she got very distressed, in fact she was sick rather oddly <laughs> but she got herself kind of all worked up. Uhm, but **partner** is happier now that she's got something to do, when it does happen. So she can solve the problem, I think she's happier that she can solve the problem. When she didn't know what to do, that, that was infinitely worse than now (402-8)

P006: I don't want people feeling "oh god" you know, you know, some, people start panicking over me, I'm probably gonna start panicking over myself, then it's gonna make the situation worse. So, if I don't let people know that that's what's happening, [I.mm] they can't start panicking thinking, I'm not gonna, I'm gonna conk out and I'm not gonna breathe. So then they'd start panicking, I'd start panicking and I'm back to square one with an ambulance again. [I. yep] So, I, I don't really let people know. (290-301)

On the mind

P001: P. So you could put it on the back of your scooter [I. Right] or put it on the back of your wheelchair.

I. Yep

P. And then you don't have to worry about having an attack when you're out and about. Obviously, you'd have your big cylinder in the house but that would be for when you're out and about shopping or whatever (287-93)

P002: P. [No, I do them every day] when I wake up in the morning, I always start off the day, before I've even left my bedroom, I do my breathing exercises. Then I have my medication, because I know then... just in case it's slipped into a sleepy state <hand around throat>. Uhm, I've given it, it's stretching, before I try and force pills down its throat.

	<p>I. mm hmm</p> <p>P. And then, always go and have me cup of tea, and then another one. And then probably lunch times... I think I do them again at lunch time and tea time, uhm, and I'm sure I do them when I'm, just before I go to sleep, in case... uhr, just in case it has a little moment in the night. (452-63) First & last things she thinks about</p> <p>P003: The big one I had. I had a big one in September, yeah. That was the worst I've ever had, and er, I never, I didn't go to the clubs til after Christmas, started going back <wheeze> erm... yeah, I'm alright but, I'm always... conscious (36-9)</p> <p>P004: it sort of lingers for about 2 months after I've had a VCD attack. [I.goodness] but not half as bad or anything, but you've still got that feeling, [I.yeah] will I go through that door and be- and it comes back. (705-8)</p> <p>P005: It's... kind of with you all the time. I'm conscious of it all the time. It doesn't, I'm not frightened of it, and it doesn't, not like I used to be, but uhm, different parts of the day I'm more aware of it. In the morning, I'm more aware, it seems to be... if it's gonna happen, it'll happen in the morning, that tends to be the worst time for me, uuuhrm... but any meal, anything I eat I have to have drink.</p> <p>P006: it it can be just with anything, that will just, sit there and happen, uhm, and... and I guess that's why I've just learned to deal with it. Because it can happen at anytime, anywhere, you know, uhm, so I don't tend to worry about it. (586-90)</p> <p>Exception – too many conditions to think about so she blocks it all out</p>
Importance of support	P001: So it, y'know. Once a month the shower has a good bleaching, and he

from trusted other(s)

does that [I.Yep]. And he shuts the bathroom door, opens the bathroom window, puts the expel air on, and er does that, and then the bathroom door's left shut [I.mm hmm] for a while. So it all goes out before I go in there. (384-8) "I'm a great believer in bleach"

AND

...if I start to choke, I mean if I'm having a barbeque and I start to cough and choke and I start heading towards the kitchen to go into the house to use my, my Heliox, [I.hm] I know my niece will be right behind me. Cause she's watching me all the time <chuckles>... And so she'll come in and sh- "I'll get it for you auntie ***** you sit there" and she'll go and get, 'cause it's on a trolley [I.yep], she'll go and get my [I. yep] my Heliox. And she'll put it on my face and she'll wait until I've used it.

I. Yep

P. "You sit there" I say, "No, I'm alright now" "No, sit there for a bit" <laughs> (561-77)

P002: I have a close friend, who is very very good if I'm having a, down day [I. Yep]. She will listen. [I. mm] Uhm, and she doesn't cast judgement. But I don't tend to do it with the family, [I. right] because I don't want to burden them again. (51-4)

AND

P. Uhm, he will go and get the Heliox. Ur, and he'll <laughs> basically say "shut up. Just stop talking. Just stop talking and relax". So, er, but the Heliox, where I sit in the living room is always accessible. But he will just grab the mask and turn it on, which happened on Saturday. [I. OK] Ur, I just had a, had a little moment and I thought, I think I- Oh, I know what I was trying- I was trying to blow bubbles over the children. [I.oh] And he just suddenly said, you've gone a really funny colour, I think you need to go on your heliox. (519-26) Compartmentalises "burden"

P003: He's been so caring, and looked after me. I can't fault him. Brings me for all me appointments, comes- if he doesn't come round, he rings me. Marvellous. (285-7)

(COMPARE WITH: "oh they've seen me yeah. Oh, they say to me, is um, oh you're alright mum, you're alright. <whispers> they don't bother. I mean they're not, being horrible, they're just being kind in a way." (499-502 Re. Son's involvement) Not understanding + undermining her experience by telling her how she is feeling. "Cause I go, I got there the one day, I- I go Sunday's for lunch, and I got there. And I walked in, and I said "oh, dear me" he said "What's wrong?" and I said "me breathing". He said "come on you'll be alright". Y'know, no sympathy." (504-7)

P004: he says in a way, it's a good job you are, er, passing the word and telling everybody and that you have got your mum by your side. Because otherwise, you'd have to write it down to tell people, because if ever you did come in on your own, you wouldn't be able to tell anybody what it was, because you'd just lose your voice [I.mm] you just can't breathe, you know, so he said they could, I mean it, it could happen, I mean he, he didn't say in so many words but they could treat you for something to-totally different, if you get a doctor that doesn't know (587-96) (for appropriate management as doctors cannot be trusted... what happens in future if she is not there?)

P005: And once you start doing it, particularly when I'm with **partner** she's really good at talking though what I have to do, and she looks, she gets right close and she looks at me, and relax and drop your shoulders, and do your little sniffs and it's only seconds and you can just start to feel, oh I'm, oh there we go. Uhm, and then a couple of minutes later and you're

		<p>fine again. (624-9)</p> <p>AND</p> <p>She says it changed, and it has changed my voice. So the voice I have now, isn't the same as the one I had three years ago. She says it's different the pitch is different uhm, and the tone... she actually says my voice is different to what it was from 3 years ago. (780-7) As a witness/ documenting his life</p> <p>P006: she'd just guide me through it you know "mum you've got to do your exercises, you know what you've got to do" come on we'll sit down and we'll do it together and she'd sit next to me doing it (480-3) daughter is a teenager, what happens when she leaves?</p>
Helpful relationships	Power of professional reassurance	<p>P001: the whole team has been absolutely fantastic because they don't poo poo you. They listen to what you've got to say <sips from drink> 'scuse me... they listen to what you've got to say and if it's um, if they can help you with advice of something you're not sure of they will do it everytime. They've always been there. I mean, it's like I got my new cylinder but I hadn't got a mask, they sent me a mask in the post, which was really nice. They didn't have to, they could have turned round and said "well we don't actually supply the mask, you'll have to go through your GP", but "Yes ***** we'll get one to you" and they got a mask to me, no problem [I. Yep] Y'know, little tiny things like that, mean a lot to somebody in my condition and position. [I.Yeah] Just some, y'know, if I've got a problem I can pick the phone up anytime and talk to somebody from the team. It doesn't have to be ***** , ***** could be in a clinic. It could be anybody from the team and they'll listen to what I've got to say. And if it's something that needs to be passed onto ***** , they will pass it on and she will contact me [I.yep]. Y'know the after care, I can't fault it at all. (932-49)</p> <p>P002: But I can come out of it very quickly, much much quicker than-</p>

much more quickly, bad English, much more quickly, er, than I used to. But that's thanks to the training from***therapist***, erm who has taught me well. She's taught me very very well. And, if I could issue, a damehood she would get it (612-616)... because she's one hell of a lady, erm, she is just remarkable. Very calm [I.yep], er sincere. I just think she's, she's way up there in my- If I won the lottery I would give it all to her (620-622)

P003: And I'm going, I have to say come on now you can do it, you'll get there, you'll be alright. Talk to meself." (401-2)

Vs.

"And they showed me that, and they've given me confidence as well.

I. Yeah, confidence in what sense?

P. That I can handle it. Because she said to me, you won't die. I said, well I nearly died. She said you won't die, you'll come out of it. (169-173)

P004: But it's given me a lot more confidence now. You know. It's something that I can live with. You know. And when it does come I thought right, you're not gonna get the better of me, I'm gonna get over this. (152-5)

P005: She told me what it was, she told me what to do. Arhm... and it was just, a revelation. The biggest bit being, it won't kill ya. Don't worry it won't kill ya. You'll pass out if it gets really bad, but your vocal chords'll relax and you'll, you'll breathe again uhm... (89-93)

AND

I get quite emotional about it actually, but it, it, it is that big a deal to be told you're alright, you're not gonna die <small laugh> (1017-8)

P006: You're thinking "god, it's still closing up" uhm, eventually you think to yourself, it's gonna open up eventually. [I. yeah] If I keep doing what I'm

	<p>doing, so... [I. stick with it and keep] yes yeah... and keep going you know. For as long as I can really. Uhm, and it's always worked so. (537-42)</p>
Breaking the panic cycle (the role of mind in recovery)	<p>P001: [If people ask me what it is] I will tell them exactly what it is [I. yep]. I said, it's not nice to have because you panic because you can't breathe, you're not supposed to panic [I.Yep]. Supposed to keep calm, and it's easier if you keep calm but. Panic and it get's worse. (870-4)</p> <p>AND</p> <p>It's erm, it's getting control of yourself and getting yourself to relax, which is the big key [I. Yep] in getting control of your vocal cords. (537-9)</p> <p>P002: ...the more you panic, the harder it gets. So you need to, almost a Thai Chi moment, uhm, it's just me thinking, OK. And I do close my eyes, and I do just switch off completely, to allow my body to recover. (569-572)</p> <p>Compare this with the descriptions (795-801) of re-jigging – it's almost like she has to realign herself as part of her recovery.</p> <p>P003: I can't breathe. I get very breathless, it makes me very sweaty, very hot, I can't talk. Panic. I used to panic, I don't so much now. I panicked <breathing sounds 15 seconds> (7-9)</p> <p>AND</p> <p>while I'm in it... I don't really know. All I'm thinking of is do your exercises, breathe properly, ahh, <fingers to thumbs in meditation type pose> and so when I'm in one. But that's about all I can do there. I don't- nobody talked, I can't talk <slight wheeze> cause I'm busy doing all this <fingers to thumbs in meditation type pose> mmm.</p> <p>I. So you're quite focused now on that...</p> <p>P. I'm beginning to focus hopefully, mmm, hopefully yeah (186-193)</p> <p>P004: now I know where to go with it and what to do with it. [I.yeah] So I</p>

		<p>do it on my own now, when I'm in hospital I can just sit in a chair, look out the window, take my mind off everything [I.mm hmm] literally close off from everything around me and do my breathing [I.yep] and it brings me round, and I thought, I'm getting there, I'm getting there <whispered> keep going, keep going [I.yeah] you know. (367-73)</p> <p>P005: It still happens. I just know what to do uhm, and me partner knows what to do, and family know what to do and, I've had- I still get them, they still happen, [I.mm hmm] uhm, it just doesn't cause as much panic or upset, I'm quite calm about it, cause I know I'll be alright. I've just gotta, lean forward, drop me shoulders, try to relax, do the little sniff, sniff, sniffs and you know. (108-14)</p> <p>P006: So when I used to start doing it, and I'd come out, well she sa- first of all, she, "well what you doing mum?" "What are you doing that for?" And I said like you know throats closing up, and it feels like it closes, you can actually feel it closing up. "Oh mum don't you panic?" and I says no because you can't panic because the more you panic the worse it gets, you know and then, you you telling yourself you're lacking oxygen then you collapse and then you, you know, so I said you just don't think about it, you just do your exercises get on with it and not worry. (494-502)</p>
Management: the balancing act	Avoiding & adapting	<p>P001: I tend to live just a little bit, slightly differently. I'm watching what I'm doing more. (587-9)</p> <p>P002: people love a log burning fire. I don't. Because, bonfire night. Bloody nightmare. Y'know, you're just a prisoner. But at least I know, well don't go out there. Whereas before, I would just think well I'm invincible. (865-868) AND she knows I have this breathing condition. [I.mm hmm] And she's, she's 13</p>

now. And she knows that Auntie ***name*** has to watch things, uhr, even things like nail polish. Er, and she likes to pamper and play, and she buys childrens, because she wants to do me, because she knows it's got no chemicals in... but she doesnt want me to be poorly, so she uses the childrens stuff on me. It's ok mummy and daddy, or mummy and aunties, and she'll do them in a different room... (480-490) adapting can facilitate involvement

P003: Oh no, I'm not saying it does but ***therapist*** said to be careful. Perfumes and things and sprays and <wheeze> and it's like in the house, I've always had <loo?> things, well I havent got any now. I chucked them the way. Not because I don't – I think they affect me, just because I thought, no, don't do it. Mmm

I. Don't risk it?

P. I won't risk it. (679-85)

BUT ALSO...

I won't go on me own there. I'll go to me clubs but I won't go tha- to there on my own. It's strange isn't it?

I. Why is that do you think?

P. Frightened because it's not a place where anybody knows me, and I think that's to do with- and she'll say, I'll take you. If she's there with me I'm fine. And we go supermarket shopping on a Friday and I'm fine with that, because she's with me – not with me, we shop, but she's there. Mmm. She's marvellous, good friend, mmm. (556-63)

P004: So there's things that I do everyday even now. You're always conscious of things and you think, I can't go in there, I can't do this, so you think, no I'm not gonna go in there because that might trigger it off, so you sort of go round things [I.right] to do it, but I'd sooner do that, than end up

having the VCD attack (482-6)

P005: Funny things, potato based foods, are difficult, you'd think mashed potato would be fine but I've got <laughs> real problems with potato – I don't like chips so that's not particularly a problem, uhm, bread, so those kinds of things are difficult, so I, I tend to avoid them. Uhm, I tend to eat a lot more sort of casserole-y, curry, type stuff. Stuff in sauces. Uhm, I don't eat red meat anymore, and I avoid those kind of doughy, stodgy type things, because you can feel them stick (262-9)

P006: I wouldn't say its changed anything, because I've not allowed it to change it to be honest. I've not ehm, let it dictate to me. And... with the other conditions that I have anyway, uhm, I don't let any of the conditions that I've got let me not have a life. Because if that was the case, the same as with vocal cord, I wouldn't do anything. I'd just be sitting down doing nothing everyday [I.yeah] and then everything's won then hasn't it. And I don't want that to happen to me. "(624-31)

APPENDIX 3K:
Example of participant theme development table

Index of themes

P3. Independence Vs. Isolation
P5. Importance of resilience and the coming and goings of confidence
P7. The significance of coming and going
P8. Restrictions & Losses
P10. Pre-emptive avoidance as management
P11. Doing things right & its implications for handling the VCD
P13. Learning to cope as a work in progress
P15. Things feel more effortful since the VCD
P16. Always on her mind
P17. Conflicting information about the self & changes to identity
P19. The ongoing trauma of the VCD
P21. Difficult to think & talk about
P23. Panic as part of the VCD (and trying not to)
P24. Loss of a sense of agency
P26. Embarrassment, fear & Social Withdrawal
P28. And why?
P30. "Getting stuck" & associated symptoms
P31. Feeling strange
P32. The power of supportive relationships
P35. The importance & difficulty of knowing

(search for understanding, making sense of it, and then trying to apply it to management and living with it)

SUPER ORDINATE THEMES	THEMES	THOUGHTS
"I can't do things like I used to do." (365-6)	P3. Independence Vs. Isolation P5. Importance of resilience and the coming and goings of confidence P17. Conflicting information about the self & changes to identity P24. Loss of a sense of agency P7. The significance of coming and going P8. Restrictions & Losses P15. Things feel more effortful since the VCD P26. Embarrassment, fear & Social Withdrawal	<p>This is about a change to her independence (central to her identity).</p> <p>This is around the restrictions & losses as a result of VCD. Coming and going takes a new significance as there is a fear that she will not get home. This contributes to soc withdrawal.</p>
Coping as a work in progress	P10. Pre-emptive avoidance as management P11. Doing things right & its implications for handling the VCD P13. Learning to cope as a work in progress P23. Panic as part of the VCD (and trying not to)	<p>This is about learning to cope and strategies adopted for management. There is an ideal serenity to aspire to which she is aware of but often fails to reach (panic). Coping therefore also involves avoidance and doing things right.</p>
The ongoing trauma of VCD	P16. Always on her mind P19. The ongoing trauma of the VCD P21. Difficult to think & talk about	
Importance & difficulty with knowing	P28. And why? P35. The importance & difficulty of knowing P31. Feeling strange	
"Getting stuck" (how it feels)	P30. "Getting stuck" & associated symptoms	
The power of supportive relationships	P32. The power of supportive relationships	

THEME	THEMES & QUOTES	THOUGHTS
<p>INDEPENDENCE VS. ISOLATION</p> <p>“And we go supermarket shopping on a Friday and I’m fine with that, because she’s with me – not with me, we shop, but she’s there.” (561-3)</p>	<p>Sadness comes from feeling isolated and left out: “I think because... or, oh, no I don’t think. I was gonna say cause living on my own, but I’m happy on my own so I can’t say it’s that. Uhm, I think a little bit is because I can see my other friends all a bit more active than me.” (802-5)</p> <p>Independence is important... “she said come on, I’m taking you to the ***Hospital 3***, I said <u>you’re not</u>. Get me home. I want to go home. And, I came out of it meself” (259-61)</p> <p>but distinct from being left alone: “ And we go supermarket shopping on a Friday and I’m fine with that, because she’s with me – not with me, we shop, but she’s there.” (561-3)</p> <p>“[Well she saw it all] she did <u>everything</u>. She made the coach man stop and get the emergency services. And then she stayed, in the hospital with me all night. And, er, they gave her a little room to stay in.” (565-8)</p> <p>Living alone: “No, I was on me own that day [I.OK] I live on me own. Mm.” (287-8) <i>(after describing how much she gets out of her ex-husband being around and helping out this short statement seemed to suggest that the positives of living alone carried an associated cost that was sometimes felt more keenly, especially as conditions such as VCD emerged.)</i></p> <p>Fluctuating independence & ability: “...my granddaughter used to come and help but now I do a bit now myself. Can’t do the garden anymore. Uhm... cause I love me garden, and I can’t get, and that upsets</p>	<p>Initially I had independence as a superordinate theme but this seems to be broken down into two aspects of this idea of independence. We have the concern of being independence vs. being isolated which for me reflects the changing circumstances of the participant’s life - she values and wants to be independent but does not want to be isolated and is somewhat reliant upon those close to her to ‘be around’. Giving her space to live her life and do the things she can do, but being able to support her and to understand her situation if it is needed.</p>

	<p>me a bit. I can potter with the pots but I can't do anything else. Erm, but general housework and looking after myself, I'm not too bad." (49-54)</p> <p>Social obligations create internal conflict: " Do you want to come? Now I thought, oh god no. I said, oh *** I don't think I can come. She said, why not? It's only an hour and a half, we'll pick you up. And, I'm going er, I don't know, I'll ring you Saturday and let you know." (733-6) <i>(with the unpredictable nature of the VCD she feels anxious about the idea of going out but is aware that people are making an effort to invite her and feels an obligation and a desire to go and be sociable but at the same time not feeling sure if she is up to it – she is independent enough to not just say yes to these invites but they require a lot of thought and weighing up of pros and cons – linked into feeling exhausted and the impact the VCD has on her social life)</i></p> <p>Wants to have someone to ask about the VCD: "Cause you don't know anybody else, it's not like if you've got, a ser- you know another illness you can say, well you know, what were you like or what did you manage, but I've got no one to ask." (860-2)</p>	<p>She feels especially isolated with regards to VCD as it is a not a well known condition and there is nobody to talk to about it or share experiences with.</p> <p>This ties in with another independence related theme that seems to encompass a concern with identity: 'confidence and resilience'.</p>
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